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Family Meeting or Care Planning Meeting? A Multidisciplinary Team Action Research study in a Hospital Setting.

by

Sarah Donnelly

Thesis submitted to the School of Social Work and Social Policy

Trinity College Dublin

In fulfilment of the requirement of the

degree of Doctor of Philosophy

April 2012

DECLARATION

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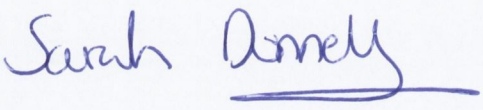

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'...the skill and effort that we put into our clinical communication does make an indelible impression on our patients, their families and their friends. If we do it badly, they may never forgive us; if we do it well they may never forget us'.

(Buckman, 2002)

This thesis is dedicated to the many people who participated in this study and in particular the older patients and their families.

SUMMARY

Family Meeting or Care Planning Meeting? A Multidisciplinary Team Action Research Study in a Hospital setting.

Care Planning Meetings (CPM's) are regularly conducted in hospital settings where patient, family members and the MDT meet to exchange information, plan for the future and facilitate decision-making. In the Age Related Healthcare Unit where this research took place, CPM's were being used more frequently to determine care plans for older people, without any particular protocol for these meetings, or consistency about the participation of the patient at the centre of the care planning process. Published literature offered limited insight into the meetings process as created by multi-disciplinary teams(MDT) and there were no practice guidelines which specifically focused on patient participation within CPM's. Although this forum is intended to encourage active participation and empowerment of older people and their families in decision -making, doubts existed about whether this was happening in practice. This study set out to gain a contextual understanding of participants' experiences in CPM's. The research was particularly concerned with the language, behaviour and communication used by participants within these meetings. It was hoped that based on findings, practice guidelines would be developed to optimise the participation of older patients.

An action research approach was chosen since this approach is of particular relevance to clinical practice because of its transformational potential and its ability to "investigate" whilst introducing change. The study design incorporated a 3 stage action research cycle which was used to develop a framework to recommend ways of improving practice as a consequence of systematic critical enquiry through partnership in working with the MDT as 'co-researchers'. Phase I involved a convenience sample of ten CPM's who were inpatients of a Department of Geriatric Medicine. Phase 2 involved a convenience sample of ten CPM's who were inpatients under the care of the Stroke Service. These patients were assessed as having a cognitive/communication difficulty. Cycle 3 involved the development of a training manual 'CPM's-Training Manual for Healthcare Professionals'. This thesis focuses primarily on Phase 1 and Phase 2. A multiple method study design was adopted which included participant observations of CPM's, questionnaires which were administered through semi-structured interviews and staff focus groups.

Findings showed some fundamental differences in MDT opinions about the purpose and outcomes of CPM's. In Phase 2, critical discourse analysis was also used and findings showed an asymmetry in participation had occurred between the MDT, and older patients and their family members, with MDT members dominating the discourse in all CPM's observed. Patients were found to have low levels of participation as indicated by verbal utterances, particularly those with a cognitive impairment however, other forms of participation were indicated through non-verbal signs. Family members meanwhile were found to have much higher participation levels. Despite findings from Phase 1 being fed back to the MDT, during Phase 2, MDT members were observed to continue to exhibit some exclusionary practices including poor eye contact, speaking about patients in the third person and directing conversation and questions to family members rather than the patients themselves.

Interestingly, all patients and the majority of family members, reported being satisfied with opportunities afforded to them to voice their opinions, ask questions and with their involvement in any decision-making process within CPM's. A minority of family members however believed that the MDT had already made decisions in advance of the CPM taking place and although dissatisfied with the outcome, felt that the meeting process itself had been useful. A minority of patients appeared disappointed that certain MDT staff were not present at their respective meetings and that the patient information booklet was received too late for it to be deemed useful. Overall this study showed that CPM's were important events for all participants. In fact, all patients irrespective of the level of cognitive impairment or communication problem reported they believed it was important for them to be involved in their CPM. Findings highlighted how healthcare professionals can both promote and impede patient participation through informal processes and good/poor communication. It is recommended that healthcare professionals should elicit each patients desire to participate in advance of their CPM. To foster a climate encouraging optimal patient participation a framework promoting an individualised approach is also recommended.

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Chapter 1

1.2 Introduction

This thesis is based on a study which used an action research methodology to examine the issue of the participation of older patients within Care Planning Meetings(CPM's)[1] in a metropolitan based hospital setting in Dublin. One of the main aims of CPM's is to promote the primacy of the patient and for the Multidisciplinary Team(MDT) to support them through a process of sharing information and decision-making with each individual patient and their family. From my own experience as a Social Work practitioner in the research setting, I was aware however that wide variations within practice existed within the hospital about whether patients, especially those with a cognitive impairment, should routinely attend their CPM. Concern over participation and ownership of the process by the patients was one of the main motivations for carrying out this study. As a practitioner I was interested to find out what patients, their family members and healthcare practitioners really thought about CPM's. It was hoped the findings would provide practice-informed evidence for guidelines which would change practices so they better addressed people's needs. There are a number of existing terminologies for CPM's which will be discussed fully within the literature review.

The methodological approach of Action Research adopted is part of a new paradigm of research (Reason and Rowan, 1981), which holds a different philosophical perspective from more traditional research studies. An action

[1]This thesis will use the terminology 'Care Planning Meeting' for the majority of the thesis however Phase I of the action research cycle (Chapter 4) differs and uses the term 'family meeting.' This is due to the fact that this was the working term for the meeting forum at the inception of the study which was subsequently changed to 'CPM' as a result of changes to practice implemented at the beginning of Phase 2.

research approach has been employed in this study to enable the MDT as healthcare practitioners, to critically reflect on their practice within CPM's and to act as collaborators by contributing to the action which is the subject of the inquiry and to the methods of the inquiry. Its contribution to the body of knowledge is through the process of 'reflection on action' (Schon,1983) through the production of a new type of knowledge that strives to begin to close the theory/practice gap and introduce changes to practice which may result in greater satisfaction for all participants within CPM's.

1.3 Research Setting

To set the scene for this thesis, it is first helpful to provide some background information to facilitate an understanding of the research context. This study was carried out in the Age Related Health Care Unit of a major teaching hospital. The unit has three main types of services delivered to patients (i) the Age-Related Healthcare ward, (ii) an Acute Stroke ward and (iii) an Age-Related Day Hospital. The latter is available to out-patients whereas the first two services are only available to in-patients.

The unit has a intense rehabilitative focus and thus there is a strong emphasis and promotion on a multidisciplinary team approach which includes the medical team, nursing(including clinical nurse specialists),physiotherapy, occupational therapy, social work, speech and language therapy and dietetics. The MDT have a vital role in facilitating and enabling the active participation of older patients, and to consider carefully the patient's wishes in relation to their care planning (Hedberg et al 2007; 2008). Multidisciplinary teamwork does not however always include the patient or family members, although patient participation is emphasized (Satterlund Larsson,1989; Roberts,2002). In Ireland, older people do not have a legislative right to participate in decision-making in relation to their

care planning/discharge planning, however the National Health Strategy(2001),the Strategy for Service User Involvement(2008) and the National Admission and Discharge Guidelines(2003) recommend the participation of individuals in decision-making about their care needs(HSE,2003;DOHC 2001;2008).

1.4 Overview of CPM's

CPM's are regularly conducted in a number of different health care and hospital settings and their objectives range from information sharing to discharge planning and decision-making. However, the published literature offers limited insight into the meetings process as created by the MDT and the level of patient participation in this process also remains unclear (Froenck, 2005).CPM's represent an opportunity for healthcare professionals to ensure that older patients and their families receive the same information simultaneously so that they can actively participate in care planning (Griffith et al. 2004; Hansen et al. 1998). Evidence suggests that working in partnership with older patients and their family can improve patient care outcomes. Older patients about to leave hospital and their family caregivers face multiple changes and difficulties which need to be addressed for a successful care plan and hospital discharge. Despite the unique role of CPM's in the hospital context, and widespread use, there is surprising little research into the processes around such meetings (Opie,2004). For this reason it is of great interest to gain a better understanding of the nature of participation of different people at CPMs including lay people and professionals, and how it is experienced within the care planning process.

1.5 How is it decided who attends CPM's?

In the hospital where this research study took place, CPM's were originally convened in response to a crisis situation however, increasingly they were viewed as exemplifying 'good practice' in multidisciplinary team work with patients and their families and they began to be used in a more preventative manner. Within the Age-Related Healthcare setting, best practice was interpreted that patients would attend their CPM unless they had expressly stated that they did not want to attend. There were also instances where patients also did not attend if they were medically unwell, if it was deemed that their level of cognitive impairment was so advanced that they would be unable to participate at any meaningful level or that it could be a distressing experience for them to attend. Inconsistencies in practices did take place on occasion and there was no formal written policy or guidelines relating to the attendance of patients whose ability to participate had been compromised as a result of cognitive or communication impairments. Family members were often unhappy that their cognitively impaired relative was allowed to attend their CPM and were opposed to this arrangement. In other clinical areas within the hospital however, it was not common practice for older patients with a cognitive impairment to attend CPM's, so there were variations in practice both within the Age-Related Healthcare Unit and the hospital as an organisation.

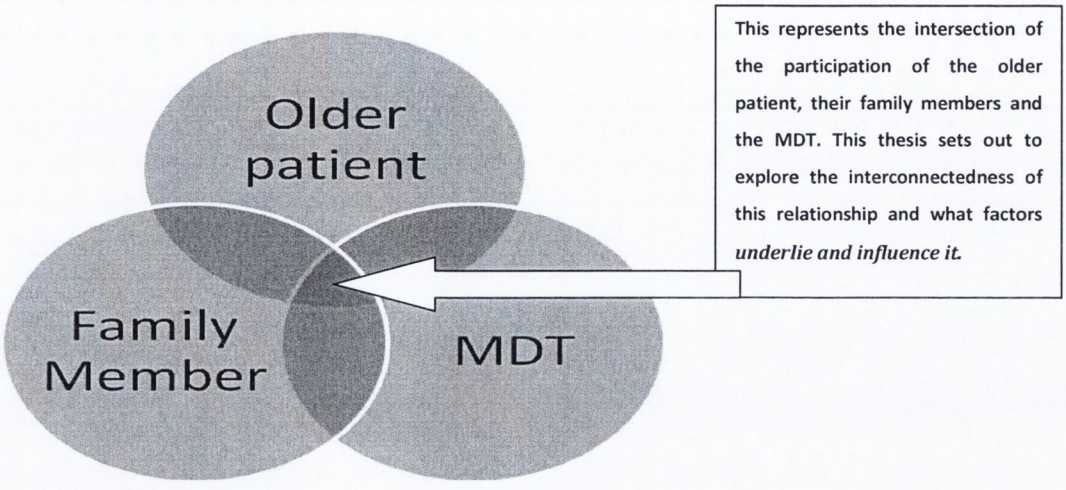
During Phase I, the process for deciding whether a patient should attend their CPM involved the MDT consulting with the older patient about whether they wanted to attend, in conjunction with an MDT assessment relating to each individual's cognitive and decision-making capabilities. As will be illustrated and discussed in Chapter 4, instances of disagreement arose in some cases between a patient's family members, and the MDT, about whether the patient had the ability to participate in their CPM and to exercise self-determination in relation to decision-making.

No official practice guidelines existed in relation to who else should be invited to CPM's so again, variations in practice occurred and attendance was dealt with on a case by case basis. As the Medical Social Worker was responsible for organizing the CPM, they also generally assumed responsibility for inviting others to the CPM. Discussion often took place at the weekly MDT meeting about what other healthcare professionals or representatives from community services should be invited and this was determined by the purpose of the CPM so that important key individuals were present. Patients were consulted about which family members they would like to have invited and patients with no family member were encouraged to invite a support person. In cases where patients had an advanced cognitive impairment, were medically unwell, or if they did not want to attend their CPM, where possible, their consent to hold the CPM with their family members/next of kin was sought. In these cases a 'family meeting' took place.

1.6 What will this study examine?

This study set out to closely examine the interactions between healthcare professionals, patients and their family members in order to fully understand the process of patient participation.(Collins et al.2007). Interpretive Inductionism has highlighted the existing theories and concepts related to patient participation and CPM's .

Figure 1; Intersection of Participation in CPM's



1.7 Background to the Study

In recent years, patient participation has become an increasingly popular topic of healthcare policy and research, particularly since there has been a move towards the promotion of individual autonomy (Eldh,2006). The promotion of patient participation in health care planning has stemmed from the belief that patients have rights and responsibilities to be involved in their health care (World Health Organization 1978; Audit Commission, 1993) and it is considered a basic condition for good care(WHO,1994).

In 1984, the World Health Organisation (WHO) first introduced the concept that patients should be provided with information and that patient participation should be encouraged. This idea was further advanced in 1994 when the WHO explicitly stressed the need to promote the rights of patients and in particular to strengthen 'beneficial relationships between patients and healthcare providers, in particular, to promote a more active form of participation'(WHO,1994).

Patient participation as a means of enhancing decision-making has been widely acknowledged (World Health Organization 1978, Council of Europe 1982, Audit Commission, 1993) and approaches to care that attempt to understand the patient in a broader context are receiving increasing emphasis throughout healthcare systems(Logue,2003). Indications exist that there is a need for special efforts to ensure involvement of the patient and family and to consider carefully the patient's wishes. In the Irish context, these goals are documented in 'Quality and Fairness, A Health System for you' (DOHC,2001) which outlines shared decision making and person centeredness as key principles of Irish healthcare policy.

Traditional methods of training healthcare professionals make it difficult to step into the shoes of older patients and thus this study set out to explore how the CPM process is experienced by healthcare professionals who are part of a MDT, family members of patients and in particular, patients with cognitive/communication difficulties. To date little research has been conducted which focuses on the participation of all participants with CPM' s and little is known about how the communication, language and behaviours of healthcare professionals promotes or inhibits the participation of older patients. It would appear that there is a distinct absence of the patients' voice in the research to date and few investigators have included the patients' perceptions, experiences or levels of satisfaction as outcome measures (Haesler et al.2006).

Much of the existing literature focuses on healthcare professional's perceptions of patient participation and the researcher has been unable to find any study that specifically explores the participation of patients who have cognitive and/or communication difficulties within CPM's. This study aims to narrow this gap in the literature by asking questions which will help gain insights into how patients and their family members participate within CPM's and their subjective experiences of this process. This thesis also sets out to gain an in-depth

understanding of how MDT types, and methods of communication, may promote or impede patient participation and influence the process and outcome of these meetings. The reflective nature of this study is also grounded in the practitioner researcher's experiences and observations as a medical social worker on how CPM's can be used by health care professionals to include or exclude older patients and their families in the clinical decision making process.

1.8 'Care and Connect Project' as a background framework to thesis.

This thesis has evolved from another major academic/service initiative titled the 'Care and Connect Project' established in October 2007. Care and Connect was a joint initiative between the Adelaide and Meath Hospital, Tallaght and the School of Social Work and Social Policy, Trinity College Dublin. It was established to promote best practice in person-centred care planning for older people, to encourage partnership in decision making between older people, families and health care professionals, and to gain a deeper understanding of this process.

A Steering Committee was established which consisted of the Hospital Director of Allied Healthcare professionals, the Hospital Social Work Manager, two Hospital Consultant Geriatricians, the University Head and an Assistant Professor of the School of Social Work and Social Policy in Trinity College Dublin. There was a desire by the Steering Committee for a practice based, social work driven study. The project also hoped to begin to develop a strong research base for the social work profession in Ireland by establishing the first hospital/university post in the United Kingdom which could act as a model for other institutions. The Research Social Work post was configured so that half of my time was devoted to carrying out research on behalf of the Care and Connect Project and the other half, employed as a Medical Social Worker to the Age-Related Healthcare Team. CPM's included in this study were in respect of patients that my social work colleagues were responsible for, and any CPM's in respect of my cases, were excluded.

The issue of older patients' participation in hospital based care planning meetings was identified as a project requiring research by the Steering Committee. The political and organisational context in Ireland at the time of the project's inception is of relevance, as a climate had developed in acute hospitals of placing older people in long term care placements in nursing homes, often without any proper negotiation process with older patients or their family members. Concerns had been raised by the hospital members of the Steering Committee, that CPM's were being used more frequently to determine care plans for older people, without any particular protocol for these meetings, or consistency about the participation of the client at the centre of the care planning process. Frequently meetings were held where older patients with a cognitive impairment were completely excluded from the meetings process and it was unclear that even when they were present, if they were being enabled to genuinely participate in discussions and decision-making processes about their future.

The Care and Connect project's brief was to carry out exploratory research to examine the area of CPM's in clinical practice. However, it was my responsibility as the appointed researcher, for the overall conceptualization of the study, for the methodology to be used including the identification of key research questions and for data analysis and write up. When first seconded to undertake work on the project, it was not my personal intention to use it to write the PhD, however the Steering Committee suggested this as a possible option at an early stage. They were anxious that the research should hold scholarly credibility and by registering for a PhD, it would also provide me with a much wider range of resources, support and academic opportunities such as presenting at national and international conferences and striving towards publications.

I also realised that a PhD would be a tool for self-development and personal achievement thereby, affording me a greater sense of ownership over the research. I was able to assume more of a decision-making and directional role

than I might otherwise have had, and it provided me with improved knowledge and research skills. By registering as a PhD student it also fitted with the wider brief of my practitioner/research post in that my post was a model for other organisations and practitioners of how research could be integrated in practice. Action research was also an underlying element of this in terms of being a methodology which would marry theory and practice.

Although action research had been suggested as a methodological approach that could be appropriate, I was given the discretion and authority to decide what would work best and what particular aspect of CPM's should be studied. An action research approach was however deemed to be most suitable for the subject under study by the researcher- see chapter 3, where the rationale for this decision is discussed. Through the adoption of an action research approach, the MDT were involved as collaborators through the mechanism of an MDT Critical Reference Group (CRG). Through this process, it was agreed that the study would focus on the language, behaviour and communication used during CPM's and would try to develop strategies to increase the participation of older patients, paying particular attention to those with a cognitive impairment.

1.9 Outlining the Field of Inquiry

My epistemological position for this study relates to a motivation to explore both the objective and subjective experiences of CPM's and to critically examine these through an action research approach. In this context, and at the outset, it is important however to declare my own beliefs which stem from practice experience as a Social Worker. It was my view that although I could see that there had been a move towards CPM's being more patient-focused and inclusive within the hospital setting, I believed that for the most part, as healthcare professionals in an MDT, we felt more accountable to family members than to the patient themselves. I wanted to explore not only the subjective experiences

of older patients and their family members, but to compare these to the more objective findings from the participant observations.

I was also keen to capture the MDT's own perceptions and understandings of their practice within CPM's, and what they believed was 'going on'. The existing literature on CPM's was somewhat limited which I found surprising given that this type of group decision-making forum was being increasingly used in clinical practice both in the acute hospital and community settings. There were recommendations within the literature that further research needed to be carried out on this topic and it was strongly identified that there was a need for education and training of healthcare professionals on how to communicate and facilitate CPM's in order to create the optimum conditions for participants.

1.10 Aims and Objectives of the Study

The overall objective of this study was to conduct exploratory research at one particular hospital site where the researcher was already employed, in order to explore what was happening in current practices at CPM's and to involve the MDT as collaborators. The research would enable members of the MDT to reflect on their practice and through the process of the action research cycle, make recommendations on how to improve practice. Published literature offered limited insight into the meetings process as created by multi-disciplinary teams(MDT) and there were no practice guidelines which specifically focused on patient participation within CPM's. Although this forum is intended to encourage active participation and empowerment of older people and their families in decision-making, doubts existed about whether this was happening in practice. This study set out to gain a contextual understanding of participants' experiences in CPM's. The research was particularly concerned with the language, behaviour and communication used by participants within these meetings. This it was hoped would result in a tangible output from the research in the form of a

training manual detailing best practice guidelines, which could perhaps be utilized in other clinical areas and settings.

It is important to point out that this study did not set out to produce a set of generalisable findings but rather it aims to offer a specific, highly contextual account of the process of CPM's and participation within that, in other words, a 'situational understanding' (Elliott,1993). The notion of dialectics is central and thus the necessary interdependence of subjective and objective perspectives, individual and social perspectives, and practice and theory are embraced (Waterman et al., 2001).This study therefore aims to gain collective understandings of the CPM process and participation within that which has relevance for practice in wider settings.

It has been argued that analytical enquiry is shaped through the meeting of epistemological concerns which inform the research questions asked, the data collection methods, the research approach adopted and the relationship between the researcher and the researched(Gilmore,2001;Payne,2002). From this standpoint, I was anxious to adopt an approach which would reflect my social work background, critical and gerontological leanings as well as the brief to carry out a study that would result in improvements to practice. This study therefore has a methodological approach which firstly utilised an action research approach. An integrated theoretical framework was embraced which applied a critical gerontological lens to the research. Finally, an interpretive inductionist and critical discourse analysis approach was used to analyse the study's findings.

1.11 Research Questions

A careful and in-depth perusal of the literature (see Chapter 2) helped the researcher identify the key research questions considered important to address in this thesis: the utilisation of a critical gerontological frame of reference

combined with the adoption of an action research approach has driven the development of the following research aims:

- What is the purpose and role of CPM's for older people in hospital settings?
- What are patients' views and attitudes about CPM's and their participation within this forum?
- What type of behaviour and communication patterns do older people with a cognitive impairment or communication problems exhibit during CPM's?
- What are the communication patterns of family members and health care professionals during CPM's?
- What level of involvement/participation have patients, their family members and MDT members at CPM's?
- What changes according to MDT members can be introduced during CPM's that might benefit patients and lead to their more meaningful participation?
- Are patients satisfied with the level of participation and control afforded to them at CPMs?

1.12 Personal Interest in this area

I am a qualified Social Worker with over 14 years in practice. In the past twelve years I have worked as a medical social worker in an acute hospital setting where the study for this thesis was conducted. My role has included a variety of clinical areas ranging from trauma-orthopaedics, neurology and age-related healthcare. I have gained much experience from working with patients who have a cognitive impairment. This has always been an area of practice that interested me and in

particular, the challenge of promoting patient autonomy whilst balancing family members concerns relating to their safety and well-being.

The primary role of a medical social worker is to advocate for patients and their family members. However, this must always be balanced with the need to progress discharge planning to ensure movement and fluidity within the hospital as an organisation. Over my years of work, the forum of 'family meetings' or 'care planning meetings' had become increasingly important as a mechanism for sharing information, consultation, negotiation and discharge planning between healthcare professionals, patients and their families. It is an area of practice that I, personally, have found to be extremely challenging as social workers have traditionally taken a lead role in organising and facilitating these meetings.

Although a variety of MDT members may be involved in any given meeting, the practitioner who organises the meeting invariably has a deep sense of responsibility for the success/failure of the meeting proceedings and outcome. My own experience is that CPM's can be extremely stressful as a high skill level is required, they are often characterised by conflict amongst participants, and the success of the meeting can be influenced by a wide variety of factors such as pre-meeting preparation, whether participants are clear about the purpose of the meeting, if there is agreement and consensus on whether the patient should be present, facilitation of dynamics within the meeting and the decision-making process(if any!).

From my own practice experience, I have been involved in numerous CPM's, many of which had caused myself and my colleagues great anxiety due to inconsistencies in practice and concern over the primacy of the patient's wishes, particularly around patient attendance and also the complete absence of any guidelines or training relating to best practices within CPM's. Although many healthcare professionals are involved in CPM's, few have received training on

how to conduct and facilitate such meetings (Fineberg,2005). This appears to be an area of practice that has been largely neglected in the university training of healthcare professionals, and in my opinion, this has directly contributed to the challenging nature of CPM's for all healthcare professionals involved, as they have often received no basic training in this area.

I was also aware from my own practice of concerns I had about how CPM's were being conducted and in particular, some of the language, behaviours and decision-making processes that I had observed and indeed those exhibited by me. I had experienced uneasiness and even embarrassment in relation to how patients and/or their family members had been communicated with and treated during CPM's. My colleagues and I had often reflected that if practices within CPM's could be improved, and if all MDT members within the hospital could adopt a consistent approach, patient and family member experiences could be greatly enhanced and patient preferences honoured. We also believed that we would achieve greater work satisfaction with reduced stress levels. Therefore, when the Care and Connect Project was introduced, I was immediately interested in its focus on conducting research into this area of practice and I applied for a secondment to the post of Research Social Worker for the project.

1.13 Personal Experience of CPM's

My family circumstances also played a role influencing my interest in CPM's as during the course of doing this study, I had the opportunity to attend a CPM in a rehabilitation unit in America organized for my grandmother who in her eighties, had a stroke, and was receiving post-stroke rehabilitation. The CPM took place a year into my PhD thesis and the experience left a deep impression on me. Firstly, I was surprised at how intimidating I found the formality of the meeting process to be, and that it was quite overwhelming to have so many healthcare professionals present (N=8). It caused me to reflect on the fact that as a social

work practitioner, I have some experience of being involved in CPM's and therefore had previous experience of this type of process, and it made me wonder how frightening the experience of the CPM process might be for older patients and their family members? The most significant thing I remembered about my grandmother's CPM was the fact that all the conversation was directed to her during the CPM and that no conversation was directed to any of the family members present. My grandmother, as the patient, was clearly the key participant within the CPM however, this was to the complete exclusion of her family and we were not afforded any opportunity to express our opinions or ask questions. It struck me that although the meeting was striving to be as patient centered as possible, the meeting process was problematic due to the fact that family members were not given the opportunity to participate. The experience therefore provided an in-depth insight into the necessity of striving to balance patient and family member participation within CPM's and how this balance could prove very difficult to achieve in practice.

1.14 Significance of Research

The study presented here makes a contribution to knowledge by examining the unique perspectives of participants in CPM's, an area not well addressed in the literature. Older people are key users of complex health resources and the participation of older patients with a cognitive impairment is poorly understood so there will be a specific focus on determinants of participation for this group. This study aims to illuminate our understanding of how we can move along the participation continuum through identifying changes to practice using an action research approach. A three stage action research cycle was utilised with the MDT members acting as collaborators. A Training manual has been developed which details best practice guidelines for healthcare professionals within CPM's, which

particularly focuses on the promotion of patient participation within the care planning meeting forum.

Chapter 2 Literature Review

2.2 Introduction

This chapter discusses the research literature relating to this study. As already stated the key focus of this study is the care planning meetings (CPM's) forum therefore the chapter will begin by defining what is a care planning meeting and outlining its function and purpose. The chapter will then outline the group composition of a CPM and the different stages that are usually involved. Since the thesis is about patient and family members' participation, literature relating to participation within CPM's will then be explored. The chapter will outline what is currently known about this area. 'Participation' as a concept invokes different meanings for different actors and thus it is necessary to discuss the complexities relating to the definition. The chapter will then progress to examining the defining attributes and tenets of patient participation. As much of the literature relating to this topic relates to patient participation in nursing and medical decision-making, patient participation relating to these areas will also be examined before moving onto looking at participation within the context of discharge planning and older persons. The chapter will conclude by looking at why there has been a move in both research and in practice towards patient participation and this will be discussed within the conceptual framework of personhood and citizenship and the redistribution of power through organisational change

2.3 Literature Review Strategy

A literature search was conducted using Pubmed, Medline, the Cumulative Index to Nursing and Allied Health Literature(CINHAL),PsychINFO, JSTOR and Refworks databases using the following MESH headings singularly and in combination: 'meetings/group meetings', 'stroke', 'patient participation', ' multidisciplinary team', 'aged' , 'family', 'family caregivers' 'discharge planning' and 'action

research'. This search strategy identified only a limited number of articles so an alternative strategy was adopted of hand-searching through bibliographies of articles and books to discover other relevant materials. Because of the paucity of literature relating to CPM's with older people/stroke patients, available literature relating to CPM's with other client groups was also examined including Australian studies in palliative care and rehabilitation settings. A significant body of the literature drawn on is based on Swedish research where there has been a strong focus on the issue of patient participation (Eldh et al.,2006;2008;2010;Sahlsten et al.2005;Florin,2007;Eckdahl et al.,2010) with some of that directly relating to patient participation in CPM's (Efraimsson et al.2004;2006 Hedberg, (2007;2008). There appears to be a complete absence of Irish and British literature relating to the specific issue of CPM's[2] and only a handful of studies were identified in the US literature (Abramson,1990;2001).

2.4 Overview

Five years ago, a call for increased patient participation and joint decision-making to coordinate decision-making in nursing, medical and care planning was made (Hedberg et al.2007). There is evidence however that creating opportunities for participation in a hospital environment is a challenging and complex process(Meyer 1993,1995) and older people who are hospital patients appear to be particularly vulnerable in this area(Mc Cormack 1998,Tutton,2001). Research suggests that the patient perspective of their involvement in CPM's is poorly represented (Asplund et.al 2000) and the structure of CPM's may also not always accommodate the needs of the older adult (Popejoy, 2005).

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[2] With the exception of that relating to child welfare

Florin(2006) points out that although studies have explored the concept of participation, it is unclear whether the expectations and experiences of the patients themselves have been considered. She concludes that there is a lack of knowledge about what it takes for participation to occur in healthcare and what conditions contribute to patient experiences of non-participation. It would appear therefore that whilst it is acknowledged in the literature that participation is a challenge in the hospital context, particularly for older adults, there is a poor understanding of how patients themselves understand and experience participation in CPM's.

2.5 Defining a Care Planning Meeting

CPM's are increasingly an integral part of multidisciplinary team work in hospital settings, however, there does not appear to be a universal understanding or definition of what is meant by this term. Although this forum is intended to encourage active participation and empowerment of older people and their families in decision-making, doubts exist about whether this happens in practice(Abramson,2001)). The scope of the literature to date has been also been quite narrow and the majority of studies have been of a qualitative nature. Studies on CPM's have largely focused on intensive care (Hollingsworth,1978), paediatrics (Mc Clain and Bury,1998),palliative care (Curtis et al,2001,Gueguen et al,2009;Hudson et al,2009),rehabilitation settings (Froenck,2005) and primary care settings (Kushner et al.1989). Much of the literature is not comparable because of different settings, aims and structures of the care planning meeting such as those concerned with end-of life decisions in palliative care. Findings relating to these studies will be discussed in section 2.16.

A review of the literature not only identified divergent understandings of what constitutes a CPM but also the existence of a range of different terms describing the same or similar processes. These range from family meetings(Griffith et al.

2004), family conferences (Hansen et al. 1998), discharge planning conferences (Efraimsson et al. 2003) and more recently care planning meeting (Popejoy,2005, Hedberg et al. 2008). It is possible that the move towards the more neutral term of 'care planning meetings' may be due to the fact that 'family meetings' or 'family conferences' could be viewed as an anachronism if the key focus of the meeting is the patient, rather than family members(Crisp,1989).

For the purposes of this thesis I will use the definition provided by Hansen et al.(1998) as it appears to be the most universally used and comprehensive definition in the literature to date. They state that a family meeting,

'involves a number of family members, the patient and hospital personnel in discussions concerning the patient's illness, treatment and plans for their discharge or care outside the hospital'(p58).

Such a myriad of terms and differing objectives suggested there is a need for clarification about the nature and purpose of this small group process and how older people as patients and their families experience this phenomenon. CPM's are regularly conducted in a number of settings. However, the published literature offers limited insight into the meetings process as created by the multi-disciplinary team and the level of patient participation in this process remains somewhat unclear (Froenck, 2005). Although CPM's are used regularly in the acute hospital setting, few healthcare professionals are prepared to conduct them out proficiently(Fineberg, 2005).

It would appear from the literature to date that evidence based knowledge on how to carry out such conferences is limited and as alluded to in Chapter 1, the literature review has been unable to find any study which examines the participation of patients who have a cognitive impairment and/or communication difficulties. Although several studies have been found which specifically focus on CPM's, the majority of these related to CPM's between patients, their families

and allied health professionals, namely nurses and social workers/discharge planners. Aside from the literature relating to CPM's in the palliative care setting(Hansen et al,1888;Hudson et al.2009; Gueguen et al.2009), the literature review revealed only one study which involved direct observations of CPM's where members of the MDT, including the medical team were present(Froenck,2005).

2.6 Functions of CPM's

The variety of terms which exist to describe this forum reflect the number of functions this process can have including education(Gueguen et al.2009),rehabilitation planning(Griffith et al.2004;Froenck, 2005), information sharing and treatment planning(Griffith et al; Hudson et al.2009 ;Gueguen et al,2009) and discharge planning(Efraimsson et al,2006;2007;2008; Hedberg et al,2007;2008). It is difficult to find a definition of care planning in the existing literature however several terms are cited as being related to this concept including 'nursing plan', 'treatment plan' ,'discharge plan' and 'action plan'. Although these terms refer to aspects of the care planning process, they do not include the concept of patient involvement, person-centeredness and shared decision-making which are central to this process(NHS, 2004).

CPM's aim to achieve adequate exchange of information so that the patient and family caregivers, in consultation with members of the multidisciplinary team are able to make the decisions that are required for treatment and plans for the patient's future. The desired outcome it is suggested, is that the patient, family and healthcare professional are satisfied with the amount of information exchange, that decisions are made with clarity and that the patient feels a sense of control over decisions that affect their treatment and future plans (Ever,1981). Neville(2005) views CPM's as being a core component of the rehabilitative process for older patients in hospital with a delirium which offers patient, family

members and healthcare professionals an opportunity to ask 'where to from here?'. The focus of CPM's therefore should be to assist patients and their family members to reach mutually agreed goals in an inclusive, supportive and positive environment (Hargrove and Dersteine,2001).

2.7 What is Care Planning?

The care planning process requires multi-disciplinary collaboration between the professional care providers, patients and their relatives and they are undoubtedly an integral part of multidisciplinary teamwork which may greatly influence and shape a patients' care and treatment during their hospital stay. Care planning is about the process of negotiation, discussion and decision-making that takes place between the professional and individual. The Irish Health Service Executive(HSE) Code of Practice for Integrated Discharge Planning(2008) recommends that the discharge plan should be developed with the patient/family/carer in order to explore options for the patient's care post-hospitalisation, including family members, voluntary services and other healthcare providers The care planning process brings together the concepts and principles of patient involvement, shared decision-making, self-care support and patient centred care. Despite growing recognition of the importance of taking a person-centred and integrated approach to care planning, the experience of people accessing services varies significantly (DOH,2008).The issue of patient participation in care planning has been studied in a variety of contexts however most studies have focused on the professional caregivers experience rather than the patient's own experience of participation (Eldh et al.2006;Jewell,1994;Sahlsten et al,2005). This study attempts to narrow this gap in the literature by taking on board patient's own views and perspectives.

2.8 Benefits of CPM's

The literature identifies that CPM's play a significant role in a patient's hospital journey. Their usefulness has been particularly highlighted in palliative care settings, where family support for treatment planning and continuing care is vital (Gueguen et al.2007). The discussion within CPM's offers a forum for information to be exchanged about the patient's condition and treatment, to make plans for the future and to facilitate decision-making and maximize patient and family member control over this process. It has been argued however that there is a need to make targeted efforts to ensure the involvement of patient and family members and in particular to carefully consider the patient's wishes(Hansen et al,2001). Joling et al.(2008) explored the benefits of CPM's for primary care givers of persons with dementia. In a small randomized control trial, they demonstrated the cost effectiveness of CPM's as a tool for preventing anxiety and depressive disorders of primary caregivers of persons with dementia as well as the postponement of nursing home placements. This study would suggest therefore that CPM's have the potential to be mutually beneficial for all participants.

2.9 CPM's as a group decision making process

As CPM's are a meeting forum that involves a group of people, it is essential to closely look at the dynamics between group members and also how participants communicate and share information with each other. Group dynamics are derived from many theoretical perspectives held in the disciplines of social work, psychology, sociology and education and these understandings are applicable to any analysis of family conference functioning regardless of theoretical perspective (Froenck, 2005). Group dynamics can be defined as forces generated from the group process (Toseland and Rivas, 1984) and key aspects of group dynamics are communication and interaction patterns. Frey, Botan and Kreps

(2000) view communication both as a tool used to exchange information and as a meaning-based, constitutive process: "Communication refers to the process by which verbal and nonverbal messages are used to create and share meaning"(P28). It can be a demanding task to involve patients in the communication about their care (Hedberg et al. 2007) and how the creation of meaning is achieved in CPM's relies predominantly on the ability of the other participants to involve and help support the patient (Sundin et al.2002).The complexities of decision-making within CPM's which are often fraught with tensions between the agendas of different participants also contributes to the difficulty of managing the group dynamics within this forum.

Healthcare professional knowledge of group decision making processes in the clinical context is neither well developed nor articulated compared to extensive research on the use family group conferencing in child welfare contexts (Connnolly,2006). It has been argued that CPM's are an important forum for addressing disagreements and to improve decision-making processes (Clemens,1995). The multidisciplinary team play a key role in this process and it has been postulated that an MDT approach facilitates the bringing together of diverse skills and expertise to provide more effective, better coordinated and better quality service through the performance of interrelated tasks (Ernst and Glazer-Waldmaan,1983). A team can be defined as a group of people, each of whom possess particular experience, each of which is responsible for making individual decisions, who together hold a common purpose, who meet together to communicate, collaborate and consolidate knowledge from which plans are made ,actions are determined and future decisions are influenced(Brill,1976).

2.10 Composition of CPM grouping

The group composition is shaped by the purpose and objectives of each individual CPM. The decision-making process can be extremely complex and may

be prone to failure if the aim is to reach decisions that suit all participants (Hansen et al.2001). The ethos of CPM's implies that the key player is the individual patient. The literature states that the remainder of the group is determined by which of their family members the patient would like to be in attendance, and the relevant members of the MDT who are involved in the patient's treatment and rehabilitation. Multidisciplinary involvement is recommended for older people and the facilitation of 'patient involvement in decision-making' is therefore an interprofessional issue (NHS QIS,2004) and the MDT have a vital role in facilitating and enabling the active participation of older patients [Hedberg et al.2008). The team may be composed of a wide variety of healthcare professionals which can include doctors, nurses, physiotherapists(PT), occupational therapists(OT), social workers, dieticians and speech and language therapists(SLT).

MDT attendance at CPM's is determined by the nature and purpose of each meeting however occasions do arise where individual MDT members who have been identified as needing to attend a CPM are unable to do so. CPM's also are held where representatives of the community services may be invited such as public health nurses, GP's or home support providers who form part of the interdisciplinary team. As the group composition is not fixed, the communication, group dynamics and group processes differ from meeting to meeting and it will be necessary to closely examine the relationships between these factors and their impact on participation levels within this study.

2.11 Different Phases within CPM's

Best practice in CPM's identifies three specific phases in the process: a pre meeting preparation stage, the meeting itself and the follow up work to be completed after the conference (Hansen et al.1998).The critical pre- meeting

phase prepares the patient and family and develops objectives for the conference in relation to the overall goals for discharge. The actual CPM aims to achieve these goals through interactive communication, exchange of information and problem solving between the participants. The patient and family caregivers, in consultation with members of the health care team, are able to make the decisions required for treatment and plans for the patient's future care. The final stage involves the follow up of participants and the implementation and monitoring of the care plan. The desired outcome from this group process is that the patient, family and health professional are satisfied with the amount of information exchange, that care planning decisions are made with clarity, and that the patient feels a sense of control over decisions that affect treatment and future plans (Ever 1981).This study therefore sets out to examine the different phases within CPM's and whether they achieve the desired outcomes for patients, their family members and healthcare professionals.

2.12 What do we know about how CPM's function?

There has been a small body of research conducted to date on CPM's, the majority of which has been of a qualitative nature and carried out in New Zealand, Australia and Sweden. Griffith et al.(2004) conducted a qualitative exploration of the views and experiences of older patients, their family members and staff members in a geriatric hospital setting in New Zealand; the patients were not identified as having a cognitive impairment. All participants in this study identified the meeting as a forum where important decisions were made and family members reported a high level of satisfaction with meetings. Two thirds of patients were comfortable with the outcome of their meeting and the majority found the meeting to be helpful. Participation posed a challenge however with a third of patients reporting having been unable to get their opinions across during the meeting and many were unclear about the purpose of the meeting.

Three key themes arose during focus groups with staff members; pre-meeting preparation, staff skills and aftermath. The need to align agendas of all participants and to have overt discussions about the purpose of the meeting was highlighted; this was cited by all three groups of participants as the key underlying reason for unsatisfactory meetings. Staff members also stressed that patient autonomy should be promoted and that patients should be afforded opportunities to express their opinions during the meeting in order for the meeting process to be effective and meaningful. These findings clearly illustrate a conflict between staff's intentions to promote patient autonomy and some of the patients own reports of being unable to express their opinions. Drawing on Griffith et al.'s(2004) findings, this study will attempt to explore the issue of pre-meeting preparation, does it take place, and participant's experiences of its impact on the CPM process. It will also be important to examine if patients understood the purpose of their CPM and if they believed their opinions were listened to.

The language and behaviours of participants in four family conferences in an Australian spinal injuries rehabilitation unit was the subject of Froenck's (1995) study where data was collected through participant observations. She found that CPM's that were characterized by language and behaviours that were open, inclusive and that allowed for a response from the patient, were more likely to elicit a two-way dialogue between the patient and MDT. Punctuality of practitioners was a feature and findings revealed that practices such as speaking in the third person grammatical, lack of eye contact and lack of opportunities to respond, inhibited patient participation. Some practitioners were observed to use technical jargon which she believed patients were largely familiar with from their rehabilitation, but which family members were not. She also describes observing 'unequal egalitarianism' in two conferences where the patient's view was dismissed and they weren't allowed to continue speaking. Although practitioners exhibited some exclusionary practices, overall findings from this study contradict

other research relating to CPM's, in that patients were deemed to play a very active role and were able to express their opinions for the most part. However, family members were deemed to be largely passive. One reason for this finding may be due to the fact that the patients in the sample were younger(range 38-49) and were physically disabled but cognitively intact. Froenck (2005) concludes by emphasizing the personal significance of family conferences for patients and identifying the need for skill development and education of practitioners to manage the complexities of this process. This study is useful as it undoubtedly provides a detailed insight into the communication interplay used by practitioners within CPM's however, it is difficult to reconcile how patients were deemed to play an active role when practices that inhibit participation were clearly occurring and the small sample size is also a concern.

2.13 Patient Participation within CPM's

As mentioned earlier, most studies reporting on patient participation in CPM's originate from Sweden and it is this body of literature which this thesis will predominantly build on. For example, the issue of participation of older patients in CPM's was explored by Efraimsson et al.(2003,2004,2006a;2006b) who observed eight discharge planning conference involving eight older women in Sweden who were cognitively intact. The purpose of the discharge planning conference was identified as an opportunity to increase the patient's influence on decision-making in relation to their care planning. Although legislation exists in Sweden to support the older people's right to participate in decision-making related to their care, this study found that the majority of woman were powerless in their discharge planning conference. Efraimsson et al.(2004) reached the worrying conclusion that all participants were actually 'fooling themselves' into believing that their participation played any role in the ultimate outcome of the discharge planning process and that in most cases decisions had already been made prior to the conference taking place. In a later study they asserted that the

basic premise of democracy, autonomy and patient participation was absent as the patient was not awake enough to participate (Efraimmson et al.2006).

In contrast, another larger study which examined 33 discharge planning conferences which also took place in the Swedish hospital system showed that six out of ten cases the patient was the main decision-maker (Lundh and Williams,1997). Interestingly however, 55% of patients in this study did not believe that they had adequate information to participate meaningfully in their discharge planning conference. It would seem therefore that there are contradictions within the literature about whether patient participation is fully realised and suggests that patients are not always adequately prepared to participate in an effective manner.

2.14 CPM's: Healthcare Professionals Perceptions and Understandings

Much of the literature relating to patient participation does focus on the perceptions and experiences of healthcare professionals rather than the patient's own experiences. Hansen et al.(1998) examine family conferences as decision-making forums in an acute and rehabilitation hospital setting and focus on social worker's perceptions of patient and family member participation. They carried out a survey with thirteen social workers and asked them about their perceptions of the last two family conferences they had attended. The most commonly identified purposes for the conferences were to provide family members with information (92%) and to facilitate collaborative decision-making about the patient's future care. They found that disagreements arose in 50% of CPM's which is higher than the 26% reported by Abramson et al.(1993). The one hour duration of the conference was also deemed to be inadequate to achieve the wide variety of objectives of all participants and for the patient and their family to adequately consider all options. This study's usefulness has limitations as it focuses only on the perceptions of social workers and relates to their

retrospective accounts. Nonetheless, this study concludes that the need for information exchange and joint decision-making involving patients and families is widely, though not universally accepted, within the hospital environment.

2.15 Communication within CPM's

A key function of CPM's is information sharing and decision-making and thus the manner, type and organisation of communication is of central importance. However, it has been asserted that the basic formality of the conversation in CPM's poses challenges to patient participation (Efraimsson et al.2004). Hedberg et al.(2008) found that one of the major factors that impacted on participation levels in CPM's was the patient's need for communicative alliances with other participants when negotiating their needs and desires of further care. They also found that the most important alliance was between the patient and their relatives. They conducted participant observations of 14 CPM's with stroke patients in Sweden and focused on what was discussed during the CPM, to describe to what extent participants were involved in the conversation, and to examine how conversation was organized.

They found that healthcare professionals dominated the discourse space to a larger extent than the patient and their family members combined. Their findings suggest that healthcare professionals have a critical role to play in influencing participation levels through supporting stroke survivors to communicate and express their opinions. They concluded that a low degree of participation may be interpreted as if the patients' voices are mostly ignored however, participation levels may also be influenced by other important factors. They recommended that further research should be conducted into how to involve vulnerable patients in multiparty talk. The current study hopes to address some of these issues.

As Hedberg and colleagues do not state that any of the patients have a cognitive impairment, it must be assumed they do not, and as stated in the introduction, a search of the available literature has been unable to identify any study that examines the participation of patients with a cognitive impairment either within CPM's or their participation in more general care planning and healthcare. It would appear that there is a lack of knowledge in the existing literature about how to involve vulnerable patients, such as those with cognitive and communication difficulties, and the literature identifies the need for healthcare professionals to receive educative training in this area.

2.16 Challenges within CPM's

Evers (1981) suggests that CPM's are not always coordinated by mutual collaboration amongst healthcare professionals and service users, but by means of established work routines which are broadly applied to categories of patients, and by the operation of the traditional hierarchy of social relations in health care. CPM's may therefore result in the limited participation and dissatisfaction of service users culminating in poor decisions and care planning (Ever 1981). Studies report dissatisfaction with the level of patient and family caregiver involvement and suggest that this is the result of hospital systems and processes and the inequitable relationship between health professionals and service users (Walker et al. 2001). Concerns have been raised that health professional staff tended to talk *about* rather than *to* the patient in meetings and that family members were seen as more important speech partners than the patient. There has also been reference to the possible 'tokenism' of patient participation within the CPM's process (Hedberg et al. 2007).

Information exchange and decision making is sometimes considered by health professionals as a routine and not demanding a high level of skill (Hansen et al. 1998) however, group work is an inherently complex process. Creating a context

conducive to participation is dependent on a range of factors such as the facilitation styles of the group,(democratic, autocratic),the number of participants, communication processes and level of consensus and conflict. Time pressures, limited choices, the stress associated with critical decisions, and conflicting agendas (Coulton et al. 1988) are additional factors. The power imbalance between healthcare professionals and patients and family members can also negatively impact on the level of communication and stress encountered by the older person (Hansen et al. 1998) and thus there would appear to be many complex, interrelated challenges associated with patient participation in CPM's.

Studies indicate that healthcare professionals need to proactively facilitate the involvement of older patients and their family and to consider carefully the patient's wishes (Abramson,1990). The need for healthcare professionals to adapt their communication approach to meet individual patient needs is highlighted in many policy and research documents (e.g. Charles et al.1999, Elwyn et al.2001). Mishler's(1984) influential work identifies the role of 'two voices' in consultations between doctors and patients and he argues that the level of patient participation will be influenced by whether the doctor integrates the 'lifeworld' voice and the 'medicine' voice or ignores the lifeworld voice. Therefore they assert that consultation is defined interactionally.

Older patients are reported as having lower levels of influence over decisions in comparison with family members which may result in older patients being left out of the decision making process (Abramas, 1988). Organisational pressures such as discharge deadlines, limited resources and time pressures can make for quick efficient discharge planning practices which can contribute to the patient feeling coerced (Clemens, 1995) into process and plans that are not sensitive to their needs. The concept of patient participation is closely tied to issues of communication and information giving and Jewell(1993) argues that her findings

suggest that communication between hospital staff and patients remains an area of practice in need of attention.

2.17 Factors that encourage and hinder patient participation in CPM's

As mentioned earlier, CPM's that run smoothly are those where the agenda has been aligned and negotiated in advance between patients, family members and staff. This involves conveying and gathering information about the patient and family, adjusting expectations and resolving differences (Griffith et al.2004). Opie(1998) found that when healthcare team members positioned themselves as expert, and the older person or family's opinion falls secondary to the expert opinion, patient input into the discussion may be discouraged and the patient's wishes may not be given full credence or considered pertinent. Hedberg et al. (2007,2008) give further weight to this argument as they observed that professionals dominated the discourse space during CPM's with stroke patients and that the professionals conversed more than the patients and relatives put together. This domination mirrors previous findings about institutional talk with patients (Agar 1985, Satterlund Larsson 1989, Johanson 1994,Baggens 2001, Efraimsson et al. 2004) and it is clear that the concept of patient participation is undoubtedly extremely complex and multifactorial in nature. All participants within CPM's have a responsibility to ensure that their behaviour is understandable and relevant to the other participants (Goffman 1983a). Communication however is not as simple as sharing information, it must also be viewed in the context of how to involve patients from their own standpoint and encompass their unique perspectives (Goodwin,1995).How patients participate in the CPM process therefore depends on how they are able to contribute, but also how they are involved by the other participants. Patients require communicative alliances with other participants, and in particular their relatives, when negotiating their needs and desires of further care (Hedberg et al.2008).

The importance of informal processes in communication has also been identified as significant. Jarrett and Payne (1995) observed that an increased awareness about how non-verbal signals, such as body movements, can indicate that patients wish to talk about something, and that these types of signals should be supported and acted on. The question must be posed however about whether healthcare professionals are actively aware of these influencing factors within CPM's and their potential impact on participation levels of patients? This study sets out to explore this issue through mini-focus groups with MDT members and also through the action research process which will require MDT members to reflect on their current practices within CPM's.

2.18 CPM's – An institutional Conversation?

CPM's are clearly not an example of everyday conversation and Efraimsson(2006) makes the point that discharge planning conferences are an example of an institutional conversation and that communication differs from ordinary talking where participants engage on fairly equal grounds (Drew & Heritage 1992, Sarangai & Roberts,1999). The difference between 'Institutional discourse' and 'everyday talk' is, according to Linell (1990), that it takes place between professionals (socially acknowledged experts with authorization to accomplish certain tasks) and lay persons.

It has been argued that one of the main conditions for a successful discharge is effective communication between all participants in discharge planning conferences (Armitage and Kavanagh,1998; Clare and Hofmeyer,1998; Weaver et al., 1998).Research into institutional conversations in healthcare context has predominantly focused on doctor–patient interactions, but rarely on other healthcare professionals' communication with patients (Sarahgai & Roberts 1999). Efraimsson et al.(2003) in their in depth case study of a discharge planning conference with an elderly lady concluded that as in most institutional

discourse(Agar,1985), the majority of the discourse and topics discussed were dominated by the professionals. They concluded that the older lady felt a sense of powerlessness and was treated as an object which is clearly an issue of concern. In a follow-up study they reflected that healthcare professionals in their role as institutional representatives, experience a tension between their caring role and their obligation to enforce the values and roles of the institution and this is often imbedded and reproduced in their communicative praxis (Efraimsson et al. 2004). It would appear that an awareness of this factor is a prerequisite for improvements in working practices congruent with a caring approach that supports patient participation.

Efraimsson et al.(2006) question the credibility of the discharge planning conference as a tool for care planning for the weak and vulnerable and advocate that further research needs to be done in this area. Criticism has been directed at the fact that patients and families are led to believe that the discharge planning conference is a democratic process where decisions are reached mutually and that the institutional frame should instead be acknowledged (Efraimsson et al. 2006). They argue that there is a discrepancy between the ideological intention and the actual realisation of discharge planning conferences. They conclude that humanistic ideals such as 'patient perspective', 'autonomy' and 'democracy' evoke expectations that aren't always met and that this results in ideological contradictions as healthcare professionals struggle to meet institutional demands. It is of crucial importance that this study considers whether the CPM's observed are a genuine tool for care planning for patients who are vulnerable within the care planning process as a result of cognitive and/or communication difficulties.

2.19 Practice principles that underpin effective CPM's

The published research explores practice-related issues that can contribute to effective CPM's however, the majority of research conducted in this area has related to CPM's in the area of palliative care. Despite the promotion of CPM's as an essential tool for information sharing and goal clarification, it has been reported that sparse evidence exists to demonstrate the process for training staff to conduct or participate in them(Gueguen et al.2007). A review of the literature has not revealed any studies or guidelines for healthcare professionals which relate specifically to the issue of patient participation in CPM's and it would appear that there is an definite need for best practice guidelines in CPM's for MDT members working in aged care settings. Nonetheless, MDT involvement in the development of guidelines has unquestionably been recommended, as it may help promote validity, and by involving key stakeholders at a local level, can help ensure the credibility and implementation of guidelines at a wider level(Ross et al.2005).

White et al's(2007) study which involved qualitative analysis of 51 family conferences in four Intensive Care Units determined that in 29% of conferences, opportunities were missed by the facilitators of the meetings. Hudson et al's.(2008) study meanwhile demonstrated the utility and effectiveness of having clinical guidelines for MDT practice within palliative care family meetings. When also referring to the palliative care setting, Gueguen et al.(2007) identify five key tasks related to family meetings: set-up of the meeting, co-facilitation emphasizing the role of the MDT, engaging in cultural sensitivity, understanding the family's strengths and vulnerabilities, and delivering resources as appropriate. In particular, they emphasize the need to identify whether patients can or should attend however,they do not offer any direction as to how this decision should be made or by whom. This is pertinent to this study in view of current inconsistencies in practices in the research setting.

Gueguen et al's(2007) study is similar to much of the literature relating to CPM's in palliative care, in that it predominantly focuses on the needs of family members as the nature of palliative care means that often the patient is medically unwell so they are not the key participant in the meeting. These studies provide useful practice guidelines on how to effectively conduct CPM's. They postulate that communication skills can be taught to healthcare professionals in a manner that participants find helpful, thus improving their experience within the CPM and improving the confidence levels of the healthcare professionals involved. While the existing practice guidelines relating to CPM's are unquestionably useful, there is a definite necessity for MDT practice guidelines that relate specifically to the issue of patient participation within CPM's.This study will strive to fill this gap in the existing literature.

2.20 Defining Participation

Participation is often seen as a concept that is elusive and ambiguous, a diversity of opinions exist on this issue and there is no clear consensus on what patient participation entails (Ashworth et al.1992; Cahill,1996). The interpretation of research in this area is unquestionably made difficult by a lack of commonly agreed definitions (Roberts,2002).Croft and Beresford (1992) claim participation to be 'one of those contentious words...which can seem to mean everything and nothing' (p20). The Oxford English Dictionary(1989) states that the word is a Latin derivative; participare which means to take part in (pars=part and campere=to take). MeSH meanwhile defines patient participation as involvement in the decision-making process in matters relating to health. One of the few explicit definitions of patient participation is that of Street and Millay(2001) given in relation to consultations between doctors and patients,

'For our purpose we define patient participation as the extent to which patients produce verbal responses that have the potential to significantly influence the

content and structure of the interaction as well as the healthcare provider's beliefs and behaviours'(Street and Miller,2001,p 63).

It is worth noting the variety of similar or related terms that are often used interchangeably with participation. For example "involvement" is often taken to mean "patient centeredness", which does not necessarily imply active participation (Cahill,1996; Elwyn et al.2000). According to McEwen et al.(1983) patient participation in healthcare, 'relates to the activities performed by an individual on behalf of others in the maintenance and promotion of health, the prevention of disease, the detection, treatment and care of illness and the restoration of health, or, if recovery is not possible, adaptation to continuing disability' (Mc Ewen et al.1983,p48).

It would seem therefore that patient participation occurs in many contexts and according to Mc Ewen et al's definition, the patient assumes an active role, implying that the patient has a desire to participate. It has been argued that many of the definitions such as Brownlea's(1987) which will be discussed in the next section, with its explicit focus on decision-making pays more attention to the collaborative aspect of participation instead of focusing on the individualistic perspective of the concept. Clayton(1988) attempted to clarity the concept and argued that the literature relating to participation could be divided into 3 broad categories; enhancement of decision-making, enrichment of quality of life and sharing of power.

2.21 Patient Participation specific to Decision-Making

One of the most cited definitions of patient participation is that advanced by Brownlea(1987,p.605) who defines it as: 'getting involved or being allowed to become involved in the decision making process or the delivery of a service or the evaluation of a service, or even simply to become one of a number of people consulted on an issue or matter.' Holloway(1993) has a similar interpretation of

the term and suggests that participation is the involvement of people in decisions, giving them some feeling of control or responsibility. These definitions could be viewed as problematic however as they specify that participation is related to decision-making and other studies have disputed whether this should be the case(Eldh,2006).

Some studies have suggested that a broader definition for participation should be embraced which focuses on tenets such as sharing of information, involvement or taking part. Thompson(2007) found that patient participation is understood by members of the public as a specific form of involvement that implies a reciprocal relationship of dialogue and potentially shared decision-making with healthcare professionals. An alternative definition of participation is provided by Rifkin and Pridmor(2001) who argue that is takes place in a situation when an individual has the information that she/he needs and applies it to that situation(Almborg 2009). Richardson(1983) in a comprehensive review of this issue proposes that participation involves, 'taking part in some activity with other people'(p8). She goes on to question the amount of involvement this implies and states that the activity should be specified. Some of the difficulties relating to the definition and conceptualisation of participation have been attributed to underlying philosophical and political beliefs and whether one is approaching it from a humanistic perspective or a consumerist ethos (Meyer,1993).

2.22 Conceptualisation of Participation

One of the biggest challenges to researchers in the area has been how to conceptualise and measure the concept of participation. In the absence of agreement on definition, confusion and ambiguity pose challenges when trying to determine if participation has taken place, and in trying to conceptualise the nature of participation which has occurred. The majority of published work in this topic has centred on patient participation in medical decision-making and

nursing care and as alluded to earlier, the area of patient participation relating to more general care planning appears to have been largely ignored.

The increased focus on the issue of participation is a reflection of the move away from a paternalistic philosophy of the patient as a passive recipient of care to one where the patient is more involved and takes on a more active role in their healthcare(Collins et al.2007).Some theorists such as Guadagnoli and Ward(1998,p337) promote patient participation on its own merits, 'it is justified on humane grounds alone and is in line with a patient's right to self-determination'. Others advocate it on the grounds of increased patient satisfaction, better disease management and encouraging patient's to take control of their health(Collins et al.2007). However, there are many challenges related to achieving patient participation and the evidence suggests that patient-centred care and shared decision-making are not widely practiced and that many healthcare professionals lack the necessary skills(Collins et al.2007). Research also shows that breakdown in communication between patients and doctors is the reason cited for the majority of complaints to disciplinary bodies(BMA Board of Medical Education,2004).

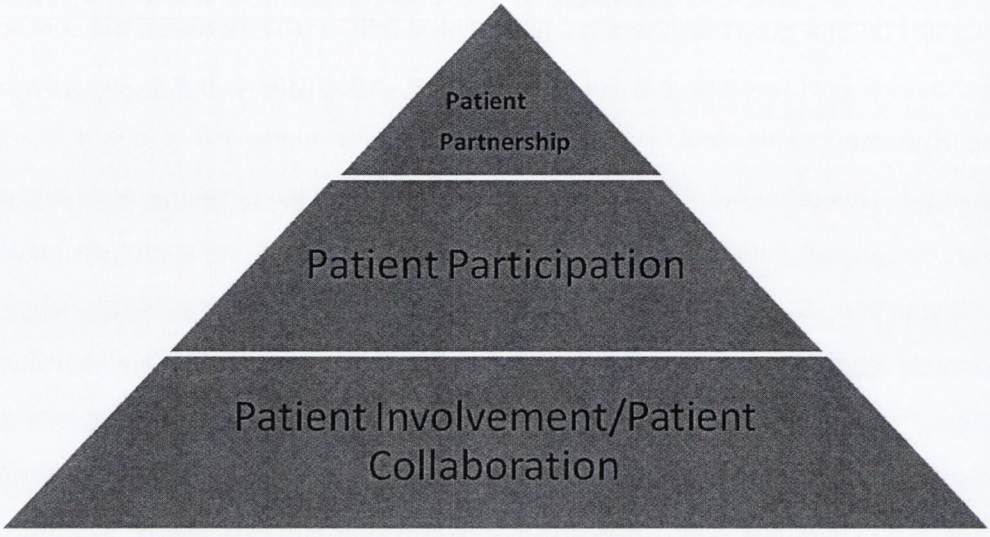
Concepts of 'involvement' and 'participation' are often used interchangeably despite being problematised individually (Elwyn et al.2000,Jones et al.2004); a notable exception however is Cahill's typology and hierarchy of participation as detailed below. Several researchers have set out to identify prerequisites relating to patient participation in nursing care; these were characteristics that were defined as essential for the concept to occur. Cahill(1996) has produced the largest body of work as she sought to clarify the meaning of the concept of participation in her influential article 'Patient Participation: A Concept Analysis' which set out to define the main attributes to patient participation within the context of nursing care

2.23 Cahill's defining attributes of Patient Participation in Nursing Care.

Cahill (1996) argues that there is a hierarchical relationship between the concepts of patient involvement, patient collaboration, patient participation and patient partnership. Cahill depicts this in a diagrammatic hierarchal pyramid format, where patient involvement /collaboration form the base of the pyramid and are precursors of patient participation, which is in turn a precursor to patient partnership. She postulates that involvement is where the patient's voice is largely ignored and that tasks are delegated rather than shared. Cahill concludes that the concepts of patient involvement and collaboration need to be achieved before patient participation is possible, but acknowledges that these terms are close in meaning and often used synonymously, particularly in the US literature(Cahill,1996,p.567). Cahill asserts that patient involvement is perhaps closer to the concept of patient participation. She differentiates between these concepts by pointing out that involvement is a one-way process where the patient's voice is mostly ignored whilst participation is a two way process. Cahill's hierarchal depiction of participation can be seen in Figure 2.

It can be argued therefore that according to Cahill's definition, there must be evidence of a two-way process within CPM's in order to deem participation as having occurred. Whilst useful, Cahill's work could be critiqued on the basis that her analysis seems to bebased mostly on studies relating to healthcare professional's perception of patient participation(Eldh,2006) rather than patient participation per se. Again, this is an area which will be picked up on in this thesis.

Figure 2; Hierarchy of Participation(Cahill,1886)



Patient collaboration is another closely related concept. It differentiates from participation as it only focuses on intellectual activities. Mc Ewen et al.(1983) report that it is a 'mental process' where individuals are joined for the purposes of making decisions and again, this would seem to suggest that it and patient involvement are precursors to patient participation. Collaboration on the other hand has also been viewed as being co-operative however this is not necessarily the case for participation (Henneman et al.1995).

2.24 Degrees of Participation

Patient participation in healthcare decision making can be placed in an independency-dependency continuum that could range from non-participation through co-determination and delegation to self-determination (Sahlberg Bloom 2001), sometimes expressed as passive to responsible, (Latvala et al. 1999, Latvala 2002) or passive to active participation (Degner & Sloan 1992; Sainio et al. 2001;Caress et al. 2002; Kraetschmer et al. 2004).

Degrees of participation depend on a number of factors which can include severity and type of illness the patient is experiencing, (Szasz&Hollender,1956), the organisational structure, the amount of knowledge the patient has, and the patient's desire to participate in their care (Biley,1989). Thompson et al.(2007) meanwhile believe that demand for participation is dynamic and multi-faceted and is influenced by the type and seriousness of the illness, the knowledge/experience and personality of the patient, and the degree of trust that the patient has with the professional.

Some patients do not want to participate in their care and are reluctant collaborators; this is a factor that must be addressed and explored within the context of the patient and family interviews during this research study and will be further explored later in the chapter. The factors that influence participation can be divided into two interrelated groups; influencing factors that underpin participation in a general manner, and factors that influence participation within the actual CPM process.

2.25 Patient Perceptions of what Participation means

The concept of participation, as understood from the patients' perspective, was reported by Eldh and colleagues(2006). As mentioned previously, most studies focus on professional rather than patient views of this phenomenon, however, their study focused on when, and why, patients experience participation. They received 362 responses from the patients surveyed, which involved patients of all ages.They divided responses into two overarching themes related to firstly, participation taking place and secondly, knowledge and respect.

Conditions for non-participation related to absence of information being tailored to individual patient needs, lack of respect(not listened to) and passivity. They concluded that having the opportunity to take part in decision-making or access to information was not enough to ensure that participation occurs and that

communication between all parties, active listening to the individual's knowledge, situation, and respect, are required conditions for participation to occur. Participation was experienced as being confident, comprehending, and seeking and maintaining a sense of control. They concluded that active listening to the individual's knowledge and situation and respect are required conditions for participation to occur.

In a follow-on study in 2010, they concluded that patients do not perceive participation as being specific to decision-making and that the dictionary definition of 'sharing' more accurately relates to how patients depict participation. Eldh and colleagues study implies therefore that patients understanding of participation is somewhat removed from how participation has been defined by theorists and it will be important for this thesis to explore whether patients participation within CPM's reflects how they define this concept.

2.26 Definition of Participation which will be embraced by this study

The literature relating to participation indicates a continuum which ranges from a simple understanding of being involved (Arnstein,1969) , to consultation (Croft and Beresford,1992), collaboration (Jewell 1996a,1996b),partnership (Cahill, 1998) to its specific association related to decision-making(Brownlea,1987). This study will take definitions at both ends of the spectrum to determine older patients participation in CPM's in a hospital setting and will identify factors that influence or impede participation. The research will also explore older patients' preferences and expectations of participation, as well as family member and MDT expectations, in order to identify changes to practice to move along the participation continuum.

2.27 Tenets of Participation

This section will begin by discussing tenets of participation as outlined in the literature as when exploring the issue of patient participation, it is also useful to identify the antecedents of the concept of patient participation. The literature has identified a wide variety of interrelated and overlapping tenets of participation, and the importance that theorists place on these varies. It is interesting that a review of the literature has been unable to find any studies that identify tenets of participation relating to care planning as this process is very different to the focus and process of nursing care with its predominant focus on the physical care needs of patients.

Ashworth et al.(1992) state that the essence of patient participation should be trust and security and that a common knowledge base is essential; Jewell (1994) believes this can be conveyed by the patient being seen as a worthy contributor. Brownlea(1987) asserts that a respect for individuality is also a key component as a patient may not want to participate in all aspects of their care and Cahill (1996) points out that there must be a desire on the part of the patient to assume a degree of power, control and authority.

One of the most important components of patient participation relates to whether they can access a broad range of appropriate knowledge and information that is understandable (Eldh et al.2006;Florin,2007). Tutton(2003) believes that the use of control is another factor to be considered, particularly in relation to in the care of older people. She quotes examples of staff controlling patients through use of emotions (Lee Treeweek,1996),through language (Hewison,1995,Mc Cormack, 1998) and through encouragement and persuasion(Draper,1996).

More recently, it has been asserted that participation occurs when patients have the opportunity of expressing their needs and that they are treated as an individual rather than as a member of a larger homogeneous group(Bramberg et al.,2010).The importance of non-verbal communication was also highlighted and how it should be treated as importantly as verbal communication.

Non-participation is deemed by patients to be demonstrated by a lack of relationship, respect and information that results in poor communication (Eldh,2004;2006).It would appear therefore that there are challenges regarding how patients participate and the decisions they feel they can take part in. Again as previously mentioned, the issue of patients desire to participate must be explored. Abdel-Halim(1983) notes that this can be addressed by considering individual differences. He suggests that studies indicate that participation is most effective for those individuals who desire this but not for those individuals who prefer not to participate.

2.28 Cahill's Defining attributes of participation in Nursing Care

Cahill (1996) again contributes hugely to this discussion about participation in health care decision making. She outlines five defining attributes relating to the concept of patient participation in nursing care. These antecedents include that (i)a relationship must exist, (ii) there must be appropriate and understandable knowledge provided, (iii) some surrendering of a degree of power or control must occur, (iv) there must be an engagement in selective intellectual and/or physical activities during some of the phases of the healthcare process and that (v) participation must be viewed as having a positive benefit(Cahil,1998). She also outlines benefits that she believes resulted from participation such as improved patient empowerment and adjustment, enhanced decision-making, clearer communication, improved quality of life and a reduced feeling of powerlessness

(Cahill,1996). Cahill therefore not only identifies the conditions necessary for participation to occur but also the associated benefits.

2.29 Sahlsten et al's (2005) four properties of participation

Sahlsten et al.(2005) further contribute to the body of knowledge relating to patient participation in nursing care. Through focus groups with registered nurses, their study offers clarity and a deeper insight into the properties of participation though the underlying principles of these properties are similar and often overlapping to those identified by Cahill. They assert that participation is an interactional process characterized by 'mutuality in negotiation' and postulate that four main properties of participation emerged from their study;

(i)Interpersonal procedure which included communication and interplay of dialogue between patients and nurses.

(ii)Therapeutic approach which referred to the importance of the therapeutic relationship and emotional involvement

(iii)Focus on Resources which involved exchange of understandable information and appropriate knowledge

(iv) Opportunities for Influence(information, choice, decisions, responsibility)

This study concluded that nurses placed great stress on the importance of the patient and nurse being equal partners, however,it fails to discuss the challenges related to this or to elaborate on how the outlined prerequisites of patient participation can be achieved within the practice environment.

2.30 Exchange of Information and Knowledge

There is much debate within the literature on patient participation and the differing characteristics that underpin this concept and the degree to which they

impact on the participation process. One of the attributes that features most strongly amongst researchers (Cahill,1996; Ashworth,1992; Sahlsten et al.2005, Ekdahl et al.2010) is that of sharing of information and knowledge. It includes different variables to consider such as do those involved have a common understanding and share a common language? (Wilcox,1995) and is there an egalitarian communication system?(Cahill,1996). Feely(1973) and Rintala et al.(1986) meanwhile found that where patients experienced difficulties understanding information presented to them, participation did not occur.

2.31 Tenets of a Therapeutic Relationship

According to Burnard(1992) 'the main point of working in the healthcare field is to communicate' and patient participation is implicitly related to the concept of 'knowing the patient' (Florin et al. 2008). A perceived good relationship with healthcare staff has also been shown to promote active participation (Sainio et al.2001) and another fundamental antecedent to participation which is repeatedly cited in the literature is that of the existence of a therapeutic relationship (Sahlsten et al.2004; Eldh et al.2004;Roberts,2002;Sainio et al.2001,Tutton,2005). A strong link between relationships with staff and medical decision-making has been demonstrated (Sainio et al.2001; Sahlsten et al.2005) with respondents reporting that when they believed they had a good relationship with staff, they were more likely to participate in medical decision-making(NHS,2004).

It is important therefore to also explore what conditions contribute to a therapeutic relationship, and when considering the possible factors that can foster or inhibit a therapeutic relationship, it is necessary to establish what a therapeutic relationship is, or how it is characterised. Lloyd (1990) argued that for genuine alliances to occur between patients and healthcare professionals, trust and respect are vital. Muetzel(1988) and Ashworth et al.(1992) also allude to the

importance of interpersonal relationships and argue that an emotionally secure environment must exist for patient participation to take place.

It has been suggested that empathy is one of the characteristics of a therapeutic relationship and in this context involves a socio-emotional connection between a healthcare professional and patient and is vital for developing and sustaining the therapeutic relationship (Roter and Hall, 1989). Empathy can be expressed through both verbal and nonverbal channels (Sleath et al. 2000). Verbal expressions may involve words of support, expressions of understanding, or invitations to the patient to tell his or her story of the experience of illness or pain. Nonverbal expressions of empathy may involve eye contact during discussion of difficult topics, leaning toward the patient, or having a closer interactional distance than in more formal interaction (Hall,1995). It will therefore be important for this study to explore whether this is demonstrated in the interactions between the MDT and patients.

Trust has been cited as key to opening communication and laying the foundation for a strong interpersonal relationship (Bull and Roberts,2001) which may help encourage participation for all. Reassurance has also been cited as an important feature and reassuring means to instil confidence by adopting an open, honest and sincere approach which reflects a genuine interest in the patient's circumstances (Sahlsten et al, 2008). Praise is another characteristic identified as contributing to the therapeutic relationship and occurs where admiration or approval is expressed for somebody or something they have achieved. It would appear that there are many interpersonal factors that help create a therapeutic relationship and it has been identified in the literature as an important antecedent to patient participation.

2.32 Tutton's Tenets of Participation based on Older people's perception of Participation

When examining this topic in the research literature, Tutton's(2005) study is particularly interesting and relevant to this thesis as she adopts an action research approach and uses interviews to identify what participation means to frail older people in hospital and focus groups with staff to explore how to enhance participation in care. She advances a framework for patient participation that identifies facilitation, partnership, understanding the person and emotional work as key elements that influence the process which concurs with earlier studies outlined in the chapter (Cahill,1996; Sahlsten et al,2004). She believes that the themes from her study particularly reflect the challenge of promoting participation for patients with high levels of communication difficulty. Tutton(2005) also concludes that empathy and trust is imperative if participation is to occur; it is viewed as a partnership and her study has a strong focus on the humanistic, emotional component of the relationship between staff and patients. In contrast to previous research, this study did not view participation as a hierarchy of decision-making(Cahill,1996) but rather as a process that occurred within the context of care-giving and Tutton is critical of the effect that a hierarchal approach can have.

2.33 Influencing Factors on Decision-making

Patient participation in healthcare inevitably encompasses issues of decision-making so it is useful at this stage to explore what some of the factors are that influence patient participation in their health related decision-making. A wide variety of reasons have been advanced as influencing patient's decision-making processes and internal and external factors have been cited as crucial.

Internal factors are described as those which are related to each individual and their personality and include factors such as life context, personal values, and

beliefs and the degree of patient involvement desired (Popejoy,2005). The patient's physical health, willingness and ability to make rational decisions (Jewell,1996) as well as cultural backgrounds, levels of medical knowledge and previous hospital experience have all been seen as influential (Henderson,2002). Sainio and Lauri(2003) meanwhile identify socio-demographic factors such as age, and marital status, as well as the time since diagnosis, as exerting an influence on decision-making.

External factors have also been identified and include the type of decision being made, as major decisions that are more stressful or have long term implications may be more vulnerable to the influence of unequal power relationships (Popejoy,2005)The power relations present among decision-maker is also cited as important. Issues of communication again crop up and the use of everyday language, time being spent with patients as well as patients being encouraged to ask questions relating to the decision have also been viewed as influential. How decisions are framed and by whom may have a significant impact on how the information is processed and used by the decision-maker (Tversky and Kahneman, 1981). In relation to decision-making and older people, safety is also highlighted as a consideration, and at the intersection of risk and safety lie the concerns and preferences of the older person, family members and health care professionals. Finally, options are highlighted, as inherent in the definition of decision-making, is the availability of options or choices (Popejoy,2005).

2.34 Patient Participation in decision-making

A decision has been defined as a choice or action about what to do or not to do (Baron, 2000). Decision- making meanwhile has been described as having a choice between alternatives, in which the process is focused on choosing a particular course of action (Dowie, 1993).It has been asserted that placing patient and carer concerns at the forefront of decision-making is an ethical

imperative(Reed and Mc Cormack,2005). Benbassett et al.(1998) identified four types of roles of involvement in health-related decision-making; active, passive, collaborative and avoiding information. Studies meanwhile have indicated that passive individuals are those who tended to be sicker, frailer, less well educated and male (Davison ,Degner and Morgan ,1995;Shawler, Rowles and High, 2001).

Charavel and colleagues (2001) meanwhile described models of decision-making as placed on a continuum: (1) a paternalistic model in which the healthcare professionals make the decisions, (2) an informative model in which health professionals provide the patients with information to enable them to select the desired treatment, (3) an interpretative model in which health professionals and patients interact to identify the patient's wishes and values and support them to select treatment, and (4) a deliberative model that is very close to the interpretative model but adds a moral dimension to the interaction that emphasises the discussion between two partners.

Charles et al.(1997,) on the other hand, proposed the 'shared model': a two-way exchange of information with both the patient and the professional stating their treatment preferences and they then reach an agreement on the decision. The key characteristics are that at least two participants share information, acting to build consensus and eventually reaching an agreement. Thompson(2007) identifies four of the most common treatment decision-making models in relation to medical decision-making: *paternalism*, where the professional knows best and patient involvement is limited to being given information or giving consent; *shared decision-making*, where both the process and outcome of decisions are shared between professional and patient; *professional-as-agent*, where professionals possesses the technical knowledge but patient preferences are incorporated into the decision being made and *informed decision-making* where the technical expertise is transferred to the patient who makes the final decision(Charles et al,1997;Coulter,1997).Thompson(2007) outlines a power

continuum and interestingly, categorise consultation and information giving with patients as paternalism.

Shared decision-making has thus been defined as a process where patients and healthcare professionals consider outcome probabilities along with patient preferences and a decision is reached based on mutual agreement; there has been an increased move towards this approach. Conditions identified as necessary for this to take place include the atmosphere being conducive to patient participation and patients being made to feel that their contribution is valued(Frosh and Kaplan,1999).

Although the definitions outlined above refer to a shared approach, Charles et al.'s(1997) definition differs in its focus on a 'two way exchange', whereas in other definitions, this does not deem this to be a fundamental characteristic of this approach. It would seem therefore that even when theorists are discussing the same approach to decision-making, there is often ambiguity about how to define approaches which again reflects the complexity of participation and decision-making.

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2.35 Do Patients want to participate in Healthcare decision-making?

The argument has been advanced that the more patients feel that they are participating and are involved in decisions regarding their care,the more satisfied they are with the outcomes (Rydeman and Tornkvist, 2006). Coulton et al.(1988) found that post-hospital outcomes were poorer for patient who did not believe they had been involved in decision-making and had an internal locus of control. Proctor et al.(1992) meanwhile found that as the patient's degree of involvement in decision-making increased, so did their satisfaction levels.

There is a lack of consensus in the literature that examines whether patients want to be involved in decision-making and some of this relates again to how the concept of participation is defined. Guadagnoli and Ward(1998) in their study, review the evidence for and against patient participation in decision-making. They concluded that when patients were provided with sufficient information, they wanted to be involved in decision-making. They acknowledge however that their literature review related to very limited samples. They advocate that the first step in addressing the issue of patient participation in decision-making is to determine what this concept means and that participation should be defined by whatever level the patient is most comfortable with; however they do not offer any suggestions as to how this should be determined.

They assert that physicians should strive to engage all patients in decision-making albeit it to varying degrees and advocate the adoption of the transtheoretical model where patients may be differentiated on the basis of their 'readiness' to be involved in decision-making. They also point out that evidence suggests that matching an intervention to a patient's level of readiness to engage in a behaviour is more effective than the universal application of one intervention (Prochasta and DiClemente,1992) and that physicians should avoid adopting a paternalistic approach even with those patients who don't wish to participate. According to Muetzel (1988) some patients derive security from passivity and 'the doctor knows best' stance and therefore their preference is for a more passive role. Deber et al.(1996) meanwhile highlight the apparent discrepancy between the promotion of patient autonomy and research studies which appear to suggest that many patients may not want to actively participate in treatment decisions.

2.36 Other Influencing factors on Participation

Research has suggested that patients should not be treated as a homogeneous group. Larsson Lund et al. (2001) asserted that patients had little understanding

of the term 'participation' and that not all wanted to be involved in decision-making and rehabilitation planning but,they desired information. It is thought that characteristics of desire for information may also influence patient participation and decision-making and a divergence in people's desire for information exists; some strongly desire information while others do not (Folkman and Lazarus,1980). It would appear therefore that the literature is suggesting that not all patients want to participate or even receive information related to their healthcare and therefore an individualized approach to participation seems to be implied.

According to Bowling and Ebrahim(2001) individuals who do not want to be involved in their healthcare are likely to represent particular subgroups of the population such as older people, individuals with poor educational qualifications and those who are socially excluded. It is clear from the literature that not all patients desire the same degree or extent of involvement. Those who prefer a more passive role have been cited as being sicker, less educated and more likely to be from ethnic minority groups, male and elderly.

2.37 Influence of Family Members on Participation

Relationships with family member or support person is also suggested as being influential(Davinson et al,1995;Shawler et al.2001). A small number of studies have looked at patient and family member participation in decision-making and the majority concluded that more time was spent in discharge planning with family members and that patients had lower levels of influence and were only minimally involved (Coulton et al,1982;Townsend,1986). Older people often face great challenges in relation to their discharge needs, often as a result of multiple health problems or changes in their cognitive status, and therefore family involvement is usually necessary which may cause complications. It has been asserted that it should not be assumed that patient and family member

preferences are the same and it has been recommended that there is a definite need to assess both patient and family members preferences early in the discharge planning process(Huber and Mc Clelleland,2003). These studies concluded that healthcare professionals spent more time engaged with family members around discharge planning to the exclusion of the older person (Kadushin and Kulys,1993).

One of the main tenets of heath care philosophy is that of holistic care and an acknowledgement that family involvement is appropriate and to be encouraged (Archbold and Stewart,1996; Tilse,1997).For older adults in healthcare settings to benefit from constructive involvement of their family members, it would appear that healthcare professionals need a fuller understanding of the issues surrounding family presence in the healthcare environment (Haesler et al.2006). This study will thus aim to illuminate our understanding of the nature of family member involvement in discharge planning, through its examination of family members participation within CPM process.

2.38 Obstacles to Participation

Longetin et al.(2010) make an important contribution to the literature and outline overt and covert obstacles to patient participation related to healthcare professionals. Overt factors identified included a desire to maintain control, time required to educate and respond to patients, type of patient illness, personal beliefs, the discipline of the healthcare professional, and insufficient training in patient participation.

Covert ways that healthcare professionals can impede participation included limiting the amount and type of information shared, using closed-ended questions and authoritative language. They do point out that some obstacles to patient participation are not within the control of either the patient or the health care worker as patients' desires reflect societal norms and the permissiveness of

the health care environment in which they receive treatment(Belcher et al.2006) They conclude therefore that patient participation reflects societal norms and depends on whether the culture of the organization openly supports it.

2.39 Patient Participation in Medical Decision-Making

The move towards patients being increasingly recognised as consumers of health care services has resulted in an emphasis on patient autonomy in decision-making, and the patient being conferred a more active role. This signifies a move away from the historical paternalistic approach in medical decision-making with the expert physician and the dependant passive patient (Charles et al.1997). Florin(2007) argues that a huge disparity exists within studies with patient participation specific to medical decision–making and cites ranges from 27-78% preferring to have a passive role, whereas a collaborative role was preferred in 17-64% of studies examined. Furthermore, 4-32% of the patients preferred an active role in medical decision-making (Satterlund-Larsson et al.1989;Beaver et al.1996;Butow et al.1997;Beaver et al.1999;Ramfelt et al.2000;Sainio et al.2001;Davinson and Denger,2002). It is possible that the conflicting results in relation to this issue relate to how patient preferences for participation are defined (Gudagnoli and Ward,1998) and thus the difficulties of defining and conceptualizing participation are reiterated. Although some patients may want to be involved in the discussions, many prefer final treatment decisions to be made by their doctor and it has been recommended that care approaches must be tailor made as a collaborative model of decision-making is not desired by all individuals (Levinson et al.2005). There is evidence to suggest that staff do not always encourage patients to take part in medical decision-making and worryingly, that patients were not given the opportunity to express their views or opinions and that their wishes had not been taken account of (Sainio et al.2001).

Stevenson(2007), in her examination of what patients perceived makes a 'good' and 'bad' consultation with a doctor, emphasized the importance of doctors not only being knowledgeable about a patient's situation, but also that patients have trust in the doctor. She expressed the importance for patients of having a relationship with the doctor and feeling comfortable to express their thoughts and opinions. The extent to which people appeared to wish to participate related to being listened to and having the opportunity to express their opinion and have issues discussed and explained; there was little evidence of a desire for active partnership.

2.40 Participation of Older Patients

It has been postulated that older people and those in poorer health prefer a 'doctor-led' style of decision-making (Levinson et al.2005) and thus it was necessary to examine issues specific to the participation of older people. Active involvement in discharge planning is essential for older patients because of their need for continued care and support after discharge from hospital. Older people rightly demand improved communication with their health care providers, and ask to be informed and empowered to make decisions regarding their health care (Grimmer, et al 2004).

Many studies demonstrate the benefits of patient participation in their healthcare (Frolsch and Kaplan,1999;Greenfield et al,1985;Denger and Sloan,1992;Benbassat et al,1998;Whelan et al.2003).However, the number of relevant studies found on the participation of older patients is surprisingly few as reported by the Cochrane review by Wetzels et al.(2007). In response to this dearth in the literature, Ekdahl et al.(2010) set out to examine the preferences of frail elderly patients in medical decision-making through a qualitative study where they conducted semi-structured interviews with 15 patients who were over 75 and deemed to be 'frail elderly'. Whist the small sample size is a

limitation of this study, nonetheless findings concur with other studies which highlight that for this group of patients, they do not want to participate in medical decision-making. They do however want to be informed, listened to and desire good communication with healthcare professionals in the hospital (Bastiens et al.2007). This study also revealed that many patients perceived the hospital as an institution of power who were better equipped to make decisions on behalf of the patient

Rotar-Pavlic(2008) explored the perceptions and experiences of older patients and their GP's for shared decision-making in Slovenia as part of the international 'IMPROVE' research project. Using a qualitative approach they conducted semi-structured interviews with 40 older patients and 26 General Practitioners(GP). They concluded that a trusting relationship between the older patient and their GP was a prerequisite for involvement and more important than decision-making per se. They also identified much diversity in older patient's preferences for involvement and asserted that the communication methods of physicians should be adapted and tailored to the individual characteristics and preferences of each patient

Walker et al. (2001) contend that an older adult's participation in their healthcare can be measured according to the following criterion: feeling that information is shared (mutuality): feeling included in decision making (inclusiveness): feeling that there is someone you can contact when you need to (clear outcomes): and a feeling that the service is responsive to your needs (person centeredness). However older adults participation in clinical decisions can be fraught with many barriers, such as the ageist and discriminatory attitudes of hospital staff, communication and cognitive impairment and the interplay of competing agendas held by family members, healthcare professionals and the hospital as an institution.

Bastiens et al.(2007) study which examined general practice in 11 countries found that people aged over 70 wanted to be involved in their care, but for them involvement meant more of a focus on person-centered care, receiving information, and the caring relationship, than active participation in decision-making (Sanio et al.2001, Tutton 2005, Roberts and Chapman,2001). Huby et al.(2007) also set out to explore how older patients and healthcare professionals perceived, experienced and enacted 'participation' in discharge planning. They found that during interviews, patients demonstrated little engagement around the concept of participation and appeared to adopt a passive stance. They concluded that patients' experience of participation was directly related to their sense of loss relating to physical, social and mental capabilities and was connected to their increased reliance on others strategically to maximize whatever independence they could.

Healthcare professionals in a number of studies stress that factors such as age, personality, and physical and cognitive ability affected older people's levels of participation (Jewell,1993, 1996b; Huby et al;2004). Physical and cognitive debility have also been identified as impairing the older adult's ability to communicate with healthcare professionals and that hearing and visual impairments as well as pain levels may further impact on their ability to listen and engage in conversation (Opie,1998).

2.41 Older People's Participation in the Discharge Process

Participation in discharge planning is defined as receiving sufficient information and involvement in discussions about medical treatment, of goals and needs, care services and follow-up (Almborg, 2008). Active involvement in discharge planning is essential for older patients because of their need for continued care and support after discharge from hospital. Participation is a critical process in collaborative decision making. There has been little published research on patient

and family member preferences for information and participation in relation to their concerns and preferences around discharge planning beyond the fact that this is important(Jackson,1994). Organisational pressures such as discharge deadlines, limited resources and time pressures can make for quick, efficient discharge planning practices which can contribute to the patient feeling coerced (Clemens, 1995) into process and plans that are not sensitive to their needs.

Roberts(2002) set out to examine the utilisation of health and social services post-discharge from hospital in a sample of people aged 70 and over. She examined how active users were with reference to the principles of participation, representation, access, choice information and redress. This study used a narrow definition of participation, that of individuals (or their representatives) playing an active role in their own care on an individual basis for personal benefit. Roberts found that most service users believed that they had been able to express their wishes and that they were involved in discharge decision-making. However, sometimes this may just have been to be informed of what was going to happen.

In this study, older people did still revert to 'expert opinion' for final decisions relating to discharge and although offered the opportunity to participate, allowed professionals to act on their behalf. On the other hand, it has been argued that it is healthcare professionals who often view their role as that of expert and therefore dictate discharge plans to patients, thus failing to incorporate patient preferences in a structured way (Huber and Mc Clelland,2003).

Roberts (2002) study also revealed that there was an important role for family and friends. She postulates that the importance placed by older people on the role of professionals is a feature of both 'paternalistic' and 'consumerist' care. For older people who wished to actively participate, she found that participation was closely tied to choice about service delivery. On the other hand, healthcare

professionals viewed patient participation positively and were able to give examples of how they encouraged this.

Fisher et al.(2006) meanwhile set out to explain the participation of older people in the discharge process by conducting a qualitative systematic review. The findings of the review revealed the passivity of many older people in relation to discharge planning resulting in low levels of patient participation. They postulated that influencing factors such as education level, social standing, illness trajectory and its impact on the older person's life plan, and lack of information to plan for the future and concluded that interventions to support older people through their hospital experience should adopt a life-perspective framework.

2.42 MDT perceptions of Older Patient's Participation in Discharge Planning

An understanding of participation from the perspective of the practitioner is also central as their perspective may influence and shape how participation is experienced by patients (Glenister,1994). Studies have shown that healthcare professionals welcome the participation of older people in the discharge process and that they view it as central to the patient's assuming a more active role in their healthcare (Jewell,1996b;Kadushin and Kulys,1994; Bull and Roberst;2001; Roberts and Chapman,2001;Efraimsson et al.2003,2004).

Abramson's (1988) study set out to specifically examine the participation of older patients in the discharge planning process and their degree of control over the final decision as judged by social workers involved in their care. The results of this study showed that social workers perceived that most patient's participated actively; however poor patient condition such as a patient's physical and mental health inhibited full participation. Interestingly, it was concluded that family

control over decision-making also inhibited participation, even for those patients who presented as being able to make their own decisions.

Patients were deemed to have participated in decision-making however, those in the poorest physical and mental health were perceived to have had the lowest participation levels and those with moderate or severe dementia's participation was severely impeded. The study also revealed that over a quarter of all patients who had the capability to be involved in decision-making did not make the final decision relating to their discharge however their family members made the final decision.

Abramson(1988) suggests that a functional approach should be adapted with dementia patients so they can be involved in choices at whatever level they can respond to. While this study does provide useful insights into participation and the discharge planning process, a drawback is that it does not examine patient or their family member perception's of participation and focuses only on the social worker's experience.

Other studies have revealed that healthcare professionals believe that older people's lack of participation in discharge planning could be attributed to their age, mental and physical ability and personality(Jewell,1993,1996b;Huby et al.2004). It would appear that the literature to date implies that healthcare professionals have a good insight into many of the barriers that older patients face in the discharge process and in particular the barriers to participation faced by those in the poorest physical and mental health as well as the influence of family members.

2.43 Why the move towards Patient Participation in Care Planning?

It has almost been taken for granted that individuals should be more than passive recipients of healthcare, and a number of advantages relating to patient

participation have been forwarded including improved patient compliance and enhancement of dignity, increased satisfaction, and greater efficacy of health education (Ashworth et al,1992). Arguments for participation can be advanced on a number of grounds including moral, practical, philosophical, and political and is consistent with human and civil rights (Croft and Beresford,1992) which are an integral part of the values and ethics of healthcare professionals. Clayton(1988) argues that participation improves self-esteem and mental health, reduces alienation, encourages a responsible attitude towards health and generally enriches the quality of life of patients.

The assumption that striving for participation automatically confers the status of participant to patients must be challenged, and it has been argued that participation may be construed as tokenism or manipulation of users by providers. Conflict of interests may also arise as well as the claim that the involvement of more patients as true participants will result in delays and additional costs (Roberts and Chapman,2001). An essential feature of participation also assumes that the individual sees themself as having the right to speak and be listened to. However, this may not necessarily be the case. The healthcare system inevitably reflects the power and status disparities that exist in wider society in relation to social interactions. In the same way, influencing factors that exist in wider society such as economic status, age, class, and gender may have an impact within CPM's in the hospital setting.

2.44 Is Participation desired by all patients?

As alluded to earlier, patients have a right to be involved in planning about their health care (Roberts,2002).However, it is important to pose the question, is participation really desired by all patients and are there circumstances where patient's participation might be harmful? Would some individuals prefer to remain passive and dependent? Although patient involvement is a right, is it not

contradictory to put pressure on those who do not want to assume this responsibility? (Waterworth and Luker, 1990).

Many health services and the World Health Organisation argue that patients have a responsibility and a 'duty' to be involved in their healthcare. Could this process of empowerment also be viewed as a way of reducing costs for the health service by having patient and families assume more responsibility? It would appear therefore that there are challenges regarding the decisions patients feel they can take part in. Again, as previously mentioned, the issue of patient's desire to participate must be explored. Abdel-Halim(1983) notes that this can be addressed by considering individual differences. He suggests that studies indicate that participation is most effective for those individuals who desire this but not for those individuals who prefer not to participate.

Ashworth et al.(1992) remind us that participation does not just entail involving patients in care plans, and thus this study will aim to explore and describe the many different types of patient participation observed within CPM's. It would appear based on the literature reviewed for this thesis, that there are many important and interrelated factors that influence patient participation and that it is a highly individualized process specific to each patient and situation. This research study must describe and explore the concept of participation both in a general sense but also in relation to each individual patient and their own understanding and experience of this concept.

2.45 The Rise of the Consumer Movement

Patient participation as a means of enhancing decision-making has been widely acknowledged (World Health Organization 1978, Council of Europe 1982, Audit Commission, 1993). Hickey(1986) attributes the move towards a participatory approach to healthcare to increase consumer knowledge, an increased awareness of consumer rights, movements towards self-help, accelerated health

care costs and economic stringency, and an increasing awareness of the fallibility of health professionals (Cahill,1998). It would seem that a consumer model has gained prominence and its aims are to increase accountability, to provide more efficient services and to counteract professional power and authority (Roberts and Chapman,2002). Critics of this model argue however that its real objective was cost curtailment through a reduction in public welfare resourcing and provision (Barnes and Walker,1996).Meanwhile Small and Rhodes argued that the consumer model of participation could 'distort priorities' by giving the more able and more organized privileged access and consequently, it (was) not necessarily egalitarian' (Small and Rhodes,2000,p221).

2.46 Power

There is an interesting debate in the literature relating to power and its relationship with patient participation. Some theorists have postulated that notions of participation are inextricably linked to the concepts of power and empowerment(Foss,2011). It has been argued that power is extrapersonal, indicating that an increase in one's power must be balanced with a decrease in someone else's power; Thompson (2007,p1308) describes patient participation as 'a degree of transfer of power from the professional to the patient.' An alternative conceptualisation of power has been embraced by Foss(2011) which stems from a Foucouldian perspective. She asserts that power is not exercised through a transfer of rights or power and instead participation depends upon how power is shaped and reshaped through interactions between healthcare professionals and older people. The recognition that power is 'exercised', rather than 'possessed '(Manais and Street,2000,p54), means that power is embedded within patient participation. In this way, older people are not only constructed as passive recipients defined by the discourse and practices of healthcare professionals, but they are also agents who are actively responding to, and withstanding the discourses being communicated.(Foss,2011). When analyzing

and examining an event such as CPM's, it is important therefore to acknowledge that the event is influenced and shaped by the discourses used to shape that event.

2.47 Control

Numerous studies indicate that individual loss of control over the social and physical environment is associated with impaired physical and mental health, decreased social and personal wellbeing, and increased mortality rates, especially for elderly people who are forced to relocate as a result of illness or other crises (Mirotznick and Ruskin, 1984; Rodin, 1986; Schultz and Brenner, 1977). It is also well known that the more the patients feel that they are participating and are involved in decisions regarding their care, the more satisfied they are with the outcomes (Rydeman and Tornkvist, 2006).

Control is also a factor which must be considered as pertinent to this study, as the hospital setting could undoubtedly be considered a situation in which patients are likely to have limited opportunities for control which may contribute to them feeling powerless (Jones et al. 2000). Langer (1975) suggests that in these situations, where there is a perceived lack of control, it may be helpful to introduce an illusion of control. Within this study, the CPM process therefore could be a valuable opportunity in which to empower patients and help them regain control over their treatment and involvement in decision making. This study will thus attempt to explore during interviews with patients as to whether they believe that the CPM process offers them increased control over their care planning during their hospital stay.

2.48 Patient Centeredness

Patient centeredness is generally viewed as an important feature of high quality patient care. The phrase patient-centeredness was originally coined by

Balint(1969) to express the belief that each patient 'has to be understood as a unique human being'. It is closely aligned with the concept of personhood (see page 95) and places a focus on the individual as a person. A broader definition of patient-centered care has since been advanced which stresses that it is care that is responsive and aligned to each patient's individual needs and preferences (Laine and Davidoff,1996). Principle characteristics of patient centeredness have also been identified; these include moving away from a biomedical perspective towards a biopsychsocial approach, not defining patients as a body or illness but instead as an individual person, sharing of power and building a therapeutic alliance with each patient(Mead and Bower,2002). It has been suggested that patient-centeredness lies at one end of a continuum with 'doctor centeredness' and medical paternalism at the other. A truly patient-centred approach however should not force patients to assume power and make decisions, and for some patients, a shared decision-making or delegated approach with healthcare professionals may be an essential part of preserving their dignity and autonomy(Katz,1984).

Autonomy derives from the Greek for self and law and in a philosophical sense,a human can be seen as autonomous 'if she does what she chooses to do so (because she chooses to do so) and chooses to do what she does because she wants'. From a healthcare perspective, autonomy has been defined as 'the exercise of considered, independent judgement to effect a desirable outcome'. In contrast, Jones et al.(1997) argues that ill health poses the most serious threat to patient autonomy and increases the likelihood of paternalism. Autonomy is undoubtedly connected to self-determination however within the existing literature the connection between these two concepts and participation and decision-making is complex and form a semantic perspective.

2.49 Empowerment

It has been postulated that older people should not be treated as a homogeneous group and that this has been the dominant approach from institutions such as hospitals for many years to the treatment and care of older people (Walker, 1999). In terms of models of service organisation, it could be argued that the Age Related Healthcare Setting aspires to the empowerment model which is user orientated, responsive, needs-led, power-sharing, open to change and outcome orientated (O'Brien,2010).

Key principles for healthcare professionals who want to change their practice to include more empowering approaches have been advanced which include the recommendation that empowerment should not be viewed as zero sum and that a partnership model should benefit both parties. Empowerment is not just a matter of shifting the balance of power between professionals and older people, there is also the potential for growth on both sides (Barnes and Walker,1996). The next section will progress to discussing two of the conceptual frameworks relating to patient participation, namely personhood and citizenship which underpin this thesis.

2.50 Conceptual Frameworks for Patient Participation

2.50.1 Personhood

The concept of personhood can be traced back to philosophy and social psychology and it is often cited as the basis for person-centered care. Its main concerns are with treating the individual as a person first and foremost and recognizing the uniqueness and humanity in each individual human being. Kitwood (1997) is the main proponent of this theory and he defines personhood as, 'A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (P8). Although Kitwood's theory developed in relation to persons with

dementia, I believe his argument for frames of reference to change from a 'person with DEMENTIA to a PERSON with dementia' are particularly relevant to this study. The question as to whether patients in hospital settings are viewed and treated as a 'PERSON in hospital' as opposed to a 'person in HOSPITAL' is central to the investigations of this study. It will be important therefore to explore whether patients are treated in a homogeneous manner by other participants in CPM's or if they are treated as heterogeneous individuals?

Brooker (2004), outlines four elements of person-centred care which are also central to personhood:

1. Valuing each person and those who care for them

2. Treating the person as an individual

3. Looking at the world from the individual's perspective

4. Promoting a positive social environment where the person can experience well-being

Kitwood(1997) highlights the influence of interpersonal relations theorising that how a person is treated will directly relate to their sense of personhood. This study therefore sets out to explore how personhood and agency are manifested for patient's within CPM's through an exploration of both objective (participant observations) and subjective(patient interviews) experiences. It is a generally accepted fact that healthcare professionals aspire to person-centred care. The question is, does this genuinely happen in practice and to what extent is person-centered care observed within the CPM's?

2.50.2 Citizenship.

Recent health service reforms in Western countries emphasise public and patient involvement in care and the citizenship model focuses on power, agency, and inclusion, and links the personal with the political (Baldwin,2008). Theorists have shifted the focus to the social practice of citizenship where it is more broadly defined and is created by individuals and groups in social contexts through the power dynamics of everyday talk and actions (Barnes et al.2004). Citizenship therefore has deeper implications than personhood as it moves into the area of critical discourse and in particular the idea that participation is inevitably shaped by power dynamics (Bartlett and O'Connor,2007).

One of the key documents that continues to shape the theoretical framework for user involvement in relation to citizenship is Arnstein's 'A ladder of Citizen Participation' which was published in 1969 (Tritter and Mc Callum, 2005). Arnstein's idea of a ladder of participation depicts rungs which are different levels of participation that authority/organisations allow to citizens; for Arnstein however the sole measure of participation is the power to make decisions and seizing control.

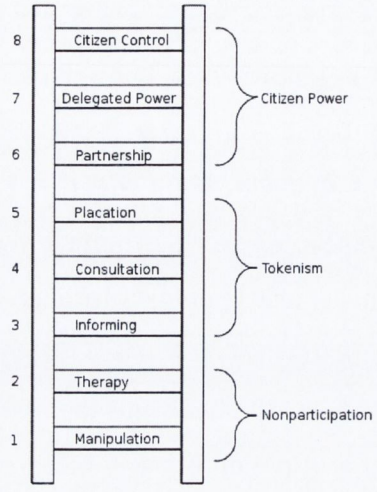

Figure 3; Eight Rungs of Citizen Participation (Arnstein,1969)

Arnstein's model has been criticised for solely emphasizing power and fails to recognize that for some users, participation itself may be a goal. It has been argued that user engagement and empowerment are complex phenomena through which individuals formulate meanings and actions that reflect their desired degree for participation (Tritter and Mc Callum,2005). Collins and Ison(2006) meanwhile, argue that Arnstein's focus on power is inadequate for explaining participatory approaches at a conceptual or practice level and they suggest that it is 'time to jump off' Arnstein's ladder.

Although Arnstein's ladder offers a useful starting point when examining the concept of citizenship, it would appear that a more nuanced model which gives consideration to the process as well as the outcome and places less emphasis on power would provide a more useful framework for this study. I believe that Wilcox (1994) provides a model that is more relevant and applicable to this study; he advances a framework for citizenship and participation that is based on Arnstein's ladder but which he has altered to five stances.

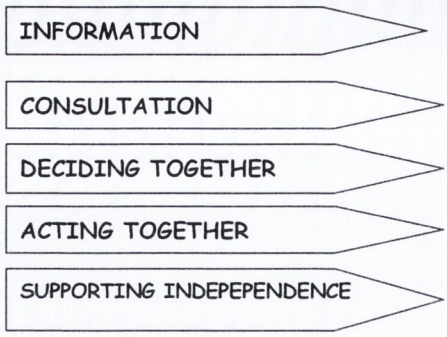

Figure 4; Framework for Citizenship(Wilcox,1998)

This framework is of particular relevance to this thesis as Wilcox goes on to suggest treating participation as a process which encompasses four main phases; initiation, preparation, participation and continuation. He stresses that if participation is to be more than a superficial consultation, it must be treated as a process that takes some time. This study examines participation within CPM's using Wilcox's framework as a guide. In relation to this thesis, I attempted to understand the subjective experience of older people in CPM's (thus taking a person-centred approach) but also to attempt to place this within the macro framework.

2.51 Biomedical Gaze and Ageism

Since this thesis will be predominantly examining the participation of older people in CPM's, it is important to note that older people are part of a wider societal system where discrimination such as ageism often exists. When exploring issues of patient participation and its underlying concepts from a critical gerontology frame of reference, it is also pertinent to discuss the subject of the biomedical gaze within the hospital context. It has been argued that the roots of the biomedical perspective are anchored in the Enlightment movement as it advanced the argument that science and technology could improve human life and as a result, medicine was seen as beneficial to understanding disease and

illness (Bond,1999). However, in recent years this approach has been criticised as it fails to acknowledge how the influence of other factors including economic, environment, social and cultural may affect how an individual experiences illness (Bond,1999). Biggs(1993) suggests that the biomedical model has a prevailing ideology of ageism as a result of its focus on physical and cognitive decline. It has been argued therefore that biomedicine constructs the identities of older people as objects of power and knowledge(Powell,2006). Under the 'biomedical gaze' people became their bodies and within the hospital context 'patients'.

On the other hand, the 'medical gaze' in Foucouldian terms(1973) refers to discourses, languages and ways of seeing that shape the understanding of ageing into questions that centre on and increase the power of healthcare professionals (Powell,2006). Ageing is not only a socially constructed problem but is also a reflection of underlying power and inequality in society. Within this framework biomedicine has been attributed to being one of the of the elements of social control and domination that has been legitimized through the power/knowledge of 'experts'(Foucoult,1972;Powell and Biggs,2000).

2.52 Redistribution of Power through Organisational Change

The practices of healthcare professionals are undoubtedly influenced by the organizational and policy environment in which they work. It has been postulated that by standing back and thinking about practices reflexively, healthcare teams can try and redress the inherent power imbalances that exist between teams and their clients (Opie,1997). Opie defines reflexivity as the metaprocess whereby healthcare professionals think about the process of their work and consciously critique it, and argues that this process should not just involve aspiring to working in a more person-centered way as antidotes to power imbalances. Opie(1997) argues that differences in power between healthcare professionals and patients should be acknowledged and by working reflexively, and critically analyzing work

practices, modes of interaction can be identified which seek explicitly to minimize power differentials. By conceptualising the work of teams differently, facilitates previously excluded, or unacknowledged issues, to be addressed. For teams to move beyond repetitive practices whose value is reinforced by their familiarity, requires an awareness of the different discourses created by the team and a critical examination to take place .

2.53 Conclusion

The literature reviewed for this thesis commenced with an exploration of the meaning and purpose of CPM's by a preliminary discussion of definitions used. Based on this literature, it is concluded that CPM's are a group decision making focus that incorporate several distinct phases. They are important information sharing, planning and decision-making forum and should constitute a lot more than institutional conversations within hospital settings. The literature points to the fact that many studies draw on healthcare providers' view of patient involvement at CPM's, but there is a paucity of studies reporting on patients' own views of these meetings and in particular an absence of studies reflecting cognitively impaired patients' attitudes to and experience of such meetings. Likewise, little is known about how patients with communication difficulties experience such meetings. A close scrutiny of the published literature shows that concerns have been raised by some experts. The review proceeds to explore the concept of participation and what this term really means particularly to patients involved in CPM's. Various definitions of participation are discussed, - the Cahill(1996) paradigm is particularly reviewed, and it is shown how this approach seems to have most relevance to the topic being investigated in this thesis about the nature of patient participation at CPM's, particularly those in the poorest physical and mental health, and whether their participation is fully realised or tokenistic. It is recognized that both healthcare professionals and family members may influence patient participation, and the communication and

behaviours of healthcare professionals have been identified as being critical to hindering, or facilitating patient participation. An understanding of patient participation in care has emerged and the challenges related to its definition and conceptualisation have been discussed. Also the idea of whether participation should be viewed in a hierarchal manner or as taking place on a continuum has also been examined. The literature on older people's participation in clinical decision-making and discharge planning suggests that many older people prefer to assume a passive role and to delegate decision-making to either doctors or their family members and a number of possible reasons have been advanced for this. It would appear that issues of power are central to the issue of participation and are inextricably linked to the concepts of personhood and citizenship. The literature review has provided the 'context' and starting point for an examination of participation within CPM's. I will now move on to outlining the research approach utilised in this study.

Chapter 3 : Methodology Chapter

3.2 INTRODUCTION

In this thesis an action research design is used to describe, evaluate and offer a method for the development of service delivery of CPM's within the context of a hospital environment. This approach has been taken since it is inherently practical, change orientated, cyclical and participatory in nature (Le May & Lathlean, 2001). When considering the Care and Connect project which acts as a basis for this thesis[3], there appeared to be a natural fit with the action research approach which would promote participation at two levels namely, the promotion of improved participation levels of patients within CPM's, and the participation of MDT in research design and fieldwork. This study encompassed a 3 stage action research cycle which focused on CPM's held in respect of hospital inpatients under the care of the Department of Geriatric Medicine. Phase I encompassed 10 meetings held in respect of inpatients, under either the care of the Stroke service or General Medicine service; all inpatients were over 65 and included a mix of cognitively impaired and cognitively intact patients. Phase 2 encompassed 10 meetings held in respect of inpatients under the care of the Stroke service; patients who were under and over 65 were included and all were assessed as having a cognitive and/or communication difficulty. Phase 3, consisted of the development of a Training Manual for Healthcare Professionals.

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[3] The researcher did not embark on this research with the intention of using an action research approach however the backdrop to this study, 'The Care and Connect Project' had suggested action research as a potentially suitable approach and the findings of the Phase I demonstrated the feasibility of action research for the study and indicated that there was a need for further exploration into the area of CPM's. There was also a definite motivation from members of the multidisciplinary team(MDT) to gather further information about current practices and to implement improvements to practice where possible and an action research approach very much lent itself to achieving these aims.

This chapter will begin by examining different research approaches and will argue why a qualitative research approach was chosen for this study. It will then explore the many definitions of action research and how they have evolved over time. Action Research will be placed within the frame of reference of new paradigm research and its usefulness as a research approach in healthcare settings will be discussed. Action research and its defining characteristics will then be explored followed by the philosophical underpinnings of this approach and its relevance as a framework to this study will be discussed. The action research characteristics of the study site will be outlined and the proposed theoretical framework of critical gerontology will be discussed. The chapter will conclude with detailing the research techniques and design that was applied.

3.3 Research Methods

A number of different research approaches could have been appropriate to use in the study of CPM's in a hospital setting and both quantitative and qualitative approaches could have been considered. However, quantitative and qualitative approaches each represent significantly different paradigms. It has been argued that a conscientious researcher should not predetermine the research approach to be adopted and rather the choice of research method should be informed by what is most appropriate to what one is trying to study (Punch, 1998). Strauss and Corbin (1996) concur with this and state that a valid reason for choosing a particular approach is the nature of the research problem. Since the research problem or key question in this study was to explore the objective and subjective experiences of participants in CPM's and to introduce changes to practice based on the findings, an action research approach was considered the most suitable.

3.4 Qualitative Research

Qualitative research historically emphasizes words rather than numbers or quantification in the collection and analysis of data and adopts an inductionist, constructionist and interpretivist approach (Bryman,2001). Qualitative research holds its roots in hermeneutics, phenomenology and the verstehen tradition; these terms generally refer to the theory and philosophy of the interpretation of meaning relating to an 'object' or the subject being studied.

Akinsanya states, 'Qualitative methods in research are concerned with a systematic approach to the examination of communication materials. This method is therefore dependent on the use of sensory data in which the researcher either observes or listens to a communicated message for information'(Akinsanya,1998,p20). Researchers who follow a qualitative approach strive to develop a shared understanding between individuals and groups (Denzin and Lincoln, 1994) and tend to view the social world as being variable, fluid and changing over time and place(Cutliffe and Goward,2000). It has been suggested therefore that a researcher's knowledge consists of developing a shared understanding between individuals and groups and the researchers own beliefs will influence the research (Denzin and Lincoln, 1994). Blumer (1969) postulates that the purpose of an exploratory investigation is to move towards a clearer understanding of how a problem is to be posed, to find out what is the appropriate data to focus on, and to develop ideas as to what are the significant lines of inquiry. In this way, it is possible to develop one's conceptual tools in respect of what is being learnt about the area under study.

Since this study is exploratory, (to the best of the researcher's knowledge and from the literature review conducted, it is the first study of its kind to examine CPM's using an action research approach) and descriptive, qualitative methods were the preferred research approach. A qualitative approach was also deemed

most suitable as in comparison to quantitative procedures which allow for greater breadth of information across a large number of cases, qualitative research methods provide in-depth information into fewer cases (Patton, 2002; Silverman,2005). As Silverman (2005,P9) reflects, 'qualitative researchers are prepared to sacrifice scope for detail'.

Many researchers choose to adopt a qualitative approach as they believe it can provide a deep understanding of the social phenomena under study. Denzin and Lincoln(2000) describe it as, 'Qualitative researchers stress the socially constructed nature of reality ,the intimate relationship between the researcher and what is studied ,and the situational constraints that shape inquiry.They seek answers to questions that stress how social experience is created and given meaning' (Denzin and Lincoln, 2000)Silverman(2005) however criticises this description and argues that social construction should focus not only on the concepts of experience and meaning but also on behaviours and interaction. It would appear therefore that qualitative research encompasses many different approaches and interpretations.

Within this study I embraced a broad definition of qualitative research that encompasses both Denzin and Lincoln's emphasis on the social construction of experience, but also Silverman's incorporation of behaviours and interaction. For this reason, a variety of data collection methods were chosen for this study which included participant observations, questionnaires, mini-focus groups and semi-structured interviews.

3.5 Challenges of Qualitative Research

Qualitative research typically involves an in-depth study of a small sample or of individuals that share similar characteristics and depth, rather than breadth, is the focus; transferability of findings may be difficult and the scope of the findings may be restricted (Bryman,2001). As Lincoln and Guba (1985) point out whether

the findings 'hold in some other context, or even in the same context at some other time is an empirical issue' (Lincoln and Guba,1985,p316).This study will strive to produce 'thick description' (Geertz,1973) so that it will be possible for others to make a judgement about whether this study's findings are transferable to other settings/populations.

Some writers postulate however that qualitative researchers are in a position to produce 'moderatum generalisations' (Williams, 2000,P.215).This is where aspects of the focus of an enquiry; in the case of this study, participants in CPM's, can be viewed as instances of a broader set of recognisable features. In this way, it is possible to draw comparisons with findings by other researchers relating to comparable groups. In forging such comparisons and linkages, the researcher is engaging in moderatum generalisation and although tentative and limited, it permits a modicum of generalisation beyond the immediate evidence (Bryman,2001). It is also anticipated that this study's findings will offer new explanations and insights into CPM's and that the findings can be used as a knowledge base to positively change the practice of healthcare professionals.

3.6 Definition of Action Research

It may be argued that action research is difficult to define as it is an approach to research as opposed to a specific method. Holter and Schwartz-Barcott (1993) reflect that the core characteristics and differing approaches and uses of action research have not been systematically identified and consequently, a monolithic definition remains elusive and existing definitions tend to centre on defining characteristics (Mc Eniff at al. 1996). Action research therefore takes many forms and in this thesis, the definition of Waterman et al. (2001) has been embraced. A systematic literature review of action research completed by Waterman et al. (2001) provides the following definition of action research;

'Action research is a period of enquiry, which describes interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem-focused, context-specific and future-orientated. Action research is a group activity with an explicit critical value basis and is founded on partnership between action researchers and participants, all of whom are involved in the change process' (Waterman et al.2001, p21). This definition emphasizes two main criteria which are fundamental to action research and inextricably linked; the cyclical process and the degree of involvement or participation of the researched.

Hart and Bond (1995) suggest that in 'dynamic interaction', action research can be clearly distinguished from other research methodologies. They suggest that there are seven distinguishing characteristics of action research;

1. It is educative; this study strived to gain insights into how CPM's are experienced by participants and through this process, a Training manual was developed for healthcare professionals.
2. It deals with individuals as members of social groups; patients, family members and the MDT were examined as members of a social group, as well as being participants in CPM's.
3. It is problem-focused, context-specific and future-orientated; CPM's were examined within the context of a hospital setting with the future aim of improvements to practice and increased participation levels of patients.
4. It involves a change intervention; changes were implemented based on the findings of each phase of the action research cycle.
5. It aims at improvement and involvement; an increased understanding of the role of the MDT within CPM's was gained through the fieldwork. The MDT then acted as collaborators to agree on suggested improvements to practice.

6. It involves a cyclical process in which research, action and evaluation are interlinked; this study encompassed 3 phases, each consisting of a period of research, action and evaluation which then informed the next phase.
7. It is founded on a research relationship in which those involved are participants in the change process; the MDT directly contributed to the change process through their role as collaborators. Patients and family members however also contributed through consideration of their subjective experiences gained through interviews, and also their suggestions for improvement to current practices.

It is anticipated that the current study will embrace all of the above criteria at various stages of the research cycle and this will be discussed in greater detail throughout the chapter.

Hart and Bond (1995) argue that within their 7 criteria for action research, 'improvement and involvement' and the 'cyclic process' are closely linked. They give the example that within health and social care, the aim is to improve professional practice for the benefit of service users and to involve those concerned in the process of change. This aim is to take account of the fact that there may be competing definitions of what counts as improvement or success (Smith and Cantley,1985) and indeed one of the challenges of adopting this approach is how to define or measure improvement or success. It has been argued that action research draws from a different understanding of science which allows for the process of change to be explored rather than solely attempting to measure outcome (Waterman et al 2001).

Meyer(2000) asserts that success can often be viewed in relation to what has been learnt from the experience of undertaking the work and that the action research process often sheds light on continuing gaps in care and issues that need to be improved. I consider therefore that part of the value of this study will lie in

the learning gained from engaging in the action research process and the Training manual that results from this, rather than any exact definition or measurement of success per se.

3.7 ORIGINS OF ACTION RESEARCH

Action Research has traditionally been defined as an approach to research which is based on a collaborative problem solving relationship between researcher and client and has the dual aim of improving a situation and addressing new knowledge (Coughlan and Brannick,1995). It originated in the United States where there was growing interest in the application of scientific methods to the study of social and educational problems. Lewin (1946) is generally credited for introducing the term 'action research' as a way of generating knowledge about a social system while at the same time, attempting to change it. Lewin introduced the concept that in order to solve practical problems and improve a situation, people are more likely to respond positively to decisions made democratically in a group compared to acting on decisions which were made without their involvement. Lewin advanced the theory that the action research process was cyclical in nature and stages of the cycle included fact-finding, planning, action and reflection/evaluation and refining the problem. This framework can be seen as the basis of many of the more modern definitions of action research (Clark,1972; Ebutt,1985;Carr and Kemmis,1986;Elliott,1991).

Corey (1953), a student of Lewin, is reputed to be the first person to write of action research as a means of improving practices; his work specifically examined improving practices in schools. Until that time, researchers had been outsiders to the setting of the research, and were seen as experts. Corey thought research should be carried out by the practitioners themselves through studying their problems scientifically, and that the research should be 'a co-operative activity'

which would support democratic values (Whitehead, 1993). Action Research was therefore initially a method that enabled theories produced by social scientists to be applied in practice and tested on the basis of their practical effectiveness. Carr (2006) argues that in this culture, action research could only legitimise its claim to be a genuine social science by conforming to the methodological principles prescribed by the epistemology of positivism. Sanford(1970) concurs with this argument and states that it was because of the failure to meet the methodological requirements of positivism that action research became marginalized and went into decline.

Action Research experienced a resurgence of interest in the 1970's in response to the issue of making academic research relevant to practitioners' problems. This revival occurred in the context of educational and curriculum research in the UK amidst a growing conviction of the irrelevance of conventional educational research to the practical concerns of teachers and schools (Kemmis, 1988). The advocacy of 'teachers as researchers' by Stenhouse(1979)and the work of the Tavistock Institute of Human Relations which promoted group approaches to changing practice meant that emphasis was now placed on case studies of situational understanding. This also signified a shift in action research as a methodological approach that now used 'qualitative' rather than 'quantitative' research methods that focused on the perspectives of participants and social actors (Kemmis,1988). Wadsworth (1998) acknowledges this important influence during the 1980's which provided 'a new epistemological paradigm of engagement (which went) beyond the narrow exclusivity of replicative and objectivist science' (Wadsworth,1998). This revised version of Lewin's action research cycle was also characterized by the fact that practitioners could assess the practical adequacy of their own tacit theories 'in action' (Elliott 1991;1998).

It would appear therefore that action research now aspired to deepen practitioners understanding of the complex situations in which they work so their

actions were better informed. Rather than specific 'findings' or 'outcomes' action research aimed to generate what Elliott(1991) called 'practical wisdom' and 'situational understanding' (Elliott,1993).

Authors such as Carr and Mc Kemmis(1986) were critical of the sentiments of Lewin's work however and suggested that democracy and group decision making were viewed as techniques to gain the cooperation of workers rather than a fundamental principle for social action. A similar criticism was advanced by Landsberger(1958) amongst others, who believed that Lewin failed to acknowledge the manipulation of the workers involved in the studies, a criticism applied recently to action research used as a possible management tool (Griffiths, 1990).

3.8 Action Research as a Change Agent

As discussed earlier there are a selection of descriptions and definitions of action research offered in the literature; these tend to be influenced by distinguishing features and their philosophical perspective rather than a prescribed narrow definition. The generic terminology of action research has been applied to this study as it does not have the defining characters of particular approaches to action research such as technical-collaborative, participatory action research or action science (Waterman et al.2001).

The primary purpose of action research is as a practical tool for solving problems; this thesis has embraced action research as a mechanism for the systematic collection and analysis of information for the purpose of taking action and making change. If an action research project doesn't make a difference, it has failed to achieve its objective (Stringer,2007). It strives to work in the conversations and communications of participants and it takes the view that practice including research is socially, historically and discursively constituted. The notion of dialectics is central and thus the necessary interdependence of subjective and

objective perspectives, individual and social perspectives and practice and theory are embraced (Waterman et al. 2001). This approach enlarges on the Aristotelian notion of praxis-of acting on the conditions of one's situation in order to change them (Meyer,1995) and has been discussed in greater detail within the philosophical underpinnings.

Kemmis (2008) further argues that action researchers should be concerned with examining practice as they are seen from the external ('objective') perspective of the observer as well as the internal ('subjective') perspective when engaging. This approach thus strives to understand practice from both outside and inside perspectives of the individual participants and the social construction of their practice. Participation is unquestionably a key component of this action research approach and it would appear that if practice/praxis is collectively constructed, then collective understandings must be gained. Thus the research should take into account the perspectives of the range of people involved or affected or, preferably, involve them collectively in the research process (Kemmis, 2008). Action research therefore is the self-reflective collective self-study of practice, the way in which language is used, organisation and power in a local situation and action to improve things (Kemmis and Mc Taggart, 2005).

3.9 Key Features of Action Research

This process generally follows a spiral of self-reflective cycles as demonstrated in the following diagram:

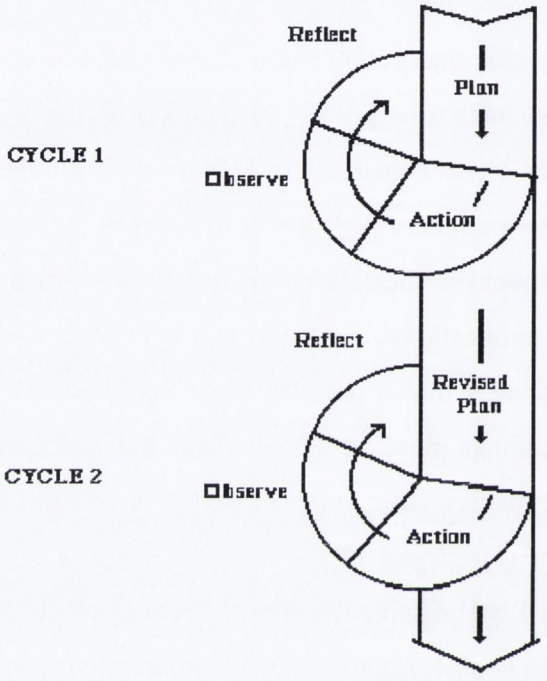


Figure 5; Action Research Cycle (Kemmis and Mc Taggart,1998)

In practice the process may not be as neat as depicted in the diagram and is likely to be more fluid, open and responsive. Most noticeably, the criterion of success is not whether participants have followed the steps faithfully but whether they have a strong sense of development and evolution in their practices, their understandings of their practices and the situations in which they practice. Each of the steps outlined in the spiral are ideally undertaken collaboratively by co-participants.

Within this thesis, the diagram is a depiction of each of the phases of the action research cycle as each will encompass a period of observation, reflection(in

conjunction with the MDT,) and a formulation of a revised plan of action(again, by working with the MDT as collaborators).Action research thus offers an opportunity to create forums in which people can join one another as co-participants endeavouring to remake the practices in which they interact (Kemmis and McTaggart,2005). It is clear that this approach is multi-faceted however its main focus is undoubtedly to discover how people experience a specific issue or problem(CPM's) and this knowledge is the key to knowing what actions will make a practical difference to people's lives.

3.10 Relevance of an Action Research Framework to this study

This study uses action research as its methodological framework specifically drawing on the complementary philosophical approaches advanced by Gadamer(1975)and Habermas(1984;1987). At this stage, I believes that this conceptual approach has relevance to this study for several reasons:

Action research's underpinning values of 'closing the practice-theory gap' and its basis in 'real' practice enables practice to change, rather than 'learning' in isolation why certain activities occurred (Ferrannce,2000). Furthermore, action research occurs 'in' practice rather than 'on' practice in which there is a clear focus on development, improvement and continuous learning (Dewar and Sharp,2006). There is no 'best' way to align research and practice however it has been argued that action research is designed specifically to bridge the gap between theory, practice and research (Meyer 2000). Since this thesis is about changing practice and empowering older people to be more actively involved in their care planning and decision-making, I recognised the potential of action research not only to enable change in practice, but also its ability to gain an in - depth understanding of the process of CPM's and the role of healthcare professionals within them.

Within this study, I examined the practice of healthcare professionals from an external perspective through participant observations of their practice within the context of CPM's. I also explored their internal perspectives by engaging practitioners as collaborators in reflecting on observations and planning the next phase of the action research cycle. Therefore, the members of the MDT were effectively co- participants and collaborators in the research. The hermeneutic circle is also of particular relevance as neither the CPM process as a whole, nor any individual part within it, can be understood without reference to one another, and hence, it is a circle. In this way it is considered that through the combination of participant observations of the meetings process, interviews with patients and their families, and engaging the MDT as collaborators, that a more complete understanding of the 'whole' can be achieved. The concept of communication and meaning are central to both a hermeneutic framework and also the focus of this research study. This study explores the relationship between the practice of healthcare professionals and the participation levels of patients within CPM's.

Communication is of critical importance both in respect of how the MDT communicate within CPM's but also how the patients communicate and comprehend meaning, particularly in view of potential cognitive/communication difficulties. This thesis examines communication at its most simplistic level but also explores the meaning behind the communication. The possibility of communication between different people depends on them being able to agree on the meaning of the signs they may exchange. The question which must be addressed is how do we know whether someone else understands the same thing that we do when we try to communicate with them and how do we know that they understood language the same way the other person did when they issued it? It would appear that this question has immense practical importance for healthcare professionals and it is considered that this study will increase our knowledge and understanding of this communication within CPM's.

3.11 Philosophical underpinnings of Action Research

The importance of outlining one's philosophical approach to their methodological framework has been stressed by several researchers (Koch, 1995). The philosophical framework of a qualitative study should therefore direct and underpin the selection and application of methods, which in turn should yield data compatible with this framework (Koch, 1995). It has been argued that action research in its most effective forms is phenomenological(focusing on people's actual lived experience or reality),interpretative(focusing on their interpretation of acts and activities) and hermeneutic(incorporating the meaning that people make of events in their lives),(Stringer,2007). This study also strives towards an emancipatory outcome and thus there is also a critical element where organizational, social and cultural issues are questioned. This section will explore the philosophical underpinnings of action research and in particular those which relate to action research and healthcare. The relevance of a hermeneutic framework to this study will also be discussed.

3.12 Philosophical Underpinnings of Action Research

There are three predominant philosophical perspectives that have been cited as underpinning action research namely, the concept of praxis, the hermeneutic circle and tradition.

3.13 Praxis

The concept of praxis was constructed by Aristotle and refers to a form of action directed towards the achievement of some end or acting upon the conditions one faces in order to change them. Praxis is cultivated and guided by good judgement

or 'prudence' (Susman and Evered, 1978) therefore it is not simply action based on reflection, it is action which embodies certain qualities. It follows from this that praxis is a form of 'doing' action precisely because its 'end' –to promote the good life, only exists, and can only be realized in and through praxis itself.

In praxis, acquiring knowledge of what the good is, and knowing how to apply it in particular situations are not two separate processes, but two mutually supportive constitutive elements. The name that Aristotle gives to this form of reasoning is phronesis. Kemmis argues, 'Since only the practitioner has access to the commitments and practical theories which inform praxis, only the practitioner can study praxis. Action research as the study of praxis, must be research into one's own practice'(Kemmis,1993, p182). In other words, as we think about what we want to achieve, we alter the way we might achieve that, and as we think about the way we might go about something, we change what we might aim at; there is a continual interplay between ends and means. Praxis therefore is integral to the concept of practitioner research and reflexive action and is a cornerstone of action research. Marx enlarges upon Aristotle's usage of praxis in that by taking action to change conditions, one is personally changed in the process (Marx, 1963).

3.14 Hermeneutics.

Hermeneutics originally referred to the art of interpreting texts however contemporary references focus on its role in the interpretation of language, culture and history (Susmen and Everad, 1978). It also encompasses not just issues involving the written text, but everything in the interpretive process. This includes verbal and nonverbal forms of communication as well as prior aspects that impact on communication, such as presuppositions, pre-understandings, the meaning of philosophy and language and semiotics(Ferguson et al.1988). It

assumes that all human action is meaningful and therefore has to be interpreted and understood within the context of social practices. It follows from this that researchers also make sense of what they are researching through interpretive schemes or frameworks.

Gadamer (1975) argues that it is impossible to separate oneself as a researcher from the historical and cultural context that defines one's interpretive framework. Instead, the researcher should strive to state explicitly which pre-conceptions they have brought to the research context and how these may have influenced the interpretation and analysis of data. This can be achieved by the researcher becoming part of the 'hermeneutical circle' which centres around interpretation and making sense of what has been observed in a way that communicates understanding. The researcher therefore engages in a circular action of studying parts in relation to the whole and the whole in relation to the parts (Denzin and Lincoln, 2005). Susman and Everad, (1978) argue that the learning process is not unlike the spiral formulated by Lewin as each turn of the spiral builds on the understanding of the previous turn.

3.15 Tradition.

An important characteristic of the hermeneutic circle of interpretation is that it always takes place against a background of assumptions and presuppositions, beliefs and practices, of which the subjects and objects of the research are never fully aware and which can never be fully specified (Scott and Usher, 1996). Gadamer calls this 'tradition' and therefore in order to understand the meaning of any action, it is necessary to understand how these are immersed and inseparable from a network of culturally conditioned beliefs, practices and assumptions. Furthermore, while actors may be conscious of intentions they are not aware of the background or 'tradition' wherein this action has meaning. Scott

and Usher (1996) postulate that a circular understanding is required because it is already an interpretation; research involves interpreting the actions of those who are themselves interpreters therefore it involves interpretations of interpretations which is the double hermeneutic at work.

Gadamer points out that we can never step outside of our tradition; all we can do is try and understand. It is thus important to examine the process of CPM's within Gadamer's context of tradition and ask why do CPM's take place? It will be important to examine within the culture of a hospital environment, what traditional significance does the process of CPM's have for participants and is there an underlying ritual tradition to this forum? It is considered that by adopting an action research approach it will enhance our knowledge about the practice of healthcare professionals in CPM's thereby improving practice, and will subsequently empower healthcare professionals, patients and their family members.

3.16 Theory of communicative action.

Habermas goes on to further develop some of Gadamer's arguments in his theory of communicative action (Habermas,1984,1987).He describes communicative action as action directed at achieving mutual understanding about what to do. Communicative action occurs when people stop to ask, 'What are we doing?' (Kemmis,1998) and attempts to answer four validity claims as suggested by Habermas:

Are their understandings of what they are doing comprehensible?

Are they true/ accurate?

Are the understandings authentic and sincerely held?

Are the understandings morally right and appropriate? (Kemmis,1998)

Within action research, participants open communicative space by working together to explore their practices, understandings and situations thus emphasizing the inclusive, collective and transformative nature of its aims which then supersedes the self- interests of individual participants. Kemmis and Brennan(2003) postulate therefore that action research is a form of exploratory action that takes communicative action into social practice, using social practice as a source of new understandings.

3.17 Action Research in Healthcare Settings

Action research has been receiving increased credibility in healthcare settings as it acknowledges the value of professional judgement in applying scientific evidence in practice. Mc Taggart(1997) states that his interest in action research was particularly stimulated by its transformative potential, and by the attention given to the question, How might we change things at the same time as studying them?

Through the use of reflexive data collection methods, action research aims to allow participants to learn for themselves but also empowers them to improve the social contexts in which they work (Meyer, 2000). The format of the action research cycle; enquiry, intervention and evaluation mirrors the iterative processes employed by healthcare professionals when assessing the needs of vulnerable people, responding to them and reviewing progress(Hart and Bond,1995). This compelling feature of action research means that many practitioners are already familiar with this approach although they might not explicitly label it as such. Action Research can be a means of enabling healthcare professionals to reclaim the authority to clarify their own roles and create conditions so they can carry out their work most effectively. It has also been argued that it is an approach which has much to offer in terms of analysing and solving problems and devising ways of improving standards of care.

3.18 New Paradigm Research

There is a growing interest in collaborative or 'new paradigm' research (Reason and Reason, 1981), this refers to a form of cooperative enquiry which is a way of doing research in which all those involved contribute to deciding on what is to be looked at, the methods of the inquiry, and making sense of what is found out. Thus, in its most radical form, the distinction between researcher and subject disappears, and all who participate are collaborators and co-subjects. Co-operative enquiry is therefore also a form of education, personal development, and social action (Reason ,1988).

Action research therefore aims to develop co-investigative partnerships with those who under a traditional research paradigm may be viewed as 'subjects' for investigation. Dewar and Sharp(2006) suggest that such approaches in which participants are seen as collaborators can lead to 'communities of inquiry' in which participants are engaged in questioning their own attitudes, actions, language and behaviour. It is hoped by involving the MDT as collaborators and by developing a community of inquiry it will facilitate examination of current practices in an open, non-threatening manner and that all participants will ultimately view the process as mutually beneficial. New paradigm research thus seeks to empower those who are the focus of the research to act on their own behalf as active participants in change.

3.19 Limitations of Action Research

Arguments have been advanced against the rigor of action research on the grounds that: it is primarily qualitative in nature; it is susceptible to 'researcher bias' because practitioners often engage in the study of their own practice, it usually involves undertaking small scale studies and that the results from these

studies are not generalisable beyond their individual contexts. Whilst criticisms like these have some validity, nonetheless, for topics that have never been investigated and which need a more in-depth understanding like that being explored in this study, what is critically important is that preliminary work is undertaken and that this is done rigorously and scientifically.

3.20 Theoretical Framework

As CPM's are a multi-faceted and complex process, and in view of the fact that several different aspects of CPM's were examined, it was challenging to find a theoretical framework that adequately fitted this study. Considerable debate exists however around how to define theory/theoretical framework and whether it is possible or necessary whilst adopting a qualitative research approach. Kerlinger(1986) in Anfara and Mertz defines theory as 'a set of interrelated constructs, definitions, and propositions that present a systematic view of phenomena by specifying relations among variables, with the purpose of explaining and predicting phenomenon'(Kerlinger,1986,p.9).

Fowler(2007) acknowledges the challenge of finding a 'single framework to adequately explain all data'(Fowler,2007,p.55) and recommended employing multiple frameworks ,when appropriate, for qualitative studies that are better suited to 'more than one theoretical framework'(p55).When there are one or more points of intersection of theoretical constructs, there is the potential to contribute to a deeper perspective and understanding of the phenomenon being studied(Anfara and Mertz,2007).

3.21 Integrated Theoretical Framework

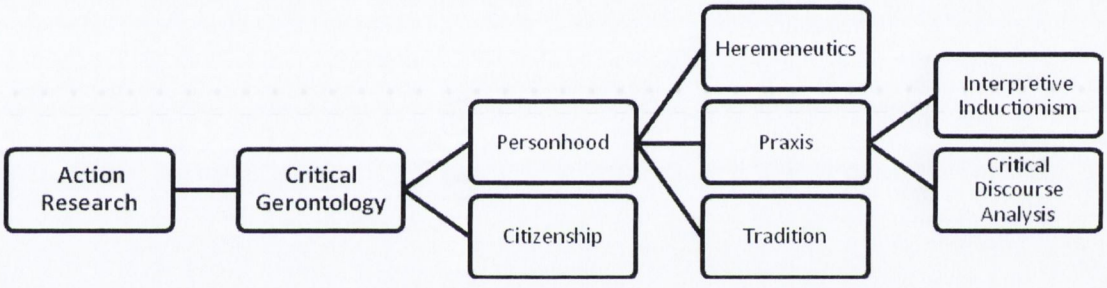
As this study does set out to examine the phenomenon of CPM's and to reconcile a number of critical, sociological and linguistic perspectives, it was decided that an integrated theoretical framework would be embraced. Action research is the primary research approach adopted for this study and its underlying philosophical underpinnings of heremeneutics, praxis and tradition are embraced. This has been allied to the theoretical framework of critical gerontology. As discussed in Section 3.36, In Phase 2,discourse analysis is used for data analysis in conjunction with an interpretive inductive approach in order to conduct an in-depth examination of the use of language and communication within CPM's This however is done from a critical standpoint, and thus demonstrates some of the characteristics of critical discourse analysis. It has been argued that an integrated approach doesn't have to mean the adoption of eclecticism in a negative sense, and Bordieu (1997) points out that in fact this could characterise and assist productive theory formation.

3.22 Usefulness of adapting an Integrated Theoretical Framework for this Study

An integrated theoretical approach does not claim to be 'more true' than the individual theories from which the conceptual ideas are drawn, but instead aims to embrace the conceptual tools which are more useful for the topic under examination thereby focusing on 'criteria of utility rather than truth' (Mouzelis,1995,p9).This study thus concurs with the assertion of Weiss and Wodack(2003) that communicative actions and social practices happen within a wider frame of reference and therefore it is too simplistic to categorise these processes into micro or macro level issues. They postulate that from an ontological perspective, micro context equals the macro context as one produces

the other. Thus in relation to the current study, the communication and language within CPM's impacts and produces the social system while at the same time, the social system has influenced and produced the nature of the interactions within CPM's. In this way discursive practices should always be regarded as structured and structuring actions (Weiss and Wodack,2003). The next section illustrates in diagrammatical form the theoretical framework for this thesis:

Figure 6; Theoretical Framework for Study



3.23 Critical Gerontology

Critical gerontology can be defined in a number of ways and began to gain prominence in the literature in the 1980's and 1990's. It has been associated with a broad spectrum of theoretical approaches including construction and deconstructions of ageing (Gubrium,1986) and a commitment to addressing issues of power and social injustice for older people.

There is no agreed definition of critical gerontology however all approaches that fall under this umbrella are critical of "a theoretical self-understanding of gerontology, which is dominated by an idealized concept of natural science as the representative of 'objective' knowledge' (Baars,1991).Broadly speaking, critical gerontology identifies perspectives on ageing that contrast with positivism (Cruickshank,2003).The theoretical perspectives used to critique the positivist position include theories of the political economy and the moral economy of ageing or cultural gerontology as it is sometimes known (Cole et al.1993). The political economy of ageing focuses on the role of economic and political systems, as well as social structures and forces, in shaping and reproducing power inequalities and systems that contribute to the domination of the aged (Estes, Biggs and Phillipson,2003).Cultural gerontology on the other hand has gained in popularity for its attention to the interplay of the relationship between culture, structure and agency (Estes,1999) and rejects the notion that economics can solely explain the nature of social institutions.

Therefore a critical gerontological approach advances perspectives on ageing that challenge positivism and encourage interdisciplinary approaches to the critique of the biomedical model through an emphasis on the subjective experience of ageing and the empowerment of older people (Minkler,1996).Some critical gerontologists argue that knowledge about older people should come from older

people, with a focus on giving voice to their experience (Kontos,1998); this study will strive to capture the older patients experience within CPM's through the format of semi-structured interviews. A reflexive approach is also integral to a critical gerontological stance and a commitment to social change and the production of emancipatory knowledge (Moody,1993) parallels with the action research approach this study has adopted.

3.24 Research Technique

The research design for this thesis incorporates 3 action research cycles namely Phase I, Phase 2 and Phase 3. According to Kemmis and Mc Taggart (1988) what is learned from reflection at the end of the first cycle informs the planning at the beginning of the next, and so on, as the work continues. In this way Phase I helped inform which data collection methods would be most suitable and also helped inform what aspect of CPM's would be examined in the next phase of the research cycle. This provided an underpinning framework for the thesis in which each phase was linked as part of an evolutionary continuum. Reflection and understanding gained as part of acting and observing from each phase led to either a revised plan or confirmation that the process and design was appropriate which subsequently informed the next phase in turn.

In order to achieve the stated aims and objectives, the methodology for this thesis adapted a multiple methods design with a three pronged cyclical approach which ;

(i)Examined in detail the communication and language used, and behaviours displayed within CPM's.

(ii)Explored the patient and their spouse /partner/next of kin's perception of the meetings process.

(iii)Analysed findings and developed a framework for implementing improvements to practice within CPM's.

The first two steps of this process were then repeated and the third step developed a Training manual which recommended best practices for healthcare professionals in CPM's.

3.25 Triangulation and Data Collection Instruments

Triangulation means employing more than one method or source of data collection in the study of a social phenomenon so that findings may be cross-checked (Bryman, 2008).Foss and Elfsen(2002) argue that triangulation or multi-method approaches have the potential of providing a multifaceted view of the phenomena being explored as its focus is upon combining different research strategies and approaches. Fielding and Fielding (1986) in identifying the possible limitations of triangulation argue however that triangulation does not in all cases increase validity or minimize bias. This view is in contrast to Denzin and Lincoln (1994) who argue that multiple methods add increased rigor, breadth and depth to investigation. By choosing multiple methods of data collection or 'methodological triangulation' it can be argued that the researcher is able to consider the research area from different perspectives therefore allowing for greater means of comparison compared to a single method approach.

In health services research, the use of a range of methods can increase the range and the scope of insights in relation to a complex phenomenon, such as patient participation, in comparison to a single methodological approach (Collins et al.2007). Due attention was given to Barbour's(1998) recommendation that mixing qualitative methods means that attention must be given to differing epistemologies and that assumptions of commonality should not be taken for

granted. By combining a number of different methodological approaches it was hoped that a well rounded understanding of patient participation and the associated practices of healthcare professionals would be gained and that this would exceed the sum of utilizing a single methodology. The combination of using a critical discourse analysis approach to describe what happened through the interaction, and combining this with what the participants think happened through interviews and focus groups, provides a more fruitful result. Like Collins et al.(2007),it can be asserted that findings from different methods form different parts of a knowledge continuum, rather than one being seen as more worthwhile or important than another. Combining research methods and perspectives also adds to the research capabilities of a researcher and fosters reflexivity and transparency.

This study has incorporated a variety of research methods namely, participant observations, semi-structured interviews and focus groups. This study adopts a triangulation approach by employing multiple methods to data collection as it was considered it would enable cross checking and validation of data i.e. participant observations could be verified and additional information gathered through follow-up semi-structured interviews. It was also considered that multiple sources of data would provide a more robust research design. The section to follow reports on the three methods whereby the data for this study was collected.

3.26 Participant Observations.

Participant observations were used to collect data concerning the language and behaviours of the MDT, the patients and their family members through the CPM's process. It has been argued that participant observations are best suited to research projects which emphasize the importance of human beings,

interpretations and interactions (Jorgenson, 1989).Participant observations are an important research tool as it is not unusual for persons to say that they are doing one thing but in reality they are doing something else. Snow(2002) asserts that participant observation can be the most accurate way of measuring the 'organisational climate' and the reality of what happens in the 'real world' and the understanding of the culture as a 'living entity' (Wilson et al,2005).Also, people may not be aware or able to articulate the subtleties of what goes on in interactions between themselves and others (Corbin and Strauss,2008). Patton(2002) states, 'Creative fieldwork means using every part of oneself to experience and understand what is happening. Creative insights come from being directly involved in the setting being studied' (Patton,2002 p.302).

One of the challenges associated with conducting participant observations however is that of observer effects. Robson (2002) suggests two strategies for minimising observer effect and the researcher endeavoured to follow these strategies when completing the observations of CPM's. The first is minimal interaction with the group. Robson suggests that this is achieved through strategies such as avoiding eye contact and the use of simple behavioural techniques such as not reinforcing attempts of interaction from the group such as smiling or making other responsive facial responses to group activity. This technique also involves planning your position in the environment to be 'out of the way'; the researcher attempted to achieve this by sitting outside the group circle so as to minimize my effect on the group. It is surmised that any impact of the observer on the process is likely to diminish as the meeting progresses and the MDT members become more involved in the meetings proceedings. However, the modification of participants own behaviour and language in response to being observed cannot be discounted (Froenck,2005).

The second strategy is habituation which involves ensuring that your presence is a regular occurrence in the setting and you are familiar to the participants so

that, when you assume the role of formal observer, participants are at ease and comfortable. It was possible for the researcher to implement this strategy to an extent as the members of the MDT were known to me and were used to my presence on the ward and at meetings as a fellow healthcare professional. To a lesser extent, the patients and family members were used to seeing me conduct my day to day work on the ward so I was a 'familiar face'.

The participant observations focused on the communication, language and behaviours of the patient, family members and members of the MDT present at the meeting. A data recording sheet[4] was designed for purposes of the study and drew on the researcher's practice experience, participatory observation and group dynamic theory(Toseland and Rivas,1984:Jorgenson,1981).The observation technique of using a data recording sheet essentially acted as a category system (Walker, 1985). A category system can be described as 'systems that unlike checklists, use a relatively small number of items, each of which is more general than a typical checklist item, but which attempts to use the system to maintain some sort of more or less continuous record' (Walker,1985,p136).

The data recording sheet included sections which recorded the use of informal processes; e.g. body language, eye contact, seating arrangements, punctuality, jargon used and any other observations which the researcher considered to be of interest were noted (Phase I and 2).The data recording sheet also documented processes and interactions, information shared or given and decisions made(Phase 1). The aim of the data recording sheet in conjunction with taped recordings (Phase 2) was to have a system which allowed me to capture information on the spot in as clear and detailed a way as possible. Much of the information detailed in the data recording sheets was in an abbreviated and

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[4] See Appendix G for Data Recording Sheet

condensed form so it was necessary to write up full, comprehensive field notes as quickly as possible after the observation. Some of the materials included in the record were;

1. A description of events
2. Recalls of forgotten material which the researcher remembered after the observation
3. Interpretive ideas which were notes offering an analysis of the situation
4. Personal impressions and feelings
5. Reminders to look for additional information/clarify observed behaviours

(Loftland and Loftland,1995,p 93-95).

I found the exercise of writing up field notes invaluable as it ensured that a detailed record of each observation which included preliminary analysis and coding of data had been documented.

When deciding what types of behaviour to observe and code, a framework developed by Weick (1968) in Robson (2002) was used as a guide:

Non-verbal behaviours-bodily movements not associated with language

Spatial behaviours-the extent to which individuals move towards or away from each other

Linguistic features-covers the actual content of talking and its structural characteristics.

It has been noted that one of the drawbacks of engaging in participant observations is that the researcher may give meaning to an action/interaction without checking out the meaning with participants. However, I aimed to reduce some of this effect by combining observations with interviews and mini- focus

group data (Phase I). As a social worker who facilitates CPM's, I would have had preconceived ideas formed by my own experiences which could impede objectivity but which may have also enhanced enquiry. It is accepted in the literature that the emotional response to a group will not be objective, but it may enrich observational analysis, and that bias in data collection and analysis is critical to the quality of the work (Fronek,2005). I attempted to record any emotional responses that I was aware of in my field notes and reflected on this during the data analysis and discussion. Where possible, clarification of meanings of interactions of participants in CPM's were sought through patient and family member interviews. Meanings were also checked with MDT members through the forum of the MDT CRG.

3.27 Interviews.

For the purpose of answering several of the key research questions posed within this thesis, a number of interview schedules were designed, and administered in a semi-structured interview format[5]. In Phase 1, three different sets of interview schedules were designed namely for patients, family members and the MDT. In Phase 2, new in-depth interview schedules were designed and administered to patient and family members only.

A semi-structured interview, '...typically refers to a context in which the interviewer has a series of questions that are in the general form of an interview schedule but is able to vary the sequence of questions. The questions are frequently somewhat more general in their frame of reference from that typically found in a structured interview schedule and the interviewer usually has some latitude to ask further questions in response to what is seen a significant replies'(Bryman,2008 P.129).

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[5] See Appendixs D,E,F,I and J, for Interview Schedules pertaining to Phase I and Phase 2

A semi-structured interview therefore is where the researcher has drawn up a list of questions or specific topics to be covered; this is often called the interview guide. The questions tend to be open-ended so that the interviewee has some leeway in how to reply. The interview process is flexible in that the researcher can probe the interviewee on certain topics which arise if it is felt that they will be of particular interest and equally the researcher can decide to 'skip over' certain questions if they believe they have already been answered or perhaps are not relevant for the interviewee in question. This method also allows for consideration of non-verbal communication which is of particular relevance to this study.

It has however been argued that this style of interview allows more potential subjectivity as the interviewer has greater potential for an increased risk of bias because they can lead the interviewee to provide the answer that the interviewer wants to hear(Bell,1993). Berdie et al.(1986) concur with this potential risk of bias and identifies that on occasion, a respondent can be more concerned with pleasing the interviewer than giving accurate responses. This view highlights that although there was a risk that participants would only tell me 'what I wanted to hear', Cohen and Manion (1997) argue that as individuals we are 'independent' in our actions and thoughts and are therefore not reliant on the person providing the knowledge.

Interviews were held in a dayroom within the Age-Related healthcare unit which was quiet, private and removed from the acute ward environment. All patient and family members were interviewed separately. Individual consent was sought and a consent form completed for each patient, family member and members of the MDT who participated in the study[6].

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[6] See Appendix B and C for consent forms

Although a standardised interview schedule was prepared in advance and was used during all interviews, using a semi-structured technique allowed for more variable information to be gathered based on flexibility and adaptability compared with a structured interview technique. This method also allows for consideration of non-verbal communication which is of particular significance when interviewing patients who may have cognitive or communication difficulties. I also attempted to adopt less formal interview strategies, which may help to reduce or even eliminate reactivity among respondents (Patton,2002).

May (1993, p91) concurs with this and states:

Questions are normally specified, but the interviewer is freer to probe beyond the answer in a manner which would seem prejudiced to the aims of standardization and comparability.

Although I strove to cover all the questions on the interview schedule with patients, this was not always possible due to their cognitive or communication difficulties and I was conscious that it was of the utmost importance that I should not upset, distress or put patients under any pressure to answer questions.

3.28 Focus Groups

Focus groups were used for data collection during Phase I of the action research cycle. Morgan (1997) defines a focus group as 'A research technique that collects data through group interaction on a topic determined by the researcher'. A focus group is therefore a group interview technique that covers a specific theme which is explored in depth with a group of participants and during which an interviewer who brings focus to the group, is concerned with how individuals address this theme/themes as group members and how perspectives on this

theme are constructed or emerge from within the context of group dynamics and interactions (Bryman,2001). Focus groups are to be distinguished from group interviews, and are usually a gathering of individuals for simultaneous interviewing in order to save time and resources and are also distinguished from nominal groups and Delphi groups (Stewart et al,2007) which do not involve interaction of group members and are used as a consensus-reaching mechanism in prioritising member issues.

Focus groups usually consist of 6-8 participants. However, as some of the MDT discipline groups in this study only consisted of two people, the term 'mini-focus groups' will be used to more accurately reflect the size of the group composition. A disadvantage of using this size of focus group is that it limits the range of experiences and information gained, by virtue of the fact that the group is smaller (Krueger and Casey,2000).

3.29 Sampling and Inclusion Criteria.

Purposive sampling was used to recruit patients for the study as it allowed participants to be chosen based on an inclusion criteria and on the subject under investigation i.e. participation levels of patients within CPM's. 'Purposive sampling demands that we think critically about the parameters of the population we are interested in and choose our sample case carefully on that basis' (Silverman,2006). In deciding on a research approach and inclusion criteria, the researcher was also aware of the importance of avoiding 'descriptive excess' (Loftland and Loftland,1995) whereby the amount of detail and data collected inhibits the analysis of data.

3.30 Phase I

Brown and Mc Entire(1981) assert that a set of tentative general principles should be derived when embarking on an action research study from a prior

observational study and then brought to bear on the situation. In other words the tentative principles are tested, refined, and re-tested through the action research. By completion of Phase I, the study attempted to satisfy this brief and also produce a 'real world focus' of the CPM process i.e. an initial assessment and description of the context in which the research is to take place.

From Phase I of the research, significant efforts were made to involve all members of the MDT in planning the research and laying the groundwork for the formation of an action research team. This process was aided by the fact that a research culture and ethos already existed within the Department of Geriatric Medicine and team members positively engaged in the concept of the research project. Participant observations, questionnaires and focus groups were the research techniques employed during Phase I. The overall purpose of Phase I was to explore the objective and subjective views and experiences of CPM's from the perspective of older patients, family members and the multi-disciplinary team(MDT) and to gain an insight into current practices both for this thesis and the Care and Connect project. The MDT involvement as collaborators in each stage of the action research cycle will be discussed in greater detail in each of the findings chapters and also in the final discussion chapter.

3.31 Research Design, Phase I

In Phase I a purposive sampling approach was adopted whereby 10 consecutive family meetings, which took place in respect of 10 patients over a 3 month period, who were under the care of one of the Age-Related Healthcare Consultants, were included. This meant that the sample included patients who

were under the care of either the Stroke Service or General Medicine[7]. The CPM's which were potentially suitable for inclusion were identified by the medical social worker on the multi-disciplinary team and this information was communicated to the researcher who then sought consent. As Phase I was very much a scoping exercise and its purpose was to inform the longer term focus for the research, it included a mix of inpatients; some cognitively intact and some with a cognitive impairment and also included some CPM's where the patient did not attend their CPM. Based on these findings, it was decided by the MDT CRG that a more in-depth analysis of the CPM's and an exploration of communication, language and behaviours would provide a deeper understanding of the intricacies and nuances of this process. It was also decided to focus specifically on those patients with cognitive impairment for Phase 2 as during Phase I, it was this group that exhibited the lowest participation levels.

3.32 Phase I-Participant Observations

The participant observations of 10 CPM's focused on the language, behaviours and communication methods of the patient, family members and members of the MDT present at each meeting. Since the quality and wealth of data available from Phase I lay in the questionnaire and mini-focus group data, Chapter 4 will report predominantly on these findings. This was because although a data recording sheet and field notes were completed for the participant observations, the meeting proceedings were not audio-recorded so the information available to analyse was somewhat limited. Although this is clearly a limitation of Phase I and perhaps is reflective of my lack of research experience at this stage, the action

[7] The Phase I sample included all family meetings which were convened, including those where the patient was not present, in order to ensure that a true representation of existing practices within family meetings could be achieved.

research cycle meant that I could refine and amend my research technique in Phase 2 in order to gain more in-depth quality data.

3.33 Questionnaires-Phase 1

In Phase 1, questionnaires were administered in a semi-structured interview format with the 5 attending patients post CPM, where I, the researcher verbally asked each participant the questions contained in the questionnaire and the response was then written down. Interviews took place within 72 hours of the CPM taking place, at a time that was convenient to the patient. All family members who attended the CPM were also issued with a questionnaire and invited to complete it (N=34) and a total of 20 questionnaires were completed and returned(N=20), representing all ten families in Phase 1. (N=13) of the family member questionnaires were completed in semi-structured interview format and (N=7) were completed as questionnaires by the family members and returned in person or by post.

The issues covered in the questionnaires included;

- Understanding the purpose of the family meeting
- Consent about family member attendance
- Opportunities to express opinions and ask questions during the family meeting
- Decision-making process
- Suggestions for improvements.

Self-administered questionnaires were administered to all MDT members present at each CPM and covered topics similar to those in patient and family member questionnaires. Additional questions relating to pre-meeting preparation and family meeting facilitation were included. In Phase 1, self-administered questionnaires were given to all 37 MDT members who attended family meetings

however, only 10 responded. The poor response rate by MDT members was clearly disappointing however,many of the MDT members were involved in multiple CPM's in Phase 1. It is likely therefore,that they perhaps found the exercise of completing several questionnaires on the same issue repetitive, or they may have been too busy to complete a questionnaire for each CPM they were involved in.

3.34 Phase I. Mini-Focus Group Data

The MDT are categorized as non-identifiable discipline groups as the aim was not to focus on the practices of a particular discipline but instead to gauge how the communication interplay, language used and behaviours of MDT members during CPM's may have impacted on participation. In view of the action research nature of the study ,I decided that strategically it would be less threatening to the MDT members engaging in the research if disciplines were unidentified as each of the discipline groups were composed of between 2-4 members so it would be extremely easy to identify individual members within each discipline group. I was also anxious to avoid ostracizing any of the MDT members or to cause any tension or friction within the MDT CRG in order to protect the participatory action research component of the study.

Mini-focus groups for Phase I were discipline-specific and were held with 7 different disciplines namely,(i) Consultants, (ii) Physiotherapists, (iii) Occupational Therapists, (iv) Nurses, (v) Speech and Language Therapists, (vi) Dieticians and (vii) Social Workers. Each focus group lasted between 30-70 minutes and was held within approximately one month of the CPM observations. Between two to four people from the same discipline attended each mini-focus group. In one Allied Health discipline, there was only one healthcare professional as the other was on maternity leave so a face- to- face interview was conducted which

covered the same themes as the focus groups. Open-ended questions were used to explore 8 key areas which included;

- Descriptions of 'good' and 'bad' CPM's
- Pre-meeting preparation
- Participation of older patient and family members
- Decision-making process
- Facilitation and Minute taking
- Seating, meeting time, punctuality and venue
- Aftermath of Meeting/Need for Debriefing
- Other/ Suggestions for Improvements

3.35 MDT Critical Reference Group (MDT CRG)

As discussed earlier, a key feature of action research is the involvement of participants as 'collaborators' and in relation to this study, the collaborators were the MDT. Participation involves consciously created structures, opportunities and processes for people to become involved and the structure whereby the MDT assumed the role of collaborators was through the formation of a CRG. The term 'CRG' tries to capture the idea that this is the group whose members' values and practices stem from their shared interests and who are thus the source of the most decisive or critical questions. Wadsworth(1997) argues that a CRG should have the capacity to identify the interests of those who are meant to be served by the services or actions being planned, provided or otherwise being researched. In this way, the MDT CRG assumed the role of trying to identify the needs of older people and their families within CPM's through an examination and reflection of current practice and then implementing changes to practice based on the findings. The MDT CRG also played a crucial role in deciding what each action

research cycle should consist of and what should be the research design and focus for the next cycle.

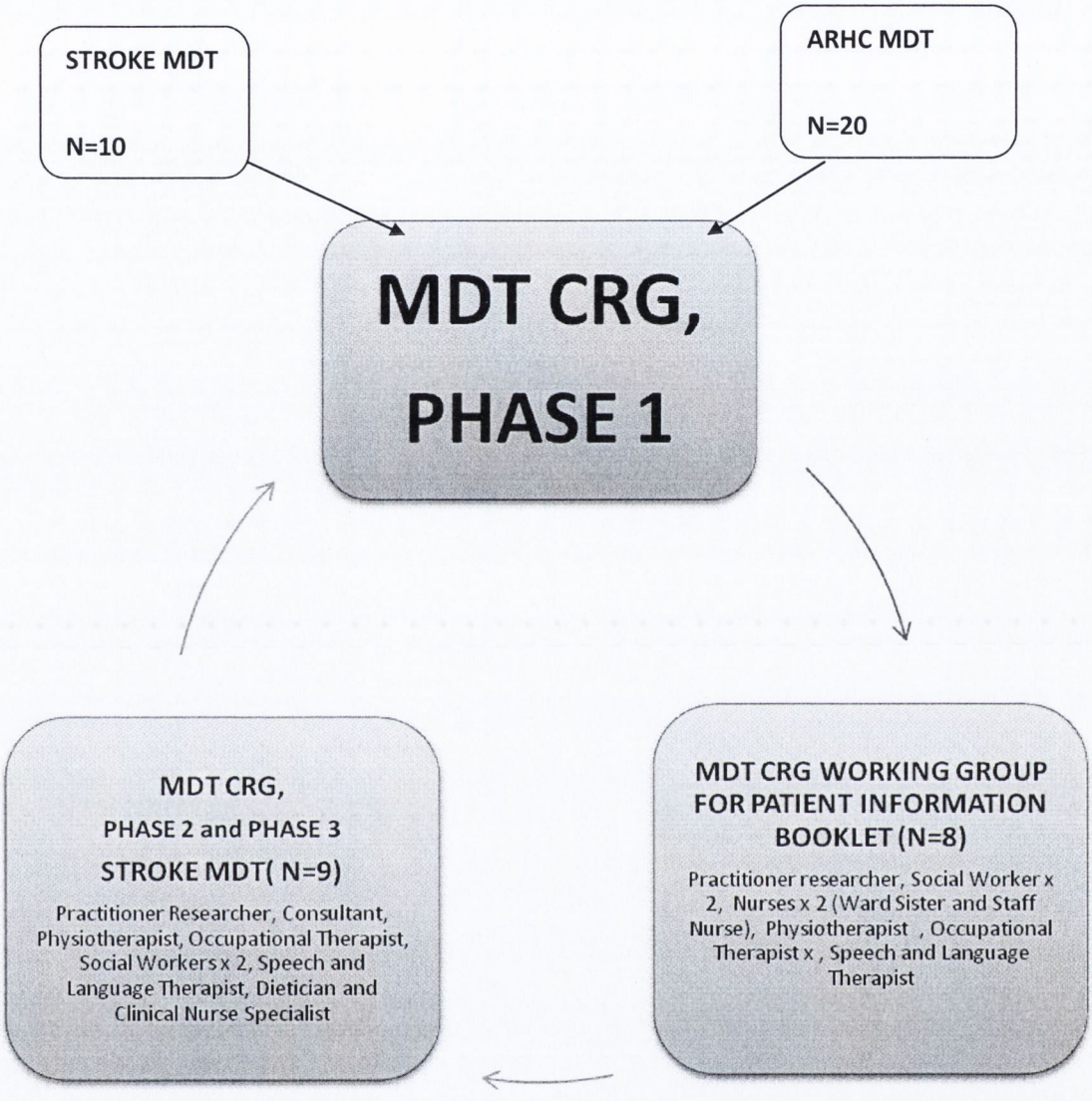
It was decided that it could prove very challenging and also impractical to involve the older patients or their family members as collaborators. This was in consideration of the fact that as inpatients, I would have a limited time period where I could easily make contact with, and have access to the patients. It would also have been quite difficult to involve some of the older people as collaborators because of the significant nature of their cognitive impairment.

3.36 MDT involvement, Phase I.

Findings from the focus groups conducted with the MDT during Phase I clearly indicated that CPM's were an area of practice viewed as a crucial part of multidisciplinary teamwork. Motivations to improve current practices and a general openness to a change process were expressed both during the focus groups and when the Phase I findings were presented to the MDT CRG, Phase 1. An MDT CRG Working Group consisting of N=8 MDT members was subsequently established, with a sub-sample of the MDT CRG (as Phase I essentially involved two multidisciplinary teams; Stroke and General Medicine, it was not practical for all MDT members to participate in the MDT CRG Working Group). The MDT CRG and MDT CRG Working Group involvement in Phase I of the action research cycle will be fully discussed within Chapter 4.

Figure 7 depicts in diagrammatical format the different formations of the MDT CRG during different stages of the action research cycle.

Figure 7; MDT INVOLVEMENT AS COLLABORATORS



3.37 MDT CRG (MDT CRG)-Phase 2

During Phase 2, the composition of the MDT CRG involved the Stroke MDT. This consisted of the Medical Consultant, Physiotherapist, Occupational Therapist, Social Workers x 2, Speech and Language Therapist, Dietician, Clinical Nurse

Specialist and myself as the practitioner researcher. All group members had also been involved in Phase I of the research as they were members of the Stroke MDT who formed part of the MDT CRG, with the exception of the Clinical Nurse Specialist. This factor greatly contributed to uniformity across the phases and aided the process of data analysis as the majority of the MDT had a sound understanding of the objective of the research and the mechanics of adopting an action research approach. They had also given a commitment to be involved in the research for its duration from the outset.

3.38 Research Design, Phase 2

As in Phase 1, participant observations of 10 CPM's took place and the researcher completed a data observation record and audio-taped each meeting. In Phase 2, questionnaires were administered to 10 patients post CPM in a semi-structured interview format and audio-taped in order to gain an insight into their perception and experience of participating in the CPM process. As in Phase 1, interviews took place within 72 hours of the CPM taking place, at a time that was convenient to the patient. The researcher also interviewed a family member/spouse/next-of-kin as nominated by the patient in order to gain their perception of how *the patient* participated in the meeting process.

Observation notes and audio-tapes were analysed in detail (see Section 3.43 on data analysis). Transcripts from CPM's and interviews with stroke patients and their family members were also studied. Data was analysed and findings fed back and discussed with the MDT by reintroducing the MDT CRG model. Team members then worked together to identify ways of improving practice within CPM's based on the findings. A Training manual was then developed by the MDT CRG outlining best practice guidelines which denoted Phase 3.

3.39 Inclusion Criteria-Phase 2

The MDT CRG identified that Phase 2 should focus on cognitively impaired patients, as they were considered the most vulnerable and least involved based on findings from Phase I. It was then necessary for the group to consider and decide what category of cognitively impaired patients should be included. It was decided by the MDT CRG that Phase 2 would be confined to studying stroke in-patients who had been assessed as having cognitive/communication difficulties, but who were deemed to have the cognitive ability to participate in a CPM; the recruitment process and screening tools used will be discussed on p 142-146. Purposive sampling of stroke patients was used in the study design to reduce heterogeneity of disease and treatment experience and also to enable comparisons within the study sample.

Phase 2 was conducted within the Department of Geriatric Medicine in the hospital which has a specialised inpatient stroke rehabilitation unit. In order to guarantee some age diversity in the sample of patients belonging to the stroke service, the inclusion criteria did not specify an upper or lower age limit. It was anticipated that the majority of the study sample would be >65 however, as the unit treats stroke patients of all ages, there would be the possibility of a small section of the research subjects who would be <65. It could be argued that the inclusion of the <65 stroke patients provided little value to the study findings but on the other hand, it was considered that the sample should be reflective of the stroke inpatient population within the hospital and that useful insights could be gained by examining the participation levels of younger and older individuals who had suffered a stroke.

3.40 Conceptual framework used for Research Design of Phase 2

It was evident from the findings of Phase I that the concept of patient participation (or lack of!) was arguably the most significant concept. In view of

this, it was decided that when planning for Phase 2, it would be advisable to review the relevant literature, particularly that relating to participation, and to use it to inform the research design of the interview schedules.

3.41 Design of Interview schedules, Phase 2

First and foremost, the interview schedules tried to capture each patient's real and lived experience of the meetings process; what emotions they felt before, during and after and whether attending the meeting had made them feel any more in control of their hospital experience. It also explored in detail their experience of communication and information sharing with the MDT. Interview schedules for Phase 2 also attempted to incorporate the 5 defining attributes of participation as outlined by Cahill(1996), and other factors such as past history of decision-making and desire to participate were explored. The spouse/family member interview schedule meanwhile focused on their perception of the patients experience and participation and not their own experience. Again, the intention was to gain a complete picture of each patient's experience and desire for participation and the role that the MDT had to play within this experience. Interview schedules for Phase 2 were developed and piloted with a patient and family members who had recently attended a CPM. The interview schedule was then amended based on feedback provided and piloted a second time[8].

3.42 Phase 2, Focus Group

During Phase 2, one focus group was held with all members of the Stroke MDT. The purpose of the focus group was to discuss and gain feedback on the usefulness of the patient information booklet on CPM's which was developed and

[8] See Appendix I and J for Questionnaires/Interview Schedules for Phase 2

introduced as an initiative to help improve patient participation levels after Phase I.

3.43 Tape-recording and Transcription-Phase 2

As mentioned earlier, the CPM's observed in Phase I were not audio-recorded and therefore the researcher relied entirely on the data observation records and field notes which greatly limited the amount and quality of data which was available to analyse. Being an action research project however meant that lessons could be learned from such an omission and therefore during Phase 2, all CPMs and interviews were taped. I was anxious therefore that richer, more detailed material should be collected for Phase 2. As cited in Silverman, Atkinson and Heritage(1984), point out that the production and use of transcripts are essentially 'research activities' and they reveal close, repeated listenings to recordings which often reveal previously unnoticed recurring features of the organisation of conversation.

3.44 Cognitive impairment post-stroke.

A significant complicating factor to a patient's physical rehabilitation is cognitive impairment. Cognitive impairment can include a progressive deterioration of intellectual ability(e.g. dementia),impairment of memory, aphasia, apraxia, or one of the agnosias (Robinson,1997). Impairments of cognitive processing speed, working memory and executive functions are frequent in older stroke patients without dementia and represent the main cognitive components of early cognitive impairment(Ballard et al.2003). It would seem therefore that diminished cognitive function in any area, such as orientation, attention, recall, judgment, or insight can form part of the clinical picture of stroke.

3.45 Screening Tools, Phase 2

Both the MMSE and the Western Aphasia Battery Screen were selected to screen patients on the basis that they were assessments that would routinely be conducted within the course of a stroke patients inpatient treatment and were deemed to be widely accepted measurements of cognitive status(MMSE) and communication skills post -stroke(WAB).

MMSE and WAB assessments of patients were completed within one week pre/post CPM. The MMSE and WAB assessments were incorporated into the research design in order to gain a complete clinical profile of each patient and to enable analysis and comparisons of participation levels of patients with differing cognitive and communication abilities post-stroke. The findings of Phase I highlighted low participation levels of patients with cognitive impairment and it was considered crucial to further explore differing participation levels and study this with specific reference to the categories of mild, moderate and severe cognitive impairment as per MMSE screen.

3.46 Mini-Mental State Examination (MMSE)[9]

The MMSE is the most commonly used scale to determine levels of cognitive function. It is an 30 item scale that takes approximately 10 minutes to complete and is usually routinely carried out on older hospital inpatients Considerable debate exists within the literature as to what MMSE score indicates cognitive impairment within an individual. For the purposes of this study it was decided that if an individual scored above 26 on the MMSE screen that this indicated a low probability that cognitive impairment existed and that the person was cognitively intact(based on Siu(1991),'Screening for Dementia and investigating

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[9] See Appendix L for MMSE

its causes') and these patients would be excluded. Cut off point in MMSE indicating low probability of cognitive impairment was 26 out of 30, scores between 21-26 were suggestive of mild cognitive impairment and 10-20 moderate cognitive impairment (NICE Guidelines, 2011). For the purposes of the study the MMSE screen was carried out either by a member of the stroke medical team or by an Occupational Therapist who were part of the MDT. Although the MMSE is the most widely used cognitive screen in practice, it has been criticised for lacking sensitivity in cognitive screening post-stroke (Blake et al.2002).

3.47 **Western Aphasia Battery Screen(WAB),** (Shewan and Kertesz, 1980)

The WAB has been designed to provide a means of evaluating the major clinical aspects of language function: content, fluency, auditory comprehension, repetition and naming plus reading, writing and calculation. The procedure is based on the principles of modern neurolinguistics and the neuro-anatomical language model. The scale can be administered in a relatively short time and enables the clinician to classify the patient in relation to various aphasic groups. The screen is scored as a percentage; a score of 100% indicates that an individual is not aphasic and has a normal level of language function. A low percentage indicates a higher level of aphasia and thus a high level of communication impairment[10]. For the purpose of this study, the WAB screen was to be carried out by one of the Stroke MDT Speech and Language Therapists and scores would be documented by the researcher.

[10] See Appendix M for WAB Screening Tool

3.48 Recruitment process, Phase 2.

It was agreed that as the medical social workers on the Stroke MDT were generally the staff responsible for organising CPM's, that they would identify potential suitable meetings and seek initial consent from patients for inclusion in the research sample. The 2 social workers therefore played a crucial gate keeping role and also informed the researcher about whether it was expected that the patient would be present at the meeting or not. This was a vital piece of information as the MDT CRG had decided that only those meetings in which the patient was present should be included in the sample so patient participation levels could be examined more closely. In conjunction with this, a general assessment was completed by the MDT to decide (i) does the patient have the cognitive/communication abilities to participate in the meeting and (ii) do they want to attend.

3.49 Phase 3

Phase 3 represented the final stage of the action research cycle both for the thesis, and the Care and Connect project and involved the design and implementation of a Training manual on best practices in CPM's for HCP's.

3.50 Data Analysis and Collection

AR CYCLE	DATES
PHASE I	March 2008 - June 2008
PHASE 2	March 2009- January 2010
PHASE 3	May 2010- November 2010

3.51 Method of Data Analysis

Analysis is the process of examining something in order to find out what it is and how it works. Analysis should ideally begin after completing the first observation or interview (Strauss and Corbin, 2008). Hammersley and Atkinson (1983) also recommend immersing oneself in the data and then searching out patterns, identifying possibly surprising phenomena, and being sensitive to inconsistencies. This sequential approach to data collection and analysis allows the researcher to identify relevant concepts, follow through on subsequent questions and to listen and observe in more sensitive ways. It has been found that immersion in data analysis during collection provides a sense of direction, promotes greater sensitivity to data and enables the researcher to redirect and possible revise interview questions/observations as they proceed (Corbin and Strauss,2008).

Analysis also involves what is usually termed 'coding' which involves taking the raw data and making sense of it at a conceptual level. This process can be thought of as 'mining' the data where the researcher Information on the data recording sheets, questionnaires and notes from the focus groups were read in depth several times to gain an in-depth understanding of the information

gathered; pattern codes were then developed (Miles and Huberman,1994). Data was then grouped for identifiable similarities and trends and convergent themes were noted and developed.

3.52 Interpretive Inductionism

There are many different forms of data analysis and in deciding on the research design, consideration was given to what data method analysis would be most appropriate; I found it challenging attempting to decide which data analysis 'fitted' this study as it aims to explore several different aspects of the meetings process using different research tools. The data analysis framework which has been applied to this study is that of interpretive induction where the researcher approaches a problem from the perspective of theoretical sensitivity to existing concepts, ideas and the theory. The researcher plays an active and deliberate role in organising and assigning meaning to the data as way of constructing higher-order categories and theories (Kuczynski and Daly, 2002).

As this study aimed to examine human action in social contexts, two layers of meaning were explored through the interpretive inductive approach. Firstly, the meanings that are held and communicated to the researcher by their subjects concerning their everyday lives, experiences and perceptions. Secondly, the meanings which the researcher brings to these meanings as they attempt to understand, explain and theorise about these experiences. This process forms part of the 'double hermeneutic' discussed in Chapter 2, as essentially the researcher, will observe and interpret the experiences of participants in CPM's who are themselves interpreting the world they are experiencing. It is also important to note that as a practitioner researcher I am also an everyday participant of the culture under study so a straddling of first and second order meanings occurred.

The goal of qualitative research is to identify, describe and attempt to understand phenomena however it also involves the interpretative ability of the researcher in making sense of the data they collect (Kuczynski and Daly,2002). Of particular relevance to this study is the use of observational methods whereby the act of creating a coding system to classify behaviour into meaningful units is a meaningful act.

Bakeman and Gottman (1997) highlight the importance of this interpretive act arguing that this process is very much a theoretical act which, in its most simplistic form, is the 'lens' through which the researcher has chosen to view the world.

3.53 Data Analysis-Phase 1

Analysis of the information on the data recording sheets, field notes, interview schedules and notes from the focus groups followed an iterative data reduction method (Crabtree and Miller 1999; Creswell 2003; Kvale 1997). Information was extracted and data grouped for identifiable similarities and trends. Convergent themes were noted and developed and supportive quotations were identified (Crabtree and Miller 1999; Kvale 1997).

3.54 Thematic Framework for Data Analysis, Phase 2

Sahlsten et al's (2005), four properties of participation were used as a thematic framework and guide for coding of CPM's and interview data. In completing the data analysis I was not seeking to quantify data, justify or substantiate this theoretical framework, rather after indexing the codes, there appeared to be a natural fit for the codes under the headings as developed by Sahlsten and colleagues. This framework contributed to the structuring of the patient interview schedule in Phase 2 and enabled the issue of each patient's participation experience to be explored. It also facilitated the application of an

interpretive inductionist approach to data analysis which allowed me to approach the analysis from a position of theoretical sensitivity to the data related to my own practice experience as a social worker. The critical discourse analysis which was conducted on each CPM predominantly focused on the language and communication of the MDT members. All other nodes(codes) were then condensed under the four main headings.

Exchange of Information and Knowledge

Existence of a therapeutic relationship

Interpersonal Procedures- Informal Processes and Discourse Analysis

Power, Control and opportunities for influence

3.55 Discourse Analysis

As this study examined the language used in meetings, a discourse analysis was also conducted. Language is the most 'accessible phenomenon, accessible for empirical investigation' (Alvesson and Karreman,2000) and discourse analysis can be broadly defined as the interaction between the written and spoken word, talk and texts as part of social practices (Potter,1996) which people use to construct meaning(Foucault,1972). Numerous readings were undertaken where details of the text are seen as essential. Variability in content and forms of account and consistency in features that are shared by the accounts were used by me to search for meaningful patterns. Final analysis is an interpretation of how communication functions and affects the people involved in meetings and finally, a search in the data for evidence supporting the interpretation is carried out. The study of discourse therefore enables people to reflect on and modify their practices (Morgan and Sturdy,2000) and create a coherent social reality which satisfies one of the aims of this study.

3.56 Critical Discourse Analysis

Critical Discourse Analysis can be described as the study of language and discourses in social institutions (Fairclough,1992). As Teo observes, the 'critical' element in critical discourse analysis encourages an examination of the ideological basis of a discourse that normalizes and accepts stances such as racism or as in the case of this study, ageism. This approach often involves the analysis of a particular discursive event, such as CPM's using a 'three-dimensional' framework;

1. It involved the examination of the content, structure and meaning of the language used within CPM's (the words that are spoken and how language is communicated and structured).
2. An examination of the form of interaction used to communicate meaning and beliefs (the CPM as a practice dimension).
3. Consideration of the social context in which the discursive event (the CPM) is taking place(the social practice dimension, (Grant et al.2004)

In this way discursive practices should always be regarded as structured and structuring actions (Weiss and Wodack,2003). Critical Discourse Analysis sees discourse, language use in speech and writing, as a form of 'social practice'. Describing discourse as a social practice implies a dialectical relationship between a particular discursive event, CPM's, and the situation(s), institution(s) and social structure(s) which frame it: the CPM as a discursive event is shaped by these forces, but it also shapes them (Fairclough and Wodak,1997).

Critical discourse analysis takes a particular interest in the relationship between language and power. The aim of critical discourse analysts is to instigate change through gaining a critical understanding and that entails making explicit one's

socio-political stance from the outset. Quite often dominance is re-enacted through everyday talk and texts that appear 'normal' and acceptable'. Thus critical discourse analysis focuses on discursive strategies that legitimizes control, especially relations of social inequality (Fairclough,1992).

The analysis had a quantitative component which was used as an indicator of participation and included an examination of number of words uttered by patients, family members and MDT within each meeting. The data analysis approach replicated elements of Hedberg et al.'s (2008) study by counting the number of words uttered by each meeting participant in order to assist with the examination of participation within CPM's, and to complement the data gathered by the participant observations of informal processes.

This type of analysis was also employed in order to study any patterns of dominance in communication (Linnell,1998; Hedberg et al.,2008). An examination of people being talked about by the MDT in the third person, as if they were not present during CPM's, was carried out as this was strongly evidenced in the findings of Phase I and has also been identified as practice of concern in other studies(Froenck,2005, Efraimsson et al.,2006; Hedberg et al.2007;2008). Attention was given to studying the number of questions asked by meeting participants and finally instances of interruptions or patients being 'talked over' were examined. A critical approach thus was taken in order to explore issues of power and inequality relating to participation within the CPM process.

In relation to this thesis, a critical discourse analysis of the study's findings provided a lens to examine issues of power within the communication interplay in CPM's through exploring issues such as,

- Usage of the 3rd person grammatical
- Which participants in CPM's controlled the topics and structure of conversation/Participation within the CPM

- What information/knowledge was exchanged and how was this communicated?
- The nature of any decision-making processes

An in-depth analysis of pace of speech and tone of voice and turn taking used during CPM's was not conducted as part of the examination of interpersonal procedures as a conversation analysis approach of CPM's was not being carried out[11].

3.57 Nvivo

The software package Nvivo was also used to assist with data management and data analysis In Phase 2. Nvivo coding of transcripts assisted the process of conducting a critical discourse analysis by enabling an analysis of the numbers of words uttered by patients, family members and the MDT. Therefore, each word which was uttered was coded specific to the individual who uttered it and was then coded under any other subthemes and topics.

3.58 Reflexivity

It is recognized that complete objectivity in qualitative research is impossible. Researchers bring to the research setting their own particular paradigms, including perspectives, training, knowledge and biases; these aspects of the self then become woven into all aspects of the research process (Guba and Lincoln,1998). Strauss and Corbin(1996) point out that we have to have some background, either through immersion in the data or through personal experience, to know what we are seeing in data is significant and to be able to

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[11] Whilst discourse analysis incorporates elements of conversation analysis, the latter method of data analysis has a greater focus on sequences of talk, tone of voice and analyses *how* a speaker says something, in order to explore the meaning behind the words used(Bryman,2008).

discern important connections between concepts. It can be argued that to suppose that an researcher enters a field without past experience or some pre-existing experience is unrealistic and to suppose that their presence will not exert an influence on the data is equally unrealistic (Silverman,2005).

Reflexivity during data collection and analysis is an important consideration in qualitative research (Finlay,2003).Reflexivity can be described as a strategy of monitoring how personal meanings and experiences creep into the process of inductively generating theory (Kuczynski and Daly,2002). Reflexivity is the awareness and recognition that our life experience and professional experience will influence and shape our work as a researcher.

From my own professional experience as a social worker, it was necessary for me to examine my attitudes and working knowledge of CPM's and acknowledge that I was embarking on research from a position of subjectivity. Kuczynski and Daly(2002) point out that reflexivity is particularly important when researchers are operating from an 'insider' position and who have particular personal experience with the topic of study. I also had to accept that I wasn't the only participant that reflexivity was pertinent to and that the MDT having been enlisted as collaborators, and the older people and their family members would also play a part as co-constructors of knowledge and theory.

3.59 Reflexivity and role of insider researcher.

This is an important consideration when conducting qualitative research. Researcher's emotions may be conveyed to participants and accordingly they react to the researcher's responses mostly at an unconscious level. It has been argued that due to this reciprocal influence, the researcher and participants co-construct the research; at least the data collection (Finlay,2002).

Insider Research. For the purposes of this research study, it was agreed that I would adopt an 'insider' researcher position, i.e. conduct research in my own workplace, into my own practice and the practice of my colleagues (Reed and Proctor,2005). It can be argued that advantages of the insider role includes familiarity with the situation and an in-depth understanding of the issues and context. The insider researcher position also contributes to increased credibility with participants as they have an established role in the team and an increased commitment to the study and to sustain change. Disadvantages of this position include familiarity clouding understanding, conflicting commitments and participants feeling threatened and therefore reluctant to disclose information. However whilst I was also working as a medical social worker at the same hospital, it needs to be pointed out that at no stage did I have any responsibility for the social work needs of these same patients.

3.60 Ethical Considerations for Research Design

Ethical issues were carefully considered both in the research design data collection phase and write up of the study. In view of the at times very vulnerable nature of the patients being researched, there were a number of considerations that needed to be addressed. These included conducting insider research, issues of obtaining informed consent, a consideration of patients cognitive and communication difficulties and the impact this had on their ability to participate. Consideration was also given to issues of confidentiality as the research site was the researcher's place of work.

3.61 Ethical Approval

The research proposal, protocols, and related information sheets and consent forms received ethical approval from the Research Ethics Committee of TCD/Adelaide and Meath/St James's Hospitals and approval was also granted by the School Research Ethics Group at Trinity College Dublin. At all times the safety

and comfort of participants was given priority in conducting the study. Data collected was rendered anonymous (in so far as is possible given that the study site will be identifiable) and all data storage was in keeping with the Data Protection Act(Amended June 2003). Careful attention was given to ensure that all information cited in any report or external publication did not identify any individual older person, family member or healthcare professional. The research study may uncover unmet needs within the patient population: these will be summarised and communicated to the relevant treating Clinician at the end of the study.

Pseudonyms were given to all research participants and consent forms were completed for all patients, family members and members of the MDT who participated at each stage of the study.

3.62 Methodological issues related to interviewing people with a cognitive / communication impairment.

Qualitative research that includes participants with cognitive and communication impairments although limited compared with quantitative studies is now becoming more common practice. Carlsson et al. (2007) found few studies where the researchers had assessed potential participants' communicative or cognitive ability in the recruitment of participants. In studies where assessments had taken place, the purpose appeared to be to check if it would be feasible to gain valid and rich narratives and not specifically to gain informed consent. Assessing an individual's cognitive capacity in the process of research is often a delicate matter as the assessment itself could be a cause for anxiety; I aimed to have addressed this challenge as cognitive and communication assessments would have been carried out as a routine part of each patient's inpatient treatment.

Researchers should also be aware during the interview for signs of verbal and non-verbal distress. It has also been recognized that responding in an interview

may tax the cognitive and linguistic abilities of someone who has a cognitive impairment so awareness of fatigue is also essential (Philpin, 2005). Within all interviews carried out, I always strove to be aware of verbal and non-verbal signs of distress or fatigue and I attempted to ensure that interviews were conducted at a time that was convenient to the patient and when they were not overly tired.

3.63 Informed Consent.

Concerns have been raised about the ability of individuals with cognitive/ communication difficulties to recognize and understand the terms of informed consent. Philpin and colleagues (2005) have suggested that communication difficulties might result in a failure to correctly interpret written or verbal explanations. In addition, those with recall problems might sign a consent form and then later forget what they have signed or that they even signed it. Carlsson et al.(2007) argue that researchers cannot assume that every person understands the content of the consent and truly gives informed consent and that the participants consent is longstanding throughout the research. Flory and Emmauel(2004) recommend that having a member of the study team or a neutral educator spend time discussing the information with participants as the most effective way of improving the participants' understanding of what is entailed in the informed consent.

In an attempt to gain informed consent, a written patient information booklet and consent form was designed explaining what the aims and objectives of the research were and what participation in the research would involve. The researcher also verbally explained the information in both documents the day before the research was due to take place and left the information leaflet for the patient to review themselves where appropriate and possible. On the day that the participant observation was due to take place, the researcher explained the information on the consent form a second time and answered any questions

which the patient might have. It was only at this stage that the researcher sought the verbal and written consent of the patient. Carlsson et al.(2007) also recommend that the informed consent form should clearly state that the interview is not an assessment of the person's communication ability and for the purposes of this study the consent form clearly stipulates that the interview is not an assessment of the persons cognitive or communication abilities.

3.64 Utility

There is an ethical responsibility to make good use of data collected (Mc Colgan, 2003) and to disseminate research findings. I believe that utility is an integral focus of this study for the following reasons; (ii) It is expected that this study will provide an insight into how patients and their family members experience CPM's (ii) closely examine the practice of healthcare professionals in CPM's and gain an understating of how language and behaviours used may relate to participation levels of patients(iii) in response to findings develop a Training manual aimed at improving current practices and (iv)add to the existing body of knowledge on CPM's.

3.65 Limitations.

This thesis has several limitations which must be acknowledged.

One of the most obvious weaknesses is that because of its design it will not be possible to generalise findings as they are quite specific to the research setting and the research subjects. It is important to note however that qualitative research does not aspire to its findings being generalisable and instead, its aim is to generalise to theory rather than to populations. In other words, it is the quality of the theoretical inferences that are made out of qualitative data that is crucial to the assessment of generalization (Bryman,2008). However not all writers accept this view and Williams(2000) argues that ,in many cases, qualitative

researchers are in a position to produce what he calls moderatum generalizations, that is, one in which aspects of the focus of enquiry 'can be seen to be instances of a broader set of recognizable features' (Williams,2000,p215). It is considered however, that this drawback can be balanced by the learning and insights gained from trying to change the practice of healthcare professional using an action research approach

A second limitation of this thesis is that while the design is described as action research, it did aspire to be participatory; however, it does not fulfil all of the principles of this approach. This research was not truly participatory as it did not involve patients or family members in the research development or design. When deciding on the research design, it was not considered possible on a practical level, to involve the older patients and family members firstly, as our ability to access the patients was restricted to the length of their inpatient stay and this also restricted our ability to feed back findings and seek validation from these participants. Secondly, it was not deemed feasible within the remit of this study to include the older patients in a Critical Reference group in view of their cognitive/communication difficulties as it was considered that this role could possibly promote anxiety and stress in the older patients.

Within the study design, the MDT act as 'collaborators' however a clear limitation of this study is the fact that their role was a secondary one to my own.

Another limitation is that as a practitioner in a hospital setting, the researcher would have an inherent bias and preconceived ideas about how CPM's should be conducted. As a practitioner who also facilitates CPM's, bias may have influenced the type of data collected and what was recorded. However, I attempted to always remain aware of this and have strived to focus on my role as a researcher and to maintain this role and focus as much as possible in an attempt to overcome this bias. It was intended that by the use of audio-recording in Phase 2,

a more objective, thorough collection of data would have been achieved. I also hope by explicitly declaring my preconceptions and expectations (those that I am aware of!) and through the use of reflexivity to minimise the extent of researcher bias.

Lastly, the research does not include the perspective of those who have suffered a stroke and who are excluded from hospital CPM's due to their significant communication deficits and the severity of their cognitive impairment. These are a particularly vulnerable group who pose a major research challenge.

Another limitation is that conducting research in the hospital setting there are existing occupational and power divisions which may have impacted on the way the research was carried out and the findings

3.66 Chapter Summary

This chapter opened with a discussion of action research and argued why the particular approach taken to undertake this study i.e. action research was chosen. Action research it was contended is an ideal methodology for a study of this kind which aims to both document the language, behaviours and communications used at CPMs in hospital settings as well as to ultimately change practice by involving doctors and allied health practitioners as collaborators in the overall research process.

The chapter then proceeded to discuss the integrated theoretical framework adopted for the study and to describe the approach to sampling used to collect information from patients, MDT members and family/relatives. The different strategies used to collect data during both phases of the action research cycle are highlighted. These included participant observation, semi-structured interviews,

questionnaires and mini-focus groups. The chapter also discusses the concepts used to inform the methodological framework developed including Critical Gerontology, Personhood and Citizenship.

In the chapter it has been shown how much effort was spent attempting to use several different approaches to gather all the necessary data particularly in Phase 2, where patients had a cognitive impairment or significant communication difficulties. The chapter shows that reliable, and validated tools such as the MMSE and the WAB were used to assess each patients' level of cognitive/communication impairment in Phase 2. It was demonstrated that data analysis was undertaken using Nvivo and an interpretive inductionist approach utilised along with critical discourse analyses, which facilitated a better understanding of observations made.

Some of the ethical concerns confronted in undertaking research work of this nature are discussed along with how ethical approval was granted. The chapter concludes with a discussion about how the researcher experienced the research process by virtue of being employed in the same setting and being a Medical Social Worker by profession. Some of the limitations of the study and the methodological approach used are also discussed.

The main aim of this study was to examine the CPM's process in a hospital setting and in particular patient participation levels. The findings of Phase I directly informed the research design and focus for Phase 2 and in conjunction with the MDT it was decided that a closer examination of participation of patients with a cognitive impairment should take place. It was recognized that frequently espoused values i.e. what people believed to be 'right' were not always reflected in the 'reality' of clinical day-to- day practice. Therefore observations and data collated were key to understanding the realities of practice with cognitively impaired older patients.

Chapter 4 Family Meetings-What's going on? An exploration of the subjective experiences of older patients, family members and MDT members. Phase I, Action Research Cycle.

4.2 Introduction

This chapter will present findings from Phase I of the action research cycle. The main aim of Phase I was initially to gain a snapshot picture of current practices within family meetings[12] which would then act as a basis for Phase I and Phase 2 of the study. The purpose of Phase I was to explore the subjective views and experiences of family meetings from the perspective of participants taking part in CPM's namely, older patients, family members and the MDT. In relation to the action research cycle, Phase I also represented a critical reflection and problematisation of current practice in CPM's (Herr and Anderson,2005) and it was anticipated that the findings would also help inform the longer term study focus and design which would be negotiated and agreed by the MDT CRG.

[12] Throughout Chapter 4, the meetings forum will be referred to as 'Family Meetings' as this was the working terminology during this stage of the research. The name of the meetings forum did not change to 'CPM's until Phase 2 of the action research cycle.

Within the study setting, there were inconsistencies within existing hospital practices resulting in instances of family meetings being held where the patient was completely excluded. This study therefore set out to examine family meetings with a particular focus on the participation of some of the most vulnerable and to explore in more detail if changes to practice could be implemented to address this problem. This chapter will begin by discussing the participant observation findings of the 10 family meetings and will move on to reporting on the questionnaire data. The findings from the mini-focus groups will then be presented. The final section of the chapter will be a descriptive reflection of the participatory action research component of the methodology and the MDT involvement as collaborators.

4.3 Findings-Different Purposes of Family Meetings

Based on data obtained from participant observations and interview data, findings revealed that family meetings within Phase I occurred for a variety of reasons; some were convened to share information with patients and their family members and to negotiate and agree on a discharge plan. Other meetings had been requested by the patient's family as they wanted to meet with the MDT to gain information and to express concerns that they had about their relative's discharge plan. Another meeting was convened in order to mediate and facilitate discussion with the family members of a patient where a decision needed to be taken in relation to artificial feeding and there was disagreement between the family members about whether this should take place.

Of particular interest is the fact that two of the meetings (Johnny and Frank's) were requested by their family members as they were opposed to their relative being discharged to home. In both cases, the patient wanted to return home and the purpose of the family meeting was so that the MDT could advocate and

support the patient's right to self-determination(in each instance the patient had been assessed as having decision-making capacity by the MDT) and to negotiate a discharge plan with their family members. In both cases, their family members also expressed annoyance at the fact that the MDT were insisting that the patient should be present at their family meeting, as their family members believed that they should not be allowed to be attend.

Other meetings in the sample were convened by the MDT to involve family members as proxy decision-makers on behalf of their relative who was either medically unwell or had advanced cognitive impairment which resulted in the patient either not wanting to attend their CPM, or being unable to participate in any meaningful way. The majority of these meetings related to discharge planning, however, as stated earlier, one related to decision-making around the artificial feeding of a patient (Marie). This meeting was convened in order to mediate and facilitate discussion with her family members as there was disagreement between family members about whether this intervention should take place.

Finally, two of the meetings were in relation to discharge planning decision-making.

4.4 Decision-making Styles

The decision-making style in Johnny and Frank's meeting has been termed 'silent delegation' as although they had communicated their wishes relating to their discharge plans prior to the meeting taking place, they did not become involved in the decision-making process during the meeting. It can therefore be argued that they 'silently' delegated the MDT and their family members to take responsibility for the final decision reached.

One family meeting was deemed to have followed a self-determination decision-making model(Brian),while another followed a shared decision-making model(Peter), which took the form of the patient and their family members jointly making decisions. Their meetings differed to those of Johnny, Frank and Patsy, as Brian and Peter demonstrated higher levels of verbal participation; this is of interest as both these patients were cognitively intact and did not have a cognitive impairment.

The next section begins with providing a summary of the characteristics of the Family Meetings observed in Phase I as detailed in the summary table(see Figure 8). I will then proceed to discuss the findings from the participant observations.

4.5 Summary of Characteristics of Family Meetings

As outlined in the summary table(see P.168,) participant observations were completed on 10 family meetings[13]; five of the meetings were with the patient, their family members and MDT in attendance, the other five meetings were with family members and the MDT only. In relation to the gender breakdown of patients for whom family meetings were arranged, seven were men, and three were women. Their mean age was 78 (range 67-89). Eight were assessed by their treating Consultant as having some level of cognitive impairment and for this reason five out of the eight did not attend their family meeting.

Of the five that did not attend, one patient did not wish to attend his meeting and was reported to be experiencing 'low mood' (Hughie). Two of the five (Marie

[13]Information detailed in participant observation summary table was obtained from each patient's medical chart and patient records. Permission to access patient record was obtained through patient consent forms.

and Denise) were medically unwell, of whom Marie was unconscious and thus the issue of whether she should be artificially fed was critical. The final two patients who did not attend were assessed by their medical Consultant and the MDT as having such a severe cognitive impairment that they would be unable to participate in their family meeting in any meaningful manner and it was likely that the experience could be distressing for them(Roger and Rita). Formal assessment of each patient's cognitive status was not carried out by the researcher and information relating to their cognition was obtained from an MMSE assessment that had been completed by other members of the MDT e.g. an occupational therapist(OT) or a member of the medical team.

All patients within the sample had at least two family members in attendance with a maximum of seven family members in attendance. The majority of family meetings were characterised by the fact that the MDT by and large tended to outnumber family members. At every meeting, a medical consultant or registrar was in attendance and a social worker. Attendance of other members of the MDT was determined by the purpose of the family meeting in question.

Figure 8; Characteristics of Care Planning Meetings-Phase 1

Patient	Cognitive Impairment	Family Member Attendees	MDT Attendees	Purpose of CPM	Decision-Making Styles	Meeting Length	Total
Johnny Attended	Yes	Brother, Sister	Consultant Social worker, PT, OT, Nursing, Patient Advocacy Officer	Medical update discharge Planning.	Delegation, 'Silent'. MDT and Family.	56mins	9
Roger Did not Attend	Yes	Daughter Son Brother-in-law Sister-in-law	Consultant Social Worker, SLT, PT, Nurse	Medical Update	Proxy	34 mins	9
Patsy Attended	Yes	Wife Daughter	Consultant Social Worker, PT ,OT	Medical Update , Discharge planning	Shared Decision-making Compromise	40mins	7
Marie Did not Attend	Yes	4 Daughters 2 Sons	Consultant Social Worker, Dietician	Decision-making re; insertion of 'peg' feed	Proxy MDT and Family	2 hours	9
Denise Did not Attend	Yes	Daughter Son	Consultant Social Worker, Dietician, Nurse Student Nurse	Medical update and decision-making	Proxy Family Members	38 mins	7

Frank Attended	Yes	5 sons 2 daughters	Registrar, Social Worker, OT, Nurse	Medical Update and Discharge Planning	Delegation 'Silent' MDT and Family members	1 hour, 10mins	12
Hughie Did not Attend	Yes	2 daughters	Consultant, Social Worker, Nurse	Medical Update and Discharge Planning	Proxy	45 mins	5
Brian Attended	No	Son Daughter	Consultant, Social Worker, OT, PT	Information giving and Discharge Planning	Self- Determination	53 mins	7
Rita Did not Attend	Yes	2 daughters Son	Consultant, Social Worker, Dietician	Medical update and Information sharing	Proxy Family Members	50 mins	6
Peter Attended	No	Wife, Son, Daughter, Sister	Registrar, Social Worker, PT, OT, Nurse x 2	Medical Update and Discharge Planning	Shared Decision-Making Patient and Family Members	1 hour 15 mins	11

PT=Physiotherapist, OT=Occupational Therapist, SLT=Speech and Language Therapist

4.6 Participant observation profiles

Data analysis focused on key generic practice issues and the significant observations relating to the meeting process that were documented on the data recording sheet and field notes.

The findings relating to the participant observations will now be presented and will be summarized under 4 key headings:

Informal Processes and Interactions

Information, Facilitation and the Decision-Making Process

Outcome of the Family Meeting

Participation of the Older Person and Family Members

4.7 Informal Processes and Interactions

Instances of informal processes[14] were recorded for all family meetings observed on the data recording sheet. At the five meetings observed where the patient was present, consistently good eye contact was noted between members of the MDT and family members. It was observed however that eye contact between the MDT, family member and patients was often poor, particularly eye contact with those patients who had a cognitive impairment.

It was observed that for example, Johnny, Patsy and Frank, each of whom had a cognitive impairment, little or no eye contact was made with the patients by any

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[14] Body language, eye contact, seating arrangements, punctuality, jargon used and any other observations which the researcher considered to be of interest were noted

of the other meeting attendees. On the other hand, it was observed that predominately good eye contact was maintained with Brian and Peter, who were cognitively intact, by both the MDT and their family members. It could be argued therefore that although the numbers are very small in this study, more respectful and inclusive practices were evident from both the MDT and the family members present during the family meetings with the cognitively intact patients.

Punctuality of staff, namely medical staff, was an issue at three meetings observed. In the case of Denise's meeting, the Consultant arrived approximately 20 minutes late which naturally impacted on the process and dynamics of the meeting in question. In each instance, the meeting was started without the doctor being present, however, often much of the information discussed in the doctor's absence had to be recapped which interrupted the meeting's natural flow.

Seating was generally in a circular format around a table. The MDT tended to sit on one side of the table whilst the patient and their family members sat on the other side. There was no evidence of integrated, mixed seating within any of the observed meetings.

Body language was also observed (open and closed such as relaxed body positioning or crossed/folded arms and legs, Froenck, 2005). It was noted that the body language of all meeting attendees was generally open, this was evidenced by the fact that meeting participants appeared relaxed and were sitting back in their seats and their arms were by their sides rather than folded.

An analysis of the data recording sheets and field notes revealed that medical jargon was seldom used and on occasions when it was used, its meaning was generally explained. For example,

'Your father has some cognitive impairment that means that his thinking and memory aren't as clear as they had been' (Frank, Family Meeting Data Recording Sheet)

and

'She is at risk of aspirating-what I mean is that she is at risk of liquids going down the wrong way and into her lungs'(Rita, Family Meeting Data Recording Sheet).

It appeared therefore that when medical terminology was used by the MDT, these hospital staff attempted to explain it where possible. Other studies have found that healthcare staff used language and ways of communicating that older people are perhaps not always comfortable with, perhaps because of their sometimes lower education level or use of jargon (Fisher et al.2006). It is important to note that although I deemed the information provided by MDT members as 'understandable', one cannot be certain how much the older patients understood the information being conveyed. However, all of the older patients within this sample(N=5) did report during the interview stage that they were able to understand all the information conveyed so this does add further weight to the argument that the information was understandable.

4.8 Information Giving, Facilitation and Decision Making Processes

Information sharing, medical update and discharge planning were the main purpose of 9 out of the 10 family meetings observed; this categorization was based on the researcher's knowledge of the content of the meeting gained from conducting the participant observations and its purpose as defined by the meeting attendees within the questionnaire data. The tenth meeting was organised to involve the family in decision-making about a medical intervention

related to a patient, Marie, who was medically unwell and who had eight children who were acting as proxy decision-makers. The meeting was convened to try and gain a consensus between her children and the MDT on whether Marie should receive artificial feeding (See Summary Table,P 168).

In relation to the ten family meetings, the hospital social worker facilitated eight and the medical Consultant facilitated two. No appointed minute-taker presided over any of the meetings observed. Each professional tended to take their own notes during the meeting. Family meetings lasted on average an hour and quarter (range, thirty minutes to two hours) which indicates much variation in meeting lengths and a considerable time commitment for all participants. Each meeting followed a general structure of (i) an opening phase with introductions, (ii) a medical update with reports from staff on the multidisciplinary team, (iii) a negotiation phase including questions from the patient and their family members and answers from health professionals, (iv) decision-making where appropriate and (v) closure.

Outcome of Family Meetings- Table 2, details the outcomes of the 10 family meetings.

Figure 9; Outcome of Family Meetings

FINAL DECISIONS REACHED	NO FINAL DECISION REACHED
2 patients discharged to home with Home Care Package	2 patients to continue with rehabilitation programme and to remain in hospital. Follow up meeting to be held Time frame specified (3 weeks)
3 patients to be listed for Long Term Care placement Family acted as proxy decision-makers as older patient 'without capacity'	1 information provided Family as proxy decision-makers to consider consenting to artificial feeding of patient and patient to remain in hospital
1 x Home Visit to be completed with patient prior to discharge to home.	1 x information given -Patient and family to discuss options -Patient deemed to have borderline capacity; second opinion to be sought re; patients capacity -Time frame specified. Patient to remain in hospital until consensus reached re; discharge plan.

4.9 Making of Final Decisions

Final decisions were deemed to mean that a decision had been made relating to the original purpose of the meeting. For example, in the case of Brian's meeting, the purpose of holding a family meeting had been to finalise a discharge plan for Brian. In this meeting, it was decided that Brain would be discharged to home with the support of a home care package. On the other hand, in the case of Marie's family meeting, her family members and the MDT were unable to reach a

consensus on whether Marie should receive artificial feeding so a final decision was not reached.

The table demonstrates that final decisions were reached in 6 out of the 10 meetings observed. It is clear from the table that many of the meetings involved a challenging, emotive decision-making process due to the complexity of the issues involved such as decisions relating to long term care and in Marie's case, life-sustaining treatment. It is also apparent that two of the meetings where no final decisions were reached, related to particularly difficult ethical issues where family members were acting as proxy decision-makers and thus decision-making would have been inherently more difficult.

4.10 Participation of Older Person and Family Members

Of the five patients who attended the family meeting, all were observed to participate to varying degrees. At the beginning of Peter's meeting, the doctor acknowledged that Peter had a hearing impairment and asked Peter to signal if he was experiencing difficulties hearing anything which was being discussed.

It was noted in the cases of Johnny, Patsy and Frank that older patients with more advanced cognitive impairment had poorer participation levels. For example, it was observed that they were often 'talked over' with usage of the grammatical third person i.e. being addressed as 'he' or 'she' by both family members and the MDT.

'...He is at risk of falls and this risk is increased by his alcohol intake'

(MDT Participant, Johnny's Family Meeting, Data Recording Sheet)

and,

'....My Mum does too much for him, what care is going to be in place before he comes home?' (Patsy's Daughter, Family Meeting Data Recording Sheet.)

Meanwhile, family members were observed by their levels of verbal communication to have higher participation levels than the patients. It was noted that only in Frank's meeting were the MDT observed to be overtly checking the patient's understanding and paraphrasing what had been discussed. Brian and Peter's meeting also differed from the other meetings observed as they appeared more engaged during the discussion and Brain also asked questions during his meeting.

'.....What is best for me? That's what I want.' (Brain, Family Meeting Data Recording Sheet).

The fact that both Brian and Peter were involved in the conversation and asked some questions would suggest that they were participating in the meeting and appeared to be understanding what was being discussed.

4.11 Paternalism vs Autonomy

Johnny and Frank's family meetings are of particular interest when discussing patient participation levels and the issue of cognitive impairment. Both Johnny and Frank were assessed as having a moderate cognitive impairment by the MDT. The issue of decision-making capacity was of particular relevance in these cases as both men also had problems with alcohol misuse which further impacted on their cognition and functional abilities when at home. In these cases, family meetings had been requested by Johnny and Frank's family members. Both families were expressing strong concerns about their relative's ability to function independently and safely if discharged to home and instead, were requesting

nursing home placement for them. The findings from the participant observations of their meetings are important to discuss, as the MDT assumed a strong advocacy role in relation to Johnny and Frank's expressed wishes which were to be discharged to home. There is an evident conflict and tension between the families making a strong stance that Johnny and Frank should be discharged to nursing home care and the MDT stressing that both men have decision-making capability, for example,

'...he can't be kept against his will in a nursing home, this is an issue of his civil liberty' (MDT member, Johnny's Family Meeting, Field notes).

As mentioned earlier, what is curious about both family meetings is the fact that Johnny and Frank have obviously communicated their wishes to both the MDT and their family members prior to the meeting however, there is little or no verbal participation by either man during their family meeting.

During Frank's meeting, the MDT members do attempt to paraphrase what is being discussed and to engage Frank in the conversation in a limited way however, his family members do not try and communicate directly with their father. It is also puzzling that in Johnny's meeting, neither the MDT nor his family members attempt to involve him in the discussion, even when quite serious concerns are being raised by his family about the dangers relating to his alcohol misuse. Both the MDT and his family discuss personal, delicate issues relating to Johnny as if he wasn't present, often in an adversarial way ,

'...if he has a fall when he goes home I want you(the hospital) to put it in writing that you said it was safe for him to go home' (Johnny's Brother, Family Meeting Field notes).

The issue of self- determination and decision-making capacity are clearly critical in these cases. It is also a concern that both men are present at a crucial decision-

making forum relating to their futures, yet they do not express their views, wishes or opinions during the meeting. This is also of feature in Patsy's meeting who was also assessed as having a cognitive impairment. In Patsy's case however, there were a few instances where he expressed his opinion, for example his agreement to accept home supports when he was discharged home, and thus his meeting followed more of a shared decision-making style. Again, it is worrying how few attempts are made to directly involve the patients who had a cognitive impairment within discussions during their family meeting and often a prevailing paternalistic attitude from both family members and the MDT is evident,

'He'll just have to do what he's told' (Patsy's wife, Family Meeting field notes).

'Does anyone here think he can go home?'(MDT member, Frank: Family Meeting Field Notes).

In relation to the cognitively impaired patients, it would appear that not only do the MDT and patient's family members fail to address them verbally, and but at times they also demonstrate a patronising attitude towards them.

4.12 Questionnaires

Questionnaires were administered in order to gain an insight into the subjective experiences of meeting participants. As explained in greater detail in Chapter 3, questionnaires asked respondents to give their opinions on the following issues; understanding the purpose of the family meeting, consent about family member attendance, opportunities to express opinions and ask questions during the family meeting, the decision-making process and any suggestions for improvements.

4.13 Patient Questionnaires

Each of the five patients who attended their family meeting reported that they had been asked to consent or nominate who they would like to attend their family meeting. Patients however provided different responses to their understanding of the purpose of the meeting. Brian appeared to believe that the meeting would focus on medical issues relating to his care,

'Update on my progress health wise; just medical issues to be discussed'(Brian, Questionnaire).

Patsy viewed it as a time to make a plan and for people to express their opinions,

'Get together to understand everyone's point of view and plan'(Patsy, Questionnaire).

Peter meanwhile reported that it was a time to discuss community supports,

'To discuss patient issues and social supports' (Peter, Questionnaire)

Johnny and Frank however were unable to verbalise why the meeting was taking place or what its purpose was.

In response to being questioned, all five patients who attended their family meeting reported they believed they had been included in the decision making process and had been given adequate opportunity to express their opinions and ask questions however, they did not provide detailed information on this subject.

'....I felt I could say anything I wanted to say' (Brian, Questionnaire).

'It wasn't too long (the meeting)...very satisfactory' (Patsy, Questionnaire)

Although all patient questionnaires were conducted in a semi-structured interview format, many of the patient's answers took the form of 'yes' or 'no' and even after probing, additional information was not elicited. This may be reflective of the structure of the interview schedule and perhaps I didn't fully explain the questions being asked or, it could be attributed to a patient's cognitive impairment, physical exhaustion or perhaps disinterest in the interview questions.

These interviews with the 5 patients who participated by and large reported satisfaction with their CPM and their ability to participate.

4.14 Family Member Questionnaires

As outlined in Chapter 3, all family members who attended the family meeting were issued with a questionnaire and invited to complete it (N=34) and a total of 20 questionnaires were completed and returned(N=20), representing all 10 families.

Of the twenty family members who returned questionnaires, four family members claimed they believed that final decisions had already been made by the medical Consultant and MDT prior to the meeting.

'I'm not happy that the decisions were already made but I'm glad I had a chance to attend the meeting and talk with the team'(Marie, Family Member Questionnaire).

'...No, the decisions were made by the medical staff before the meeting even took place' (Johnny, Family Member Questionnaire)

and

'....If they say they are having a meeting to express your opinions, those opinions should be listened to' (Marie, Family Member Questionnaire I).

Whilst these family members expressed dissatisfaction at this perception of predetermined courses of action and appear to be suggesting that the family meeting may have been just lip service to democratic decision-making, they still felt that the meeting process had been useful.

'I appreciate the length of time and the detailed answers to questions but I feel the decisions were made before the meeting even took place'(Marie, Family Member Questionnaire II).

All family members surveyed (N=20) felt that they had been given adequate opportunities to ask questions and express their opinions during the meeting,

'Yes, I feel I was given enough opportunity to ask questions' (Rita, Family Member Questionnaire) and

'Yes, definitely. Well fielded meeting' (Roger, Family Member Questionnaire).

Family members reported some differing experiences in relation to the information shared during meetings. Roger's family appeared somewhat taken aback at the information conveyed,

'We were not prepared for how bad the news was going to be, but it was handled well' (Roger, Family Member Questionnaire).

Denise's family meanwhile reported that they had been conveyed much of the information shared prior to the meeting,

'The communication was very good beforehand so there were no surprises really ' (Denise, Family Member Questionnaire).

It is clear therefore that although the sample of family member respondents were not always happy with their experience of the decision-making process, the majority expressed great satisfaction about the meeting forum itself.

'Keep talking to families- it helps!'(Marie, Family Member Questionnaire)

'I had more opportunities to ask questions than I could possibly ask for' (Peter, Family Member Questionnaire).

Meanwhile, the majority of family members (N=16) reported that they believed that they had been actively involved in the decision making process during the meeting,

'Yes, they (decisions) were reached collectively' (Frank, Family Member Questionnaire)

and

'A decision was made to review my father's condition at a later date. The decision was reached after much dialogue between patient, patient's family and medical staff' (Brian, Family Member Questionnaire).

The majority of family member respondents therefore reported that they viewed the decision-making process as a consultative, collaborative process between patients, family members and the MDT.

'I think it was a good way of me finding out what was going on. I wanted to hear the medical staff's point of view, alongside my fathers and I got that opportunity' (Brian, Family Member Questionnaire).

4.15 MDT Questionnaires.

As discussed in Chapter 3, self-administered questionnaires were given to all 37 MDT members who attended family meetings however, only 10 responded. Although this response rate was very poor, an interesting finding following data analysis is that MDT members expressed differing views about the purposes of some of the family meetings and this was also a key finding within the MDT mini-focus groups.

For example in relation to Peter's meeting, the following responses were given about its purpose,

'To discuss discharge date and identify needs...to give a platform to discuss any other anxieties re; discharge by the patient or their family'(MDT Questionnaire Respondent, Peter's Family Meeting)

'*Inform family about discharge date next week '*(MDT Questionnaire Respondent, Peter's Family Meeting).

It is evident that whilst one of the MDT members viewed the meeting forum as a time to discuss any concerns relating to discharge, the other viewed it as a time to inform the family about when the discharge will take place.

This point is further evidenced in the MDT questionnaire responses in relation to the purpose of Johnny's meeting. Responses included,

'To plan a successful discharge for the patient and to answer any questions that the family might have' (MDT Questionnaire Respondent, Johnny's Family Meeting)

'Family Members had requested the meeting as they were unhappy with the patient's proposed discharge from hospital' (MDT Questionnaire Respondent, Johnny's Family Meeting)

and

'To commence planning for discharge to home in a complex case where the patient wants to return home against strong family opposition'(MDT Questionnaire Respondent, Johnny's Family Meeting).

It would appear that one of the MDT members see the family meeting as an opportunity to address Johnny's family's concerns about his ability to return home. Meanwhile, the other two MDT members appear to be of the opinion that Johnny will be returning home and the meeting forum is an opportunity to inform his family about this and to finalise his discharge arrangements to home.

Further information relating to the MDT members perceptions and experiences will now be presented from the mini-focus group data.

4.16 MDT Mini-Focus Groups

Six mini-focus groups and one in-depth interview were held to collect information on 8 key areas which were derived from the findings of the participant observations and also existing concepts in the research literature. As outlined fully in Chapter 3, the mini- focus groups were held with seven different disciplines namely (i) Consultants, (ii) Physiotherapists, (iii) Occupational Therapists, (iv) Nurses, (v) Speech and Language Therapists, (vi) Dieticians and (vii) Social Workers. A total of 20 participants were involved in focus groups.

I will now present findings on the eight key topics discussed in the MDT mini-focus Groups.

4.17 Descriptions of 'good' and 'bad' family meetings

MDT mini-focus group participants were asked to describe what they believed constituted 'good' and 'bad' family meetings.

'Good' family meetings were described by most as those where the purpose of the meeting was clear from the outset.

'...I think a good family meeting is one where there are clear goals and purpose' (MDT Focus Group Participant).

A meeting was considered to be successful when pre-meeting preparation had taken place and goals had been set. The MDT highlighted the need for good time management during the family meeting and stressed the importance of decisions being made and good facilitation skills.

'...patient's needs should be met with understanding to decrease distress and friction' (MDT Focus Group Participant).

Conversely 'bad' family meetings were described as being characterized by poor pre-meeting preparation and, in particular, MDT members not anticipating questions or issues that might be brought up by the patient or their family.

'...a bad meeting is where we (MDT), are poorly prepared and questions which the patient or family ask are not anticipated by us, this can be very problematic' (MDT Focus Group Participant)

It was also suggested that poor facilitation skills could contribute to a bad meeting experience.

' A bad meeting can occur if the facilitator doesn't have adequate skills and uses too much jargon or is very authoritarian' (MDT Focus Group Participant)

and

'The facilitator needs to have a high skill level in order to elicit contributions from everyone and ensure that the meeting moves along' (MDT Focus Group Participant).

Finally, results from the mini-focus groups demonstrated that meetings were often a distressing experience for all attendees if the patient/family were not adequately prepared for information provided during the meeting.

'It can be very distressing for everyone if the patient or their family ask questions that we haven't anticipated or if they're not properly prepared for what has to be discussed'(MDT Focus Group Participant).

The above findings highlight the importance that the MDT place on pre-meeting preparation not only for the older patient and their family members, but also for the MDT themselves.

4.18 Findings; Pre-meeting preparation

Except in complex cases, it was generally felt that pre-meeting preparation should occur at the weekly multidisciplinary case conference and this opinion appeared to be largely related to the issue of time pressures on the MDT.

'Pre-planning should take place at our MDT case conference,I think the responsibility lies with each staff member to adequately prepare' (MDT Focus Group Participant).

Social Workers and Occupational Therapists were the only professional groups who expressed a desire to have a pre-planning meeting outside of the MDT Case Conference.

'...I think we would definitely benefit from a pre-planning meeting, especially for those very complex cases' (Social Work Focus Group Participant).

It was felt critical that patient and family members' expectations were clarified before the meeting as it was believed that this would contribute to a positive and productive meeting for all.

'...I think that expectations need to be broached with family members so that we know any concerns they have before the meeting' (MDT Focus Group Participant).

It was suggested by several MDT mini-focus group participants that it would be beneficial to develop a patient information booklet containing in-depth information about the meeting which could form part of the pre-meeting preparation for patients and families.

'...the development of an information booklet, detailing what a family meeting is and what the process is should be put together...we could also include a list of things that patients and families can do to prepare for the meeting'(MDT Focus Group Participant).

It was acknowledged that this tool could prove particularly useful for those patients with a cognitive impairment and who may have difficulty retaining verbal information and that it could potentially enhance participation levels of this group of patients,

'...I think that participation levels would be increased if patients were briefed on what is going to be discussed and any decisions that need to be made'(MDT Focus Group Participant).

4.19 Findings: Participation of Older Person and Family Members

Several MDT members in the mini-focus groups recommended that older patients with a cognitive impairment should routinely attend family meetings unless it is likely to cause them distress.

'...we need to have a consistent approach and guidelines about attendance and participation of cognitively impaired patients as different practices exist at the moment' (MDT Focus Group Participant)

and

'There's no point in bringing the patient along for lipservice' (MDT Focus Group Participant).

The importance of pre-assessment in relation to this was repeatedly noted.

'We should be asking the patients who they would like to attend their meeting....sometimes the patients doesn't want to be at their meeting and they shouldn't be harassed to attend' (MDT Focus Group Participant).

Another questioned

'Is it abusive to insist on someone attending if they are very confused or distressed?'(MDT Focus Group Participant)

It was recognised that family meetings where there were large numbers of attendees could be intimidating for patients and their family members.

It was also acknowledged that in many meetings the older person doesn't participate hugely.

'Sometimes the patient might as well not be there because they don't speak at all during the meeting' (MDT Focus Group Participant)

These findings suggest that the MDT perceive that patient participation in family meetings is sometimes tokenistic and that participation should be more meaningful.

As mentioned earlier, there was a general consensus that the participation levels of the older patient could be increased if pre-meeting preparation was improved. Another suggestion made in relation to increasing patient participation was,

'...We should give the patients a chance to speak at the beginning of the meeting and to set any goals they might have as very often those with a cognitive impairment tend to get spoken over...'(MDT Focus Group Participant)

and

'We need to keep checking in with the patients during the meeting' (MDT Focus Group Participant).

Discussion took place about the fact that very often family members were more active participants than patients themselves and that they were better informed about their rights and what services are available.

The MDT appeared to have insight into the fact that grammatical use of the third person did occur as they reflected that this practice as well as 'talking over' the older patient greatly inhibited participation.

'Sometimes we all just talk over the patients, especially those with memory problems so they can't get a word in edgewise' (MDT Focus Group Participant. Another MDT member commented,

'Even if the patient is present, are we really involving them a lot of the time...how much are we speaking to the patients directly?...talking in the 3rd person is a big problem, someone needs to take responsibility to ensure that the patient understands and is involved'(MDT Focus Group Participant).

The MDT clearly appeared to have insight into the fact that some of the current practices within family meetings may be in inhibiting patient participation and that there is a need to address these practices.

4.20 Findings: Decision Making

Fundamental differences were evident within the MDT mini-focus groups about the decision making process within family meetings. Some indicated that if adequate pre-meeting preparation took place, the outcome of the meeting would be largely pre-determined,

'... if pre-planning is good, the outcome is often already decided before the meeting takes place' (MDT Focus Group Participant)

There were however some notable differences in opinion emerging between MDT members about what constituted the purpose and outcome of family meetings. Some believed that they should be purely an information sharing forum where patients and families were then given time to make an informed decision.

Others were of the opinion that this defeated the purpose of the family meeting as the decision making should be a participatory process which involved the patient, family members and the MDT in a joint decision making exercise.

'...really decisions should be made during the meeting by everyone involved, what's the point in having a meeting if the decision has already been made...'(MDT Focus Group Participant).

This theme also included discussion around the need for the purpose and outcome of the meeting to be clear to all attendees if decisions are to be made and again this was framed within the context of pre-meeting preparation.

'...patients and families need to be prepared for what is going to be said and that a decision needs to be made' (MDT Focus Group Participant).

Finally, some of the MDT considered the meetings as a time to consult with patients and families on outcomes that had already been achieved/ decided.

'Meetings are a consultation process on decisions largely achieved' (MDT Focus Group Participant).

There was a recognition that particular challenges emerged when decision making was about medical/legal matters e.g. 'risky discharges' or the decision to begin artificial feeding of a patient, as these were inherently ethically difficult and often the source of tension and conflict.

4.21 Findings: Facilitation and Minute Taking

As conflict and distress can often arise during meetings, it was recognized that the facilitator required high mediation skills to competently facilitate the meetings. It was also acknowledged that the facilitator needed to be highly skilled and impartial.

'...the facilitator needs to be able to elicit contributions from everyone and ensure that the meeting moves along smoothly'

and

'...the facilitator needs to be able to stay impartial to what is being discussed' (MDT Focus Group Participants)

It was also proposed that the facilitator's role should include summing up key decisions and any planning that took place. Some of MDT felt strongly that social workers should facilitate meetings.

'I think the social workers are better at handling sensitive issues' (MDT Focus Group Participant).

One MDT member felt quite strongly that when meetings were facilitated by the medical staff, they tended to be unstructured and medicalised,

'If the medical team facilitate it isn't as structured and there is too much focus on medical issues' (MDT Focus Group Participant)

It was also suggested that Social Workers, because of their training could offer more psychological support to patients and families during the meeting and could help establish a good rapport between meeting participants. However, others felt that it was not the profession of the facilitator per se but rather his or her skill level as facilitator that was important.

To standardise family meetings and to ensure efficient use of time it was suggested that meetings should strive to have a start and end time. Some discussion occurred about whether there was a need for a minute taker to be appointed and for formal minutes to be taken. The benefits of having a formal record of decisions made for the medical chart was also identified particularly in

relation to important ethical decisions such as artificial feeding or 'risky discharges'. Some of the MDT members argued that,

'...taking of minutes is a very good idea as people can have different understandings about what has been said or agreed' (MDT Focus Group Participant)

Differences in opinions were again evident when it was proposed that a minutes template should be developed however concerns were expressed.

'...who would take the minutes and type them up? Also, how would we get agreement from everyone about the content of the minutes, it would be very difficult to manage this in practice' (MDT Focus Group Participant).

Some mini-focus group members on the other hand felt that the current practice of each professional taking their own notes was sufficient.

4.22 Findings: Seating, punctuality and venue.

The Department of Geriatric Medicine at the hospital where this research was undertaken has two meeting rooms which are used for family meetings. When questioned about the suitability of these venues most MDT members who participated in the mini-focus Groups were satisfied with such venues.

It was suggested by some MDT participants that seating should be more integrated in meetings as demarcation did occur with family members tending to sit on one side of the circle and patients and family members on the other.

' For me, the seating in meetings needs to be more integrated so that we are sitting amongst the patients and their family members- at the moment we sit on one side and they sit on the other'(MDT Focus Group Participant).

On the other hand, MDT members suggested that comfort and support may be derived from these seating arrangements for patients and their families,

'I think clustered seating is fine as it means that family members can support each other' (MDT Focus Group Participant).

However it was claimed that whilst seating arrangements were mostly acceptable, for older patients with hearing difficulties, best practice might be for the person speaking to rotate so they were always sitting beside the patient.

'I think for patients with hearing problems ,we need to make sure that whoever is speaking sits beside them so they can hear as much as possible of what's being discussed'(MDT Focus Group Participant).

Punctuality was reported to be a key issue relating to family meetings. It was recognised that MDT members who arrived late contributed to anxiety levels of all attendees; this was viewed as disrespectful.

'People arriving late definitely makes the meeting more stressful for everyone and is disrespectful '(MDT Focus Group Participant)

It was also noted that when members of MDT arrived late to a family meeting, it served to reiterate the power imbalances present by potentially making patients and families feel that the MDT's time was more valuable than patient/family time.

'Why should our time be seen as more important than theirs? Most of the family members have had to take time off work to be at the meeting so it sends out a very bad impression when we are late' (MDT Focus Group Participant).

4.23 Findings : Aftermath of the Meeting-need for debriefing?

It was agreed that patients and their family members were not always adequately prepared for the information conveyed during meetings and therefore debriefing was often necessary.

'People process information at different rates and sometimes they (patients and families) need that extra time at the end to have things explained again'(MDT Focus Group Participant)

and

'I think preparation is more important than debriefing' (MDT Focus Group Participant).

The current practice whereby the MDT Social Worker usually provides debriefing to the patient and family after the meeting it was claimed worked very well.

'Social Workers can debrief and recap on any decisions if needed' (MDT Focus Group Participant)

Another commented,

'I think it's advisable for family members to have debriefing and we(MDT) can debrief informally'(MDT Focus Group Participant)

Social Workers confirmed that they usually provided any necessary debriefing but this could be time-consuming.

'We usually take on this role but it's very time intensive, especially after a long meeting...I think there needs to be a time-limit to meetings and debriefing' (Social Work Focus Group Participant)

Members of the MDT reported that they usually provided informal debriefing to each other and it was not deemed necessary to formalise this practice however another suggested,

'Debriefing for staff would be nice though' (MDT Focus Group Participant).

4.24 Findings: Other suggestions for improvements.

MDT members and Social Workers in particular, believed that it was imperative that a dedicated time should be allocated to family meetings, this is probably due to the fact that Social Workers largely held the responsibility for organizing and coordinating family meetings.

'Blocked meeting times would be hugely beneficial-I spend huge amounts of time trying to get agreement on a meeting time and date that suits everyone...'(Social Work Focus Group Participant).

The Medical Consultants were not supportive of this suggestion as they felt that the unpredictability of their schedules meant that they would be unable to commit to this arrangement. Other MDT members, and in particular the social workers, were disappointed with this perceived lack of commitment by the Medical Consultants. Although all MDT members acknowledged that their

schedules were unpredictable at times, they felt this was an issue of importance that the Medical Consultants should be willing to compromise on .

It was also proposed that an agenda should be agreed with the older patient and their family at the beginning of the meeting.

'Patients should be the first to speak at meetings as this would empower them and they should also be given an opportunity to meet with the MDT without their family present'(MDT Focus Group Participant).

It was considered that this could improve participation levels and give the older patient a greater sense of control over the meeting process.

Finally, it was suggested by many of the MDT mini-focus group participants that further attention should be given towards examining the low participation levels of older patients with a cognitive impairment and efforts should be made to improve and standardize current practices. Discussion also took place by the MDT members relating to pre-meeting preparation, particularly for cognitively impaired patients,

'Cognitively impaired patients need to get more preparation and input if we want to participate more' (MDT Focus Group Participant).

The MDT related this to the fact that very often, family members did dominate the decision-making process during meetings and this appeared to be an area of concern for the MDT. Several MDT mini-focus group participants suggested that a training programme would be extremely beneficial so that MDT members were better equipped to manage the dynamics within meetings.

'I really feel that I would benefit from proper training on how to handle difficult families during meeting- this is an area I find very challenging'(MDT Focus Group Participant).

It is evident that the MDT appeared motivated to improve current practice within family meetings and that they believed that a Training Manual could be a useful starting point.

The following is a summary of some of the key practice recommendations suggested by the MDT mini-focus group participants:

1. Overt discussions between MDT and patient to clarify the meeting's purpose
2. Paying more attention to pre-meeting preparation, particularly for cognitively impaired older patients.
3. Good Facilitation skills
4. Real as opposed to tokenistic patient participation
5. Importance of punctuality of healthcare professionals
6. Vulnerability of cognitively impaired patients
7. Development of a Patient Information Booklet for family meetings
8. Genuine discussion and consent from patients about whether they want to attend meeting and which family members they would like to be invited
9. Try and offer good opportunities and support for the patient to express their own views during the meeting
10. Adjusting expectations of all parties, conveying and gathering information and resolving any differences
11. Need consistent approach to cognitively impaired patients and guidelines on their attendance at family meetings.

See Below:

Figure 10; Summary Table of Key Findings Phase I(provides a comprehensive summary of key findings

Participant Observations of Family Meetings.	Questionnaires	MDT Mini-Focus Groups
• In half of family meetings observed, patient wasn't in attendance • Patients had different understandings of purpose of CPM • Poor Eye Contact with cognitively impaired patients(MDT and family members) • Good eye contact between MDT and family members. • Body language open. • If medical jargon used, explanation given. • Information sharing and **D**ischarge Planning purpose of 9/10 meetings. • Social Worker facilitated 8 meetings, Consultant facilitated 2. • Meetings lasted between	• Patients had differing understandings of purpose of family meeting; some were unclear as to why meeting taking place. • All patients believed they had been included in decision-making process. • All patients and family members felt able to express opinions and ask questions. • Two families believed decisions had been made by MDT before meeting took place; although dissatisfied with outcome, they believed the meetings process had been useful. • MDT expressed different understandings about purpose of family meetings. • Some believed they should be a collaborative decision-making forum whilst others believed they were a time to consult with patients and their family members on decisions that had already been decided/ achieved.	• 'Good'=purpose of meeting clear. Pre-meeting preparation takes place. Goals set. Good time management. Decisions made. • 'Bad'=Poor preparation/ questions not anticipated. Poor facilitation skills. • Pt/family not prepared for info to be given. • Pre-meeting prep should occur at weekly MDT Case Conference, except for very complex cases. • Expectations of Pt and family should be clarified before mtg.- • Development of Patient Information Booklet to assist with pre-meeting preparation.

30 mins and 2 hrs. • Final decisions reached in 6 /10 meetings • Older patients with higher levels of cognitive impairment had lower participation levels. • Family members had higher participation levels • 3rd person grammatical used by MDT and family members when speaking about patient • Paternalism of family members towards cognitively Impaired patients • Circular seating arrangements –inclusive. Demarcation did occur however as families tended to sit on one side and staff on the other. • Punctuality of staff was an issue in a third of observations. • Half of sample characterised by proxy decision-making process as patients not present. • Of five patients present, decision-making styles were self-determination, shared, 'silent delegation' and proxy.	• Facilitator needs to have a high skill level and mediation skills. • Have start and end time for meetings. • MDT recognised possible 'tokenism' of patient participation and how poor practice may be contributing to this. • Participation levels of older patient, particularly those with a cognitive impairment could be improved if more pre-meeting preparation provided (written info) • Staff and family use of 3rd person inhibits participation. • Fundamental differences amongst MDT about decision-making process and whether they should be pre-determined or made in consultation and collaboration with Pt and family members • If debriefing of Pt and family required, social worker should provide this. • Name of meetings forum should be changed from 'Family Meetings' to 'Care Planning Meetings'.

The next section will discuss the role of the MDT members in the action research process and changes to practice that were implemented as a result of this.

4.25 MDT Involvement in deciding on Changes to Practice .

As discussed in Chapter 3, a key feature of action research is the involvement of participants as 'collaborators' and in relation to this study, the collaborators were the MDT. Within action research, participants open communicative space by working together to explore their practices, understandings and situations thus emphasizing the inclusive, collective and transformative nature of its aims which then supersedes the self-interests of individual participants. Kemmis and Brennan(2003) postulate therefore that action research is a form of exploratory action that takes communicative action into social practice, using social practice as a source of new understandings.

The participation of the MDT as collaborators in Phase I occurred in three distinct stages, each involving a slightly different composition of MDT members. Although the motivation to examine the area of MDT practice in CPM's had been verbalised by the MDT from the planning stages of the research, the action research focus of the study didn't fully manifest itself until after completion of Phase I fieldwork, when the findings were presented to the MDT CRG.

4.26 MDT CRG , Phase 1

Findings from Phase I of this study were presented to all MDT members(Age-Related Healthcare MDT and Stroke MDT) who had participated in the research; this grouping of individuals comprised the first formation of the MDT CRG[15].

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[15] See Figure 4, Chapter 3, for diagram and more detailed description of MDT CRG, Phase I

The feedback involved me presenting findings back to the research community (MDT CRG) and the understandings and conclusions that I had come to during the research process (Herr and Anderson,2005). The presentation also involved seeking the views of all MDT members about what direction they believed the next phase of the research should take. A brainstorming session on what changes to practice should be implemented also took place. According to Kemmis and Mc Taggart (2003) what is learned from reflection at the end of the first cycle informs the planning at the beginning of the next, as the work continues. In this way, Phase I helped inform which data collection methods would be most suitable in Phase 2 and also helped the MDT identify what aspect of family meetings should be examined in the next phase.

Findings from the mini-focus groups conducted with the MDT during Phase I had strongly indicated that family meetings were an area of practice viewed as a crucial part of multidisciplinary teamwork. Motivations to improve current practices and a general openness to a change process were expressed both during the focus groups and during the feedback session with MDT members. There was a general consensus amongst the group that the most significant finding from Phase I was the low participation levels of the cognitively impaired older patients and the potential impact that MDT language and behaviours within family meetings might be having. It was suggested that it would be useful if Phase 2 could examine this aspect of practice in greater detail, particularly in relation to the participation levels of cognitively impaired patients.

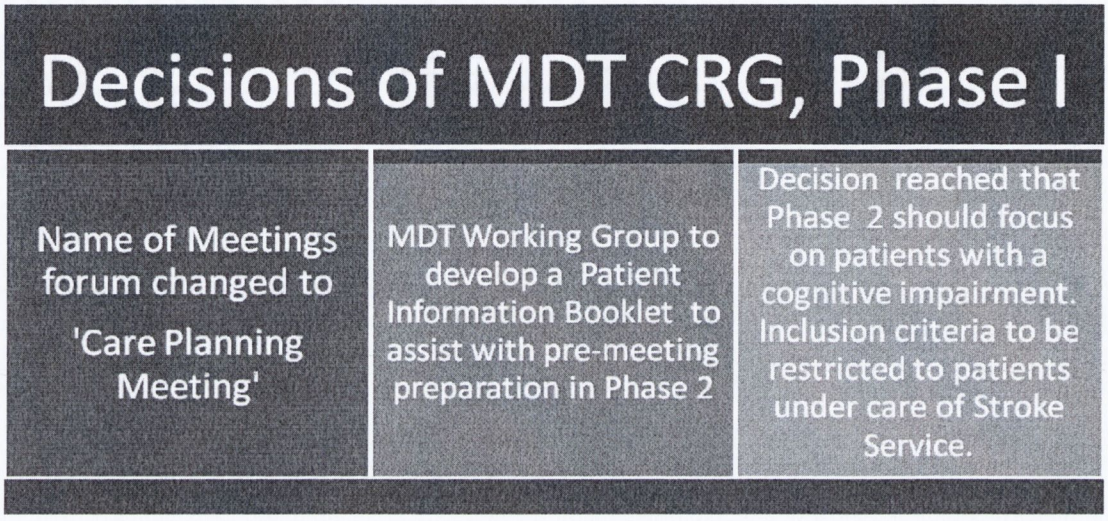
Discussion also centred around the recurring theme of pre-meeting preparation and several members of the group proposed that an information booklet for patients and families to assist with pre-meeting preparation should be developed for use in Phase 2. Moreover, the MDT CRG were eager to study whether if increased attention was paid to pre-meeting preparation of patients, it would impact on participation levels. It was decided that an MDT CRG 'Working Group'

should be formed in order to develop the Patient Information Booklet in preparation for Phase 2. It was agreed by the group that as the MDT CRG was composed of 30 members at this stage, it would be unrealistic and impractical for the entire group to work on this task so it was decided that volunteers would be sought to join the sub-working group.

Several other possible changes to practice suggested during the MDT mini-focus groups included the setting of an agenda at the beginning of meetings and setting aside a dedicated time each week for family meetings. Other recommendations made by mini-focus group participants related to trying to promote the involvement of nursing staff in meetings and striving to have a consistent policy relating to the participation of cognitively impaired older patients in family meetings.

The MDT CRG in Phase 1 decided that it would be unrealistic to try and implement a large number of changes to practice so early in the research process. They also were of the opinion that it would be beneficial to gather further information on CPM's specific to patients with a cognitive impairment before implementing wider changes. It was thus agreed by the group members that for Phase 2, changes to practice would only relate to pre-meeting preparation and that all other changes to practice identified during Phase I should be incorporated into the Training Manual which would then be based on the findings of both Phase I and Phase 2.

Figure 11; Decisions of MDT CRG, Phase 1



4.27 MDT CRG Working Group: Development of Patient Information Booklet

An MDT CRG Working group which as mentioned earlier, was a subgroup of the MDT CRG, was subsequently established with a sub-sample of MDT CRG members who volunteered to participate. I stressed to the group that ideally there should be a representative from each MDT discipline to ensure that each discipline's interests were communicated and represented. The final group composition consisted of myself as the practitioner researcher, Social Workers x 2, Nurses x 2(Ward Sister and Staff Nurse), Physiotherapist x 1, Occupational Therapist x 1, and Speech and Language Therapist x 1. No member of the medical team volunteered to be part of the working group. It is unclear whether this points to the fact that the Medical Consultants did not consider it important to be

involved or whether they had too many demands on their time to commit to being involved in the group. It is important to point out however that during the course of the research, three different Consultant Geriatricians were involved as they rotated the responsibility for the Stroke Service on a six monthly basis. It could be contended therefore that they may not have fully embraced ownership or responsibility for involvement in the MDT CRG throughout the research process.

The MDT CRG Working Group developed the patient information booklet over the course of three months involving five meetings together. It was decided by the group that the booklet should explain the meaning and purpose of the meeting forum, that it should have a strong patient focus, and that it would be written predominately with the patient in mind. When considering the content of the booklet, discussion arose around the current name of the meeting forum, family meetings, and alternative names in the existing research literature were provided by the researcher[16]. The group concluded that the term 'family meetings' could be viewed as a misnomer as it inadvertently put the focus on family members rather than the patient themselves.

The MDT CRG Working group therefore decided that the name of the meetings forum should be changed to 'Care Planning Meetings' which we hoped was a more neutral term and would represent a more patient-centred ethos. There was also consensus within the group that the booklet needed to explicitly state that all patients routinely attend their meeting unless they did not wish to attend or were advised not to by the MDT. It was hoped this could help overcome a challenge which often arose whereby family members assumed, or requested, that the older patient, particularly those with a cognitive impairment, would not

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[16] As outlined in Chapter 2, existing names included Family Meetings, Care Planning Meetings, Discharge Planning Meetings and Case Conferences.

attend the meeting. The group recognised however that there would still be instances where patients would be unable to attend meetings due to medical issues or cognitive status and for that reason,it would not be feasible to name the meetings 'Patient Care Planning Meetings'.

The MDT CRG Working group process ensured that MDT members directly contributed to the initial problem identification phase of the research which consequently informed the planning for Phase 2. Although the MDT CRG Working Group embraced the task at hand, there were often strong differences of opinion, particularly in relation to content, wording and phrasing and some group members were quite pedantic during the process. This caused some frustration and tensions within the group as some group members felt this attention to detail was delaying the task unnecessarily. A 'majority rules' approach to decision-making was adopted to keep the process moving and the group were able to create a final product with which everyone was eventually satisfied.

Another challenge of establishing the MDT CRG Working Group was the time pressures of the individuals involved. Decreased staffing levels meant that people were stretched for time and reluctant to engage in a process that would possibly increase MDT time commitments.

In a busy hospital environment, it is often difficult to get people to commit to additional meetings over and above their already busy caseloads, so it was of crucial importance to ensure that the MDT understood that the running of the group would be time limited and the number of meetings kept to a minimum. In order to achieve this, yet make sure that the brief of the group was satisfied, it was necessary to invest significant time into pre-meeting planning and preparation by all members of the MDT Working group. This was largely achieved

through exchange of emails which enabled continual updating and input into the working document of the patient information booklet between meetings.

Emails also facilitated distribution of meeting minutes and agendas for upcoming meetings and enabled ongoing communication of group members between meetings. Any planned changes to practice could be difficult as literature would suggest that there is generally resistance to organisational change (Coughlan and Brannick,2005).A final consideration was that any changes implemented would have to be cost neutral or be implemented through existing hospital resources as the project and MDT CRG Working Group had no allocated budget and would be unable to access any funding/monies.

The draft patient information booklet was compiled by all members of the working group, both during the meetings convened and through exchange of emails which enabled group members to amend the content on an ongoing basis. The booklet was then circulated to the wider MDT CRG for comments and feedback. It was also reviewed by several members of the hospital's Speech and Language Department for understanding and comprehension. Finally, it was reviewed by the hospital's Communications Officer to ensure that it met the necessary and recommended readability standards for patients.

The wider MDT CRG also decided that it would also be important to pilot the booklet with some older patients and family members (N= 3 patients with a cognitive impairment and their family members) who had been subject of a family meeting. The booklet was also piloted with local representative consumer groups (N=2) who were involved with older people[17].

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[17] Patient Information Booklet was piloted with the local Home Help Service and 'Age Action Ireland' which is an advocacy group for older people.

All comments and feedback received were then considered by the MDT CRG Working Group and any further amendments were made to the booklet[18].

4.28 MDT CRG: Deciding on Research Focus for Phase 2 of the Action Research Cycle

It was part of the role of the wider MDT CRG to also decide what focus Phase 2 of the action research cycle should take. From the outset of discussions relating to Phase 2, the MDT CRG had been clear that the second phase should focus on cognitively impaired older patients as these patients had been shown to be most vulnerable within family meetings in Phase I. They were anxious to more closely examine this group of patients who would be vulnerable within the family meeting forum but who would have the ability to participate. However, in order to also examine patients with communication difficulties and to ensure care planning based on diagnosis, it was agreed the inclusion criteria for Phase 2 would be restricted to patients who were under the care of the Stroke service[19]. This now meant that the composition of the MDT CRG would change and would only include Stroke MDT members.

Engagement with the Stroke MDT as the new CRG began with a briefing prior to embarking on the fieldwork for Phase 2; it was intended that this forum could also be used to provide them with information and consent forms for their

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[18] See Appendix H for Care Planning Meetings Patient Information Booklet

[19] Issue of inclusion criteria for Phase 2 and the decision-making process relating to this is discussed in greater detail in Chapter 3.

participation and involvement. I also hoped that it could be a relationship building exercise as I would be reliant on them to not only participate as research subjects in Phase 2, but to also assume the role of collaborators to assist with data analysis.

The MDT CRG reported that they needed clearer direction and clarification on key issues relating to the research design for Phase 2. They stated that they needed a definite indicator of what constituted a cognitive impairment and thus have a specified cut-off on the Mini-Mental State Assessment scoring. Moreover, it was evident that the group had not fully grasped the crucial role that I was asking them to take on as collaborators, so I decided that I needed to invest additional time into preparing them before embarking on the fieldwork for Phase 2. Subsequently a second briefing was held a few weeks later once I had clarified all points and questions raised in the initial briefing. Greater attention was also paid to explaining in detail the action research process that was being employed and my expectations of the MDT's role and involvement as the CRG within that for the Phase 2 cycle.

4.29 Conclusions

Based on observational research, interview data, and mini-focus groups a wealth of very valuable information was gathered from key informants about the purposes and meaning of family meetings. Data was also collected on patient's experiences, expectations and desires for their meetings. Phase I findings showed that the family meeting is an important forum for older patients, their family members and the MDT involved. The low participation level of cognitively impaired older patients was a source of concern particularly to MDT members, given these peoples' vulnerability and supports literature findings which argue that the voice of the older patient may sometimes get lost within the meetings process(Abramson,1998). The findings add weight to the argument that lack of

pre-meeting preparation meant that patients were unable to fully take part in the discussions about essential questions regarding their future life. These findings would suggest that there is a need to develop training and education programmes for healthcare professionals which would focus on ways to increase patient participation levels, particularly those with a cognitive impairment.

This study's findings have produced many other valuable insights which may be used to improve communication, behaviour and the type of language used during the family meeting process. Included amongst these are results based on observation data about decision making styles adopted by patients. These included, self determination, shared decision making, silent delegation and proxy decision making. The mini-focus groups with the MDT showed that MDT members were well able to identify what for them constituted good and bad meetings. Good meetings they claimed were those where the purpose was clear, goals were articulated and met and there was attention to efficient time management and pre-meeting preparation. Conversely, bad meetings occurred when facilitators were not proficient and lacked good facilitation skills and when staff members had not anticipated the type of questions posed.

Overall findings showed how the MDT CRG played a crucial role in validating the findings from Phase I and helped to decide on the research focus and design for Phase 2 of the study. The group decided that the name of the meetings forum should be changed to 'Care Planning Meetings' and a patient information booklet should be designed which it was hoped would assist with pre-meeting preparation in Phase 2. The next phase of the study will thus involve a close examination of the patterns of communication interplay and behaviours of the MDT, family members and the participation of stroke patients with a cognitive/communication difficulty within family meetings through carrying out participant observations. Patient's desire for participation meanwhile will be gauged through semi-structured interviews.

Chapter 5 Phase 2, Action Research Cycle. Are patients really active participants in decision-making in Care Planning Meetings?

This chapter will discuss findings from Phase 2 of the action research cycle. Phase 2 set out to examine how stroke patients (who's ability to participate had potentially been compromised as a result of cognitive and/or communication difficulties), their relatives, and MDT members participated in Care Planning Meetings(CPMs). The key focus however was on the participation patterns of patients at these meetings, since Phase I showed that patients exhibited low levels of verbal participation, particularly those 3 patients who had a cognitive impairment as presented in chapter 4. The analysis of the participant observations in Phase 2 will replicate that of Hedberg et al's study(2008) and will set out to identify (i) the topics discussed during each CPM (ii) how information was communicated and organised, and (iii) the level of involvement patients and other participants had in discussions. As mentioned before, the key focus in this chapter will be on patients who are particularly vulnerable due to either a cognitive impairment, communication difficulty or both arising as a result of a stroke.

As shown in chapter 3 (See Methodology chapter) a total of 10 different CPM's were the subject of investigation in this next phase of the study through participant observation. Additional data was collected during in-depth semi-structured interviews which were held with 10 in-patients who were the subject of the CPM. Finally, 10 in-depth semi-structured interviews were conducted with a family member/support person as nominated by each patient.

In Phase 1, the purpose of family member interviews/questionnaires had been to gain an insight into *family member* experiences of CPM's and all family members attending the CPM were invited to participate. In Phase 2 however, only one family member attending each CPM was interviewed, as the objective was to capture *their perception of the patient's participation in the CPM*, rather than their own experience. Interview schedules drew on existing themes relating to patient participation in the research literature(Cahill,1996;1998.,Popejoy, 2001.,Hedberg,2007; 2008., Efraimsson;2006).

Potential impact of changes to practice implemented during Phase 2 were[20] also explored with patients and their family members within the interview schedule and during the meetings with the MDT CRG. It was hoped that the findings would provide a rich description of the language, behaviour, interactions and discourses present in CPM's and the participant's voices provide a powerful narrative which informs the emerging themes.

The chapter will begin by discussing the MDT CRG's role in the data analysis of the findings from Phase 2 of the study. The chapter will then move on to outline findings from the participant observations of the 10 CPM's with stroke patients beginning with findings from informal processes observed and moving onto the critical discourse analysis .The chapter will then report on findings obtained from the semi-structured interviews with patients and their family members. This will be followed by results on patient and family member perceptions of each patient's participation during their CPM and reported satisfaction relating to CPM's. An overview and discussion of the findings from the three sources of data

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[20] Name of Meetings form was changed from 'Family Meetings' to 'Care Planning Meetings' and a patient information booklet on CPM's was developed which it was hoped would assist with pre-meeting preparation. This was a key finding based on Phase I results.

collected will then be explored. The description of findings of Phase 2 will lead to a more detailed analytical discussion and exposition in Chapter 6.

5.2 MDT Involvement in Data Analysis

In keeping with the action research approach, the Stroke MDT participated in the data analysis of the findings of Phase I through their feedback received during the reconvening of the MDT CRG[21].

5.3 Initial MDT Brainstorming.

An initial briefing was held with the MDT to seek their opinions on what would be an acceptable and practical method of involving them in the data analysis in keeping with an action research approach. I acknowledged within the briefing that ideally the MDT would review the transcripts of all the CPM's. However, the consensus of the group was that this would not be practical given many transcripts were very long. It was agreed therefore that the MDT would review the transcripts of two CPM's and that I would provide a guidance document explaining the method of data analysis employed and a list of the key themes that had emerged when the coding was condensed. I also made available a list of the Nvivo coding summaries relating to each transcript which would provide a greater insight into the coding process. The MDT CRG (Stroke MDT) were not asked to code the transcripts blindly, but instead they were asked to validate the identified themes, highlight any divergences in opinion or themes which they disagreed with, and to identify any additional themes which they felt that I had overlooked within my coding of the data. The MDT decided that three weeks would be a sufficient period of time to complete this task and that we would

[21] See P. 140, for details of MDT CRG composition, Phase 2

reconvene our MDT CRG at this stage. I will now move on to discuss the second meeting with the MDT CRG.

5.4 MDT Feedback and Contributions to Data Analysis

All members of the MDT attended the MDT CRG meeting with the exception of the Consultant who was on leave the date of the meeting. Most of the group came to the meeting well prepared and it was evident from the discussions within the meeting that they had taken time to review the transcripts and themes and prepare their feedback. I strove to maintain a passive role within the discussion so that the other members would have the maximum opportunity to express their opinions and lead the discussion; I also took brief notes on the main points of the discussion.

The process of reviewing the transcripts and seeing the meeting proceedings in written form appeared to have a much stronger impact on members of the MDT CRG about the nature of some of their practices and communication styles during CPMs . Many were shocked at the extent to which they dominated the discourse during meetings and others were taken aback and embarrassed at some of the language used and in particular the widespread use of the third person in relation to the stroke patients.

The group claimed they were happy with how the data had been analysed however, they made suggestions about possible additional themes, most of which related to the critical discourse analysis. These included documenting (i) instances where patients were talked over or interrupted within meetings, (ii) numbers of questions asked by patients and (iii) searching the data for instances where the patient was asked 'how do you feel' about a particular topic or decision. The group also provided some useful insights. For example, a few

commented and explained that patients may have exhibited low levels of verbal utterances and asked small numbers of questions as they may have already been aware of much of the information being communicated, whilst their family members may not. The group also suggested that it could be useful to examine instances of interruptions within the meetings i.e. people arriving late or leaving and also pagers sounding which could potentially impact on the dynamic and process of the meeting.

Some of the discussion on the themes within the data developed into suggestions for improvements to practice, many of which had already been identified during Phase I. These included the need for dedicated meeting times (i.e. that a designated time would be assigned to CPMs each week), the importance of pre-meeting preparation and also the crucial role of the person who would chair/facilitate the meeting. All suggestions were documented and the group were reminded that all recommendations relating to changes to practice would be incorporated into the Training manual which would be compiled in Phase 3. It appeared that for the MDT CRG, that a focus and motivating factor in the data analysis was for practical changes to their everyday working practices which would hopefully improve experiences for patients, families and the MDT themselves.

The MDT were also asked to provide feedback on any potential impact of the changes that had been introduced in Phase 2, i.e. the name of the meeting forum changed to 'Care Planning Meetings' and the CPM Patient Information Booklet. All of the MDT CRG believed that the introduction of the new title for the meetings had been a very positive development and that it was a more neutral term that more accurately reflected the true function and purpose of the meeting.

In relation to the Patient Information Booklet, it became apparent that only the social workers had been using this as preparation tool with patients as they had the responsibility of organising CPM's. The social workers believed that the booklet had been very useful in assisting with preparing patients and their family members for CPM's however,they were also of the opinion that other members of the MDT should be using it as a tool with patients also. It was suggested therefore that the information booklet should be used in conjunction with the Training manual which would be developed in Phase 3 so that all team members were routinely using it as a tool with patients.

Discussion also took place on ways in which the Training Manual could be utilised within the Age-Related Healthcare Unit but also how it could be disseminated to other healthcare professionals in the wider hospital in order to try and implement changes to practice. At the Age-Related Healthcare level, it was suggested that once a year, the weekly 'Journal Club' could be used as a training forum and that the Training Manual could also be incorporated into the unit's Stroke Education Course for Nursing Staff. At the wider hospital level, it was proposed that it could be incorporated into the hospital's induction programme for new staff and that perhaps a specific training programme could be set-up as a continuing professional development initiative for healthcare professionals. Finally, it was put forward that a Study Day could be held to launch the Training Manual which would be open to healthcare professionals working in other hospitals and in the community services which would be a mechanism for dissemination outside of the research setting.

5.5 Findings

The chapter presents findings from Phase 2, beginning with those derived from the discourse analysis conducted on the 10 CPM's. This will be preceded by a

Summary Table detailing key characteristic of the CPM's observed and a table documenting the patient's suggestive MMSE AND WAB screening scores.

5.6 Brief Summary of Characteristics of CPM's Phase 2

As discussed in the Methodology chapter,(see P.141), Phase 2 involved participant observations carried out on 10 CPM's which were audio-recorded. All patients were in attendance at their CPM, had a stroke and had been assessed by the OT or medical doctor as having a cognitive impairment. Stroke patients may also experience communication difficulties, in particular aphasia. This factor may also affect their ability to participate in their CPM so details of communication impairments in the patient sample were also recorded. 5 of the 10 patients in Phase 2 were assessed by the Speech and Language Therapist as having a communication difficulty. The MMSE was used as an indicator of cognitive impairment[22] while the WAB was used to measure communication difficulties.

The sample included 5 women and 5 men whose mean age was 64 (range 36-91). All patients had at least two family members in attendance with the exception of Amy who only had her husband in attendance. As the researcher,I singularly determined the purpose of each CPM based on information received from the medical social worker responsible for arranging the CPM as well as the actual content of the CPM gained from the participant observations.

MDT member attendance at CPM's was determined by the purpose of the meeting and on their availability. Each patient was asked by the MDT to nominate a family member or a number of family members they would like to attend their CPM. Half of the meetings were attended by a medical Consultant whilst half

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[22] Cut off point in MMSE indicating no cognitive impairment was 26 out of 30, scores between 21-26 indicated mild cognitive impairment and 10-20 moderate cognitive impairment (NICE Guidelines,2011).

were attended by a Registrar. A medical social worker and occupational therapist were present at all CPM's. It is notable that in Phase 2, a representative of the nursing staff were in attendance in only three out of 10 CPM's and that concerns about the low attendance of nursing staff at CPM's had been highlighted by the MDT CRG in Phase I.

The length of meetings varied from 12 minutes to 33 minutes which was notably shorter than the Phase I sample. CPM's in Phase 2 also differed to those in Phase I as the majority of meetings took place within a week of the patient's discharge to home. Thus, some CPM's appeared to be arranged in an ad hoc manner and took place on the day the patient was discharged to home.

Figure 12; Summary Table of Characteristics of CPM's

PATIENT and Model of Decision making	Family Members Attendees	MDT Attendees	Meeting Length	Purpose of Meeting	Timing of Meeting	Total Attendees
Amy(Age 36) ..... Self-Determination	Husband	Registrar, Social Worker[23], OT	12 mins	Info provision re; rehab progress and follow-up	Day of discharge	5
David(Age 69) ..... Deferred	Niece, Sister	Consultant*, Registrar, SHO, Nurse, Social Worker, OT, SLT	26 mins	Discharge Planning and info provision	Day prior to discharge	10
Ellie(Age 87) ..... Shared	Sons x 2	SHO, Social Worker*, Nurse, PT, OT	33 mins	Discharge Planning and Info Provision	Week prior to discharge	8
Florrie(Age 89) ..... Delegated	Son, Daughter	Registrar, Social Worker*, PT, OT, Discharge OT	17 mins	Discharge Planning and Info Provision	3 days prior to discharge	8
Jack (Age 90) ..... Shared	Son, Daughter-in-law	Registrar, Social Worker*, OT, SLT	35 mins	Discharge Planning, Info provision	Week before discharge	7
Larry(Age 58) ..... Deferred	Wife, Son, Daughters x 2	Registrar, Consultant(arrived 45mins late),OT, Social Worker*, Discharge OT, PT, Nurse	Pre-planning mtg took place 17 mins	Discharge Planning and Info giving	3 weeks prior to discharge	12
Mark(Age 76) ..... Shared	Wife, Son	Registrar, Social Worker*, OT, SLT, Discharge OT	15 mins	Discharge Planning and Info Giving	Day of discharge	8

[23] MDT member underlined denotes the facilitator for each individual CPM

Sarah (Age 91) ..... Proxy	Daughter, Sons x 3	Consultant*, Registrar, Social Worker, OT,	19 mins	Info Giving re; rehab progress and follow-up	Day of discharge	9
Tommy(Age 82) ..... Proxy	Sons x 2	Consultant*, SHO, OT, Social Worker, SLT, Physio	21 mins	Decision-making re; discharge home or LTC	Patient listed for LTC.	9
Vera (Age 84) ..... Shared	Daughters x 2	Consultant*, OT, Social Worker	18 mins	Discharge Planning and Info giving	4 weeks prior to discharge	6

Figure 13; Summary Table of patient MMSE and WAB scores indicating levels of suggestive cognitive and communication impairment

Patient	MMSE SCORE(suggestive)	WAB SCORE(suggestive)
AMY	24/30(mild)	43.9%
DAVID	25/30(mild)	100%
ELLA	20/30(moderate)	No score available*
FLORRIE	18/30(moderate)	65.6%
JACK	16/30(moderate)	64%
LARRY	25/30 (mild)	100%
MARK	22/30(mild)	66%
SARAH	22/30(mild)	100%
TOMMY	15/30(moderate)	75%
VERA	22/30(mild)	100%

*Patient declined to engage in Speech and Language Therapy WAB assessment.

All patients within Phase 2 were assessed as having either mild or moderate cognitive impairment(CI). Six had a mild CI (range 24/30-22/30) and four had a moderate CI(range 20/30-15/30). Five of the patients were assessed as having post stroke communication difficulties of which Amy was assessed as having the most severe communication impairment (43.9%). All patients in the Phase 2 sample therefore had a level of cognitive impairment with half of the sample also being assessed as having varying levels of communication difficulties.

5.7 Interpersonal procedures: Informal Processes and Critical Discourse Analysis.

Interpersonal procedures refer to the communication, interaction and behaviours between participants during CPM's. This section will outline the findings from the analysis of the discourse within CPM's and an exploration of the informal processes observed.

5.8 Informal processes

Non-verbal communication is extremely important, particularly with patients who have cognitive and verbal communication difficulties. The data recording sheet collected detailed information on issues such as seating arrangements, punctuality, eye contact and other body language. Informal processes were again of particular interest in this phase as the majority of patients exhibited low levels of verbal participation. In view of this, a comparison of the CPM transcripts and informal processes documented on the data recording sheets was conducted.

Findings relating to seating in CPM's were similar to those in Phase I whereby meetings were conducted in a circular format. Seating arrangements were not integrated and family members tended to sit on one side of the circle and the MDT on the other. As discussed in Phase I, this could be seen as demarcation taking place but on the other hand, it could be viewed as family members being able to offer comfort and support to the patient and each other. No conclusions can be drawn as to whether this is a practice which should be changed or not.

An interesting finding was the fact that although some patients demonstrated low levels of verbal participation, other forms of participation as reflected in their body language such as eye contact maintained with speakers during the meeting and head nodding, suggesting their engagement (N=7) and involvement.

One exception however was found in the case of Sarah's CPM (MMSE 22/30). She was observed as having little or no eye contact with the person speaking and appeared to look quite confused throughout the meeting. This behaviour was not noticed or addressed by the MDT or her family members. It is interesting though that although Sarah demonstrated few indicators of participation and in fact appeared to be disengaged however, during her CPM when her family members reported that she didn't wear her pendant panic alarm, Sarah interrupted the discussion to inform the group that her alarm was broke and that is why she hadn't been wearing it. Another exception was found in Florrie's meeting where she appeared to look uncomfortable at times and she was observed to be shifting in her seat and did not appear to be relaxed. However this did not appear to be noticed or commented on by the other participants.

Levels of eye contact between the MDT and patients varied quite significantly within the CPM's and some MDT members were consistently observed to have higher levels of eye contact with patients than others. This observation could be reflecting the professional training of a particular discipline or could be the result of the personal communication characteristics of a particular MDT member, length of contact with patient, or the nature of the therapeutic relationship with a particular patient.

In relation to body language, it was observed that more responses were elicited from patients when the speaker turned to the patient and addressed them directly and this was particularly evidenced in Jack and David's meetings. Ellie meanwhile demonstrated her engagement and involvement in her meeting as she turned to face each person as they were speaking. Relaxed body language was also deemed to be an indicator that patients were at ease during the meeting and this behaviour tended to relate to those patients who exhibited higher levels of verbal interaction who were observed to be sitting back in their chairs with arms by their sides instead of folded. These patients did however

exhibit signs of frustration at times within their CPM at not being able to express themselves mainly when they experienced word finding difficulties due to their aphasia and the MDT response generally was to try and guess what they were trying to say or to finish off their sentences for them.

It is noteworthy in Phase 2 that the length of meeting times ranged from twelve minutes to thirty-five minutes. This contrasts sharply with meeting times in Phase I where the average duration was longer and meeting times ranged from thirty-eight minutes to two hours. It is significant that the shortest CPM in Phase I (38 mins) lasted longer than the maximum in Phase 2 (35 mins). It is difficult to draw conclusions about this fact however attention must be drawn to the fact that in half the meetings observed in Phase I(N=5),the patient was not in attendance at their family meeting so the meeting was specifically a 'family meeting'. In Phase 2 however, the patient was in attendance at all meetings observed and thus the focus and content of the CPM was notably different. The purpose of the CPM's in Phase 2 may also have influenced their duration as the majority were for the purpose of discharge planning and as suggested by the MDT CRG during the data analysis phase, it is possible that a great deal of information had already been shared with each patient and their family prior to the CPM taking place so there was less to discuss. Nonetheless one might expect that meeting times during Phase 2 would have lasted longer as patients in the Phase 2 sample had a cognitive impairment or a communication problem and therefore probably needed more time to have matters concerning their health and welfare explained to them.

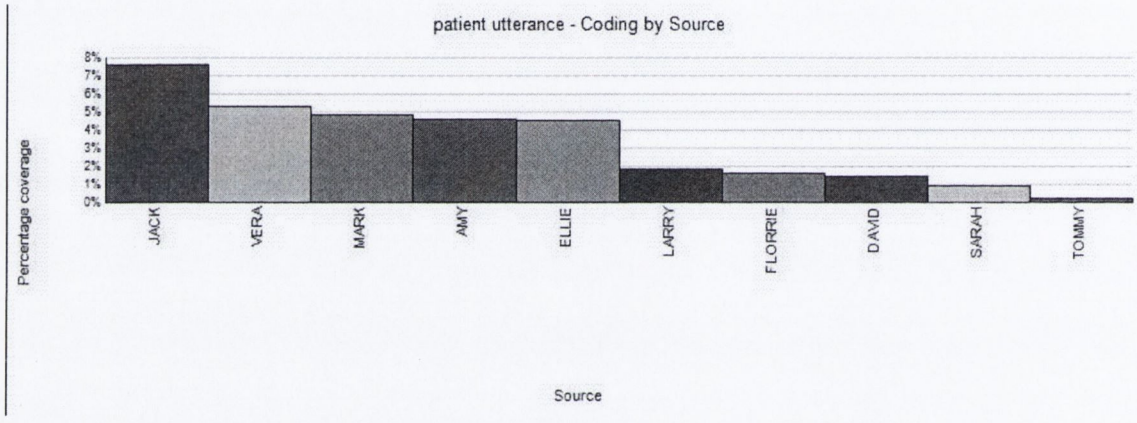
The timing of meetings in Phase 2 is also worthy of examination as seven out of the ten CPM's took place within a week of each patient being discharged, with three of the meetings taking place on the day of discharge. This issue was raised in the patient and family member interviews in relation to Amy and Sarah.

5.9 Critical Discourse Analysis

This section specifically examines patient, family member and MDT use of the discourse space which is an examination of how language is used during CPM's and the nature and organisation of communication.

5.10 Patient Utterances in CPM's

Figure 14; Nvivo summary of Patient Utterances

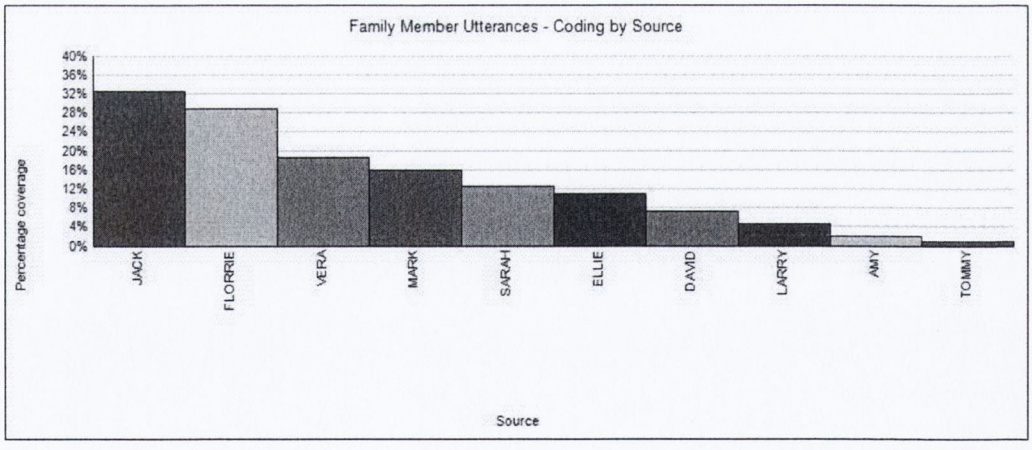


The summary table of patient utterances above details the percentage coverage of patient utterances as coded through the NVivo software analysis programme. It is evident that patient utterances formed a very small percentage coverage of the total discourse within each meeting. Jack has the highest percentage of utterances and the second lowest MMSE score however, surprisingly his utterances form less than 8% of total utterances within the meeting. The percentages for the rest of the sample range from 5% to less than 1% in the case of Tommy's Care Planning Meeting which indicates practically no verbal interaction by Tommy during his meeting.

As suggested by the MDT CRG, instances of patients being interrupted by the MDT or their family were investigated. A quantitative examination of this issue was not conducted however an analysis of the data showed that there were many instances of patients being interrupted both by the MDT and family members.The majority of interruptions occurred where patients were not allowed to finish what they were trying to say and the MDT/family members completed their sentences for them or interjected with a different point. It is important to note that this finding may also have been present in a sample of cognitively intact patients so it cannot be assumed that it was due to the patient's cognitive impairment.

5.11 Family Member Utterances

Figure 15; Nivio Summary of Family Member Utterances



In relation to family member utterances again, there were quite marked differences in the percentage of utterances relating to each meeting. Jack and Florrie's family displayed the highest percentages (33% and 29%) whilst Amy and Tommy's displayed the lowest (3% and 1%). Numbers of family members who

attended the meeting cannot explain the variation in family utterances as Jack, Florrie and Tommy all had two family members in attendance while Amy had one. In fact, all patients within the sample had two family members attending their meeting with the exception of Larry and Sarah who had four. Where it is impossible to draw any conclusions in relation to this observation, interestingly, Jack and Florrie were amongst those with the highest levels of cognitive impairment within the sample(16/30 and 18/30). They were also amongst the oldest members of the sample (89 and 90) so perhaps in view of this, their family members adopted a strong advocacy role. On the other hand, some of the family members in attendance at the CPM also exhibited low levels of verbal participation and in particular, there was little verbal participation from Tommy's family.

5.12 MDT Utterances and instances of Non-Person Status (MDT-NP3)

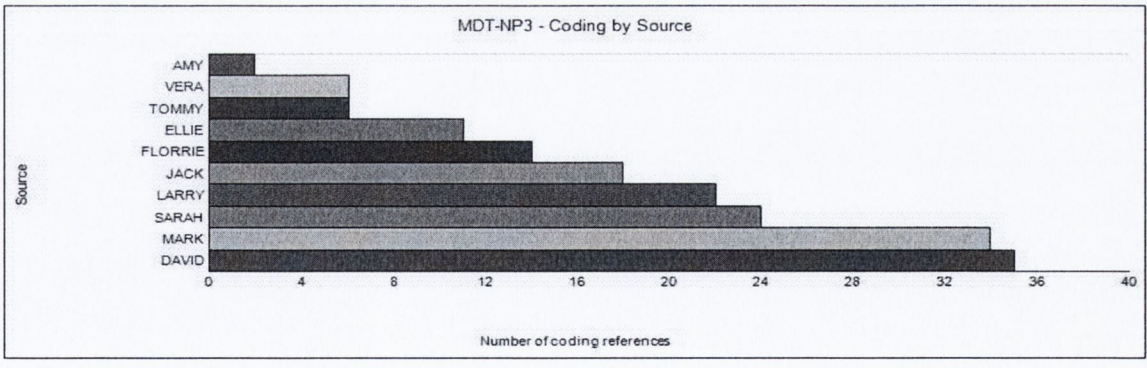
MDT attendees varied between meetings (see Summary Table of CPM's,P.221-222), however, all meetings within the sample were attended by a Consultant/ Registrar, Social Worker and Occupational Therapist(OT). It is important to draw attention as mentioned earlier, to the fact that a nurse is present in only 3 out of the 10 meetings, despite this also being a finding from Phase 1. It is reasonable to estimate that amongst the MDT staff, nurses are likely to have had the most contact and interaction with patients during their stay in hospital. This observation is of particular significance when placed in the context of the current literature, which suggests that nurses have an important function as moderators and supporters of communication for patients in CPM's(Hedberg,2007;2008).

It is clear from these data that the MDT dominated the discussion in all of the CPMs observed with their dominance ranging from 60%(Jack's meeting) to 98%(Tommy's meeting). When combining the patient utterances with family member utterances into one group and the MDT into another, an overall

comparison of discourse space showed an asymmetry in participation. Significantly, the MDT used the discourse space to a larger extent than the patients and family members put together. This dominance is in line with the existing literature on institutional talk with patients (e.g.Satterlund Larsson,1989;Johanson,1994;Baggens 2001;Efraimsson, 2004;Hedberg,2008).

The discourse analysis also examined instances of Non-Person Status (Goffman,1981;Hedberg,2008), 3rd person grammatical(NP3), i.e. instances where the patient was referred to as 'he' or 'she' were coded as NP3(non-person status,3rd person grammatical) which replicates elements of Hedberg et. al's (2008) coding structure. Figure 16 reports on findings relating to MDT utterances of third person grammatical(NP3) in Phase 2. This category was viewed as important when examining levels of patient participation as it occurred in instances when the MDT or family member talked about the patient with other participants and the patient was overhearing the conversation; this was also a strong theme in Phase I and the value of discussing a person in their presence without involving them or speaking to them directly must be considered relevant.

Figure 16; Nvivo summary of MDT NP3



It can be seen that Amy's meeting was characterized by the fewest instances of NP3(N=2) and it must be considered relevant that Amy at 36 years of age was the youngest person in the sample and was a professional (Nurse Manager). However, Larry who was also one of the youngest within the sample(58) and had been working prior to his stroke, had a much higher number of instances of MDT NP3 (N=22). Tommy, meanwhile, who had the highest level of cognitive impairment(15/30) had a much lower level of instances of MDT- NP3 within his meeting than others in the sample(N=6). It is reasonable to assume however that this may be due to the fact that little or no conversation was directed towards him during the meeting.

There are probably a wide number of factors that contribute to usage of MDT-NP3 and in particular, conversation style and means of communicating with patients by individual members of the MDT must be considered important as well as the strength of the therapeutic relationship with each patient.

5.13 Analysis of Questions asked during CPM's

In order to further explore the language, behaviour and communication which took place and in keeping with recommendations made by the MDT themselves who acted as collaborators, an analysis of questions asked during CPM's was carried out. An investigation of the number of instances where patients were asked, 'How are you feeling?' was also conducted as recommended by the MDT CRG during the data analysis process. Findings showed that 4 patients asked no questions and 3 asked only one question; accordingly 7 out of 10 patients asked either one or no questions. Hence, the findings suggest that CPM's were used as a time for the MDT to question the patients and family members, rather than it providing an opportunity for patients to ask questions.

Table 17; Summary table of questions asked during CPM's

Care Planning Meeting	Patient - No of Questions Asked	Family-questions directed to patient	Family-questions directed to MDT	MDT-questions directed to patient	MDT-questions directed to family	MDT - questions directed to MDT
AMY	6	0	1	3	0	0
DAVID	1	0	3	3	0	5
ELLIE	0	0	5	2	1	1
FLORRIE	1	4	8	4	1	1
JACK	2	2	8	12	1	0
LARRY	1	1	4	10	2	4
MARK	0	0	11	3	1	0
SARAH	0	1	14	6	3	2
TOMMY	0	0	2	2	0	1
VERA	10	1	14	12	11	0

The number of questions posed by patients at these meetings could be interpreted as an indicator of participation levels and their engagement and involvement(Thompson,2007). In this context it is noteworthy that 8 of the 10 patients asked less than two questions. Also of note is the fact that as many as four patients asked no questions and two out of these four were assessed as having a mild cognitive impairment (MMSE 22/30 and 20/30). Analysis of these cases contrast sharply with those of Amy and Vera who asked comparatively more questions with Amy asking 6 and Vera asking as many as 10 questions. This data becomes more noteworthy when consideration is given to the comments made by some patients during their interviews where they report that they were looking forward to their meeting (Larry and Sarah) and that their CPM was going to be an opportunity to talk with their doctor(David).

The fact that Larry only asked one question is particularly striking in view of the fact he was one of the youngest in the sample(Age 58), who had been in fulltime

employment prior to suffering a stroke and it is puzzling that that he did not have more questions relating to his recovery or ability to return to work that he wished to ask during the meeting. By virtue of having his wife and three children present at the meeting, Larry being a relatively young man, may have felt inhibited and hence his reluctance to raise questions. Larry did however have the third highest number of questions directed to him by the MDT(N=10) so perhaps the MDT had pre-empted some of the questions he may have wished to ask and concerns/anxieties were communicated through his responses. It is also possible that many of Larry's questions may have been answered during the course of his rehabilitation and through his interactions with different MDT members.

Data analysis showed that family members meanwhile asked more questions than the patients themselves although these questions were for the most part directed to the MDT with a huge variation ranging from Amy's meeting(N=1 question) to Vera and Sarah's meeting(N=14 questions). In half of all CPM's observed, no questions were directed towards the patient by their family members and the remainder were asked between one and four questions by their family. It is difficult to determine whether patients and family members had already engaged in prior discussion about issues covered in the CPM so this reduced the need for questions during the meeting or on the other hand, whether family members were not consulting with patients during the CPM and were making decisions on their behalf and thus their focus was meeting their own needs and agenda.

The findings suggest therefore that the CPM's were used more as an opportunity for family members to pose questions to the MDT and for the MDT to address question to the patients and there was little evidence that CPM's were used as a forum for patients to get questions answered.

5.14 Questions being asked of Patients by Staff and Family Members

Further detailed analysis revealed how all patients had questions directed to them by the MDT however, there were noticeable differences in the number of questions posed. This varied from the fewest number asked by MDT at Ellie and Tommy's meeting(N=2 questions) to the highest number asked by the MDT at Jack and Vera's meeting(N=12 questions). It is possible that Jack and Vera had the highest number of questions directed to them by the MDT as the MDT appeared to have a strong therapeutic relationship with both individuals as discussed earlier and the fact that both had been inpatients significantly longer than others in the sample may also have been a contributory factor[24].

In keeping with the recommendations made by the MDT CRG (see page 179) analysis of the number of instances when patients were asked by MDT 'Is that ok?' or 'How do you feel?' was also conducted. There were 17 instances of this type of question being asked but to only 5 of the 10 patients. Indeed in most cases such questions were only directed towards Jack(N=5) and Vera(N=5). As previously mentioned, it is interesting that both Jack and Vera had the longest length of inpatient stay so again, perhaps the nature of the MDT therapeutic relationship was thus stronger and this may have been an influencing factor in the number of these types of questions directed towards them.

It must also be noted that Vera who asked 10 questions, had the highest numbers of questions directed to her by both the MDT and her family members and this may have helped to encourage Vera to ask more questions(Vera asked 14 questions).The table shows that half the sample were asked less than four

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[24] Data obtained from hospital inpatient record on number of inpatient days

questions by the MDT and no questions by their family members and in this sense were excluded by the other participants. Interestingly, Amy is included in this group however she asked the second highest number of questions in the sample. It is also curious that the MDT did not monitor or check the emotional status of half of the sample.

Only three of the five men in the sample asked any questions and the highest number of questions asked by men came from Jack(N=2) who had one of the higher levels of cognitive impairment. As mentioned earlier, it is noteworthy that three out of the five men had MMSE scores of 22/30 or above and it is curious that they asked so few questions during their CPM.

Consideration must also be given to the MDT's suggestion during the MDT CRG that perhaps the patients already had been provided with a large amount of information relating to their rehabilitation and progress and thus they did not need to ask as many questions as their family members. Finally, it may be that some of the patients did not desire additional information relating to their medical condition and rehabilitation progress or that they did not feel comfortable asking questions within the meetings forum. In summary, most patients therefore asked one or no questions. Most questions were posed by the MDT towards patients. When family members asked questions they tended to be directed to the MDT members.

5.15 Findings: Pre-Meeting Preparation and Care Planning Meeting Patient Information Booklet

As discussed in Chapter 3, during this phase in-depth semi-structured interviews were held with patients (N=10) and a nominated family member(N=10) were interviewed separately as part of the fieldwork for Phase 2. As pre-meeting

preparation was a theme that had featured strongly in Phase I, the interview schedule attempted to explore this issue with the patients and check out if they felt they had received adequate pre-meeting preparation. The interviews also sought to gain patient and family member feedback on the patient information booklet developed by the MDT CRG. The interviews were conducted in a quiet room which was away from the busy ward environment in an effort to limit distractions and interruptions and optimise patient engagement in the interview schedule.

Patients provided a variety of responses relating to pre-meeting preparation. The majority (N=9) stated that they had received pre-meeting preparation and that they understood the purpose of their CPM to be related to their discharge plan. They confirmed they had been consulted about who they wanted to attend. One person reported that he did not remember receiving any preparation. Others as the below dialogues reveal suggest that patients were looking forward to their CPM as it appeared to signify to them that they would be going home.

Researcher *'Did anybody explain what your meeting would be about beforehand?'*

Jack *'They did'*

Researcher *'And what did you think was going to be talked about in the meeting?'*

Jack *'Well, I think I knew that they were going to ask that I'd be leaving soon, to leave here'*

Researcher *'So is what you mean that we'd be talking about you going home?'*

Jack *'Exactly, yeah'*(Jack, Interview Transcript)

Ellie also understands the purpose of her CPM as discussing her discharge plan;

Researcher *'Did anybody explain what your meeting would be about beforehand?'*

Ellie *'Yes, just to see how I would manage when I go home'* (Ellie, Interview Transcript).

Interestingly, two patients reported they had been looking forward to their CPM. Sarah stated however that she did receive preparation before her CPM,

Researcher *'Did someone explain what your meeting would be about beforehand?'*

Sarah *'Yes, somebody told me about it that information'*

Researcher *'Were you told that it might be in your interests to attend the meeting?'*

Sarah *'No I wasn't, but I was looking forward to it'* (Sarah, Interview Transcript) and,

Larry *' Grand, looking forward to it-to see what would happen'*(Larry , Interview Transcript).

It would appear that these patients were looking forward to their CPM and did not express any nervousness or anxiety during their interview about this event.

5.16 Care Planning Meeting Patient Information Booklet

In response to being asked about whether they had received a CPM patient information booklet, two patients stated that they did not remember having received a booklet. Meanwhile, three patients reported they had received it, but

had failed to read it. The remaining five patients stated that they had been given a booklet and went on to provide further feedback and comments. Mark reported,

Mark *'I got one last night some sort of thing from the Doctor....'*

Researcher *'And did you find that the information booklet explained about the meeting well?'*

Mark *'I used it just to get all the details'* (Mark, Interview Transcript).

Amy also confirmed that she had received a booklet but that she had not been given it in sufficient time of her CPM,

Researcher *'You were given your booklet?'*

Amy *'Oh yes, it was given yesterday when I was..well when ..this is too late..'*

Researcher *'You thought it was given too late?'*

Amy *'Because it was given yesterday and yesterday was not the best day because I was um...had to go to go to an appointment...'*(Amy, Interview Transcript)

Amy went on to explain that if she had wanted to invite another family member it would have been too late for her relative to make arrangements to take time off work. She did state however that she had used the booklet to write down questions she wanted to ask during the meeting and had found it useful for this purpose.

David meanwhile reported that he received an information booklet but expresses regret at not having written down questions in advance of his meeting.

Researcher *'Did you receive a Care Planning Meetings Information Booklet before your meeting?'*

David *'I didn't write anything down'.*

Researcher *'You mean you didn't write down any questions?'*

David *'No I didn't, I forgot to'*

Researcher 'And do you think now looking back it might have been a good idea?'

David *' Yeah ,definitely'* (David, Interview Transcript.)

It would appear from an analysis of the interview data relating to pre-meeting preparation that the majority of patients did receive preparation prior to their CPM, but in some instances the information was provided too late. It is a concern that half the sample reported that they did not receive/remember receiving the information booklet, particularly as when this was checked with the assigned medical social workers who gave assurances that all patients in the sample had received the booklet in advance of their CPM.

It is also disappointing that half the sample did not appear to benefit from the introduction of the patient information booklet, as pre-meeting preparation had been targeted as the area of practice that the MDT CRG hoped to address and improve on based on the findings of Phase I. Indeed, it is difficult to surmise from the sample size and information gathered during the interviews what impact greater pre-meeting preparation had on patient's participation and their experience during their CPM.

5.17 Patients preferred degree of participation, opportunities for participation and desire for information based on in-depth semi-structured interviews

Patients' views about preferences for participation, desire for information and choice regarding their healthcare and past history of decision-making was also ascertained through in-depth interviews.

Interview schedules drew on tenets of participation as identified in the current literatur (Cahill,1996;Sahlsten et al.,2004;Tutton,2005). Patients find it hard to define what participation is (Greteis et al.1993) so, in this study, the patients perceived participation was based on (1)Whether they believed they had received adequate information (2) Did they believe that they had been given adequate opportunities to express their opinions and ask any questions that they had (3)In addition, it was based on whether they believed they had participated in any decisions and (4) Did they feel listened to. Additional information was also sought on these topics from a nominated family member(N=10) through interviews which also explored the family member perception of each patient's participation in their CPM. Socio-demographic data and information related to past history of decision-making were also collected on each patient and will be addressed within the discussion section.

Interestingly, when questioned about opportunities to participate, all patients (N=10) interviewed believed that they had been listened to, given adequate opportunity to participate and to express their opinions during their CPM. They did not believe that anything could have been done which would have increased or enhanced their participation. The following comment made by Larry reflects that he felt comfortable to express his opinion or ask questions, a comment fairly typical of that of several of the other patients in the sample:

Researcher *'Did you feel free to express your opinions?'*

Larry *'Oh yeah, if I wanted to know anything, I'd just ask'* (Larry ,Interview Transcript).

It would seem that Larry felt that he could be assertive and ask questions if he wanted to.

5.18 Patient Participation

As participation of cognitively impaired older patients at CPM's was identified as a concern in Phase I, this therefore was an issue that the MDT CRG had been anxious to examine in greater detail in Phase 2. The majority of patients in Phase 2 made reference to the role of their family members during their CPM and that they liked to involve their family members in important decisions.

When Florrie, who had a moderate cognitive impairment(MMSE 18/30), was asked about her participation within her meeting she clearly acknowledges that she has allowed her family to speak on her behalf,

Florrie *'You might have noticed that I stopped talking-I just failed the talking and my family took over'*

Researcher *'And were you happy they took over or would you have like to have talked some more?'*

Florrie *' No, I was happy'* (Florrie, Interview Transcript)

Florrie's daughter meanwhile believed that Florrie had been afforded opportunities to participate,

'She didn't say much but she could have because everybody at the table involved her...' (Florrie, Family Member Interview).

David who had a mild cognitive impairment(MMSE 25/30), conveyed that he wanted to be involved in his CPM but related that to being able to see the doctor;

David *'I'd prefer to go(to the meeting). Because I mean I haven't seen the doctor and I thought he was great there today. '* (David, Interview Transcript).

While patients reported being happy with the process, several relatives questioned the usefulness of the meeting for the patient involved.

David's sister comments that in the past, and prior to becoming ill, David was not an out-going person and she questioned how much of the meeting proceedings he really understood;

David's Sister *'David would just sit there always and he really wouldn't pass comment or ask a question, he's always been like that'* (David, Family Member Interview).

David's sister elaborated further and makes reference to David's pre-morbid personality stating that he would not have participated no matter how the meeting was conducted;

David's Sister*' ...I just think because of the kind of person he is, um, I think he'd just go along with if he was in hospital, if somebody asked him to do something he'd just do whatever he was told.'*(David, Family Member Interview Transcript).

David on the other hand reported that he liked to receive some information and that he was able to understand the majority of the information shared during his CPM,

'....Yes, information is better for yourself, I don't like too much information...I was able to understand 90% of the information' (David, Interview Transcript).

The family members of Tommy who had a moderate cognitive impairment(MMSE 15/30) and Sarah who had a mild cognitive impairment(22/30), also raised doubts about how much of the proceedings of the CPM their relative was able to understand and questioned the usefulness of Tommy and Sarah being present during the meeting.

Although Sarah's family questioned how much of the CPM proceedings she really understood, nonetheless they did acknowledge that it was important for her to be there,

Sarah's daughter*'...it wouldn't be held without her because she would be central to whatever was going on'*

Researcher *'And she wanted to be here?'*

Sarah's daughter *'Oh she wanted to be here, oh very much so'* (Sarah, Family Member Interview).

Sarah's opinion differs to that of her family and during her interview she reflects on her experience of her CPM,

'I could understand ok, the others (family members) all asked the questions' (Sarah, Interview Transcript) .

During her interview Sarah was able to relay back what her discharge plan was and explained that she was being discharged that day but that she would be staying with her son over the Christmas holidays. Sarah then went on to express her satisfaction with her CPM,

'I was very pleased with it you know...I don't think there was anything hid'(Sarah, Interview Transcript).

Florrie who had a moderate cognitive impairment(18/30) meanwhile raises the pertinent issue that her family had to become her proxy decision-makers for a time as she was unfit to, due to the severity of her stroke,

Researcher *'How do you usually make important decisions in your life?'*

Florrie *' Well, I didn't'*

Researcher *'Would your family usually make important decisions for you?'*

Florrie *' They would have made anything that had to be made'*

Researcher *'But would they have discussed the decisions with you or would they have just made it themselves?'*

Florrie *'Well I was so unwell they couldn't'* (Florrie, CPM Transcript)

Analysis of these transcripts regarding patient's participation at their CPM's suggest that from their relatives' perspective, in several incidences, patients degree of cognitive impairment meant that they were unable to fully understand what was going on at these meetings and therefore unable to actively participate.

When family members were questioned about whether their relatives decision making had changed, some reflected on the fact that their relatives would have been quite independent prior to having a stroke however since their admission to hospital they defer to them much more in relation to decision-making(Jack, Sarah, Florrie, Ellie and Tommy).

Florrie's daughter makes the following comment during her interview,

'I suppose she would depend on us more... ..you see for her age she was very strong person and she was very ..always did everything like that...and I knew she'd be very organised in that way and ahh maybe she needed..maybe she'd

depend on us a little bit more but I don't know whether that will change- I can't be sure until she comes home but I know that she remembers ..she knows like ..things, so, hopefully yeah.'(Florrie, Family Member Interview Transcript).

Tommy's son reflects on the challenge Tommy's family have faced trying to make decisions on his behalf and that they would prefer that Tommy was able to make his own decisions,

Researcher *'Do you believe your relative's wishes were reflected within the meeting?'*

Tommy's son(sighing) *'...I think so..Well.....'*

Researcher *' Or is it hard to know?'*

Tommy's Son *'I know he sat there and to see him sitting there um, with people talking about him and whether to put him into a home and this and that ..I just wish he could make up his own mind and say a little bit more but when it comes to the day, we have to be realistic'* (Tommy, Family Member Transcript).

It would appear that in some instances, family members are not always comfortable with the decision-making responsibility they have had to assume in relation to their relatives. Interestingly, both Tommy and Sarah were widowed and had no spouse present at their CPM and perhaps this placed them in a more vulnerable position in this context.

5.19 Cognitive and Communication Difficulties

Interviews also attempted to explore with patients whether they had felt left out of the discussion at any stage and whether they believed that their cognitive or communication impairments had impacted on their ability to participate.

David who had a mild cognitive impairment (MMSE 25/30) and who did not have any communication difficulties reported that he hadn't felt left out of discussions but does acknowledge that he experienced difficulties expressing himself at times and remembering everything that he wanted to ask.

Researcher *'Did you feel left out of the discussions at any stage? If yes, when did this occur?'*

David *' No ,No I find it very hard to express myself'.*

Researcher 'And is there anything that could've been done maybe to help you express yourself more?'

David *' No, I thought they did very well...I'm still trying to think of something and I want to ask something...it goes away and then after a while it comes back'*

Researcher 'You forgot about it by the time there was a break or something to ask?'

David *'Yes'* (David, Interview Transcript).

Jack who had a moderate cognitive impairment(16/30) and communication difficulties(WAB 64%) expresses similar sentiments to David in his awareness of his communication difficulties and there appears to be a sense of loss about the fact he can no longer talk in the way that he used to,

Researcher 'Was there anything that we discussed during the meeting or anything about the meeting that you were very happy with?'

Jack *'No I didn't, no. I was quite happy with everything'.*

Researcher *'...Was there anything else that you wanted to say about the meeting Jack?'*

Jack *'I used to talk and now I won't be able to talk. I came in making me mind that, gold I feel like* and *I was relaxed and everything and I relaxed with it...'*(Jack, Interview Transcript).

5.20 Levels of Satisfaction with CPM's and Suggested Improvements.

Similar to the patient interviews in Phase I, some patients provided vague, often monosyllabic answers to many of the questions asked of them about their level of satisfaction with the CPM and suggestions for improvement and when the questions were further probed by the researcher, they were unable to elaborate

Sarah for example who had a moderate cognitive impairment(MMSE 22/30) reported that she was happy with her meeting and the information she received;

Researcher *'If you were asked to go to another Care Planning meeting, what would you like to be done differently?'*

Sarah *' Oh I couldn't see anything different'*

Researcher *'You were happy?'*

Sarah- *'like the doctor and all was very frank and asking and answering and I really was very satisfied. '*

Researcher *'Did your meeting help you in any way?'*

Sarah- *'Well I suppose it did in a sense-it gave you confidence'* (Sarah, Interview Transcript).

David who had a mild cognitive impairment (MMSE 25/30) also expressed satisfaction and equated this to the fact that he learned for the first time that he had suffered a stroke,

Researcher *'Is there anything about your meeting you were very happy with?'*

David *'I think I was happy anyway..he(the doctor) explained what was happening-you see I didn't know that I had a stroke at all'* (David, Interview Transcript).

It is indeed startling that David reports that his CPM is the first time that he has been informed that he has suffered a stroke and that he has received this information the day before he is discharged and raises questions about timing of information giving for patients. It may be possible however that as a result of David's cognitive impairment, or the fact he was medically unwell, that he didn't remember receiving this information previously and reiterates the need for patients to be provided with written as well as verbal information repeatedly.

Amy meanwhile equated the most positive aspect of her meeting as the fact that she would be going home;

Amy- *' I can be discharged'*(Amy, Interview Transcript).

Vera who had a mild cognitive impairment (MMSE 22/30) also reported that she had been expecting her discharge to home to be discussed during her CPM,

Vera *'Ahhh(long pause).There was one part of the meeting that I thought was what I expected'*

Researcher *'And what was that?*

Vera *'that was about when I go home and home help'*

Researcher *'going home and home help, so you expected that that would be discussed? And do you feel that you got the answers that you wanted to?'*

Vera *'Oh yeah'* (Vera, Interview transcript).

The majority of patients stated that they were pleased that their CPM had offered them an opportunity to meet with the MDT and in particular their Medical Consultant/doctor. Several patients did however expressed dissatisfaction at the Medical Consultant or specific allied health professional therapists not being present at their meeting and obviously had been under the impression that they would be. For example during Florrie's interview she was asked,

Researcher *'Was there anybody who you thought should have attended your meeting who didn't?'*

Florrie *'Well I guess that was who was coming-but I thought the main doctor would be here and he wasn't'* (Florrie Interview Transcript).

Florrie who had a moderate cognitive impairment (MMSE 18/30) thus made reference to the fact that although a Registrar was in attendance at her CPM, it appears that she was disappointed nonetheless that her Medical Consultant wasn't present.

Amy who had a mild cognitive impairment(MMSE 24/30) but who had the most significant level of communication difficulty(WAB 43.9%) in particular expressed dissatisfaction at neither the Speech and Language Therapist or the Physiotherapist being able to attend and stated that the meeting shouldn't have gone ahead if they couldn't be present. Amy presented as being somewhat

offended about the absence of these MDT members at her CPM and is perplexed as to why they couldn't make the time to attend.

'.... no, it was just that I was thinking that even if xxxx (SLT) was on her day off, why couldn't she even just come here for half an hour and maybe xxxx, the physiotherapist, why couldn't she just leave her work for a few minutes to come along- it's not like its gonna be a whole hour... xxxx in the Physio, she promised me yesterday that she will be in the meeting, so I don't know.'(Amy, Interview Transcript).

It is evident that Amy is very disappointed that the Speech and Language Therapist and Physiotherapist were unable to attend and that the Physiotherapist has breached Amy's trust by promising to attend and then failing to. Other complaints made by the patients included lacking control over provision of home supports, community services and uncertainty relating to follow-up rehabilitation and appointments.

It is unusual that patients in Phase 2 had following observations and data analysis, such low levels of verbal participation during their CPM's however, in a one to one interview, the majority were quite talkative about their experiences of their CPM and were able to articulate clearly the positive and negative aspects of their meeting experience. Patients therefore expressed little dissatisfaction about their participation within their CPM, and they clearly expressed unhappiness about aspects such as certain notable staff members not being present.

5.21 Findings from the Participant Observations of CPM's

As discussed in Chapter 3, participant observations were carried out using a data recording sheet to complement the transcriptions of the CPM's and it was hoped that they would also greatly enhance the process of data analysis. All meetings followed a general structure which was consistent with that observed in Phase I.

Some of the meetings observed involved a decision-making process while others signified more of a discussion forum and this was determined by the content and outcome of the CPM.

5.22 Information Shared

For many of the CPM's observed, the main function of the meeting was information sharing. The type of information being given could be classified into two categories;

(i)Update from MDT on patient's medical situation, rehabilitation progress and prescriptions and

(ii)Options; care planning, equipment, home supports, follow-up. The topics and their percentage of the total amount of talk varied for each meeting and certain topics had more significance for particular patients.

5.23 Topic 1, Update from MDT on patient's medical situation and rehabilitation progress and prescriptions

The medical team dominated the discourse relating to this topic however, practices varied from some medical information provided being explained and more 'understandable knowledge' and other where no explanation was given whatsoever. For example in Amy's CPM she is being provided with information about her memory and cognition by a member of the MDT,

'Um your cognition is intact-it is fine-the first time actually one of my colleagues seen you, you scored 24/30 on the MMSE but most of the subtests you scored a bit off as you have problems with language otherwise you have problems with

language anyway .I never did an MMSE but I would say that you would score perfect on it. Your perception is intact before you had some problem with attention but that has completely resolved'. (Amy, CPM transcript).

It is not explained to Amy or her family what the term MMSE means or what the implications of a score of 24/30 were for Amy in terms of her day to day functioning. The MDT member is using technical jargon without considering that Amy may not be familiar with this medical language and what it means. Other examples of medical jargon used without an explanation being provided include;

'..... pre-morbid functional status'(Sarah, CPM Transcript)

and,

' ..... and at the moment as you know we're doing the daily swallow treatment called DPNS so we're going through 90 swabs a day just to try and strengthen up those muscles in your throat'(Jack ,CPM Transcript).

Other members of the MDT did, however, make a noticeable effort to communicate in the patients' and their relatives' common vernacular and to explain any medical terminology being alluded to.

For example, in David's CPM the doctor explains the reason why David is presenting as more confused;

'...he had an infection so he's much more muddled than he was now and that's called a delirium.' (David CPM, Transcript).

Although this information is presented in language that is easy to understand, unfortunately, it is conveyed in the third person grammatical and was directed at David's family. This finding is consistent with results from Phase I.

During Florrie's CPM, the doctor also explains her diagnosis in simple language and what exactly a stroke is;

'There was a clot on the brain yeah-that's what a stroke is. So there's 2 types of stroke really, there's a bleeding stroke and a clot stroke.'(Florrie, CPM Transcript).

This again was deemed to be understandable information which Florrie and her family were able to comprehend and absorb; Florrie's engagement and understanding of what the doctor is saying is then further demonstrated by her participation with the doctor in the information he is providing,

Doctor *'... and, it's just in case of when you're..., when everyone else, I mean the community, multi-disciplinary team is happy that you'll be back to your baseline'.*

Florrie *'Yeah. Well I feel I'm improved and I'll be better when I get home and in my own environment.'*

Doctor-*' Well you've certainly -- you've made very good progress and you've no major medical concerns at the moment, other than just you're still a little bit unsteady, a little bit weaker on one side, and...'*

Florrie *'Yeah, I walk slowly'*

Doctor *'Yeah. And that's good for safety awareness'*

Florrie *'Yes it is '* (Florrie, CPM Transcript).

Although Florrie was one of the older patients who had a moderate cognitive impairment, the above excerpt suggests that she was able to understand the information being provided. The two-way dialogue between the doctor and Florrie is also noteworthy. This was an unusual case as within the CPM's observed, two-way dialogues were uncommon as most of the meetings were

characterised by MDT members giving dense and long monologues of information where interaction with either the patient or family was minimal or completely absent. For example in Larry's CPM, the Physiotherapist was asked to provide feedback on his rehabilitation progress,

'Larry is walking independently with the stick now which is great and we're trying to get him to do a bit more on the ward himself so I've told the nurses that he's allowed to walk around the ward by himself now and if his relatives are here seeing him, I've no problem with them bringing him out for a walk and you could bring the wheelchair with you in case he wants a rest but it would be great to do a little bit more with him when you're in so he gets used to walking because he'll fatigue quite easily otherwise at home you know? Um, the stairs, he's much better this week, ...last Friday we did it as well and he's much safer coming down the stairs so I would see now in a week or so that he would be independent on the stairs ,I hope um, he's much safer going up and down than he has been just from practice and that, that's obviously a huge thing that we want him to be able to do to be able to go up to the bathroom and things like that, and um,I think Cara(the Occupational Therapist) was saying there are some steps in front of the house as well so those don't have railings I don't think, but we might practice without railings. I didn't realize they didn't have railings and I think you can manage that with a stick. Maybe with someone there but obviously we'll try and make sure that there will be times when he will need to do it himself, but I don't think there will be a huge issue with that either as his balance is much better and everything, so...'

Larry *'mmm'*

Physio *'Hopefully we'll get there and I think another week or so should do it'* (Larry, CPM Transcript).

The passage could be compared to the previous passage(dialogue between Florrie and the doctor) as in the former, a huge amount of important information for Larry and his family is presented in such a concentrated manner that it would be very difficult to understand and remember. It would perhaps have been more useful to involve Larry in the conversation by asking him about the rehabilitation he had received and stopping throughout to ask him to confirm that the information being discussed was correct. It is significant that the entire passage is communicated in the 3rd person grammatical and there is only one instance where Larry is addressed in the first person. It must be highlighted that during Larry's CPM, other MDT members also communicated information in a similar one-way manner and this is of particular significance given that Larry was one of the youngest members of the sample(Age=58) who was among the least cognitively impaired(MMSE =25/30). This method of the MDT conveying information in this manner was a feature across the majority of the CPM's observed and is undoubtedly an area of practice that requires attention if patient understanding and participation are to be optimised.

5.24 Topic 2, Planning options; home supports and follow-up.

5.24.1 Equipment

In the CPM's observed, patients and their family members were told what equipment each individual required and there was no evidence found in the data of anyone be it patient or family member challenging the MDT's expert opinion in relation to what was recommended. Conclusions cannot be drawn as to whether patients and their family members were satisfied with recommendations or if they chose to be passive recipients of the information provided as they did not express satisfaction or dissatisfaction in relation to this issue.

5.24.2 Home Supports

Home supports were an important topic within the CPM's observed. Home supports can be defined as paid staff or equipment which assist individuals with personal or domestic tasks in order for them to maximise their independence This topic was generally instigated by family members who were advocating on their relatives behalf. The need for home supports mainly related to issues of independence, safety and confidence.

In Florrie's CPM, it is clear that neither the social worker or the patient and family have any real control over the provision of home support and that the local Case Manager who is based in the community makes the final decision when the patient goes home.

Florrie's son *'yeah, she(case manager) rang me yesterday and said that she won't be here(at meeting) but she'll wait until we're all at home together and then she'll help us decide what we need rather than do it in a meeting room, she said it would be better in a hands on situation.'*

Social Worker *'Yeah, ok'*

Florrie's Son *'So I asked her...she said what do you need and I said I don't know, but everything, anything that's available but she said, no, it doesn't work that way ..so I said if we could get everything that's available and then ...give some back if necessary, but she said no it doesn't work that way at all. She said that when your mother comes home we'll arrange a meeting immediately and she said that the buck stops with her but anything that she(patient) needs she will get.'*(Florrie, CPM).

This excerpt illustrates the vulnerability of family members and the uncertainty that all of the patients faced regarding what home supports would be provided

for them when they returned home and it could be argued that this contributed to their feelings of lacking control over their care.

Provision of information relating to home supports was often confusing due to multiple service providers being involved. It was also characterised by ambiguities and uncertainties due to the fact that MDT had little or no control over decision-making process or provision of home supports and very much reflected a segregated health care system with overly bureaucratic processes and duplication of roles.

Social *Worker 'I suppose that resources are low and she has to prioritise and I think particularly the home help organizations ,you know resources for cleaning when there is another adult living in the house ,they don't prioritise in that case ...'* (Florrie, CPM Transcript).

It can be seen that information provision was a key function of all CPM's within the sample observed. Although some CPM's demonstrated examples of information not explained this represented a very small percentage of overall information provided (maximum 5% coverage, Nvivo coding summary).

5.25 Existence of a Therapeutic Relationship

Evidence of close relationships or more intimate relationships developing between the MDT and patients emerged when data was analysed. One of the most striking examples occurs in Larry's CPM when the doctor praises him and acknowledged the existence of a relationship between Larry and the MDT by using the analogy that he has become part of the family.

Doctor *' Larry, I mean you really have done very well- you came in on the 10th March um, so you've been like part of the family now really...'* (Larry, CPM Transcript).

In another case, the bonding and possibly affection which has developed between a patient and an MDT member is evidenced. During Jack's CPM, the OT addresses Jack, *'Jack I've seen you many times...'* , this is followed by rapturous laughter by the meeting participants which suggests that participants were comfortable and at ease with each other. Jack then speaks but gets extremely emotional when doing so and there appears to be a genuine relationship and bond between Jack and the MDT.

Jack-*' I know, I know but I know what I'm trying to say... you're all so very nice(getting very emotional) and so good'* (Jack, CPM Transcript).

Further weight is added to the finding that a strong therapeutic relationship existed between Jack and the MDT from feedback communicated by Jack during his interview,

Jack *'No, No I understood that whatever, the lads here(the MDT) were going to look after me, you know?'*(Jack, Interview Transcript).

It is clear that Jack has placed his trust in the MDT to care for him and believes they have his best interests at heart and will look after him.

Jack's son also reflected on the relationship that he and his father had developed with the MDT when he was asked whether his father had been able to say everything that he wanted to during his CPM,

Jack's Son *'....he has come to know most of these people as I have '*

Researcher *'Yes, I could see he was very relaxed'*

Jack's Son *'Friends as opposed to going into a group of strangers you know...I think it was the fact that it was the people on the ground and we had a good relationship with them...'*(Jack, Family Member Interview).

Empathy,which is another tenet which contributes to a therapeutic relationship, was also demonstrated during many of the CPM's as the MDT attempted to convey their understanding to patients about their particular situations.

During Mark's CPM the doctor demonstrates empathy and active listening,

Doctor *'... you wonder if things are going to be very different'*

Mark *'yeah'*

Doctor *' and that's understandable as well'*

Doctor *'if you've had a big life changing event..Mark you know'*

Mark- *'yeah, yeah'*

Doctor *' a stroke is a big deal..you've been through the mill really'*

Mark *'yeah'* (Mark, CPM Transcript).

It is clear that the doctor is trying to explain to Mark that he understands that the stroke has been a major event in Mark's life and that Mark shouldn't underestimate the significance of overcoming this hurdle.

Empathy is also demonstrated during Jack's CPM in relation to his communication difficulties;

Doctor *'yeah, yeah, I know it might be frustrating at times and thinking I wish you'd stop asking me to name this thing or whatever but it would be a good thing'*

Jack *'I appreciate that, I really do'*

Doctor *'But we understand from your point of view that it must be quite frustrating at times when you're saying I know in my head what I want to say but it's not coming out the way I want it, you know.'* (Jack, CPM Transcript).

In both examples, the MDT are acknowledging the challenges both patients have faced as a result of suffering a stroke and the impact it is having on their lives.

During Amy's CPM meanwhile, she is reassured about returning home,

Doctor *'So are you excited?'*

Amy *'Yeah'*

Doctor *'Apprehensive?'*

Amy *'Yeah'*

Doctor *'you've done all the preparation work and there's no real unknowns here in that you've managed very well overnight. I think you'll be fine- just enjoy being at home. Let's get out of here (laughter)*'(Amy, CPM Transcript).

In this quote the doctor is searching for Amy's true inner feelings about her imminent discharge. The light-hearted tone of the conversation is also suggestive of a relaxed comfortable relationship between Amy and the doctor.

Florrie on the other hand receives praise and reassurance in relation to her confidence;

Doctor*'...but I'd say at large your probably nearly as good as you were before you came in ,are you?'*

Florrie *' I'm not quite as good but I can manage'*

Physio *'yes, you can manage well'*

Florrie *'If I have help'*

Florrie's Son *'Confidence'*

Doctor *'Yes, absolutely'*

Son *'Confidence, that'll come back'*

Doctor *'Yes'*

Florrie *'But I do need the help at home,'*

Doctor *'But Florrie as your son was saying there is a confidence thing- you've had this stroke and it really knocks your self confidence and your way of going on, you know..that this has happened to you and it's hard to come to terms with it, so I'm not surprised but I think when you get back into your own environment that you'll build up your confidence again and that should improve. And I think, you know that I suppose for us it's a good outcome for someone to be as good or nearly as good as they were beforehand having had a stroke'* (Florrie, CPM Transcript).

It is evident that Florrie is quite anxious about how she will manage when she goes home and she is particularly worried about getting help at home and not having to overly rely on her family members for practical support. The doctor, physiotherapist and her son all attempt to reassure here and explain that her confidence has been affected by having suffered a stroke. The choice of language used by the doctor also warrants some analysis as words such as environment (referring to home) and outcomes (referring to prognosis or recovery) are not that patient friendly.

The MDT demonstrate their awareness and understanding of many of the patient's concerns about their ability to manage when they return home and they

attempt to restore their confidence in their ability to manage and praise them about the progress they have made during their rehabilitation.

David and Mark also received praise for their progress and are reassured about their capabilities;

OT ' ....and she(discharge planning OT) was very pleased with how you did it as well, there was perfect safety awareness, you were able to concentrate and keep your attention up' (David, CPM Transcript).

Doctor *'Yeah, I know well actually considering the time from here you know Mark, you've done very well in terms of your progression...it's really been great' (*Mark, CPM Transcript).

Meanwhile Vera's strength of character in particular is recognised and praised ,

Doctor-'*But medically,I'm very happy with you and I think you've done a great job personally to get over the trials and tribulations –that requires a bit of strength of character which you have because its difficult if your just getting better and something nasty happens to you and that does dent you psychologically, so you've done a great job, very much a source of admiration from members of the team I can tell you*'(Vera, CPM Transcript).

The doctor attempts to convey to Vera how strong and courageous she is to have not only recovered from suffering a stroke, but that she had the added complication of her hip fracture[25].

These examples certainly suggest that in several cases, a therapeutic relationship existed between the MDT and patients in the Phase 2 however the nature and

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[25] During Vera's inpatient stay, she unfortunately sustained a fall and fractured her hip

strength of this relationship undoubtedly differed. On the one hand, it could be presumed that the MDT would naturally have a stronger relationship with those patients who had been in hospital the longest and therefore had more involvement and contact with. On the other hand, factors such as patients' cognitive and communicative ability as well as both the patient and MDT unique personality traits may also have influenced the nature of the therapeutic relationship.

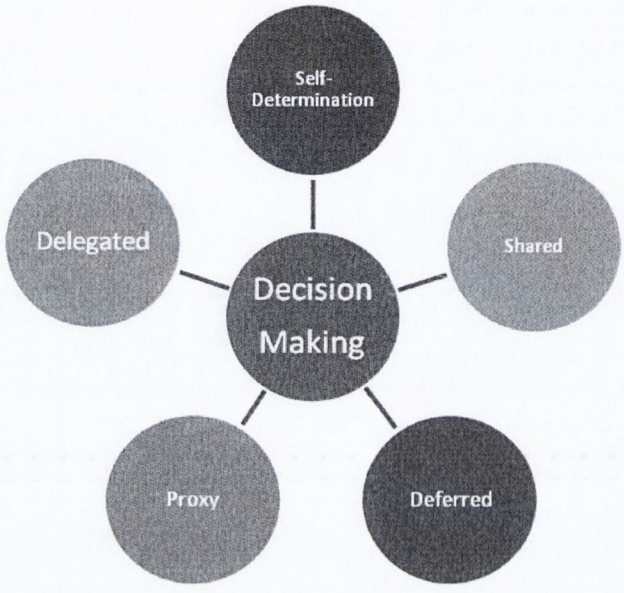
5.26 Power, Control and Opportunities for Influence

The qualitative data was analysed to see the extent to which patients were actually participating in the decision-making process in a meaningful way. Opportunities for influence therefore relate to opportunities created during CPM's for patients to participate and be involved in decision-making processes. This final section to follow will explore issues of power and control relating to framing of decisions, autonomy and institutional discourse.

5.27 Communicative approaches in the decision-making: Framing of Decisions.

Discussions relating to framing of decisions mostly concerned home supports and discharge arrangements. With the exception of Tommy who was discharged to a nursing home, all patients in Phase 2 were discharged home. As Amy and Larry were aged under 65, they were ineligible to access funding for carer support through the home care grant initiative. Findings from patient interviews indicated that the majority of older patients did not want to assume an active role in decision-making. Within this study, five different styles of participation relating to decision-making were found which are illustrated in the diagram below; self-determination, shared, deferred, delegated and proxy decision-making.

Figure 18; Styles of Decision-Making Observed in Phase 2



5.28 Self-Determination

For the most part, the MDT addressed Amy directly in discussions relating to home supports and follow-up. Although Amy's husband was in attendance at her MDT, he spoke only a few words and did not become involved in any discussions related to decision-making. Amy's CPM was characterised by the fact that she seemed to articulate what she did and did not want during the meeting, and for this reason, could be deemed as demonstrating a self-determination style of decision-making. The following excerpt illustrates this point and involves discussion relating to follow-up rehabilitation for Amy once she is discharged to home,

Social Worker *'What I'm going to do is to talk to speech and language(therapist) and Physio and find out like what exactly what days and I don't know how many days a week'. (reference to rehabilitation after discharge)*

Amy *' ONE(*loudly)'

Social Worker *'One day a week'*

Amy *'And he going to accumulate the hydro and the physio in one day'*

Registrar *'um'*

Amy *'So that if we can go, we will..if we can come here we will go as one'.*

Registrar *'So you're going to have one tough day per week'*

Amy *'Yeah'*

Social Worker *'Yeah, that all happens on the one day-that makes sense'*

Registrar *'Absolutely'* (Amy, CPM Transcript).

It must be pointed out however that although Amy verbalised her opinions and wishes, she ultimately did not have control over the frequency of her follow-up therapy which was a source of frustration for her.

5.29 Deferred Decision-making

Larry on the other hand, makes reference during his interview to the fact that he believes it is the responsibility of the MDT to make decisions on his behalf and thus has been deemed as exhibiting a deferred model of decision-making. Larry's CPM is also characterised by the majority of the conversation being directed to Larry's wife and children.

Physio *'Has anyone any questions about what we're doing with him...?That's grand well we'll be hoping to bring him back and do follow up for a while and um and get Physio maybe once a week for a while'*

Larry's wife 'Where?'

Registrar 'At the day hospital we were thinking, right?'

Social Worker *'Too young for the day hospital'*

Registrar 'Too young?'

Physio *'Well he can come back as an outpatient to us once a week he can come back to myself for a few weeks just to make sure that he's improving'*(Larry,CPM Transcript).

This approach of deferring responsibility to the MDT is also demonstrated in David's meeting and the presence of long monologues of information provision is particularly evidenced in his CPM.

Consultant *'We'll get the scan. If the scan is all right, we'll be happy to let him go tomorrow'*

David's niece *'OK'*

Consultant *'How would that be? '*

David's Niece *'Yeah'*

Consultant *'And we'd follow him up at the day hospital'*

Social Worker *'If you go tomorrow, the Home help can probably start on Thursday'*

David's niece *'Yes'*

Social Worker *'They probably just needs a day or two notice'* (David, CPM Transcript).

Although it would appear that neither Larry or David want to assume responsibility for decision-making, it is nonetheless somewhat extraordinary the extent to which they are excluded and ignored in the above excerpts.Both the MDT, and their family members, conduct the conversation as if their relative wasn't even present, and as noted previously, refer to them throughout in the 3rd person grammatical.

5.30 Proxy Decision-making[26]

Tommy's CPM was convened so that a decision could be reached in relation to his discharge plan. Within Tommy' s CPM, discussions relating to his discharge were framed in the context that Tommy would require assistance at all times and twenty-four hour supervision; information about home supports that could be accessed were given however, it was made clear that the community services would be unable to provide the level of support that Tommy required. It was outlined to Tommy that unless his family could provide this level of support, then his only other option would be nursing home care. It would appear somewhat misleading and dishonest for the MDT to frame this decision as a choice, as Tommy's family had already made it clear to the MDT that they could not offer the level of care he required and Tommy was also aware of this.

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[26] Decision-making for those without decision-making capacity in Irish healthcare has not been formalised. A helpful ruling in the Courts has proposed that the doctor should make the decision with the patient in consultation with their family. Should this not be consensual, a second opinion should be sought(Ward of Court, Mr Justice Lynch,5th May 1995).Decision-making is thus taken by others in whom trust is placed but this does not constitute a formal healthcare proxy.

It could be concluded that the MDT and Tommy's family were using the CPM for the purpose of informing Tommy that he would have to be discharged to the care of a nursing home and thus he was never genuinely afforded the opportunity to participate in the decision-making in relation to his future. The outcome of Tommy's CPM therefore was that Tommy remained an inpatient in hospital whilst awaiting a long term care placement in a nursing home to be organised. It would appear that Tommy's family members and the MDT are acting as proxy decision-makers on behalf of Tommy but it is unclear whether they have sought explicit consent from Tommy to do so.

In the case of Sarah however, it would appear that both the MDT and her family members completely excluded her from any decision-making processes and similar to Tommy's situation, they act as proxy decision-makers. Paternalism was also demonstrated by Sarah's family members and the MDT regarding her discharge plan,

Doctor *'I think she's actually near her baseline...I think she already has, you already have, assistive devices in place at home and she already has enough support in the morning and evening. I think I'm happy for, for...she's able to go home'.*

Sarah's Son *'So you're saying she's capable of being on her own during the day?'*

Doctor *'Yes'*

Doctor *'....Ok, from our point of view, she can go whenever you're ready to take her'.*

Sarah's Son *'Mum's ready to go.'*(Sarah, CPM Transcript).

It is evident that Sarah has been completely left out of the decision-making process. Interestingly though, there are indications during the CPM that Sarah

was listening and taking in what is being discussed as she volunteers information during discussions relating to her pendant panic alarm,

Sarah's Daughter *'The strap broke recently doctor, and it was only an accident that we noticed'*

Sarah *'It wasn't working properly so I couldn't use it'* (Sarah, CPM Transcript).

5.31 Delegated Decision-Making

In Florrie's CPM meanwhile, all discussions and negotiations relating to home supports and discharge were directed to family members and she was not involved in the discussions or her consent or agreement sought at any stage about provision of home supports. In Florrie's case, during her interview, she alludes to the fact that she was happy for her family members to talk on her behalf which could be interpreted as her having delegated them decision-making responsibility.

5.32 Shared Decision-Making

Four meetings in Phase 2 were deemed to follow a shared decision-making style. In Ellie and Mark's CPM, discussion was directed to each individual and their family however it was evident that a great deal of pre- meeting discussion had taken place with each of the patient's to clarify their preferences in relation to home supports. This appears to have enhanced their ability to participate in discussing this topic within the meeting as the social worker was able to refer to the previous conversations and advocate on their behalf. A praxis of bureaucracy did appear to occur with the social worker advocating and supporting patients but also having to explain and rationalise eligibility and entitlement criteria for social services.

On the other hand, Jack and Vera's CPM were characterised by a two stage process of discussion and decision-making. Information relating to home supports were discussed and negotiated firstly with family members. Consent was then sought from the patient about whether they were in agreement about a decision that had largely already been made; this demonstrates more of a shared decision-making approach. The following excerpt from Jack's CPM illustrates this,

Jack's son 'Well the way we are at the moment-Monday, Tuesday, Wednesday, we're both working so in the mornings I would make breakfast-we'll have our breakfast together. Then I'd be going out to work so I felt that if he was ok on his own..if he's not going to a daycentre ,he'd be alright there sitting there on his own

OT 'mm hmm'

Jack's son 'and maybe someone coming in at lunchtime....'

SW ' Is it ok with you then on the days that Anthony works that somebody would come in..a Home Help?'

Jack 'you could come in' (Laughter)

Jack's son 'you don't get to choose'

Jack ' I understand'

SW 'would it be ok with you if somebody came to help you make your lunch the days that Anthony's at work?'

Jack 'well I can ,I can come to an arrangement. '(Jack, CPM Transcript).

5.33 Protection of Patient Autonomy during Decision-making

Patient autonomy is clearly integral to any decision-making process and appeared to be of particular significance within Ellie's CPM as there was a tension between her son's wishes re; home supports and Ellie's own wishes and thus differing agendas were evident.The following excerpt illustrates the social worker advocating on Ellie's behalf and explaining the importance of Ellie's autonomy being maintained when Ellie's son is insistent that Ellie should attend a daycentre when she returns home.

Ellie 'I'm not inclined to go out though'

Son 'you're not being stimulated any way, that's probably a very good way to....'

Social Worker ' I mean, I suppose at the end of the day, it's up to your Mum if she wants to attend a daycentre...'

Son ' Sure'

Social Worker ' I suppose the other thing just to say to you, and, and I suppose you were touching on it there, suppose it a balance between allowing Mum to continue to do as much as she can for herself, versus getting in a lot of services and my sense of you is you are kind of keen to keep doing as much as you can'

Ellie 'Yes, I want to keep doing as much as I can' (Ellie, CPM Transcript).

Although Ellie has moderate cognitive impairment (20/30 MMSE) she is able to clearly verbalise her wishes. Later in Ellie's CPM, the doctor also tries to rationalise with Ellie and her son about the importance of Ellie maintaining her independence when she goes home. Both the doctor and the social worker attempt to advocate on behalf of Ellie in order to empower her to maintain as

much independence as possible when she returns home and are clearly acting on Ellie's expressed wishes.

Findings indicated that the majority of older patients did not want to be actively involved in any decision-making processes during their CPM. Some appeared satisfied for their family members to act as proxy decision-makers whilst others delegated family members to act on their behalf. Two patients meanwhile chose to defer to the MDT 'expert' opinion and four CPM's were characterised by a shared decision-making approach. Amy's was the only patient who demonstrated a self-determination style of decision-making and in this context, Amy's age(36) and professional background (nurse manager) must be considered pertinent.

5.34 Institutional Discourse

An interesting observation about the CPM's is the language used to describe the discharge process and who controls it. There is a strong recurring theme of 'getting home' within the sample and for many patients the meeting really signified a decision being made about when they could return home.

During Mark's meeting, the social worker concludes the CPM with the following statement,

Social Worker *'So I think if there are no more questions it's just a question of giving you your exit papers...'*(Mark, CPM transcript).

Meanwhile during David's meeting the doctor states,

' We'll be happy to let him go tomorrow.'(David CPM).

Both these examples strongly suggest that MDT perceive themselves to be in control of the decision-making to the extent that language incorporated into the discharge planning discussion,is that which is usually used to describe situations

where people are detained or imprisoned. Discourse in Tommy's CPM further evidences this when the doctor is outlining the possibly that Tommy may need nursing home care,

Doctor *'Alright, so it's not a prison that we're sending you to if that's the case'* (Tommy, CPM Transcript).

These statements must however be considered within the wider meeting context and the audio-recordings would suggest that they were made in a 'tongue in cheek' manner rather than as serious statements. Nonetheless, the discourse is perhaps more indicative of the MDT's perception of the patient's hospital experience and feelings of lack of control than the MDT's desire to be in control.

The next section advances this theme further by discussing patient's perceptions about control and decision-making during their CPM which were captured during the semi-structured interviews.

5.35 Control and Decision-making

Patients were asked whether attending their CPM made them feel any different about the amount of control they had over their care planning and treatment and were prompted with suggestion of more control, less control or no difference. The data shows how most felt that they had little control as many of the sample responded that attending their meeting didn't make any difference to the amount of control they had. One example however was David who claimed that it had given him more control. Larry was of the opinion that it didn't increase his control.

David *'Yes, more control...I have to behave myself, don't run amok or anything or I'll be back in here '(*David, Interview Transcript).

Larry on the other hand was of the opinion that it didn't increase his control,

Larry *'No it didn't give me more control,I would just listen to what's going on'* (Larry Interview Transcript).

Larry appears to have a resigned passivity to his involvement in his CPM and when asked about whether he had been involved in any decision-making during the meeting he clearly conveys that he sees decision-making as the responsibility of the MDT and that he has deferred to them to make decisions on his behalf,

Larry *'No, because it's up to the doctors, you know. And the Physiotherapists'*

Researcher-*'So you don't feel that you really played any part in that?'*

Larry *'No'* (Larry, Interview Transcript).

Larry is clearly aware that he has adopted a more passive role and that he has deferred to the 'MDT as expert' decision-makers however he clearly verbalised his desire to receive information,

'Oh yeah, yeah it(the CPM) gave me a lot more information about meself and all that...you might learn something'(Larry, Interview Transcript).

Tommy meanwhile appeared to be saying that he was prepared to accept whatever decision was made but that it was important to him to be involved and to play a part in what was decided,

Tommy *'Well it's.....it's how would I say it.....I, oh gosh, how would I say this.....ahhhh.....I,I I accept it ,I accept what was said at the meeting and the whole lot,I did, yes and I wanted it to be my end of it I didn't want the 2 boys ...sorry,I wanted to let the 2 boys understand that I wanted to do it my way..not their way'* (Tommy, Interview Transcript).

Several patients made an association between their lack of control and the doctor/MDT being viewed as expert and for this reason they deferred to the MDT to make decisions on their behalf.

David *'Everyone explained ...but he knows better'*

Researcher *' Who knew better?'*

David *'The Doctor in charge'.* (David, Interview Transcript)

Amy expresses strongly her feelings of helplessness in the following excerpt:

Amy *'It's ...there's not a control... we have to follow what's given to us...'*

Researcher *' You feel that you have no control really, ok. And why was that Amy?'*

Amy *'Because they are the one who decides'* (Amy, Interview Transcript).

It would appear that Amy clearly felt that she had no control over the meeting proceedings and that she must accept the decisions reached by the MDT. In relation to Amy, it must be noted that Amy may also have been referring to the lack of control she had over her therapy follow-up as this was an issue that dominated her interview. Amy expressed strongly her dissatisfaction with the uncertainty relating to her Speech and Therapy follow-up which was obviously an area of great concern to her as her stroke had severely affected her speech. As mentioned earlier, she also complained about the Speech and Language Therapist not attending her CPM which was another issue which she had no control over.

5.36 Patient's desire for control in CPM's

During Vera's interview she offers a different perspective and states that her CPM didn't provide her with more control however she qualifies this by acknowledging that she didn't want any control.

Researcher *'Did you feel that you had any control over what happened in your meeting?'*

Vera *' No,no but...'*

Researcher*'Not really?'*

Vera *' I didn't want control'* (Vera, Interview Transcript).

Vera also offered an interesting opinion when she was asked if she liked to be given information and choices in relation to her healthcare and reports that she likes to have knowledge about most things but not everything,

'Well, I think if I had something that could kill you, I'd rather not know' (Vera, Interview Transcript).

It would appear that Vera does not desire to have control within her CPM and thus it is evident that not only did the patients differ in their perception of the amount of control they had, but their desire for control within their CPM also varied considerably.

Figure 19; Summary Table of Phase 2 Findings (see P.275).

Findings from Participant Observations Phase 2	Findings from Questionnaires Phase 2
• All patients in sample had mild-moderate cognitive impairments and half of the sample also had communication difficulties. • Length of CPM's ranged from 12 mins- 35mins. • More responses elicited form patients when speaker turned to address them. • Variations in levels of eye contact between MDT and patients. • Signs of frustration exhibited from patients in relation to word finding difficulties. • Patient's verbal utterances ranged from 8% to 1% of total discourse space. • Participation indicated however through levels of patient eye contact. • Family member utterances ranged from 30% to 1% of discourse. • Asymmetry in discourse occurred and MDT utterances took up more of the discourse than patient and family member utterances combined. • Use of Np3 towards patients by MDT and family members. • Four out of 10 patients in sample asked no questions. • 9/10 patients reported receiving pre-meeting preparation however only 5 reported receiving Patient Information Booklet. • Main topics discussed in CPM's = update on medical situation and rehabilitation progress and home supports, discharge planning and follow-up care. • Therapeutic relationship seen as influencing factor on patient participation levels. • Decision-making styles=self-determination, shared, deferred/delegated, and proxy.	• All patients reported that they had participated in their CPM and that they had felt listened to, able to express their opinions and express their opinions. • Majority of patients made reference to their family members being present and some alluded to deferring to their family members to talk for them and make decisions on their behalf. • Some family members questioned the usefulness of cognitively impaired patient being present at CPM. • Patients placed importance on being able to meet with doctors and MDT during CPM and many believed it signified 'going home'. • Some patients expressed disappointment and dissatisfaction at their Consultant or specific therapists not being present during CPM. • Several patients referred to feeling a lack of control and associated this with doctor/MDT being viewed as 'expert'. • Other patients reported that they didn't desire any control.

5.37 Conclusion

Findings from Phase 2 provide some valuable insights into the type of information conveyed to patients at CPMs by MDT staff, and how this communication is organized. Results show how CPMs can be used both to promote patient participation as well as impede it. Tenets of participation were demonstrated to be of significance amongst patients and in particular, information sharing and existence of a therapeutic relationship were of importance. Through the completion of a critical discourse analysis, it was evident that the MDT dominated the discourse in all CPM's observed and that an asymmetry in discourse occurred. Interestingly, although patients made up a very small percentage of the total discourse space, all felt that they had been given adequate opportunities to participate, ask questions (even though a large majority refrained from doing this). Findings raise important questions about what participation means for each individual patient and whether they desire it. Cognitively impaired older patients in Phase 2 all demonstrated low participation levels during their CPM's as indicated by verbal utterances and numbers of questions asked however, participation was demonstrated through informal processes. Phase 2 findings have provided an important addition to the findings from Phase I, and will be incorporated into developing the MDT Training manual in Phase 3 of this study.

Given that MDT staff were part of this action research study, and were aware from Phase 1 of some of the poor practices in existence (having received feedback from early findings), it is disappointing to find that poor and exclusionary practices still continued in Phase 2. Examples of these practices include MDT staff dominating discussions, their speaking about the patient in the third person, and in some few cases, their being oblivious to the body language of their patients. These findings might suggest that changes to healthcare practices

and particularly, to the way in which CPMs are delivered in hospitals, take considerable time and effort and require on-going training and perhaps video-taping of behaviour.

As mentioned in the literature review, Charavel and colleagues (2001) have described a continuum for decision-making in healthcare work, from essentially one extreme, paternalistic, to the other, deliberative. One might have assumed given the cognitive status of these patients that a paternalistic model would dominate but this was not always the case. Although some shared decision-making was obvious during the CPM's, for the patients in this study, some of the conditions needed to promote this, as outlined by Frosh and Kaplan (1999), i.e. patients being made to feel their contribution was valued and the atmosphere being conducive to patient participation were absent in part, and different models of decision-making emerged. Chapter 6 will now provide a comprehensive discussion of the findings from Phase 1 and 2.

Chapter 6 Discussion

6.2 Introduction

This study set out to gain insights into current practices within CPM's in a hospital setting and to gain an understanding of the objective and subjective experiences of meeting participants. There are a number of terminologies and purposes for CPM's highlighted in the literature and such diverse terms and differing objectives suggested that there was a need for clarification about the nature and purpose of this small group process and how older people as patients, and their family caregivers, experience this phenomenon.

The results of this study showed that overall, patients and their families viewed CPM's positively and this concurs with previous studies (Bull et al.2000; Griffith et al.2004). The CPM's which formed the basis of this thesis served a wide variety of purposes including information sharing, decision-making and discharge planning. Patients viewed CPM's as an important event, many had looked forward to their CPM and for several, it signified when they would be discharged home. The majority of family members also reported being satisfied with the CPM process although a minority raised concerns about the meeting as a collaborative decision-making forum as they believed decisions had been made by the MDT prior to the meeting taking place.

Interestingly, this viewpoint was also reflected in the MDT member's explanations where a divergence in opinions was evident. Challenges related to CPM's as identified by the MDT correspond to other research and include difficulties co-ordinating a suitable time for all participants to attend, poor pre-meeting preparation (Froenck,2005), defective communication, and the lack of the patients' perspective within the meeting (Efraimsson et al.2006), the

importance of appointing a skilled facilitator and keeping within a time limit(Griffith et al,2004;Hudson et al,2008).

This study is based on a limited number of CPM's and the data relates to one research site, in one country. Nonetheless, there are several valuable clinical and research implications that arise from this research study. It is encouraging that older patients and family members reported being able to express their views, even if they differed from those of the MDT. This study has also shown the clinical feasibility of the care planning meetings process as a tool for decision making as patients and families found the meetings process to be a positive experience even though they were not always satisfied with the outcome.

6.3 Informal Processes

There were several themes that arose from this study about what promoted or impeded participation and patients in this sample were vulnerable not only because of cognitive/ communication difficulties but also because they had experienced an acute medical event. This is likely to have had a psychological and emotional impact on their functioning and the very fact that they were inpatients in hospital may also have been a disempowering experience for individuals.

Punctuality of MDT staff was an issue in three meetings observed in Phase I, and this is consistent with other studies (Froneck,2005).It could be argued that disrespect for the patient was revealed by the medical team not attending the meeting on time, shown by the value that the MDT placed on their own time compared with patients and their family members. MDT members must consider the negative implications that this disregard for punctuality could have for the patient and family for whom the CPM may have significant personal relevance and importance(Froenck,2005).The MDT mini-focus group participants did express their dissatisfaction at the fact that punctuality was a feature of some CPM's and they appeared anxious to address this problem.

Poor eye contact was observed with patients by both the MDT and their family members, particularly the cognitively impaired patients in the sample. On the other hand, higher levels of eye contact were observed to be maintained between the MDT, family members and patients who were cognitively intact (Phase I). Consistently good eye contact was also observed between the MDT and family members during CPM's. This practice undoubtedly inhibits engagement of patients in the meeting process but it also suggests that the MDT were placing higher importance on communicating with family members rather than the patient themselves. In some instances CPM's were also characterised by the use of the 3rd person to address patients by both the MDT and family members and this finding is consistent with other studies which documented this practice in CPM's(Froenck,2005;Hedberg,2007;2008).Again, the MDT demonstrated their insight into this exclusionary practice and related it as contributing to 'lipservice' of patient participation in CPM's.

Seating arrangements for meetings were generally segregated as the patient and family tended to sit on one side of a circular formant and the MDT on the other. There was no consensus reached between MDT mini-focus group participants as to whether integrated seating would promote a more inclusive meetings process. There was little evidence of the use of medical language in the CPM's observed and if jargon was used, generally an explanation was given.

6.4 Pre-Meeting Preparation

Findings identify that pre-meeting preparation of older patients and family members whilst emphasized in the literature as an essential stage in CPM's (Griffith et al,2004;Efraimsson et al.2006)) is in practice rarely addressed or implemented. This study's findings point to the importance of patients being adequately prepared for their CPM in order to ensure that they get the most out of this event and lend weight to the argument that lack of preparation may result

in the older patient being unable to fully take part in their discharge planning conference (Efraimsson et al.2006). It has been postulated therefore that if patients' participation in decision-making is to be optimised, the benefits of participating must be fully explained to them so they can make an informed decision (Robinson and Thomson,2001) about the nature of their participation in their care planning.

The results of this study found that some patients reported being unclear about the purpose of their CPM (Phase I), whilst others conveyed that they had not received any pre-meeting preparation (Phase I and 2).The MDT CRG in Phase I of this study, identified that there was a need to pay greater attention to pre-meeting preparation. A patient information booklet for CPM's was developed in response to this and it was hoped that this initiative would improve patient participation levels, particularly those of cognitively impaired patients.

It was difficult however to conclude from the results of Phase 2 what impact the patient information booklet had made, as half of the sample did not remember receiving it, whilst one person reported that she received it too late for it to be of any real value, and another said he forgot to write down questions after reading it. These findings suggest therefore that greater emphasis must be put on the utilisation of the patient information booklet by the MDT in order to adequately prepare patients for their CPM and that the usage of the booklet at present may be more salient for the MDT than for patients and families. MDT members need to ensure that patients are given the booklet sufficiently in advance of their CPM and should read through the booklet with patients to ensure they have understood its contents. MDT members should encourage patients to think about issues they would like to discuss and any questions they might wish to ask during their CPM. Patients should also be encouraged to write any questions down in the *'Questions I might like to ask'* section of the booklet.

6.5 Knowing the Patient and the Quality of the Therapeutic Relationship

Findings concur with other studies which found that the quality of the relationship was of central importance to patient participation (Sahlsten et al.,2005;Ekdahl et al.,2010).In Phase 2, the importance of the therapeutic relationship was very much evidenced and supported by the rapport and language observed between the MDT and many of the patients. Knowing the patient and the importance of the therapeutic relationship were a key theme within this study and this is in accordance with the literature which suggests that conditions such as respect for each individual and the unique knowledge they possess, are contributory to participation taking place(Eldh,2006).The analysis of this condition focused on reflecting on how the approach and behaviour of the MDT within the therapeutic relationship may have influenced patient participation levels and how MDT expressions of praise, reassurance and empathy encouraged and elicited responses from patients.

O'Brien (2010) found that in an age-related setting, staff had time to form a therapeutic relationship with patients and as a result of this, older people trusted that the healthcare professionals would follow through on their wish to return home. It is important thus to consider that the ethos of geriatric settings does differ from that in more acute settings, and it is likely this may have contributed to the strength of the therapeutic relationship between the MDT and patients within this study. Of interest in the literature is the fact that one dimension highlighted by patients as improving participation, related to feeling understood and reassured, being treated respectfully and rapport, empathy and openness (Perakyla et al.2007). Likewise, it would seem reasonable to deduce that if members of the MDT have become acquainted with a patient through the course of their inpatient stay and a relationship has formed, then it would seem natural

that patients are going to feel more relaxed within their CPM and will be comfortable expressing themselves during their meeting.

6.6 Participants Understandings of the purpose of their CPM

Participating older patients, family members and the MDT indicated that the aims and outcomes of CPM's are not always apparent, clear nor consistent. This raises questions as to procedural effectiveness of CPM's as they may not always achieve clear outcomes or decisions and this was indicated in Phase I, as final decisions were reached in only half of the meetings observed. An analysis of the interview data from Phase I revealed that two patients were unclear about the purpose of their CPM and why they had been asked to attend. Hayden (2001) postulates that interview data that is meager is sometimes a consequence of the lack of self-confidence and insecurity amongst respondents. It can also occur when respondents are asked to talk about unreflected experiences. In such situations, individuals can have difficulty creating personal and detailed narratives.

When interpreting the patient interview data for Phase I, it appears that several patients had difficulty formulating their experiences of taking part in the CPM. This perhaps further strengthens the assumption that they did not understand the meaning of the event and this may have impacted on their participation levels. This argument is supported by Efraimsson et al.(2006) in their study of older patient's participation in discharge planning conferences who found that patients were unprepared and that they lacked essential knowledge about this event and future care options. This acted as a barrier which was a hindrance to dealing with the situation. They concluded that the patient's pre-understandings were insufficient to make sense of the discharge planning conference and this impeded participation. The findings from this thesis thus concur with previous research which suggests that if greater attention was given to pre-meeting

preparation, then patient's understanding of the CPM process and participation within it may be improved(Griffith et. al.,2004;Froenck,2005).

It is also noteworthy that many of the older patients in this study communicated that they had looked forward to their CPM and wanted to be present and involved, and this does not suggest that they were frightened or intimidated by the prospect of the meeting taking place. It is also of interest though, that many patients in the study were able to clearly verbalise areas of dissatisfaction related to their CPM during interviews. For example, their expectation that their Consultant, or specific therapists would be present at their CPM, and their disappointment when this did not occur. This would indicate that if they had been dissatisfied with other aspects of their CPM, they would have communicated this during their interview.

6.7 Opportunities to Participate

The findings revealed that all patients and their family members reported that they were able to express their views, ask questions and that they had been given adequate opportunity to do so, even if at times those viewpoints differed from those of the MDT. Reports of the patient having lower levels of influence over decisions in comparison with family members and healthcare professionals in other studies, raises the possibility that patients may be left out of the decision-making process (Abramson,1990).All patients who attended their CPM and the majority of family member respondents reported that they had been involved in the decision-making process. It is curious therefore that many patients, particularly those with a cognitive impairment, were observed to play little or no part in the decision-making process during their CPM. Perhaps the patients in question had low expectations about their involvement in the decision-making and this influenced their locus of control relating to the CPM? (Coulton et.al. 1989).The findings suggest that patients were undoubtedly involved in their CPM

although, it seems unlikely that active participation was occurring according to existing definitions in the literature.

6.8 Communication Practices and Information Provision

Findings indicate that patients received high levels of information during CPM's and that they were satisfied with the amount and type of information they received and that it was understandable (Phase 2). Whilst the majority of information communicated by the MDT during the CPM's was explained in clear language, free of medical jargon, which was deemed to be understandable, other information was clearly difficult to understand and often de-personalising to the older person.

Low levels of verbal interaction by patients, combined with their passive role in decision-making, raises questions however about how much of the information communicated to them was truly understandable? Some of the observed methods of information delivery by the MDT are a concern, particularly the prevalence of one-way dialogues and usage of the third person to address the patients, and it must be questioned whether this is conducive to patients understanding and retention of information and their participation in the CPM.

Healthcare professionals must communicate in the language of their patients in order for them to be provided with the information that they desire (Ekdahl et al.2010). Communication is not merely a question of sharing understandable information but also entails developing a process for involving patients from their own unique standpoint (Goodwin,1995).It would appear that despite calls for the promotion of patient autonomy, patients' voices are still lacking in conversations between healthcare professionals, patients and their families (Eldh,2008). This study indicates that there is a need to educate healthcare professionals on how best to invite patient's to be conversational partners in CPM's so that their ability to participate is maximised.

This study suggests that the physical involvement of older patients in CPM's does not necessarily guarantee genuine patient involvement. Similar to Hedberg et al.'s (2007,2008) studies, it was not uncommon for older patients to be talked *about*, in the third person, rather than talked *to* during the CPM. When patient's cognitive ability becomes impaired, power relations may change and the social status of older people reduced when they are 'ghosted' in language situations such as CPM's(Davis and Pope,2010,p10). This practice could be regarded as patients 'being deprived of participation' which was characterized as patients being treated 'as a thing' or an object (Bramberg et al.,2010). Family members meanwhile were frequently attributed higher status by the MDT and exhibited higher levels of participation than the older patient during meetings. This raises ethical and moral questions as to the use, if not misuse, of CPM's to promote more influential or powerful agendas set by family members or healthcare professionals above those of the older patient.

CPM's are institutional conversations that differ from everyday talk (Efraimsson et al.2006) as evidenced in this study by the near complete absence of two-way conversations and the underlying thread of the MDT institutional agenda. The findings from this study are in line with other research relating to institutional conversations where the interaction is asymmetrical and the structure of the conversation tends to be formal and inaccessible(Efraimsson et al.2006;Drew and Heritage,1992;Sarangai and Roberts,1999) instead of being in a conversational style which is more user-friendly. This method of communication did appear to help elicit more responses from patients, however there were few examples of conversational style dialogue within the study.

The findings of this study have demonstrated the importance of MDT communication and active listening and the need for their awareness of both expressed communication (verbal) and tacid (body language and eye contact) in the patients they are communicating with. CPM's involve inbuilt symmetries

between patients and the other participants within CPM's and MDT members must support patients in their communication and be aware of their need for communicative alliances (Hedberg et al.2007).Previous research has suggested that by directly requesting patients to talk about themselves, they are afforded the opportunity to directly participate (Linnell,1998). Within this study, the fact that patients participated verbally at a much higher level during patient interviews (Phase 2), than during CPM's, would indicate that the posing of direct questions encourages verbal participation and engagement.

6.9 Barriers to Communication

Lower levels of participation from older patients with higher levels of cognitive impairment during their CPM were also a key finding. Low levels of verbal utterances from patients in comparison with their family members and the MDT is a concern. This combined with the fact that in some CPM's, little or no efforts were made by either the MDT or their family members to speak to patients directly or involve them is surprising. It is paradoxical that within Phase I, the main purpose of two CPM's was to enable the cognitively impaired older patient's right to self- determination in relation to their discharge arrangements. Yet, neither of the patients were actively encouraged to participate and make their wishes heard within the meeting forum and in one case the patient was for the most part completely ignored.

Evidence from the findings of this sample show that overall all patients exhibited low participation levels during their CPM in relation to their number of verbal utterances, regardless of whether they had mild or moderate cognitive impairment. Cahill (1998) however exercises a note of caution and reminds us that the number of utterances gives little indication of quality of utterances and in the case of this study, it cannot be concluded that a low number of utterances

indicates that participation did not occur. In spite of this, a consideration of the low numbers of questions asked by patients along with the high prevalence of one word answers given by patients during CPM's add weight to the argument that 'active' participation in the conventional sense of the term was not occurring.

When the findings are combined with the participant observations which found poor eye contact with patients, questions must be raised about whether cognitively impaired patients are participating in a meaningful way and being included. How the patients participate in the meetings process is therefore not only dependent on how they are able to contribute but also how they are involved by the other participants (Hedberg et al.2007,2008) and this would appear to be an issue that requires further exploration.

6.10 Patient Attributes as an influencing factor

There are many socio-demographic and personal characteristics such as age, gender and social class, that can have an impact on patient's communication and participation during encounters (Street,2002). With caution we can speculate on how some of these factors[27] may underlie the results of this study as this issue was explored within Phase 2 of the action research cycle.

In reflecting on these findings, consideration must be given to each individual patient's attributes. It is clear that cognitive and communication difficulties alone cannot explain the disparity in participation level within Phase 2. In Phase 2, two patients were assessed as having similar MMSE scores of 16/30 and 15/30 which indicated moderate cognitive impairment. When patient use of discourse space

[27]See Appendix L for Patient Attributes Table

was examined however, these cases are at opposite ends of the spectrum as one patient exhibited the highest number of utterances and the other, the lowest.

The findings would also suggest that gender does not feature as an attribute that greatly influences participation levels, as both females and males within the study exhibited low levels of participation within the sample. It would seem that other patient attributes may have a more influential role such as educational level, previous occupation and socio-economic group (as suggested by housing status and means test related to medical card).

Previous qualitative studies have shown that variability in participation levels could be related to demographic factors such as age and educational level however these findings are not consistent (Ekdahl et al. 2010). Roberts and Chapman (2001) come to a different conclusion and linked the older person's life course to their level of participation in discharge decision-making. Meanwhile, O'Brien (2010) when examining the participation of older patients in the discharge process also found that their previous roles played a part in older patient's attitudes and their interaction with hospital professionals.

Within this study, it is remarkable that within Phase 2, the patient who had the highest number of verbal utterances, had been very high functioning and independent prior to his stroke and had written a book during his retirement. Meanwhile, two patients who had asked the highest number of questions during their CPM, and who exhibited a higher number of verbal utterances, had also had successful occupational careers; one had been employed as a nurse manager prior to her stroke and the other had been a civil servant before retiring.Another patient who exhibited the fourth highest number of utterances, made reference in his interview, to his trade union experience during his working years. These facts lend weight to the argument that life course may have played an important influencing factor on participation levels within this study.

The findings from this study would certainly appear to confirm that those who were most frail and physically dependent exhibited some of the lowest levels of participation. This finding is consistent with other studies which concluded that participation is an issue of concern for the frail elderly (Tutton,2003). Numerous studies have reported that those in the worst physical and mental condition were the least likely to participate(Abramson,1988; Jewell,1996a; Efraimsson et al.,2003; Huby et al.,2004). Ekdahl et al's(2010) study, found that patient's reported that they would have participated more in decisions when they were younger, so age and frailty must be considered as contributory factors in influencing patient's to desire to participate.

This thesis does however contradict previous findings that concluded that individuals with cognitive impairment were unlikely to participate and one of the most important findings of this study related to the fact that although many of the sample exhibited low levels of verbal utterances, participation was indicated by informal processes such as eye contact and body language.

6.11 Patient Participation

All patients were vulnerable within their CPM as low participation levels were observed which suggests that patients with cognitive and/or communication difficulties experienced challenges associated with participation during CPM's. The findings also concur with those of Kadushin and Kulys (1994) who found that cognitively impaired patients had less influence than others in the discharge planning process and that they lack power in comparison to other participants in the process; Phase I and Phase 2 findings indicate this was also the case within the CPM's observed in this study.

The majority of the patients in this study preferred an overtly non-participative role in decision-making as evidenced by the findings but did desire involvement and information. There appears to be a contradiction with patients reporting in interviews that they had adequate opportunities to express their opinions and ask questions whilst at the same time stating that they had 'no control' during their meeting and this raises the question what are they associating control with? Are they referring to medical decisions rather than care decisions which are very different areas of decision-making? Many of the aspects where they believed they had little or no control related to organisational issues such as the Consultant or specific therapists being present at CPM's(Phase 2). Patient's powerlessness within the institutional setting was reinforced by this situation as they had no ability to control or influence whether specific members of the MDT attended CPM's. Several other patients within the study also expressed frustration at their lack of control and choice over home supports and follow-up arrangements indicating that there are aspects of patients' hospital experience that they clearly feel strongly about and did choose to make their opinions heard during the patient interviews.

Some of the patients within Phase 2, appeared to be aware that their family members were advocating on their behalf during the CPM and were happy for their family to assume this role and for a co-decision making approach to be adopted. In another way, it is puzzling that many of the patients were able to communicate verbally at a higher level during the semi-structured interviews than during their CPM. This may imply that the nature of CPM's and the communication interplay and group processes within that, may have negatively impacted on patient participation levels.

6.12 Preferences for degree of participation.

The majority of the patients in this study preferred an overtly non-participative role in decision-making as evidenced by the findings but did desire involvement and information. As individual care is essential, some patients do prefer to assume a passive role and it would appear that the MDT need to ascertain how much patients want to participate in their CPM and any decision-making within that. The patient does not always have to be the decision-maker, but must be given the power to decide or give consent for others to take responsibility for decision-making (Waterworth and Luker,1990).

In addition, did patients report that they found information understandable because they weren't always engaged or listening during their CPM or had they already been given much of the information conveyed during the meeting which assisted their ability to comprehend and understand it? I believe that the main paradox and one of the most interesting findings from this study is that patients with a cognitive impairment were observed and deemed to have low participation levels while, patients themselves and their family members felt that they had been given adequate opportunity to participate and ask questions.

This study highlights that participation is an individually constructed phenomenon which means different things to different people. All patients reported that they wanted to attend their CPM, even those with more advanced levels of cognitive impairment who were observed to have little or no verbal utterances during their CPM. Cegala et al.(2009) define active participation as that where patients ask questions, provide information, show evidence of assertive utterances and expressing their concerns. The majority of patients in this study asked few, if any questions, and there were few instances of patients spontaneously expressing their concerns or indeed, the MDT or their family members seeking out their opinions during the CPM's.

The findings of the present study would suggest that patients were not 'actively participating' according to existing definitions of this term in the existing literature. The question must be posed however that within the sample observed, why are patients not appearing to desire more active participation? Perhaps it is because they are frail elderly patients who no longer want to actively participate and are happy to defer decision-making to their family members? This would be consistent with Ekdahl et al's (2010) study, who found that for the frail elderly, participation means *information* and *good communication* and that they do not want to participate in decisions relating to their care.

6.13 Explaining Older Patient's Low Expectations of Participation

Critical Gerontology, offers a mechanism to help explain why the practices within CPM's may be occurring and the underlying factors which contribute to the practices observed. Older people's experiences are largely shaped by how others react to them in a social context and the importance of cultural meanings has been highlighted (Estes,1981).In this way, how the MDT interact with older people within the hospital is also going to influence their social construction of reality in this context and ultimately their experience within CPM's.

Poor overt participation of older patients within their CPM and lack of involvement in decision-making may be attributed to low expectations of the nature of their role and involvement. It is possible that older patients did not expect to be afforded meaningful opportunities to participate reflecting and mirroring wider ageism in our society. Their experience of being ignored, talked over and having questions and conversations directed to their family members, may have mirrored their experiences of social interactions in other spheres of their life (NCAOP,2005).The patients therefore would have viewed these interactions as 'normal' and satisfactory. Minchelleo et al.(2002) also found that older people had experienced a number of negative experiences in their

interactions with healthcare professionals which resulted in the removal of their personal autonomy. They concluded that for some older people they did not feel they had the social power to change this situation so they accepted the way they were treated and did not challenge the discriminatory behaviour they had experienced.

The participation of family members within CPM's will now be discussed and an exploration of how this may have affected patient participation levels will be provided.

6.14 Family Member Participation in CPM's

Despite some criticisms voiced, overall results show that families considered these meetings to be a positive experience, despite the fact that final decisions were not always reached and that some family members were not always satisfied with the outcomes. Of particular significance is the fact that although two families believed that decisions had been made by the MDT prior to the meeting, they believed that the meeting process itself had been useful. These family members expressed appreciation for the time that the MDT committed to the CPM (for one family, the family meeting lasted two hours) and they were also grateful for the opportunity to get all of their questions answered.

One possible interpretation of this finding is that the family members were so grateful for the opportunity to meet with all members of the MDT together and to have the opportunity to clarify information, ask questions and have their voice heard, that this superseded their feelings of dissatisfaction with the decision-making process. It is likely that by virtue of being afforded the opportunity of being listened to, family member's dissatisfaction with the outcomes and decisions reached within the meetings, may have been diffused.

Findings contradict previous research (Froenck,2005) where it was concluded that patients were viewed as 'participatory team members' and active participants while their family members were not. Patient's age must therefore be considered relevant as Froenck's study related to a younger sample of disabled patients and it appears that the MDT methods and types of communication differed significantly to the older group of patients in this study.

In spite of this, the clinical feasibility of the CPM process as a tool for decision making in relation to care planning has been demonstrated by this thesis. For older adults in hospitals to benefit positively from the involvement of their family members, healthcare professionals need a fuller understanding of the nature and impact of family involvement (Haesler et al.,2006) and patient participation. Decision-making processes are very complex and are prone to failure if the goal is to reach decisions to suit all participants. It would appear therefore that in particular, there is a need to learn how MDT members can best balance family member involvement whilst still ensuring that the wishes of the older patient are promoted (Abramson,1988).

The findings of this study supports other research relating to discharge planning as for many of the patients there was an inverse relationship between patient and family member participation, so where family participation was high, patient participation was low(Abramson,1988). Findings showed how family members assumed a more active role in discussions and decision-making, compared with their relatives, the patients, who played little or no part in conversations during their CPM's. In some instances the family members even sought out the 'expert opinion' of the MDT in order to try and exert control over the patient. The findings from this study differ from other studies which found that family members did not feel that they had participated in the discharge planning process, particularly in identifying patients' needs (Almborg et al.2009), and that they had played a passive role(Froenck,2005).

Griffith et al.(2004) meanwhile reached a different conclusion and found that CPM's were more often set up to provide family members with information in order to make decisions rather than being focused on the patients need for information. The results of this study concur with this finding as many of the meetings were requested by family members. The majority of the conversation within the CPM's was directed to family members rather than the patients themselves which was also shown in Hedberg et al's studies(2007;2008) and in the majority of CPM's observed, family members and/or MDT members were the dominant decision-makers. Other research has suggested that family involvement is higher when patients are functionally or cognitively impaired (Kadushin and Kulys,1994); the results of this study support this finding. They also show that family member involvement was high for the majority of patients within this study, even those who were cognitively intact (Phase I) or who had a mild cognitive impairment(Phase 2).

In four cases, family members questioned the usefulness, and the older person's right to attend their CPM. Within the Irish context, it is clear that a systems perspective to practice is adapted and older patients are treated as part of a wider family system. O'Brien (2010) concluded from her study which examined older people and their participation in the discharge planning process, that the wishes of an older person with a functional impairment were considered secondary to their family members. The findings of the present study diverges from this conclusion as there were several examples where the MDT advocated on behalf of cognitively impaired patients where their wishes directly conflicted with their familys'. This was particularly evidenced in the case of Johnny and Frank (Phase I) where their family members were requesting that their relative should not attend their CPM, and should be discharged to nursing home care. In both instances however, the MDT ensured that each patient attended their CPM, and they strongly advocated for the patient's expressed wishes which were to be discharged to home.

On the other hand, most of CPM's within this study were characterised by the fact that the majority of the conversation within CPM's was directed to family members and that they had much higher levels of verbal utterances and question posing than patients. A challenge related to the participation of family members during CPM's is that often the MDT assume that family members are supportive of patients, and that they have an agreed agenda(unless information indicating otherwise has been brought to their attention); however, if this is not the case, it ultimately increases the vulnerability of the patient within their CPM. Although research has shown that successful ageing is linked to interaction with family members or support persons, these relationships can also serve to disempower older adults through families being overly concerned and protective and thus promoting dependence(Nussbaum,1985).Thus, although older adults can identify patronising behaviours as inappropriate, this behaviour is often excused when attributed to good intentions (Hummert and Mazloff,2001).The assumption that family members will automatically advocate for the needs of older patients is questionable given that relatives have their own agenda, needs and priorities.

Within the Irish context, the state undoubtedly relies on family members to provide care to their relatives and current social policy is very much underpinned by this factor (Pierce and Timonen,2010). Family members often have to assume a dominant role as it will be necessary for them to assume the role of carer when the older person returns home. Likewise, it is possible that the MDT direct the majority of the discussion towards family members rather than the older person themselves as they are also reliant on the family members to facilitate discharge arrangements by providing care and support.

6.15 Do Patients Purposefully Allow Family Members to take the lead in CPM's?

Moreover, it must be considered that perhaps it was a strategic choice by patients to allow their family members to assume the dominant role in advocating and making decisions for them as ultimately, they are also dependent on them to help them get home and to support them when they are there. Whilst undoubtedly home care may place strain on family members, Irish research has shown that overwhelmingly this is the type of care older people themselves prefer(Garavan et al.,2001). It could be interpreted as patients empowering themselves by allowing their family members to assume control on their behalf. Evidence for this exists in the findings by the fact that some of the patients recognised, and acknowledged that their family members were speaking on their behalf.

The existing literature also suggests that there is some evidence that lack of engagement by patients is a purposive strategy. Huby et al.(2004) found that patients lack of engagement in decision-making was part of active management to get family members to look after them when they returned home. Their study found that patients had no wish or motivation to engage in decision-making and the findings of this thesis appear to lend some weight to this argument. Furthermore, it has been asserted that for older adults with a low locus of control, choosing to rely on others is in effect an adaptive coping mechanism (Reich and Zautra,1991), so again it may be a strategic choice by some older patients to assume a more passive role and delegate decision-making responsibility.

It must also be considered that patient responses in relation to participation and decision-making may have been very different if the 'expert' MDT decision-makers or family members were advising nursing home placement. In this

sample, each patient's right to self-determination (with the exception of Tommy), was not directly challenged and it is probable that they may have assumed a very different role and participated in a different way if this had been the case.

6.16 Styles of decision-making and participation

Some older people in the study clearly desired and assumed a more active role during their CPM's, others preferred to confer decision-making responsibility to their family members whereas others preferred to defer to the doctor or MDT members 'expert' opinion. In Phase I, half of the CPM's observed involved proxy decision-making; some patients had advanced cognitive impairment and they were unable to attend their CPM and so their family members and/or MDT acted as proxy decision-makers on their behalf. Proxy-decision-making was also a feature of two the CPM's observed in Phase 2.

It has been postulated that the patient's choice of a passive role in decision-making can be a deliberate action, which indicates not a totally passive role, but more of a definitive decision to adopt a passive role. Different types of patient preferences cannot act however as a justification of a paternalistic decision-making approach for patients preferring a passive role (Florin,2007). There was evidence in this study that the older people weren't always recognised as rational decision-makers, yet it has been argued that this is necessary in order to allow and empower older people to exercise their agency and participate in the discharge process (O'Brien,2010). Autonomy is an underlying principle which encourages self-determination and patients ought to be afforded the opportunity to decide how they want to exercise their autonomy, even if that is by intentionally adopting a passive role (Florin,2007). Patients therefore should be supported to make decisions based on their own preferences for participation.

6.17 Delegated and Deferred Decision-making

One of the contributory factors for the low rate of patient participation within CPM's in this study may be the issue of 'delegated and deferred decision-making' and for some patients, they preferred either their family or the MDT to make decisions on their behalf. The findings from this study suggest that some older people believed that healthcare professionals alone have the expertise to know when they are well enough to manage outside the hospital and therefore, they deferred to their judgement and didn't expect to participate in decision-making relating to this issue (Huby et.al 2004).

Previous studies have also found that many older people expected healthcare professionals to make final decisions relating to healthcare issues (Roberts and Chapman,2001; O'Brien,2010). What is unclear on the other hand, is whether these roles were adopted by the patients themselves or conferred on them by their family members and the MDT? Some of the patients in this study clearly verbalised that they had delegated their family members or the MDT to make decisions on their behalf however, for other patients in the study, it is unclear whether explicit consent was given. Related to this, is the issue that older people delegating the MDT or family members to make, and execute decisions, may result in decisional control being exercised beyond that which was explicitly authorised(Collopy,1998) which increases their vulnerability within the care planning process.

When reflecting on the subject of deferred/delegated decision-making, the issue of 'role theory' (Beisecker,1988) is of relevance.It refers to the fact that most older people grew up in an era where doctors and healthcare professionals were viewed as very powerful people and must be deemed important in terms of an age cohort effect. It also highlights the importance of developmental considerations that is, as people age, they want to rely more on others, such as

family members, and assume less responsibility in relation to decision-making. All these issues are possible contributory factors in this study and add further weight to the argument for clarification of patient preferences relating to participation and decision-making. It is reasonable to assert that each individual's desire for participation and interpretation of what this is will change depending on the situation and the decision-making within that. Although some patients reverted to 'Doctor knows best' it is perhaps unlikely that they would assume this position if the decision was in relation to nursing home placement.

6.18 MDT Understandings of the Purpose of CPM's

Results showed that there were fundamental differences in the MDT members' understandings of the purpose and function of CPM's. Some believed that they should purely be an information sharing forum where patients and families were then given time to make an informed decision. Others reported that CPM's should be a forum where collaboration and shared decision-making occurs. Finally, some of the MDT considered the meetings as a time to consult with patients and families on important decisions that had been largely achieved / decided. This divergence in viewpoints is consistent with patient and family members' experiences from questionnaire data and it would appear that there is a need for further exploration and consensus on this issue. These findings raise questions about why CPM's are held, what is their real purpose and whose agenda do they serve?

The mini-focus group findings suggested therefore that the purpose and aim of the CPM's studied were unclear for participating healthcare professionals, reflecting general confusion amongst the MDT over the use and potential abuse of CPM's. The MDT members admitted that the aims and outcomes of CPM's were not always apparent nor were they consistent. They were divided as to whether CPM's were solely about information sharing, support or joint decision

making, or all three. On the other hand, findings suggested that the MDT were experiencing two competing agendas. MDT members recognised and were able to articulate exclusionary practices e.g. directing most of dialogue and questions to family members, use of 3rd person grammatical, poor eye contact, recognising that attendance of patients at CPM was often 'tokenistic' however this is contradicted by some of their understandings of what the purpose of the meeting forum is.

There was a strong consensus amongst MDT members however that a consistent approach was required in relation to the attendance and participation of cognitively impaired older patients at CPM's. It was also recognised that changes to current practice could increase their sense of participation. The lack of formal practices and protocols to guide and regulate the facilitation and quality of CPM's e.g. minute taking, meeting times, designating a meeting facilitator, further served to promote this confusion and undermine the MDT's commitment to patient and family participation. Results about the importance of pre-meeting preparation and facilitation skills are in accordance with the literature showing that paying attention to pre-meeting preparation, routinely clarifying expectations of patients and their family members, setting an agenda for the meeting and having a consistent approach to the involvement of cognitively impaired older patients during the meeting could result in more satisfying outcomes for all (Griffith et al.2004). These were some of the most compelling themes in the MDT mini-focus groups as they were repeatedly identified as areas of practice that could not only improve patient participation levels but also the overall meetings experience for all participants involved.

This research study showed that MDT members were cognisant that CPM's may not reflect participatory expectations given the lack of attention to basic group work processes. Mutuality between professional, patient and family participants, person centred and inclusive practices, and clear outcomes empower older

people in the discharge process and prevent CPM's from becoming tokenistic service user involvement (Arnstein,1969). One of the major barriers to older people's participation in CPM's appeared to be the lack of clarity as to the purpose of patient and family involvement in decision making and planning. The dual themes of ambiguity of purpose and the discretionary nature of meeting practices were highlighted from the mini-focus group findings. Healthcare professionals were mindful that this level of discretion and ambiguity allowed for the manipulation of the participatory agenda and the continued domination of the clinical perspective to the exclusion of the needs of the older person.

Concerns were raised in relation to the use of manifestly exclusionary practices. For example, advanced cognitively impaired older patients were actively excluded from participating in CPM's (Phase 1) and effectively had no voice in identifying either their needs or direct influence in deciding their care plan. The notion of participation and choice needs to be redefined for older people with more advanced cognitive impairment and or 'borderline' capacity issues. Again this raises issues as to the rights and treatment of older people with conditions, such as the diagnosis of Alzheimers Disease and Stroke, within the hospital context.

The CPM process itself affects the ultimate satisfaction with the outcome (Abramson,1990) and thus there are many opportunities for advancing patient control within CPM's. In many ways, the meeting process appears to be a contradictory one. Examples of good practices by the MDT were observed however there were also many sub-optimal practices observed that need to be addressed. The MDT were able to identify areas of 'good' and bad 'practice' during the mini- focus groups but these insights weren't always applied to the practice environment and the ideal didn't always match the reality of what was observed.

6.19 'Tokenism' of Patient Participation

The MDT identified a paradox/contradiction within their work of differing purposes and there is undoubtedly an inherent tension and conflict of interest. This may reflect confusion over the original purpose and aims of the meeting but it also raises important questions as to the potential tokenistic use of CPM's and potential for such group processes to reinforce ageist attitudes towards older patients in health care settings The literature notes that there is a discrepancy between the ideological intention and the actual realisation of discharge planning conferences (Efraimsson et al.2006) and there is reference to the possible 'tokenism' of patient participation within the care planning meetings process (Brownlea,1997). If patients are not addressed directly or asked to confirm, negate or select different options, it can be argued that they are awarded 'passive participant status' (Efraimsson,2004). This appears to have been the situation in many of the CPM's observed within this study and instances of the MDT directing conversation and questions to patients was the exception rather than the rule. It is surprising therefore, that patients voiced so few complaints themselves about their experiences during CPM's and indeed did not appear to believe they had been excluded or ignored within their CPM.

Bartlett and O'Connor (2010) raise the interesting point that people with dementia are discriminated against every time that someone assumes that because they have a diagnosis of dementia, they cannot speak on their own behalf. This behaviour reinforces the neurological-related problems a person already has and reduces their opportunities for self-expression. In the same vein, in the present study the MDT must strive for anti-discriminatory practice by encouraging cognitively impaired older people to speak and express themselves even if the older patient ultimately chooses not to do so, the necessary conditions for this to occur should be in place.

CPM's where the object is tokenistic or rubber stamping are not a collaborative, transparent participatory decision making activity. This raises ethical and moral questions as to the use, if not misuse, of care planning meetings to promote more influential or powerful agendas set by family members or health professionals above those of the older patient. This lack of emphasis as to transparency may be seen to reflect ageist attitudes toward the rights of older patients to fully participate in decisions relating to their own personal care.

6.20 Understanding MDT Communication Practices in CPM's

It is peculiar that although the MDT members were aware that practices of concern had been observed during Phase I, particularly in relation to the cognitively impaired older patients, that they did not seem to have modified their communication or behaviours within CPM's during Phase 2. It is important to raise the question of why this was the case? Had the MDT distanced themselves from the communication and behaviours exhibited in Phase I or did they lack the insight to realise how their exclusionary communication practices could be affecting patient participation within CPM's?

There is a definite incongruence between the MDT insisting on the older cognitively impaired patients being present at the CPM, sometimes against the wishes of their family members, whilst at the same time MDT members often ignoring the older person during the CPM and demonstrating other exclusionary practices. It would appear that MDT members may be uncomfortable in sharing power and knowledge with patients in practice, even though they acknowledge this idea in theory(Henderson,2003;Florin,2007). On the other hand, it is the researcher's assertion that MDT members did not fully comprehend or accept the nature and extent of their exclusionary practices until they reviewed transcripts of CPM's during the data analysis stage of Phase 2 and thus had not consciously been trying to change their practices at this stage.

On the other hand, it could be asserted that MDT members chose to direct conversation within CPM's to family members as they were operating within the organizational frame and were under huge time pressures. It is reasonable to deduce that as the majority of patients in the sample had cognitive and/or communication difficulties, it may have taken much more time for the MDT to communicate with patients directly and to ensure that they understood what was being discussed, and thus part of their behaviour may be attributed to time pressure and the need to be efficient. Previous research has alluded to this as a factor and proposed that when older people's cognition was an issue, even intermittently, supporting the older person to participate in decision-making required extra time and resources (Proctor, Marrow-Howell and Lott,1993).

CPM's are essentially a forum where social interactions and social relations take place between older patients, family members and the MDT. In any social interaction there are a number of assumed preconceptions about the nature of social relations such as the shaking of hands being understood as a greeting sign. Both Schutz (1967) and Berger and Luckman (1971) have argued that behaviour exists in a 'commonsense awareness' whereby behaviour is accepted in an unquestioning way and, if taken for granted, as normal and acceptable. Unfortunately without critically examining 'common-sense' behaviours, it is accepted as 'the reality' and social interactions can be viewed as habitual and normal when they should not be (Biggs, 1996).

Using this frame of reference, it must be questioned why participants within CPM's have not questioned many of the exclusionary practices which were observed during this study such as failing to address cognitively impaired patients by their name and directing conversation to their family members rather than the patient themselves? Is it possible that observed behaviours have been accepted as 'normal' and thus have remained unchallenged? Biggs (1996) provides a cautionary note that solutions to addressing the problem of common-sense

behaviours lies 'in the degree to which the dominant assumptive reality allows the tolerance of ambiguity' (Biggs,1996,P.74). This study has attempted to consider solutions through a critical examination of social interactions within CPM's and consciously trying to change 'the reality' as is, through creating a heightened awareness in the MDT members and the introduction of a Training manual which recommends better ways of communicating.

6.21 Conceptualising Patient Participation

There are longstanding difficulties surrounding how to define patient participation and there is a lack of consensus about how this term is defined and conceptualised; this has been discussed in detail In Chapter 2. It could be argued that whether patient participation can be deemed as having occurred within CPM's, very much depends on how the concept is defined and measured. The findings from this study show that older patients, particularly those with a cognitive impairment, exhibited low levels of participation during their CPM's. The majority of patients asked few questions and did not embrace self-determination in relation to any decision-making processes within the meeting. Interestingly, all patients reported that they believed they had been listened to, were given adequate opportunities to ask questions, express their opinions and to participate. It has been argued that it is not possible to avoid participating in a healthcare consultation and that by being bodily present, making eye contact, and even the act of silence and refraining from talking, it could be contended have their influence on the CPM process (Thompson et al.2007). In Phase 2, there appeared to be a contradiction in the findings in that although patients exhibited low levels of verbal utterances, it could be argued that two way participation was indicated by many of the patients who maintained eye contact with each speaker and nodded their head, which suggested they were engaged in, and following the discussion.

Previous research has asserted that patients' definitions of participation lay closer to the dictionary definition of sharing and thus opportunities should be provided for sharing of information and promotion of two-way communication should occur (Florin,2006). O'Brien (2010) concluded that older people with a cognitive impairment were less likely to be granted agency to make decisions affecting their lives. Guadagnoli and Ward (1998) however make the important point that 'participation should be defined by whatever level the patient is most comfortable with'. It is important therefore to avoid imposing participation on people if they do not want it and to accept that some older patients may prefer healthcare professionals to assume the role of expert.

When considering the combination of factors such as participation indicated through observations of non-verbal signals (Phase 2), patients reported satisfaction with their CPM and patient perceptions of their opportunity to participate(Phase I and II), the results suggest that patients were participating but at a level that they may have felt comfortable with and not in the traditional sense of 'active' participation. It is important to bear in mind though that patients may have also naturally reduced and adjusted their type of participation to compensate for new cognitive and communication difficulties.

It should also be considered that older patients may feel so disempowered by the whole hospital experience that they no longer view participation as a real possibility? It is of note that in Phase 2, three of the CPM's took place on the day of discharge so these patients may have been afraid to verbalise their true feelings least it might compromise their discharge to home. Patients may be fearful and are therefore vulnerable as they want to return home however are restricted by the power imbalances which means they are dependent on family members and healthcare professionals to support their discharge to home. Furthermore, the patients' usual resources may be greatly diminished and their

vulnerability increased due to the fact that they suffered a stroke or another acute medical event.

It has been claimed that the main difference between patient involvement and patient participation is the degree to which patients are involved in decision-making (Thompson,2007). On the other hand, it has been asserted that patients who chose to leave healthcare professionals to make decisions on their behalf should be considered as 'active participants' (Collopy,1988) and that this should be viewed as 'paternalism with permission'(Peters,1994); the present study's findings support this position and philosophy.

This study also thus concurs with previous research (Larsson-Lund et al.2001; Peters,1994;Benbassat et al.1998;Guadagnoli and Ward,1998) in stressing the need for clarifying patients' preferred form of participation, rather than acting on the assumption that all patients want to participate in the traditional sense of the word. If participation is to be more than a superficial consultation, it must be treated as a process that takes some time (Wilcox,1994). It is a process that should be continually redefined for each patient and shouldn't be a tick box/tokenistic gesture and patients should not be a 'silent witness' to the CPM process. The results of this study support the claim that a 'blueprint' or model for patient participation is not achievable as an individualised approach to patient participation is required (Stevenson,2007).

Eldh et al.(2008) meanwhile advance the argument that non-participation is a separate concept rather than the opposite of patient participation. They argue that non-participation is related to not getting enough information, getting information that is inappropriate to an individual's needs or that is provided in a manner that is inaccessible to patients and finally not seeking information or being listened to. This thesis's findings do not indicate that 'non-participation' as defined in this way was taking place.

6.22 Moving Along the Participation Continuum

If a narrow definition of participation specific to decision-making is championed, then it could be argued that patients within this study have not actively participated within their CPM's. Based on the findings of this study, the researcher asserts that a much broader definition of participation must be utilised, preferably one which is individually defined by each patient. This recommendation is also widely promoted within the current nursing literature relating to patient participation (Cahill,1998;Ekdahl et al. 2010;Sahlsten et al.2005,2007).

This study did not commence by promoting or adhering to a particular definition of participation however, it will conclude by contributing to the existing body of knowledge by offering new insights and understanding of patient participation within the context of care planning. I believe this is possible as although the concept of participation was not explicitly explored within patient interview schedules[28], questions within the interview schedule were based on indicators of participation as outlined in the literature. Ultimately participation would appear to be dependent on its definition and the findings of this study suggest that participation is best defined by each individual patient and what it means to them. However, healthcare professionals have a crucial role in encouraging or impeding this process and it is therefore imperative that the conditions necessary for participation to occur are understood and promoted. This thesis asserts that older patients must be afforded agency and control over decision-making even if their exercised choice is not to participate, this should be accepted as their preference and viewed as a valid and respected form of participation

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[28] This was because of the lack of agreed definition relating to participation and the term could be interpreted ambiguously by patients

This research study showed that all patients allowed to attend their CPM placed great importance on being involved in their CPM, getting access to information by meeting with the MDT and appearing to place value on the therapeutic relationship with the MDT. Most however did not express a desire to be actively involved in any decision-making processes. This is in keeping with previous research studies (Bastiens et al.2007) which showed that for older patients, factors such as good, clear communication and the doctor/patient relationship were influential factors for patient participation. Similar to this study, patients placed importance on the caring relationship, a person-centred approach and receiving information rather than 'active participation in decision making'. Findings therefore have highlighted the contradiction between the promotion of patient autonomy within CPM's and the existing research literature which points to the fact that many patients do not want to actively participate(Deber,1994).

Many of the present study's findings also concurred with those of Hedberg et al.(2007,2008) and their conclusion that the participation of stroke patients must be strengthened within CPM's. However, while they question if patients felt they were important participants within the CPM, this study found that patients did feel that what they said in their CPM's was treated as important and valued.

The findings from this study indicate therefore that older patient's desire information, involvement and opportunities to ask questions within their CPM's and that they believed that the other participants valued what they had said. The interactional processes of CPM's are crucial in terms of a patient's ability to move from one level of participation to another. Dialogue is seen as underpinning shared decision-making and should be characterised by two-way communication typified by openness and respect (Florin,2006).

Patients desire to be involved in care planning and decision-making can only be effected through a matching willingness by professionals which has been labelled as *co-determined involvement* (Thompson,2007).

6.23 Tension of striving for Person-Centred Practice vs Institutional Agenda.

The motivation and intention to include older patients in CPM's demonstrates a person-centred, strengths-based approach however their actual treatment and involvement (or lack of) is not, which signifies another contradiction between MDT intention and action. The MDT appear to be experiencing conflict and tension between their own professional and perhaps personal values and the external demands including those of the organisation and the agenda of the hospital . Findings show that participants adopted/were conferred different roles within CPM's and that healthcare professionals desire to offer a humanistic approach within CPM's clashed with the institutional agenda (Efraimsson et al.2006). These were marked by two different perspectives. The first related to the concept of personhood where participants were presented as persons/individuals and was characterized by the existence of a therapeutic relationship. The second perspective represented the institutional frame where participants were assigned the status of patients, next of kin/relatives and MDT or institutional representatives.

On the one hand, the MDT exhibited a motivation to ensure person-centred practice and to empower the older patients within their CPM and advocate on their behalf when required. This however is paralleled with the institutional agendas of time pressures, discharge deadlines, pressure to make decisions and reduced resources.

'...They need to understand that a decision has to be made' (MDT Focus Group Participant).

This quote very much echoes the findings from O'Brien's (2010) study who found that hospital professionals admitted that their principles were 'greyed' in order to adhere to discharge pressures. The institutional agenda must be acknowledged and the question raised as to whether CPM's are merely a vehicle to facilitate discharge and therefore a means to an end? Similar to previous research (Moats,2006), it could be contended that the needs of the organisation did take precedence over that of the older people. It is evident that the effort to involve patients as genuine participants ought to be self-evident to professions widely accepted as having human interpersonal relationships at heart (Ashworth et al.1992). However, participation is all too often viewed as straightforward and merely a matter of intent being sufficient instead of ensuring that actual and meaningful participation has taken place which appears to be the case within this study.

The MDT/patient encounter is one of necessity, not choice, which by its nature it can be argued makes it unequal, and it could be maintained that the traditional view and paternalistic model appears to be sustained within CPM's i.e. patients as passive recipients of professional advice. There appears to be a friction for the MDT between the ideal of achieving effectiveness and efficiency whilst simultaneously striving towards holistic care (Hau,2004).

6.24 Hospital as an institution of Power

Within the results of this study, a more latent theme emerged which could be described as patient's viewing the hospital as an institution of power, and this was based on many of the patients perceiving the doctors and MDT as expert, more competent decision-makers. This finding concurs with that of Ekdahl et al.(2010) who also found that older people were happy for "the hospital' to make decisions on their behalf and viewed doctors as people who were more important than themselves.

Patient's perception of the hospital as an institution of power can be compared to the "power/knowledge" described by Foucault who believes that knowledge is forever connected to power. This power/ knowledge as well as rituals such as CPM's, Foucault calls 'governmentality' where experts such as healthcare professionals lay claim to the power of governance (Waterworth and Luker,1990). Indeed, it must be considered to what extent this has influenced those patients who exhibited lower participation levels. On the one hand, there is an increasing dependence on professional expertise such as that of healthcare professionals, while there is also clearly a drive to make older people active participants in their own role via empowerment (Biggs,1999) such as promoting the agency of older people through the CPM process.

Habermas(1987) argues that it is the interpersonal situation in which we converse that provides the necessary context for informed opinion and change. Power may lead to distorted communication, but by becoming aware of the ideologies that dominate in society, groups such as the MDT can themselves not only strive to empower older people but also be empowered to transform society and their praxis. The opportunity to exercise self-determination must be afforded to all patients and taken seriously which is very much the opposite of a paternalistic approach, in that the patient is given the opportunity to take responsibility for him/ herself. However, it also important to note that not all patients desire participation as was evidenced from the findings from this study and therefore each individual's preferred level of participation within their CPM must be elicited.

6.25 What does this study suggest?

Previous studies have also suggested the 'tokenism' of patient participation; (Brownlea,1997) however, I believe the findings from this study offer a new, deeper insight into the complex nature of the concept of participation. On the

one hand, CPM's undoubtedly are determined from the institutional agenda and the need to facilitate discharge planning; it would be naive to believe that in an acute hospital environment where resources are scarce, and there is an ever increasing demand on beds, that discharge planning is not one of the key functions of a hospital as an institution. CPM's, it could be argued, have a primary function in facilitating this. Findings indicate that the theory of assumed participation of patients poses an ethical dilemma for healthcare professionals as resources are often scarce and priority may be given to family/ organisational concerns over patient's own interests (Bauer et al.2009). It is my assertion therefore that within this study, the espoused values of individualised, person-centred care were overshadowed by the organisational agenda of discharge planning.

From a position of theoretical sensitivity and interpretive inductionism, it is my opinion that as practitioners, we do feel more accountable to family members, as they are usually more assertive and vocal in their opinions. Healthcare professionals are also often heavily dependent on family members to offer practical and emotional support and care to patients when they are discharged to home in the absence of adequate provision of home care supports. On the other hand, CPM's signify a move away from a paternalistic discharge planning style to one which offers a more inclusive, person-centred and transparent way of meeting the institutional agenda that may result in more satisfactory discharge outcomes for all participants.

From this perspective, although this research study shows that the CPM process is far from perfect, it can be argued it is a better way of doing things and shows an attempt to engage in a more meaningful way with patients and their families, in the hope of greater satisfaction and better discharge outcomes. Improved communication between the MDT, patients and their families also means that issues and concerns identified can also be passed onto the community services

thus ensuring more continuity of care and potentially contributing to reduced readmissions to hospital.

6.26 Is Personhood being achieved in CPM's?

Whilst reviewing the literature relevant to this study, the concept of personhood was identified as an important concept particularly in the context of cognitive impairment and dementia and the question was raised that although healthcare professionals aspire to person-centred care, does this actually happen in practice during CPM's?

Within CPM's, it can be argued that putting the patient at the centre stage and promoting a personhood approach was in evidence as CPM's allegedly provided an opportunity for patient's opinion to be voiced and listened to, and for them to exert agency in decision-making specific to the issue of their care planning. This undoubtedly signifies a change in the hospital culture and a move way from a paternalistic approach towards a more empowering person-centred way of working. It is a concern however that although patients were provided with the opportunity to communicate their opinions and preferences through the CPM taking place, this occurred in a very limited way. Neither the MDT or family members were seen to be actively encouraging the older person's participation and in fact, they frequently referred to the older person in the third person and talked over them.

It is also important to raise the question of who's agenda is the CPM really fulfilling. If the CPM forum is intended to be an opportunity for patients to have their voice heard and participate in decision-making, why did the MDT exhibit both exclusionary and disempowering practices within the CPM's observed? Was the evidence provided to them from the first stage of this project (Phase 1) not sufficiently convincing for them, to in some way change their practice and adopt a more person-centred approach? A cynic might argue that these events are

purely being used for hospital staff to promote their own professional competencies in a collective forum and that the patient is not really the central focus. One could also question why were certain service providers absent at various stages in the research cycle? As an example why were community service providers not present at CPMs where they may have had a valuable contribution to make? Why was the medical profession not represented in the meetings leading the design of the patient information booklet or when opportunities to provide feedback on data collection was provided? Finally, it is a concern that the majority of patients assumed/were conferred a passive role in decision-making either by way of their family members making decisions on their behalf or their deference to the 'expert opinion' of the MDT members.

This finding is in line with recent research conducted in Ireland on the subject of older people's perceptions of elder abuse which found that older people believed there was a general perception in Irish society that older people are unable to speak-up for themselves as a result of declining physical and cognitive health. The study revealed that older people's personhood is diminished as they are not afforded the right to properly express their opinion or make decisions in relation to themselves and concluded that withdrawal of personhood can be viewed as a form of abuse (O'Brien et al.2011).It could be argued therefore that older people's personhood is actually being diminished within CPM's, by exclusionary practices exhibited by the MDT and their family members.

Personhood is however essentially an apolitical concept focused on psychosocial issues(Bartlett and O'Connor,2010) and thus in order to broaden the debate and to look at this issue at a more macro level, it is helpful to also consider the study's findings through the social citizenship lens. At present there appears to be an abundance of knowledge about micro level practices such as experience of care and communication however less is known about the macro level such as ways to

address discriminatory practices and the social citizenship lens facilitates beginning to look at issues of power within CPM's.

6.27 The Challenge of Moving from Personhood to Social Citizenship

A social citizenship approach to practice involves a process of critical self-reflection and within this study, this reflexivity has been achieved through the action research process, and in particular an examination of interactions and language used through the participant observations of CPM's. This approach raises much wider issues of power and agency and highlights the influence of micro level practices on possible macro level changes at societal level.

A social citizenship approach assumes that an individual has the ability to participate at some level regardless of their cognitive capacity and that the principle of maximising and valuing participation should be respected (Bartlett and O'Connor,2010). The findings show that this principle was ingrained within the culture of the Age-Related Healthcare Team by their recognition that older cognitively impaired patients should attend their CPM and by virtue of the fact that CPM's were viewed as inclusive and demonstrating good practice. The reality of observed practices within CPM's was however somewhat removed from the aspired ideal.

Although the concept of personhood was aspired to through the CPM's taking place, it does not appear that personhood and social citizenship were being truly achieved but instead were taking place in a tokenistic manner. The social citizenship of older patients was undermined by the MDT directing the majority of the conversation to family members and allowing them to speak on their behalf thus according them a higher status than the patients. This method of communication indirectly resulted in the older patient being valued less and placed in a subordinate position, reinforced power imbalances, and eroded their right to full social citizenship (Bartlett and O'Connor,2010). MDT members,

through their methods of communication and interactions, therefore did little to encourage and maximise the participation of cognitively impaired older patients and in fact did much to impede it.

Phase 2 of the action research cycle attempted to begin to address this contradiction through focusing on pre-meeting preparation and by changing the name of the meeting forum. It is clear however, that there is still a need for more fundamental changes to the language and interactions within CPM's if the participation of older people is to be truly optimised and valued. Key aspects of maximising participation involve not speaking for, or over patients, as observed in CPM's but implementing strategies and changes to practice that ensure that their voices are heard such as directing questions in order to elicit responses (Froenck,2005). Improvements to practice can help address 'unequal egalitarianism' (Toseland and Rivas 1984;Crisp;1989) and findings support those of other studies that show that skilled facilitation and mediation skills can also encourage and optimize the participation of all participants in CPM's(Griffith et al.2004; Froenck,2005).

6.28 How can MDT methods of communication promote Social Citizenship for Patients?

It is through our language that we position others and thus some of the practices observed in CPM's such as directing conversation to family members rather than the patient themselves, and referring to patients in the third person grammatical, effectively positions older people as a non-person and subordinate, and unintentionally may undermine social citizenship. As language helps to construct the reality we experience, it is logical that one's experience of reality can be altered and changed by consciously and strategically changing our language (Bartlett and O'Connor,2010).Historically it has been argued that family members are often positioned in more important manner than patients whether this is

warranted or not (Bartlett and O'Connor,2010). The findings of this study show that it is necessary to promote the balancing of patient and family member issues with observed behaviours within CPM's, and each patient's expressed preferences. There is a need for the MDT to encourage and create the conditions whereby patients might want to, and may feel motivated to participate more, without feeling pressurized to do so. It is also important to avoid labelling older patients as a homogeneous group and instead individuality and heterogeneity should be respected and should be the focus of interactions within CPM's in order for change to begin.

Older patients perception of self and agency can be adjusted and changed by the way people interact and communicate with them. It is possible therefore that if MDT members adjust their methods of communication during CPM's, this may in turn affect change in the way older patients participate in CPM's, thus moving closer to fully realized personhood and citizenship. Naik's (2011) study concluded that patients are more likely to change their decision-making style to a more active one if physicians were more supportive or actively encouraged participation. Patient-focused responses may also lead to patients being more engaged and it has been asserted that empathy in particular is fundamental to increasing patient interactions(Morse et al.1992).By making explicit the language and discourses used within CPM's, the use of power at a micro level has the potential to challenge dominant discourses at the wider level.

This research study asserts that healthcare professionals have the ability to introduce new ways of talking and communicating that challenge the current position of older patients, and in doing so can create the space for social citizenship to become more visible (Bartlett and O'Connor,2010). It is not enough to aspire to person-centred care processes in the hope that it will serve to empower, there is a need to purposefully change and move towards a more individualized needs-based language. By ensuring that each individual has the

opportunity to participate in a manner that is meaningful to them, the principle of maximising and valuing participation is achieved. Healthcare practitioners must actively want a person to participate, aspiring to this because it is a policy that undermines attempts to promote citizenship (Bartlett and O'Connor,2010). From an anti-oppressive practice perspective, healthcare professionals must also help each person to define his/her own needs and to develop the skills and a method to communicate those needs (Mullaly,2007).

Understanding participation involves understanding power and the ability of different individuals and stakeholders to achieve what they want (Wilcox,1994). There are formidable institutional barriers to the participation and empowerment of older people in their healthcare in relation to the challenges of organisational principles and structures such as power differentials based on knowledge, control over resources and professionalisation of healthcare staff (Walker,1999). Healthcare hierarchies involve an intricate matrix of inter and intra professional rankings of status and that orderings are not structured in a simple, unitary manner (Ashworth et al.1992).

6.29 Ageism in Healthcare and Wider Society

Given that the people who were involved in this research were for the most part older patients(aged 65 or over), it is important to place this study's findings within the debate on ageism in the healthcare sector. Critical Gerontology offers a mechanism to help explain why the practices observed within CPM's may be occurring and this study suggests that ageism may be an underlying contributory factor.

It has been postulated that the devaluation of older people in Western Society may contribute to the existence of prejudiced views within healthcare

professionals and this has the potential to cause older patients to become passive and submit to authority (Henderson,2002). Ageing is not only a biological process but it is also socially constructed as it is created by social interactions and power relationships in society, ageism occurs at many levels (Pierce and Timonen,2010). The argument has been advanced that the macro level(state and economy) influence the experience and condition of ageing, however, older people also actively construct their world at a micro level through social interactions and at a meso level through organisational and institutional structures that are part of their everyday lives in society (Phillipson and Baars,2007).

Patient participation reflects societal norms (Longetin et al.2010); older people's experiences are largely shaped by how others react to them in a social context and thus older patients are likely to have experienced ageism in other social contexts. The importance of cultural meanings, for example, the way the MDT interact with older people within the hospital context, has been highlighted as it is also going to influence their social construction of reality in this context and ultimately older people's experience within CPM's (Estes,1981).Ageist language and behaviours reinforces ageism and creates a negative cycle of dissatisfying and disempowering interactions that are often so pervasive in society that they begin to be perceived as appropriate (Naussbaum et al.2005).

It has been postulated that ageism within medicine is a reflection of the ageist attitudes that exists within the wider society (Bowling,1999). Minchiello et al.(2000) meanwhile observe that ageism within healthcare often takes the form of more covert practices such as individuals not being provided with sufficient information or being excluded from major decisions regarding their care. Indirect ageism is subtle and often covert or invisible, and very often individuals and organizations practice it unaware, making it difficult to challenge (Adams et.al 2006). It is possible therefore that MDT members may have had ageist attitudes

that they were unaware of and this may account for some of the exclusionary practices which were observed in CPM's

6.30 Influence of Wider Healthcare System on Participation

Concerns are increasingly being voiced about the stereotypical perceptions of older people and the extent to which these perceptions feed into negative policy, practice and service provision (O'Sullivan et al.,2010). The Irish healthcare system differs from that in many developed countries as it continues to reflect a medicalised model of health care with a significant reliance on family members as informal carers.

Social policies define old age in different societies and in particular, whether older people experience dependency or not and can make an important contribution to the participation potential of both older people and their family caregivers (Levin.et al.1983) within the care planning process. Healthcare professionals therefore have a crucial role to play in influencing whether older people are empowered or powerless. It could be argued that if older people are to participate in a meaningful way, their dependence and that of the MDT, on family members as informal carers must be eliminated by the proper resourcing of community services and homecare packages. Healthcare provision in both acute hospital care and community services exist within a distinct framework within each country. Ireland has been remarkably slow to develop support services for older people in the community and even when a Home Care Package Scheme was introduced in 2007, there was no legislative framework which would have ensured equality of access and entitlement to all older people.

It can be argued that difficulties exist at many levels (individual, organisational, system and legislative) in relation to the entitlement, empowerment and participation of older people in Irish society. It would also appear that legislation and service provision for older people in Ireland has been of a low priority until

recent years which it could be reasoned is reflective of systemic and legislative discrimination.

6.31 Revisiting the Participation Framework

It is important to revisit the existing theoretical frameworks surrounding participation and to discuss the findings of this study within these models in order to move toward a new model of participation Tritter and Mc Callum(2006) add weight to this debate recommending that this approach should be applied to all types of patient participation. They believe that by gaining an understanding of the impact of patient participation on the practice of healthcare professionals such as an examination of practices within CPM's, will ultimately help transform the healthcare culture by bridging the gap between micro level changes and system-wide reforms.

The findings of the present study confirm and support Tritter and Mc Callum's(2006) assertion that dynamic structures and processes are required at four different levels; healthcare system, organisation, community and individual if patients are to have agency and be enabled to fully participate. Such an approach provides a useful starting point however the findings of this study would imply that if true and meaningful participation is to occur, wider socio-political and cultural changes are also required such as addressing the underlying ageism that appears to exist and enabling older people to have more power and control over resourcing of services.

The adaptation of a critical discourse analysis to the findings has also facilitated the theoretical bridge between a micro(language, discourse and communication within CPM's) and macro approach(power, dominance and authority). It is important to remember that power is never absolute, and is specific to certain situations or domains. The power of dominant groups may be integrated into norms and rituals and thus take the form of what Gramsci (1971) called

'hegemony' and ageism is one example of such hegemony. In this way, it can be argued that dominated groups such as the older patients, may more or less accept, comply with or legitimate such power and in some instances find it 'natural'(Van Dijk,1998) or expected. The observed practices of MDT members and even family members were not obviously abusive acts but instead were enacted within taken-for granted practices within the hospital as an organisation. It can be argued that doctors and the MDT have more or less exclusive access to medical and professional discourse and although attempts were made to explain some of the discourse conveyed during CPM's, the MDT undoubtedly wielded more power as they also had control over the semantic macrostructures such as topics discussed during CPM's and topic changes. This thesis sets out to advance a new practice framework for participation in CPM's, so that power imbalances begin to be addressed through the empowerment and optimisation of patient participation during CPM's, so that the concepts of personhood and social citizenship can begin to be realised.

6.32 Narrowing the Theory/ Practice Gap

It is not possible within the scope of this study to address the barriers to participation, particularly those at a systems, legislative and societal level however, it is possible to try and address the micro level barriers to participation within clinical practice. The social practice of citizenship asserts that citizenship shouldn't be applied 'from above' such as the state and instead should be developed by individuals or groups in a social context through the power dynamics of everyday talk and action (Barnes et al.2004). Following this recommendation, this study has strived to narrow the theory/practice gap by striving to improve the professional practice of the MDT members within CPM's and promoting a shift in attitudes. Through the development of a Training manual which will effect change at the micro level, it is hoped it will also be the foundation for wider macro level changes. The participation of key stakeholders

has been shown to help to ensure the credibility and usefulness of best practice guidelines at a local level (Lomas,1993), so the involvement of MDT members in this task is likely to be beneficial.

6.33 Reflections on the Action Research Cycle

This study focused on an examination of CPM's as it was an opportunity to gain knowledge and understanding about current practices and whether improvements were necessary and could be made. CPM's were an increasingly common occurrence within the hospital setting however, there were few existing standards of practice or consistencies in practice. I was aware that the process was always going to be challenging as I was trying to carry out two competing agendas namely (i) the Care and Connect Project and (ii) completion of my thesis, and this meant that I had to try and balance personal gain and organisational gain. Action research was a useful approach nonetheless to adopt when striving for quality of care in practice, as it allows healthcare professional to take responsibility for and to integrate their own learning, research and practice development (Waterman et al,2001).

As a practitioner researcher, I naturally had some preconceptions embarking on the research about what I thought the results of the study would yield. My practice experience as a social worker led me to believe that the MDT would dominate the discussions within CPM's however I was surprised that this occurred to such a large extent. The high number of instances of use of the third person grammatical was also expected but, I did not anticipate that this practice would be observed from the family members as well as the MDT. I had expected that the older patients would express dissatisfaction about how they were involved and communicated with during their CPM's, and that they would express a desire for increased participation, particularly in relation to decision-

making. When reflecting on the findings, I was most surprised by the older patients' lack of desire for increased participation during their CPM's and their reported satisfaction with their involvement and participation within the CPM process and decision-making that occurred within that.

6.34 Reflections of Process: Parallel Challenges of Participation of MDT members within the Action Research Project

Reflexivity is central to action research; it is an integral part of the process and demands great self awareness from the researcher (Eden and Huxham,1996) and thus it is important to reflect on the action research process and issues that it raised. One of the most stressful elements of carrying out this piece of research was its participatory nature and the involvement of the MDT as collaborators. Integral to this discussion were issues of ownership and power relating to conducting the research using an action research approach. Since all practices of inquiry stimulate anxiety (Devereaux,1967), it was important that the communicative space that had been opened by the action research project was able to contain any anxiety and that it could be expressed. Action research has a dual purpose of intent to address and solve practice issues and its ambition to liberate and empower people which often raises tensions, as indeed do the dual aspirations of action and inquiry (Reason and Gaya Wicks, 2009).

It was ironic that the focus of this thesis was an examination of the participation of older people within CPM's, yet many of my anxieties also related to the participation of the MDT members within the research process and the ability of the action research process to truly empower the MDT within their own practice. It was important to me as both a practitioner and researcher that the MDT involvement was not purely tokenistic and that they genuinely felt a sense of ownership and participation in the research. I was also aware that I had my own

personal agenda of completing my PhD which was obviously a motivating factor specific to myself and therefore, I was anxious that the MDT wouldn't feel coerced into being involved and that there would be tangible benefits and outcomes for them. It was evident from the outset that the MDT role as collaborators would be of a secondary nature nonetheless, it was important that their role should be as active and influential as possible.

Concerns relating to the participation of MDT members as collaborators was particularly heightened during Phase 3 when the Training Manual was being devised. I was aware that the MDT needed to be actively involved and 'own' this process nonetheless, it was clear that I would need to take responsibility to drive the initiative in order to achieve an output and conclusion. During our first MDT CRG meeting relating to the manual, the MDT members clearly communicated that they wanted me to take the lead yet I was very aware that as an action research project, I would be dependent on them to also provide me with ideas, suggestions and guidance about what to include within the manual. The MDT members were very honest and acknowledged that due to work pressures within the hospital they would not be in a position to do the groundwork in terms of practically drafting the content for the manual. They did however participate in an initial brainstorming session where they volunteered suggestions of what content should be included and the format the training manual should take. A draft manual was then compiled based on the ideas forwarded by the MDT CRG which also drew strongly on the key practice implications that had arisen from carrying out the research. The conceptual model for participation in CPM's outlined earlier in this chapter also illustrates many of the fundamental concepts which underpinned the content of the Training manual.

At one level, I was unhappy with the fact that the MDT had expected that I would take the main responsibility for compiling the manual because at the initial planning stage of the project, I had envisioned that it would be more of a group

process with a much greater level of involvement and commitment from the MDT CRG and at that time, it was negotiated and agreed with the group, that they would assume a very active role. On the other hand, I was also cognisant of the fact that there had been significant organisational, system and wider economic changes in Irish society since the inception of the research project; most significant of the changes to the action research process, were reductions in all areas of staffing. This had increased the time and work pressures of the MDT with the knock-on effect that for many healthcare professionals in the hospital, their time and energies needed to be completely devoted to frontline work with patients and families and there was less time available for research-based activities. In light of this, it was necessary to concede that if the action research project was to reach completion with the expected output of a completed training manual, it would be necessary that I would assume main responsibility for this task. It is thus paradoxical that there were such evident parallels between the challenges relating to the participation of the MDT in the action research process and the participation of the older people in CPM's and how macro level factors were significantly influencing both processes.

It has been argued that it can be difficult to predict or evaluate the outcome of action research projects and the setting of objective measurements can be problematic. Habermas(1987) postulates that knowledge production is never neutral and is generally pursued with some interest in mind. This study did not set out to specifically change practices but rather to learn about current practices so that decisions could be made by the MDT about whether changes to practice were necessary. The purpose of action research is to begin to narrow the theory/practice gap as its power lies in its use to develop critical reflective practice and learning in which theory and understanding are integrated, and in which theory and understanding are generated from practice (Hart and Bond,1995). This was demonstrated in how the MDT were able to reflect on their practices, particularly during the data analysis stage of Phase 2 and then apply

their learning into practice in Phase 3 through contributing to the manual in conjunction with each individual MDT member making changes to their own practice.

In my opinion, one of the most important contributions of this study relates to the heightened awareness it created about practices within CPM's. In terms of outcomes, positive change was generated within clinical practice through professional development, in particular, skills development was achieved in the area of education and continuing professional development of healthcare professionals with the production of the MDT training manual. It is considered that the action research approach was also an empowering experience for the MDT members as it enabled them to feel that they could exert power over their professional practices. It is hoped that the Training manual will highlight the importance of micro level practices within CPM's that healthcare professionals may not have viewed as of great importance prior to the research, such as addressing people in the first person, maintaining good eye contact and directing questions to patients, in order to elicit responses.

Changes to practice within this study may not be 'measurable' or 'observable' changes but are those of a more subtle nature i.e. cultural changes within the hospital and changes in perceptions and attitudes of the MDT through a 'heightened awareness' of their practices. Meyer(2009) asserts that success can often be viewed in relation to what has been learnt from the experience of undertaking the work and that the action research process often sheds light on continuing gaps in care and issues that need to be improved in future developments. The themes that emerged from this study were specific to a particular area of investigation i.e. CPM's in a hospital setting, however, it is possible that broader themes relating to communication, older people, participation and the culture of the hospital environment are transferable to

other areas of action research and practice development which focuses on the participation of older people in their care planning within hospitals.

6.35 Conclusion

This chapter has discussed the findings of this study within the context of both micro level practices and examined their influence and relationship with macro level structures such as the hospital as an institution, the Irish healthcare system and wider society. It has shed further light on our understanding of the thesis's findings through examining them using the lens of critical gerontology and framing them within the concepts of personhood and social citizenship. Issues of power were highlighted along with how ageism in wider society may be impacting on practices within CPM's.

A conceptual model for participation of older people in CPM's has been advanced. The model asserts that it is necessary to gauge how each patient defines participation and what it means to them. Participation can be defined very narrowly for example, only being involved in medical decision-making or can be defined much more broadly. The findings from this thesis show a need for a better understanding of patient preferences (Deber,1994) and echoes the general consensus in the literature for a comprehensive assessment of patient's preferences for participation (Lyttle and Ryan,2010). There is also a need for the MDT to address the issue of shared decision-making, not just in theory but also at a practice level, and to acknowledge that professionals have a responsibility to invite patients to engage in dialogue. This chapter has concluded with a reflection of the action research process which identified some of the parallels between the participation of the MDT in the research process, and the participation of older people in CPM's. The next and final chapter of this thesis will detail the conclusions of this study and will include the training manual which was the output of Phase 3 of the action research cycle.

Chapter 7 Conclusion

7.2 Care Planning Meetings (CPM's): Overview

CPM's are an increasingly common decision-making forum in the hospital-setting both in Ireland and worldwide (Hansen et al.1998). Despite their widespread use in the hospital context, little research has been done into the processes around such meetings (Opie,2000) and explorations of patient and family member experiences and participation within CPM's to date has been largely neglected. No universal understanding or agreed definition exists for this important forum. The study set out to address this gap in the literature by providing a unique insight into how older patients, their family members and the MDT define CPM's and in addition to explore how the communication, interactions and behaviours of all participants influence both the process and outcome. The CPM process requires multi-disciplinary collaboration between the professional care providers, patients and their family (Jones,1997). This study has demonstrated that CPM's are undoubtedly an integral part of multidisciplinary teamwork which may greatly influence and shape a patients care and treatment during their hospital stay. For this reason, it is an extremely important and significant event for the patient, their family and the healthcare professionals involved in their care, and should be viewed as mutually beneficial for all participants.

Although the CPM sample of patients for Phase 1 (N=5) and Phase 2 (N=10) are small, the study has the advantage of using three complimentary sources of data i.e. participant observations of ten CPM's in both Phase 1 and 2, which were audio-taped and analysed (Phase 2), the patients perception of their CPM experience and opportunities to participate through in-depth interviews, as well as their family members perception of the patient's participation and mini-focus groups with MDT members. This offers a unique insight into the CPM experience

as a whole but also each individual part and its relationship to the whole, so that the hermeneutical circle can be fully explored.

This study has demonstrated the importance of care planning which is effective and patient-centred, particularly for those who are vulnerable as a result of cognitive and communication impairments. The motivation for doing this study arose from the increased complexity and greater rehabilitation needs of hospital populations and concerns about the participation of older patients within that process. Care planning and discharge planning are one of the least well-developed areas of hospital and research activity: this project has strove to begin to address the gap in the existing knowledge to ensure that care planning allies itself not only to the patient's needs, but also their wishes, thus leading to more effective discharge capabilities. Care planning is also an area with considerable potential for patient and family dissatisfaction with hospital care, and a higher quality, patient-centred approach is likely to lead to better satisfaction, and reduced levels of complaints.

An action research approach was adopted for this thesis and through the stages of observation, reflection, and action, detailed insight into current practices within CPM's was gained which then resulted in changes to practice and further investigation. By examining the discourse of the participants through the adoption of a critical gerontological lens, it has been possible to illuminate how older patients' experience of participation in CPM's is controlled and shaped. Findings from Phase I and Phase 2 of the action research cycle raised concerns with the MDT CRG about the participation of cognitively impaired patients and how exclusionary practices such as poor eye contact, use of the 3rd person and directing conversation to family members rather than patients, may be influencing patient participation. It is important to note though that the findings of this study also highlighted examples of good intent and practice. The MDT members were committed to the continued use of the CPM process as an

effective tool for inclusive decision making and as a consequence had insight as to the risks and pitfalls of service user involvement.

There was recognition that person centeredness requires an understanding of, and attention to group processes that promotes older peoples participation as well as outcomes (Walker et al 2001). MDT members demonstrated a capacity for innovative strategies to promote participation, however such opportunities are dependent on the support and resources of the clinical and organizational context. This in turn has led to an improved understanding of participation in relation to cognitively impaired older patients; the conditions that encourage and hinder participation have been identified and a framework for participation within CPM's has been advanced.

As outlined in Chapter 6, it is important to acknowledge that CPM's are undoubtedly a vehicle to facilitate the discharge planning agenda of the hospital as an institution however, they also signify a move towards a more inclusive, patient centred approach and a move away from paternalistic professionally dominated decision-making. CPM's also aim to help maximise patient and family member control over decisions affecting their lives and allow everyone an opportunity to gain a more detailed understanding of the patient and their family's individual situation. On the one hand, the findings show that there were aspects of tokenism related to patient participation within CPM's. On the other hand, patients viewed their CPM as an important event in their hospital stay which they wanted to be part of. For many patients there appeared to be an element of ritual and closure to their CPM as it signified the beginning of their journey home.

7.3 Consistent Approach to attendance of Cognitively Impaired Older People

Critical gerontology has promoted critical understandings as a way to capture the meaning and experience of ageing; this research study indicates that gerontological hospital care strives to place importance on agency and power for cognitively impaired older people as evidenced by their inclusion in CPM's and by the promotion of CPM's as a care planning tool. It would appear however, that the MDT and the wider healthcare system appear to experience difficulty trying to integrate this philosophy fully to the practice setting.

In an acute hospital environment, the care planning process can often be fraught and characterised by a lack of patient involvement and negotiation around discharge planning. Older patients, specifically those with cognitive and other such difficulties relating to understanding, and communication, are particularly vulnerable in clinical decision making processes dominated by healthcare professionals and family members who may have different goals and agendas regarding the outcomes of care.

The implementation of a consistent approach to the inclusion of older people with a cognitive impairment in CPM's within the Age-Related Healthcare Unit is a positive development. This principle is ingrained in the best practice guidelines for healthcare professionals and signifies a conscious shift away from the act of no longer excluding older patients in care planning. Nonetheless, it is important to emphasise that the majority of older patients in hospital are not the subject of CPM's and the reasons as to why some patients have a CPM and others do not was not the focus of this thesis and is an area for future research. The literature highlights the need to understand how CPM's succeed or fail and to demonstrate the necessary condition for the creation of positive care outcomes for older patients in hospitals (Evers, 1981).

7.4 Participation-How can it be achieved?

This study has demonstrated that participation is still a challenge for patients, and healthcare professionals, and has confirmed that the structures and processes within CPM's do not always accommodate the needs of older adults. Healthcare professional's methods of communication, language and behaviours have an important influencing role in how patients experience and participate within CPM's.

The importance of the therapeutic relationship as a foundation to patient participation has been demonstrated and trust, empathy, praise and reassurance are key to cultivating a therapeutic relationship between patients and healthcare professionals. For older people to feel comfortable expressing their views and preferences openly, the fostering of a therapeutic relationship is paramount to help create an emotionally secure environment for them to do so (Sahlsten et al.2006)

This study's findings show that healthcare professionals need to invite and make room for patients in conversations, listen with attention to what they are saying, and communicate with them in a clear and explicit way to facilitate understanding (Efaimsson,2003; Hedberg,2007,2008).The findings emphasise the importance of an open communication and a democratic group culture, which is respectful of the needs and rights of older people, if CPM's are to achieve truly participatory outcomes. This must be balanced with strategies to prepare and empower older patients and family carers for CPM's and their participatory role.

Pre-meeting consultation and preparation of all participating should occur routinely, especially with the older patient and family caregivers. Issues of potential conflict or power imbalances between the participating members should be identified at this stage of the process. Written information on the purpose, and processes involved, should be provided to older patients and family

members as an integral part of the pre-meeting process. Specialist advice and guidelines are required for enabling the participation of older patients with a cognitive impairment. The aims and goals need to be clearly negotiated and clarified between healthcare professionals, older patients and family caregivers.

The outcomes of CPM's need to be clearly articulated and communicated to older patients and family caregivers and opportunities provided for feedback. CPM's should preferably be facilitated by skilled professionals trained in small group processes, and with knowledge of power, patient autonomy and decision-making issues involved, and empowering strategies to address these issues. Specialist advice and guidelines are required for enabling the participation of older patients with a cognitive impairment and is an urgent priority. Finally, the need to avoid excluding the patient through the use of complex and unexplained professional and technical jargon would appear to be obvious.

Out of this study, healthcare professionals have identified a broad range of participatory strategies that can be considered and adapted to diverse clinical settings. This thesis study concludes that individual care is essential, that some patients do prefer to assume a more passive role, and it would appear that the MDT need to ascertain how much patients want to participate in their CPM and any decision-making within that.

7.5 The Nature of Participation

It is important to acknowledge that power does not always have to have negative connotations and CPM's can be a mechanism whereby older people can reclaim power over their healthcare and care planning. The issue of participation needs a multi-dimensional approach that is both micro and macro in nature and assessments of patients should be strengths based and focus on retained skills and knowledge rather than deficit focused. It is important for healthcare professionals to address implicit hierarchal power structures and to realise that

valuable input and contributions can be gained from patients by attending to power issues. In this way, no knowledge is seen as superior and healthcare professionals can learn from patients and families and vice versa.

Bartlett and O'Connor (2010) raise the interesting point in relation to persons with dementia that when they afforded the status as expert in his/her own experience, their involvement becomes less tokenistic. This principle also holds true for older cognitively impaired patients and in this way, all partners in the participation process within CPM's can contribute their unique knowledge that is important and complementary. However, in this study, patients were not afforded many opportunities during their CPM to volunteer their unique information or their knowledge.

Findings support the argument that it is not enough strive towards achieving patient participation because 'it's the right thing to do' at a tokenistic level; healthcare professionals must genuinely want patient participation if social citizenship is to be fully realised. There is a need to move from the rhetoric of patient participation to actually implementing it in the maximum way possible in clinical practice. Current motivations within healthcare to 'involve' patients, and to promote participation, are likely to prove detrimental if interactions between patients and healthcare professionals are not informed of the interpersonal complexities that have been found in this study.

Participation needs to be a function of not only organisational and administrative arrangements, but must also be carefully constructed at an interpersonal level if it is to occur in a meaningful way (Ashworth et al.1992). Older patients are not a homogeneous group, desire for participation varies, and participation represents something different to each individual. Therefore an individualised approach is necessary, which involves eliciting each person's desire for participation and tailoring interactions accordingly.

7.6 Reflection on the Action research Process

The adoption of an action research approach has been shown to be an effective method for conducting research into the practice of healthcare professionals. It has facilitated MDT members to closely examine their practices within CPM's, and through this process, to identify ways to improve practice. An action research dissertation should consider how well the knowledge generated can be utilised by those in the setting, as well as beyond. Geertz's (1983) work on local knowledge asserts that this approach aims to address the immediate needs of people in specific settings, and it is the utility of this knowledge that is one of the major strengths of action research.

Future research should strive to fully embrace the participatory element of conducting action research and aim to involve patients and their family members as co-participants and collaborators within the research process. Freire's (1972) concept of praxis which stems from the position that action and reflection are inextricably linked and enable the world around us to be changed provide a useful concluding reflection on the action research process of this study and its underlying principle of heremeneutics. In this way, this study has strived towards his dichtum that, 'reflection without action is sheer verbalism or armchair revolution and action without reflection is pure activism or action for action's sake' (Freire,1972, P.93).

7.7 How has conducting this study impacted on the way that I communicate at a personal level and within my professional practice?

When reflecting on if, and how, this research study has impacted on my own methods of communication and social interactions, I must acknowledge that I believe it has had a profound effect both on my personal interactions and within my professional practice. Within both spheres of my life, I believe I have

developed a heightened awareness in relation to how I communicate with people both through body language and verbal interactions. I find myself more aware of maintaining good eye contact and ensuring that I turn to face people when I address them. This has been particularly beneficial when communicating with my own grandmother and father-in-law who are both in their eighties and have hearing difficulties. The simple act of directly facing them when I speak means that they have a much better chance of understanding what I am saying both acoustically, and also because they can read my lip movements.

Within my professional practice, the above example is also relevant however the issue of being aware of how I address older patients and in particular, striving to always speak in the first person rather than the third person has made a strong impression on my practice. Furthermore, other practice issues that emerged from the study have remained fresh in my mind and have been incorporated into my day-to-day practice. This study therefore has been an exercise of knowledge generation about CPM's but has also served as a mechanism for closely examining and questioning my own practice and accepting that there is room for much improvement! Undertaking a doctoral thesis has also advanced me from being in a position of having no research skills or training to being in a position where I have learned and developed my capacity to carry out a piece of research and now have much greater confidence to do so.

7.8 Revisiting Original Research Aims and Implications of Findings

This study has aimed to provide a better understanding and improved practices within CPM's through a process of collective, reflective inquiry, using an action research approach. Older patients with a cognitive impairment or communication difficulty were consulted on their views of CPM's and in their opinion, how they could be conducted better. This process enabled the identification of older

patient's interests and concerns and how each patient desired and experienced participation. One main outcome has been the promotion of the guiding principle of the need for a consistent approach to cognitively impaired older patients and this principle has been ingrained into the Training Manual for healthcare professionals.

This has become even more relevant in the Irish context where the introduction of the Nursing Home Support Scheme (2009),which states that older people must participate and be involved in decisions relating to nursing home placement has brought the issue of participation, capacity and consent to the fore. As a result of this research, a better understanding of older people's experience within CPM's has been gained, and in particular the experiences of those with cognitive and communication difficulties. Healthcare professionals now have a clearer insight into how to create a climate which encourages and maximises participation.

Labonte (2004) conceptualised empowerment as a shifting or dynamic quality of power relations between two or more people such that the relationship tends more towards equity. It is hoped that this study has instigated a move in this direction through a tilting of the balance of power, the older person becomes central to the meetings process, which signifies a move away from a paternalistic model. This study has shed light on how MDT members can best balance the role and input of family members. It is anticipated that there will be increased effectiveness within CPM's and greater satisfaction for all participants as a result of an improved understanding of the nature of participation and the communication, language and behaviours which promote and impede it.

7.9 Contribution to Original Knowledge

This study is the first of its kind in an Irish context to look at participation within the context of care planning meetings. The literature review was unable to find any other Irish or international study that specifically examines the participation

of older patients with cognitive and communication difficulties within CPM's, or the care planning process.

This study has enabled a comparison to take place between observed behaviours in CPM's and patients reported preferences and experiences. It supports and builds on previous research, yet also throws light on the conditions that facilitate and help optimise participation so that we come to understand how the process impacts on the experience and outcome. It adds to a body of knowledge that already exists relating to patient preferences for decision-making in nursing and medical care. The study has improved our understanding of older patient's preferences for participation in the care planning process with a multi-disciplinary team. It is anticipated that the outcomes of this research may be beneficial not only for patients, but may also have a positive outcome of for family members, and the MDT, and will improve the experiences of all participants in CPM's.

The real focus and conclusion from this study is the importance of 'meaningful participation' which is effective and successful for each patient and not tokenistic in nature. This thesis builds on the existing literature by further illuminating our understanding of participation and findings support the recommendation that the definition of participation should be broadened so that it corresponds with the International Classification of Functioning, Disability and Health's (WHO,2001) definition, which stresses the sharing of knowledge, communication, and interpersonal relations (Eldh,2010).

It would be easy to conclude that participation is not realistic/ achievable for everyone however this over simplifies the issue and prevents the adoption of a broad continuum of participation as evidenced by this study's findings. A careful, context-sensitive and questioning approach to the changing forms of the concept, and practice, of patient participation is required. Rather than a 'one size fits all' approach to participation, this study supports the recommendation of Collins et

al.(2007), that the emphasis should be on sensitising healthcare professionals to the complexities and different types of patient participation in different contexts, and in relation to different decisions, and that a dynamic approach to patient participation is required. Patient participation may mean one thing to a healthy individual and something very different to a cognitively impaired older person and something different again to a healthcare professional.

It has been recommended that formal educational settings such as third level education, and continuing professional development courses, could be beneficial in providing training for healthcare professionals (Naussbaum et al.2005). Early exposure to training at an undergraduate level for healthcare professionals would promote professional development in multidisciplinary practice by shaping attitudes toward the value of MDT collaboration (Fineberg,2005) and would help develop communication skills to promote and maximise participation in CPM's.

Through the process of 'opening communicative spaces', this thesis has produced a tangible output in the form of best practice guidelines for healthcare professionals[29]. Guidelines for CPM's have been developed for meetings relating to palliative care and child welfare (Gueguen et al.2009;Hudson et al.2004) however, to the best of the researcher's knowledge, these are the first CPM guidelines developed which relate to CPM's with older patients, with particular reference to those who have cognitive and/or communication impairments. The guidelines which have been developed have the added benefit of specific communication strategies which can be employed by healthcare professionals to optimise communication for these vulnerable groups within CPM's.

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[29] See Appendix for Training Manual

7.10 Practice Implications

MDT members were committed to the continued use of the care planning meeting process as an effective tool for inclusive decision making and as a consequence, had insight as to the risks and pitfalls of service user involvement. There was recognition that person centeredness requires an understanding of, and attention to, group processes that promotes older peoples participation as well as outcomes (Walker et al. 2001). The MDT members demonstrated a capacity for innovative strategies to promote participation however, such opportunities are dependent on the support and resources of the clinical and organisational context.

This study demonstrated the importance of clarity of aims and outcomes, mutuality of relationship between participants, and the use of patient centred and inclusive practices to achieve truly participatory CPM's. Practical suggestions to be considered include extensive pre-meeting consultation with older patients and their families, adoption of open and democratic meeting facilitation styles, documentation of outcomes and plans and post-meeting follow up. The power imbalance between the healthcare professionals, patients and family members must be made transparent and openly discussed at the multidisciplinary team level. Written information on the purpose, and processes involved in care planning meetings, will help facilitate older patient and family member participation. Enabling the participation of older patients with cognitive impairment also appears to be an urgent priority.

In summary, care planning meetings work best when facilitated by skilled professionals trained in small group processes and with knowledge of power, and patient autonomy, who employ empowering strategies to address these issues. Social workers are perhaps in a unique position to work with the healthcare professionals in clarifying the reality of the limits to choice and the involvement

of the patients and family. They can provide expertise in the facilitation of such processes and support the patient and the family in their participation of problem solving, advocacy, negotiations and mediations.

One of the main outputs of this thesis which is also paramount to its original contribution to the existing body of knowledge, has been the development of a comprehensive Training Manual. This received input from the MDT CRG and draws on the findings of this study, as well as best practice guidelines within the current literature. Although the training manual has been developed specifically for the research site, and has specifically focused on the participation of older patients who may have a cognitive and/or communication difficulties, it is hoped that it can be adapted and used in relation to other clinical groups in different settings.

See Appendix P for 'Care Planning Meetings Training Manual' (2011), AMNCH/TCD.

7.11 Study Limitations

One of the main limitations of this study is the comparatively low attendance rate of older patients during Phase I of the study. Only five of the 10 patients attended their CPM and therefore the data available to analyse was limited. This factor also meant that there was a low response rate in patient questionnaires and thus it limited the researcher's ability to gain an in-depth picture of patient's participation within CPM's or their subjective experiences during Phase I. If carrying out this research study again, I would strive to repeat the data collection techniques and analysis carried out in Phase 2, i.e. to audio-tape the CPM's in Phase I, which would enable a critical discourse analysis to be carried out.

Another limitation is that although a critical discourse analysis approach was adapted, the data analysis strategy did not employ all the tenets of this approach such as examining instances of pauses, silences and the tone of voice used by participants when conversing. This level of more in-depth analysis may have provided richer, more detailed information relating to the communication interplay within CPM's which may have enabled stronger conclusions to be drawn from the findings.

Although an action research approach was adapted, the study design did not fully adhere to all the participatory principles of action research as the older patients were not involved as collaborators and thus the study was not fully participatory and empowering. It was decided however that it would not be practical to include the older patients as collaborators in view of the fact that they were inpatients and therefore it would be difficult to sustain their involvement once they were discharged.

It also needs to be acknowledged that in my role as participant observer, I may have had some preconceived ideas and inherent biases about how CPM's should be conducted and facilitated, and these may have influenced data collection and analysis. A strength however of this study is the technique used to sample (purposive) and the wealth of complementary data collected using this multiple methods approach.

When reflecting on what could be changed if the study was to be repeated, in hindsight it may have been preferable when completing the critical discourse analysis to identify each MDT profession and to examine their specific discourses and language. This may have provided useful insights into the way different healthcare professionals communicate with patients and their families and how their professional training may have influenced this. It could also be illuminating to examine more closely the relationship between participation in CPM's, the

decision-making process and post-discharge outcomes and to compare the experiences and outcomes for patients who were subject of a CPM with those who weren't.

7.12 Future Research

Future research on this topic should use larger samples and a more in-depth comparison of the nature of participation in a sample containing older and younger patients. A more detailed examination of the factors that may influence participation would also be recommended such as age, educational status, past-history of decision-making, life course and socio-demographic factors. More information is needed on how pre-meeting preparation affects the experiences of older patients within CPM's, particularly those with cognitive and communication difficulties, and how it impacts on how they participate within the meeting.

As stated, one outcome from this study was the development of a Training manual for the MDT on best practices within CPM's. Future research is needed to evaluate the effectiveness of this manual as a skill development tool and to examine whether introducing a learning tool for healthcare professionals can result in improvements to practice and ultimately optimise of patient participation within the care planning process.

Further research is needed to determine the type of pre-assessment tools needed as preparatory aids prior to CPM's in order to elicit patient's desired level of participation and/or to clarify their preference for a co-decision making or shared decision-making approach. The assessment tools could (1)Determine the patients' preferences for receiving information (2)Elicit patient's values, beliefs, and goals, particularly those that may lead to conflicting decisions between patient and others (3) Clarify patients' preference for degree of direct involvement in decision-making and/or preference for co-decision-making or delegated/deferred decision-making approach (4) If the patient is unable to

participate or ability to participate has been compromised, to draw on previous discussions or documentation that suggest the patient's values, wishes or directives.

The adoption of an action research approach has been shown to be an effective approach for conducting research into the practice of healthcare professionals and facilitating them to closely examine their practices within CPM's and through this process to improve practice. Future research could strive to fully embrace the participatory element of conducting research and aim to involve patients and their family members as co-participants and collaborators within the research process.

7.13 Concluding Thoughts

This chapter has aimed to identify the achievements and limitations of this study which was undertaken in an Age-Related Healthcare setting of an acute hospital in Dublin, Ireland. The work has not only represented a journey of investigation into practice using an action research approach but also my own professional and personal development that at times has been intertwined and interrelated. By centring this study in real life practice, a much greater understanding of the complexities of clinical practice within CPM's has been afforded and the challenges associated with trying to instigate genuine changes to practice that will empower practitioners as well as the older people they work with.

This study would not have been possible without the commitment of all those older people including those with a cognitive impairment and those with communication difficulties who took part. Although the research study has now ended, in many ways the real challenge lies on the road ahead as the organisation and all members of the MDT strive to implement and maintain the changes to practice and in doing so, keeping the older patient at the forefront of our practice.

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Appendix A

CARE AND CONNECT PROJECT

PATIENT INFORMATION LEAFLET

Care and Connect is a project being jointly undertaken by the Adelaide and Meath Hospital, Tallaght and Trinity College Dublin. Its objective is to promote best practices in person-centred care planning for older people and to promote partnership in decision-making between older people, families and healthcare professionals. It will involve exploratory research which will examine how the practice of healthcare professionals impacts on the participation of stroke patients in family meetings in a hospital setting.

What will you have to do?

If you decide to take part in this study you will be asked to;

(1) Give oral and written consent for the researcher to observe and audio-tape your Care Planning Meeting and access your medical record if additional information is required.
(2) Have one face-to-face interview lasting approximately 30 minutes :this will take place at a time that is convenient to you after your Care Planning Meeting has taken place.

What will your family members have to do?

If you decide to take part in this study, your family members who are attending your Care Planning Meeting will be asked to;

(1) Give their consent for the researcher to observe and audio-tape your Care Planning Meeting.
(2) A face-to-face interview lasting approximately 30 minutes: this will take place at a time that is convenient to them after your Care Planning Meeting has taken place.

Topics that will be addressed within these interviews include:

- The purpose of the Care Planning Meeting
- Communication and language used within the meeting
- The role of the healthcare professionals within the meeting
- Your ability to participate within the Care Planning Meeting

CONFIDENTIALITY

Your identity will remain anonymous throughout the research. Your name will not be published and will not be disclosed to anyone outside of the Multi-disciplinary Team who will be involved in the research as collaborators. You can choose to drop out of the research or discontinue at any time and this will not affect your care or entitlements to services. If you do decide to take part, you will be required to sign a consent form before your family meeting takes place.

This research has been approved by the Research Ethics Committee of the Adelaide and Meath Hospital, Tallaght and Trinity College Dublin.

About the researcher

My name is Sarah Donnelly. I am currently employed by Trinity College Dublin as a Research Social Worker to the Care and Connect Project. Half of my workload is devoted to research and half of my workload is devoted to casework in the Age Related Health Care Unit of Tallaght Hospital. If you have any questions or queries about this research or the researcher please contact Professor Des O'Neill (Tallaght Hospital) at 01-4143215 or Professor Robbie Gilligan(Trinity College) at 01-8961331 who are both overseeing this study.

Appendix B

Care and Connect Project, Patient/Family Member Consent Form, Phase 1

Please circle yes or no for each answer:

Did you read the patient information leaflet? **YES NO**

Have you had opportunities to ask questions? **YES NO**

Do you have any other questions about the Research **YES NO**

Do you understand that being involved in this research will not affect your healthcare or social care entitlements now or in the future? **YES NO**

Do you know that this project is being carried out by Tallaght Hospital and Trinity College Dublin? **YES NO**

Do you know that you can refuse to allow the researcher access to your medical record? **YES NO**

Do you know that information collected will be kept confidential and that your name will not be associated with anything observed during your family meeting ? **YES NO**

Do you know that you can ask the researcher stop her observation of your family meeting at any time? **YES NO**

Do you know that you/your family member can refuse to answer any questions and stop the interview at any stage? **YES NO**

Do you understand that the interview is not an assessment of your communication/cognitive abilities? **YES NO**

Do you know that you can drop out of the

research at any point? **YES NO**

'I consent to take part in this project'

Signed respondent.....

Date.....

Signed Patient/ Family Member.....

Date.....

Witness Researcher..... **Date**.....

Appendix C

Care and Connect Project

Consent for Healthcare Professionals

Synopsis of Project

Care and Connect is a research project being jointly undertaken by the Adelaide and Meath Hospital, Tallaght and Trinity College Dublin. Its objective is to promote best practices in person-centered care planning for older people and to promote partnership in decision-making between older people, families and healthcare professionals. It will involve exploratory research which will examine how the practice of healthcare professionals impacts on the participation of patients in Care Planning Meetings in a hospital setting.

An action research model will be adapted for the project. This means that the study will be composed of a cycle of phases which will involve an enquiry phase, an intervention phase and an evaluation phase.

Phase 1 will consist of the researcher observing and audio-taping 10 Care Planning Meetings which you will be participating in. The researcher will be analysing the practice of you as a healthcare professional and examining the relationship between your practice and the participation of patients within Care Planning Meetings. The researcher is seeking your permission to observe your practice within Care Planning Meetings.

The researcher will also issue you with a questionnaire after each Care Planning Meeting included in the research, which will seek your views on the Care Planning Meeting process. The researcher will also be holding a number of focus groups with each allied heal discipline to gather additional information on Care Planning Meetings and any suggestions you may have for improvements to practice.

The researcher is also seeking your permission to become ***collaborators*** on the research project. The researcher will set up an MDT Critical Reference Group which will be composed of you, as the healthcare professionals whose practice was observed. The researcher will feedback the findings and analyses of the observations and interviews, and will be asking you to help analyse the data and identify and instigate changes to your practice within Care Planning Meetings.

'I consent to take part in this project'

Signed Respondent.....

Date.....

Appendix D

Care and Connect Project, Patient Questionnaire

Phase 1

1. Have you ever attended or had experience of a family meeting before?

(If yes, please give brief details)

2. Were you asked if you wanted to attend this meeting?

(If yes, who asked you?)

3. Were you asked which of your family members you would like to be invited to the meeting? (If yes, who discussed this with you?)

4. What is your understanding of the purpose of having this meeting?

5. Were you informed who would be attending this meeting?

(If yes, who discussed this with you?)

6. Did you feel that you had adequate opportunities to express your opinions and to ask questions during the meeting?

7. Are you happy with any decisions that were made during the meeting?

8. Is there anything you feel should have been done differently during the meeting or have you suggestions for improvements?

ANY OTHER COMMENTS?

Many thanks for taking time to meet with me and to complete this questionnaire.

Appendix E

Care and Connect Project,

Family Members Questionnaire, Phase 1

1. Have you ever attended or had experience of a family meeting before? (If yes, please give brief details)

2. Who invited you to the meeting and how was this invitation issued?

3. What is your understanding of the purpose of having this meeting?

4. Were you informed who would be attending this meeting?

   (If yes, who discussed this with you?)

5. Did you feel that you were given adequate opportunities to express your opinions and to ask questions during the meeting?

6. Are you happy with the decisions that were made during the meeting?

7. Is there anything you feel should have been done differently during the meeting and have you any suggestions for improvements?

ANY OTHER COMMENTS?

Many thanks for taking time to meet with me and to complete this questionnaire.

Appendix F

Phase 1, Care and Connect Project.MDT Questionnaire. Please return questionnaires to Sarah Donnelly, Social Work Department.

1. What is your understanding of the purpose of holding this meeting?

2. Was the patient asked if they were willing to participate in the Meeting? (If yes, by who?)

3. Was permission sought from the patients about which family members they would like to attend?(If yes, by whom?)

4. Was there an MDT pre-meeting held to agree team objectives for the meeting? If not, do you feel that this would have been beneficial?

5. Was there a facilitator or minute taker appointed prior to the meeting?

6. Were you informed who would be attending the meeting? (if yes, who discussed this with you?)

7. Are you satisfied with the decisions that were made during the meeting?

8. Is there anything you feel should be done differently during the meeting and have you any suggestions for improvements?

ANY OTHER COMMENTS?

Many thanks for taking time to complete this questionnaire.

Appendix G ,Data Recording Sheet-Phase 1 and 2

Participants	Body Language	JARGON	Seating Arrangements	Punctuality	Eye Contact;	Other Observations
Patient						
Family Member						
Family Member						
Occupational Therapist						

Social Worker						
Consultant						
Nursing						
Physiotherapist						
Other						

Appendix H

Patient Information Leaflet

Care Planning Meetings

Statement of Values

Respect - Caring - Openness - Partnership - Teamwork Fairness & Equality

What is a Care Planning Meeting?
It is a meeting to make plans for your future care.

What will happen during my meeting?
You and your family/ carers can **ask any questions** that you might have.

Members of **the team** who are involved in your care will give **updates** on your **progress.**

We would **encourage you** to **think in advance** of **any questions** you may want to ask during the meeting.

Information and **options** will be given about your **future care needs.**

We will **help you** and **support you** if you need to make any **important decisions** about your **future.**

If you have any worries about your meeting, we would encourage you to please talk to your social worker.

Who will be attending my Care Planning Meeting?
You, as the patient, your **family/carers, doctors, nurses**, **social workers** and **therapists**.
Professionals from the Community Services may also be present.
As far as possible, we will let you know in advance which Health Care Professionals will be attending.

Do I have to attend my Care Planning Meeting?
All patients **are encouraged** to attend their Care Planning Meeting unless otherwise advised by your Consultant.

Do I need to invite all of my family to my Care Planning Meeting?
It is **your decision** who, if anyone, you would like to **attend** your Care Planning Meeting **e.g. family** member, friend, neighbour, **carer,** etc.

How long will my meeting last?
Care Planning Meetings usually last between **30mins-1hr.**

Where will my meeting take place?
A meeting **room will be arranged** within the **hospital.**

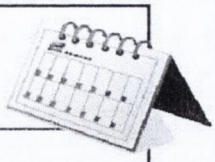
Who will arrange my Care Planning Meeting?
Your **hospital social worker** will **arrange** your meeting

You, as the patient, are the most important person at the meeting;

It is your meeting

QUESTIONS I WOULD LIKE TO ASK

Date:



Time:

Venue:

Contact Person:

Phone No:

Appendix I

Schedule for Patient Interviews-Phase 2

(Interview will take place a maximum of 72 hours post-meeting)

Begin interview by making sure patient understands what I mean by their Care Planning Meeting and reminding them when it took place.

Pre-Meeting Stage

- Have you ever been to a Care Planning meeting before?

- Did you feel that you were given enough notice about the meeting?

- Did you agree to take part in the meeting?

- Could you have said, 'No, I don't want to go'?

- Can you tell me how you were feeling before your meeting?

- Were you asked who should be invited to your meeting?

- Is there anybody else you would have liked to have been there who wasn't?

- Were you told who would be at your meeting?(If so, by whom?)

- Did anybody explain what your meeting would be about beforehand?

- Were you told that it might be in your interests to attend the meeting?

- Did anyone explain that the meeting might be upsetting?

- What information(if any) were you given before your meeting?(Prompt: diagnosis, treatment, care options etc)

- Were you able to fully understand all the information you were given?

- Is there any way this information could have been explained to you better?

- Would you prefer to have been given more or less information at this stage?

I'd like to like to find out a little bit more about how you coped with making important decisions before you came into hospital.

- How do you usually make important decisions in your life?

- Do you prefer your family members/someone else to make decisions for you?

- Do you like to be given information and choices about your healthcare?

Care Planning Meeting Experiences.

- Can you tell me how you felt during your meeting?

- Did you feel that the hospital staff knew enough about you and your family's circumstances?

- Did you feel free to express your opinions?

- Did you feel that you could ask any questions you had?

- Did you feel that everyone listened to what you had to say?

- Did you feel that the hospital staff treated what you said as important?

- Did you feel that your family treated what you said as important?

- Did you feel that you had any control over what happened in your meeting?

- Was there anything that was talked about that you didn't understand?

- Did you feel left out of the discussions at any stage? If yes, when did this occur?

- Were any plans/decisions made about your future?

- If yes, did you feel that you played a part in the decision-making?

Reflections on Care Planning Meeting Experiences and Suggestions for Improvement.

- How do you feel about your Care Planning meeting now that it is over?

- Did your meeting help you in any way? If yes, how?

- Did attending your meeting make you feel any differently about the amount of control you have over your care planning and treatment?(prompt; more control, less control, no difference)

- Is there anything about your meeting you were very happy with?(ask to elaborate)

- Anything you were unhappy with?(ask to elaborate)

- Was there anything you would have liked to have been talked about which wasn't? What was this?

- Is there anybody who was at your meeting that you would have preferred not to be there?(either family/staff)

- If you were asked to go to another Care Planning meeting, what would you like to be done differently?

- Is there any advice you would give to other patients going to a Care Planning meeting?

- Is there any advice you would give to hospital staff about Care Planning meetings?

- If you were asked to choose where you would like your Care Planning meeting to be held-where would that be?(give prompts; your own home, a family members home, other)

Any Other Comments?

Appendix J

Schedule for Family Member interview, Phase 2

Pre-Meeting Stage

- What types of feelings do you believe your relative experienced (i) before their Care Planning Meeting?

  (ii)during their Care Planning Meeting?

  (iii)after their Care Planning Meeting?

- In your opinion, did your relative understand what the purpose of their Care Planning meeting was beforehand?

- Did your relative receive any preparation before their Care Planning meeting?

- If yes, could you tell me about the preparation they received.

- Is your relative normally the type of person who likes to be given choices and information about his/her healthcare?

- In general, does your relative normally like to make his or her own decisions about important things?

- If not, do they like to (a) make a joint decision with a family member/someone else or (b) do they prefer to allow a family member/someone else to make the decision on their behalf?

- In your opinion, has your relative's decision making behaviour changed since they were admitted to hospital?

Family Meeting Experiences and Reflections

- Did you feel that your relative was able to say everything they wanted to during the meeting?

- Do you think they were able to freely express their opinions during the meeting?

- Do you believe your relative's wishes were reflected within the meeting?

- Does your relative have any communication difficulties?

- If so, what strategy (if any) can you tell me was put in place at the family meeting to compensate for your relative's communication difficulties?

- Does your relative have memory difficulties?

- If so, what strategy (if any) can you tell me was put in place at the Care Planning meeting to compensate for your relative's memory difficulties?

- How were they accommodated?

- Was there anything talked about during the meeting that you feel your relative was unable to understand?

- In your opinion, was your relative unhappy with anything that was discussed during the meeting?

- Was there anything your relative would have liked to have been talked about which wasn't?

- Was there anybody at the meeting that they would have preferred not to be there(either family/staff/other)

- In your opinion, was your relative able to participate in the meeting to the extent they would have liked to?

- Did you feel that your relative was able to play a part in any decisions that were made?

- Could anything else have been done at the Care Planning Meeting that might have given your relative more opportunity to participate?

Any other comments?

Appendix K

Patient Profile Checklist-Phase 2

1. HOUSING STATUS
   Owner Occupier
   Council Tenant
   Private Rented

2. Martial Status
   Single
   Married
   Separated
   Widowed

3. Education
   No formal Education
   Primary Level
   Secondary Level
   Third Level

4. Income
   Old-Age Pension
   Occupational Pension
   Savings/Assets

5. Medical Cover
   Medical Card
   Private Health Insurance
   Employment Related Health cover

Appendix L ,MMSE Screening Tool

THE ADELAIDE & MEATH HOSPITAL, DUBLIN INCORPORATING THE NATIONAL CHILDREN'S HOSPITAL

OCCUPATIONAL THERAPY DEPARTMENT

STANDARDISED MINI-MENTAL STATE EXAM (SMMSE)*

Name:_____ **Therapist**

Signature:_____

DOB: _____ MRN: _____ Date of Assessment:_____

1.0	**Orientation (Time, Place & Person):** Allow 10 seconds for each reply	**Score**	**Comm**
1.1	a) Say ***"What year is it?"*** (Accept exact year only) b) Say ***"What season is it?"*** (During last week of old and first week of new accept either season) c) Say ***What month of the year is this?"*** (First / last days of month accept either month). d) Say ***"What is today's date?"*** (Accept previous or next date e.g. on 7th accept 6th or 8th) e) Say ***"What day of the week is this?"*** (Accept exact answer only)		

1.2	Accept exact answer only: a) Say ***"What country are we in?"*** b) Say ***"What province / county are we in?"*** c) Say ***"What city / town are we in?"*** d) Say ***"What is the name of this hospital / building?"*** e) Say ***"What floor of the building are we on?"*** Sub Total	/10	
2.0	**<u>Immediate Recall:</u>** Say ***"I am going to name three objects. After I have said all three objects. I want you to repeat them. Remember what they are because I am going to ask you to name them in a few minutes".*** BALL FLAG TREE For repeated use .... BELL JAR FAN BILL TAR CAN		

	BULL WAR PAN ***"Please repeat the three items for me"*** (Score I point for each correct reply on first attempt, allow 20 seconds for the reply. If the subject did not repeat all three, repeat until they are learned or up to a maximum of 5 times). Sub Total	/3	
3.0	**Attention and Calculation Skills:** Say ***"Spell the word WORLD"*** (You may have to help the subject spell WORLD correctly) Say ***"Now spell it backwards please"*** (Allow 30 seconds to spell backwards – if the subject can not spell "World " even with assistance – score 1) **OR**		

	Alternatively the calculation task ***"Serial Sevens"*** may be used instead of WORLD. Decide at the start to use Serial Sevens or WORLD. Do not use Serial Sevens if subject is unable to spell WORLD or vice versa....(PTO) Say ***"Subtract 7 from 100 and keep subtracting from what's left until I tell you to stop".*** (May be repeated three times if the subject pauses just repeat the same instruction – allow one minute) Sub Total	/5	
4.0	**Delayed Recall:** Say ***"Now what were the three objects that I asked you to remember"*** (Allow 10 seconds to remember – score 1 point for each correct response regardless of order) Sub Total	/3	
5.0	**Language and Parietal Skills:**		

5.1	Show the wristwatch. Ask ***"What is this called?"*** (Allow 10 seconds to respond. Score 1 point for correct response.)		
5.2	Show the pencil. Ask ***"What is this called?"*** (Allow 10 seconds to respond. Score 1 point for correct response, accept pencil only, and score 0 for pen.)		
5.3	Say ***"I'd like you to repeat a phrase after me" "No Ifs , Ands or Buts"*** (Allow 10 seconds for response. Score 1 point for a correct repetition which must be exact e.g. "No ifs, or buts" score 0).		
5.4	Say ***"Read the words on this page then do as it says"*** Hand the subject the laminated sheet with "Close your eyes" on it. If the subject just reads and does not close their eyes you may repeat ***"read the words on the page and do what it says"*** to a maximum of 3 times. (Allow 10 seconds to respond, score 1 point only if subject closes eyes. Subject does not have to read aloud.) Ask the subject is he / she is right or left-handed. Alternate right / left in the statement.		

5.5	Say ***"Take this paper in your right / left hand; fold in half once with both your hands; and put the paper on the floor".*** (Allow 30 seconds to respond, score 1 point for each of the following correctly executed a) taking paper in correct hand, b) folding in half and c) putting it on the floor.) Hand the subject a paper and pencil. Say ***"Write any complete sentence on this piece of paper"*** (Allow 30 seconds for completion. Score 1 point for a sentence which makes sense. Ignore spelling mistakes).		
5.6	Place the design, pencil and paper on the table in front of the subject. Say ***"Copy this design please"*** (Allow 1 minute maximum. Allow multiple tries until subject is finished and hands it back. Score 1 point for a correctly copied diagram. The subject must have drawn a 4-sided figure between the two 5-sided figures).		
5.7	Sub Total		

		/9	
	TOTAL	/30	

Total SMMSE Score: (Circle as appropriate)

30 – 26 ……. Normal Range 20-10……..Moderate Cognitive Impairment

25 – 21 ……. Mild Cognitive Impairment 9-0……..Severe Cognitive Impairment

Appendix M

	Year	Month	Day
Date of Test			
Date of Birth			
Chronological Age			

Record Form
Part 1

Western Aphasia Battery™ REVISED

Name: _____ ID Number: _____

Sex: ☐ M ☐ F Age: ____ Address: _____

Phone Number: _____ Years of Education: ____ Native Language: _____

Present/Former Occupation: _____

Examiner's Name: _____

Referral Source: _____

Date of Onset: _____

Hemiparesis:	Side of Hemiparesis:	Severity of Hemiparesis:	Hemianopia (loss of visual field):	Neglect:	Handedness:
☐ Yes	☐ Right	☐ Mild	☐ None	☐ None	☐ Right
☐ No	☐ Left	☐ Moderate	☐ Right	☐ Right	☐ Left
		☐ Severe	☐ Left	☐ Left	☐ Ambidextrous

Site of lesion (or attach report): _____

_____

Site of lesion established by: ☐ CT Scan ☐ MRI ☐ Other (specify): _____

_____

Contact Person(s): _____ Phone Number: _____

Address: _____

Notes:

General Recording and Scoring Directions

1. Unless otherwise indicated, score 1 point for a correct response and 0 points for an incorrect response.
2. Write NR if the patient does not respond and score as 0.
3. Unless otherwise indicated, the maximum point value for each item is in parentheses in the lower, right-hand corner of the score column.
4. If the patient's response is different from the target, write it verbatim in the space provided.

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1 2 3 4 5 6 7 8 9 10 11 12 A B C D E

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Spontaneous Speech

A. Conversational Questions

Materials: Audio- or Video-tape Recorder (Optional)

Directions: Read the stimulus as written or substitute similar questions as appropriate (e.g., "What *was* your occupation?"). If you substitute a question, write it next to the question replaced.

Repetition: Repeat the question if the patient requests or does not appear to understand.

Recording Responses: Write the patient's response verbatim in the Response column. Place a checkmark (✓) in the Correct or Incorrect columns as appropriate.
Optional: Audiotape or videotape the patient's responses for later review.

Item	Response	Correct	Incorrect
1. **How are you today?**			
2. **Have you been here before?**			
3. **What is your first and last name?** (For incomplete responses, probe for first or last name.)	First Name Last Name		
4. **What is your full address?** (For incomplete responses, probe for the street, city, or state. No ZIP code is needed.)	Number & Street City State (Country)		
5. **What is your occupation?**			
6. **Why are you here (in the hospital)?** *or* **What seems to be the trouble?**			

B. Picture Description

Materials: Stimulus Book

Directions: Turn to page 1 in the Stimulus Book, and say, **Tell me what is happening in this picture.** If the patient lists single words, say, **Try to talk in sentences.** Ask for a more complete response if he or she produces only a few words. Encourage the patient to pay attention to all aspects of the picture. Move the picture toward the patient's intact visual field if necessary.

Recording Responses: Write the patient's response verbatim.

Scoring Information Content of Spontaneous Speech Tasks A and B

Directions: Circle the point value corresponding to the statement that best describes the information content of the patient's speech on Tasks A and B. Count recognizable phonemic paraphasias as correct.

0 = No information.
1 = Incomplete responses only (e.g., first name or last name only).
2 = Correct response to any 1 item in Task A.
3 = Correct responses to any 2 items in Task A.
4 = Correct responses to any 3 items in Task A.
5 = Correct responses to any 3 of the items in Task A plus some response to the picture in Task B.
6 = Correct responses to any 4 of the items in Task A plus some response to the picture in Task B.
7 = Correct responses to any 4 of the items in Task A and a mention of at least 6 things in the picture in Task B.
8 = Correct responses to any 5 of the items in Task A and an incomplete description of the picture in Task B.
9 = Correct responses to all items in Task A and an almost complete description of the picture in Task B; at least 10 people, objects, or actions should be named. Circumlocution may be present.
10 = Correct responses to all of the items in Task A and a reasonably complete description of the picture in Task B. Sentences of normal length and complexity, referring to most of the items and activities.

Information Content Score ☐

Scoring Fluency, Grammatical Competence, and Paraphasias of Spontaneous Speech Tasks A and B

Directions: Review the point values and corresponding statements. Circle the point value that best represents the fluency, grammatical competence, and occurrence of paraphasias in the patient's speech during Tasks A and B.

0 = No words or short, meaningless utterances.
1 = Recurrent, brief, stereotypic utterances with varied intonation; the emphasis or prosody may convey some meaning.
2 = Single words, often paraphasias, effortful and hesitant.
3 = Longer, recurrent stereotypic or automatic utterances without information, or mumbling.
4 = Halting, telegraphic speech; mostly single words; paraphasias; occasional prepositional phrases; severe word-finding difficulty. No more than two complete sentences with the exception of automatic sentences (e.g., "Oh I don't know."); characteristic of agrammatic, nonfluent aphasia.
5 = Often telegraphic but more fluent speech with some grammatical organization; marked word-finding difficulty. Paraphasias may be prominent; few, but more than two propositional sentences.
6 = More propositional sentences with normal syntactic patterns; may have paraphasias; significant word-finding difficulty and hesitations may be present.
7 = Phonemic jargon with semblance to English syntax and rhythm with varied phonemes and neologisms. May talk excessively; must be fluent; characteristic of severe Wernicke's aphasia.
8 = Circumlocutory, fluent speech; moderate word-finding difficulty; with or without paraphasias; may have semantic jargon. The sentences are often complete but may be irrelevant.
9 = Mostly complete, relevant sentences; occasional hesitations and/or paraphasias; some word-finding difficulty; near normal, but still perceptibly aphasic.
10 = Sentences of normal length and complexity, without definite slowing, halting, or paraphasias.

Fluency, Grammatical Competence, and Paraphasias Score ☐

Auditory Verbal Comprehension

A. Yes/No Questions

Materials: None

Directions: Say, **I'm going to ask you some questions. Answer Yes or No.** If the patient cannot respond consistently verbally or gesturally, train the patient to close his or her eyes to indicate Yes responses. Because aphasics often elaborate and circumlocute, it is particularly important to remind and reinforce the patient to respond Yes or No as requested.

Repetition: Repeat the directions and the question if the patient gives an ambiguous or confabulatory response.

Scoring: Indicate the type of response given by checking (✓) the box in the appropriate column. Score 3 points for each correct response and 0 points for each incorrect (ambiguous or confabulatory) response. If the patient self-corrects, score the last response he or she gives.

Item	Target Response	Type of Response				Score	
		Verbal	Gestural	Eye Blink	NR	Correct	Incorrect
1. **Is your name Smith?**	No					3	0
2. **Is your name Brown?**	No					3	0
3. **Is your name _____?** (Patient's last name)	Yes					3	0
4. **Do you live in _____?** (Nearby city/town where patient does not live)	No					3	0
5. **Do you live in _____?** (Patient's city/town of residence)	Yes					3	0
6. **Do you live in _____?** (Another nearby city/town where patient does not live)	No					3	0
7. **Are you a man/woman?**	Yes					3	0
8. **Are you a doctor?**	No					3	0
9. **Am I a man/woman?**	Yes					3	0
10. **Are the lights on in this room?**	Yes					3	0
11. **Is the door closed?**	Yes					3	0
12. **Is this a hotel?**	No					3	0
13. **Is this _____?** (Actual location)	Yes					3	0
14. **Are you wearing red pajamas?**	No					3	0
15. **Will paper burn in fire?**	Yes					3	0
16. **Does March come before June?**	Yes					3	0
17. **Do you eat a banana before you peel it?**	No					3	0
18. **Does it snow in July?**	No					3	0
19. **Is a horse larger than a dog?**	Yes					3	0
20. **Do you cut the grass with an ax?**	No					3	0

Yes/No Questions Score ☐ (Max = 60)

B. Auditory Word Recognition

Materials: Stimulus Book, cup, matches, pencil, flower, comb, screwdriver

Directions: Refer to the specific directions for each set of items (e.g., Items 1–6; Items 7–36).

Repetition: Repeat each item one time if the patient requests or does not respond.

Scoring: Score correct responses as 1 point and incorrect responses as 0 points. If the patient points to more than one choice, score as 0, unless it is clear that the patient is self-correcting.

For Items 1–6, place objects in a random cluster, making sure they are within the patient's intact visual field if hemianopia is present. Say, **Point to the ____, or Show me the ____.**

Real Objects	Score
1. Cup	
2. Matches	
3. Pencil	
4. Flower	
5. Comb	
6. Screwdriver	

For Items 7–36, begin with page 2 in the Stimulus Book. Say, **Point to the ____, or Show me the ____.**

Pictured Objects	Score
7. Matches	
8. Cup	
9. Comb	
10. Screwdriver	
11. Pencil	
12. Flower	
Forms	**Score**
13. Square	
14. Triangle	
15. Circle	
16. Arrow	
17. Cross	
18. Cylinder	
Letters	**Score**
19. J	
20. F	
21. B	
22. K	
23. M	
24. D	
Numbers	**Score**
25. 5	
26. 61	
27. 500	
28. 1867	
29. 32	
30. 5000	

Colors	Score
31. Blue	
32. Brown	
33. Red	
34. Green	
35. Yellow	
36. Black	

For Items 37–42, if an object is not in the room, substitute a comparable item and note the substituted item. Say, **Point to the ____, or Show me the ____.**

Furniture	Score
37. Window	
38. Chair	
39. Desk/Bed	
40. Light	
41. Door	
42. Ceiling	

Body Parts	Score
43. Ear	
44. Nose	
45. Eye	
46. Chest	
47. Neck	
48. Chin	
Fingers	**Score**
49. Thumb	
50. Ring Finger	
51. Index Finger	
52. Little Finger	
53. Middle Finger	

For Items 54–60, the patient must get both the side (right or left) *and* body part correct to receive credit.

Right-Left on Body	Score
54. Right Ear	
55. Right Shoulder	
56. Left Knee	
57. Left Ankle	
58. Right Wrist	
59. Left Elbow	
60. Right Cheek	

Auditory Word Recognition Score ☐ (Max = 60)

Note. Add the scores for Letters Items 19–24 and transfer the score (Max = 6) to the Letter Discrimination score box on page 5 of Record Form Part 2.

C. Sequential Commands

Materials: Pen, comb, book

Directions: Say, **I am going to ask you to do some things.** Read each item.

Repetition: Repeat each item in its entirety one time if the patient requests or appears confused.

Scoring: Score the maximum point value if the patient correctly executes the entire command. If not, score each underlined segment of a multi-part command separately according to the number above the segment.

Item	Score
1. Raise[2] your hand.	(2)
2. Shut[2] your eyes.	(2)
3. Point[2] to the chair.	(2)
4. Point[2] to the window, then to the door.[2]	(4)

Arrange the pen, comb, and book (from left to right) on the table in front of the patient. Point to each and say, **See the pen, the comb, and the book? I will ask you to point to them and do things with them. Are you ready?** Proceed to Item 5. If the patient does not understand Item 5 say, **If I ask you to point to the pen with the comb, you would do this...** (demonstrate). Repeat Item 5.

5. Point[2] to the pen and the book.[2]	(4)
6. Point[4] with the pen to the book.[4]	(8)
7. Point[4] to the pen with the book.[4]	(8)
8. Point[4] to the comb with the pen.[4]	(8)
9. With the book[4] point to the comb.[4]	(8)
10. Put[4] the pen on top of the book,[6] then give[4] it to me.	(14)
11. Put[5] the comb on the other side[5] of the pen and turn over[5] the book.[5]	(20)

Sequential Commands Score ☐ (Max = 80)

Repetition

Materials: None

Directions: Say, Repeat these words. Say ____. Present the words in the order listed.

Repetition: Repeat each item one time if the patient requests or does not appear to hear the stimulus.

Scoring: Score the maximum point value if the patient correctly repeats the target word or phrase. Score 2 points for each recognizable word. Deduct 1 point for each phonemic paraphasia (e.g., shindow for window) and each error in word sequence. Give credit for responses that differ due to dysarthria (e.g., slurring), dialectal variations (e.g., winder/window), or word contractions (e.g., "He isn't coming back.").

Verbal Apraxia Rating: Rate phonemic substitutions, stuttering, repetition, segmentation, dysprosody and other features of verbal apraxia as absent, mild, moderate, or severe.

Item	Score
1. bed	(2)
2. nose	(2)
3. pipe	(2)
4. window	(2)
5. banana	(2)
6. snowball	(4)
7. forty-five	(4)
8. ninety-five percent	(6)
9. sixty-two and a half	(10)
10. The pastry cook was satisfied.	(10)
11. The telephone is ringing.	(8)
12. He is not coming back.	(10)
13. delicious freshly baked bread	(8)
14. no ifs, ands, or buts	(10)
15. Pack my box with five dozen jugs of liquid detergent.	(20)

Repetition Total ☐ (Max = 100)

Verbal Apraxia Rating:
☐ Absent ☐ Mild ☐ Moderate ☐ Severe

Naming and Word Finding

A. Object Naming

Materials: Book, ball, knife, cup, safety pin, hammer, toothbrush, eraser, (pad)lock, pencil, screwdriver, key, paper clip, watch, comb, rubber band, spoon, tape, fork, matches

Directions: Present the objects in the order listed. Say, **What is this?** or **What is the name of this object?** If the patient does not respond or responds incorrectly, ask him or her to hold the object (tactile cue) and to tell you what it is. If the patient still does not respond or responds incorrectly, present the first phoneme of the word (phonemic cue), or, if it is a compound word, the first half of the word (semantic cue).

Time Limit: Allow 20 seconds maximum for each item.

Scoring: Score 3 points if the object is named correctly or with a minor articulatory error (e.g., dysarthric slurring) and no cue is needed. Score 2 points if the object name is recognizable, but with a phonemic paraphasia (e.g., "fife" for "knife") and no cue is needed. If a tactile, phonemic, or semantic cue is needed, circle the *T*, the *P*, or the *S* in the Tactile, Phonemic, or Semantic column and score as 1 point. Score an incorrect or no response after cueing as 0 points.

Item	Other Response	Type of Cue (if needed)			Score			
		Tactile	Phonemic	Semantic				
1. Book		T	P	S	3	2	1	0
2. Ball		T	P	S	3	2	1	0
3. Knife		T	P	S	3	2	1	0
4. Cup		T	P	S	3	2	1	0
5. Safety Pin		T	P	S	3	2	1	0
6. Hammer		T	P	S	3	2	1	0
7. Toothbrush		T	P	S	3	2	1	0
8. Eraser		T	P	S	3	2	1	0
9. (Pad)lock		T	P	S	3	2	1	0
10. Pencil		T	P	S	3	2	1	0
11. Screwdriver		T	P	S	3	2	1	0
12. Key		T	P	S	3	2	1	0
13. Paper Clip		T	P	S	3	2	1	0
14. Watch		T	P	S	3	2	1	0
15. Comb		T	P	S	3	2	1	0
16. Rubber Band		T	P	S	3	2	1	0
17. Spoon		T	P	S	3	2	1	0
18. Tape		T	P	S	3	2	1	0
19. Fork		T	P	S	3	2	1	0
20. Matches		T	P	S	3	2	1	0

Object Naming Score ☐ (Max = 60)

B. Word Fluency

Materials: None
Directions: Say, **Name as many animals as you can in one minute.** If the patient is hesitant, cue him or her by saying, **Think of a domestic animal like the horse, or a wild animal like the tiger.** After 30 seconds, prompt the patient to continue if necessary.
Scoring: Score 1 point for each unique animal named (except for *horse* or *tiger* if given as an example), even if distorted by phonemic paraphasias.
Recording Responses: Write the patient's responses verbatim on the lines provided below.

_____

_____

_____

_____

_____

Word Fluency Score ☐ (Max = 20)

C. Sentence Completion

Materials: None
Directions: Say, **Complete what I say. For example, ice is . . .** (cold). Present the test items.
Scoring: Score 2 points if the target response or a reasonable alternative response is given (e.g., Sugar is . . . fattening). Score 1 point for a phonemic paraphasia or off-target alternative responses (e.g., Grass is . . . brown). Score 0 points for an unreasonable response (e.g., Grass is . . . cold).

Item	Target Response	Other Response	Score		
1. The grass is ____.	green		2	1	0
2. Sugar is ____.	sweet/white		2	1	0
3. Roses are red, violets are ____.	blue		2	1	0
4. They fought like cats and ____.	dogs		2	1	0
5. Christmas is in the month of ____.	December		2	1	0

Sentence Completion Score ☐ (Max = 10)

D. Responsive Speech

Materials: None
Directions: Say, **Answer the following questions.** Present the items.
Scoring: Score 2 points if the target response or a reasonable alternative response is given (e.g., Nurses work in a . . . clinic). Score 1 point for a phonemic paraphasia or off-target alternative responses (e.g., Nurses work in an...office). Score 0 points for an unreasonable response (e.g., Nurses work in a...store).

Item	Target Response	Other Response	Score		
1. What do you write with?	pen/pencil		2	1	0
2. What color is snow?	white		2	1	0
3. How many days are in a week?	seven		2	1	0
4. Where do nurses work?	hospital		2	1	0
5. Where can you get stamps?	post office/store		2	1	0

Responsive Speech Score ☐ (Max = 10)

Score Summary Worksheet

Western Aphasia Battery™ REVISED

Spontaneous Speech	Patient's Score
Information Content	(10) p. 3
Fluency, Grammatical Competence, and Paraphasias	(10) p. 3
Spontaneous Speech Total	(20)
(20)	**Spontaneous Speech Score** (Use to calculate AQ, LQ, and CQ)

Auditory Verbal Comprehension

A. Yes/No Questions	(60) p. 4
B. Auditory Word Recognition	(60) p. 5
C. Sequential Commands	(80) p. 6
Auditory Verbal Comprehension Total	(200)
÷ 20	
(10)	**Auditory Verbal Comprehension Score** (Use to calculate AQ)
÷ 10	
(20)	**Auditory Verbal Comprehension Score** (Use to calculate LQ and CQ)

Repetition

Repetition Total	(100) p. 7
÷ 10	
(10)	**Repetition Score** (Use to calculate AQ, LQ, and CQ)

Naming and Word Finding

A. Object Naming	(60) p. 8
B. Word Fluency	(20) p. 9
C. Sentence Completion	(10) p. 9
D. Responsive Speech	(10) p. 9
Naming and Word Finding Total	(100)
÷ 10	
(10)	**Naming and Word Finding Score** (Use to calculate AQ, LQ, and CQ)

Aphasia Quotient (AQ)

(20)	**Spontaneous Speech Score**
(10)	**Auditory Verbal Comprehension Score** for AQ
(10)	**Repetition Score**
(10)	**Naming and Word Finding Score**
(50)	
× 2	
(100)	**Aphasia Quotient (AQ)**

WAB-R Aphasia Classification Criteria

Numbers in the Fluency column represent the Fluency, Grammatical Competence, and Paraphasias score. Numbers in the Auditory Verbal Comprehension, Repetition, and Naming and Word Finding columns represent section scores used to determine the Aphasia Quotient.

Directions: Compare the patient's four scores with the row of scores associated with each aphasia type to determine the WAB-R Aphasia Classification.

	Scores			
Aphasia Type	**Fluency**	**Auditory Verbal Comprehension**	**Repetition**	**Naming & Word Finding**
Global	<5	<4	<5	<7
Broca's	<5	>3	<8	<9
Isolation	<5	<4	>4	<7
Transcortical Motor	<5	>3	>7	<9
Wernicke's	>4	<7	<8	<10
Transcortical Sensory	>4	<7	>7	<10
Conduction	>4	>6	<7	<10
Anomic	>4	>6	>6	<10

Adapted with permission from Kertesz & Poole, 1974, *The Canadian Journal of Neurological Science, 1*(1), 7–16.

AQ = Aphasia Quotient LQ = Language Quotient CQ = Cortical Quotient

Appendix N PATIENT ATTRIBUTES TABLE-PHASE 2

	Age Groups	Education	Gender	Housing Status	Income	Martial status	Medical Cover
Amy	36	Third Level	Female	Private Rented	Disability Allowance, Sick Pay	Married	Self- Payers
David	69	Primary Level	Male	Council Tenant	Old-Age Pension	Single	Medical Card
Ellie	87	Second Level	Female	Owner Occupier	Occupation Pension	Widowed	Private Health Insurance
Florrie	89	Second Level	Female	Owner Occupier	Occupation Pension	Widowed	Medical Card
Jack	90	Second Level	Male	Sheltered Housing	Old-Age Pension	Widowed	Medical Card
Larry	58	Primary Level	Male	Owner Occupier	Disability Allowance, Sick Pay	Married	Self- Payers
Mark	76	Second Level	Male	Owner Occupier	Old-Age Pension	Married	Self- Payers
Sarah	91	Primary Level	Female	Owner Occupier	Old-Age Pension	Widowed	Medical Card
Tommy	82	Primary Level	Male	Owner Occupier	Occupation Pension	Widowed	Employment related health Insurance
Vera	84	Third Level	Female	Owner Occupier	Occupational Pension	Widowed	Private Health Insurance

Appendix O Phase 2 : Emerging themes from data analysis.

Information and guidelines for MDT CRG (Stroke MDT).

Method of data analysis.

Data analysis will consist of 2 approaches. A qualitative computer software programme has been used to analyse all meeting and interview transcripts(Nvivo).

Interpretive Inductionism. Essentially this means that the researcher will approach the data analysis from the perspective of theoretical sensitivity to existing concepts, ideas and theory in the literature and from my own experience as a practitioner.

Critical Discourse analysis. This can be broadly defined as a close examination of the language used and an interpretation of how communication functions and affects the individuals involved in Care Planning Meetings e.g who dominates discourse space in meetings, interaction patterns, use of 3rd person grammatical. What is being observed about participation of the 3 different groups within the meetings; patients, family members and MDT?

Sahlsten et al's(2005) four properties of participation will be used as a thematic framework for coding of Care Planning Meetings. All other nodes(codes) have been condensed under these headings.

Main Themes and Codes:

1. Exchange of Information and Knowledge.

Two main topics reflecting the content talked about in Care Planning Meetings were found.

(i)Medical update and Rehabilitation progress report from MDT

(ii)Options- equipment, home supports, follow-up

2. Existence of a therapeutic relationship

3. Power ,Control and opportunities for influence

-Planning and decision-making

-Institutional conversation

5. **Discourse Analysis; Interpersonal Procedures**- Nvivo Codes

Base Node = (1)PATIENT (2) Family Member (3)MDT

-anxiety

-any questions?

-checking understanding

-Direct Question asked

-Direct utterance

-Empathy

-Expert Comment

-NP 3(3^{RD} person grammatical)

-patient addressed directly

-patient utterance

-Praise

-reassurance

Analysis of Informal Processes will also be completed through an analysis of data collected in participant observation data recoding sheet in conjunction with transcription record of meeting. This will include observations of seating arrangements, eye contact, body language pace and clarity of speech.

Appendix P

THE ADELAIDE & MEATH
HOSPITAL, DUBLIN
INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL

CARE PLANNING MEETINGS

Best Practice Guidelines for Healthcare Professionals

An Individualised Approach to Patient Participation

School
of Social Work
and Social Policy

Care Planning Meetings: Multidisciplinary Team (MDT)

Guidelines for best practice(See definitions at the end of the document)

Introduction

This training manual was designed for healthcare professionals and multidisciplinary team members (MDT) to provide guidelines which outline best practice when undertaking Care Planning Meetings(CPM's) with patients/families/carers. It focuses specifically on practice relating to CPM's held with patients who have a cognitive impairment and/or a communication difficulty. The training manual draws on a number of sources namely,

Findings from the Care and Connect Research Project AMNCH/TCD and a PhD thesis using an action research approach.

Best practice guidelines as developed by a working group of social workers in the Age-Related Healthcare Department, AMNCH

Best practice guidelines as cited within the current research literature

<u>Guiding Principles for Care Planning Meetings</u>

- The overriding guiding principle is to promote and support the primacy of the patient. CPM's can be a useful way to help patients and family members to share in-formation, clarify goals of care and make decisions.

They should provide a safe environment where issues and questions can be raised and appropriate plans of action agreed on.

- CPM's should be viewed as mutually beneficial for patients, families and healthcare professionals.
- CPM's should be used in a proactive way so that issues are anticipated and ad-dressed before they reach a crisis level thus avoiding their use as a crisis intervention tool.

Purpose

Care Planning Meetings can be arranged for a number of reasons including;

1. Promote communication between the patient, their family members and the MDT.
2. Patient/family issues identified/discussed
3. Facilitate decision making
4. Share Information (two-way)
5. Present feedback on patient's present condition/future potential
6. Facilitate discharge planning
7. Educational
8. Arrive at a consensus where different viewpoints exist about outcomes for patients

Timing of Care Planning Meetings

- The purpose of a CPM will largely determine when it takes place e.g., discharge planning and information sharing. It should primarily be responsive to the patient's/family's needs and/or the Hospital's ability to facilitate the patient's discharge.

- When scheduling CPM's it is important that it is planned sufficiently in advance to facilitate attendance and to allow for all necessary pre-meeting preparation to occur.

Pre-Planning Meeting

There may be occasions when it is helpful to have a MDT pre-meeting. If so ,at pre-meeting:

- Agree/confirm purpose/team's objectives
- Clarify information to be shared at meeting
- Agree team's plan/position
- Agree contingency plan to facilitate varying family/carer responses
- Agree Facilitator and Minute Taker
- Nominate individual to carry out pre-meeting preparation with patient e.g. Social Worker, Facilitator or other nominated person. The nominated individual is given responsibility for giving the Patient Information Booklet to each patient and carrying out all necessary pre-meeting preparation with them.

Length of Care Planning Meeting

- An estimated length for time for the meeting should be discussed prior to the meeting. CPM's should have a maximum time allocation of 1 hour.
- Punctuality of MDT members at CPM's is imperative as it is important to be respectful of patient and family members time commitments.
- Late arrival may mean that issues discussed need to be re-visited thereby delaying the duration of the meeting.

- It is also important that normal practice should be that MDT attendees stay for the duration for the CPM. There may however be exceptional circumstances where MDT member participation is required for only part of the CPM; in this situation be explained to the patient and their family members which MDT members will be leaving the meeting early, and an explanation provided.

Decisions to be made before the Meeting

At MDT Case Conference:

- Agree purpose/agenda for care planning meeting
- Discuss team's objectives for meeting
- Decide if there is a need for a pre-meeting prior to CPM
- Consent should be sought from the patient about who they would like to be invited.
- Agree attendees from the MDT. Consideration should be given to the number of MDT attendees and only those who are essential to the purpose of the CPM should attend so that the patient/family do not feel overwhelmed; this is particularly relevant for patients with significant communication difficulties and should be decided on a case by case basis.
- In particular, attendance of nursing staff at CPM's should be encouraged. Nursing staff are often the MDT member who has had most contact with the patient during their hospital stay, and thus have a vital role to play in supporting patient communication and participation during the CPM.
- Decide if an interpreter is required.
- Agree whether people from external agencies should attend. If so, decide if minutes of the meeting are to be circulated.

Communication Strategies for Healthcare Professionals during CPM's

- Patient participation is influenced and increased by the strength of the therapeutic relationship with the MDT. In view of this, it is advisable in so much as is practical, to foster a therapeutic relationship with patients as much as possible in advance of the CPM.
- Ensure that only one person speaks at a time during the CPM.
- Do not talk over the patient and allow sufficient time to enable the patient complete what he/she is attempting to say.
- Turn to face the patient when you are speaking to them.
- Address the patient in the first person grammatical i.e. by their name/title/ 'you' or by how they wish to be addressed.
- Avoid usage of the third person grammatical i.e. referring to the patient as 'he' or 'she' when they are present.
- Use simple, clear language and avoid the use of medical or other technical (discipline specific) language is used, an explanation of its meaning should be provided.
- Maintain good eye contact with the patient/family members when you are addressing them
- Be aware of your tone and clarity of speech when talking
- Speak to patients in a non-patronising manner
- Where possible, support patients in their communication
- Ask patients direct questions as this will promote active participation

- Check patient and family member understanding throughout. For example, *'Is that ok?'* and await response or *'Do you understand everything we have been talking about? Would anyone like the information to be explained again?'*
- Be aware of body language and look for signs of distress or that the patients is uncomfortable. If signs of distress are observed in patient body language, try to address this.
- Strive to maintain a conversational style /dialogue format that is two-way.
- Don't overload the patient/family members with too much information. Tailor in-formation provision to each patient's individual needs.
- Try to communicate short pieces of information rather than long, dense pieces of information.
- Use the 'teach back method' – ask the patient to repeat what you have told them in their own words to make sure they understand.

Patient Participation

- In general patients should be given the option to participate however their level of involvement is likely to be influenced by their cognitive capacity. Patients with a mild or moderate cognitive impairment should be encouraged and supported to attend their CPM if it is their wish to do so. The Medical Consultant, in conjunction with the MDT should decide whether it is appropriate/ practical for patients with a more advanced cognitive impairment to attend their CPM.
- Discussion should take place with the patient about which family members/support persons they would like to be invited and patients should nominate which family members they wish to attend.
- If the patient does not want to attend, seek their permission to conduct the CPM with the key family members/support persons that they nominate. If the patient cannot make an in-formed decision, offer the meeting to the next of kin/key family/support persons who have been identified to receive information and care planning decisions relating to the patient.
- Pre-meeting preparation is extremely important for all patients however, particular attention should be paid to pre-meeting preparation for patients with a cognitive or communication impairment in order to optimise their participation during their CPM.
- Advice should be sought from a Speech and Language Therapist(SLT) on strategies to support and facilitate the participation of patients with cognitive and communication impairments during their CPM. In certain cases, a joint session with SLT should form part of the patient's preparation for their CPM.
- The patients desire to participate should be determined prior to the meeting. This should include discussing what level of participation and

decision-making they are comfort-able with and what level of involvement they would like their family members/support person to have.

- In relation to decision-making within the CPM, it is important to try and clarify the patient's preferred style of decision-making; self-determination, shared decision-making, deferred, delegated or proxy decision-making.
- Patients should be given a copy of the Care Planning Meetings Patient Information Booklet to read in sufficient time to enable them understand and remember the content of the booklet.
- The patient should be informed about the purpose of the meeting and the expected attendees.
- A follow-up discussion should take place with the patient where a verbal explanation of the booklet is provided and the patient has an opportunity to voice any questions relating to their CPM.
- The patient should be encouraged to identify any issues/topics they would like to be discussed during their CPM.
- The patient should also be encouraged to write down any questions they would like to ask/would like to be asked, on their behalf during the meeting.
- Use of scaling questions/diagrams can be helpful in eliciting the importance of an issue to a patient and may be a useful tool to help determine their wishes prior to the CPM taking place.
- In so far as is possible patient should receive as much information as possible about care options and resources prior to their CPM.
- If relevant, please ensure that the patient brings any communication aids to their CPM.

Family Participation

- If the patient cannot make an informed decision/does not want to attend, offer with the patient's consent the meeting to the next of kin/key family/support persons who have been identified to receive information and care planning decisions relating to the patient.
- Family members should also be given a copy of the CPM Patient Information Booklet.
- They should be offered an opportunity to ask any questions they might have relating to the CPM prior to the meeting and encouraged to identify any issues they would like to be discussed.

Facilitation

A skilled facilitator should chair the meeting. Any member of the team who has the relevant skills/experience should be able to facilitate the meeting, however this is usually a role shared between the Social Worker and senior medical personnel.

Desirable Skills

- Organisational
- Mediation
- Conflict resolution
- Information giving
- Basic counselling e.g. listening/active listening
- Observation
- Delegation

Tasks of the Meeting Facilitator: pre-meeting

- Invite patient/family, explaining purpose of the meeting
- Identify a time to meet when all participants can attend and clarify expected duration of CPM
- Confirm the CPM time and location. Identify and book a suitable room, preferably free of interruptions, tissues should be made available and conducive seating arrangements are recommended.
- Ensure that there are enough chairs
- Arrange interpreter when required.
- Take minutes or delegate another MDT member to do so.

Tasks of the Meeting Facilitator: in the meeting

Beginning of Meeting

- Thank everyone for attending and facilitator to introduce him/herself.
- Establish appropriate ground rules e.g. *'We would like to hear from everyone, however we would ask that one person speaks at a time and I will make sure that everyone gets a chance to speak and ask any questions they have'.*
- Indicate the estimated maximum duration of CPM
- Explain and agree the purpose of the meeting and then confirm with the patient and family that they have the same understanding of the purpose.
- For example, *'We arranged this Care Planning Meeting today to talk about your progress and discharge planning options. Is that your understanding of the purpose of the meeting?'*
- Explain format e.g. MDT give feedback on progress of treatment
- Encourage patient and family to ask questions during the meeting
- Encourage the patient/family members to participate during their CPM

During The Meeting

- Check patient and family member understanding
- Make sure everyone has opportunity to speak and raise any issues and concerns
- Allow people time to reflect on what is said.
- Where appropriate acknowledge emotional content of meeting
- Give people opportunity to express emotions in appropriate and safe way
- Summarise and acknowledge different points of view while keeping a focus on agenda and desired outcome
- Mediate when conflicts arise
- Where appropriate (e.g., family conflict, patient or family member very distressed) bring meeting to conclusion
- Emphasise positive outcomes arising from the meeting but also acknowledge areas of disagreement
- Offer final opportunity for comments, concerns or questions. For example, *'Are there any questions which you had which haven't been answered yet?'*
- Make sure minute taker has noted decisions made and plan agreed
- Establish need for further meetings

After the CPM

- Facilitator should stay back after meeting to check with patient and family how they experienced the meeting.
- When necessary, debrief with the patient and/or family members.
- There may be times when it is necessary for the team to debrief.

Documentation of the Care Planning Meeting

- The written record of the care planning meeting should include the following-
- Who was present, what decisions made, time frame for follow-up, responsibilities assigned.
- It is recommended to keep writing to a minimum.
- Further notes can be taken at the discretion of the MDT.
- A summary of the CPM proceedings should be placed in the patient's medical chart.
- Discretion regarding any further documentation can be used depending on the nature of the meeting e.g. high-risk discharges.
- The patient and family should be informed that a record of the meeting is being made and stored. It may be helpful to provide a summary of the main decisions reached to the patient and family.

Definitions: For the purpose of this document the following definitions can be applied.

Multi-Disciplinary Team (MDT): Includes doctors, nurses and allied health professionals.

Case Conference: Where MDT meets on a weekly basis to discuss the patient list

Multi-Disciplinary Care Planning Meeting: involves the patient, family members/carers/support person and members of the MDT in discussions concerning the patient's illness, treatment and plans for their discharge or care outside the hospital.

Family: is defined broadly to reflect the patient's inclusion of important people in their lives, biologically, legally or otherwise related.

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