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BODY, SELF AND WORLD: THE EMBODIED EXPERIENCE OF CHRONIC ILLNESS AND MEDICAL TECHNOLOGY

This thesis was submitted to the University of Dublin, Trinity College for the degree of Doctor of Philosophy

2009

Gráinne Ní Mháille

DECLARATION

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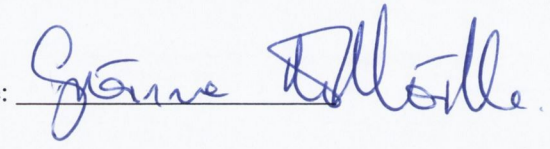
Signature: 

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ABSTRACT

BODY, SELF AND WORLD: THE EMBODIED EXPERIENCE OF CHRONIC ILLNESS AND MEDICAL TECHNOLOGY

Objectives: Illness and medical treatment profoundly alter how we experience the body and relate to our worlds. The aim of this thesis is to carry out a conceptual and empirical analysis of the role of the body in the experience of health and medical treatment. **Design:** 20 (7 men, 13 women) semi-structured interviews were carried out with individuals who had been diagnosed with renal failure or cancer. The technologies of haemodialysis (5), radiation therapy (7) and surgery (8) were investigated. **Analysis:** The interviews were analysed using a two-step analysis: (i) a thematic analysis that generated themes, which described the participants' experiences of illness and treatment, was conducted; (ii) an interpretative analysis that generated themes pertaining to the embodied experience of illness and medical treatment. **Results:** Two overarching motifs were generated in the findings: (i) the impact of illness and medical treatment on the individual in a physical, personal and social sense; (ii) the role of embodied meaning in the experience of illness and medical treatment. **Conclusions:** Embodied experiences are meaningful. Bodily changes are not experienced objectively: rather they have repercussions for the individual. Conclusions were drawn which suggested practical implications for healthcare as well as theoretical implications about how we can reintroduce the body into psychology.

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~ CHAPTER ONE ~
THE BODY IN PSYCHOLOGY

Introduction

The primary goal of psychology is to understand the person; to explain how we as human beings think and why we think the way we do, how we act and why we act the way we do. Clearly, this is a problematic and arduous undertaking. To even attempt to understand the person, many diverse and conflicting factors need to be considered. However, the difficulty of this undertaking makes it all the more pressing. Indeed, what it means to be a person is an issue of enduring human concern. According to one view, espoused by thinkers such as Descartes, the person is made up of a union between an immaterial mind and a material body. Body and mind are different substances and it is the mind that gives us our distinct identity and shapes our thoughts, behaviours and experiences. Mind and not body, therefore, characterises the person. This view is slowly being rejected. As mental functioning can be explained in terms of the functioning of the brain and the central nervous system, it would be surprising if the body and the mind were entirely distinct substances. Other views, therefore, identify the person and the mind with their physicality, the body or the brain. Indeed, it is difficult to image a person or self without a body of some sort.

Approaches in psychology, however, typically iterate the view that mind and body are separate entities. This has led to the conceptualisation of the person and his or her existence as being defined largely by mental processes and functioning. The dearth of ecological and theoretical validity in this approach is concerning. Of course, it would be wrong to say that we have not gained a considerable understanding of the person though the investigation of mental processes. However, the limitations and drawbacks inherent in such approaches must also be recognised.

Cognitive Psychology and the Body: The New Cartesian split

The fundamental principles of cognitive psychology

Cognitive science is the interdisciplinary study of mind and embraces the disciplines of philosophy, linguistics, neuroscience, anthropology, artificial intelligence and psychology. The intellectual origins of the cognitive sciences can be traced to the development of models of mind based on computational procedures. Cognitive psychology represents a branch of this interdisciplinary endeavour that concerns itself with the mental processes that are internal to the person. Within the cognitive paradigm the person is envisioned as engaging in complex mental operations that gear the person to respond to given situations. At the core of the cognitive paradigm in psychology is a focus on the mental processes of the individual. Core topics in cognitive psychology include language, memory and learning and how individuals understand, diagnose and solve problems. Today, the paradigm represents the dominant approach to the study of psychology. The cognitive revolution in psychology refocused psychological attention on cognitive processes.

According to cognitive theories of mind, mental processes such as cognition, learning and remembering to sensation and perception are heterogeneous. Hence, cognitive psychology has adopted a facultative approach to the person. This approach differentiates between different 'faculties' of mind and then aims to localize these faculties in specific areas of the brain. Accordingly, cognitive psychology affiliates itself with nativism, according to which, mental processes are hardwired into the brain (Chomsky, 1965; Fodor, Pylyshyn & Demopoulos, 1986; Pinker, 2005). In other words, people are born with an innate propensity for certain attributes and these attributes are seen as being supported by specialised and evolutionarily adapted areas of the brain. Hence, mental processes are seen as supervening on the intrinsic physical assets of the individual (the brain). This approach encapsulates the "modularity thesis" (Fodor, 1986). According to this thesis, the mind consists of modules, which are separate and innate structures with specific functions. The best way to study these modules, and by extension mental processes, is in isolation from each other. A piecemeal approach to the study of the person is instantiated. That is, by investigating mental processes in their separate state and coming to fully understand them, we can eventually create an aggregate reservoir of psychological knowledge that describes the person.

In cognitive psychology, mental processes are represented by computational models and are depicted as occurring inside the head of the individual. The construction of these kinds of mental models which focus on information processing, coincided with the introduction of the 'mind as computer' analogy. The funadmental tenet of this analogy is the idea that the workings of the human

mind are similar to the workings of a computer; therefore, the mind is an information processing device comparable to the running of a computer software programme. In other words, the person acts like a computer. We process information (albeit frequently subjectively and erroneously) and execute abstract calculations on that information. Cognitive theories of how people engage in social situations propose that mental representations of such objects determine thinking and behaviour. In social scenarios people are seen as using formal processes such as self-monitoring, goal-setting and evaluative judgements to guide their behaviour (Bandura, 1986). For example, Social Cognitive Theory (Bandura, 1986) proposes that individuals process and amalgamate information regarding a given situation, with information regarding possible behaviours that can be engaged in, and with one's beliefs about one's own capabilities. The outcomes of these judgements are seen as determining social behaviour. In this model and similar others, the person is depicted as an information processor carrying out computations on the information at hand in order to arrive at a decision. People are depicted as being similar to formal scientists; collecting, processing and interpreting data. The use of these types of models in psychological research has become prolific. Model building and testing are typical of realism and logical positivism.

Realism and logical positivism

Realist psychology did not originate with cognitive psychology. However, cognitive psychology has certainly promoted the doctrine of realism as the appropriate ontological foundation for psychology. The ontological assumption of realism is that a reality exists 'out there' independently of our perceptions of it. Adherence to this doctrine has achieved considerable success in the natural sciences. A platform of realism allows cognitive psychologists to assert the tangibility of mental processes. Thus, what happens inside the head of the person can be assumed and causal explanations for psychological properties, cognitions and behaviour may be advanced. Realist psychology espouses cognitive properties as natural properties, and as such can be studied objectively and can be isolated from the context in which they occur. This supports the idea of a psychological reality that can be truthfully known. Hence, cognitive psychology allies itself with the realm of the natural sciences, alongside physiology and biology. This in turn allows for a following suit of the natural sciences in terms of methodology. In other words, a logical positivist approach is amenable to psychological enquiry. Positivism dictates that only scientific knowledge, which can only be extrapolated from objective observation, is authentic knowledge. So, not only does a psychological reality exist but we can come to know it objectively if rigorous procedures for conclusively determining the nature of phenomena are used. Quantification and experimentation, therefore, constitute the *sine qua non* of our understanding of

psychological properties (Michell, 2003). Psychological research has been considerably influenced by these doctrines. Experimentation, and its related hypothesis testing and statistical analyses, is considered to be the foundation for an objective psychological knowledge. Experimentation necessitates controlling for extraneous variable, or noise, in order to examine the specific issue of interest to a researcher. In psychological research, therefore, the individual and the phenomenon of interest are removed from the context in which they are found.

Solipsism

A solipsistic approach to human life is instantiated by cognitive psychological research. That is, an individual's psychological properties can be seen to supervene on an internal state of the individual and can be understood without any reference to the environment in which the individual exists (Fodor, 1986). The environment in which the individual exists is inconsequential. Therefore, an individualistic depiction of mind is offered. According to cognitive psychology, formal mental processes occur inside the head of an isolated individual. Thus, the mind can do its work without reference to the outside world. A central processing mechanism for thought is proposed and constitutes the proper starting point for understanding human existence and experience. This is typified in cognitive approaches to child development, where the child is seen as passing through specified and universal stages of cognitive organisation (Piaget, 1954). Mental processes are seen as being uniform and, therefore, can be studied without regard of the context or culture in which they occur. An isolated, de-socialised individual is construed. The individual is abstracted from his or her environment and the cause of psychological states must be understood in terms of properties which are intrinsic to the individual.

Metaphysical implications: An asocial mind

Despite the accomplishments and dominance of the cognitive paradigm within psychology, the metaphysical implications of the information processing and model building approach are such that psychological attributes are reified and individualised. Furthermore, mental processes are given a super ordinate status in psychological life and the body is treated in a reductionist manner. The doctrines adhered to by cognitive science, modularisation, realism, positivism and solipsism, have been largely accepted and can be seen to constitute *a priori* constraints on psychological theorisation. An emphasis on the modular mind and a facultative approach to the study of psychological processes atomises psychological enquiry. It is arguable that theorising in psychology has been stifled and this militates

against a holistic view of the person. The philosophical and methodological approach of cognitive psychology has resulted in the depiction of the person as being made up of a collection of processes. Indeed, grand theories in psychology, such as those in a psychoanalytical or behavioural framework that aim to account for the make-up of the entire person, appear to have disappeared from psychology (Bretherton, 1999). Wilson (2004) argued that the unit of analysis in psychology has become smaller, thus, the conceptualisation of the person in psychology has become less encompassing, more partial and increasingly linked to specific models, techniques and research strategies. Psychology in this sense has become less theoretical, or perhaps more theoretically suspect, as the person is reduced to processes that occur inside his or her mind and studied in a, piecemeal fashion.

Furthermore, the cognitive premise that suggests the mind consists of formal processes and exists in abstract form inside the head of the individual can be argued to be suspect. For example, from a cognitive perspective interpersonal verbal and non-verbal communication are understood in terms of having representations of social situations and knowing the rules of how to act appropriately in social interactions. The actual social situation in which interpersonal communication occurs is inconsequential and the input of environmental factors into the psychological make up of the person is minimised as human thought and mental processes arise from the mind's internal machinations and not external sources. Social or environmental concepts such as class and culture are theoretical 'dead ends' and approaches that investigate such concepts are seen as leading psychology down a blind alley (Wilson, 2005). However, it is highly unlikely that the human being can be delimited without reference to the outside world.

Wittgenstein (1953) argued that psychology essentialised certain psychological attributes and then projected those attributes inside the head of the individual. Taking the example above of communication; communication cannot be seen as merely messages or signals that have no meaning. Rather, communication is inherently about creating meaning and sharing meaning with other individuals. Language can be used to create one sense or another depending on use. For example, using the term 'retarded' implies a very different meaning than the term 'learning disabled'. Likewise, gestures in communication demonstrate complicated, non-verbalised social relationships, such as social distance (Parker, 2007). Thus, forms of communication have a social significance that can only be understood in a social context. The cognitive processes involved in communication cannot be seen as a trait of an isolated individual as it is individualistic in neither origin nor location. Cognition is increasingly being seen as an activity in an environment as opposed to a formal and abstract process

(Bem & Keijzer, 1996). The individual is not an isolated cognitive agent. Rather the person is engaged with others and is embedded in a socio-cultural environment (Martin, 2003). However, cognitive research has numerous examples of how actions or cognitions that are fundamentally social are essentialised, reduced and then projected inside the head of the individual. For example, recognition or the process of recognising another individual, by its very nature, is an inherently social process. This, however, is absent from cognitive theories of recognition (Bem & Keijzer, op.cit.). Likewise, memory may be less an attribute of the individual than a social process. However, traditional cognitive research often depicts social influence on an individual's cognitions as leading the person astray and inherently dangerous (e.g., Laney, Fowler, Bowman, Nelson, Bernstein & Loftus, 2008). Yet memory can often be enhanced by interactions with other people, and "forgotten' information can recalled and improved. Mental phenomena, in a sense, are not *entirely* mental (Parker, 1996). Society is inherently involved in experiences and the influence of social processes must be recognized.

Cognitive psychologists depict the human mind as a syntactic machine (e.g., Chomsky, 1981). However, given the intrinsically social nature of the mind, it is perhaps more accurately understood as a semantic machine (Bem, 2001; Wittgenstein, 1953). People are embedded in a sociocultural environment; therefore, they are meaning makers not just information processors. That is, people do not respond to an objective event or an object, rather they respond to the meaning inherent in the object. Consequently, we can only gain insight into the human being when we grasp the meaning that people attach to their activities and objects in their environment and consider the person as embedded in a sociocultural context. Meaning is not in the head of the individual. It is embedded in human customs and institutions and in a cultural context. Therefore, many psychological properties do not lend themselves easily to operationalisations that allow for quantification. Thus, adhering to a theoretical and methodological approach that demands quantification will impoverish psychological knowledge, as quantification cannot elucidate the meaning inherent in phenomena (Harré, 2004). Furthermore, a solipsistic approach to the person cannot lead us to a true understanding of the person as it ignores the social conditions that inform people's activities.

Cognition, therefore, is part of a wider cultural context. In contrast to Piaget, Vygotsky (1978, 1986) emphasized historical cultural and social influences on cognition and thought. According to Vygotsky human and cognitive development is mediated by social interaction and cultural forces. Through the medium of language and through the social interaction between the child and his or her social groups, a child comes to possess the habits of mind of his or her particular culture. In this sense,

human knowledge is primarily social. The mind cannot be understood in isolation from a community of human beings; therefore, the impact of the socio-cultural on psychological attributes cannot be ignored. Cognitive psychology can help us learn about how the mind works. Vygotsky (1978, 1986) argued that we are cognitive machines, however, we are machines which are activated by social interaction. Social processes cannot be ignored and in many cases should be given primacy. Yet cognitive psychology studies the mind as distanced from a social environment. Furthermore, the mind is also given a diaphanous nature and is depicted as being detached from a body. However, the body is the constituent of our presence in the world and as such creates an influential context for human existence and interaction, yet cognitive psychologists ignore the body and its role in psychological life.

Neo-Cartesianism and reductive materialism

According to cognitivism, mental processes consist primarily of computations and operate on symbolic or syntactic representations of the world. The mind is seen as an abstract entity that operates inside the head of the individual. Cognitive psychology, therefore, promotes a functionalised conception of mental processes that has strong links to dualist doctrines. Cartesian Substance Dualism proposes that thinking constitutes the essence of human nature. As Descartes (1647) argued, the person is made up of two utterly distinct substances; a non-physical substance or the cognitive machinery a person possesses, as well as a physical substance made up of mechanical machinery that is the body. According to dualism, the body is an object and bodily events are explainable by physical, mechanical formula. This body can also be removed from psychology, as an understanding of the mind can not be furthered illuminated by reference to physical events[1]. Therefore, a conception of the human nature without reference to the body is promoted in Psychology and precedence is given to the mind. Like it or not, the philosophy of dualism has had an enduring influence on our conception of human nature and the body. Indeed, one could argue that dualism was instrumental in the development of psychology as a separate and successful field of academic enquiry as it created a space for investigation of the mind, which was separate from biological inquiry and philosophical inquiry (Wilson, 2004).

While the cognitive paradigm accepts that psychological life is based on a physical substrate, the brain. Essentially mental processes are studied without reference to the body. Thus, the cognitive

[1] The blame for dualism in psychology cannot be laid entirely at the feet of Descartes. For a historical analysis of the development of dualism in psychology see Leder (1990)

approach of functionalism introduces a type of neo-Cartesianism whereby mind and body are seen as two different substances (Plumwood, 2002). However, cognition in the real world differs from the cognitive processes advanced by cognitive research. Cognition is not abstract, it is an activity and the body plays an important role in such activity. Consider for example, when doing a jigsaw puzzle, we do not rotate the pieces inside our head. We interact with the pieces, picking them up and rotating them (Bem & Looren de Jong, 2006). Bodily sensations play an important role in everyday choices and decisions. The bodily experience of emotions, happiness, sadness, uncertainty, inform people actions and cognitions (Immordino-Yang & Damasio, 2008). Indeed, we often talk about "following our hearts" when it comes to major events and decisions about our lives. Bodily experiences have an important role in our mental and social lives. For example, touch is something that has vast emotional significance in our lives. To receive a caring hug or to be touched threateningly can have enormous personal and social significance. Similarly, the experience of a serious illness is far more significant to us than merely a body that is want of repair. The body is inherent in all our social interactions and plays an important role in meaningful experience. However, in psychology a reductionist account of the body is typically espoused.

The body that has been produced in psychology is neutral substrate for mind and is portrayed in a physiological manner. This is widespread, even in a field like health psychology that professes to challenge the mind body-split in medicine and psychology, the body is seen as an object and studied in a mechanical manner (Ogden, 2003). Health psychology is concerned with how biological, behavioural, social and psychological factors influence health and illness. Within this general objective, health psychological research is exemplified by a cognitive approach. The associated philosophical underpinnings of cognitive psychology advance the primacy of mental processes and undermine the influence of physical processes in the experience of health and illness. The clear separation of mind and body characteristic of mainstream psychology is reflected in most theories in health psychology. Health behaviours are conceptualised as being driven by mental processing of information and visceral aspects of human existence are only minimally involved. In illness bodily signs and experiences are interpreted by the mind. Bodily sensations and experiences, at best, constitute a peripheral or augmentative component in human thought and experience in the context of health and illness.

Likewise, in developmental psychology, Theory of Mind research focuses on the ability to attribute mental states to other people (e.g. Baron-Cohen, 2005; Carpenter, Akhtar & Tomasello, 1998). The development of a theory of mind in children is considered to be an important cognitive

development. Acquiring a theory of mind allows a child to understand the causes of other people's behaviour and as a result, explain and predict behaviour. One can say in defence of Theory of Mind research that it is useful to understand how people learn to reason about how other people think and behave. However, such theories are implicitly dualistic as they suggest our understanding of other people is forged out of our understanding of mental states and eliminate any scope for the body in understanding self and other people (Overton, 2008). The body is absent from the development and execution of mental activities and interpersonal interaction. The role of the body and perceptual and sentient experiences during development are marginalised. Cognitive psychology, and its subdivisions, centres on a pre-eminent mind which is independent of social and bodily influences. However, dissatisfaction with this approach is growing.

The Turn to Language in Psychology: The Discursive Body

Social constructionism, language and meaning

Dissatisfaction with the cognitive approach and a growing critique of cognitivism has become ever more prominent since the late 1960s. The idea that the mind, and indeed the person, is an encapsulated and socially isolated entity has been heavily criticised by social constructionists. According to social constructionism human phenomena are socially created and language is seen as the crucial defining characteristic of human life. However, language cannot be fully understood if it is conceptualised as being encapsulated in the mind. Language is not simply something that happens in the head of the individual, nor is it an objective tool for communication between people. Language is not passive; it is an actor and a constructor and mediates discourse.

In social constructionism, discourse represents an institutionalised way of thinking and defines the way human beings can think about objects and events in their lives. Social constructionist approaches promote a cultural and discursive psychology in which language is a critical symbolic tool. Social discourse originates meaning and is central to how people make sense of their lives. The "turn to language" in psychology reflects the increasing impetus for the study of discourse and the linguistic, contextual and social context of human practices. Increasingly, social constructionist approaches are being used to provide social explanations for a broad range of phenomena such as attitudes, memory, "self", personality and emotions. Thus, the fundamental tenet of this approach is that human life is a

social phenomenon and develops in a social context. Psychological phenomena, therefore, are always meaningful to human beings because they develop in the socio-linguistic contexts in which we are immersed. To fully understand human life and experience it is necessary to grasp the meaning people attribute to objects and events in their lives.

Social constructionists take issue with the individualistic nature of cognitive psychology. It is argued that individualising a given phenomena is to essentialise it. For example, Lafrance and Stoppard (2006) argued that the way mainstream psychology portrays depression as a biomedical and individual "disorder" results in the stigmatisation of women's bodies and pathologises their everyday experiences. Social constructionist approaches refuse to locate psychological phenomena, such as depression, inside the head of the depressed person. This is argued to depathologise the individual by locating not phenomenon, such as depression, within the individual but rather in his or her social world. This enables the reframing of such phenomena as social constructions by focusing on the discourse inherent in the way people talk about their experiences. The recognition of the role that language plays in the construction of concepts and values has opened up a space for critical psychological enquiry. Human experiences are refashioned from individualistic, natural phenomena to social, relative phenomena. Furthermore, the nature of psychological enquiry and the findings that emanate from research are brought into critical dispute (Gergen, 1984).

Relativism

Social constructionism generally adheres to an ontological relativism. That is, human worlds and human experiences are relative to the socio-cultural and historical context to which they are tied. Relativism repudiates the realist assumptions of mainstream psychological research. Social constructionists that adhere to relativism argue that even if a real world exists it is only accessible through the language and discourse used by humans to understand their experiences and their worlds. Thus, social constructionists refute the idea of an objective access to a "reality" outside of language. Therefore, a social ontology is necessary. Danziger (1997) gives a good historical account of how psychology and its categories developed because of cultural and social constructions and, hence, questions the naturalness of psychological categories. As psychological categories are always constituted by discourse, the aim of psychological research must be to uncover the social construction of reality, the texture and quality of experience and the subjectivity or meaning inherent in experience.

The realism-relativism debate in psychology has been considerable. According to realism and logical positivism, psychologists, their ways of describing phenomena and their methodologies are objective and generalisable from time to time and place to place. Psychological constructs are assumed to be unproblematic and purely descriptive, therefore, can guide psychological investigation regardless of context or culture. However, according to social constructionist psychology even psychological knowledge cannot be removed from its socio-cultural and historical context. In other words, the vocabulary of psychology defines its subject. Social constructionists argue that there are many different languages, many different ways of being and therefore, there are many different psychologies. Gergen (2005) claims that there are no universal, fixed meanings. Therefore there are no facts or fixed human characteristics that are not dependent on social discourse. Therefore, psychological research must not make *a priori* assumptions about the person. Knowledge and human activity are intertwined and are socially constructed. Therefore, they are historically and culturally specific (Bem & Keijzer, 1996).

Social constructionism rests on the primacy of language as a constructive factor in social and psychological phenomena (Burr, 2006). My own position is largely sympathetic to these claims. Social constructionists are very much correct to question the idea of an intransitive human reality and to characterise psychological phenomena in terms of the meaning they hold for individuals. Therefore, social constructionist approaches have benefited psychological research greatly with the recognition of the historical and cultural specificity of psychological life. However, the limits of social constructionist approaches in the context of the prospective research have to be recognised.

The discursive body

A central issue to both cognitive and social constructionist approaches is the ontological status of the body. While cognitive approaches treat the body in a physiological and reductionist manner, social constructionist approaches to the body are also reductionist, albeit in a different manner. Social constructionists eschew positivist approaches in favour of discursive analyses. Discursive analyses constitute a set of qualitative approaches to the study of psychological phenomena. A wide range of different qualitative analyses are available, such as conversation analysis, grounded theory and discourse analysis. The commonality among qualitative approaches is their commitment to analysis of the meaning inherent in written or spoken language. They aim to gather an in-depth understanding of human behaviour and to elaborate the why and how of subjective experience. Such research is

particularly good at illustrating how meaning and experience can be constructed and deconstructed in social settings. However, Burr (1997) asks "what happened to the person" in social constructionism (p. 115)? By focusing on social discourse social constructionist approaches reduce the idea of self to the status of text. Although, mainstream psychology's conception of "self" is deeply flawed, social constructionism has also stumbled when it comes to its conception of the "self".

The idea of the self, therefore, has become a problematic concept for social constructionism. Social constructionists' total emphasis on discourse highlights the role of language in the construction of the psychological concepts of personality, traits, motivations, emotions and attitudes and self. It is these concepts that we as folk psychologists often employ to explain our sense of uniqueness and individuality and to explain our self-hood. The focus on discourse, however, implies that these phenomena are illusory (Foucault, 1969). While social constructionists have endeavoured to show that the facets of the self as studied by cognitive psychologists are in fact social phenomena, and to replace positivist research with the investigation of a social self (Cromby & Standen, 1997), the resultant emphasis on fluidity, variability and contextualisation has reduced the self to a narration. The idea of 'self' in social constructionism is seen as a construction which is deployed by individuals to effect specific social meanings. Thus, the 'self' in discursive studies, is a concept that we have and which is malleable in the face of certain social exigencies. In this sense, self has no real existence, or is redundant to our understanding of processes involved in meaning. The interactions between self and society, the persons' personal histories and their embodied existence in the world have to be considered to be influential in the meaning persons create in their experiences and worlds (Cromby & Standen, 1999).

Language cannot be seen as the only actor in the psychological make-up of the person. The material aspects of human life include the environment, institutions, tools and technologies available to us in our environment, and also the body. While pursuing a line of enquiry whereby reality is shaped by cultural conventions is a necessary and valuable endeavour, we must also take into account the material features of human existence. Humans are embodied beings; embodied existence must play a prominent role in the construction of meaning. The body, however, has been banished from social constructionist accounts of the person. Foucault (1969) examined the relationships between power, knowledge and discourse and argued that historical systems of thought and action determine our behaviours. The body in this sense can be seen as a social entity rather than a natural identity as the emergence of a notion of 'the body' can be linked to social practices and historically emergent discourses. This outlook refutes

the idea of a primordial self or human nature. Furthermore, conceptions of the body are located in practices of power which discipline the body and tell us how individuals and society should treat the body and behave. In this portrayal the human body is plastic and malleable and an instrument for social control. The body is, therefore, seen as being discursively produced (Foucault, 1969). However, the body is natural and physical. Hence, it has a materiality that cannot be ignored. Human life is material, and there are possibilities and constraints in this materiality that social constructionism needs to take into account. That is, the properties and dimensions of the body can limit or enable the discourse that can be placed on the body.

While acknowledging the progress social constructionism has made in advancing theory and research about socially mediated nature of human life, when it comes to bodily matters the approach has faltered. Adopting a relativist ontology has privileged language and has eliminated the embodied aspects of human life. Thus, social constructionist approaches are undermined by the materiality the body. To date social constructionist approaches deal with the body by providing detailed analysis of the discourse of bodily matters. Undoubtedly our understanding of embodiment has been furthered by examining how discourse is written on the body and how it can shape people's experiences and perceptions of the body. Douglas (1999) speculated that the body was a microcosm of society. From this perspective social categories constrain physical experience and the body is seen as a medium for expression of social meanings. Goffman (1959) similarly examined the body in interaction and how bodily appearance is carefully managed to express aspects of the self to others and to create an image that is socially expressive in some way. Lupton & Seymour (2000) showed how the disabled body is shaped in discourse. While these studies appear to deal with the body, they simultaneously dismiss the body by failing to consider the role of embodied as agentic and as limiting and enabling discourse.

We cannot remove the physical aspect from the social lives of human beings from our conceptions of the person in psychological theory. That is, we cannot understand psychological life if it is examined solely as a social construction. The body is inherent in all of our experience. Therefore, it must be seen as an actor in human life. Even language cannot be treated as something with a life of its own having a totalitarian power of construction. Language is not just a social activity; rather language has embodied characteristics. Lyons & Farquhar (2002) showed how cardiovascular activity when talking about oneself increases. Increased cardiovascular reactivity correlates with the process of self-construction in talk. Furthermore, cardiovascular reactivity varied depending on whether the conversation took place with a family member, friend or stranger. Interpersonal interactions and also

self-constructions are not just social. Rather, they are embodied activities that require physical work as well as the navigation of social mores set out in discourse. Moreover, language development in children is preceded by and strongly linked to physical development and development of gestural communication (Gallagher, 2005). Also, Lakoff and Johnson (2002) argue that the body, and worldly experiences through the body, plays a crucial role in shaping thought, language and language use. Indeed, Lakoff and Johnson argue that abstract concepts and metaphors and the many ways that human beings think are shaped by bodily dimensions, aspects of the body, the way the body allows us to move around space and can be used as a frame of reference[2]. The body, therefore, plays an important role in human life and cannot be ignored.

The role of the body, or rather embodiment, in shaping experiences and human understanding has been neglected by social constructionism., While taking into account the embeddedness of the person in social, cultural and historical circumstances, social constructionism does not recognize the body as a space where meaning is created and embodied. The body cannot be ignored or treated as a metaphor or text and treated purely discursively. Social forces do influence the body. The body is part of a social world and society teaches us how to think about the body. However, the body and consequently the person cannot be fully understood as a social construction. The drawbacks of social constructionism are therefore, the limits of relativism. Despite the importance of the social context of human life, the physical reality of human life must also be recognised. Human beings have bodies and the production of meaning has to be seen as linked to the possibilities inherent in the body, as well as in the social world. Indeed, many social constructionists are beginning to recognize the physical reality of human life and its role in the psychological makeup of human beings (Burkitt, 2003; Burr, 2006; Harré 2001, 2005). For example, Harré (2001) recognizes certain conditions, including human embodiment, which stand outside of discourse. A notion of the embodied person is vital for social constructionist approaches. Therefore, there is a need to understand the embodied person as being more than just text or symbolic.

[2] A more detailed discussion of such studies will be conducting in the next chapter.

A Real Body in a Social World

Critical realism

Social constructionist approaches allows for the exploration of the way subjectivity is socially generated. However, adherence to a relativist epistemology in social constructionism has set the stage for social determinism. That is, the emphasis of the socio-linguistic aspects of psychological properties has been neglectful of the possibilities of other influences on human experience, such as the influence of the body (Parker, 1999). Undoubtedly, social constructionist approaches have aided our understanding of embodiment through the elaboration of how discourse and cultural specifications influence perceptions of the body. To an extent aspects of experience such as perceptions, sensations and emotions are socially defined and constructed, however, they are also fundamentally visceral in nature. Failing to account for the materiality of human life will ultimately undermine our ability to understand how the whole person understands and relates to the world. Human experience, therefore, has to be understood as both embodied and socio-culturally mediated.

Certain social constructionists, in an attempt to remedy the problems caused by relativism, have proposed a critical realist framework for the social sciences (e.g. Bhaskar, 2002; Williams, 2003; Willig, 2000). Critical realism adopts a realist ontology and represents a non-relativist approach to social constructionism (Willig, 1998). The idea of a realist social constructionism approach can be traced to Bhaskar (1989, as cited by Bhaskar, 2002). Bhaskar (ibid) argued for a position that combined the idea of human agency with the idea of social constructive mechanisms. Critical realist approaches are beginning to gain considerable support and are garnering substantial interest in philosophy of mind and science (Willig, 2007).

The overall aim of critical realism is to combine realist and social constructionist perspectives to create a position whereby non-discursive elements are understood as having an impact on meaning. Critical realists accept a materiality to human life, which is non-discursive. These material aspects are ontologically distinct and can facilitate or inhibit certain discursive constructions being active. Critical realism, therefore, allows for the exploration of the impact of materiality on discursive practices as they are conceptualised as being situated within a material context and talk is seen as a way of negotiating that materiality. So, according to critical realism, meaning is still seen as arising out of social discourse, however, materiality is also accorded an agentic and significant role. That is, critical the material

structures in human life are understood as being able to accommodate discourse. Combining realist and relativist doctrines allows for discourse and materiality to be able to influence one another and to play an agentic role in subjectivity. Thus, a bi-directional relationship between the material aspects of human life and the socio-linguistic is substantiated. The position represents a significant advancement over entirely relativist approaches that make token or no gestures to the role of material factors in psychological life. Thus, critical realism can help us to avoid treating the human body in a reductionist manner.

Critical realist approaches have received some criticism. Indeed, many social constructionists would accept that material reality exists 'out there'. However, they believe that it is inaccessible to us. That is, once we start to debate an object which is in the world, we necessarily enter a world of rhetoric and discourse. So, what we know of the object is always mediated by language rather than any of its material properties (e.g., Shotter, 1993). Critical realists refute this argument. In critical realism a distinction is made between ontology and epistemology. Critical realism subscribes to epistemological relativism which recognises that our ability to access 'true knowledge' and to understand people's experiences is always mediated. However, the approach also recognises that "there is a material dimension to our lives that is, at least, partially non-discursive" (Sim-Schouten, Riley & Willig, 2007: 103). Thus, in critical realism, language is retained as the principle technology for representing, constructing and communicating information and maintains that objective access to people's meanings can never be simply assumed. However, critical realism argues that a material dimension to human life cannot be denied. Furthermore, discourse and materiality should not be conceptualised as being remote of one another, nor estranged from us. Rather, discourse and materiality are seen as being necessarily tied to one another and interpretation must be based on this link. Thus, in critical realism language maintains the status of a primary force in constructing social reality. However, this does not ignore the materiality of the world and all its inherent possibilities and constraints.

> "...for critical realists, material practices are not reducible to discourse, or without meaning unless interpreted discursively; rather, material practices are given an ontological status that is independent of, but in relation with, discursive practices" (Sims-Schouten et al., 2007, 2007: 102).

Critical realism, thus, proposes an ontological realism which recognises the material influences on human life. Cromby & Nightingale (1999) list these material influences on human life as (i) the embodied nature of human life, (ii) material aspects of human life including physical geography and (iii) institutional power. The existence of these material factors emphasises that psychological phenomena are underscored by real structures, such as corporeal as well as other material and tangible factors. These structures must be seen as being generative of meaning in their own right. Sims-Schouten et al. (2007) have promoted the concept of a critical realist discourse analysis as exemplified in their study conducted on women's talk about motherhood, employment and childcare. In this study, Sims-Schouten et al. (ibid) trace how factors such as financial and familial pressures shape how women talk about their specific decisions regarding their employment and childcare.

Few empirical critical realist studies have been carried out. Indeed, one of the main criticisms lobbied at critical realism is that there is no systematic way of distinguishing between discursive and non-discursive practices. Sims-Schouten et al. (ibid) develops a critical discourse analysis that focuses on the material influences, including embodiment, materiality and institutional power, that structure discourse. This approach is outlined in their study of women's beliefs, attitudes and talk in relation to childcare procurement for their children. Other approaches which can come under the rubric of critical realism include phenomenological approaches. Phenomenological approaches constitute a material-discursive approach to psychological phenomena (Yardley, 1996, 1997). Material-discursive approaches, as the name suggests, share with discursive approaches a focus on the socially and linguistically mediated nature of human subjectivity but also reflects a concern with the material features of human life. Phenomenological approaches can maintain a constructionist emphasis on society and rhetorical practices but to also take into account the materiality of human life, such as embodied factors.

Phenomenology is concerned with exploring the lifeworld of individuals. Thus, the aim is to make discoveries about persons, their experiences and the experiential world (Giorgio & Giorgio, 2003). Yardley (1997) and Smith, Flowers & Osborne (1997) argue that a phenomenological approach is consonant with investigating the experience of physical disruption. Yardley (op.cit.) states that the "*phenomenological perspective is able to encompass the prominent and active role of embodied being in the construction of the meaning of health and illness*" (Yardley, 1997: 14). Phenomenology focuses on human experience. As with other discursive approaches, phenomenological approaches focus on

meaning and interpretation. Phenomenological investigations are concerned with personal perceptions of events and how people perceive the worlds in which they are immersed. The phenomenology of the body argues that embodied existence is meaningful and purposeful. Thus, phenomenology represents a potential way of reconciling materiality and discourse as it provides the scope for exploration how both materiality and discourse influence human experience (Butt, 1999).

A holistic as well as ontologically sound psychology must take the material aspects of human life into account (Burkitt, 2003). A critical realist, phenomenological perspective can bring embodied being into qualitative psychology and allow us to investigate the bidirectional relations between society and the embodied person (Bendelow & Williams, 1995; Willig, 2008). Thus, we can begin at least to understand the person, or the self, as an embodied being embedded in a social and material world. Williams singles out critical realism as a way of "bringing the body back in" to discursive psychology (Williams, 1999: 797). In a critique of the debate on models of chronic illness and disability, Williams (ibid) argues that the body in social constructionist and politically-correct models is treated in a reductionist manner. Thus, the body is construed as being negotiated, shaped and labelled by social and discursive practices. However, Williams points out that these debates on the body omit the physical body itself, or at least eliminate the materiality of the body. Using medical examples Williams points out that despite variability in disease labels, they do have descriptive value. Thus, the label cannot be understood as being entirely constitutive of the disease itself. Similarly, society has various descriptions for disability. Examples of such descriptions range from 'handicap' to 'differently abled'. According to the Social Model of Disability (Oliver, 2007) these differential terms are seen as reconstituting disability, indeed eliminating disability. However, simply because we label disability differently, does not mean disability does not exist. The body, regardless of what we call it or how we chose to address it, is a real entity.

Our embodied nature constrains who we can be and what we can become, how we think and what we can think about. Critical realism can readdress the absence of the body in discursive psychology by giving it the status of a real entity, one which underlies discourse and orients the individual to discourses of different kinds. A critical realist framework, therefore, allows us to assess the agentic and generative force which is the embodied nature of human life, the organic infrastructure for self in the body and the contingencies that our embodiment prescribes for the individual.

Conclusion

We must consider the body as a meaningful entity in our lives (Radley, 2003). The body can configure ways of being. We understand the world because of our visceral experiences of the world. However, the body has been all but absent from psychology. In fact, in psychology the body has been deliberately abandoned by adopting as a fundamental ontology the doctrine of Dualism. Thus, psychology has a long history of ignoring the body. However, as physical beings the body plays a major role in our lives. Ironically, despite the considerable 'stand-off' between cognitive and social constructionist protagonists, where both approaches are inadequate is in their theorisation, or under-theorisation, of the body. The lack of interest in the body in mainstream psychology has not been challenged by the self-proclaimed alternative approaches of social constructionism. On one hand we have a picture of the person as a mechanistic information processor and on the other hand we have a picture of the person as a disembodied constructor of meaning. In both of these outlooks the body, despite its primacy in human life, remains absent. The body can shape our lives in many different ways. Throughout our lifespan, physical developments and changes bring evoke meaningful changes in the social and emotional experiences of the individual. The significance of the body is highlighted in its deviance from the norm. When the body confers frailty in illness, it has a significant impact on experience and subjectivity. A 'malfunctioning' body or disabled body shapes our experiences and impinges on social interactions. Thus, the body is significant, yet rarely dealt with in the arena of psychological enquiry.

The body is beginning to receive more attention in the social sciences. A recent upsurge in interest in bodily matters is becoming increasingly apparent. This can be seen as originating in an increasing dissatisfaction with. Furthermore, social developments such as the expansion of a consumerist society which increasingly commercialise the body, and technological developments which portent dramatic changes to how bodies are and how they relate to the world, have thrust the body to the forefront of both the public's and academia's awareness. Social changes have also brought bodily matters to the fore. The body is increasingly becoming more and more problematised and medicalised. A growing culture of control has encouraged a need to mould the body and the idealization of the slim body type increasingly objectifies the body. However, we are also seeing increasing numbers of people develop chronic illnesses such as obesity, cancer and chronic heart disease. The proliferation of new technologies to shape, control and mediate our corporeal relation to others has led to significant existential questions being asked by both an academic and lay populace (Bendelow & Williams, 1998).

Embodiment is a central condition in social life. Not only does a sense of embodiment allow people to engage with and come to know their worlds, being embodied also allows individuals to symbolize their worlds and take a stand to each other (Radley, 2005). Thus, subjectivity and sense of self is at least partially constituted through embodied interactions. The body is, therefore, significant in our lives and sense of self. Thus, it cannot be ignored nor relegated in psychological theory to the status of mere object or text. This has implications for both theory and methodology in psychological research. Embodiment theory has important considerations for Psychology. The objectified and neglected body of psychology needs to be replaced by a phenomenological body, a body that symbolizes aspects of our social life (Stam, 2004). The phenomenological body is juxtaposed to the body we treat as an object or text. The scale of body perception and bodily action in the production of meaning must be taken into account. We are embodied and embedded in the world; neither the world nor meaning is external to us. The critical realist approach represents a step in the right direction by aiming to identify the structures underlying social reality. While recognising the limitations inherent in current discursive methodologies, critical realism can create a conceptual space where reality is seen as being based in being. Therefore, knowledge can be seen as being situated in a world of embodied, material as well as social relatedness. We are not just exploring discourse, but also the world that is inherent in discourse.

~ CHAPTER TWO ~

A PSYCHOLOGY OF THE BODY

Error!

Introduction

A compartmentalised view of human life that dichotomises the biological and the social is insufficient for a thorough understanding of human existence. Indeed, dualism is hardly fashionable in the psychology today. Despite disavowals of dualism, psychology, purposely or otherwise, continues to hold to the basic assumption of dualism and to bifurcate mind and body. Based on the preceding discussion, if we accept that adhering to metaphysical dualism of mind and body is no longer tenable; how can we incorporate the body into psychology, theoretically and empirically? Undoubtedly, the body, as described by Vernant (1989), is "an entirely problematic notion" (p. 20, as cited by Csordas, 1994). The body itself has a story. Across generations and lifespans it mutates and fluctuates. The body changes and body concepts change. The body, therefore, is intransient and ambiguous.

However, if anything can be assumed about human life it is that the body is ever present. It is impossible to imagine mind or person without body. Alfred Whitehead captured the dissonance in conceiving of mind-body separability in his humourous statement:

> *"No one ever says, 'Here am I, and I have brought my body with me'" (Whitehead, 1938: 156)*

The body is always a part of human life and the above quote captures some of the impossibility of thinking otherwise. The body necessarily has a permanence and stability. Yet this discussion of the body began by elaborating on the absence of the body from psychology. The body itself ought to be recognised as an important theoretical and empirical focus in the social science. To fail to account for the body in a non-essentialised, non-reductive way, is to misunderstand a fundamental aspect of human experience; the experience of embodiment.

The Human Body: Mechanistic Views of the Body to Embodiment Theories

The human body is made up of a complex network of tissues and cells. By the time the human body reaches adulthood these tissues and cells number in their trillions. The human body consists of a head, torso and limbs, there is a circulatory system, a respiratory system, a digestive, excretory and urinary system, an immune system, a reproductive system, a musculoskeletal system, and a nervous and endocrine system. What the human body is, and what it becomes over the course of an individual's lifespan, is determined by multiple factors. Heredity, prenatal ontogenesis and a multitude of postnatal factors are all critically involved in shaping the human body.

Historically, the move from seeing the body as a receptacle for the soul imbued with religious import, to seeing the body as the object of scientific enquiry is appreciable. The inexorable scientific and medical breakthroughs that accompanied technological growth in the study of biology, physiology and medicine have furthered our scientific understanding of the physiological body and our ability to treat physiological dysfunction. Jardin (1999) describes how scientific study of the human body began in earnest with the advent of the Renaissance. Dissections, autopsies and experiments were carried out with the aim to understand what the body was and how it worked. Thus, a religious understanding of the body was abandoned. More and more, the body was thought of in a mechanistic fashion as the human body began to be understood in the light of technological developments of the time. Human bodies were automaton machines with invisible internal cogs and funtional mechanical organs. The development of microscopes and resultant ability to view and study compositional aspects of the body too small to be seen by the naked eye, reinforced mechanistic explanations for the workings of the body and promoted general acceptance that the principles which underpin the greater physical world, atoms and molecules, are the same as those that underpin the physiological make-up of the body. The post-war explosion of molecular biology and a push towards understanding the genetic make-up of the body. Crick & Watson (1953) solved the question of the molecular structure of DNA. The discovery was a major scientific breakthrough and revealed for the first time the molecules which contain hereditary information. This set the stage for rapid advances in molecular biology and the scientific exploration of how genes and DNA convey and transmit genetic information. Therefore, molecular biology examines how specific characteristics or traits are encoded in the genetic information contained in DNA. The instigation of the Human Genome Project signalled an advanced stage in understanding the molecular basis of human life.

The aim of the Human Genome Project is to delineate the genetic make-up of human beings. A rough draft of the genetic make-up of the human body was published in 2006. The coding of the human genome has brought us to previously unimagined understanding of the complex make-up of the body. The project is ongoing and offers increasing avenues for medicine and biotechnology. Such research provides the potential for developing cures for genetic and heredity disorders and informing people of the genetic risks to which they are susceptible. Biotechnology and genetic engineering, therefore, among other advanced technologies have led us to a unique point in history in terms of our scientific capabilities in the respective fields of biological and medical science.

The impact of the Human Genome Project from a scientific perspective has been immense. The minutiae of the body's make up and functioning have been elaborated and the potential for medical breakthrough augmented. However, from a psychological perspective these developments are the cause for some concern. A negative outcome of the Human Genome Project is that it reinforces biologically reductionist views of the body. Avoiding biological determinism is important for psychological theorising. Bodily experiences are not just physiological, they are phenomenological. However, as the body becomes more atomised, or broken down into its cellular make-up, a more holistic understanding of the body and bodily experiences becomes more distant. A notion of a meaningful body is not permitted by a mechanistic understanding of the body. Understanding the molecular make up of the body does not tell us anything about an individual's embodied experiences. A person does not experience the physiological body. One is rarely aware of how the internal, physiological functions of the body work. That is, eating a hearty meal is not understood by a hungry individual in terms of the digestive workings of the body. Rather, it is experienced in of terms desire, satisfaction and enjoyment. Therefore, as human beings, we experience the body on a meaningful level.

Chronic illness is a severe breakdown of the functioning of the physiological body and is a most critical concern for modern Western societies and an increasing number of people are living and suffering with a chronic illness of one kind or another. Understanding chronic illness from a biomedical perspective has clear value. Understanding disease aetiology and progression is important in terms of patient information and treatment. However, a biomedical view of illness can lead to an impoverishment of our understanding of the illness experience. Indeed, 'illness' creates a different sense than 'disease'. Illness refers to the way in which an individual interprets his or her experiences (Turner, 1996). Illness has personal, social and cultural implications for an individual and is significant

to the person in terms of discomfort, disruption of life and their interpersonal relationships. Bodily changes in illness represent more to the individual than disease symptoms or disease progression in that they have meaningful weight in personal terms. Biologically reductionist views of illness cannot help us to understand the illness experience as it does not allow for an understanding of meaning and suffering (Radley, Cheek & Ritter, 2006).

The increase in chronic illness also means that more and more people are experiencing and living with medical technology. Previously unavailable medical therapies have now become standard, if not commonplace. Some of these medical technologies, such as life support machines or ventilators are supporting, indeed enabling life for some people from a physical perspective. Other types of technology enable the 'correction' of physical disability. 'Old fashioned' technologies such as canes, wheelchairs and eye-glasses have been joined by newer, more advanced technologies such as catheters, hearing aids, cochlear implants and contact lenses. Furthermore, plastic surgery enables the 'correction' of disfigurement and allows for aspects of physical appearance that are considered to be aesthetically displeasing to the person to be augmented, altered or removed. More people are availing of plastic surgery to change the way they look for non-medical concerns (Zuckerman, 2008). Thus, the physical body is increasingly being moulded at will. Notions that once belonged in the realm of science fiction, the possibility of growing new body parts or creating new bodies, are now spoken of by the scientific community as inevitable and as a natural progression of scientific discovery. Increasingly, the possibility of the 'body-machine' being repaired and serviced with new parts, improved, and replaced in its entirety is being suggested.

Such technological and medical capabilities, while welcome and progressive in many respects, have raised complex and frequently threatening existential questions amongst an academic and lay populace alike. As the field of medical technology has grown, increasing concerns about the implications of these developments are being voiced. Not all biotechnological developments have been welcome. The cloning of Dolly the sheep was not heralded as a great scientific discovery. Rather, the announcement of the first successful cloning attempt was greeted with considerable outrage, moral disquiet and was vehemently opposed, particularly in the media. The achievement was portrayed as leading humanity down a dangerous and unknown path (Petersen, 2005). Developments in biotechnology are seen not as transforming 'bodies' but human beings and the lives of human beings for the worse. Considerable concern that the natural borders of life are changing is evident. Such doubts about the naturalness and ethical correctness of medical technology betrays the significance of the

human body. The body, therefore, is considered to be essentially human, a critical part of who we are, who we become and who we portray ourselves to be in our social world. Despite the outrage and controversy that has sometimes surrounded medical and biological technologies, a distinction between some more advanced and questionable technologies and the routine technologies ordinary patients experience in standard hospitals needs to be made. Individuals suffering from a serious illness face medical technological treatments to cure or to manage that illness. Under these circumstances, the person experiences the physical disruption of illness and the often equally disruptive consequences of medical treatment. Such treatment, however, is necessary for the person's survival. One wonders how such bodily changes are experienced by the individual.

These issues have driven interest in embodiment theory. The core assumption of an embodied approach is that the body which we as human beings experience is qualitatively different from the physiological body of the scientific and medical world. In an embodied outlook, the body is seen as a living thing, not just an automaton that is unimportant to our everyday social and psychological life. The embodiment perspective is capable of producing a conception of the whole person, as a social, cultural, psychological and embodied entity, in psychological science as it allows for a meaningfully embodied person as well as a social, cultural, and psychological person.

> "Embodiment is the claim that the person's perception, thinking, feelings, desires – that is, the way that the person experiences or lives the world – is contextualised by person's being active agents with this particular kind of body" (Overton, 2008: 11 – 12).

For human beings the body is experienced as meaningful. Therefore, the body is different from a biologically reduced and determined body. However, this body is also different from a body that is discursively produced.

Any notion of 'the body' is problematic. Indeed, *bodies* are increasingly being referred to by cultural psychologists and sociologists as a means of indicating the body is not fixed nor can it be seen as a given (e.g. Csordas, 1994). There are a myriad of different factors and issues that demand an account if we are to understand what it means to be embodied. The crux of the problem is that we are

not theorising about the body *per se*, rather about embodiment. Embodiment references the body as a physical entity and also as a lived entity, that exists within and actively engages with a sociocultural and physical environment. Embodiment research is being carried out in a variety of different fields and disciplines, including linguistics, neuropsychology, discursive psychology, sociology, anthropology and philosophy. Within these various strands of embodiment research, different theoretical formulations of the body elaborate different ways in which the body actually embodies the person and how environmental, physical and pychological factors interact to generate human experiences.

Embodiment theory and research seek to overcome the hegenomy of the mind in matters of human existence and to restore meaning and significance to the body. In doing so, it must also tackle the equation of corporeality with biology. The privileging of biological factors in explanations of phenomena that are social conditions essentialises bodies and furthers the gap between the physical and the sociocultural. Physical existence, in a sense, is not just physical. True the human body is visceral. However, corporeality is experienced in realms that are psychological, social and cultural. That is not to suggest that corporeality is constituted solely by social or psychological conditions. Rather, that the bodily and the social are continually interconnected and reciprocally influence each other. The purpose of embodiment theory therefore, is to theorise the body as an agentic force in human experience in a non-essentialised, non-reductive way (Csordas, 1994). Overton (1997) describes embodiment from a relationist perspective that objects do not exist in pure forms. In this instance, mind is not seen as causing body, nor does body cause mind. Rather they are co-constituted and form indivisible complementarities.

Dimensions of embodiment theory and research

Defining embodiment and providing an overview of embodiment theory and research is a difficult undertaking. Roher (2006) delineates twelve dimensions of embodiment theory and research in total, which catalogues some of the contemporary usages of the term embodiment. These dimensions are listed in the table below:

Table 1: Dimensions of embodiment theory and research taken from Roher (2006)

	Dimension	Research
i.	Philosophy	Based on counter-Cartesian movements and

		metaphysical investigations into language, meaning and knowledge
ii.	Sociocultural situation	Based on the social and cultural practices within which the body is situated
iii.	Phenomenology	Based on the existential body and the role the body plays in shaping self identity and culture
iv.	Perspective	Based on research that focuses on the embodied stance of a speaker and the way in which the body forms a vantage point from which a particular perspective is taken
v.	Development	Based on the developmental changes a person goes through, the ontogenesis of the body, the acquisition of sensorimotor skills and increasing capabilities of the body and how ontogenis is critical to emergent sense of self
vi.	Evolution	Based on reseach that investigates how evolutionary history has shaped the body
vii.	Cognitive unconscious	Based on research that focuses on unconscious cognitive schema
viii.	Neurophysiology	Based on an interest in measuring the activity of the particular neural structures and cortical regions during embodied tasks
ix.	Neurocomputational modelling	Based on research into neurocomputational modelling which seek to model the functioning of neural circutry and illustrate that experiential activity and cogntition is grounded in neuronal activity
x.	Morphology	Based on research in linguistc derivational morphology which seek to illustrate how the physical limitations of the body place constraints on cognition
xi.	Directionality of metaphor	Based on the assumption that the way we map information from an embodied domain onto another domain, thus giving rise to complex cognitve skills
xii.	Grounding	Based on research which seeks to illustrate how the use of metaphor can be linked to embodied experience

The many dimensions, listed above, of embodiment theory and research clearly illustrates the diversity of the field. Both critical and empirical investigations of embodiment reference many issues and many lines of inquiry. Across these lines of inquiry there are different emphases and multiple methodologies are employed. Indeed, it would be impossible to deal with all of the aforementioned perspectives on embodiment in one project. The twelve dimensions (which should not be taken as exhaustive) reveal the

concept of embodiment to be a synthesis of perspectives including the biological, phenomenological and sociocultural and environmental. This outline constitutes a rough division of the field of embodiment that can provide a general overview of embodiment theory.

Overton (2007) describes three broad standpoints on embodiment. A biological standpoint explores embodiment at the level of brain mechanisms, genes, and physiology. Well known researchers within this area include Damasio (e.g. Bechara, Damasio, Tranel & Damasio, 2005) and Edelman (e.g., 2007). Among other issues, such researchers tackle the conceptualisation of the mind as a functional mechanism. Damasio (1994: 234) argued that "mind is probably not conceivable without some sort of embodiment". Thus, mind must be considered to be embodied. If mind must be found in the organic foundation of neurological and physiological entities then cognition, affect and behaviour have organic underpinnings. A sociocultural and environmental standpoint on embodiment examines the influence of sociocultural forces on the body. Researchers such as Young (e.g., 2005) examine the discursive body and the way the body is treated by culture. However, a sociocultual embodiment perspective must also questions the hegenomy of sociocultural influences on human psychology so often seen in the discursive human sciences. There is increasing recognition by social constructionist theory that it is necessary to anchor discourse in an embodied world (e.g., Cromby & Nightingale, 1997). Indeed, the body and the demands and needs of the body can be conceptualsed as having an influence on culture and discourse. Overall, sociocultural and environmental perspectives on embodiment see the body as the medium for our actions and as having an agentic role in the shaping of social discourse. A phenomenological and person-centred standpoint explores the body from the perspective of the person (e.g., Merleau-Ponty, 1962). As an experiential perspective, it tackles how the body is the vantage point from which people experience and explore their worlds. The body is seen as a critical aspect of lived experience and the person is conceptualised as being situated and actively engaged in their environment through their bodies. Phenomenological and person-centred approaches emphasise the meaning people attach to their experiences and how their activities are shaped by bodily experiences. The embodied person, therefore, is seen as an actor who actively represents his or her world, and experiences the world.

The central concern of this thesis relates to embodied persons. It is unassailable that one body implies one self. We tend to think of persons as being delimited by their bodies and as such being made up of concrete, corporeal matter. Thus, the body undoubtedly plays a critical role in personhood. However, we can still ask what is the nature of the relation of the body to identity? How are abstract

concepts and characteristics such as personality or identity influenced by the physical body? If the body plays a role in shaping self then what happens to the self when the body is disrupted in the instance of chronic illness and medical intervention? Both the phenomenological body and the socio-cultural and environmental body are pertinent to these concerns. The phenomenological body has to be seen as being situated in a social environment. One's relationship with the body constitutes a very private relationship upon which even the individual himself or herself need not reflect. However, we cannot understand the body fully from this solispistic perspective. So, the body is privately experienced, but it is also publicly experienced. Thus, culturally determined influences on the body must be taken into account. The aim of this discussion is to pull multifarious threads of embodiment theory and research together to illuminate the examination of how our embodiment can influence self, impinges on our experiences and shows up in social circumstances. This will be reflected on in light of the interest on the relationship between the person, the body and the experience of chronic illness and medical treatment.

The Embodied Person: The Role of the Body in Psychological Life

Human beings are corporeal. Therefore, the world is experienced through the body. Our eyes allow us to see, our ears allow us to hear, and our skin and hands allow us to touch and to feel. The body is inherent in all human experience. Our perceptual organs mediate our experiences and understanding of our worlds. Furthermore, through the body we can react to and interact with our surroundings. The mobility of the body allows us to move around our environment, to manipulate our environment and to respond to and interact with other people. Behaviour is driven by our corporeal emotions and desires. From the basic cravings of hunger and thirst to cognitive and intellectual pursuits, the body is involved. Bodily experience, perceptual, sensorial and visceral, plays a formative role in experience. Human experience of the world is physical. Human possibilities are delimited by the body and its underlying biology. The body generates physical and emotional experiences, and provides us with the cognitive capabilities that govern our experiences of our worlds (Millward & Kelly, 2001). According to the embodiment perspective, the body is fundamental to human experience, indeed the basis for experience. Such a base not only provides for an understanding and awareness of the world, but also an understanding and awareness of self.

Merleau-Ponty, phenomenology and embodiment

Phenomenological approaches to embodiment aim to describe the essence of human experience and perceptual contact with the world by focusing on the way objects appear to us in our consciousness. Phenomenology attempts to move philosophy and psychology away from abstract theorising and reductive explanations of the body. This project became an abiding commitment of Merleau-Ponty. As a phenomenologist and existentialist, over the course of his career he studied topics of aesthetics, metaphysics and psychology. In particular, the exploration of non-dualistic embodied experience was of considerable significance to Merleau-Ponty (1945, 1968). No other philosopher has dealt with the body to such an extent. The depth and significance of Merleau-Ponty's thought is still important for embodiment theory and his work provides the backdrop and inspiration for much of the contemporary research into the concept of embodiment. The chief inspiration for Merleau-Ponty's work was the German phenomenological tradition that emerged in the twentieth century, in particular the reflections of Husserl and Heidegger. Merleau-Ponty continually returned to human corporeality to better understand human experience and noted the denigration of the body that governed the majority of metaphysical enquiries. Thus, he sought to rearticulate the relationship between subject and object, self and world, primarily though an account of the lived and existential body. According to Merleau-Ponty, the body's significance is considerable and too often underestimated. He saw the body as more than a mere mechanism which was controlled by a diaphonous mind. Rather, human beings are embodied beings and existence is corporeal, therefore, separation of the person or the mind from the body was metaphysically incorrect.

In his major work the *Phenomenology of Perception* (1945) Merleau-Ponty exposes the problems inherent in coercing apart from one another, what he saw as the inseparable entities of mind, body and world. Adhering to metaphysical dualism whereby the body is treated as object enables scientific analysis to establish an objective world 'out there' (p.72). However, the scientific study of the material world and human life, however, cannot have the same significance or meaning for us as the world we perceive. The body seen in a scientific and objectified sense is problematic, as the subject cannot be understood as distinct from the physical. To counteract the pre-eminence given to the mind in Western culture and the social sciences, Merleau-Ponty gives a perspicacious account of the perceptual and sensory abilities of the person and how these primordial talents both shape our existence and insert us into the world. In order to understand human existence, one could not move away from this concrete world of experience. The body, therefore, defined the fundamental basis of human existence. Being a

body renders the world intelligible to us. The body must be seen as skilled, thinking, perceiving and erudite. Seeing the body soley as mechanistic and examining it from the third person perspective is inadequate for philosophical and psychological investigations of human existence.

The body-subject, perception and knowledge

Merleau-Ponty recognized that a person's body is a permanent condition of experience and existence in the world. Indeed, experience is grounded in the bodily nature of human existence. For Merleau-Ponty, the shape of the human body and its innate capacities enabled human life. The body, therefore, cannot be conceived of as simply a vessel in which we are present (Merleau-Ponty, 1945, 1968). Merleau-Ponty saw the human body as inextricably intertwined with the mind and self. In some ways he decried the idea of a person having a relationship with his or her body. Rather the body and the person are one and the same and cannot be conceptualised as separate. The embodiment perspective of Merleau-Ponty introduces the idea of a "*body-subject*" which is juxtaposed with the objectified, reduced and mechanical body of the human sciences. Furthermore, the body-subject connotes the inseparability of the person and one's sense of self from the physical body. The body, therefore, is understood as being the foundation for self, rather than a mere substrate.

As his major work "*Phenomenology of Perception*" (1945) indicates, Merleau-Ponty took as his point of departure the world of perceptual experience. He begins his phenomenological account of the body by according primacy to perception. Perception, according to Merleau-Ponty is the fundamental unit of human experience and, therefore, it must be accorded a critical role in every action of which the individual partakes. The perceptual capabilities of the body allow us to experience and to engage with our worlds. Therefore, it is through the body that we come to know the world around us. Unlike a reductionist conception of perception quite frequently perpetuated by mainstream psychology, perception in the Merleau-Pontian sense is not just the product of sensations. Psychological and physiological aspects of perception interact and influence each other. Thus, perception is not purely sensation. However, perception cannot be seen as pure interpretation either. Furthermore, the body as a whole is seen as the organ for perception of the world and bodily experiences give perception meaning. Thus, Merleau-Ponty argues that knowledge and consciousness are embodied and are dependent on embodied perception and bodily investment in the world.

According to Merleau-Ponty, perception has an active dimension. In other words, perception is projective; the perceiving person projects themselves and their intentions into the perceptual field to which the perceiver belongs. Merleau-Ponty uses the example of the vase/face diagram to illustrate how what we see and notice in our surrounding environment is conditioned by multiple factors. The vase-face diagram is made up of blocks of colours separated by the contours of two lines. When describing this diagram, however, we can make out two separate and meaningful entities. So, the experience of perception represents a type of gestalt which is made up of aspects of the world combined with psychological and social factors. The world is, therefore, a phenomenal field and perceptions assign meaning to objects in this field and the field itself. The natural and perceptual capabilities of the body insert the person seamlessly into the world.

Merleau-Ponty took issue with the traditions of empiricism and rationalism as they fail to account for the reciprocal determination of perception and consciousness. We cannot separate ourselves from our perceptions of the world. Our relationship with the world is holistic in that we are part of the world and co-exist with it: both constituting and constituted (p. 453). We do not see things as they really are, nor do we construct things in our minds. Rather, objects we perceive and experience are understood through our embodied relationship with the world. Thus, as human beings, while being part of the world we do not just passively experience our worlds, we also have the ability to construct our worlds, physically and emotionally (Kelly & Field, 1996). Being a body, therefore, represents a condition of intelligibility. The body allows us to experience and know our world. Thus, by providing this basis the body is critical to the development of consciousness and an understanding of the world and of self.

Corporeal relations to the world: "Being in the world"

According to Merleau-Ponty (1945) the body constitutes a fundamental way of being in the world. The body is the medium through which we experience the world and the body also locates us in the world. The body allows us to exist and sustains life and submerges us in the world. The body, therefore, not only acquaints us with a physical and biological world but brings forth the world. Thus, Merleau-Ponty put forward the idea of our '*being in the world*' (*être au monde*), which highlights the corporeality of our existence and the mutual engagement of the embodied person and the world. Our 'being in the world' means that we are located in a physical world in a physical manner, thus, we are in the world in

a unified, holistic way. Through the physical nature of the body, the perceptual and sensory skills of the body, and the body's engagement with the world, our world becomes available to us.

The body, therefore, provides us with an erudite way of interacting with the world. Indeed, we have an intuitive understanding of the world and of our existence thanks to our embodiment. Young infants, for example, do not have to learn how to breath, suck or eat. Thus, we have an instinctive knowledge of the capabilities of our bodies as well as their limitations. Being embodied provides us with an innate form of intelligence that allows us to go about our everyday lives. Our bodies and the way in which we implicitly and unknowingly use our bodies in everyday life testify to this phenomenology of being a body in a world. This perspective refutes dualistic thinking. Being a body constitutes a prereflective way of interacting with our world. Merleau-Ponty refers to a 'third genus' which is reducible to neither the mental nor the physical. Acts such as perceptions and gestures, and the experience of situations are of this third genus. It is in these acts that the intuitive and pre-reflexive body is evident. The erudite way in which we use our bodies in the world illustrates that the body and the world are not reducible nor separable, rather the body and the world co-exist.

As embodied beings we always experience the world and objects in it from the perspective of the body. Objects in our environment exist for us because we always experience from the body and what our embodiment affords us. A chair, for example, is something to sit on, or a desk is something to sit at and write on[3]. Objects in the environment therefore, are seen as allowing for certain bodily engagements and disallowing others. Thus, knowledge of the world is always brought about because of our embodied perspective on the world. The ways in which we live through and with the body in the world, expresses our embodiment and our being-in-the-world. Situations, actions and perceptions have to be seen as being co-constituted by both the body-subject and the world.

According to Merleau-Ponty, the way in which the body determines what shows up in our world is threefold. The innate structures of the body, its basic general skills, and its cultural skills shape our worlds and bodily experiences. To exemplify this point Dreyfus & Dreyfus (1987) use the instance of how to Western human beings a chair is solicitous of sitting to illustrate the contribution of innate structure, general skills and cultural skills to everyday life. As we have bodies that can be physically

[3] This idea is also referred to as Brentano's Thesis of Intentionality.

exhausted and that bend forward at the knees, chairs can entreat sitting. However, chairs can only afford sitting once we have learned through our engagement with the world to sit: in other words once we have acquired the basic habit of sitting. Finally, only because we Western human beings are brought up in a cultural environment where one sits on chairs do chairs afford sitting on them. Chairs, for example, do not solicit sitting in traditional Japan. By embodiment, Merleau-Ponty examines these three ways in which he saw the body as opening us up our world. The body is our general medium for having a world, it projects itself into the world and is an instrument through which we learn about the world. Merleau-Ponty argues that the body is situated, and the mental and physical are inextricably intertwined. Mental activities and human subjectivity are not seen as existing in grand isolation from the world, therefore, cannot be located in the private domain of the mental. The bodily, the worldly and the social are interwoven. Behaviours, feelings and thoughts are based in the body and have physiological repercussions. However, these embodied acts are inevitably publically manifested and therefore must make sense in an intercorporeal world[4]. The body confers a sense of capability and of engagement. Hence, the body plays a formative role in our sense of self.

Embodied existence and the person: A sense of self

From a phenomenological perspective the body is seen as the basis for understanding everyday human experience. The boundaries and capabilities of the body allow for the development of a concept of self, which delimits the individual and which is personal. The body immerses us in the world and therefore provides a sense of agency and purpose, thus confering a sense of capabilities and limitations. Laing (1960) argued that:

> "the embodied person has a sense of being flesh and blood, of being biologically alive and real. He knows himself to be substantial. Being in the body allows for a sense of personal continuity. The body is a base from which he can be a person with other human beings.....everyone even the most unembodied self fells himself as inextricable bound up with or in his body. To the extent that one feels one's body to be alive, real and

[4] The way in which the body exists in a sociocultural situation will be dealt with in-depth later.

> substantial, one feels oneself to be alive, real and substantial" (1960: 13).

The body confers an understanding of our world and a sense of who we are. The body that allows us to project ourselves into mental life. Therefore, the body can be seen as the basis for mind and for an understanding of self and others. Neonate propioceptive awareness can be seen as evidence for how our embodiment gives rise to self-consciousness. Gallagher (2005) uses the example of newborn infants' imitative abilities to argue that newborns have a sense of body and of movement and as a consequence, of self and other. Thus, consciousness of self is structured from our earliest moments by our embodiment. It is the body, and not a diaphanous mind, that lays the foundation for consciousness, thought and an understanding of oneself. The body, therefore, establishes self through the pre-reflexive engagement of the body with the world. Furthermore, through this engagement the body allows for ongoing development of consciousness and thought. Hence, we can develop specific, more explicit, concepts of self and our body. The body, therefore, plays a critical role in thought processes, meaning and social life (Selinger, 2008).

The role of embodied being in thought, meaning and social life

Cognition must be seen as the product of an embodied person situated in an environment. The body is the basis for all experience, it is a permanent presence and the very medium through which world itself comes into being (Borret, Kelly & Kwan, 2000). It is the body, not that mind, that first perceives objects. We first engage with the world through our primordial sensorial and perceptual capabilities. It is these sensorimotor abilities and experiences that are seen as forming the basis of cognitive functioning. Though most of Piagetian developmental theory instantiates a separation of mind and body, Piaget's account of cognitive development in neonates emphasises the role of bodily capabilies in acquiring cognitive skills (Müller & Newman, 2008). The sensorimotor stage of cognitive development posited by Piaget bears a considerable resemblence to Merleau-Ponty's description of being-in-the-world. In the sensorimotor stage, sensory and motor capabilities allow us to engage with our worlds in perception-action cycles. Infants use reflexive actions like sucking, pushing and grasping to interact with the world. These experiences are seen as forming the basis for meaning. Thus, experience and subjectivity is bound up in embodied action. In adulthood the way in which we think, how we think, and what we think about, is dictated by these early corporeal experiences as well as ongoing corporeal relations with the world.

Smith and Thelen (2006), by analysing children's movements when confronted with a "visual cliff" (an apparent steep drop covered by transparent glass) argued that children's cognitive development is dependent on bodily factors like movements. Infant behaviour emerges out of a perception and action integration which must be seen as embodied. Similarly, when learning to walk newborn infants do not pass through neat behaviour transitions, rather they develop strategies to deal with environmental conditions which they confront. Infants learn by interaction (Thelen & Smith, 2003). Indeed, bodily movement is consequential for cognitive development as witnessed by research which shows that severe physical disability in childhood can hinder and impair cognitive development (e.g., Uye, Alant & Llyod, 2005). Developments in behaviour and actions are emergent. Human experience cannot be understood as developing out of a single factor or a pre-ordained genetic blueprint. It arises out of many combining properties in a mutually engaged being-world system.

A brief look at research that investigates embodied cognition illustrates the many ways in which the body serves to guide and shape human thought. For example, it has been shown that the functioning and morphology of the body serve to shape cognition. Parsons (1995), in a series of mental imagining studies where participants were asked to mentally rotate line drawings of human hands, found that subjects were quicker and better at judging which hand was pictured when mentally rotating the hand did not require difficult bodily movements, such as rotating one's hand to the left. Thus, mental tasks can be easier or more difficult to perform depending on the types of bodily limitations we have as embodied beings (as cited by Roher, 2006).

Furthermore, affective bodily states can affect the way individuals encode, process and use informational input from the environment (Niedenthal, 2007). Damasio's somatic marker hypothesis argues that the body and emotional processes guide decision making in everyday life scenarios, particularly ambiguous situations (Damasio, 1994). Niedenthal and colleagues (2007) asked participants to rate the funniness of different cartoons while holding a pen in their mouth. Half the participants were asked to hold the pen between their teeth but not touching their lips, which entailed these participants holding a smile-like facial gesture. Other participants were instructed to hold a pencil between their lips, without touching the pencil with their teeth, which prevented them from smiling. Results revealed that individuals who were led to smile evaluated the cartoons as funnier than did participants whose smiles were prevented. It appeared smiling (a bodily state) facilitated the comprehension of the comic meaning of the cartoons. Indeed, language use and understanding can be linked to bodily states. Studies also illustrate that social information processing involves embodiment. For example, Schubert, Waldzus

& Seibt (2007) showed that making a fist facilitated men's and women's processing of words related to concepts of power. Wells and Petty (1980) found that nodding or shaking one's head while listening to a message influenced later judgements of the message. Participants who were instructed to nod revealed more favourable judgements of the message subsequently.

Stefanucci, Proffitt, Banton, & Epstein (2005) found that the research participants perceived hills as steeper and distance as further when asked to wear heavy backpacks. Similarly, elderly volunteers or individuals who rarely exercised saw hills as steeper than younger or active volunteers. Furthermore, Bargh, Chen and Burrows (1996) found that participants walked slower subsequent to being primed with an elderly stereotype. These studies indicate that bodily experiences are closely linked to cognitive processes. Likewise participants' estimates of an unemcumbered woman's ability to jump were lower when they were wearing ankle weights themselves as compared to when they were not wearing ankle weights (Ramenzoni, Riley, Shockley & Davis, 2008). Gibson's ecological theory of percpetion stress that visual perceptions are meaningully interpreted and it appears that embodied understanding and experiences as well as bodily sensations can influence this meaning.

Cognition is part of a perception-action cycle and, therefore, can only make sense if understood as a coupling between the embodied being and his or her world. Cognitions are not just mental and cannot be understood as abstract symbol manipulations (Bem & Keijzer, 1996). Bem and Looren de Jong (2006) reference the 'on-line' strategies (Clark, 1997: 42) of behaviour to encapsulate the way in which human beings use adaptive physical behaviours to solve problems as they engage with the world. For example, when considering where to hang a picture on a wall we often use our hands to gauge where it would be best positioned. Cognition, therefore, is part of an action in an environment. This promotes a conceptualisation of mind as being embodied and world embedded (Bem & Looren de Jong, 2006).

Embodied cognition

Bodily structures, capabilities and experiences provide the basis and guide for human subjectivity which we create in our everyday lives. Varela, Thompson and Rosch (1991) provide a particularly influential outline for how cognition is embodied. Varela and colleagues saw cognition as an 'enaction'

(term borrowed from Bruner, 1986). Enactive cognition argues that knowledge comes to a person through action and interaction, thus, is constructed through sensory-motor skills.

> "the enactive approach consists of two points: (1) perception consists of perceptually guided action and (2) cognitive structures emerge from recurrent sensorimotor patterns that enable action to be perceptually guided" (Varela et al., 1991: 173).

Thus, cognitive structures are emergent and interpretative. Cognition is, therefore, embodied and situated (Varela et al., 1991). In enactive cognitive science, the individual and society, mind and world are seen as existing in a co-constituitive relationship. Therefore, cognition is dependent on being embodied in an environment. Thus, there is no "inner mind" and "outer world", rather there is the integration of sensory, perceptual, motor and psychological functioning which brings forth both the world, sense of self and subjectivity. Enactive cognition research is transforming concepts of consciousnesss and first-person cognition, situated action, social perception and cognition and intersubjectivity (McGee, 2005a, 2005b).

Johnson (1987) examined how the body can shape world understanding and activity. The bodily basis of experience, the nature and limits of our perceptual systems, motor systems, anatomical make-up, the environment, evolutionary history, our needs, and emotions dictate what it is possible to think about and how we think about it. Thus, knowledge and understanding depends on bodies and embodied interaction with the world. Lakoff & Johnson (1980) proposed that the way our bodies work and the nature of bodily interactions with the environment shape the nature of human reasoning. Johnson (2007) argues that meaning is linked to sensorimotor experiences. That is, early in life we develop image-schemas based on bodily perception and action. These image schemas support thinking, which in turn must be seen as being based in embodiment. In other words, basic schemas and concepts are anchored in bodily experiences. We talk of a 'head' of steam, the 'foot' of the mountain, the 'face' of a mountain, the 'eye' of the needle, the 'hand' of justice and so on. The usage of these terms according to Lakoff & Johnson is based in knowledge and experiences of the body. The Lakoff-Johnson approach argues that embodied experiences since early childhood synthesise into image schemas. These image schemas have a "corporeal logic" (Johnson & Lakoff, 1999: 90). The body's structure and the

natural abilities of the body such as perceiving, manipulating, moving and eating give rise to image schemas which in turn delineates ideas, ways of communicating, memory, and other concepts. For example, the body is seen as a container with dimensions for in, out and boundary. These body-based meanings are then extended to imaginative thinking and conceptual thinking. Thus, bodily experience allows for meaning and abstact thought, meaningful symbolic interaction, expression and communication.

The body and abstract thought

Bodily based concepts can also be seen as leading to more abstract concepts. Thus, the abstract world does not come out of nowhere. In fact philosphers such as Johnson have argued that abstract concepts can be understood as being rooted in embodied being. For example, Johnson and Lakoff (1999) argued that thought and language consists of bodily based metaphors metaphors. Cavallaro & Vago (1997) detail terms referring to the body and how they are often used to describe people. Thus, descriptions of the body are frequently used in a metaphorical way. People are described as communicating in a tongue-in-cheek manner, as having guts, they may be shouldering a burden or turning a blind eye to something or someone. Lakoff & Johnson (1980) attempt to illustrate how abstract thought is tied to the body and how the body achieves symbolic expression. So, abstract concepts like justice, love, freedom can be explained as being based in understandings of embodied meanings which are tied to sensory and motor experiences. We use metaphors of uprightness to represent a moral way of living, we talk of falling in love and following our heart, and we desire up move up the career ladder. For Johnson and Lakoff these metaphorical descriptions are representative of the way in which we as humans know our worlds through our embodiment. Thus, bodily senses, experience and the spatiality of the body allow for the extrapolation of abstract concepts. It is the link to bodily orientation, manipulation, movement, perception and sensation that makes metaphorical and abstract concepts meaningful to us.

Grady (2005) put forward a theory of how complex metaphors are built from body based image schemas. He argued that children conflate sensory and motor experiences. For example, they do not differentiate between subjective experiences and judgements. When an infant is held by his or her mother, the infant experiences affection and warmth simultaneously, and does not differentiate between these. Later in cognitive development, the child acquires the ability to differentiate these, however, they remain coactivated and associated. This gives rise to a primary metaphor "affection is warmth". Grady argued that this metaphor underlies expressions such as "She was cool towards me". Metaphorical

statements and beliefs in this sense are seen as being based in sensorimotor experience, in this case the sensorimotor experiences of temperature and closeness. Grady (2005) lists other metaphors including "Bad is stinky" which underlies statements like "this reeks of corruption" or "this smells fishy". This metaphor is based on sensorimotor experience of smell. Embodied knowledge is, therefore, seen as a primary source of metaphorical meaning and understanding.

It must be recognised that such theorising has been criticised. The claim that all our thought, language, abstract conceptualisation and reasoning is ultimately tied to our embodiment is a strong argument in favour of a philosophy of the embodied mind. Pinker (2008) argues that the metaphors used in everyday language can be linked to embodied image schemata. However, he qualifies this with the idea that the original user of metaphorical phrases such as "the eye of the needle" may have been motivated by the corporeal logic of such a phrase; however, in their contemporary everyday usage they are nothing more than hackneyed phrases which have no significance for the speaker other than a convenient way of expressing oneself. Regardless of the veracity of Lakoff and Johnson's theories, they challenge us to rethink the relationships between body, mind and language. It is certain that from birth, the human capabilities for perception and thought are shaped in some way by bodily activity. Thus, corporeal activity can be understood to be, at the very least, an important factor that drives development of thought and meaning and shapes the development of representations of the world in childhood.

Summary

Returning to a Merleau-Pontian perspective, human beings must be seen as embodied entities that are immersed in a fluctuating environment. Embodiment is, therefore, a process of involvement and co-constitution of body and world. The body plays a fundamental, indeed, primordial role in the way we think and the way we experience our worlds. Consciousness, self-awareness, cognition, thought, conceptualising, decision making, language and language comprehension can be understood as being moulded by our embodied existence in world. Through the body's innate skills and by being the conduit through which we interact with the world, human experience is shaped. Human experience, from the way we perceive and act in an environment, to the way in which we think about things, or our relationships with others, and the way we experience ourselves must be considered to be embodied.

The body, as the conduit that allows us to exist and to engage in our surrounding world, provides us a sense of self. In other words, we have a sense of experience as a result of our being embodied. The body is central to self and to social life. The body is constantly engaged in the world and provides for experiences and interactions with the world. These visceral experiences, in turn provide scope for subjectivity and self-reflection. This, in turn, permits differentiation of self from other and provides the basis for a sense of self as bounded and unique. Thus, the body not only confers a pre-reflective self-awareness but it also provides for the development of conscious concepts of self and body. The concept of the Cartesian *cogito* is invalidated in an embodied approach to the person as the body has to be understood as being integral to the human experience of self.

The Body in Everyday Life

Despite the pivotal role played by the body in all experiences, the body can also be seen as disappearing from experience (Leder, 1990). The body is an intrinsic part of experience and yet it is also intangible and paradoxically absent from experience. According to Merleau-Ponty this absence is an important aspect of the phenomenology of the body. He points out that the perspectival nature of embodiment means that we cannot see the perspective itself. This absence, therefore, is necessary and constitutive of embodiment. Though the body is absent from our everyday lives, it represents the ground in which experience is realised. The body, therefore, operates outside the range of consciousness (Dreyfus & Dreyfus, 1989). We perform inherently complicated actions everyday without conscious reflection. It is these pre-reflective skills that allow us to cope with the demands of our environment. Thus, the body is the most abiding, critical and inescapable presence in our lives, yet it is also essentially characterised by its absence.

The body projects itself into the outside world yet the body itself falls back recessively from conscious perception. Thus, the body is central to developing a sense of self and maintaining that sense of self. Paradoxically, though we depend on the body for continued physical and social engagement, our fundamental relationship with our body usually blends into the background of life. That is, we usually lack consciousness of the body until something goes wrong with it (Kelly & Field, 1996). Leder (1990) provides a seminal critique of this bodily disappearance. He argued that the body-subject is lived through, rather than reflected upon. Thus, the relationship we have with our bodies is ambiguous. Bodily experience is an ambiguous mode of existence, because the idea of the body cannot be separated

from the experience of the body. However, despite their inseparability, the mind and body each have their own being. Being a body allows us to project ourselves into a mental life.

The body sustains life, enables social interaction and guides us in ways which are rarely reflected upon. However we do also have an awareness of the body; in many circumstances the body is perceived and attended to. For example, in times of hunger, thirst, fatigue and pain we take notice of our bodies. However, when we think, read, talk to others or engage in other such tasks in out day-to-day lives, we rarely pay heed to the body. Unconsiously we may adjust our posture, mimic facial expressions or alter our gestural stance, yet the corporeal features of these actions and interactions remain largely unnoticed, even when physically exerting ourselves (Leder, 1990). In activity the body normally remains silent and regresses from awareness. The body, therefore, supports action and is used as a tool in our everyday lives yet the body disappears from our consciousness. Human life, therefore, though essentially embodied is paradoxically also typified by bodily absence Thus, the role of the body in psychological life is significant, but ambiguous. As embodied beings we are intimately tied up with the body, yet uniquely estranged from it as we go about our everyday lives. Indeed, as Merleau-Ponty states there is a "truth to dualism" (1945: 209, as cited by Müller & Newman, 2008). We are embodied beings, yet we can conceive of a relationship between mind and body and can distinguish mind from body. We often think about our bodies and we can distinguish a sense of mind from a sense of body. Thus, there is an inherent duality in the lived body, in that we experience the body as a lived entity, however, we can also think about and experience the body as an object.

Human beings are bearers of mental states and we construct a perspective on ourselves and our worlds which are socially and culturally informed and play an important role in behaviour. The disappearing body affords the human immersion in a mental life. As human beings, we associate with a mind and a self as immaterial rather than with the material body (Leder, 1990). Discursive cultural theorists (e.g., Goffman, 1959; Foucault, 1970) argued that the idea of self itself is an illusion and is merely the product of discourse which allows people to construct a specific sense of self to fit the exigencies of the social situation which is faced. However, simply because we do not 'experience' the body does not mean that it cannot and does not play an agentic role in human life. Though we often associate ourselves with a mental rather than a physical life, the body can still be argued to play a significant role in our experiences of self.

The body is an object in the world that can be touched and moulded. Thus, the body can be experienced in the presence of others and objects in the material world. Thus, our embodiment facilitates a sort of 'splitting' of mind and body (Weiss, 1999). Weiss describes the embodied being as a 'split subject' as the body is experienced by the individual as both a subject and an object. The Lacanian thesis on *the mirror phase* draws our attention to the idea that the body can and is experienced at the level of object as well as subject. Lacan (1935) argued that during development, the child begins to identify with an external image of himself or herself, be it in a mirror or in the image of another child. During the mirror phase children become captivated by this image. Their image, which exists as a whole, contrasts with the child's fragmented bodily experiences given their physical immaturity. In other words, the apparent integrity of the reflected body contrasts with their own uncontrolled and fractured bodily experiences and movements. This gives rise to an internal conflict which results in an identification with the external image. This provides the basis of an understanding of self. While Lacan stressed that identification with this image is fundamentally alienating, I wish to emphasise here that identification with an image gives rise to an understanding of self as both inner and outer. Self, therefore, is dyadic in that it involves both a self as subject and a self as other. The body, therefore, is not just privately experienced, it is also experienced in a public sphere. We exist in an intercorporeal world (Merleau-Ponty, 1945), and being in this world and more specifically experiencing the body as an object in that world, promotes the adoption of a third person perspective on self. The idea of intercorporeality highlights that the experience of embodiment is always mediated by the continual presence of other human bodies as well as the physical world.

Though the body is organic, it is part of the world and so is also shaped and molded by cultural standards and norms. Thus, it can be argued that there are potentially an infinite number of different ways of being a body. Returning to Merleau-Ponty, the body is seen as the foundation for sense of self. It allows us to communicate with others persons who are also embodied. Thus our relationships with others are intercorporeal. Intersubjectivity can be, similarly, seen as being grounded in the corporeal relations between people. Social identity, therefore, is influenced by our embodiment in many ways. Embodiment provides us with an agency and can be considered to be a vehicle for expression. The body is central to our social lives and to social relationships as it is the medium for individuals to display things that matter to one's self and other people (Radley, 1994). Our everyday embodiment is evidenced when we look at the intricate ways in which the body and the world reflect each other. For example, the way in which contemporary 'stressful' lifestyles are become embodied through the response of the physiological systems of body. Psychoneurimmunology (PNI) research illustrates how illness can be caused or exacerbated by stress. For example, psychosomatic illnesses such fibromyalgia,

irritable bowel syndrome (IBS), chronic fatigue are more prevalent illnesses are seen as being linked to the psychological resources of the individual. Psychosomatic illnesses, therefore, can be understood in terms of embodying culturally valid expressions of psychological distress (Kiramayer & Allan, 1998).

Summary

The body enables social life and the body is central to how we interact with the world. Thus, the body is agentic and interacts with psychological and sociocultural forces to influence sense of self and experience. Undoubtedly, the body constitutes a pre-reflective and primordial way of being in the world. However, despite the co-constitution of self, body and world, as humans we also have the capacity for conscious reflection on the body. Thus, the body is experienced from within, but it is also known as an object. In other words, as human beings we can consciously reflect on the body and on ourselves in relation to the body (Müller & Newman, 2008). Thus, arising out of a private relationship with the body is a publicly mediated relationship with the body. For example, imitative games engaged in by infants illustrate the purposive and agentic body. However, through these games the infant is also learning to take the attitude of an other toward oneself and learning to objectify oneself. This in turn gives rise to an explicit self-consciousness, a self-conscious understanding of self and to new body concepts and perceptions. The development of self and bodily concepts must be seen as a product of being a bodily being engaged in the world, thus, social and cultural influences play a critical role in this process. Our awareness of the body is inherently social and arises out of experiences in an intercorporeal and intersubjective world (Csordas, 2008). Our embodiment can be mediated by our interactions in a physical and social world. Self-understanding, therefore, involves experiencing oneself for others as well as for one's self. After all, blushing can only convey embarrasment if we understand that the body exists for others. Thus, conveying the status of other on the body facilitates understanding of self and intersubjectivity. Unfortunately, however, objectifying the body in this way frequently results in self-effacement and shame (Fredrickson, Roberts, Noll & Tweng, 1998).

Being a body involves being located in a social sphere. The body is part of public experience and is, therefore, potentially subject to external judgment. The body can be experienced in terms of its social and symbolic meaning. As well as being involved in the unique and private aspects of self, the body is socialised into specific, cultural bodily practices (Young, 1997). Embodiment, therefore, becomes a symbolic representation of our personal and socio-cultural worlds and is central to how to people take a stand to each other (Radley, 1998). The human body provides people with an expressive

space to communicate with others and the body is also the origin of meaningful and expressive movement. Thus, we use our embodiment to convey aspects of ourselves that would otherwise remain invisible. Therefore, our embodied being facilitates our feelings, thoughts, beliefs and our sense of selfhood, which are also socially and culturally defined. Embodiment, therefore, can reify sense of self and allows for expression in an intercorporeal world.

The Body in the World: Socialising the Body

The body is always present in a social, cultural environment. We are immersed in a living world and subject to its vissicitudes (Wilson, 2005). This environment has important implications for experiences of the body. Indeed, Foucault (1969) questions the possibility of an unmediated relationship with the body. The work of Foucault draws attention to the ways in which bodies are disciplined and how this disciplining of the body shapes personal experiences of the body. In the same way that Foucault saw the self as being the product of discourse, he argued that the body is socially constructed. Although we only have a world to think about thanks to our embodiment, the body is also of the world. The world contextualises all of our activities. As discussed in the preceding chapter, for Foucault (1973) the body is a product of power relationships which constitute 'the clinical gaze'. Foucault (ibid) suggests that the way in which we perceive and speak about the body and medical matters is the product of wider historical conditions and power relations within society which both shape and condition the knowledge basis and, hence, the prevailing mode of discourse of the world in which we live.

Foucault proposed the idea of the gaze to conceptualise how cultural factors manipulate the production, regulation and representation of bodies. Foucault uses the idea of Bentham's panopticon to illustrate the idea of the gaze. The panopticon is a prison of circularly design so that the cells radiate around a central watch point. While the cells are light up, the centre remains in darkness. So, the prisoners never know exactly when they are actually being watched. Consequently, the prisoners begin to watch themselves. Foucault uses the idea of the panopticon as an analogy for modern society. Thus, society and various social institutions such as medical institutions, have become a sort of panopticon that regulates bodies. Fredrickson and Roberts (1997) proposed objectification theory that explores how culture objectifies bodies. Fredrickson and Roberts (1997) argue that bodies are constantly being looked at and evaluated. Therefore, bodies have become expropriated and objectified. This encourages people to objectify their own bodies and regulate their own bodies. The body, therefore, is not just a

physiological entity. It can be a cultural construction. The body is shaped by social forces and the body is an important medium which allows people to symbolise cultural norms. The body communicates to others and it says something about the person we are or aspire to be. Cultural and psychological forces, therefore, combine with biological factors to shape experiences the body. Take as an example the wrinkles that develop with age. Wrinkling is an anatomical process triggered by age. However, depending on cultural interpretation, wrinkles can be positively representive of wisdom or perjoratively representative of age and loss of vitality and sexuality. Thus, cultural representations of the body can condition they ways in which we think about and relate to our bodies.

Perceptions of the body vary culturally and what is considered the 'ideal' body ossicilates across cultural and historical boundaries (MacLachlan, 2004). For example, Western ideals for the body has swung from voluptuous, to slim, to waif-like models. In Western cultures "the thin ideal" for bodies prevails. These sociocultural discourses do shape experiences of, beliefs about, and one's relationship with one's body. Approximately, 44% of women reported negative feelings about indivdual body parts as well as their body as a whole (Cessin, von Ronson & Whiteford, 2008; Monteath & McCabe, 1997). Fallon & Rozin's (1988) seminal research illustrated that females often demonstrate perceptual distortion of their actual body size, often overestimating their body size. They also desired to be thinner and believed that the opposite sex preferred a thinner body shape than was actually the case. Men are also increasingly displaying body image dissatisfaction (Mussap, 2008). Body image involves perceptions and cognitions as well as affect. That is, thinness can be understood in certain cultural contexts as a positive characteristic, emulating self-control and higher social class. Though population weight is in actual fact increasing, the 'ideal' body type is getting smaller and smaller. Objectification theory posits that Western culture socialises indivduals to adopt an observer's perspective. Objectification of self promotes shame about the body and was found to promote restricted eating (Fredrickson et al., 1998). In *Bodies that Matter* (1993) Butler looks at the cultural prohibitions enforced on the body. Being female or male, black or white, homosexual or heterosexual and so on, has symbolic significance. Thus, body image and our embodied activities are influenced by intercorporeal interactions. Body image distortion, objectification and alienation from the body occur all too frequently. For example, there has been marked increases in the incidence of eating disorders in modern Western cultures. Orbach (1988) argued that, though eating disorders have been medicalised, the blame lies with a society that places unreasonable and unhealthy pressures on women to be thin. Other feminst writers' analyses of anorexia, see the 'disorder' as an attempt or desire to remove oneself from the body, and the pressures of being a body, particularly being a sexual body (Bordo, 1993).

However, social constructionist accounts, in particular Foucauldian discourse analytical accounts, of the body contradicts arguments for the agentic role of the body. It is important to do justice to the role of the experiential, phenomenological and physiological aspects of the body. The body is undoubtedly influenced by culture. However, the body can also be argued to reciprocally shape cultures. Young (1997) argued that the way the body is treated culturally is shaped by the significance of embodiment and how it expresses symbolically aspects of the personhood. Young points to how the body is reframed during medical examinations to exclude its symbolic properties, especially its sexual ones. Parts of the body are concealed with gowns to mask the contours of the body and to reduce sexual signalling and other social communications. Young argues that during such situations the person is removed from the body and the body or parts of the body are objectified. This is done to preserve the dignity of the self. However, Young also argues that the treatment of the body in medical situations illustrates how bodily factors can influence sociocultural situations. That is the properties of the body can shape certain social situations. Thus, social and cultural environments can be influenced by the body.

On a larger scale, Leder (1990) argues that the ambiguous nature of embodied existence can be seen as leading to the endemic dualism in Western society. Thus, we must be careful not to ascribe too much power to social constructions of the body. Conferring too much emphasis on the way in which the body is socially constructed threatens to disembody human beings. The body itself must be accorded a generative role in human experience and social lives. Thus, examination of the constructive power of social discourse must be seen as supplementing accounts of the pre-reflective body/self and as illustrating how the body can become the site for culture and normative standards of social life. Furthermore, Weiss (1999) points out, both Merleau-Ponty and Foucault fail to fully account for the way in which bodies are singled out by their gender, race, ethnicity, class and abilities. Thus, it is critical to consider the interrelations between the body, bodily attributes and the culture in which it is immersed in order to understand human experience.

Experiences of corporeality: Body image

Body image is a popular term and focus of investigation. The somatosensory cortex located in the parietal lobe provides for neuronal representation of the body. The brain area allows integration of information about the body from several different modalities. The somatosensory cortex tells us what the body is up to by integrating information about sensations such as touch, temperature, pain, location

of the body in space, as well as providing kinesthetic information. Brain deficits can affect our awareness of body, for example the condition of hemineglect or unilateral neglect, caused usually by injury to right parietal lobe, which can result in the individual neglecting a limb or the entire side of the body and the surrounding space. Sacks (1986) documents a case where a patient with hemineglect fell out of bed after pushing what he perceived as the severed leg of a cadaver hidden in his bed. However, though our internal representations of the body are constructed by the brain, these representation are not deterministic of how we experience the body. The term 'body image', originally coined by Schilder (1935), refers to a person's internal and external sensations and perceptions of their bodies, and his or her thoughts and feelings towards the body. Perceptions of attractiveness are perhaps most commonly associated with body image and have been much researched. In many cases a person's body image can be dramatically different to how others perceive them. Decades of research (e.g., Cooper, Taylor, Cooper & Fairburn, 1987; Strauman & Glenberg, 1994) illustrate that people in modern Western society betray considerable body image dissatisfaction. Furthermore, people consistently over or underestimate their actual body size. While many of these studies rely on cultural interpretations to explain such findings, this omits from the explanations the role of the body itself.

Schilder and Merleau-Ponty argue that body image can fluctuate depending on physiological and environmental changes. Indeed, Schilder (1970) argued that an individual can have almost an infinite number of body images. Bodily factors such as anatomical integrity, appearance and bodily capability play an important role in an individual's concept of self. Throughout our lives we must continually construct and reshape concepts of, attitudes towards and feelings about the body (Scholnick & Miller, 2008). Merleau-Ponty, Schilder and Foucault all provide important conceptualisations of the experience of the body. While Merleau-Ponty and Schilder emphasise body image as kinaesthetic and physiological, Foucault emphasises socio-cultural influences on the body. However, in these accounts we get little, if any, sense of the actual shape and appearance of the body. Weiss (1999) argues that these theorists give little insight into what it means to be a specific type of body.

Drawing on feminist theorists, Weiss points to the implicit assumption of the male norm in many accounts of the body and body image, including Merleau-Ponty's account of the embodiment of human life. Weiss argues that it is critical to consider the way in which bodies are marked by their specific attributes and assumptions made about the body. For example, society makes assumptions about the gender, race, class and abilities of specific bodies; medical authorities make assumptions about the frailty of bodies; religious authorities about the wickedness of bodies, and so on. When the

body is experienced as being displayed before the world or when the self appears to the person in the role of another, the body becomes a symbolic expression of self. Issues of value and meaning which are reified by the body come to the fore when body-self is highlighted such as in disability or dysfunction. Lifestyle, character and interpersonal stance can, therefore, be understood as bodily expressions of self. We choose to wrap the body in certain types of clothes or to mark it with tatoos, pierce the body and decorate it to promote a certain image. The body represesents who we are supposed to be. We must consider, therefore, what it means for a person to be a specific type of body and the way in which bodily and cultural experiences influence sense of self.

Otherness, disembodiment and the unconventional body

Weiss (1999) recounts Franz Fanon's *Black Skin White Mask* (1967) to illustrate the effect of race on corporeal concepts. Fanon describes his experience of being a black body in a world of white values and norms and expectations. Resultant feelings of inferiority and otherness illustrate the social processes that shape concepts of the body, and enforce separation from the body. Rodriguez (1990) also recounts in an autobiographical paper his experiences of alienation from the body and feelings of shame about his body as a result of his dark skin (as cited by Weiss, 1999). Race and ethnicity therefore, can be understood as important factors in body image and how we perceive ourselves. Indeed the skin is the body's most visible organ and as such is an important part of our relationship to others. The skin and its colour can be seen as embodying a specific social class. Culturally, many darker-skinned ethnicities prefer and strive to maintain a paler complexion to signify being of a higher social echelon. This can sometimes result in dangerous bleaching practices, particularly amongst women. Likewise, disorders of the skin such as acne can affect how we perceive the body and ourselves. Murray & Rhodes (2005) found that the experience of severe acne seriously affected sense of self as well as interpersonal relationships and social interaction.

The lived-experience of a particular type of skin or a particular type of body as it appears to others can create disruptions in sense of self. Being "fat" or overweight (Herndon, 2002) impinges on lived experiences. Similarly, the experience of an ageing body can undermine sense of self and confidence in the body (Wainwright & Turner, 2006). Facial disfigurement, congenital and acquired, has profound implications for self-esteem, body image, quality of life, interpersonal relationships and social interaction (Rumsey & Harcourt, 2004). Severe burn injury results in significant body dissatisfaction and psychosocial impairment (Thombs, Notes, Lawrence, Magyar-Russell, Bresnick &

Fauerbach, 2008). Therefore, it appears that transgressing accepted standards of beauty can alienate the person from his or her body.

Engenderment of the body can also reinforce the alterity of the body and give rise to experiences of alienation from the body. This is particularly the case for women who are typically held up against entrenched and considerably high bodily standards (Bordo, 1993). However, it is also a growing issue for men. Male embodiment is constructed in terms of sexual prowess, being a skilled body, being tall and strong. Bodily shape, capability and appearance, as relates to a normative, desirable body is significant for men and can contribute to a lack of confidence for men in their body and effect poor self-esteem. As much as for women, embodied masculinity governs behaviour, ways of being and feelings about the body. Furthermore, societal standards for 'masculine' comportment can marginalise non-normative bodies such as disabled or homosexual males (Robertson, 2006). Female embodiment has been investigated to a greater degree and will only be looked at briefly here. Young (2005) argues that girls experience a clash between how they experience their bodies and societal expectations about their bodies. Being "feminine" is to have a specific type of body, to appear to others in a specific way and to adopt a specific comportment. Shame caused by aging, 'lumpy' and sagging body is common. To behave in masculine or unfeminine ways can result in chiding, taunting and stigmatisation. Women's relationships with their bodies can be seen as problematic as women are more frequently objectified and are encouraged to objectify their bodies more (Weiss, 1999).

This is also evident in the lived experience of bodily disorder and disability. The body supports our existence in the world and provides us with a sense of vitality and agency. This, however, can be diminished by "deficiencies" of the body. The body can manifest itself as a limitation. For example, biological limitations of the body mean that we can fatigue, experience illness, pain and dysfunction. If the body can be seen as the foundation and expression of self, what does it mean for sense of self when the body is limited or impaired as in illness or disability? Leder (1990) and Williams (1996) argued that when the body becomes an obstacle, a state of *dysembodiment* ensues. This state is characterised by an alientation from the body and resultant dimished feelings about self. The body can become an object when it poses a problem for us (Müller & Newman, 2007). The object-body represents a condition which is juxtaposed with the prereflective body. As discussed earlier the body typically blends into the backdrop of life. However, this condition is tenuous and subject to disruption when the body becomes an obstacle for us as we go about our daily lives (Gallagher, 2005).

When the body is a "broken" body or a "bad" body and does not function in socially accepted ways, we lose symbolic control of the body (Gregory, 2007). Such bodies are stigmatized, treated with suspicion and seen as dangerous. Foucault argued that disabled bodies determine and define what is normal. Perhaps we even have a biological preference for what is deemed conventional and normal. *Koinophilia* is a term used in biology meaning that when sexual creatures seek a mate, they prefer that mate not to have any unusual, peculiar or deviant features. Sexual creatures, in the animal kingdom, tend to prefer mates with a preponderance of common or average features. Being a 'different' body has significant implications for sense of self. The body is defined and judged in the social world and in accordance to cultural conventions. Gregory (2007) relates experiences of the disabled body and argues that in disability, the body owns the person, demands attention, and imposes restrictions on the person. Society dictates that we have command over a functioning body. This, necessity for control is heightened by modern practice whereby the medical gaze objectifies the body (Van Dijck, 2005).

As with disability, in chronic illness the body exists in a relatively permanent state of difference and disruption. In both chronic illness and disability, the physicality of the body impinges directly in self. Furthermore, such bodies are more likely to fracture social protocol and to intrude on the social world. To paraphrase Susan Sontag (1978), to be ill is to live in a different country than the country of health. To be ill, therefore, is to be removed from a state of normal living, to be constricted and to experience disruption in bodily being. Reduced bodily capacities in turn reduce the person's ability to achieve socially acceptable ways of being; for example, the person's chance of engaging in the labour market is limited, thus, a "productive" self is militated against. Concomitant physical disfigurements of illness fracture social standards of beauty. Thus, bodily changes and limitation in illness and disability can be seen as altering the sense in which people perceive themselves. Illness experience research illustrates that self-conceptions are redefined and reappraised in relation to illness (Charmaz, 2006; Radley, 2000; Pierret, 2003). The body becomes an alien presence in the person's life and is seen as an object. This object, however, is seen as no longer expressing one's true sense of self. Bodily shame and disgust are often engendered. Loss of self, the creation of uncertainty, changed relationships with others and the world are also engendered in the embodied disruption caused by illness.

Breaches in bodily experiences effect a radical transformation in the relationship between the body and the self. The body is no longer a silent partner; it exerts itself as an owner of the self. Malfunctioning bodies create a tension with the self in a way that functioning bodies do not. Thus, when a body malfunctions we experience a split between the body and the self. Dysembodiment,

therefore, is a common response to the experience of ruptures in bodily experiences. Leder (1990) argues that pain and disability reorganizes the lived experience of the individual, our relationship with the body and our engagement in our social worlds (Osborn, 1995). The body in pain is restricted, thus, the body becomes an alien presence in our lives and disallows engagement with the world. The body becomes an object; an unwanted other in our lives. Illness experience research has frequently noted how individuals suffering from chronic pain frequently feel a significant sense of alienation of self from body (Morse & Mitcham, 1998). Pain forces a reassessment of meaning, thus, the concept of self has to be distinguished from the concept of the body although intuitively for most, their body and mind together is their self. Under such circumstances we feel disconnected and alienated from the body.

Summary

The body is the conduit of our being in the world. The body, however, is also an object in the world and is, therefore, shaped by the world. As Keirans points out "the body is the space where meaning is made and embodied, recast, re-embodied" (Keirans, 2005: 25). Thus, concepts of self and identity are based in the body but are also rooted in symbolic interaction. Cultural and bodily experiences reciprocally link to shape experiences of self. The body, therefore, can be seen as an inscripted carrier of social life (Kelly & Field, 1996). This has implications for when one's body contravenes social exigencies as when the body fails in illness or disability. The impaired body has serious implications for sense of self.

Conclusion

Embodiment theory and research engages critically with issues surrounding the theorisation of the self and body relation. Empirical research as well as theorisation in psychology frequently fails to address the role of the body in phenomenological life. Despite growing interest in embodiment theory, there is still a lack of research in embodied social practices. Exploring experiences of the body empirically can allow us to address a range of psychological issues and to gain insight into human experience (Stam, 1996). Furthermore, embodiment theory acknowledges both the biological and social facts of psychological life and, thus, provides for the possibility of integration of inquiry from disparate areas of psychology, like integrating neuropsychological experimentation with discursive research, as well as allowing for integration with other disciplines.

Bodies matter: the make-up of the body set limits on human potential and opens the person up to a variety of physical and emotional experiences. Despite the pivotal role the body plays in an individual's sense of self, the body is increasingly a contested site in modern Western society. Trends such as the rise in chronic illness means that more and more individuals are experiencing 'differences' in embodiment. The body is the source of engagement with the world, vitality and self. The body is also a source of uncertainty, otherness and dysfunction. Thus, the body moderates and mediates experience. The body and embodiment are subject to vicissitudes throughout the lifespan. Embodiment can be seen as a way of tracing our social and cultural experiences from the standpoint of bodily being. When the body is altered, interfered with, appropriated or transformed; experiences are phenomenologically altered and new modes of intending towards our social worlds can be generated (Keirans, 2005). Thus, the understanding of embodied experiences in relation to the experience of illness and medical technology is an important area for investigation. Though there has been some theoretical consideration of these issues there remains a dearth of empirical investigation. This issues needs to be addressed. Investigating this issue can provide important insights into embodiment in an age where the body is becoming increasingly contested and unstable.

~ CHAPTER THREE ~

CHRONIC ILLNESS AND MEDICAL TREATMENT

Introduction

The body, social and cultural influences on the body, and the interaction between these agents must be seen as playing an important role in personhood and the experience of everyday human life. The lived and embedded body, therefore, is critical to experiences of self and world. Social and phenomenological approaches to embodiment primarily inform this thesis. From this outlook being a body is central to human life, not just as a substrate, but as an actor in the development and maintenance of a self-system and in everyday experience. Trends such as the rise in chronic illness mean that more and more individuals are experiencing disruptions in their embodiment. Furthermore, developments in the field of medical technological mean that more and more people are living through and with technology. In a modern, technolgised and medicalised society, new forms of embodied being are increasingly becoming available. The body is potentially becoming increasingly uncertain. In such circumstances, experiences of the body are phenomenologically altered. Embodied disruptions can expedite new understandings of self and of the world. Hence, a changed sense of self and new modes of interacting towards our social worlds can be generated through the experience of illness (Keirans, 2005).

Chronic illness is an increasingly pressing concern. Since the late 1800s the number of deaths arising from chronic illnesses has been steadily growing as the unfortunate consequence of the changing lifestyles of a modern industrialised society. As more people are living with a chronic illness so too, are more people experiencing ever more advanced and intensive medical treatments in response to these illnesses (Petrie & Weinman, 1997). The need, therefore, for a psychological understanding of the experience of chronic illness and medical treatment is paramount. Given embodiment theory's emphasis on the lived body, it is possible that an approach to chronic illness and medical treatment that encompasses some central tenets of embodiment theory can further our understanding of such experiences. The understanding of embodied experiences in relation to the experience of illness and medical technology is, therefore, a potentially important area for investigation. Though there has been some theoretical consideration of these issues there remains a dearth of empirical investigation in this

area. Investigating theses issues empirically can provide important insights into the experiences of self and world, in an age where the body is becoming increasingly contested and unstable.

Theoretical concerns also propel this interest in chronic illness. It has been mooted that the context of health and illness is a fertile area to glean insight into the experience of embodiment (Williams, 2003). This chapter will be divided into two main sections: in the first half the research into the experience of chronic illness will be discussed while in the latter half of the chapter the research into experience of medical treatments will be examined. A discussion of how such research pertains to the experience of embodiment will follow.

Making Sense of the Experience of Chronic Illness

Chronic illness can be defined as any illness that lasts three months or more (Onega, 2008). This definition allows chronic illness to be any illness which lasts a relatively long period of time. Indeed, such a loose definition is needed when one take into account that chronic illness is heterogeneous in nature. Some of many illnesses which spring to mind when considering chronic illness includes diabetes, asthma, arthritis, cystic fibrosis, HIV/AIDS, coronary heart disease (CHD), fibromyalgia, cancer, multiple sclerosis, and perhaps more controversially obesity and depression. Chronic illnesses can range in severity and are often, though not always, incurable in nature. Likewise, the symptoms of chronic illness can range from mild nuisances to considerable pain and disability.

As mentioned earlier an ever-growing number of people are living with a chronic illness. This pattern has been developing for a period of considerable time and these figures look set to rise even more. A World Health Organisation (W.H.O.) report (2007) projected the leading cause of global deaths in 2030 to be cancers, heart disease, HIV/AIDS. The number of mortalities due to chronic illnesses is predicted to be far in excess of deaths caused by pulmonary tuberculosis (TB), malaria, along with other infectious diseases, as well as road traffic accidents (WHO, 2007). In Ireland approximately 23% of the general population and nearly 80% of older adults are currently suffering from at least one chronic illness such as arthritis, CHD or diabetes. Chronic illness is a particular burden on the Irish health care system. Approximately 80% of GP consultations and 60% of hospital admissions are in relation to chronic illnesses and related complications. Mental health morbidity is

high and economic consequences for the individual and family are also evident (Department of Health and Children, 2008).

Chronic illness, therefore, is an urgent concern for the human and social sciences. Health psychology has been described as the "aggregate of the specific educational, scientific and professional contribution of the discipline of psychology to the promotion and maintenance of health, the promotion and treatment of illness and related dysfunction" (Matarazzo, 1980: 815, as cited by Ogden, 2004). The fundamental tenet of the discipline of health psychology is that illness and health are more than just biological in nature. In other words, the cause and treatment of illness must involve psychosocial factors. Health psychology rests on the biopsychosocial model of health and illness (Engel, 1977, 1997). Since its inception as a discipline, one of the principle areas of investigation in the field of health psychology is the human experience of chronic illness. Some of the driving questions in the study of health psychology include: (1) how do people come to understand and experience chronic illnesses and their treatments and (2) how do people cope and adjust to life in these circumstances? In its investigation of these questions, health psychology uses a variety of different theoretical and methodological approaches (Ogden, 2004). However, for the most part, social cognitive approaches which emphasise beliefs, attitudes and appraisals dominate health psychological research. It would not be possible to do justice to the vast amount of research that has been carried out on the experience of chronic illness in this thesis. Indeed, it would be difficult to review the literature if one was to concentrate on just one particular chronic illness alone. Thus, this discussion will be limited to the major themes in chronic illness research. The main question area of interest concerns the impact of chronic illness on the individual and the question of how the individual learns to adjust to chronic illness.

Psychological response to chronic illness

Emotional reactions to chronic illnesses include severe depression, anger, personality change, anxiety and feelings of lack of control. More generally, chronic illness has been found to have a significant effect on the domestic environments, social environments, sexual relationships and the work life of an individual. Chronic illness, therefore, has been found to radically reduce quality of life as well as psychosocial health (e.g. Kramer, Kapteyn Kuik & Deig, 2002; Leventhal, Idler & Leventhal, 1999; Petrie & Weinman, 1997). Leventhal (1980, 1997) developed a framework which aims to elaborate how people cope with and understand their illnesses. According to Leventhal, 'illness cognitions', defined as

a person's own common sense beliefs about their illness, guide reactions and adjustments to illness. Five dimensions of illness cognitions were identified including identity, perceived cause, time line, consequences of the illness, and the perceived controllability and curability of the illness. These cognitive representations of an illness are thought to give the illness meaning and provide the person with a coping strategy. Research has shown that illness representations have been found to predict psychosocial adjustment in sufferers of chronic illness (e.g. Moss-Morris, 1996). Other psychological frameworks which have been developed and used in the investigation of the experience of chronic illness include the individual's attribution styles, cognitive processing as well as his or her personality. These frameworks have been promoted as being beneficial to the investigation of how people interpret and react to chronic illness. In general, these approaches have provided valuable insights into how individuals think about their illness. For example, these studies have helped to provide insight into the likelihood of psychological distress and mental health morbidity as a result of chronic illness (Petrie & Weinman, 1997). Likewise, interesting insights into the impact of illness on people's lives and how people make sense of illness from a cognitive perspective have been gained. Furthermore, useful measuring scales and questionnaires have been developed as a result of such studies which are helpful for assessments in clinical settings and for the provision of therapy to individuals who may be experiencing distress as a result of the experience of chronic illness.

Cognitive health psychology research has, however, also been criticised on a number of issues. Methodologically, social cognitive approaches tend to rely on cross-sectional, correlation studies. Such studies have limitations in determining causality as well as the longitudinal validity of findings. It is not surprising that an individual would experience a considerable degree of depression, anger and/or other types of psychological and emotional distress upon receiving a diagnosis of a chronic illness. Thus, such findings do not give us insight into the processes through which people overcome psychological distress and find new meanings in a life with illness. Critics, therefore, have called for a more ideographic approach which can produce insight into the processes through which chronically ill individuals create meaning in their experiences. In other words, a call for the exploration of meaning and the way in which such meaning is influenced by social and cultural factors has been issued (Murray, 1994). Researchers such as Stam (1994) and Radley (1993) have criticised cognitive health psychology research for being decontextualised, solipsistic and reductionist. Indeed these criticisms have been directed at psychological research more generally and have been discussed in more depth in the first chapter of this thesis. A failure to take into account social processes and meaning and a tendency to fall back on reductionist accounts of the illness experience can never approach the reality of what it is really like to live with a chronic illness.

Health psychology sets out to investigate the interaction of mind, body and society in the cause and experience of illness. It aims to provide a holistic approach to understanding health and illness underpinned by the biopsychosocial model. Despite establishing a mind-body interaction, mind and body are still defined separately from one another. For example, health psychological theories that focus on illness cognitions implicitly accept that illness is physical and that making sense of illness and coping with illness is mental. Accordingly, much research into the role of psychology in illness implicitly accepts that mind and body are separate, serving only to reinforce a bio-medical approach rather than challenging them (Stam, 2001). Stam (2004), in his critique of research on chronic illness in health psychology, suggests that health and illness are "remarkable undertheorised" in contemporary health psychology and that health psychology theories remain oriented towards the biomedical system, thus, fails to challenge biomedical assumptions of dualism (p. 273). The concepts of illness and health, and mind and body, therefore, remain encased in a Cartesian framework. This approach conceptualises ill persons, hence patients, in a mechanical fashion. Health psychology, therefore, is remiss in its understanding of the sick person and limits its potential for contribution to patient care. Critical health psychologists express dissatisfaction with the assumptions of mainstream health psychology and its ignorance of the broader social and cultural environments within which health practices are situated. Thus, critical health psychologists promote socio-cultural theorisation, reflexive practices, qualitative methods and the exploration of the illness experience (Lyons & Chamberlain, 2006).

The illness experience

Critical health psychology constitutes a challenge to mainstream cognitive approaches and aims to reintroduce meaning into the study of chronic illness and to embed the person in their social context. Qualitative approaches aim to give people a voice, thereby locating illness in the life of the individual and elaborating on the experience of illness as it is understood by the person. Exploring sociocultural and political influences on the experience of chronic illness is a primary concern to critical health psychology research. Despite the increasing growth and development in social constructionist approaches in health psychology, overall, such enquiries remain marginalised. The beginnings of research into the illness experience can be traced back to the groundbreaking study of Strauss and Glaser (1967). This study was seminal, not just because of the insights it gave into the experience of illness, but also because of its elaboration and promotion of qualitative methods. Since then, research into the illness experience is garnering more attention. While a systematic review of the literature that

deals with the illness experience is beyond the scope of this thesis, the major findings from such research studies will be outlined.

Inceptive studies that explored the experience of chronic illness have elaborated the meanings which people create in their experiences of illness. One of the most notable concepts to emerge from such studies is Bury's (1982) concept of *biographical disruption*. According to Bury, illness provokes negative consequences for the person on both a practical and social level. Illness disrupts the individuals' everyday life and results in considerable uncertainty being introduced into the individual's life. In turn, an individual's sense of self can be seriously undermined. Furthermore, Bury argued, the onset of illness can result in the shattering of an individual's previously held assumptions about his or her life path. The consequential threat to the individual's identity and sense of loss of control over his or her own life constitutes the experience of biographical disruption. Disruption of subjectivity is the unfortunate result of biographical disruption.

Charmaz (1983) argued that illness incurs the loss of meaning upon which the ill individual's former sense of self was founded. The consequences of illness include loss of productivity, and interaction in familial, work and social environments often become more difficult for the individual. Furthermore, chronically ill individuals are often faced with increased financial pressures, as well as having to deal with feelings and experiences of stigma and social isolation. Charmaz's study also emphasised how chronically ill individuals can lead an increasingly restricted existence and also experience decreased control over their lives. This contributes to experience of a discredited self, loss of self-esteem and fears of becoming a burden to others. Thus, Charmaz elaborated the concept of *loss of self*. This concept describes the way in which former self-images become unmaintainable for chronically ill individuals. Illness challenges previously held assumptions about self. Furthermore, chronically ill individuals have limited opportunities to develop new, valued identities. Consequently, individuals who suffer from a chronic illness are often unable to negotiate new identities. The result is a gradual erosion of self-image over time (Charmaz, 1983).

Loss of self is postulated to be a primary cause of suffering in chronic illness (Charmaz, 1983). Identity reconstruction has been a prominent concept within the research on illness narratives. Charmaz (2002) argued that despite the negating consequences of illness, the experience of a chronic condition also provides opportunities for people to come to know themselves and to change their identities. Thus,

though chronically ill individuals are facing losses in terms of sense of self and identity, people can also find continuity for identity and self in the ways in which they habitually respond to situations. Furthermore, perceived positive changes in the way they interact with others in illness, can lead to reconstructions of a new, valued self.

Radley and Greene (1987) elaborated the conceptualisation of *illness as adjustment* to examine the ways individuals who are suffering with a chronic illness rebuild their lives and reconstruct new, positive meaning. They established a conceptual framework which was based on the self's response to illness, whether the response of the self to illness was opposed or complementary and whether the individual's social participation was retained or lost. Adjustment to illness is obtained when a particular balance between these continua is achieved. Different styles of adjustment amongst individuals with a chronic illness were delineated: (1) Accommodation involves the individual making modifications in his or her life and maintaining positive engagements in social circumstances. Accommodation involves accepting that adjustments were necessary in a life with illness. Accommodating illness also involves the individual being active in treatment and/or recovery; (2) active-denial involves adopting an attitude that minimises the condition and maximises the perception of an active life. Active-denial can be seen as an attempt to maintain the life an individual had prior to illness. The individual attempts to resist changes in lifestyle and often experiences feelings of guilt, resentment and anger when this cannot be maintained; (3) secondary gain involves achieving benefits through the experience of illness, mostly from other people or from welcomed changes in lifestyle such as giving up work; (4) resignation involves dwelling on the condition and consequential feelings of hopelessness and depression. The illness is experienced as dominating one's life (Radley & Greene, 1987). Certain coping styles are considered to be more adaptive than others. The studies discussed above illustrate how social structures shape the illness experience and how individuals seek to overcome the constraints of illness through social negotiations.

In general, research into the illness experience focuses on *illness narratives* to gain insight into the experience of loss of self, stigma, and changed life path in the lives of individuals with a chronic illness (Pierret, 2003). The meaning and significance of illness for persons and the consequences of illness on self and identity and persons' experiences, constitute the primary focus of such research. Furthermore, the aim is to take social discourse into account and to assess the impact of such social structures on the experience of illness. Concepts such as gender and social class are explored and are conceptualised as generative structures which condition meaning in illness. The aim of social

constructionist research in the area of health and illness is to provide a holistic account of the experience of chronic illness. This involves considering the mediating role of the social world in which the person resides as well as the person and their customary response to situations which he or she faces in his or her social world. Ironically, omitted from this account is the role of human embodiment. To be human is to live in a world of physical experiences. That is, experiences are mediated through the body and its underlying biology. Given the visceral nature of illness, the materiality of the body cannot be ignored in the examination of the experience of chronic illness. It is the physical vulnerability of the body that gives rise to chronic illness. Thus, integrating material, biological descriptions with social description of chronic illness is critical for a holistic and theoretically sound understanding of the experience of chronic illness. The fundamentally embodied nature of human life, as well as sociocultural factors, has to be taken into account in our investigations of the experience of chronic illness

Chronic illness and embodiment

Bendelow and Williams (1998) remarked, "In the field of chronic illness the tendency to concentrate upon social meaning and consequences through notions such as suffering self, has led to the relative neglect of corporeal issues of embodiment and an isolation from the philosophical debates over mind and body" (1998: 41). As discussed in preceding chapters, the body is frequently absent from research in the social sciences. However, consideration of the body in the experience of illness can hardly be avoided. Illness is inherently associated with the body. Indeed, some researchers have endeavoured to account for the corporeal exigencies of the body and the nature of the human experience of illness in a social and material world and calls for the incorporation of the body into the investigation of chronic illness are gaining voice (e.g. Millward & Kelly, 2003; Radley, 2000; Stam, 2004).

These calls for the incorporation of embodiment into the investigation of chronic illness are frequently accompanied by theorising about the inter-relationships between embodiment and the experience of illness. Millward and Kelly (2003) critiques the body, experiences of embodiment, and how embodiment can determine sense of an individuals' self and life experience in the context of illness. The body has boundaries of size, strength, endurance, movement, and sensory capabilities. Furthermore, the body gives us a sense of existential permanence and continuity upon which assumptions about ourselves and our worlds can be built. In many ways, the body is the basis for self as well as the medium through which we interact with our social worlds. However, the body's parameters

are changed as a consequence of illness. In illness the body is different from what one has come to expect and the consequent derailing of taken-for-granted assumptions about self and world is incurred. The body that ceases to function in expected ways creates uncertainty and transgresses social norms and protocols. This in turn, can potentially give rise to a change in an individual's subjectivity and self concepts. Assumptions about one's social and material environment may also be reappraised and redefined in illness.

Williams (1996) elaborates on the relationship between the body and the self along the course of chronic illness. Williams argues that the body plays a pivotal role in an individual's sense of self. In the normal course of life we are embodied in what is a taken-for-granted, unproblematic relationship between the body-self. However, the body typically blends into the backdrop of life. When a body malfunctions the assumptions held about the body and the world are fractured. Thus, a malfunctioning body is 'dysembodied' (Leder, 1990; Williams, 1996). Dysembodiment refers to the undermining of the corporeal basis of identity and the feeling of being disengaged from the body. In illness the body becomes an alien presence in a person's life, which undermines previously held concepts of body, self and society. The symbolic significance of the body and issues of meaning and legitimacy come to the fore when an individual experiences dysembodiment. That is, the diseased or ill body is conspicuous and propels the individual into an inescapable sense of his or her embodiedness. A heightened awareness of the body can lead to the experience of disconnection from others. This, as is argued by Williams (ibid), leads to feelings of stigma, difference, uncertainty as well as having a negating effect on self.

Influential authors such as Bury, Charmaz, Radley and Frank have all considered the interaction between the experience of illness and embodiment. For example, Bury considers that the disruption of the body plays an important role in the creation of uncertainty and biographical disruption. Likewise for Charmaz, bodily disruption caused by illness causes a loss of control and, hence, loss of self. Frank's (1991) moving autobiographical account of illness in *At the Will of the Body* (1995) describes his own experiences of a heart attack and cancer. In this autobiographical account Frank describes the disruption of his own body, his resultant fear and uncertainty and the impact of illness on his sense of self. In a later monograph Frank (1997) argued that illness constitutes a threat to the body-self. He states, in illness "People who have always been bodies have distinct problems continuing to be bodies, particularly continuing to be the same sorts of bodies they have been. The body's problems during illness are not new [but] illness requires new and more self-conscious solutions to these general

problems" (1997: 27). Frank begins his discussion by pointing out that any embodied person faces certain bodily problems throughout the course of everyday life. These problems are problems of body use, or the body in action, and we have all been facing and resolving these problems constantly. These problems are the problems of control, desire, body-relatedness and other-relatedness.

In illness, the problem of control relates to the functioning of the body and the predictability of bodily functioning. People define themselves along this capacity for control as long as it is predictable and does not require conscious regulation. Thus, Frank argued that the body is lived along a continuum of predictability. However, contingency is experienced when the body is subject to forces that are outside of its control. When adult bodies lose control, stigma and embarrassment ensue. Thus, experience and sense of self is contingent on the body. The problem of body-relatedness relates to living in the body. In the normal course of healthy life people can choose to be associated with or dissociated from the body. However, illness forces an association and attention to the body. The problem of other-relatedness relates to the nature of the relationship between a body-self and others who are also bodies. Illness can serve to disconnect people from others. The problem of desire relates to the wants of the body. Frank points to the way that ill bodies cease desiring. Loss of desire constitutes a "falling out of love" with oneself (p. 39). Frank delineates four "ideal, typical body types" which are adopted by people in illness. (1) The disciplined body refers to the regimented body which is controlled and carefully monitored. The disciplined body produced in illness is described by Frank as an unpleasant way to live. Disciplining the body allows for the restoration of some level of control, however, the body is objectified; (2) the mirroring body reflects the use of the body to "mirror" body types of others. In the case of illness, a mirroring of healthier bodies is desired; (3) the dominating body serves to undermine relationships with others; (4) the communicative body is an idealised body which constitutes an ethical ideal. Frank's ideal body types are not intended to represent actual bodies, rather, they they represent theoretical extremes. Furthermore, a person's illness experience changes with, among other factors, varying physiological and psychosocial stages, thus, most people suffering from illness would vary from one body type to another depending on their current physical and psychological status.

From a lived, phenomenological perspective the experience of physical disruption, such as illness, has to be considered to have a serious impact on sense of self and interpersonal and social interaction. The healthy body is lived in that it is easily controlled, unproblematic and forms an unobtrusive basis for self and experience. However, illness seriously disrupts the lived body (Bendelow

& Williams, 1998). Moore, Schaefer, Crago, Ladd, Lammers and Echenberg (1999) carried out repeated conversations with five women diagnosed with ovarian cancer. Moore et al. found that the women who participated in the study interpreted their bodily changes, which resulted from their illness and treatments, as violating their sense of being. Gurevich, Bishop, Bower, Malkad & Nyhof-Younge (2004) conducted a qualitative enquiry into the experience of testicular cancer and their findings revealed that the men's sense of masculinity was threatened by their diagnosis. Watson (2000) and Robertson (2006) outline similar findings for the impact of illness on male identity and body image. Other qualitative studies also illustrate how chronic illness threatens self and identity as a result of the experience of embodied difference. For example, Grytten & Maseide's (2006) study of Multiple Sclerosis and the experience of stigma illustrates the negative impact of bodily difference on sense of self and interpersonal relationships. Willis, Miller and Wyn (2001) illustrate the impact of Cystic Fibrosis (CF) on young men and women. Young women with CF tend to suffer greater morbidity and higher mortality rates, accounting for this difference, Willis *et al.* found that engendered experiences of CF shaped young men's and women's beliefs surrounding the meaning of life, life path and body-image. Differences in these beliefs were found to affect medical regimen adherence. Willis *et al.* concludes that the different coping styles of young men and women with CF, illustrates that engendered embodiment impacts on how these young individuals make sense of and cope with their illness.

Despite the numerous calls for incorporation of embodiment into the study of chronic illness, little empirical research that investigates the lived experience of the body in illness is evident. Much of the extant research that exists falls into the category of social constructionist accounts. Social constructionist accounts emphasise the productive power of social discourse. For example, in the studies listed above the majority of authors focused on the social production of engendered or disabled and dysfunctional bodied and the impact of transgressing prescribed bodily norms on the individual. A focus on the social production of bodies creates a malleable body that is constituted purley by narratives and social discourse. The body, therefore, is conceptualised as passive in the face of societal forces. Social expectations, dictates and norms undoubtedly influence the body. However, these studies often underestimate or omit the influence of the body on the experience of the social. This can be argued to be a major gap in our understanding of the experience of chronic illness. The limits that embodiment can impose on discourse must be taken into account. The challenge of research into the experience of chronic illness, therefore, is to unite phenomenological accounts of the lived body with social, cultural and cognitive accounts of illness. Illness has to be considered to be an embodied experience, without relapsing into biological reductionism and dualism and at the same time avoiding social determinism.

Medical Treatment and the Individual

Medical intervention and technology have the power to shape the quality and texture of the person's sense of self and life experience in chronic illness. Medical treatment and technology invariably entails several psychosocial side effects, as well as physical side-effects. Many medical procedures are uncomfortable and can result in physical side-effects which can have a significant impact on the person's life. Most medical treatments have adverse physical implications which can range from the mild to severe. Surgery can have a number of undesirable effects such as loss of subsequent functioning, disfigurement and scarring. Radiation therapy can cause burns and alterations in the skin, radiation sickness and hair loss. Haemodialysis can result in hernias, infections, low blood pressure, cramps and itchy skin. Adverse effects of medicines can include dizziness, diarrhoea, nausea, vomiting, dermatitis and other allergic reactions. The experience of physical side-effects can have significant psychological and emotional consequences for a patient. Medical treatment requires a whole host of changes to an individual's life. Medical regimens must be adhered to which often requires the self-administering of medications, altering behaviours as well as engaging in new health behaviours. Therefore, changes in lifestyle are common, frequent interactions with medical professionals are required and medical treatment can also involve frequent hospitalisations. Time spent abiding by medical regimens, waiting in the doctor's office and being physically confined to hospital, is time taken away from other preferred pursuits and habitual activities (Keirans, 2005). Limitations in physical capacity and social performance can cause considerable distress. Patients can tend to become withdrawn and can have difficulty in coping with disease. Therefore, the prevalence of psychosocial distress and mental disorders can be elevated amongst individuals undergoing medical treatment. Social and interpersonal problems are also common (Poleschuck, Katz, Adrus, Hogan, Young, Kulik, Dworkin, 2006).

Reactions to medical treatment and its repercussions, can include anxiety, depression, anger, guilt and denial. Patients' reactions to a given medical treatment can reflect not just its objective characteristics but also their beliefs and attitudes about the treatment itself. Halkett and Kristjansen (2007) studied patients' attitudes towards radiation therapy. It was found that the concept of radiation therapy was frightening to the patient and adverse side effects of the radium were feared. Given the horrors that have been related to radiation in Hiroshima, Three Mile Island and Chernobyl this is not surprising. These fears, however, can actually have physical manifestations. Studies with sham radiation showed that participants developed nausea, fatigue and radiation sickness (Holland & Rowland, 1989). Patients frequently have considerable concerns and erroneous beliefs about treatment,

particularly those which are intensive and highly technical. However, patients' fears and concerns about their treatments are frequently left unaddressed by healthcare professionals.

When the chronically ill individual is introduced to medical treatment, he or she is absorbed into a new culture. The individual must then come to terms with a changed physical status, adapt their behaviour and become familiar with a new medicalised way of life. The experience of medical treatment can often result in feelings of emotional distress which in turn can be exacerbated by dealings with medical professionals. A mismatch between the language and knowledge of the health professional and the medical understandings of the patient is common. Most of the general public are unfamiliar with basic physiological and medical facts. Contact with medical professionals and adhering to prescribed medical regimens can enframe the body-self in highly technical and medicalised language and vocabulary. This can contribute to the medicalisation of the person and to feelings of depersonalisation in medical situations and examinations. Therefore, rather than allaying fears, interactions with medical professionals can sometimes add to patients' distress and feelings of uncertainty. To be aware of patients' concerns and reactions may help them to accept treatment and assist in optimising quality of life. However, patients are expected to be cooperative and pleasant, to give up personal responsibilities and are also expected to follow the instructions of the medical professional. Furthermore, patients are often not encouraged to ask questions about their care. Health professionals may even inhibit questions by the use of closed statements and other non-verbal cues during patient consultations (Radley, 1994). Indeed, there has been a general failure to develop psychological care as a part of general thinking, culture and routines of general hospitals and health centres (Kooperman & Schoenhofer, 1998). Psychological care is still an uncommon provision in hospitals and even more infrequent in general practices. Therefore, patients can sometimes be surrounded by care staff but alone with their distress. Emotional disruption provoked by poor information exchange and lack of emotional care can contribute to mental health morbidity and poorer adaptation to illness and treatment. General health can also be placed at risk as a result. If a patient's reaction to distress is maladaptive it can undermine medical efforts and obstruct rehabilitation and can also result in immuno-suppression which can in turn complicate the person's already existing health problem (Petrie & Weinman, 1997).

Beliefs about medical treatment and technology

Technological development and expansion has had a massive input into health care, affecting medical organisation and professional practice as well as the experience of medical treatment for patients. Medical technology can be described as being made up of a large heterogeneous group of devices intertwined in various ways with healthcare professional and patient interactions (Fennel, 2008). The character of medical technology is distinctive; the field of medicine is in itself a vast discipline and within it technology is used on a large scale and in a variety of complex ways. Throughout our lifespan we will experience a variety of medical technologies. Some are commonplace like the thermometer or a stethoscope; others, however, are highly technological and estranged from our understanding. Medical technology can include new treatment machines, other new equipment and treatment techniques, and even medicines. Technology now informs both patient and professional accounts of illness, disease and health, accountability, allocations of resources of material and human resources, on professional and inter-professional practice, and on the patient-health care professional relationship. It can be argued that technology has been institutionalised within the healthcare system and is becoming ever more of a major actor in our experiences of health and illness (Webster, 2008).

Growing concern regarding medical technological development is evident. Indeed, given the controversy surrounding the possibility of human cloning and stem cell research, many are questioning if whether what is now possible with medical technologies is actually desirable. Medical technology is often cast in a negative light (Gallagher & MacLachlan, 2003). Philosophical arguments point to the disruptive nature of medical technology and can potentially cause increased medicalisation of health problems. Illich (1975) arued that the expansion of the medical realm has resulted in the medicalisation of life's vicissitudes such as birth and death. The phenomenon of medicalisation was characterised as dangerous and a threat to health as it promotes overdependence on the medical establishment, thus, disempowers the individual and renders society as a whole unhealthy (Illich, 1975). Though the views of Illich are considerably trenchant, the increasing focus on healthcare technology by medical professionals could potentially give rise to a detached, mechanistic practice of healthcare which may have a negative impact on patient care. Furthermore, Foucault (1963) argued that the political power of the medical establishment serves to reinforce power relations between the doctor and the patient and undermine questioning of the doctor's understanding of the body. The clinical gaze conceptualises the regualtory functions of modern medicine and serves to objectify patients and pathologise their experience of the body which can result in patient distress. Medicine, therefore, ignores patients'

subjectivities, their sense of self, culture and beliefs, and importantly their own perceptions of illness and treatment are also ignored.

In spite of the negative theorising that has surrounded medical and bio-technologies, the public's perception of medical technology may not always reflect apprehension and alarm. On the other hand, outright acceptance of medical technologies may be similarly unlikely. Sociologists appear to differ in the way they portray the public's ideas about modern medicine. The medicalisation thesis assumes that the public accepts that modern medicine is effective and has faith in the value of scientific medical knowledge. While other lines if enquiry suggest that medical advancements are believed to be potentially dangerous and moving humanity in an unfavourable direction (e.g. Williams, 1997). However, the public's perceptions of modern medicine may be more complex than these arguments allow. Fox (2006) carried out a study that investigated the public's perceptions of modern medicine. He found that while in general hip replacements tended to be seen as good due to their life enhancing quality and independence restoring capacities. Other medical interventions such as the use of tranquillisers were seen as unnecessary and even dangerous as they can lead to addiction and dependence. This illustrates clearly the limitations of the medicalisation thesis. There is considerable ambivalence towards modern scientific medicine and the complexity of lay thinking on these issues is not often credited. It has been illustrated that the general public's statements on medical technology do not represent blanket dependence (Heath & Luff, 1996). Indeed, public attitudes regarding medical technologies betray hope, as well as fear and scepticism regarding treatments; hope because medical technology offers the potential to improve health and health care and fear because technology threatens many of the fixed assumptions we hold about human life. Therefore, medical technology is viewed as having some undesirable social, ethical and political consequences yet contradictorily also many potentially positive consequences.

Other aspects of lay thinking regarding medical treatments can reflect perceptions of the naturalness or unnaturalness. Concerns about an estrangement from nature and disrupting the natural course of life-processes as a result of use of medical technologies have been found to be somewhat prevalent amongst the lay populace (ibid). Even commonplace medical treatments such as medications have been associated with negative outcomes (Isacson & Bingefors, 2002). The increasing use of complementary and alternative medicine amongst the general populace, is believed to be symbolic of this fear of an estrangement from nature and a reaction against contemporary forms of technological intervention which are felt to be unnatural. Approximately 62% of American adults frequently use some

form of complementary health management techniques including chiropractic care, acupuncture, diet-based techniques, homeopathy, meditation and yoga (Bishop, Yardley & Lewith, 2006). However, the increasing use of complementary and alternative medicines may not be reflective of dissatisfaction with conventional medical care. Eisenberg *et al.* (1998) found that most adults who use alternative health management techniques also regularly use conventional care such as visiting a medical doctor and regularly comply with conventional medical advice.

Beliefs regarding medical treatments are, therefore, complex and are influenced by a variety of factors. Social and cultural factors, can inform beliefs regarding medical technology. For example, students with an Asian background were found to hold more negative beliefs about medicines than students with a European background. Other social factors such as gender and age were also found to influence beliefs about medical interventions. Furthermore, positive or negative past experiences of medical treatments were also a factor in the beliefs people expressed about medication (Horne, Graupner, Frost, Weinman, Wright & Hankins, 2004). A self-interested focus in people's beliefs about modern medicine is also evident. Often considerations of medical treatment are less concerned with general issues, such as concern over the naturalness of treatment, and more concerned with private issues such as personal need for treatment. Therefore, people may express concern over the potentially negative aspects of medical technologies, yet they often put aside this concern if they consider the treatment in relation to their own health and their potential healthcare needs (Heath & Luff, 2006). So, people may be afraid of medical technologies and their potential effects on humanity, but would also be willing to undertake such treatments if their health and survival so necessitated.

It is also arguable that the general population is increasingly technophilic. In modern Western cultures technology is neither unusual nor uncommon (Allen & Pilnick, 2005). There is little doubt that we are living in a technological culture. Technology is a part of our everyday lives. Everyone is reliant on technology in one way or another; we rely on alarm clocks to wake us up in the morning, cookers and microwaves to cook our food, televisions to entertain us and computers to make a living. Technology is embedded in and intertwined with social, economic and cultural developments. Heath, Luff & Sanchez-Svensson (2003) argue that technology only gains sense and significance within the practice of its use. Hence, Heath et al. argue that medical technologies will not be regarded in a negative light if they are developed and used within a general culture of care. However, this argument also precipitates potentially negative experiences of technology. Devices designed in Western societies typically coincide with biomedical discourses that dominate Western thinking. This reinforces the

allopathic model of the biomedical sciences and the traditional dualistic concept that the body and the mind are distinct and can be treated separately. Therefore, medical technologies can potentially increase medicalisation of life, objectification of the patient and a dehumanised health care. Cultural beliefs about body parts clash with medical beliefs. In medical interventions, people can experience conflict between mechanistic and reductionistic views of the body and their wider cultural beliefs about the embodied nature of self-identity. Similarly, people's experiences of medical technology are never simply neutral. Rather, emotional and personal factors influence interpretations of medical technology (MacLachlan & Gallagher, 2003). The particular impact of the treatment on the individual must, therefore, be taken into account. Furthermore, experiences of technologies are not just shaped by personal and cultural factors. The technology itself, its features and the consequences of the technology have to be understood as being critical to the experience of treatment technology.

Medical technology can exert a significant influence on patients' experiences of healthcare and their bodies. That is, medical technology can have significant effects on the relationship between the patient and healthcare staff, as well as having unique and often major effects on the individual in a physical sense. Medical technology has undoubtedly made considerable progress in recent times. However, people have been using materials to augment the body for a very long time. Spectacles, false teeth and prototype prosthetics are examples of 'original' technologies that have augmented and enabled human bodies. Furthermore, an object can easily become an extension of the person and be transformed into a medium for self disclosure. Merleau-Ponty (1945) pointed out how cane becomes the extension of a blind man's hand (as cited by Murray, 2004). Similarly, we can see ourselves as being embodied in objects outside of the body. For example the clothes a person wears, the way one styles their hair, the decoration of the body with tattoos can be understood as becoming an embodiment of a particular worldview and a construction of self. However, the act of refashioning the body via technological means, in particular the trend towards cosmetic surgery, has taken a remarkable turn in contemporary medicine (Behling, 2005). Technologies, by changing the way in which we relate to our bodies can potentially have a major impact on sense of self and experiences of the world.

Despite the controversy that surrounds medical technologies, new developments have undoubtedly refined healthcare treatments and new developments for previously untreatable illnesses and conditions have been welcomed. However, new technological capabilities in the field of medicine have simultaneously raised complex debate in the area of healthcare. However, little empirical research has been carried out into how patients experience medical treatments. Thus, there appears to be a gap

between our understanding of the scientific, objective view of medical technology and our understanding of the subjective experience of medical technology. It is vital to understand what the effects of technology on the patient are, not only in a physical sense, but also in a psychological sense (Gerhardt, 1990). On the whole, there is an increasingly evident push towards understanding the social and ethical implication of technology use in health care. It is important to avoid the vilification of medical technology and indeed to recognise its potential to ease suffering and to improve healthcare provision overall. Given the dearth in research into the experience of medical technology, it is vital to reflect on how individuals who are confronted with intensive medical treatments actually experience those interventions and what are the actual impacts of medical technology on the embodied experiences of the patient.

The experience of medical technologies

In illness the corporeal basis of self and engagement in the world is destabilized. Medical intervention can serve to bring a compromised body further into focus. Hence, the experience of medical interventions may serve to further reinforce the split between the body and the self that arises in illness (Williams, 1996). Time given up to medical regimens means less time spent engaging with preferred identities. Charmaz (2002) describes the self as habit. That is, our sense of self is comprised of our habitual behaviours. We are what we do, so to speak. In illness, physical impairments combined with the implications of medical regimens force a change of habit, thus, forcing a change of self. Concern over the role obligations left unfulfilled and uncertainty over treatments, can contribute to feelings of helplessness and dependency. In treatment, the body, its symbolic properties and the person's capabilities and functioning are made apparent to oneself and to others. A sense of self and body-image, already fragile because of illness, may be affected by medical technology. Furthermore, treatment can bring the threat illness makes to life into focus. The illness experience can be shaped temporally and qualitatively, by medical intervention. This aspect of the illness experience has certainly received less attention than is its due (Pierret, 2003). To a large degree, medicine frames life in chronic illness and has the power to shape experiences of the body-self in illness (Benét, 1996).

The symbolic significance of the body and bodily cues emerge as evident in medical investigations (Young, 1997). Medical interventions violate the body in the sense that they require the body to be touched and examined by another person and by instruments. Young postulated that the body is recast for the purpose of medical examinations as an object rather than self. This excludes the

body's symbolic properties, especially its sexual ones, and removes the personal aspects of the self from the body. As persons become patients they relinquish their social personae. Objectification of the body and of the self is commonplace in medical examinations and treatments. The body is de-selfed and made inanimate by both the physician and the patient. During medical examinations and treatments, medical personnel speak in certain ways and wear certain clothes, as does the patient. The doctor frequently wears a white coat and the patient a robe. In particular, parts of the body that are symbolically and sexually charged, such as the genitals and the breast, are concealed. This depersonalises the situation as gowns conceal the contours of the body, therefore, reducing social communication. The depersonalising and alienating impact of medical intervention comes to the fore. Patients in the medical examination and treatment are treated as objects and the self is dislodged from the body. During medical examinations doctors and other healthcare professionals tend to refer to "the tumour" or "the back" and not the patient. The effect is to turn the person's attention to his or her body as made up of parts and not as a whole. This objective referencing can also be witnessed in the language of patients during medical examinations (Young, 1997). The body becomes an object during medical examinations in order to preserve the dignity of the self. However, the self can never be wholly removed from the body; therefore, procedures can often be found to be humiliating and degrading. Patients often experience medical treatment as dehumanising as the body is treated as separate to self (Hudak, Mc Keever & Wright, 2007).

Medical intervention, therefore, can make an enormous contribution to the life of the chronically ill person and can have widespread implications for the individual's sense of self. The experience of medical technology on the lived body-self has to be considered. Medical treatment affects the body physically. When the body depends on medical treatment for survival, the corporeal basis of our identity is undermined. Thus, patients not only have to cope with the detrimental affects of the disease but must cope with the effects of the treatment. Many medical treatments are, by their very definition, destructive. Treatment, therefore, may involve a detrimental change in bodily function, loss of a body part, scarring and disfigurement, and result in limitations in functional abilities (White, 2000). Often these changes may be observable to others such as hair loss, weight gain or loss, or skin discolouration. Appearance-related side effects can seriously influence the individual's body-image and self-confidence. Feelings about the body are inseparable from feelings about the self; hence, bodily changes result in changed feels about the self. It has been demonstrated that cosmetic surgery is used by individuals as part of a quest to establish a new self (Askegaard, Gerten & Langer, 2002). Hence, surgery and other medical treatments that affect sudden and radical changes to the body ought to profoundly influence body image and social identity. The emotional and psychological aspects of

mastectomy are many. The experience of mastectomy induces profound changes to body image and self-perception. Women report that their sense of normalcy is disrupted, they feel changed and embarrassed about the body as well as conjuring feelings of self-consciousness about the body. Therefore, the result of mastectomy is an enormous alteration to body image. The way we would like to look and the way we present ourselves to the world is fractured, therefore, a loss of self and identity is incurred (Keeton & McAloon, 2002). Medical technology has the potential to create a sense of alienation from the body in chronic illness and to reify the patients' experience of disease and stigma. Thus, experiences of dysembodiment may be the unhappy consequence of people's dealings with modern medicine.

Wentworth (1998) found that women having undergone mastectomy report feeling a loss of control over their lives (Wentworth, 1998). Social membership demands control over the body, surgery and other medical technological treatments undertaken to cure disease often results in loss of control over all or part of the body or bodily function. Paradoxically the body which is cured of disease as a result of successful treatment continues to be a sign of bodily decay and failure as the body is put out of the control of the person (Manderson, 1999). The consequence is frequently feelings of shame, stigmatisation and perceptions of social distance are made greater. Loss of dignity appears to be a major concern for patients undergoing treatment. Kelly & Dickenson (1997) found that many medical procedures undergone by patients were found to be humiliating and degrading. Even medicines, a commonplace and familiar form of medical technology, are considered to be potentially stigmatizing by users. Hanson, Scherman & Lowhage (2004) found that asthma sufferers reported who frequently use medicine believe that medicines, while important to relieve discomfort and avoid fear, were damaging to identity without curing the illness. Furthermore, they felt that the use of medicine disrupted their relationship with the body as it camouflaged the body's own signals, making it harder to read the body and damaging the body's natural ability to cure itself (Hanson et al., 2004). It would appear that people believe that there is something in medical technology that lack humanness and medical technology has the potential to destabilize the humanness of the body.

Persons undergoing medical treatment are confronted with the symbolic and social significance of the body. They must consider the integrity of the body, what happens within the body and what the ramifications of manipulations of the body mean for the person corporeally, physically and interpersonally. Patients who receive replacement organs are confronted with the dilemma of being a body that contains the organs of another individual (Fox, 2006). Studies of transplant patients report

that patients' are preoccupied with and fantasise about the transfer of aspects of the donor's personality along with the organ. Most patients are anxious to learn about the donor's sex and age. The origin of the organ is not insignificant for the recipient. Public attitude research towards transplantations, receiving organs and donating organs reflects some of these concerns, particularly in relation to xenotransplantation and artificial device transplants. People felt that a human body is unique and could not or should not be repaired with artificial or animal material. The potential influence of transplants on body image and appearance and fear of being singled out as different and stigmatisation was also a concern. Disgust and concerns about trespassing nature's borders were common (Sanner, 2006). The influence of transplants on personality and behaviour was a major concern for the general public. Questions frequently arise over whether the donor lives on in the person in some way. The ethics and morality of transplantations were also called into question. Fear that the transplantation of organs was somehow akin to cannibalism was reported. Furthermore, people fear of having the sensation that the body would not be itself and the person would become akin to a spare-part man or a cyborg (ibid). The issue of face transplants has received considerable attention in the media in recent times. Fears surrounding face transplantation include concern that the receiver would more closely resemble the donor than their own visage and that the donors' facial expressions and, hence personality, would also be transplanted. It is clear that the psychological effects of such undergoing such a procedure would be enormous for the person. Psychological implications may include grief, disappointment and guilt as well as other serious issues regarding identity. It has been evidenced that persons who undergo hand transplants can struggle to cope with the subsequent effects on identity. Clint Hallam, who received the first successful single hand transplant, subsequently became uncomfortable with the transplanted hand and failed to follow the anti-rejection drug programme. His body began to reject the transplanted hand and later the hand was removed at his request (www.handtransplant.org). It has also been illustrated in the case of double hand transplants that serious issues regarding the patient's identity, their disability and their newly formed image and regained abilities are engendered (Burloux & Bachmann, 2003). However, it has to be noted that few studies on these issues have been carried out, therefore, these findings must be treated with caution.

Reliance on medical technology to survive or reduce symptoms may potentially blur the boundaries between the body and the machine for both the patient and the medical professionals. Extant phenomenological studies of the experience of haemodialysis document the struggle patients experience between defining where the body ends and where the machine begins (e.g. Giles, 2003; Keirans, 2005; Moran & Gallagher, 2003). It is not surprising that being entangled in a situation where one must rely on a life-saving machine which you have no control can have a significant effect on an individual's

sense of self. Medical technology, therefore, can evoke disruption to personal identity as well as fear of depersonalisation and dehumanisation. The shock of initial encounters with a highly technological environment can be disturbing and surreal for patients (Giles, 2003). However, research on haemodialysis suggests that the dialysis machines tend to be personified and are considered in a social way by the user of the technology. Thus, in dialysis a form of technological embodiment occurs, whereby the person assimilates the machine into their concept of self (Moran & Gallagher, 2003).

Technologies in medical interventions present a challenge to our relationship to our bodies and can potentially threaten anatomical wholeness and sense of human integrity. While technologies can enable and even augment the human body, at the same time, technologies can reifying illness and disability. For example, being dependent on technology highlights the disability and frailty of the body (Williams, 1997). Furthermore, technologies make disability and illness visible to the intercorporeal world, thus, can potentially stigmatise and alienate the person from their social worlds (Lupton & Seymour, 2000; Moser, 2006). Technology in this sense can become the embodiment of difference and disability. Patients confronted with medical technology must endeavour to maintain a sense of self and wholeness in an environment that threatens to fragment and disembody them. Giusti (2005) found that patients in the intensive care unit reiterated this paradoxical relationship between the body/self and the machine. Though the patients felt reassured by the presence of the machines, they simultaneously felt trapped by the equipment and experienced major body-image diffusion whereby all sense of their physical limits was lost and their sense of connectivity with their body was weakened. The environment, ultimately, was seen as an extension of the self. Therefore, the objectifying and dehumanising effects of the machines were strongly felt by the patient, as well as personification of the machine.

Healthcare workers can unconsciously reinforce this feeling Nagel (1998). Often the focus of the staff is on the technological facets of the treatment and not on the person. The alienating and stigmatising effects of technology have been considered theoretically. While technology is seen as simply fixing physical problems by medical authorities, the possibility that it also bears negative meanings and implications for its users must be considered. Lupton and Seymour (2000) found that a group of physically disabled individuals found technological intervention beneficial in a variety of ways; however, they also felt that the technology identified them as disabled and malformed in someway and, hence, singled them out from others in society. Technology was seen as an obstacle to the achievement and presentation of their preferred self (Lupton & Seymour, 2000). Thus, being

dependent on technology can effectively accentuate disability and as a result, users felt stigmatised. For example, being given a prosthesis forces an amputee to face the fact that they have lost a limb (MacLachlan & Gallagher, 2001). Overall, the interaction between bodies and technologies is complex and multidimensional. Factors including personal characteristic, illness related characteristics, aspects of the context in which technology is used and the characteristics of the technology itself must be considered.

The Implications of Technology for the Lived Body-Self

Chronic illness and medical treatment challenge our sense of self and threaten assumptions about our lifeworld (Pierret, 2003). When people talk about their bodies in the context of health, illness and medical treatment, they are not just giving objective statements about their physical health, or the lack of physical health as the case may be, rather they are talking about how they see themselves. The body is of the self: It is inherent in all our experiences, it is what others see when they are looking at us and it is through the body that we communicate to others messages about ourselves. The body and experiences of embodiment are central to our sense of being and who we think we are in the context of illness and medical treatment. The way in which we conceive of the body is representative of the way in which we conceive of ourselves on a personal level, however, this also operates on a broader social and cultural level. That is, the way the body is thought about is representative of social and cultural standards of ways of being. Beliefs about the body in illness and medical treatment pertain to an individual's sense of validity or of being a fit person in the social world.

There has been little empirical focus on the psychosocial aspects of medical technology and less still research on how such treatments affect identity and subjectivity for the people who undergo them. Much of the extant research appears to echo concerns that the body is becoming increasingly malleable in a way that is possible undesirable. For the user, the experience of modern medicine is not just physical but phenomenological and has huge symbolic significance. The experience of illness and medical technology has many implications for the person and his or her previously held concepts of body-self and society. Individuals who develop a chronic illness must learn to cope with destruction of the self, come to terms with this self-destruction and somehow manage to find a new meaning in a life with chronic illness. A new self must be navigated by accommodating bodily losses and limits and resolving the lost unity between body and self and resolving changed concepts into a new sense of self

(Charmaz, 1995). Meaning and self-identity must be restored. Coping with the experience of being necessarily dependant upon medical technology and having to tolerate its intrusion in everyday life, involves a negotiation between autonomy and dependence and an acceptance of uncertainty. Coherence between the body and the self can be achieved by interpreting the situation in a meaningful way (Williams, 1996) and can help to ease the stress and burden placed on relatives and families due to illness.

It can be argued that in a technological age, the corporeal body is no longer as important for individuals to feel connected with themselves and society. Medical interventions and examinations have been described by theorists and researchers in terms of their capacities to threaten the embodied self and their ability to dehumanise existence (Keirans, 2005). Perhaps we should look on it as simply creating alternative ways of being embodied rather than dehumanising existence. Indeed, technological embodiment may even be beneficial for rehabilitation and adjustment to life after bodily functions and capabilities have changed. In prosthetics, for example, it is recommendable to users to become embodied in the prosthetic to optimise sense of wholeness and function (Murray & Fox, 2002).

Conclusion: The proposed research

A growth in embodied-centred research is evident. However, a gap remains between our understanding of the biological and physiological aspects of illness and healthcare and our understanding of the experiential and phenomenological aspects of illness and medical treatment. This research aims to address this gap by exploring through recounted narratives the experience of serious illness and related medical treatments and to examine the role of embodied being in this experience. Two illnesses, renal failure and cancer, and related corrective medical treatments, haemodialysis, surgical intervention and radiation therapy will be explored[5]. To inform this study, a brief overview of the extant literature relating to the experience of these illnesses and treatment will be given.

Haemodialysis, surgery and radiation therapy (RT) can have serious physical effects on the individual. Haemodialysis immediately improves physical health, however, can have serious long term

[5] This reasons behind this choice will be discussed in greater detail in the following chapter.

consequences such as low blood pressure and heart failure. Treatments for cancer, such as surgery and RT, have immediate negative effects in order to bring about long term improvements. The negative effects, nevertheless, can be severe and long lasting. The participants in the current study form a particularly heterogeneous group. Participants were diagnosed with very different illnesses, experienced different illness trajectories and different medical treatments. The effects of illness and treatment can change the way people think, feel and act. These experiences are explored here. When an individual falls ill everyday aspects of their lives are interrupted, routines are changed and time once spent on the general task of living is often over taken by medical routines. Serious illnesses and medical treatments, and the physical changes inherent in such experiences, can effect the individual personally and socially. The impact of bodily change, or rather a change in embodiment, on the participants' sense of identity, interpersonal relationships and their experience of their lifeworld was investigated. When people are talking about bodily changes they are not talking about objective changes, rather they are talking about how they subjectively perceive their illness, their treatment, and moreover their bodies as well as themselves.

The experience of renal failure and haemodialysis

Renal failure is diagnosed when the kidneys are no longer able to function adequately. Renal failure can be caused by a range of medical problems. Renal failure is treated with dialysis, the filtering of the blood through an external machine which acts as an artificial to restore the body's internal appropriate equilibrium of water and minerals. The experience of renal failure and haemodialysis is complex and can involve several significant and sometimes distressing physical and psychosocial effects on the person (Timmers et al., 2008). Haemodialysis is a relatively old medical technologies and since its introduction has been considerably advanced. In spite of these improvements, haemodialysis remains a complicated and inconvenient therapy. The physical effects of illness and treatment in renal failure include lethargy, itching, cramping, chest pains, nausea and headaches. The effects of dialysis on quality of life have been demonstrated by numerous studies (Christensen & Ehlers, 2002; Krespi et al., 2004). Timmers et al. (2008) in a study of illness perceptions found that dialysis patients generally report a lower quality of life compared to the general population. Furthermore, physical and social functioning were impaired and individuals exhibited emotional problems and dimished mental health (White & Grenyer, 1999). Psychsocial effects include loss of self-esteem and self concept. Anxiety, depression, existential issues such as feelings of uncertainty and fear of mortality are common amongst individuals surviving on dialysis (Cameron, 1996). Social problems are also common. Dialysis can give

rise to problems in many aspects of an individual's life such as work and family (Christensen & Ehlers, 2002).

The impact on renal failure and dialysis on an individual's mental and social life has also been explored through qualitative research. Such studies illustrate the subjective meaning individuals attach to the experience of dialysis. Hagren, Petterson, Severinsson, Lűtzén (2001) examined the impact of living on dialysis and the experience of suffering amongst patients with renal failure. The study investigated how individuals made sense of their situation and uncovered the sense of conflict that individuals on dialysis often experience. Living on dialysis was experienced as a dilemma which created a sense of dependence and often disrupted the individuals' social life. The narratives of individuals living with renal failure revealed that dialysis constituted a threat to personal identity and incurred loss of self and diminished body-image. Feelings of loss of freedom and living a restricted life were also common. Moran and Gallagher (2004) also illustrate the impact of 'technological enframing' in the life of the dialysis patient. Technological enframing refers to the physiological, social and psychological manifestations of dialysis. Dependency on treatment requires several mental and lifestyles adjustments on the patients' behalf. Giles (2005) illustrate the phenomenon of dialysis personification. Individuals living on dialysis frequently create identities for their dialysis machine and describe the machine as a friend. This phenomenon suggests that the dialysis machine can be considered in a social way. However, research into the experience of dialysis also reveals the dehumanising effect that living on dialysis can have on an individual. Individuals on dialysis frequently reveal significant existential concerns about the impact of living in dependency with a life-saving machine and concerns over the boundaries between the person and the machine.

The experience of cancer and cancer treatment: Radiation therapy and surgery.

There has been considerable interest in the psychological aspects of cancer, adjustment to cancer, coping with cancer treatment and adjustment to cancer. The field of psycho-oncology is dedicated to the investigation of the psychological dimensions of cancer and is representative of a move towards a biopsychosocial understanding of cancer and cancer treatment. Psycho-oncology examines the psychological functioning of the patient as well as their family and the role of psychological factors in cancer risk and survival (Greer, 1994).

Numerous studies illustrate the psychological impact of cancer on the individual. Depression, anxiety and fear are common. Zambora, BrintzenhofeSzoc, Curbow, Hooker & Piantadosi (2001) in a large scale study found the prevalence of psychological distress in cancer patients to be 35%. Rates of distress varied according to site, prognosis as well as other lifestyle factors such as greater number of life burdens. Psychological distress to cancer diagnosis can be predicted by personality or personal traits such as pessimism and poor coping styles, more personal concerns, high anxiety, more recent life changes, marital problems and little social support. Cancer can also have significant pathological implications for an individual's social life and can have deleterious affects on an individual's familial and other social relationships. Overall, cancer can give rise to significant life-path disruption, body image disruption as well as existential concerns.

Qualitative studies of the experience of cancer reveal in depth accounts of what it means for the person to have cancer. For example, individuals diagnosed with lung cancer often experiences feelings of stigma, guilt and blame due to the association of lung cancer with smoking. This led individuals to attempt to conceal their diagnosis from friends and colleagues and interactions with friends and family was adversely affected as a result (Chapple, Ziebland & MacPherson,, 2004). Qualitative studies of the breast cancer experience illustrate that that breast cancer negatively affects sense of self, gender identity and body-image. Psychosocial concerns for family and children, and sexual health concerns are common as well as anxiety and fear of reoccurrence of cancer (Ashing-Giwa et al., 2004). Other qualitative studies focus on specific cancer diagnosis sites. These studies are ideographic in nature and generally cancer site specific. These studies illustrate the impact of social factors such as social attitudes towards cancer and illness, cultural beliefs and other social factors such as gender roles can influence the meaning which is attached to the experience of cancer.

Cancer treatment can have considerable psychological, emotional and social ramifications for individuals who have to undergo such treatments. The oldest and most common cancer treatment is surgical intervention. Normal psychological responses to cancer surgery include fear, fear of pain and death, a sense of vulnerability, fear of repercussions, anger, anxiety and panic. However, in some cases these emotional reactions can lead to refusal of treatment (Jacobsen & Holland, 1992). Psychological reactions to cancer surgery can vary according to the psychological stability of the individual as well as medical related issues such as cancer site, stage of the illness, functional deficits which will result from the surgery and rehabilitation that will be needed. The subjective meaning that individuals attach to the procedure and its consequences influence are also important issues to consider. Persons who have major

surgery undergo profound physical changes such in deficits in physical function and/or bodily or facial disfiguration. All parts of the body can be considered to have personal significance, however, the experience of surgery for sites which have particular personal and emotional significance for the individual such as the face, breast, genitals and colon can have considerable ramifications for the person. The experience of mastectomy can have enormous implications for women's sense of bodily integrity, body image, gender identity, and sense of self (Keeton & McAloon, 2002). Facial areas are associated with attractiveness, social interaction, communication and emotional expression. Surgery which affects areas of the head and neck can lead to strong negative implications on self-esteem and body image as well as disruption the individual's social life (Goldstein, Genden & Morrison, 2008). Overall, cancer surgery can be seen as a critical life event that has considerable implications for the individual. Physical, social and emotional well-being can be seriously impaired by the impact of cancer surgery (Boehmer, Luszczynska & Schwazer, 2007).

Almost half of the individuals who are diagnosed with cancer undergo some form of RT. RT involves many uncomfortable procedures including constriction in movement and isolation during treatment. This has been found to contribute negatively to patients' experiences of treatment (Kwok-wei So & Chui, 2007). The frequency and extent of psychosocial distress experienced by cancer patients undergoing RT, is similar to cancer patients undergoing other treatments (Fritzche, Lipton, & Heinke, 2004). Radiotherapy disrupts everyday life and can result in limitations in physical and social capabilities. Undergoing radiation treatment can be very frightening. Patients frequently report fear of the effects of radiation. Psychological reactions to radiation treatment include anxiety, depression and anger (Holland, 1992). Surprisingly, there has been very little research into the experience of RT or the patient's perceptions and beliefs about the treatment and the meaning they attach to the treatment.

Summary

The purpose of this discussion was to highlight some of the specific issues relating to the experience of renal failure and dialysis and the experience of cancer and cancer treatments, surgery and radiation therapy. This description of the research exploring the impact of renal failure and haemodialysis on the individual and the impact of cancer and cancer treatment on the individual has been brief.

General findings from research into the experience of renal failure and dialysis indicate the difficulties individuals living on dialysis can experience. These difficulties include psychological issues as well as social ones. Research that focuses what the experience of haemodialysis highlights some of the special issues that are specific to individuals living on haemodialysis. A life on dialysis entails attending hospital regularly, self-administering of medications and adhering to a strict diet and fluid restrictions. The individual's lifestyle may completely change and several psychosocial adaptations are needed to cope with these changes. Furthermore, this engagement with medical technology or the dialysis machine has also been shown to have considerable implications for the individual's sense of personhood. Living on dialysis can be seen as a struggle between the embodied individual and the machine. Research indicates that while individuals personify the dialysis machine and think of it in social terms, living on dialysis also has dehumanising effects. Overall, the experience of haemodialysis has been shown to be difficult physically and psychosocially and can result in the experience of personal suffering and loss of self-identity. The psychological, social and emotional impact of cancer and cancer treatment is considerable. Cancer and cancer treatment confront the individual with specific problems. The individual's life course, personality and social support network can mediate reaction to illness and treatment. Similarly, medical related issues such as specific cancer diagnosis, stage of illness and treatment required must also be considered. Societal attitudes, such as stigma surrounding cancer, as well as subjective and sociocultural meanings can also shape the individual's experiences of cancer and cancer treatment.

The research into the experience of renal failure and cancer as well as associated treatments is 'illness specific'. In general, little research comparing different illness experiences has been carried out. This limits our understanding of the similarities between different illness and treatment experiences and what it means to an individual to experience a specific illness and treatment. Furthermore, while much research has focused on the psychosocial implications of the experience of renal failure and cancer, embodied have been relatively neglected. Embodied concerns are paramount when addressing the experience of illness and medical treatment. Thus, a non-reductionist account of bodily issues is called for. Bodies are apparent in illness and medical treatment. Illness and medical treatment involve changes in bodily capacities which are reciprocal with experiences of self. It is possible that our understanding of chronic illness and medical treatment can benefit hugely from a more serious engagement with embodiment theory. Investigations of illness and medical treatment therefore, must investigate both material-discursive factors in the human experience of illness and medical treatment. Only in doing so can we create a genuinely holistic account of experience of illness and healthcare. Furthermore, we can also hope to augment our understanding of embodied experiences. By empirically investigating the

experience of illness and medical technology we can examine how bodily changes (the physical consequences of illness and treatment) and social factors (the discourse surrounding illness and healthcare) influence how subjectivity is created by human beings in their everyday lives. A growth in embodied-centred research is evident. However, a gap remains between our understanding of the biological and physiological aspects of illness and healthcare and our understanding of the experiential and phenomenological aspects of illness and medical treatment. This gap must be addressed.

~ CHAPTER FOUR ~

METHOD

Aims and Objectives

The overarching research question concerns how the person makes sense of his or her experience of illness and medical technology.

The study has three main aims:

1) Describe the experience of chronic illness and medical treatment and examine the impact of the physical changes which are caused by illness and medical treatment on the person.
2) Assess the impact of chronic illness and medical treatment on the individual's sense of self and his or her personal and social identities.
3) Explore patterns of engagement with the world which arise from the person's experience of chronic illness and medical treatment.

The study objectives, therefore, are to examine the impact of chronic illness and medical treatment on the person of a variety of levels:

Physically – how does the experience of illness affect the individual on an embodied level?

Personally – how does the experience of illness and medical treatment affect self-representations and identities?

Socially – how does the experience of illness and medical treatment affect familial and social relationships?

In particular, the study aims to examine the associations between physical, personal and social changes. Thus, how embodied sense of self and experiences are shaped in the context of illness and medical treatment will be explored.

Design

A semi-structured qualitative interview design examining within and between group differences was used.

The participants were divided into three groups which were categorised in relation to the treatment they received. The groups were (1) Haemodialysis; (2) Radiation Therapy; (3) Surgery. In total 20 semi-structured interviews were conducted. One face-to-face interview was carried out with each participant. Interviews allow the exploration and elaboration of in-depth, idiographic accounts of subjective experiences and also allow for the elucidation of meaning and significance of a phenomenon, event or experience for the individual. Semi-structured interviews are considered to be one of the optimal ways of creating data for qualitative research as they generate in-depth knowledge of experiences. Furthermore, interview research permits investigation of complex issues such as the issues at hand, the experience of illness and medical treatment. Using interviews as the main research tool allows the research to explore idiosyncrasies in participants' experiences and also to elaborate inconsistent attitudes and beliefs held by individuals. Furthermore, as a tool it provides the researcher with the flexibilty to explore interesting and unanticipated avenues generated by the interaction between the researcher and participant.

Within and between group differences were examined by assessing similarities and differences across the three participant groups. Individuals who experienced end stage renal disease or cancer were invited to participate in this research. Both of these illnesses are serious chronic illnesses, can cause significant debilitation, and are life-threatening if treatment is not received. Therefore, both illnesses can have a serious emotional and psychological impact on the individual.

The technologies of haemodialysis, radiation therapy and surgical intervention were purposely chosen for exploration. All of these treatment technologies have a serious impact on the body and are considered intensive. These technologies can cause serious and long-lasting physical side effects. However, the technologies are also fundamentally very different in a variety of ways.

- Firstly, the temporal nature of the treatments differs. Haemodialysis is typically an ongoing treatment, which can last from a period of months to several years. Radiation therapy usually lasts a series of weeks or months. Surgery, however, is typically a once-off treatment, which may or may not require a relatively lengthy stay in hospital.

- Secondly, the treatments differ in terms of the agency afforded the patient. Haemodialysis requires an active patient: the patient must be adherent not just to treatments but also diets and medical regimens. Radiation therapy places the patient in a prone or supine position: however, the patient is

also active to some extent in the treatment. For example, the patient is typically not hospitalised and therefore, must present for treatment. During surgical intervention on the other hand, the patient is usually unconscious during treatment. Therefore surgery can be seen as requiring the patient to passively submit to a surgeon (although the patient must consent to surgery).

- Thirdly, these technologies impact on the body in different and contrasting ways. For example, the fundamental function of haemodialysis is to extract the patient's blood and to purify that blood, a process which takes place outside of the body. However, in radiation therapy the patient is treated with invasive beams that obliterate cancerous cells within the body. During surgery the patient is treated by either the removal of a body part, (for example, hysterectomy), or the addition (organ transplant) or augmentation (cosmetic surgery) of a body part. The surgeries investigated in the current study were characterised by the removal of part of the body. For example participants had undergone tissue or other bodily organ removal or partial removal of bones.

By taking into account a wide variety of differential illness experiences and physical disruptions, this design allows for the exploration of the role of the body in the construction of meaning in the arena of illness and medical treatment.

Procedure

The interviews took place in a variety of settings depending on the convenience and preference of the participant. The participants were met and interviewed in their homes, a quiet hotel or café, their office and the School of Psychology, Trinity College Dublin. Due to practical limitations the sample was a convenience sample. Participants were recruited within the time period from October 2006 to January 2008. Participation in the study was on a voluntary basis. The study was advertised through voluntary organisations and support groups, the Irish Kidney Association and the Irish Cancer Society. Participants were made aware of the research via support group organisers and were given an information sheet (see Appendix A) outlining the general scope of the research and what participation would involve. Participants contacted the researcher if they were interested in taking part and were again told about the scope of the research and asked why they would would like to participate. On first meeting there was a general conversation about the participants' background and participants were again informed about the scope of the research. Participants were also informed of the principles of

confidentiality and anonymity, and of their right to withdraw from the research at any stage if they wished to do so. Informed consent was obtained (see Appendix B) and the interview proceeded. All the interviews were carried out by the same person, the primary researcher and author. In general, the interviews lasted between 40 minutes to two hours. Some participants had some difficulty in talking as a result of their illnesses and treatments. These participants were informed they could take a break anytime they wished. During the interviews, I was alert for potential signs of distress being caused by the content of the interview. However, none of the participants displayed signs of distress as a result of the interview.

All of the interviews were audio-recorded with the consent of the participant. At the conclusion of the interview, participants were asked if they would like to divulge any other information about their illness and treatments which they felt was important to their experiences and which was not covered in the interview. Once the interviews were concluded participants were debriefed. Debriefing included the interviewer giving the participants a verbal summary of the interview, reiterating the purpose of the research and reiterating the participants' right to withdraw from the research. The participants were also given a debriefing sheet which summarised the research (see Appendix C). The debriefing sheet also contained telephone numbers of support lines if the participants wished to discuss any issues that emerged in the interview with a professional counselling service. The researcher's contact details were also made available to the participants.

Participants

Twenty participants, seven men and thirteen women, agreed to participate in the research. took part in the research. The illnesses the participants experienced include: renal failure (5), breast cancer (4), uterine cancer (1), prostate cancer (1), colrectol cancer (1), head and neck cancer (8). Head and neck cancers refer to a group of similar cancers of the upper digestive or wind tracts and oral regions such as the lips, mouth and the nasal cavities. The participants ranged in age from 32 to 75. Eleven participants were married and nine of these had children. Two participants were bereaved, one participant was divorced and four were single. Two of the participants who were single lived with their parents, one lived alone and one described herself as a lone parent.

The majority of renal disease participants were experiencing continuing illness and treatment. One participant received a successful transplant and was no longer receiving dialysis. Three participants had previously received transplants which had failed. For participants with renal disease, the length of time since their diagnoses and treatment varied from three to eleven years.

Participants who had been diagnosed with cancer had all been successfully treated. They were no longer ill or receiving treatment, except for regular medical checks-ups. Time since diagnosis and treatment ranged from 3 to 16 years. See Appendix E for detailed information in the form of vignettes on each of the participants' general backgrounds as well as their illness and treatment backgrounds.

Table 2: Participant code[6] and information

Participant Code	Gender	Age	Diagnosis	Time (yrs since diagnosis)	Treatment	Current treatment
1	F	42	Renal Failure	11	Haemodialysis	Haemodialysis
2	M	60	Prostate cancer	7	Radiation Therapy	None
3	F	59	Breast Cancer	16	Surgery and Radiation Therapy	None
4	F	38	Renal failure	3	Haemodialysis	Haemodialysis
5	F	47	Renal failure	12	Haemodialysis	Haemodialysis
6	F	32	Renal failure	11	Haemodialysis	None
7	F	48	Breast Cancer	12	Surgery/Radiation Therapy	None
8	F	47	Renal failure	3	Haemodialysis	None
9	F	52	Head/Neck Cancer	5	Radiation Therapy	None
10	M	62	Head/Neck Cancer	3	Surgery	None

[6] This code will be used in the results chapters to reference each quote to the participant

11	F	48	Breast Cancer	9	Surgery/Radiation Therapy	None
12	M	60	Head/Neck Cancer	5	Radiation Therapy	None
13	M	40	Head/Neck Cancer	4	Surgery	None
14	F	61	Breast Cancer	3	Surgery/Radiation Therapy	None
15	M	58	Colon Cancer	8	Surgery	None
16	F	68	Head/Neck Cancer	16	Radiation Therapy	None
17	M	75	Head/Neck Cancer	4	Surgery/Radiation Therapy	None
18	F	59	Head/Neck Cancer	4	Surgery/Radiation Therapy	None
19	M	50	Head/Neck Cancer	6	Surgery/Radiation Therapy	None
20	F	61	Endometrial Cancer	3	Surgery	None

Interviews

The interviews conducted were semi-structured and guided loosely by an interview schedule. Constructing an interview schedule is recommended practice. This facilitates the researcher to think about issues that might come up in the interview and difficult situations that might be encountered. Devising an interview schedule also prompts the researcher to confront their own agenda implicit in carrying out the research and to consider his or her own conceptions and preconceptions which he or she brings to the research.

This interview schedule was generated after conducting a comprehensive literature review. The interview schudule comprised of general prompts and questions. The aim of the interview schedule was to keep the interviews on track and to ensure they had some degree of commonality. Issues and situations which were emphasised in the literature as problematic for persons who had experienced a chronic illness and medical treatment were identified. The interview schedule was designed to probe the participants' illness and treatment background; when they developed the illness and how it impacted on them; when they started treatment and how it impacted on them; the experience of treatment itself how it and related side-effects affected them in their everyday lives; what the impact was on the individual both personally and socially; and how they coped with illness (see Figure 1 for examples of interview schedule questions). The questions were designed to be as open-ended, neutral and non-directive as possible. The ethos adopted for the interviews was to allow the participant to tell his or her own story as much as possible (see Appendix D for the full interview schedule).

Participants were open to the interviewing process and generous with the information they provided. Participants offered in-depth, detailed accounts of their illness history. Therefore, though an interview guide was used to ensure all interviews had commonalities in terms of subject matter, the interviews were allowed to evolve naturally. Thus, not all questions were asked in every interview.

Table 3: Questions and prompts in interview schedule

Section of Schedule	Prompts and Questions
Part 1	• Can you tell me the brief history of your problem from when it started to you beginning (and finishing) treatment? • Do you remember any particular feelings at this stage? • Did that have an impact on your coming to terms with your diagnosis?
Part 2	• I would like you to tell me a little about how you think about your treatment. Can describe what happens/happened during treatment, in your own words? • What do you do when you are having treatment? • What do you think about? • How do you feel when you are having treatment? Physically, emotionally, mentall

Part 3	• How does illness and treatment affect your everyday life? • Have you experienced side effects? Are you worried about side effects? How do you think the treatment affects you body? Do you feel in control of your body during treatment? • Social side effects? I mean have you had to adjust your life-style much? Does receiving treatment take up much of your time?
Part 4	• So how would you describe yourself as a person? • What are your most valued characteristics? • Has having illness/treatment made a difference?
Part 5	• Do you see yourself as being ill? • Do you worry much about your health? • On a day-to-day basis, how do you deal with all that's been going on?

Data analysis: A Critical Realist, Phenomenological Analysis

A critical realist analysis, based on phenomenological concerns, was carried out to investigate how embodied being impacts on the person's experience of chronic illness and medical technology. It is recognised that other material factors can also play an important role in the experience of illness and medical treatment. Financial factors such as the patient's ability to pay for treatments, the patient's ability to acquire health insurance, and the organisation of the healthcare system are likely to play an important role in patients' experiences. The primary focus of this study is the role of embodied factors in the experience of chronic illness and medical treatment. The corporeal nature of illness and medical treatments implies that embodied factors are likely to have a particularly strong influence on such experiences.

Once an interview was conducted it was transcribed at the earliest possible opportunity (see Appendix H for a sample transcript). The audio-recordings of the interviews were transcribed verbatim. Analysis of the data was continuous throughout the data collection stage. Analysis began with several readings of the transcripts, note-making and becoming thoroughly familiarised with data. Advanced analysis began once all the data had been collected. The analysis consisted of two main steps: (i) an

experiential analysis which examined the lived experiences of illness and medical treatment and consisted of a synthesis of the participants' narratives, and a thematic analysis; (ii) and an interpretative analysis which consisted of a theoretical analysis of the findings from the initial experiential analysis. The first step corresponded to an analysis of the participants' experiences which consisted mainly of describing the participants' experiences. The second step corresponded to an analysis of the meaning which participants attach to their experiences. Interpretation of the thematic categories identified was based on phenomenological, embodiment principles. A diagrammatic example of how this process was conducted can be seen in Table 3 below.

Table 4: Brief illustration of two-step analysis

Stage	Analysis	Findings	Example
ANALYSIS OF PARTICIPANTS' EXPERIENCES			
Data Collection	Initial Impressions, transcriptions & readings of transcripts	Integrating experiences within and between transcripts	*"there was no bargaining with it, there was no arguing with it. I couldn't talk my way out of it, I couldn't pretend it wasn't happening. This was something real that couldn't avoid. That was the real shock"*
Interview transcripts	Coding of lines	Description of participants' experiences	Participant describes the impact of illness diagnosis on life and self
	Integration of codes	Emerging themes	Physical changes could not be escaped/real effect on lives Illness causes confusion, throws life into disarray
Literature and transcripts	Integration of themes Refining thematic categories Traingulating themes	Final themes	**DISORDER IN ILLNESS** illness impacts on life in a serious way, has an emotional impact and seriously disrupts life.

ANALYSIS OF MEANINGS PARTICIPANTS ATTACH TO EXPERIENCES			
Themes from experiential analysis	Synthesis of experiential themes	Emergent conceptual themes indicated	The body is experienced as a constraint on self and lifeworld
Literature	Integration of conceptual themes with extant literature	Fleshing out conceptual categories Validating categories	Triangulating with embodiment theories Merleau-Ponty, Williams
Back to transcripts	Traingulating conceptual themes with transcripts	Refining of conceptual themes	Changes in corporeality can influence our lives. Illness has negating effects on life experience/self
Final analysis	Integration of findings	Final conceptual categories	**BEING A BODY**

(i) Analysis of participants' experiences

This stage of the analysis took a step-by-step approach to the transcripts. After thorough familiarisation with the data coding of the transcripts begun. This first stage of coding consisted of summarising and paraphrasing participants' statements, identifying connections between statements, indicating concepts, noting contradictions and similarities and differences between statements. These codes were them amalgamated into groups and then integrated to form themes. The second major phase of the analysis consisted of integrating analyses of individual transcripts into a whole.This process was reiterated for all of the transcripts. This phase of the analysis was grounded in the transcripts themselves (see Appendix F for a worked example of how the analysis was conducted).

Once the intial thematic analysis was completed, a move away from the transcripts was required. Preliminary interpretations of themes documented and initial, preliminary themes were outlined. Themes were classified into higher-order and lower-order themes. Themes which did not have suffient evidence were subsumed into one another where appropriate or abandoned. Appropriate literature was used to reinforce and validate themes. For example, concepts such as Bury's (1982) biographical disruption and Charmaz's (1983) loss of self were used to triangulate the findings. This contributed to the trustworthiness of the data. The completed experiential analysis generated themes that were considered to be accurate and thoroughly descriptive of all participants' experiences.

(ii) Analysis of the meaning participants attach to their experiences

The interpretative analysis conducted on the data consisted of subsuming the existing experiential themes which emerged from the first step of the analysis into conceptual categories. A phenomenologically interpretative meaning was ascribed to the experiential themes. This stage of the analysis therefore went beyond description of the phenomena that are investigated and attempted to delineate how participants' narratives and experiences pertain to their experiences of embodiment. How their sense of embodiment has changed as a result of the experience of illness and medical treatment and how the materiality of embodiment shapes experiences, identities, and sense of self was elaborated. cThis stage of the analysis consisted of a conceptual analysis that integrated academic accounts of embodiment theory with the participants' accounts of their personal and social experiences. Once the final conceptual themes were generated, inter-rater reliability checks were conducted (See Appendix G for an illustration of how the analysis of the meanings participants attached to their experiences was carried out). This check involved a second researcher who was unfamiliar with the research examining the themes and how they corresponded with the data from the narratives. A reliability coefficient of .86 was obtained.

Rigour

Ethical considerations and considerations of quality are paramount in qualitative research. Qualitative research is judged by criteria that are appropriate to the unique formation of qualitative endeavour. Rigour refers to the thoroughness of the study. To ensure a rigorous approach to the study, fit between the study and the philosophy that underpins the research and a complete and thorough analysis are

paramount. Furthermore, transparency and coherence are paramount and each stage of the research must be clearly outlined.

Fit between the study and the philosophical underpinnings was addressed in several ways. Firstly, an appropriate sample was chosen for the research. While the participants who took part in the research constitute a convenience sample, they had all experienced serious illnesses and intensive medical treatment. Therefore, the participants can be considered 'experts' on the experience of illness and medical treatment. The participants' rights, interests and wishes were put first at all times. For example, the individual's right to withdraw from the research was respected. Two individuals who were initially interested in taking part in the research were spoken, however, they chose not participate in the research. Both these individuals initially contacted the researcher. However, one individual did not participant due to change of heart. The second did not participant due to difficulties in speaking.

Fit between the method of analysis and the philosophical foundation of the research was achieved by adopting a critical realist, phenomenological approach. This allowed for an exploration of both the physical and embodied, material aspects of illness and medical treatment experiences. An Interpretative Phenomenological Analysis (IPA) was not carried out as it adheres to a relativist ontology. This would limit the exploration of material influences on the participants' narratives.

Data provided by individuals who chose to participate in the research was treated with the utmost care. Audio recordings and transcripts were stored in secure drawer. Data analysis, likewise, was treated in an ethical manner. Validity and quality of qualitative research are crucial considerations. Yardley (2000) argues that sensitivity to context should be demonstrated by the qualitative researcher. Sensitivity to context can be demonstrated on different levels. Firstly, an awareness of the existing literature which is relative to the research ought to be displayed. This was addressed in the current research by triangulating the findings with existing literature, in particular with major, well validated studies in the area such as Bury (1983) and Charmaz (1983). Theoretical perspectives, in particular literature on embodiment, were also used to triangulate the findings from the research. The degree to which the study is sensitive to the data itself is also a critical consideration. The unfolding analysis and argument must be evidenced with material drawn form the participants. To ensure that the analysis is sensitive to the data generated a systematic approach to the transcripts is required. This was achieved by immersion in the data and using a continuous comparative analysis as is recommended in several forms

of qualitative analysis such as grounded theory or Interpretative phenomenological analysis (Willig). In other words a 'line-by-line approach was used to ensure each transcript was thoroughly analysis. Theoretical abstraction is an important aspect of qualitative analysis; however, the analysis must simultaneously remain 'grounded' in the data. To ensure a grounding of the analysis in the material themes were only considered when there was sufficient material to reinforce it. This ensured the material was truthful to the participants' narratives. Themes which did not have sufficient evidence were discarded or subsumed into larger themes. Furthermore, the analysis is evidenced throughout using verbatim quotes from the participants.

Reflexivity

Sensitivity to context also requires attention to the socio-cultural milieu in which the study takes place. That is the relationship between the researcher and participants is an important context in which the research takes place. Reflexivity is a huge issue in qualitative research. Reflexivity refers to the consideration of the role of the researcher in the process. Qualitative research does not assume researcher objectivity (Banister, Burman, Parker, Taylor & Tindall, 1994). Rather, the researcher is an integral part of the process and generating the findings. The process of reflexivity highlighted the 'gap in expertise' between the researcher and the participants. The interviews took place between a healthy interviewer and individuals who had experienced compromised physical health. This gap provides an important context within which the interviews developed. It is possible that as the participants were interacting with an interviewer who was a 'stranger' to the experience of illness that they may have felt the need to justify how they portrayed their experiences. This point will be returned to in discussion of the findings.

To assess the role of the researcher and reflect informal diaries were maintained. Details of initial impressions of interviews were recorded. Questions and issues that arose in the interviews that may have provoked a reaction from the participants such as confusion or surprise were noted. This reflexive examination of the interviewing process facilitated development of the interview schedule and the research design. Reflexive analysis was also used to inform the initial analysis of each of the transcripts. Diaries were maintained throughout the analysis stages, cataloguing emerging themes. This constituted an 'audit trail' which contributed to the trustworthiness of the findings.

Generalisability

The generalisability of qualitative research can be limited. Indeed, generalisability is less of a concern in qualitative research than in the case in quantitative research. Nevertheless, the degree to which the findings from this study can be applied to other scenarios and situations is an important consideration. Certain limitations in the participant sample must be recognised and which may have affected the generalisability of the research. Firstly, there were no males in the haemodialysis group. Therefore, the findings that pertain to the experience of haemodialysis may be more applicable to women's experiences than to men's. Furthermore, participants who had been diagnosed with cancer no longer considered themselves to be ill and were not receiving treatment. This is likely to have had a significant influence on their reconstruction of their experiences. Other sample characteristics must also be considered. A significant proportion of the participants had suffered from head and neck patients. Furthermore, the participants' age is also a factor. Most of the participants were relatively older adults. Given that this research focuses on embodied experiences, the embodied changes in adulthood may have impacted on the participants' narratives and the consequent findings from the analysis. All participants were also involved in a support groups. Therefore, the participants may have been more adjusted to their illnesses and also had more practice retelling their stories. However, it must be taken into account that there remains considerable diversity amongst participants' illness, treatments, backgrounds and characteristics. This can actually be considered to contribute to the generalisability of the findings. Consistent themes can be generated across all the transcripts, in spite of this heterogeneity. This suggests that findings generated from the analysis can potentially be applied to other scenarios.

~ CHAPTER FIVE ~

RESULTS: THE EXPERIENCE OF ILLNESS AND MEDICAL TREATMENT

Preface

Individuals who were diagnosed with renal failure and received haemodialysis treatment, and individuals who were diagnosed with cancer and received surgery or radiation therapy were asked to recount their experiences of their illness and treatment. This chapter is intended as a contextualising chapter by providing a description of the experience of serious illness and medical technological treatment. A thematic analysis was performed to elaborate such experiences. The analysis revealed how the experience of illness and treatment cause major and continued disruption in the participants' lives. Seven overarching themes were generated. These are listed and described in brief below. The findings presented in the present chapter will inform the later analysis of the narratives from a socio-cultural, embodiment perspective where the ways in which illness and medical technological treatment challenge our sense of embodiment and how people reconstruct their personal embodiment as a conseqeunce of illness and medical treatment.

Table 5: Description of themes generated relating to participants' experiences

Theme	Description
Disorder in illness	Illness is a physical disorder, however, it can also cause major psychosocial disruption. *Disorder in illness* connotes how illness threw the participants' sense of self and life into disarray.
Disorder in treatment	Treatment aims to correct disorder, however, treatment can also give rise to emotional and psychosocial disruption. *Disorder in treatment* connotes the experience of uncertainty and fear in the face of medical treatment.
The inconsistent self	The effects of illness and treatment on the person result in differences which are inconsistent with former perceptions and representations of self and which must be reconciled
The limited self	The effects of illness and treatment can cause feelings of

	increased restriction and dependence. Illness and treatment affected the participants' sense of agency which in turn had diminishing effects on the participants' sense of self.
The wayward self	The *wayward self* expresses the participants' changed sense of self. However, the wayward self also captures how the experience of illness and treatment prompted considerable existential questioning and participants also talked about positive changes to self and to life, as well as a changed perspective on the world.
Threatened stability	The disruption that illness and treatment caused in the participants' lives undermined their taken-for-granted assumptions about their life-worlds. Participants' patterns of engagement with the world were altered and participants expressed a sense of vulnerability.
The adapted self	The *adapted self* concerns the processes and practices participants used in order to come to terms with the effects of illness and treatment on sense of self and lifeworld.

Disorder in Illness

Illness is a physical disorder. However, illness can also throw one's life and sense of self into disarray. Disorder in illness, therefore, is not just a physical experience but also has significant social and emotional ramifications for the individual. Two subthemes were identified which relate to the participants' illness trajectories and the experience of biographical disruption.

Illness Trajectories

Some participants were confronted with the sudden discovery of an illness; for example, one woman was unaware of any possible threats to her health until she was diagnosed with hypertension during her third pregnancy and subsequently told she would require dialysis. In this case the participant did not

feel particularly ill prior to diagnosis and then was suddenly confronted with a diagnosis of serious illness. However, confirming the presence of chronic illness usually came after the person had felt unwell and sought medical advice. For other participants there was a gradual deterioration of health and many participants mentioned that they had a feeling for a long time that there was something wrong with their health. Some participants reported struggling with doctors to take them seriously or to get tests done. Often there was a period of time where they were looking for second opinions, or a period of waiting for test results prior to diagnosis. Most participants balanced an expectation of an illness diagnosis against a hope that there would be nothing wrong with their health:

> *"I guess I knew when the doctor was sending me for tests and seemed concerned that there was something wrong. And I knew myself, it didn't feel right, I didn't feel right. So I guess I knew, but at the same time I was hoping that there was nothing wrong"*
> Participant 20

> *"During all the time leading up to it, from the time I saw it was a precancerous condition on the net I was wondering. There was a part of me that was wondering and there was another part of, you know, you have these dialogues going on in your head all the time and there was a part of me that was saying 'this could be really serious'"*
> Participant 18

Despite many of the participants fearing or anticipating a diagnosis of illness once they sought medical advice, most reported surprise, shock and even bewiderment when they were officially diagnosed. Some participants experienced denial or expressed disbelief at their diagnosis. This was due to a lack of serious symptoms, not feeling particularly sick or a lack of knowledge about the illness.

> *"He said 'I have to tell you now [name] that you've got cancer'.....and I said 'Jesus' and I sat there and I think, not that I think, the tears came into my eyes and then...(pause)"*
> Participant 10

"Because I never had anything like that and I didn't really believe I had kidney problems because I wasn't have any symptoms and some other things. Later I started falling sick but initially I was OK"

Participant 4

"... Actually just before, the day I went in, the day I went in, the first day I went into Dr. [name], he told me... I was out playing golf and and I was feeling alright like apart from a sore throat and I've had a lot worse... like often I'll have a lot worse. And as I, I couldn't believe it, I was playing golf on whatever day it was, and whatever day I'm told I've cancer"

Participant 10

People who receive a diagnosis of serious illness are confronted with a sudden change in direction in their lives. Receiving and illness diagnosis attests to a possible shift in an individual's way of living and can consequently affect sense of identity. The variety in the participants' reponses, ranging from shock to disbelief and denial, conveys a sense of betrayal which was experienced by the participants. Participants felt betrayed by their bodies and no longer in charge of their future. Therefore, for the participants an illness diagnosis threatened the fabric of their sense of self and the individual is suddenly transported into a new way of life which is unfamiliar. A sudden tension arises within the participants' old way of life and their former perception of self. Thus, the participants' experience of illness gives rise to biographical disruption.

Biographical disruption

The discovery of a serious illness had a considerable impact on the participants' lifeworlds. Being diagnosed with an illness and experiencing the ramifications of theat illness creates uncertainty for an individual and triggers disruption of an individual's life. The narrative reconstructions of the early experiences of illness portray the coming to terms with a diagnosis as a confusing time in the participants' lives. Thus, illness creates the need for considerable readjustment of one's life.

"And em, I didn't know what the hell was happening to me"

Participant 10

Enduring questions of 'what will happen to me?' and 'what will be the impact on my life?' were evident in the participants' narratives. Illness, therefore, interrupts and disrupts our taken-for-granted world and shatters our assumptions about our sense of self and life-path. This impact was not brief, but rather had ongoing implications for individuals. That disorder in illness continued to be experienced for many years after diagnosis and continued to affect the individual socially and emotionally. Resultant fractures in experience of self and world prompted serious concerns and worry amongst the participants. Most participants expressed concern about the future, what would happen next and what impact illness and treatment would have on their lives:

"I didn't know what was waiting me me on the other side in terms of quality of life or anything like that"

Participant 18

Concern and worry were very common in the initial stages of illness as well as after treatment had begun. In particular, concern for themselves and for their family was common. Amongst the participants, differential reactions to the threat caused by illness could be elaborated. While some participants actively sought out information about their illness and treatment options:

"By this stage I was all over the net"

Participant 14

Others, perhaps being overwhelmed and suffering from anxiety about their illness and treatment, avoided considering the future and how the illness was likely to progress.

"I see other people and they look everything up on the internet....I don't understand why they want to know"

Participant 10

"I have to say, I never asked an awful lot of questions. I didn't want to know what was happening and I took everything basically at what they told me"

Participant 10

Undoubtedly, illness can cause a significant disruption in an individual's life. That is, fissures can develop in the individual's assumptions about his or her world. Furthermore, assumptions about what the future holds for the individual can be brought into question. Overall, considerable anxiety can be prompted by the experience of illness. Illness, therefore, is experienced as bringing daunting changes to a person's life.

"That worried the life out of me".

Participant 19

"it was very daunting"

Participant 11

The experience of illness caused considerable emotional disruption. Throughout the experience of illness participants experienced a whole range of emotions in response to their experience of illness. Anger, irritability, impatience, frustration, sadness and helplessness were all common emotions throughout the illness experience. In particular, fear was an abiding theme throughout the narratives. Some participants reacted with self-blame and questioned decisions they had made in the lifetime. For example some of the participants who had experienced cancer expressed regret about their decision to smoke early in life. However, some participants who had quit smoking questioned this decision since they developed cancer anyway. Others questioned why they had not been more proactive in seeking medical treatment or looking for second opinions when they first became aware that they may have been something wrong with their health.

"why didn't I pusue it sooner? Why weren't you more proactive in going after it?"

Participant 18

Most participants described the initial stages of their illness as a very frightening experience. Undoubtedly, the experience of illness prompted serious contemplation of mortality. Fear of treatment and the impact that treatment would have on them physically and socially was also relatively common.

"So you know, there was that fear. There was the whole fear of the nature of the cancer itself and the extent of the cancer, survival rates and probabilities"

Participant 18

"there was no bargaining with it, there was no arguing with it. I couldn't talk my way out of it, I couldn't pretend it wasn't happening. This was something real that I couldn't avoid. That was the real shock"

Participant 18

The experience of illness had a substantial impact on the participants, their lives and their families. All of the participants reported being greatly affected by their illness. Illness can be seen as constituting a serious biographical disruption that impacted highly negatively on their lives. In their own words, participants described the experience as traumatic and as being a particularly difficult time in their lives:

"God....I've have a really bad time".

Participant 11

"It was a terribly traumatic time in my life".

Participant 3

"Coming to your lifestyle or your family life style as well (sic). It was terribly upsetting in that kind of way"

Participant 7

Participants with families often reported concern about the impact of illness on the lives of their families, particularly if they had young children. However, this was also the case for participants with adult children. Some participants hid the illness from their children for some time to protect them from worry and concern.

Bury (1982) proposed the concept of biographical disruption as a way of defining the sense of an individual's lifecourse being undermined as a result of receiving a diagnosis. Biographical disruption was described metaphorically by Radley (1994: 113) as 'a tear in one's fabric of life' that can suddenly

bring into question all of the assumptions upon which it was based. The concept of threatened biography is linked to the experience of three dimensions: biographical time, conception of self and bodily capacities. One's sense of life course, validity and identity are threatened. Thus, illness has important consequences for an individual, personally and intersubjectively. The participants described the experience of illness as being 'like a thunderbolt', 'a disaster', 'a major shock'. Participants were often at pains to remove themselves from the illness or to highlight the discrepancy between themselves and the illness. The narratives capture an experience of a rupture in sense of self. The experience of illness was seen as being juxtaposed with former assumptions about self. Thus, the narratives reflect the rupture between former sense of identity and self with an illness. Participants create a contrast between themselves as active, healthy and vital not sick or as a carer or parent not dependent and ailing.

> *"Eleven years, yes...well I didn't have to. I never had kidney problems.... "*
> Participant 1

Despite having suffered from end stage renal disease for eleven years, this participant saw herself as never having had kidney problems. The participant saw herself as being a healthy, vital person and the experience of illness was at odds with that definition of self. This sentiment is also reflected in similar comments from other participants *("I was never sick before", "I never had to worry about my health before"*). An experience of loss of health can lead to loss of self and experiencing a changed self. Former definitions of self are often discredited by illness, for example, when a sick person can no longer engage in acticities that were once taken for granted. No longer being able to engage in normal everyday tasks can promote feelings of helplessness and dependency.

> *"my ability is different now than what it was...em, I feel more vulnerable than I did"*
> Participant 18

Furthermore, illness can mean that the ill individual is no longer able to indulge or display characteristics which were once part of self identities. For example, one participant who felt that she was an outgoing person, however, the consequences of illness resulted in her no longer being able to socialise to the same extent. Gradually, she was forced to relinquished this definition of self. Undoubtedly, illness places an individual at odds with what one used to be and enforces changes to life and sense of self. Charmaz (1983, 2000) argued that a fundamental form of suffering in chronic illness is *loss of self.* Suffering in chronic illness is exacerbated by living a restricted life, beoming socially

isolated, and feelings of being discredited and becoming a burden. Thus, increased negative self sentiment can be common. In the current study, the narratives reveal reduced social engagement and betray a sense of diminished self-esteem and sense of self worth. Illness is experienced within a particular social and cultural context. Thus, socio-cultural influences impact on the illness experiences. In adult life, healthy individuals are supposed to look a certain way and to be a certain way. The individual is often evaluated on the basis of how his or her functioning 'lives up' to specific social norms. Thus, not 'living up' to societal standards can lead to feelings of difference and of stigma. Illness, therefore, results in experiences of self disruption and changed self[1].

> *"I don't need to know my weight...because I find especially the way society is, you're supposed to be you know a certain weight ot whatever"*
> Participant 8

However, self change is not always bleak. The participants also illustrated how they maintained a consistent sense of self and establish new identities and definitions of self. In other words, participants can and do make sense of their illnesses, reinterpret their experiences and adjust to living with a serious illness and major physical changes[1].

> *"I've had depressions and stuff but I'm not that type of person. I do try to snap out of it, you know"*
> Participant 1

Participants displayed a will to get on with life and to return to normal conditions of living and self. Furthermore many participants found positive changes to self as a result of illness and descriptions of a 'stronger', 'better' self were evident.

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[1] The experience of changed self will be discussed later in the chapter.

Disorder in Treatment

It is impossible to extricate the experience of illness from the experience of treatment. Medical treatment technology is designed to correct physical disorders. However, treatment can also be the cause of disorder and disruption in a physical domain and also in a psychological and emotional domain. In many ways, the findings described above are not directly caused by illness but rather as a result of what illness entails: medical management and treatment. Medical technological treatment is intensive, time-consuming and can have gross as well as minor physical implications for the patient. A large part of coping with illness is coming to terms with the treatment that is required. Furthermore, most particpants in this study were no longer suffering from an illness, yet were left with the physical reminders of illness as a result of the effects of treatment. Thus, the experiences of treatment are an important part of the larger illness experience and was found to have had a long-lasting impact on the participants. While some participants' treatments were ongoing, (participants who were currently undergoing haemodialysis), others were no longer receiving any active treatment. The effects of treatment on the participants, however, were found to have significant implications for the participants and affected physical status, as well as the participants' sense of self and their experiences of ther worlds. Despite the fact that many participants had been finished treatment for a considerable number of years, the impact of treatment on these dimensions remained evident. The disarray which treatment prompted in the participants' lives can be attributed to the physical disruption and dysfuction which treatment caused as well as fear of the effects of treatment.

Preparedness for experience of treatment

Most participants began receiving treatment immediately or very soon after receiving a diagnosis. Overall, most participants reported that they felt unprepared for treatment. For example, one participant experiencing kidney failure felt that at the time when her treatment began she was too sick to take in what medical staff were telling her about dialysis.

> *"I think at then time I was too sick to listen. I just, I just, I just all I thought in my heart you know. There was a long time before I started feeling better"*
> Participant 5

"When I had the biopsy done, it came back that I had invasive duct carcinoma of the breast. Now, em, then things started to happen very quickly. I had the, those on the Thursday I done the scans on the next day and the Sunday I booked in and I had the operation on the Monday. So I had only four days which was a bit scary to be honest"

Participant 11

This lack of preparedness is not reflective of a lack of prior explanation of the treatment and what it entailed from medical staff, but rather reflects the confusion, fear and emotional disruption the individual was experiencing at that time in their lives. When an individual is diagnosed with a serious illness, the participant is almost immediately confronted with treatment. Thus, the individual is quickly subsumed into a medical world. The individual must quickly come to terms with a new set of relationships with healthcare staff; one must also grasp a new vocabulary and come to terms with new terminology; one must come to terms with a new medical technologies; and lastly, one must deal with going from a healthy individual to becoming a *patient*. When a person begins medical treatment, he or she officially become a sick person and, therefore, must acquire and adapt to a new role in life, which is more passive and frequently less valued.

Medical treatment is disruptive to the individuals' lifeworld. Individuals with a chronic illness must spend a considerable amount of time engaging with healthcare staff and managing their own health. Therefore, people receiving medical treatment must give up time spent on other activities and change their behaviours and instead spend time 'being a patient'. Thus, treatment can reify the reality of the illness. Treatment can be a daunting and frightening process for patients. The introduction to and use of technology for the treatment of an individual is almost certain to affect the person. Two participants in the current study with kidney failure had gradual introduction to their treatment in that they were aware for some time that their kidneys were failing and would have to start dialysis at some stage in the future. However, even in these instances a sense of shock and lack of preparedness for treatment was reported by these participants. One of these particpants commented that, in retrospect, perhaps nothing could have prepared her for the shock of treatment.

" you know, it was coming to a stage you know where, that I needed dialysis .... I don't think you are really prepared for that even though you know, in theory you know what they look like and you've seen pictures of them you know, whatever, but I mean you see pictures but pictures don't make noise and they are very noisy, you know and there are

alarms going off and that kinda thing ... and it is , it is...I think it is a big shock when you see them for the first time, like you know, and you see people on it and you kinda go 'oh God, that's... your life is over', you know what I mean. Because it does look very, ah, intimidating. The actually reality of it"

Participant 6

Medical technologies are experienced subjectively and emotionally and can potentially give rise to negative experiences and outcomes. Medical technology has the potential for objectifying and alientating the person from both their bodies as well as other people. Medical care is becoming increasing technological. A move from a 'person focus' to a 'machine focus' within healthcare provision provides increased opportunity for distancing the person from medical staff. There is an increasing concern about the escalating use of technology in the field of medicine. Indeed, the experience of medical technology can be a frightening experience for the individual. Technologies can be seen as having a serious impact on our sense of identity which is frequently negative. Hence it is natural for patients to experience anxieties about their experience of medical technology and what the impact of medical technological treatment will be on their bodies and their identities.

Personal attributes, treatment and fear

The experience of fear in response to treatment was particularly common amongst the participants. Most of the participants, reported feeling considerable apprehsion about their treatment and the effects it would have on them physically, personally and socially. At times this fear mediated treatment choice, where there was a choice available to the participant. For example, one male participant with prostate cancer opted against surgery, and chose chemotherapy and radiation therapy over fears of losing sexual functioning which is a potential risk of surgical treatment for prostate cancer. A female participant with oral cancer also opted for chemotherapy and radiation therapy over surgery as her preferred treatment plan as a consequence of her fear of the effect surgery would have on her appearance.

"all I could see was the neck open and the eye drooping and I said I'm not having that...rather than have the surgery, I said, I'm going for that (chemotherapy and radiation therapy)

Participant 9

Fear of the effects of dialysis was also found:

> *"(I) try not to think about it. It is wearing me out. I do get tired. I know the effects it's going to have on my heart. I think in the long term, I think 90% of people of kidney patients die of heart failure... it makes the heart weak"*
> Participant 1

Fear was also experienced by participants who were underwent surgery. In a similar instance to the one illustrated above, a woman with oral cancer voiced considerable concern over the effect surgery would have on her appearance.

> *"there was the whole concern about the effect the surgery would have on me; on how I look for start, which was one thing"*
> Participant 18

> *"there is a personal thing about a face. When you encounter other people your face is what they first see of you and how they begin to make their judgements and I didn't know if I'd be able to get past all that. And I was afraid of all that"*
> Participant 18

The same participant also reported a fear of losing her voice as a result of surgery.

> *"Funnily enough my biggest fear was that I would lose my voice, or it would be changed because that was a possibility eh, and (pause) it's something that I used in work .... besides just the personal thing about a voice"*
> Participant 18

> *"My voice is what I hear of myself. It seemed enormous to me around this time because, whatever about my face – my face is how other people see me, but my voice is how I hear myself. Obviously I can see my own face in the mirror and other people hear my voice but for some reason it seems to belong to me much more than my appearance does – one is outer, one is inner. If I lost my voice it would be like losing part of myself"*
> Participant 18

Fear of treatment stems from a fear of the effects it will have on the individual and their capabilities. This fear is not just reflective of concern about reduced physical capabilities or a less attractive appearance. Rather, the subjective and symbolic importance of physical changes are critical to the individual's concerns. Sexual functioning, for example, was considered to be important for self-esteem and gender identity for both male and female participants. Thus, a potential loss of sexual functioning constituted a threat to self-perceptions as masculine or feminine. The participants' fear of losing valued attributes constituted a fear of losing an important part of themselves and their identities. If appearance is affected, for example, a significant threat to self-identity can be provoked. In other words, changes to what one looks like, changes to what one sounds like and changes in physical capabilities are not perceived as mere physical changes, but rather, as changes in being and self.

Furthermore, participants were concerned about the impact physical changes would have on their relationships with others. In other words, participants feared that the physical effects of treatment would change how others perceived them as persons. Thus, not only are physical changes experienced subjectively, they are also experienced in a social context. Physical changes have social implications, and the participants experienced a not insignificant fear that physical changes would single them out from other people as well as influence judgements made about them.

Representations of treatment

Given that the participants experienced considerable fear in relation to their treatment and its effects, it is not that surprising that negative representations of treatment can be elaborated. In particular, participants who had undergone radiation therapy and surgery, tended to talk negatively about their treatments. However, interesting differences in the way participants talked about their treatments were apparent. Furthermore, in contrast to other participants, those who were receiving haemodialysis tended to talk favourably about their treatment and portrayed it as unremarkable, cleansing and spoke about the treatment. Radiation therapy was described by participants as being unusual as well as destructive. Surgery similarly was described as destructive. These differences in treatment representations point to interesting disparities in people's illness and treatment experiences and pertain to how they attempt to come to terms with their experiences.

Haemodialysis machine as a life-support

Haemodialysis obviously becomes a significant part of the life of a person with end stage renal disease. Once diagnosed with end stage renal disease, continued haemodialysis is needed in order for the person to stay alive. Indeed, many of the participants had been receiving treatment for many years (however, the views here are also reflective of one participant who had received a successful kidney transplant and, therefore, no longer receiving dialysis). Dialysis is required at least three times a week and much time is spent receiving dialysis. In a very real way haemodialysis is a life support for individuals with renal disease. Participants' descriptions of their treatment were indicative of this sentiment. In other words, participants tended to think of the dialysis machine as a 'life-support'. Three subthemes were identified; (i) treatment as unremarkable, (ii) treatment as cleansing and restorative (iii) personification of treatment.

(i) Treatment as unremarkable

A tendency to describe treatment in matter of fact ways was evident in the narratives:

> *"It was just a machine and it cleaned me blood, and it would make me feel better and that's that"*
>
> Participant 5

> *"So they put the needle in me in the fistula and they put and they draw the blood and they attached to the tube and fix it to the machine and that is it ... Whatever you want to do you can do it"*
>
> Participant 4

In their descriptions of their treatment, the haemodialysis machine was spoken about by participants as being 'just a machine' and 'that's that'. Thus, the treatment was reflected upon as being unremarkable. While receiving treatment participants said 'they didn't notice it', they 'get on with things' and do everyday activities like sleep or read. It could be considered from the above illustratory statements that these participants have become accustomed to treatment and had incorporated dialysis into their lives effectively; and, therefore, were well adjusted to their treatment. It is possible that the group of participants in this research study were particularly good 'copers' and had adjusted well to a life with haemodialysis. It is evident that the majority of this group of participants were 'adherent', in that they

were good at following recommended dietary allowances and attended dialysis. The depicting of haemodialysis as unremarkable, could also be interpreted as being reflective of the lack of choice these persons have with regard to undergoing dialysis. In other words, if they want to continue to live they have to receive dialysis. Thus, 'that's that' and 'get on with things' could be interpreted to mean that the participants were reflecting on the absolute necessity of dialysis and that they have no choice but to cope with such treatment in order to live. It must also be remembered that the participants were recounting their experiences to an apparently healthy interviewer. The interviews must be interpreted in light of dynamic. It is possible that the participants may have felt the potential for criticism in this situation. It is possible that participants felt that they should be grateful for treatment. Therefore, they may have been at pains to prove to the interviewer that they were not 'suffering,' and also not to appear as complaining.

(ii) Treatment as cleansing and restorative

Treatment was also depicted as cleansing and restorative. Participants frequently referred to the treatment as 'cleaning' and saw the treatment as being like a 'washing machine' which 'cleaned' the person:

> *"I should really know a bit more about the machines. I just know they clean me out, they take the fluid off. I do know an awful lot about dialysis you know obviously, I do know the benefits of everything"*
> Participant 1

> *"Well it's, em, it's cleaning, it's like a washing machine ... basically it does what a washing machine does. And it's taking the blood out, cleaning it and putting it back in"*
> Participant 6

Participants also saw time spent being dialysed as a time for being by oneself and for relaxing. Thus, treatment was represented as restorative:

> *"I'd looked at it as my time, my relaxing time ... my time on me own"*
> Participant 5

Thus, the meaning participants' who were undergoing dialysis attached to their treatment can be generally understood as being beneficial to the person.

(iii) Personification of machine

A tendency to talk about the haemodialysis machine as a person was evident. Some of the participants gave the dialysis machine nicknames and often referred to the machine as a person. The machine, therefore, was seen as taking on some form of life in the eyes of the participants. Indeed, some participants referred to the machine as a 'best-friend' or 'boyfriend'. The machine, therefore, was in some ways seen as a partner in their lives and was recognised was being a very significant other to the person. This is indicative of a close relationship between the person and the dialysis machine and highlights the major role haemodialysis plays in the life of a person with kidney failure. In other words, haemodialysis was seen as being essential to survival and highly significant and important to the person.

> *"Do you have a nickname for it or anything? P: Well there's, there's a few, depends on the day, whether I'm in a good humour or bad humour I call it...but just looking at it now I'm going in here to my best friend in the world ..."*
> Participant 5

This phenomena of personification of the machine has also been found in other studies (e.g. Nagel, 1998). Personifying treatment, at times, sees the machine portrayed in positive, beneficial terms. However, despite the close nature of the relationship between the participant and the machine, often narratives reveal the relationship with the machine as conflicted and negative. For example, the participant above refers to her dialysis machine as her boyfriend, who made her feel better. However, later she revealed this to be an 'unloving relationship' in which the machine was seen as being uncaring despite making her feel better.

> *"I just wish it was all behind me though. In one way it doesn't give a shit about me"*
> Participant 5

Another participant also echoed this sentiment of aversion for the machine.

"I don't have a nickname for it. I don't because I despise it because it's in the room... and in everyroom in the house twas Baxter, that's the company that makes the products. So everywhere you go in the house, there's something belonging to Baxter in it. So you're not actually getting away from it. Everywhere you go there's Baxter, so you've this little, em, yeah flashing light to remind you that you're on dialysis"

Participant 6

Here, treatment can be seen as being personified and given the identity 'Baxter' (name of company). Unlike earlier personified depictions of treatment, however, in this case dialysis was seen as a stranger in the room or an unwanted and uninvited guest rather than as a friend. This highlights the participants' feelings of being constantly aware of the necessity of treatment. Furthermore, treatment was seen as time-consuming. Thus, despite treatment being seen as a means of survival or a life-support, treatment was also seen as taking time and, to an extent life away from the person.

"It just meant to me a means of, of survival I suppose ..... like you know what I mean. But, em, I still went away when I was on dialysis, I still did things. It wasn't like 'Okay, now I've got to stop like for whatever', you know what I mean"

Participant 6

"Oh! I wouldn't survive! I wouldn't be alive now you know if I hadn't gotten dialysis over the years. I'd be dead along time ago you know, so yeah that's you know ...so for me kids I'm here even if I'm home in bed I'm here. Oh yeah ... I wouldn't do without it so it's the lesser out of an awful lot of evils, really"

Participant 1

In these instances, treatment was seen in beneficial terms and recognised for the facilitation of life and quality of life it had given to the participants. However, many other statements betray an enmeshed relationship with the technology of haemodialysis. The negative aspects of treatment including the necessary monitoring of diet, fluid intake and weight as well as the self-administration of medication were never far away from the participants' thoughts. Moran and Gallagher (2003) illustrate the paraxodical technological enframing which describes the regime of haemodialysis, where compliance with the treatment regime is compulsory and the arising physical and psychosocial manifestations of treatment 'enframe' the individual in technology. Thus, haemodialysis requires people to face a great

amount of difficulties. For example, treatment was described as being like a 'shift'. Therefore, in some ways treatment was seen as being like a job or work that one has to do. Also, treatment was described as being 'tough' and 'difficult'.

> *"I suppose I'm giving a really lighthearted kinda view on it, it's not cause.... I mean it is tough. It is tough going"*
> Participant 1

Thus, the narratives uncovers the complex nature of the experience of being a patient on dialysis. The struggle to get on with life is hindered by dialysis and yet dialysis enables life. Despite feelings of gratefulness towards the treatment, participants also feel constrained by medical technology and a wish to be free of the technology. Therefore, though the dialysis machine was seen as a life-support, it was also seen as time-consuming and as affecting their independence and social and personal life. Therefore, dialysis enables life, but it does so at the cost of giving up a measure of independence and living a more resticted life.

'Radiation therapy as a curative detriment'

In contrast to the participants who were receiving haemodialysis, the participants who received radiation therapy (RT) tended to speak about their treatment in a more evidently negative manner. Furthermore, participants who had experienced RT described the treatment as being highly unusal and dangerous. Therefore, two main subthemes were extrapolated; (i) treatment as unusual and (ii) treatment as destructive. However, descriptions of RT also emerged which portrayed it a route to cure despite it adverse qualities. Thus, despite RT being portrayed in a negative way, it was also as a means through which restoration of health could be achieved and, therefore, something which was to be endured.

(i) Radiation Therapy as unusual

Participants typically found their introduction to radiation therapy (RT) as an unusual experience. One particular participant described the treatment as being like something out of science fiction and another described the machines as fascinating. This highlights that treatment was experienced as being unusual and unfamiliar:

"Ah, I was fascinated by them"

Participant 19

"It just, it can be a bit overwhelming"

Participant 7

"... It's like something out of a horror film"

Participant 9

One participant described the machines as being like something out of "a horror film". The above statement illustrates a sense of the suspense and fear that was experienced by this participant during RT. Thus, the technological environment that RT is administered in, was experienced as surreal and even disturbing. Other participants also experienced the treatment as being frightening and overwhelming. However, while some participants reported being frightened by the machines, others contradicted this sentiment in spite the treatment being seen as unusual:

"But I thought I'd be scared by them but I wasn't and it wasn't a problem to me at all. I got used to that very quick"

Participant 10

Participants reported becoming accustomed to treatment as it continued. However, despite becoming accustomed to the treatment, participants still reported finding the treatment as physically uncomfortable and, in particular, described the noise made by the machines as disconcerting. Therefore, unlike the experience of haemodialysis being seen as a time for relaxing, the experience of RT was experienced as being disconcerting.

"I just felt for that bit, for that time you feel, God if they had anything else but the buzz there, a bit of music or something....This awful kind of a .... it's a piercing noise and you kind of think Jesus it is, it reminds you"

Participant 7

"... em, there's this buzz when you're inside in the radiotherapy room"

Participant 7

"Well, your strapped down, well, I mean the strapping down part of it is the worst because you're held down extremely tightly and that actually you know, being tied down"

Participant 10

"OK it's a short burst but its, it could be very frightening to some people because eh you are strapped down. And you have this mask. In my case, I had this mask down over my head and shoulders, em, to prevent movement"

Participant 12

(ii) RT as a destructive cure

RT was also described by the participants as dangerous and destructive. For example, participants who received RT reported being conscious of the fact that they were being treated with radium. This was felt more due to the way in which treatment is administed to the patient in isolation, while the therapists and medical staff are in a separate room. Participants frequently referred to the treatment as 'burning' and fears of the radium damaging healthy organs around the site were also apparent.

"You're having your radiation for X amount of time and there's no-one else can go into this room because ...'"

Participant 7

"At the beginning I'd say 'Now, this must be really dangerous because they're running outside to look behind a piece of glass at this'. And, and you can wonder what the hell it was. It was a laser I knew and it was burning ..."

Participant 9

"You're actually saying 'what the hell is inside of me?'"...and you're wondering what the hell is this in my system. So it, it does bother you"

Participant 9

Some concern over the effects of radium on the body in the long term was also expressed by the participants:

"I'd like to know more about the amount of radiation they pump in through you ..."
Participant 3

"What does frighten you, see, well is this going to have eventually down the years, is this going to have an effect?"
Participant 10

However, despite RT being seen as unusual as well as potentially dangerous and damaging to the body, the treatment was seen as a 'means to an end'. In other words, the participants who received RT saw the treatment as a route to cure. Therefore, despite concerns participants had about the treatment, they nevertheless believed that the treatment would result in a cure.

" I just felt that it was like a means to a cause (sic), just it had to be done, you know, at the end of the day"
Participant 7

"Em, how we went along the first day and eh, em,... I was eager for it. Had to say I was greedy for any kind of treatment they could give me"
Participant 18

A typical course of RT lasts 4 to 6 weeks where treatment is administered usually five days a week. People who undergo RT do not live with technology in the same sense as those undergoing haemodialysis. Thus, though RT is an 'intensive' treatment, it is short lived and the treatment does not require the same assimilation into an individual's life as is the case for haemodialysis. Furthermore, RT differs from haemodialysis in that RT has a definitive end. Therefore, patients see RT as something that has to be endured for a limited period of time and as a cure to their illness.

'Surgical intervention as destructive'

Some participants in the current study had undergone major surgery which resulted in major physical changes. Surgery was described by participants as destructive. It was seen as physically invasive and considerable fear of the effects of surgery on the body was evident. Thus, surgery was experienced by

the participants as frightening as well as daunting and surgery was also seen as damaging, invasive and destructive:

> *"it was very frightening. I knew it was a really big operation and that they were going to remove half my face basically and I knew it would take a long time"*
> Participant 18

> *"Well eh, surgery was eh very drastic and I suppose I was a bit taken aback just eh, that the surgery was as big as it was"*
> Participant 13

It must be noted, however, that in contrast to the other treatments, participants' representations of surgery are less well developed. That is, participants tended not to think about surgery in ways that give the surgery itself a specific meaning. While surgery was seen as being destructive and invasive, particpants only infrequently described their thoughts on the surgery itself. Participants who had surgery tended to concentrate on the effects of surgery on the body and their identity rather than the surgery itself. Also, surgery was not portrayed by the participants as a 'means to an end' or a 'route to a cure' in the same fashion as RT. Perhaps this was due to the fact that frequently additional treatments such as chemotherapy and/or radiation therapy were required. Thus, for these participants surgery only indicated the beginning of the treatment process and was not seen in itself as a route to cure. Furthermore, the effects of surgery on the body were major and permanent, sometimes requiring long periods of rehabilitation and often resulting in permanent effects. These physcial changes had practical and symbolic repercussions for the participants such as increased dependence, increased self-awareness and loss of identity as well as increased perceptions of social isolation. Thus, surgery may have been seen as an unwanted solution to ill health, regardless of its necessity. The considerable physical changes that surgery caused could mean that upon reflection or reconstruction of the experience of surgery, it was difficult for participants to see the beneficial effects of surgery. Furthermore, participants often intimated that they would be reluctant to have further sugery in the future.

Unlike the other treatments explored in the present study, patients are unconscious during surgery. Therefore, surgery itself is not experienced *per se*. Rather, the participants experienced apprehension before and the subsequent effects of the surgery. Participants who underwent surgical intervention appeared to have assumed the role of patient quickly and compliantly. For, example, one participants spoke about how before surgery she tried to be a 'good patient':

"I said is there anything I can do to prepare myself. You know being helpful and willing, the cooperative patient, trying to get brownie points probably"

Participant 18

Participants often reported placing their faith in the doctor, or letting the doctor take responsibility and authority for their treatment. In this respect, surgery is diferent from the other medical technologies assessed in this study. Firstly, surgery is not consciously experienced. Secondly surgery is a 'once-off' treatment and not received over an extended period of time like RT and haemodialysis. Furthermore, patients who receive surgical intervention are dealing with a person, a surgeon and not a machine. Thus, surgery is perhaps seen as being more 'comprehensible' from a lay-person or 'patients' perspective and, therefore, patients may not need to make sense of the treatment for themselves.

Summary of treatment representations

Differences in the way people thought about their treatment were apparent. Clearly the treatments that are investigated in this study are very different from each other. Therefore, the differences in the way people represent aspects of their treatments can be seen as being at least in part due to the characteristics of the treatment itself. How the treatment impacts on the body (or doesn't impact on the body), for example, plays an important role in the way treatment is represented. In the case of haemodialysis the treatment is seen as cleansing. This can be seen as being due to the way in which haemodialysis purifies the blood and returns it to the patient's body. However, surgery is cast in more negative and destructive terms. This can be seen to be due to the invasive and excisive impact surgery typically has on the body. Furthermore, surgery typically leaves the patient with more immediately evident repercussions than radiation therapy and haemodialysis.

Additionally, the temporal nature of the treatment must be taken into account. Treatment for participants who had undergone RT and surgery was finite. However, most participants in the haemodialysis group were currently receiving treatment. Participants representations of treatment must be seen as being constructed in light of his or her current health status. Participants who had undergone RT and surgery were reflecting on the experience of treatment from a position of relative health. Participants, therefore, are living with the effects of the treatment rather than the illness. This could explain the negative representations of treatment. Participants who were living with haemodialysis were doing so on a permanent basis. Therefore, it is likely that they have reflected more on the treatment itself and how it affects their lives.

The nature of the illness and the social discourses surrounding the illnesses also need to be taken into account. Awareness of cancer and cancer treatments is high amongst the general population. 'Cancer' is perhaps the one of the most resonant words in the field of health and illness. Fear of cancer is common and to be diagnosed and treated for cancer is commonly accepted to be a very traumatic occurrence in the life of an individual. This may have facilitated individuals who have experienced cancer and undergone treatment for cancer talking about their treatment in a frank manner. However, in contrast kidney failure is less well known and understood amongst the general populace. This in turn may have inhibited open discussion of the experience of haemodialysis.

Illness and treatment can be seen to exert a major impact on the participants' lives. Illness and treatment require signigicant changes in a persons' life and are frequently reflected upon negatively. Furthermore, the disuption caused by illness and treatment can impose changes on the self which particpants experienced as being inconsistent with preferred self identites.

The Inconsistent Self

Throughout the vicissitudes of illness and treatment all of the participants faced a range of stresses, losses and challenges. Some of these stresses, losses and challenges bear some similarities across the different treatment types which were explored. Illness and treatment give rise to an altered physical status or physiological functioning, as well as concomitant social, emotional and psychological consequences. These changes and consequences can be serious and long-lasting. The effects of illness and treatment on the person can result in changes to sense of self which are inconsistent with former perceptions and representations of self. Overall, the experience of illness and treatment was found to constitute a major threat to the individual's perceptions of their identity. Participants' experiences of illness and treatment placed constraints and created a tension with their previously held sense of their personal and social identities. A diminshed body image, for example, was often the consequence of the impact of medical technology on an individual's physical and social well-being. Often valued attributes, characteristics and roles were unwillingly relinquished. These changes can threaten engended identity as well as other social identities. Furthermore, when physical disruption is experienced, heightened self-consciousness can be experienced. Hence, participants' self-representations were altered as a result of the experiences of illness and treatment.

Body Image and Self-Perception

Individuals who undergo medical treatment can experience profound changes to self-perception and body image. The physical impact of treatment undoubtedly had a considerable impact on participants. Particpants who had undergone surgery, for example, felt that treatment had taken a extensive toll on them physically. Most participants went through lengthy periods of rehabilitation and convalescence after treatment.

> *"physically I was a wreck I suppose. I, eh, the surgeon said it was like I was hit by a bus"*
> Participant 13

Participants who were receiving dialysis commented that their initial treatments were very difficult and physically draining. Though most participants receiving dialysis felt that they adjusted to treatment physically, they continued to experience a substantial degree of tiredness as well as other negative physical side effects. People who undergo medical treatment often acquire conspicuous physical changes such as facial and/or physical disfigurment. Other less conspicuous, or indeed inconspicuous physical changes are also acquired such as increased fatigue, or a weakened immune system. Body image and self-perception can be affected by both the impact of treatment on the body as well as the side effects of treatment.

Haemodialysis does not require the loss of a body part, but rather an 'addition' to the body in the form of a fistula or catheter which is the 'port' that attaches the person the the dialysis machine. Participants who were receiving dialysis often expressed a dislike of their fistula or catheter. Often participants were concerned that the fistula was prominent, detracted from their appearance and often made them feel less attractive. This frequently made the participants feel more self-conscious and consequentially affected what clothes they wore. Therefore, for the participants who experience haemodialysis the fistula or catheter acted as a barrier to maintaining or attaining a preferred appearance. It could be argued that this is a relatively minor manner in which treatment affects patients. However, even these minor changes had great significance for the participants[7]. A forced change in

[7] All participants who had experienced haemodialysis in the present research were female. It is possible that issues of appearance have greater significance for women rather than men who receive haemodialysis.

apparel, therefore, represented another restriction which treatment has imposed on the participants' lives. Moreover, this restriction can be seen as having a negative impact on the participants.

> *"And when I seen it I completely freaked out completely, the long tube hanging down like, you know. So, em, that was kind of, I mean that, again I got used to it, you know, but that was probably the most awkward thing like, you know, 'cause it was in such a prominent place as well. You had to watch what you wore there like and, you know, that kind of thing like, you know.... think that kind of bothered me really more than anything else like, you know"*
>
> Participant 6

> *"And my dress sense, my dress sense is affected. I have to buy long sleeve clothes every time. I cannot wear short sleeves because the fistula"*
>
> Participant 4

Medical technological treatment and its physical manifestations, can have negative consequences for self-perception and body image. The physical changes that resulted from treatment were experienced by participants as impinging on the person's life and hampering attempts to maintain or reestablish a preferred sense of self. For example, participants who were fitted with a fistula or catheter for dialysis wore particular clothes to conceal the fistula or catheter. Another participant undergoing dialysis commented on the weight fluctuations associated with her illness and treatment and expressed unhappiness with the way her body looked as a result of this weight gain. She felt that these weight fluctuations prevented her from wearing clothes she wished to wear. This resulted in her feeling less feminine. She commented that she loved "*girly*" clothes but was unable to wear them as a result of the weight changes she experienced as a side effect of treatment.

> *"One side effect that would be the worst would be the weight issues. Em you don't wish to be a size 8 any more. You know I just hope my clothes fit me (laughing). Cause I mean I could put on a stone in two days.....you get up and nothing will fit you. I get extremely excited if I've ankles and that can be great, you know? People think I'm mad. I get really excited 'cause I love skirts and high shoes and I would really like, that's why I rarely wear em, em, especially for going out, a nice skirt , a nice pair of shoes. You go*

out with lovely skinny ankles and you come home with big fat ankles by the end of the night. That, that bothers me"

Participant 8

The effects of treatment clearly impacted on the participants' body image. Side effects experienced by the participants ranged from physical sensations such as pins and needles, cramps, to nausea and diarrahea, to weight gain or loss. Weight gain, in particular, was a common side-effect of the different treatments and was felt keenly, particularly by female particpants. Weight loss, on the other hand, had more of an impact on men. Changes to physiological functioning also had a negative effect on the participants' self-perceptions and body image. For example, cessation of menstruation in women had a negative effect on self-percpetion. Other side effects included loss of hair, changes in skin texture, loss of sexual interest, general fatigue and physical weakness as a result of treatment experience. The combined effects of medical treatment and the side effects caused by treatment had a detrimental effect on participants' self-perceptions and body image. Participants freqently felt that they had personally changed as a result.

"I used to joke if I had cancer in some organ that you had two of you know that you could get rid of that would be in some place that would be hidden by your clothes and nobody would know and I do think in many ways that might make it easier to kind of forget and go back to a normal life. But, I have an amount of physical restriction now, my ability is different now than what it was. In the most fundamental ways. I mean I've got used to it and I go out and it doesn't usually bother me at all but eh, I look different and sometimes people do stare. It's an effort to speak, it's an effort to eat I have and these are things that you do all the time. Moving your mouth and, and I still have an amount of pain that we are still working to try and control and there's the effects of the medication and all of that that I'm living with all the time, my leg (pause) so I have to carry all of that, it's a lot to carry round with me all the time."

Participant 18

While diminished body image was more strongly evident amongst female participants, it was also the case that many male participants were unhappy with their appearance, and felt more conscious of their bodies, as a result of the physical consequences of treatment. One male participant commented with regret, for example, of how he had lost all his facial hair as a result of his treatment. Another male

participant who had radiation therapy for oral cancer also commented how he felt as if his treatment had left him 'marked' and that he was conscious of the changes that had resulted after treatment.

> *"Unlike people who have had operations and they are left with a scar and it heals and they walk freely again, my life has been affected by it in the sense that you're conscious of it every moment of the day that you have been marked by it"*
> Participant 12

The physical effects of treatment were experienced by participants as a loss. One female participant with breast cancer who had her ovaries removed as a precautionary measure commented:

> *"So, em, that to me I found it hard, em, because it's emotional because I said, this is it, even though I knew I wasn't going to have any more children, that's it like, you know what I mean ... your ovaries are gone. I said this yet again, he's taking another part of femininity and I found that very hard"*
> Participant 7

In the above excerpt it is possible that the participant is referring to either her cancer or the medical doctor as the agent which provoked loss of femininity. Nevertheless, the excerpt illustrates that physical changes can have significant implications for body image, self-perception as well as an individual's social identities. In other words, physical changes often have considerable psychosocial and emotional implications.

While participants experienced major physical changes, 'subjective' changes were also experienced. Many of the participants felt that their appearance or bodily functions were different despite this difference not being evident to others. These subjective changes also had a negative effect on body image and self-perception.

> *"Well I think that I didn't like this before I started treatment. These jowls here I never had them The only thing now with the, I didn't know that I was going to get old woman's lips, like this...now I never had all these creases around my mouth"*
> Participant 9

In another instance, a participant who had radiation therapy to treat oral cancer spoke about how she disliked having photographs taken and often refused to let photographs of herself be taken.

> *"Other people would, now if they were taking snaps or something like that I wouldn't get into them, you know. But, eh, they'd say 'Ah, come on, turn your good side' or something like that like, you know. But that's all like. I didn't want to be doing anything like that, I just didn't"*
>
> Participant 16

She went on to comment that when she looked in the mirror that she didn't feel like it was herself looking back. The participant felt that her physical appearance no longer represented what she once was or ought to be. Such changes in behaviour such as changing dress and refusing photographs, though subtle, can be seen to be indicative of a changing representation of self-image. The participants experience a 'splitting' or a 'paradoxical' change in their self-image. In other words, the participants felt their current appearance not correspond to the self representations which they had previously held internalised. Thus, participants' inner experiences of their bodies differ from the image which they see projected.

Lacanian (1935) theory argues that during *the mirror stage* of development in infancy, an infant comes to recognise one's own image and is captivated by this image. Lacan argued that the experience of seeing one's image allows the child to experience physical appearance in its entirety, or as a whole, which is in contrast to their physical immaturity. The process of identification with the *specular image* is seen as being fundamental to the formation of self as it allows for recognition that one's image is not identical to one's self. Thus the ground work for 'self' as constituting both self and other is laid. However, identification with one's image creates a consciousness of the body and of how one appears to oneself and for others. Thus it is more than just a process that occurs in childhood and it illustrates the conflictual nature of the 'self'. Self is can be experienced as an inconsistent other which can be a profound source of alientation. This is illustrated in the self-negating effect that physical changes can provoke in the participants. The physical changes which participants experienced forced them into a position whereby their former image of self was inconsistent with their current image. When their image does not reflect nor substantiate internalised, socially and personally validated individual or social self-representations, new and more negative identifications of 'ageing', 'older', 'ugly' and 'different' were adopted. Participants reported feeling different directly as a result of

physical changes caused by medical treatment. Bodily changes, therefore, had subjective reprecussions for the individual and often had significant emotional implications, particularly when the body part affected had significant symbolic implications for the individual, such as a face or the sexual organs of the body. Thus, the experience of the body must be seen to be as being important to sense of self. One is positioned within an unfolding dialectic between a body-self and one's world. As inter-subjective beings we live in a society with determines what the body should be. What happens, however, when the body controverts those dictats? For example, what happens if a man looks less masculine, or a woman loses a breast or ovaries?

Masculine and Feminine Identity

Respective masculine and feminine identity clearly constitute a large part of human identities and body images. The physical changes caused by medical treatment threatened the masucline and feminine identities of the participants. A panoply of social discourses on gender exist. Formal teaching, to folk stories to informal interactions with others dictate gender roles, ways of appearing and ways of being. Indeed, discourses on gender are dominant and paramount. Judith Butler (1994) points to the many penalties that exist for "doing one's gender wrong" (p. 256). The regulatory function and oft criticised restrictive nature of these social discourses on gender has been well documented and theorised. Thus, when one's body transgresses society's normative expectations for one's gender, then the body can pose a problem for an individual and lead to feelings of devaluation. A clash between how one feels one ought to look, feel and behave according to society's expectations and actual bodily existence can emerge. Within the narratives a sense of loss of gender identity can be elaborated.

For female participants a loss of feminity was incurred by a variety of factors. As mentioned earlier, some participants commented that restrictions in the way they can dress made them feel less feminine. Perhaps most patently, loss of feminity was incurred through physical changes such as the loss of a breast, womb or ovaries. These changes had significant implications for women in the current study.

> *"But, em, it is, it's, it's, it's, like kind of grief or, or, or holding your breath or you know you will never be the same, you know"*
>
> Participant 7

Physical changes have important repercussions for one's sense of self and personal identity. The surgical removal of a body part, such as a breast, was experienced as a personal loss and affected the participants' body images and self-peceptions. For example, the above participant felt less feminine as a result of mastectomy. The removal of a breast had significant symbolic implications for the participants' sense of identity.

Changes to physique do not just result in loss in corporeal terms, but also a loss in personal, symbolic terms. In particular changes in body parts which are symbolic of gender can result in changes to how they perceive themselves as sexualised and engendered. For women it is not surprising that loss of a breast challenges their feelings of feminity, given the cultural associations between breasts and feminity. Consumerist culture strongly promotes the connection between breasts and feminine beauty and promotes large, symmetrical, 'perfect' breasts. Having undergone mastectomy or partial mastectomy, the participants' controvert this representation of 'ideal' feminine beauty. The loss of a womans' womb or ovaries and the cessation of menstration was also associated with loss of femininity at times. However, female participants were less unaminous on this front. One participant commented, for example, that she was "glad to have rid" of her periods. However, two participants were particularly saddened by the loss of a functioning womb and ovaries (one through ablation and one through hysterectomy). In particular, one participant commented how she felt the loss of her womb and ovaries in some ways threatened her image as a mother as she had carried her children in her womb and now that had been taken away. She felt that in some ways this threatened her sense of closeness to her children, particularly one miscarried child, as she felt that the only way she had known this child was through the time spent in her womb. Physical changes, therefore, which contradict symbolic femininity can lead to feelings of a loss of engendered identities.

The links between body and gender identity were also important for men. Robertson (2006) argues that maculinity is inextricably tied up with the body. The "normal" male body is portrayed as stong, muscular and as active. Men's perception of masculinity was tied to ideas of strength and virility. Male participants' masculinty was threatened when they felt they did not conform to this representation. For example, weight loss had negative consequences for male identity as it can oppose attempts to preserve a public masculinity of health, strength and activity. An unwillingness to talk to others about their illness and their treatment was evident in the interviews. For example, one participant commented on how he found it hard to open up to his male friends and talk about his experiences of prostate cancer. Indeed, he concealed his illness from them for a long time. Showing vulnerability to other males was,

therefore, considered to threaten masculinity. Furthermore, perceiving themselves as being 'weak' or 'weakened' as well as feeling vulnerable, threatened sense of masculinity. This, clearly, has profound implications for men who experienced physical incapacity which affected their ability to be active and engaged, and hence, to fulfill traditional male roles. One participant in particular commented on how his wife did not visit him in the hospital due to her own ill health. He was happy with this as he did not want her to see him in what he felt was an incapacitated and weakened state:

> *"I can't eh, my wife unfortunately, she's got multiple sclerosis and so she couldn't come in and I didn't want her in anyway cause I didn't want her seeing me like in a such a way..."*
> Participant 10

Whereas women tended to concentrate on the physical nature of their feminity, men were inclined to think of masculinity more in terms of bodily function rather than appearace. Thus, male participants focused on engagement and displaying their masculinity. Cultural presumptions about males portray men as the breadwinner. For male participants being unable to maintain employment maintain active participation in daily life tasks had a significant impact on their sense of self. For one participant not being able to drive had significant emotional repercussions. Other participants commented on not being able to engage in their favoured pastimes such as hill-walking and golf. Thus, inactivity had a significant impact on the male participants. Futhermore, participants felt that not being able to socialise, in particular, not being able to drink with their friends led to feelings of emasculation as well as feelings of difference and stigma. Maintaining paid employment, staying active and engaging in physical activity was seen as being vital to maintaining and regaining masculine identity after illness and medical treatment.

Heightened Self-Consciousness: Personal and Social

Heightened self-consciousness was evident throughout the participants' narratives. Evidence of this heightened self-consciousness is apparent in many of the excerpts already presented in this chapter. Personal or private self-consciousness reflects an increased tendency to introspect and reflect on oneself. This self-consciousness reflects a heightened awareness that one exists as an individual and as a body. Social or public self-consciousness, on the other hand, reflects a heightened awareness of what others think of us. Participants experienced both increased personal and social self consciousness and

this gave rise to increased negative perceptions of self. It can be deduced that participants' increased feelings self-consciousness gave rise to significant feelings of self-doubt. In a sense, participants experience increased doubts their normality and validity as persons as a result of their experiences. Individuals who are suffering from a disease must face their own mortality, thus, significant existential questions are prompted. While this will be dealt with in more detail later, it is worthwhile to note that increased self-consciousness may be linked to an increased sense of vulnerability due to greater awareness of mortaility.

Independent of other people's reactions, people who experience gross physical changes experience are more aware of their bodies and its appearance. Almost all participants commented directly on experiencing a heightened consciousness of their appearance as a result of the changes treatment caused to their bodies. For example, one participant who had a mastectomy commented on how she felt she was more aware of how she looked.

> *You kind of, you can let it get, it can let it worry you, d'you know what I mean? You are conscious of it when you go and you're going to, especially at summer time and you're going to this, eh, wedding or you're going to some thing and you're there with, I'd be more conscious than anybody even in my cleavage or anything like that. Whereas like another person wouldn't take as much, you know what I mean? I'd be, you know, and I'd look at people and that can get to me. I can cry my eyes out on the beach. I can cry my eyes out, you know"*
>
> Participant 7

However, it is not just appearance that is in focus for the participants, but also how the body *feels* to them. Their inner experiences of their bodies are altered as a result of their experiences.

> *"People around me see that I'm functioning apparently well and assume that I am, that I'm back to normal, with a few visible changes. Sometimes I feel quite isolated by the fact that no one knows how I feel on a physical level. For example my voice. People say I sound the same – most of the time – and assume that is what matters to me, how I'm perceived. But what matters to me is how it feels; it feels different, takes much more of*

an effort and is tiring to talk. I am constantly aware of how the changes feel. Of my new restrictions and limitations"

Participant 18

Changes to the body caused by treatment caused participants to feel changed personally, in an internal, self-reflexive sense. There is a sense that people are constant aware of this change. That is, the bodily changes that participants experience and must continue to confront, impinges on their sense of self, preoccupies their awareness and refuses to let them feel like themselves. Often the participants commented that these bodily changes were private experiences, and others who have not had similar experiences cannot understand. This in turn may contribute to participants experiencing increased social isolation. Furthermore, participants often feel that the physical changes that they have acquired single them out from other people. For example, participants also felt highly conscious of how other people perceive them. This male participant who had surgery for cancer felt that he would feel worse about his physical appearance if others commented on it:

"Just to say I'm, I suppose sometimes I'd be conscious of that ah, my because of where they operated on the neck and they took so much out whether I look different. I suppose I look a bit different but people don't say. If people started saying 'oh you're really ugly' or something oh they wouldn't, they wouldn't. Now and then I think I worry about that then"

Participant 13

Overall, participants felt less confident about their bodies, as well as in their bodies. This affected how the participants felt about themselves in a personal sense. However, it also placed strain on their social interactions, as they were more conscious of how others perceived them and often anticipated or feared that other people's perceptions of them would be pejorative. The physical effects of treatment, therefore, can be seen to result in a threat to the participants' social identities.

Impact on social identity

Heightened private self-consciousness goes hand-in-hand with heightened public self-consciousness. In other words, participants experienced not only increased awareness of themselves, their bodies and their appearance, but they were also more aware of how they appeared to others. Many participants

commented that they do not like to talk about their experiences, often even with close friends and relatives. Some fear the reactions of others if they were to tell them about their illness or if they were to see the physical manifestations of treatment.

> *"If people ask I'll say 'oh it was just and accident' and I'll push it off .... and I don't want to be talking about it all the time constantly"*
> Participant 1

At times this reluctance to tell other people or to talk about their treatment was based on previous negative reactions from other people. For example, one participant receiving dialysis recalled a friend seeing her fistula and reacting negatively.

> *"There was one day one of my friends saw it. The way she screamed the way she did... I don't want it to happen again"*
> Participant 4

Other participants also reported that they were more conscious of how they appear to other people. Sometimes this impacted on their willingness to engage in social and interpersonal settings. One participant commented that it took her a great deal of courage to engage with others and to let herself be seen by other people immediately after her treatment.

> *"You'd have to clip these drains to the side of my dressing gown pockets and head out into the corridor and it took so much courage just to leave the room in those days. Just to go out there"*
> Participant 18

Social membership often demands a particular body. The way the body is perceived and thought about is disciplined and constrained by social discourses. The experience of the body, therefore, will be moderated by the social discourses which dictate bodily practices. Social systems of discourse can demand that women must be slim, attractive and have two breasts while men are called upon to be physically and sexually vital. Physical changes caused by treatment can controvert these social

exigencies. Consequently, the body has to be seen as social[8]. When the body is physically altered, social dictats such as those of feminity and masculinity, 'beauty' and health are contoverted. Thus, the participants' 'validity' as members of a particular social group had been brought into question. Foucault (1973) provides a critical analysis of how the body represents the normative site for cultural expectations and the way in which cultural values inscribe themselves on the body. Csordas (1994) examines the relationship between phenomenological experiences of the body, the medium of life and the body as the object of sociolinguistic construction. Self as a social being and as a corporeal entity have to be considered to be co-existing. As a result, corporeal changes have to be considered in light of the socio-cultural environment in which they are experience. Given the images of men's and women's bodies in a consumerist, Westernised society, participants experience a dichotomy between their bodies and and these images. This creates a sense of being feel abnormal and difference from other people. In turn a sense of distance from other people can be enforced. Furthermore, people can self-enforce social distance themselves and effectively 'self-stigmatise'. For example, some participants reported that they feel that they no longer socialise with their friends as they used to prior to their treatment or engage in activities they once enjoyed because of their changed physical status. It is also possible that people become more reliant on other people reactions to them to determine and to reassure themselves of their normality and to reassert their personal identity. This is evidenced in a quote above where a male participant's concern about his possibly less attractive appearance is allieviated due to the lack of comments from other people to such an effect. Therefore, he felt reassured of his physical appearance being normal. Another participant spoke of the great relief she felt and comfort she received when her sons commented to her after her mastectomy that they had "*decided she was still the same person*".

Participants were sometimes at pains to point out their normality. Some participants illustrated this by pointing other people's reactions, or non-reactions, to them. However, others asserted their normality by pointing out that no-one could tell that they were ill unless they told them.

> *"You know, if I didn't tell you I am on dialysis, you cannot tell"*
>
> Participant 4

Clearly, participants are experiencing increased difficulty in sustaining former body images and self-perceptions which had previously been taken for granted. A more negative body imge, lower self-

[8] This will be readdressed later

esteem as well as increased awareness and consciousness about appearance is evident in the narratives. Overall, self-perception and body image are placed under duress by the physical ramifications of illness and medical treatment. Bodily identities are inextricably intertwined with feelings about self. Thus, if the physical self is undermined, it can and often does have detrimental effects on body image and self-perception. However, it must be noted that it is also the case that a more vulnerable sense of self can undermine body image and self-perception. Both Merleau-Ponty and Schilder stress that body image is not just affected or altered by changed physical status but also by changed psychological and social status. It is evident that participants who recounted their experiences in the present study are not just experiencing changes in their physical being but they are also experiencing shifting social circumstances and are coming to terms with significant psychological and emotional issues. People who suffer from a serious illness and undergo drastic medical technological treatments, therefore, have a multitude of factors to adjust to and to cope with. For example, individuals may no longer be able to engage in activities or fulfill roles once valued; and frequently individuals lose contact with or feel their interpersonal relationships have changed as a result of the process of illness and treatment. It is likely that these factors also impact on body image and contribute to ongoing reinforcement of feelings of vulnerablility and a more negative body-image and self perception.

Interpersonal support was found to be vital to participants, not just to allievate distress, but to reaffirm identities and to maintain a sense of normality. Furthermore, participants also commented regularly that the environments, social and physical, in which they were embedded were critical to their sense of well-being and sense of personhood. Describing their experiences of hospitalisation, participants felt that they were disconnected from their worlds and this contributed to feelings of loss of identity. Experiences of the hospital environment, such as interactions with medical staff as well as interacting (or non-interaction) with the physical environment of the hospital provided the potential for feelings of objectification and dehumanisation. However, the hospital environment could also contribute to positive experiences of treatment. For example, participants commented that being able to go outside and walk around while hospitalised contributed to feelings of well-being.

> *"and the atmosphere in [hospital] is great. You know you've the grounds you can walk around you know, you can get outside and stroll around. You know the atmosphere, I think has a lot to do with it. Well the nurses and all that were very helpful as well, you know"*
>
> Participant 19

However, the experience of illness and treatment often placed restrictions on the participants which inhibied engagement in preferred activities. These restrictions could be seen to impact negatively on sense of self.

The Limited Self

Feelings of helplessness and dependency were reactions to the participants' experiences of illness and treatment. These feelings are rather unsurprising given the often long periods of rehabilitation, incapacity and adjustment participant were faced with. For many participants the difficulties experienced in functioning 'normally' and regaining control over their lives and bodies gave rise to feelings of helplessness.

> *"So I went home and I felt, I dunno what I felt. It was like everything was against me and I would never even be able to walk on my own two feet again and I was, anyway, I couldn't get up. When I was at home and I was on the sofa, I couldn't even get up to stand without having somebody there in case I fell because I couldn't take my weight. So I couldn't even get myself a glass of water, d'ya know I could do nothing I was really, really helpless"*
>
> Participant 18

Simple restrictions to everyday life such as being restricted to bed or physically weakened, being unable to look after one's self in basic ways resulted in feelings of helplessness. Feelings of helplessness and restriction can have signficant implications for the individual's personal and social identities.

> *"And its amazing eating is involved eh, in one's social life and it eh you know its one of the joys of living to be able to eat, eat normally should I say. So eh, that's an ongoing em, problem. Your voice is an ongoing problem because if its not good one day that you feel that you have to be cautious and eh, careful about it. You know there are limitations that you have to live with"*
>
> Participant 12

Restrictions to everyday life as a result of illness and treatment were evident. Physical changes often resulted in the person becoming more restricted socially. Thus, participants experienced physical limitations that enforced reduced social engagement and an inability to engage in normal everyday activities. Loss of self stemmed from feelings of helplessness and restriction. Charmaz (2002) described the self as 'habit'. In other words, we determine who we are through our everyday ways of behaving and engagement in the world and in our social environments. An inability to engage in these habits, therefore, results in loss of self.

> *"Em, I've had to do, I've had to stop doing a lot of things that I, I can't just physically, not able to do any more. I don't have the energy, em, the energy levels are quite low. Em, I wouldn't have the interest, you know, like even to do normal day-to-day things that I love ..."*
>
> Participant 5

Experiencing physical limitations, therefore, can have a significant effect on the individual and contributed to changed perceptions of self.

Threatened Stability

Vulnerability of self and world

Treatment and its repercussions had serious implications for participants' personal identity and social identities. However, also threatened was the particpants' sense of stability. Participants experienced increased feelings of vulnerability and an undermined sense of security. Often vulnerability was prompted during the experience of treatment. For example, this female participant felt that her experience of radiation therapy prompted the experience of both physical and emotional vulnerability:

> *" you're more vulnerable again because you're isolated, you're alone, you're lonely ... you feel like, em, you know, the tears come"*
>
> Participant 7

Treatment can place individuals in a prone position where they can feel vulnerable. This may contribute to the often considerable emotional reaction people experience in relation to illness. However, feelings of vulnerability extended beyond receiving treatment. General feelings of being more vulnerable and fragile both physically and emotionally were reported by the participants:

> *"Em, I feel more vulnerable than I did all the time. On all kinds of levels. From a practical physical point of view I'm not as strong as I was. I have to consider things before I do them I have to make allowances for that that I don't have the energy to you know, whatever. That my stamina isn't what it was, em but emotionally too I'm a lot more fragile in some ways"*
>
> Participant 18

Increased feelings of vulnerability to illness and physical frailty could be argued to give rise to increased belief in an unstable, perhaps even, dangerous world.

> *"I still know it's like we take something like gravity for granted, you know. You stand up you expect to remain vertical; you expect buildings to remain vertical around you. That s just something we take for granted when we move around. You know, the street horizontal, the buildings will be vertical. The bus will make its way through the town... (pause)... and for me that doesn't apply anymore. (Pause) I know, it's like you have to juggle the two things because I don't live with the expectation that eh this is going to come back everyday but at the same time I know that it's possible that it will"*
>
> Participant 18

Feelings of uncertainty and a shaken faith in the world were evident in the narratives. For example, this participant felt more vulnerable when out of familiar surroundings and exercised more caution when visiting friends and leaving her home. She also spoke about feeling fearful for her home and belongings. For example, she worried more about her belongings and her house. This perhaps reflected her fear of reoccurrence of her cancer.

> *"I'm not as outgoing because I used to like going out but now I wont go out of the area...like I want to get home, I want to be at home. I just want to be here. I just want to*

be around my own surroundings. And if my friends say are you coming out they say were going across town, I'll say no I have to be in the area... then if, if, if, if that didn't, after the treatment, no, I think I'm a little bit more cautious. I'm a little bit more aware of what's going on around me when before it didn't bother me. Now the house would be on me mind, every ache and pain I get is cancer"

Participant 9

Thus, experiencing vulnerability can have a significant impact on experiences of self as well as of the world.

The Wayward Self

In illness and medical treatment people experience changes in sense of self. The participants' illnesses and treatments were serious and frequently distressing for them. Participants were faced with and asked themselves serious existential questions. In many ways, participants were forced to question their sense of self and their existence as a result of their illness and treatment. For example participants made comments like, '*I was never like this before*' or '*that was never me'* which pertain to a sense of changed self. It is necessary to remember that participants made these comments in light of the interview. It is possible that it is possible that participants may not have thought about such matters before. However, the interviewing process provided an opportunity for the participants to create a narrative that described their experiences, creating meaning and significance. I do not see a reason why the statements pertaining to a changed self should not be taken to reflect their beliefs and feelings regarding their illness and treatment.

Participants were asked directly if they felt they had changed personally as a result of their experiences. Only two participants commented that they felt they had not changed. One participant commented that she had been dealing with illness from a very young age so she felt that she had developed good coping strategies to deal with illness and was adjusted to her illness. The second participant who felt she had not changed as a result of her experiences put any changes that she experienced down to getting older rather than her illness and treatment. The vast majority of participants felt that they had changed as a result of their illness and treatment. Changes to self were prompted by physical changes, changed body-image, as well as the emotional impact of illness and

treatment. Among other factors that gave rise to feelings of changed self, added restrictions in life and reduced activity were prominent.

> *"Yeah I would have. Would have. Because I can't (pause) I can't do, I can't do a lot. I eh, run things, I took early retirement and I run a pensioners club and that partially involves eh, a few lunches a year or what have you. OK so I'm there but when you feel you can't eat normally. When you feel you have to make special exceptions all the time, you're terrible conscious of your position all the time with your social strata. That em... em that you can't participate in the way that you feel you ought to be participating"*
>
> Participant 12

Overall, the experience of a changed self was a common theme running through the participants' narratives. A sense of changed self was created by both the experience of physical changes and by the limitations such changes imposed on the person. Restriction in activity imposed restrictions on opportunities for constructing a valued and unchanged self. In turn, normative values of independence and sovereignity were contravened. Participants felt that they could no longer engage in preferred activities, which can result in a sense of a loss of competence and loss of independence and this can be exacerbated by feelings of social atigma and difference. For example, the above participant feels that the physical changes he experienced singles him out from others, creating social isolation and also threatens his perception of his social standing. A sense of stigma can be provoked as a result of physical changes. Restriction in activity and ability can be seen to give rise to feelings of difference, isolation, and stigma. Thus, the interactive effects of illnesss and medical treatment can lead to feelings of discredited and changed self. It is evident that participants felt their former self-images slowly slipping away from them. For example, this participant receiving haemodialysis described how initially she tried not to let illness and treatment get in the way of her preferred lifestyle. However, she described how eventually illness and treatment enforced a change in lifestyle and impacted on her sense of self.

> *"I used to be always going out and everything, which you know I was younger then obviously...but that slowly went. I'm not able for that anymore...yeah I hardly go out at all anymore you know that sort of way. And financially as well, things have gone so bloody expensive anyway but no, I don't have the same energy, you know I'm older now"*
>
> Participant 1

This quote also reveals an interesting theme in the narratives. Participants often attributed changes in sense of self to factors as well as illness and physical changes caused by treatment. For example, age was singled out as having a detrimental impact on sense of self. In the above excerpt, the fault is placed on finances and the spiralling cost of living. This can be seen as a way in which the participants avoid viewing themselves as chronically ill or, indeed, vulnerable to illness. Participants, therefore, despite making many comments illustrating the deleterious effects of illness and treatment on their sense of self and on their lives, resist portraying themselves as ill. Indeed, when participants were asked if they worried about their health, all answered in the negative citing their relative good health. Participants also commented on how they do see themselves as having an illness, but qualified this with the distinction that they were not sick. Often participants compared themselves to other people and other patients to illustrate their relative health. This helped to create a discourse where participants were able to portray themselves as healthy and as being a 'normal' person. This allows them to eschew some of the changes imposed on their sense of self and their lifestyles as a result of illness and treatment.

Existential questioning

For some participants the experience of illness and treatment prompted considerable existential questioning. For a few participants, the experience of illness and treatment forced them to face their mortality.

> *"It was a harrowing time and you are facing... and I faced my own mortality. I had to look at the fact there is a possibility that I am going to die"*
> Participant 11

Thinking about mortality was experienced by some as distressing and was linked strongly with feelings of vulnerability. For example, the participant quoted above who had been diagnosed with breast cancer, experienced a heightened sense of physical vulnerablity and often commented on needing to continue hormonal treatments to protect her from reoccurence of illness in the future:

> *"I was happy to stay on the Tamoxifen because I felt it was protecting me as well you know, but as they say sometimes treatment can be worse than the cure but eh, at the same time I wanted to be you know, to have the security of it"*
> Participant 11

Facing mortality also prompted participants to reassses their lives and their lifestyle:

> *"There was the whole issue of mortality to deal with and actually that was the big thing. That was the kind of reverberating theme of the whole. It was such a shock it was a real shock that someone could just say that is your times up now and pull you out of the game and that's it its over. And (pause) there was no bargaining with it, there was no arguing with it. I couldn't talk my way out of it, I couldn't pretend it wasn't happening, this was something real that I couldn't avoid that was the real shock and it changed the way that I feel about everything. It changed the way I see everything. Just that one thing, all of the rest is stuff you know. Like noise in the background"*
>
> Participant 18

This was a common theme that was evident among many participants. As seen above, participants often questioned whether they were the same person anymore as a result of their experiences and perceived a change to their sense of self and preferred identities. Undoubtedly, the experience of illenss and medical treatment can considerably undermine beliefs, values, identities and sense of self. However, in other instances, beliefs such as spiritual beliefs can be strengthened. There exists a sense that the experience of illness prompted considerable reassessment of the meaning of life. Indeed, many questioned whether they want to be the same person anymore and also whether they want to live in the same fashion as they once did as a result of their experiences.

> *"I'm back to busyness and chasing around and going from one appointment to another. I do try to take things more easy – more than I did. I try. I'm pretty much back to what I did before (pause) just not to the same extent... yet. But I'm getting there and I could probably get back to some kind of outward imitation of what my life used to be like. But the big question for me now is whether that's what I want. Whether I want to live exactly like that anymore"*
>
> Participant 18

Participants talked about making changes to their sense of self and in their lives. Therefore, despite the many negative changes which the participants experienced to their sense of self and lifestyle, there is also evidence of participants constructing positive meaning in their experiences and reconstructing their sense of self in a positive way as well as making perceived positive changes to their lifestyles.

Positive finding

Participants often felt changed as a result of their experiences. This was often experienced as having a negating effect on self. However, illness was also understood by the participants as having a positive effect on self. For example, participants talked about being a better person as a result of the experience of illness.

> *"I must say I pray quite a lot now, but I do pray, pray a lot now. Don't take things for granted that much and eh, I think I'm a better person... that eh may sound strange"*
> Participant 10

Participants also talked about being "stonger" as a result of their experiences. Thus, despite feeling emotionally and physically more fragile as a result of their experiences, participants also contradictorily felt stronger as a result of their experiences. Participants also saw other positive changes to their sense of self as a result of their experiences. For example, this female participant talked about how she felt that she had made some positive changes in the way she interacted with others.

> *"Im a lot quiter than I used to be. Part of that is because I actually do have difficulty talking. Em but I find where before, I'd always be, god, motor mouth and id kill myself afterwards... 'why the hell didn't you just think before you opened your mouth?' id always be diving in with the smart remark, you know, or what ever and now I don't do that anymore"*
> Participant 18

Changes to lifestyle which were caused by illness could also perceived as being positive. For example, many participants talked about "slowing down". Frequently, slowing down was experienced as negative and as enforcing a negative change in the individual's life. However, it was not always seen as a negative aspect of life after a diagnosis of illness and medical treatment. Indeed, slowing down could reflect a positive change in the individual's life.

> *"Oh I changed, oh yeah, I had to slow down. My mother had died when I was nineteen, my father died when I was twenty-three, six months married. My brother was an orphan*

like at eleven years of age so he came to live with me. So like, and I was working and all that, you know, I was constantly going, going, going. I had to come up with the mother role in the house. I was always going... Like, I had to look at my life and I was kind of saying 'Just slow down, you just say no' and I did and I kind of like, I didn't take life as seriously, you know what I mean. I kind of like, I started enjoying life then. I kind of started going out more with the girls and all this sort of thing. I did, you know what I mean?"

Participant 7

In this sense slowing down, therefore, reflected a positive life change rather than a negative change. Other participants also echoed this statement and commented on making positive adjustments in their lives. For example participants talked about giving up unnecessary or unwanted responsibilities.

"I have more of a backseat role in things.... I don't have to be responsible for everyone. I never did have to be responsible for everything I just took that on"

Participant 18

This represented for participants a positive slowing down. Slowing down in these instances afforded participants an opportunity for positive personal change. For example, the participant above felt that she was able to be less "*managerial*" in her daily activities and interactions with friends and family. Other participants also spoke about taking more time for themselves and being more relaxed in their day-to-day lives. Making a positive change in lifestyle after the occurrence of illness can be seen as a way by which participants were able to reassert control over their lives and re-establish their independence and freedom. Thus, participants were forced in some respects by their illnesses and medical regimes to give up some control over their everyday lives; however, when participants felt that this was they were restructuring activities and lifestyle by own choice and for their own benefit, such changes were experienced positively.

Participants also spoke about taking up new hobbies and developing new skills. For example, one male participant had taken up piano lessons. Participants, therefore, made an effort to change their lifestyles in an effort to reestablish positive meaning in their lives. A change in life perspective was also evident amongst the participants. Participants, for example, talked about appreciating life more than they used to prior to their illness.

I think that was one of the seminal moments in my life in the sense that I now had a brush with death. I now realised I didn't have time to waste. So it didn't happen over night I was deceptively. I am a Christian, a nominal one before that much more committed after. So I changed my spiritual life as well as my emotional life and my physical life. So the three elements changed. I wasn't incontinent I wasn't impotent. They were plusses. I suppose the major change though was my attitude towards people and my wife and so. I realised I didn't know how long I had. I realised I wasted time. I realised I didn't have time to waste. I realised there were hundreds of things I should do. And relationships I should improve.

Participant 2

"I feel as if I was sleepwalking before, and I'm awake now. I understand something urgent and crucial and as basic as air, that I just didn't get before. I was oblivious."

Participant 18

Participants felt as if they had learned many positive lessons from their experiences. In general, participants felt as though they had learned more about themselves, about their lives and about what is important in life. Therefore, participants found positives in their experiences of illness and medical treatment.

"that's an interesting question; do you worry about your health?..... Em, I suppose I should worry in the sense that there has been an increase in my PSA levels and I'm being checked at the moment to see has it reoccurred. Do I lie awake at night worrying? Not really, I'm more philosophical about things. I'm more Eastern about it, I don't know because in the West its all do something about it. The eastern side is what do you want me to do, what can I do? I can pray and I can waste time. To me to try to not waste time, to try to appreciate the moment, to try to live in the moment. To appreciate what you have, the fact that I'm sitting here with you talking about this, trying to see where are you coming from with this. Trying to help other people around me"

Participant 2

The experience of illness, treatment and concomitant impact on the person can be understood as an incredibly difficult time in the informants' lives. However, participants were able to evaluate and make sense those experiences in a positive sense. Thus, while the participants can be seen to have struggled

with their experiences and the physical, emotional and social upheaval illness and treatment caused in their lives, participants were also able to maintain a positive relationship to themselves and their worlds. Thus, the participants' narratives document personal journeys which reveal suffering and loss, however, there is also an evident changed or better self and/or a changed attitude towards self and life. Thus, participants were able to integrate their experiences into a meaningful narrative. Participants established new images of self, reorganised their lives and also adjusted their attitudes to their lives. Illness and treatment undoubtedly causes considerable disruption to sense of self and lifeworld. However, adjusting and coping with this disruption is also evident.

The Adapted Self

Participants sought positive meaning in their experiences and frequently talked about positive changes in their sense of self and lives. The participants, therefore, had to confront the impact of illness and treatment on their everyday lives. Different ways by which participants' strive to resume a normal life can be illustrated. Two different ways of adjusting to illness and the ramifications of treatment can be illustrated. Firstly, dealing with illness, treatment and one's life was seen as requiring a shift mental attitude towards oneself and life. Secondly, adjustment can also be seen as an outgrowth of the person's activities and engagement with the world. Adaptation as a mental state and adaptation as process and engagement are not mutually exclusive. Both processes used in tangent by participants.

Participants integrated their experiences of illness into larger perspective on life. For example, participants minimised the disruption of illness in their lives. Illness was compared to other hazards that everybody faces. This recasts the experience of illness from one that has serious implications for the individual, to one which is relatively benign.

> *"Anything could hit you tomorrow you could be gone. You know nobody could live like that, sure you wouldn't live"*
> Participant 1

This quote also illustrates a change in perspective on life. Participants talked about "living" life; focusing or ruminating about one's experiences, and allowing oneself to be emotionally perturbed by

one's illness was seen as having a negative impact on the day-to-day task of living. Participants often talked about taking life 'as it comes'. Participants, therefore, felt that they did not let themselves get stressed out or upset by what are seen as trivial things in life.

> *"I try not to think about the future you know that sort of way. That's the way I used to be like 'oh, what if that goes what am I going to do?' Now I'm just if it happens, it happens and I'll deal with it when it happens"*
> Participant 7

Such statements testify to how individuals adjust their lives and their outlook on life as a result of the experience of illness. Coping with illness, therefore, can be seen as adopting a new frame of mind. Participants, for example, talked about focusing on other, positive aspects of their lives and not focusing on their illness. Participants also talked about not thinking about the future and living "*one day at a time*". Maintaining a positive mental attitude was seen to be critical in fighting illness and overcoming medical treatment. Participants felt that to not have a positive attitude towards their illness would be detrimental to chances of recovery.

> *"You can't think like that, if you did it would kill you..."*
> Participant 4

Being positive mentally was experienced by participants as being very important in the struggle against illness and treatment, particularly the participants with continuing illness. Participants felt that having a positive outlook on life helped them emotionally overcome the impact of illness in their lives. However, one participant at the conclusion of the interview commented on how during the interview she was giving a "light-hearted" view of her experiences and that in reality the experience of illness and treatment, in this case renal failure, was a particularly trying experience emotionally. Despite her positive attitude towards her situation she frequently experienced negative affect relating to her illness and treatment. In some ways, people who are ill are expected by society to be warriors and survivors, and to have a positive outlook on their future and be upbeat about their condition. This is perhaps revealed in the participant's statements regarding how she was portraying her illness in a positive light, but in reality she often experienced days where she struggled with the illness. The context of the interview can be seen to echo many social situations which the participants would experience. People who have experienced illness are often called to recount their experiences to others who are healthy. In

this case the interviewee is asked to recount their experiences to an interviewer who occupies a position of health. The participants, therefore, may have been placed in a situation where they felt they had to establish their relative health, normality and their positive outlook on life. Furthermore, the participants may even have felt the potential for criticism if they did not create appear to have a positive attitude towards their situation and did not portray themselves as being able to overcome their illness.

'Fighting spirit' was considered to be vital by the participants for adjusting to illness and the effects of treatment. Adjusting, however, cannot be attributed entirely to mental acceptance. Activity and engagement was also considered by participants to be important in adjusting to life after illness and medical treatment. Participants talked about going back to work, taking up new hobbies as well as re-engaging with old activites, as being important for their sense of adjustment. Thus, physical process and engagement contributed positively the task of adapting to illness and physical dysfuntion and recreating positive meaning.

> *"I didn't have to miss work or, and em. No I think that life went on the same as before and eh, I got back into...I like orienteering as a sport so I got back into that and that's you know, just gentle but yeah I suppose I'm quite similar to before really you know. Maybe I just feel a bit more peaceful myself"*
>
> Participant 13

Recovering and mantaning activity and engagement can be seen as a way of restoring former self-images and also constructing new self-images. A sense of engagement can be seen to extend to a feeling of being reinserted back into one's normal life. For example, the participants felt that being at home amongst their own possensions and belongings, and being around their family helped them to feel better about their conditions and about themselves. Activity and engagement therefore, helps towards receding sick and compromised images of self. Furthermore, activity and engagement positively contribute to the reconstruction of images of self as competent, vital and healthy. Activity and engagement also helped to recede feelings of uselessness and dependency and contributed to positive self images.

> *"I'm here, I'm, I'm living and I'm great....because I'm playing golf. I mean if you'd seen the amount of golf I played in the summer time ... you know. I just get on with my life. I have to"*
>
> Participant 7

Concluding Issues

Overall the experience of chronic illness and medical treatment could be considered to be a negative experience that threatened sense of self and sense of stability. However, people can respond to these experiences and learn to cope effectively with the effect of illness and treatment on their lives. Some revision of self concept is evident amongst all participants. These revisions contain both positive and negative connotations. Participants can be seen to attempt to fit illness into a coherent life story, to establish positive meaning and to construct images of themselves as strengthened by the experience. However, it must be noted that illness, the effects of medical treatment, physical incapacity and frequently pain and disfigurement must still be borne by participants. Negative effects of the experience of illness and medical treatment on self, social relationships and social experiences are evident.

Experience of illness and treatment has significant implications for the individual. The experience of disrupted biography and loss of self were evident. Furthermore, the physical effects of treatment impacted negatively on body image and created heightened self-consciouness. Sense of identity, both personal and social, was also affected. Participants also experienced isolation, increased feelings of vulnerability and a threatened sense of security. Participants, however, also illustrated how they called on mental and physical resources to adjust to their experiences. Reconstruction of self emerged though adjustment of perspective on life and though restored engagement and activity. Positive changes in images of self were evident. At times this was explained as a better self. Other times this was a restoration of former self, though somewhat revised. The participants' accounts of their illness and treatment experiences illustrate the strain such experiences place upon the person; sense of self and identity is threatened and often deminished, and relationships and social engagement can be affected in a variety of different ways.

The obvious impact of the physical effects of illness and medical treatment on the person are indicative of the symbiosis between the person and their body. Changes to the body result in changes to sense of self. Dominant medical as well as popular discourses, commonly separate the body and the mind. Indeed as Leder (1990) argues modern medicine gained substantially from this conceptualising of the body as object. Viewing the body as a machine, separated from the mind contributed to the development of efficacious medical technologies and treatments. However, from an individuals' perspective, illness and treatment are not experienced in an objectified manner. For people, the body is not experienced as separate from the self or from one's world, rather the body is the site for meaningful

experience. Thus, illness and medical treatment can result in serious ruptures in experience of self and ability to live in their worlds as it was once known to them. As Merleau-Pontian theory elaborates, the body is not separate from the person. The experience of illness and medical treatment, therefore, must be seen as having an impact on embodied experiences. In this empirical study, I have endevoured to pursue the experience of embodiment. Already, I have endeavoured to outline the experience of illness and medical treatment. The focus shall now turn to the participants' experiences of their embodiments. It is hoped that by using the concept of embodiment to analyse the narratives, new insights into patients' experiences will be generated. Thus, in the next chapter, the impact of illness and medical treatment on participants' sense of self and their lifeworlds will be readdressed.

~ CHAPTER SIX ~

RESULTS AND DISCUSSION: ILLNESS, MEDICAL TREATMENT AND EMBODIMENT

Preface

Osborne stated "if anything makes the collectivity we call the body somehow primordial, it is not so much that we possess a body, but that one of its fundamental attibutes is that it can go wrong, or at least that we perceive it can" (1996: 196, as cited by Fraser & Greco, 2005). A fundamental aspect of the nature of embodiment is that despite the stability the body provides us as persons, the body simultaneously confers a fragility. Thus, examination of the role of embodiment in the experience of illness and medical treatment is warrented. Such an endeavour will augment our understanding of embodiment, illness and healthcare and has implications for psychology as well as other social sciences.

Many academic, theoretical and third-person accounts, as well as autobiographical, first person accounts exist that describe what it is like for persons to live with illness, to cope with medical treatment and to recover from or adjust to illness and the deleterious effects of medical treatment. Indeed, the study of health, illness and medical treatment is a particular area of interest in many applied fields of the social sciences, such as health psychology, medical sociology and medical anthropology. These disciplines and typical research and exploration in this area act in accordance with principles of understanding and alleviation with the overall aim of contribution to patient care and more generally health care systems. Most of the investigations focus on experiential aspects and socio-cultural shaping of living through illness and living with technology and the deleterious effects of medical treatment. Mention of the body in these accounts can hardly be avoided, after all, the body is the source of ill health and the focus and target of medical treatment. The social sciences have been largely accepting of the body as a physical substrate which is shaped by the mind or by its socio-cultural embeddedness. Recording people's perceptions of their illness and treatment frequently casts the body as an object. Thus, in spite of endeavours to explore the experience of illness from a more holistic and sociocultural approach rather than from a physiological, objectified standpoint, the experience of bodily disruption is still enframed in a biomedical framework. This cannot add up to an understanding of embodiment. So, the experience of embodiment in the context of illness and medical technology remains largely unaddressed.

It is the central undertaking of this chapter to delineate the experience of embodiment during illness and medical treatment. The issues at stake revolve around the role of the body in the experience of illness and health care. So far I have recounted the participants' experience of illness and medical treatment; how people suffer through these experiences and how people react to such experiences both detrimentally and beneficially. The dominant themes which emerged from the participants narratives related to the participants' sense of threatened and changed sense of self and identity, changed experiences of lifeworld and changed social relationships. It is evident that the participants experienced a change in how they thought of themselves, in both a sense of self-diminishment as well as self-enhancement and improvement. Participants reported feeling more vulnerable and more fragile both physically, personally, emotionally as well as socially. The participants' perceptions of their world were adjusted as a result of their illness and medical treatment. Processes of adjusting to illness and physical dysfuntion were also elaborated. It can be argued that individuals who have experienced vastly different illnesses and disparate treatment technologies often experience similar ramifications and sequelae in experiential and phenomenological terms.

The findings described above fit with many approaches to the study of illness and medical treatment in that it pays heed to experiential and socio-cultural discourse. However, in this research I have aimed to investigate the contribution of the limitations and possibilities that the material reality of embodiment places on discouse. A phenomenological, critical realist approach has been adopted. Accordingly, discourse and materiality, experience and body are seen as being interlinked with one another. The aim is to redress the hegemony of discourse by bringing together the physical and social, material and cultural, experiential and representational in an account of the experience of illness and medical treatment. How the participants' experience of embodiment was influenced as a result of illness and medical treatment was assessed. The experience of embodied self was disrupted as a result of illness and medical treatment and the individual experienced a sense of alienation from the body. Furthermore, the body was no longer experienced as being under the control of the individual. Rather the body was experienced as an object. Changed patterns of engagement with the world could be attributed to the participants' changed sense of embodiment. Lastly, the body can be seen as an important factor in adjusting to the personal and social consequences of illness and medical technology. Four overarching themes, which consisted of sub-themes, were identified and are listed below.

Table 6: Themes generated that pertain to participants' experiences of embodiment

Theme	Description
The inseparability and duality of the body	The participants' experience of illness revealed the inseparability of the body and the self. The body and self are intertwined and when physical changes occur they impact on the individual's sense of self.
Being in the world	*Being in the world* elaborates the role the body plays in the participants' experiences of their social worlds. Frequently, patterns of engagement with the world were altered as a result of changes to sense of embodiment
The medicalized body	Medical treatment had a significant impact on how participants experienced their bodies. This in turn affected their sense of self as well as their experiences of the world.
Realigning the body, self and world	Disrupted embodied experiences had diminishing effects on the participants' sense of self and their lifeworlds. The body, however, also plays an important role in reconciling disrupted perceptions of self and reconstituting relationships with the world.

The role of *embodied factors* in shaping the experience of illness and treatment will be elaborated. This chapter will be divided into two main sections: the first section will address the role of the body in identity, while the second section will address the role of embodied experiences in perceptions and experiences of the world in which participants are embedded and act within. As the chapter proceeds the findings from this interpretative analysis will be discussed in order to tease out potential insights into the character of embodiment in the experience of illness and medical treatment. The discussion will draw on academic accounts of embodiment theory and combine them with insights from the empirical work presented to elaborate the role of embodiment in the experience of everyday life.

An embodied person who experiences a disruption in his or her embodied experiences is forced to confront the 'problem' that is the body. The corporeal person must consider 'how can I be this body?' In other words, the ways in which people defined themselves in the past, knowingly or not, in

terms of their being a body can be called into question. Changes in bodily experience, appearance and bodily capacity contribute to this provocation of doubt. Prior to disruption, the way in which the body confered a sense of sameness, predictability and, therefore, constituted a stable foundation from which we can extrapolate to a stable, unchanging world. The body is the vessel through which we experience the world and, therefore, disruptions of bodily experiences can evoke profound changes in perceptions and experiences of the world. Loss and change in an embodied sense can prompt questioning of reliability and predictability of the body and this quickly expands to a questioning of the reliability and predictability of the world. These issues are certainly central in the narratives from the present study. Thus, the main telic of the present chapter is to illustrate how persons' embodied nature (particularly those who experience embodied disruption) can shape, limit and offer potentialites for the participants' experiences identified in the previous chapter. That is, the way in which embodied factors can be seen as a structuring narrative descriptions of illness and treatment experiences will be elaborated. Embodied factors can be seen as faciliating and inhibiting certain explanations of experiences as well as orienting participants towards certain discourses.

The body, or the embodied nature of human life, has given rise to theoretical and methodological questions in psychology. Indeed, analysing the body has been seen as unnecessary in terms of social and psychological inquiry. However, embodiment is synonymous with existence, a condition which is brought to the fore in the domain of illness. The person is inextricably intertwined with his or her body, no-one more so than the person suffering with an illness. It is our embodiment that allows us as human beings to come to know ourselves and our worlds. The body, therefore, has a critical role to play in sense of self and in the person's relatedness to a social, cultural, and interpersonal context. The experience of illness and healthcare is essentially an embodied experience, and confronts the person with the 'problem' of embodiment. That is, in the wake of bodily disruption the person is forced to consider their embodied nature and the problem of continuing to be a person in a different kind of body.

Embodiment is problematic in that in that offers the individual a range of possible ways of being and courses of action. Thus, the body can evoke disruption of self, but simultaneously can also offer solutions to a sense of loss of self. The 'problem' that is the body can be understood in a positive sense. The body is the site and medium for expression and instrumentality, and in spite of illness and the deleterious disruption caused by medical treatment, the body can still allow for positive expressions of self. This task, therefore, to examine the '*problem*' of the body, echoes the sentiment forwarded by

Osborne (1996). Osborne (ibid) calls for an approach to the exploration of embodiment which, rather than argue over what bodies irrevocably are and to continue to outline a panoply of bodies that can potentially exist, focuses instead on what bodies do in terms of the day-to-day situations which people experience. It is important to recognise that experiences of embodiment can be very different from person to person. But if we are to talk endlessly (as would be possible) about the multiplicity of the body and bodies then we may as well be arguing that the body does not exist. After all, if the body is everything, then it is nothing. Osborne stated that investigating "the ways in which the body is a problem, not as just an obstacle but also in a positive sense and as a vehicle for thought and action" (p. 192). This approach can be seen as forming a productive way of investigating the body as the focus is shifted from what embodiment is to what we see as a more informative stance of what embodiment does; in other words, what it means to be embodied for individuals in the context of their everyday lives.

PART 1

The Body and its Connection and Disconnection from Identity.

The inseparability and duality of body-self

Body-self unity is undeniable. Conceiving of an alive and entirely disembodied person is unfathomable. The body, therefore, is an intergral apect of human life and of identity. It is the body that enables life and forms the basisfor sense of self. The body enables life, it is the ground for all experiences and is the vessel through which we can interact with the world. The body sets the scene for certain potentialities as well as for certain limitations. The existential ground for self has to be the body. However, despite the inseparability of the body and the self; the body and the self are not identical to one another. The body, given that it confers both potentialities and limitations, is both a source of subjectivity and alterity. Hence, a dialectic of relations between self and body must be explicated. The body and how it affects sense of self must be seen as a multi-level relationship.

As a primordial aspect of experience, the body can be seen as providing an organic mooring for sense of self. Thus, the body can be seen as establishing, supporting and maintaining sense of self. The body, however, can also prohibit certain experiences. Thus, the body can result in self-disruption and dislocation of self from the body. Illness and treatment transform the relationship between the body and the self. In the case of illness and dysfunction of the body (often caused by the deleterious effects of medical treatment) people experience the body differently. Physiological experience, for example, is altered and a heightened awareness of the body is evoked. Loss of control over bodily functions, was a common experience amongst the participants. Such changes in experiences of the body can be seen to constitute a rupture in embodied experiences. The body is transformed. Thus, our relationship with the body is transformed and our experiences of the body and through the body are altered.

Threatened sense of self, changed perceptions of self and loss of self were evident throughout the narratives. Formerly internalised representations of self were displaced as the body no longer substantiated such representations. Diminished self-perceptions and body-image, as well as loss of self were patent. However, alongside feelings of loss of self and changed self, participants talked about enhanced experiences of self. Testimony to being a 'stronger' and 'better' person was found in the narratives. Partcipants' experiences of self was, therefore, changed. Changed self was one of the most prominent findings that emerged from the narratives illustrated a significant sense of participants'

feeling that they had changed as a result of their experiences of illness and medical treatment. The physical changes which were the result of illness and medical treatment can be understood as prompting this rupture in the participants' sense of self and their personal and social identities. The oscillations and changes in experience of self can be understood in terms of participants' experiences of embodiment. In the following section I turn to describe how the discourse of changed self is influenced by embodied experiences. Two levels of relationships between body and self will be described: (i) being a body and (ii) having a body.

(i) Being a body

Embodiment theory rests on the assumption that as human beings we are physical beings. The body is a dynamic, organic site of subjectivity. The body is not just a mere physical object; it is lived and experienced. The lived body testifies to the fundmental and primordial nature of our embodiment. From this perspective, illness and bodily dysfunction can be understood causing fissures in persons' ability to live in their worlds in their ususal way. It certainly, cannot be denied that the self in illness and healthcare is intimately wrapped up with experiences of the body. Indeed, the participants' narratives testify to this *being a body*. Furthermore, the body can be illustrated as being a critically important part of who the participants saw themselves to be in the past, how they continue to be and how they perceive themselves as being in the future. The materiality of the body, therefore, confers a sense of direction and agency. A healthy body can give rise to a multitude of possible selves and lifepaths. However, a disrupted body can limit these possibilities for self and life. Thus, the body and embodied experiences have to be understood as an important part of how individuals understand themselves. However, it is inevitable that persons who experience bodily disruptions face particular difficulties in being a body. Hence, persons face difficulty maintaining a valued sense of self.

The body-self can be seen as a dialectic. Participants oscillate between states of cohesion of body and self and states of tension between the body and the self. This undulating course of changes in experiences of the body and experiences of self will be charted, beginning with the importance of the body for participants' sense of self.

It can be derived from the participants' narratives that the body is experienced as an important aspect of self. 'Physical' attributes and the physiological workings of the body are not understood

simply in terms of their physicality. Rather they are seen as being physical characteristics in which self is inherent. Physical appearances, such as a persons' facial features and his or her bodily contours and shapes, were seen as '*personal*' attributes, rather than being seen in just a pure physical sense. The loss of a breast, weight changes or skin tissue removal, were all experienced as taking something from the person in a symbolic, personal sense. Thus, physical appearance is experienced as part of self. Physiological functioning was also understood in this sense. For example, the workings of one's voice, menstruation and sexual functioning were all taken to be important characteristics of one's self. Self, thus, is clearly experienced as and believed to be tied up in the body. When talking about the effects of treatment was having on her, this participant receiving haemodialysis described the treatment as having the following effect:

> *"It is wearing me out. I do get tired. I know the effects it's (dialysis) going to have on my heart"*
> Participant 1

This quote exemplifies how the experience of illness and treatment is an embodied experience. In the theoretical sense of the biomedical sciences, it is the body that is being treated. However, clearly illustrated here is that the body and the self are experienced as inextricable constituents of one another. Thus, if the body is being 'worn out', this is seen as having a direct effect on the self. Stated simply, both body and self are experienced as being the same. Thus, what happens to the body is experienced as affecting the self. The body is experienced and known as being a critical part of the person. Participants continuously referred to their bodies and body parts as being constituents of the self. For example, participants spoke about 'my voice', 'my breast', 'my neck', and 'my leg'. The use of personal pronouns in reference to different body parts betrays an appreciation of the body as being intrinsic to our being. The narratives that the participants created witness self as being inserted into the body.

The participants' understanding of their experiences of illness and treatment has to be appreciated as being an embodied experience. The meanings that the participants attached to their experiences are realised by and through embodied experiences. For the participants in the present study, dysfunction and deleterious effects on life are realised through the body. That is, the effects of illness and medical treatment are manifested in the body which in turn influences the way people come to understand their experiences, and the meaning and significance experience has for them as individuals in a certain social setting. Thus, change in self is manifested by changed experiences in embodiment.

Changes to sense of embodiment are evident in the participants' accounts of their experiences. For example, recounted below is an example of how experience of the body is qualitatively different after illness and medical treatment.

> *".. what matters to me is how it feels; it feels different, takes much more of an effort and is tiring to talk. I am constantly aware of how the changes feel"*
> Participant 20

Change in sense of embodiment for the participants gives rise to a change what the body means to the person. Thus, changes to their sense of embodiment can be seen to result in changes to subjectivity. In the case of the present study, the body establishes more negative meanings for the participants. The body constitutes the way in which we exist as persons, and as such orients one toward a specific way of being in the world. The participants' bodily predicaments orient them towards a 'sick role'. Instead of being active, fit and healthy, the individual is ill and requires medical treatment. Thus, bodily disruption causes uncertainty, vulnerability and potential dependency, as well as creating a sense of diminished and devalued self. So, for the participants, the body no longer substantiates former, valued self-representations, as the participants' compromised embodiments no longer facilitate preferred self-identities. Thus, in spite of the body's identity with the self, it can act against the self, The body, therefore, can have a negative impact on self. In these circumstances, self can be distanced or alienated from the body. The participants' narratives display this sense of alienation from the body. Changes to participants' sense of embodiment, in terms of participants' body-relatedness (how they feel they are tied up with the body) are evident. That is the body is experienced in its alterity or as an 'other'.

The alterity of the body

The body is critical to the person and the basis of our being in the world. Under normal circumstances, as human beings we are a body and this inserts us seamlessly into the world. The body, therefore, is not just something the self acts through, rather the body and the self together are the acting. The body itself, therefore, is ordinarly absent from our conscious awareness. For example, if walking one is rarely aware of the need to move one's body, yet one can become profusely aware of the body if the act of moving prompts pain and discomfort. Typically the body is marginalised from our conscious awareness. In our everyday lives, we are aware of what we are doing, walking, talking, eating, or working. These actions which are embodied, and yet, only in certain circumstances are we aware of the

corporeal basis of these actions. Only when the body is dysfunctional, when it signifies something we do not wish it to, or when the body is a source of social embarrassment, does the body impinge on our counscious awareness. Leder (1990) highlighted the phenomenological indifference that is the experience of the body. Despite the permanance of bodies and their constancy in experience, they are only marginally present in our everyday lives. The body and its disappearance from our moment to moment consciousness is important in order to give us the freedom to engage, act and articulate. The body, therefore, or our embodied actions and their corporeality are taken for granted. This can be illustrated through the participants' statements regarding their bodies:

> *"It's funny, I was so fit and healthy. And then all of a sudden... poof! It's gone. I went from playing sports to lying on the couch resting. I didn't appreciate what I was able to do back then"*
> Participant 20

> *"But I used to be, it's a killer you know. I didn't know how much energy I had until I lost it. (Pause) I didn't know how competent I was until I lost that"*
> Participant 18

These quotes illustrate how for participants the body was taken for granted and absent from their everyday lives. Illness and dysfunction of the body, however, ironically established the importance of the body and embodiment for everyday life. As corporeal beings we engage with the world through the body. Participants' narratives portray the healthy and phenomenologically absent body as the source of energy and agency. The body, therefore, is seen as opening the person up to certain possibilities and allowing the person to act and be instrumental, though previously unknowing of its importance. However, the above quotes also illustrate how the body becomes noticeable in dysfunction. The dysfuntional body no longer opens the person up to certain possibilities, rather it closes off certain possibilities. The body asserts itself in the event of disease and dysfunction. We are forced to notice our bodies when illness and impairment interfere with daily activity. Therefore, in illness, the body becomes salient in a way which is problematic for the self.

In chronic illness and medical treatment, bodily disruption is consuming. For the participants, their bodies are experientially different. The partcipants' bodies are not just functioning differently but also they are more aware of of their bodies and more sensitive to bodily sensations. Heightened

awareness of the body is evident throughout the narratives. The body becomes central to experience, however, the body is experienced in its alterity. Awareness of the body as an object rather than a lived entity, prompts new negative subjectivities for the participants. For example, the participants experienced a heightened sense of self-vulnerability due to the experience of a compromised or dysfuntional sense of embodiment. The disruptions to embodiment can, therefore, evoke feelings of instability of identity.

> *"my ability is different now than what it was...em, I feel more vulnerable than I did"*
> Participant 18

This quote illustrates the participant's compromised sense of embodiment. Changed experience of the body prompted the participant's sense of increased vulnerability. The participant, therefore, was more conscious, and perhaps afraid of being affected by the world and being less able to affect the world in turn. Thus, fractures in experience of the body-self are evident. Overall, the participants' narratives illustrate a significant sense of alienation from the body. Furthermore, disruption to sense of embodiment threatens confidence in the body and as a consequence a sense of having been betrayed by the body arises. Self is, therefore, alienated from the body.

In illness and dysfunction the body was experienced by the participants as being a burden to the self rather than facilitating self. Heightened consciousness of the body and a loss of confidence in the body results in a sense of estrangement from the body. Being more aware of the body, therefore, can result in a fractured sense of embodiment. Rather than experiencing the body as a whole, certain aspects of the participants' corporeal existence rose to prominence for them. Their appearance (often subjectively felt to be changed for the worse), and the ability of the body to function normally (for example, to walk, eat, talk) were heightened in the participants' consciousness.

> *I'm living with all the time, my leg (pause) so I have to carry all of that; it's a lot to carry round with me all the time."*
> Participant 18

Thus, living with the effects of illness and treatment led to a state of disaffection with the body. The body is experienced by the participants as hostile, and unsympathetic to the self. Thus, a sense of estrangement from the body as a whole is evident:

> *"unlike people who have had operations and they are left with a scar and it heals and they walk freely again, my life has been affected by it in the sense that you're conscious of it every moment of the day that you have been marked by it"*
> Participant 12

The dysfunctional body, can give rise to profound disruption to one's sense of self and to experiences of one's lifeworld. The male participant above did not have physical impairments in walking, however, he felt that his body did not allow him to 'walk freely'. As an individual who had experienced a serious illness and was left with considerable physiological dysfuntion (inability to eat and swallow as well as difficulty talking) he was experiencing considerable turmoil personally, emotionally and socially. He felt 'marked' as a result of a changed embodiment. The dysfunctional body orients the person toward a sense of changed and stigmatised self. The body which has a presence dominates the self and places restrictions on the self. For the participant quoted above and for the other participants, the body can no longer seen as being an unproblematic part of the self. This excerpt above illustrates the inherent embodiment of human everyday life. Often unknowingly, the body is part of our actions and part of our self. The way in which we interact with the world in an embodied manner and, therefore, constitutes a large part of who we believe ourselves to be. Thus, struggling with a dysfunctional body is not just a physical struggle. Rather, it is experiened as a struggle within the self.

Our sense of embodiment allows us to determine a symbolic sense of self. That is, the body typically allows us to insert ourselves into a mental and social life. However, the body can also be a barrier to preferred personal and social identities. The body plays a critical role in shaping our being in the world, our understanding of the world, and of who we are in the world. Our sense of self is based on a corporeal existence. The spatiality of the body, enables movement and, hence, enables us as human beings to be active individuals within our worlds. Bodily orientation, sensation and movement are, therefore, critical to our experiences of self. It is our embodiment that shapes or enables perceptions of self as agentic. This can be seen in the multiple roles, such as employee, parent, carer, friend, golfer and driver, that require embodied actions and are adopted by the participants in the current research. Embodied experiences play an important role in meaning and self conceptions. The body is a means of

engagement, communication and expression and as such, provides us with a sense of agency, vitality and substance. Therefore, the body provides the basis for subjectivity and meaningful experience. However, in illness and dysfunction the body can no longer form the basis of a valued and preferred self. Consequential diminishing effects on sense of self are frequently evident. The body, instead of being the source of subjectivity, can work against the self and subtract from the person a sense of agency, vitality and substance.

Leder (1990) argued that alienation from the body can fragment experiences of the self into a series of "lived oppositions" (p.123) which gives rise to the experience of dysembodiment. The individual's normal state of embodiment is no longer attainable and a destabilisation of the relationships between the body, the self and society occurs. Dysembodiment, therefore, reflects a state of separation of the self from the body. For the participants, their taken-for-granted world and their familiar roles in work and life are shattered. Participants commented on their subseqent (to illness and treatment) reduced mobility, inability to move, do simple household tasks, work as well as reduced opportunities and willingness to socialise. Habits and activities that were previously engaged in easily, even automatically, were disrupted. Prior to illness and treatment, the body automatically and unconsciously supported these activities. However, the dysfunctional body no longer supported these activities. The cohesiveness of experience and of self is disrupted by the experience of a disrupted embodiment. Hence, the participants experienced a devaluation of self whereby their perceptions of self and understandings of self were disrupted. First and foremost, a profound disruption of biography is evident in the participants' narratives. For, example, a sharp distinction in participants' perceptions of life and self before, and life and self after illness and treatment is evident. Participants persistently testify to the experience of illness and of physical impairment as being different from the person who they once saw themselves as. For, example, participants referred to themselves as having never being ill before, not feeling ill or not being "*one of the sicker ones*". Comments that pertain to changed self and lifeworld are ubiqitous throughout the participants' narratives. Diminished self-perceptions and diminished body image were experienced as a result of changes to embodiment and taken-for-granted assumptions about self which were previously accepted unquestioningly could no longer be maintained. Basic assumptions about being a healthy individual, for example, were ruptured. Other assumptions about self-identities such as engendered identities were also ruptured and were elaborated in the preceding chapter. These changes can be understood as the consequence of a changed sense of embodiment. Thus, profound changes in self-perception, as well as loss of self, can be understood to be interpreted by the participants in light of a changed sense of embodiment.

Summary

The body is the site for meaningful experience. Our reliance on the body is important to our sense of self. Being a body, though rarely reflected upon, can be understood as the corporeal basis for self and as being meaningful and symbolic for the person. In other words, being a body signifies being a specific type of person. The body, therefore, is a vehicle for self but it is also a vehicle for a sense of otherness and alterity. Physical changes, therefore, draw attention to the interrelatedness of the body and the self. However, this changed sense of embodiment can be an alientating experience that results in loss of self and dysembodiment. The self's place in the body becomes problematic. The body, therefore, no longer facilitates self; rather it is a barrier to self and exerts a negating effect on self. Loss of self, and devalued self is triggered by a changed sense of embodiment and alientation from the body. The onset of illness, concomitant bodily disruption and the negative effects of medical treatment, precipitated amongst the participants a disruption to sense of self. Changed self, therefore, can be understood as being realised through the body.

(ii) Having a body

The body is an intergral part of who we are, and as corporeal beings we are inherently tied to the body. The experience of our embodiment is inseparable from our personal and social experiences. In short, the body is inherent in all of our experiences. The unity of the body and the self is disrupted in the instance of illness and bodily dysfunction. Throughout illness and dysfunction, the body and the self remain united, despite this unity becomes more problematic. Thus, when our normative sense of embodiment is changed or threatened a changed sense of self can ensue.

The mechanisms by which this change occurs are vital to consider. As was discussed above, our normative, unproblematic and generally prereflective sense of embodiment creates for the individual a sense of permanance and stability. In illness and dysfunction the instablity of the body is revealed, creating a sense of alterity. Thus, the undermining of our sense of embodiment gives rise to a sense of vulnerabililty and fragility. Hence, significant existential questioning and threatened sense of self are engendered. The negating effect that dysfunction has on the 'utility' or 'instrumentality' of the body can impact deleteriously on sense of self and must also be taken into consideration. Being a body is clearly an important aspect of self. Being a body, however, is also *having* a body. To return briefly to the idea of the phenomenologically absent body discussed above, the body is typically not reflected upon during

the course of our everyday lives. The body however, can and often does comes to the forefront of our conscious awareness. As human beings we can deliberately use the body to engage with our surroundings and to express ourselves to others. Experiences of embodiment, therefore, have to be seen as multi-layered. We are a body and as corporeal beings we have an unconscious or prereflective understanding of what the body is and how it is part of us. Indeed "knowledge of one's body is an absolute necessity" (Schilder, 1950: 52). As corporeal beings we have implicit knowledge of having a body, in that we act with the body and that in acting we use the body. This knowledge of the body constitutes an important aspect of our body-image and our sense of embodiment. The body-self, therefore, reflects a primordial existence. However, we also have a conscious relationship with our body. We have opinions, beliefs and attitudes about our body.

As cognitive beings, we have the ability to see ourselves as having a body. Thus, we can think about ourselves and our bodies. Though, Merleau-Ponty (1945) refuted the idea that we have a relationship with the body and stipulated body-self unity. We do have a relationship with the body in that we can think about our bodies and can treat our bodies in a certain manner. This 'having a body' is also an important aspect of embodiment. Our embodied existence, therefore, has to be seen as dyadic. That is, the we osscilate betweeen the mind and the body. The experience of embodiment, therefore, is complex and stratified. We can oscillate between subjectification and objectification of the body. Thus, the body is 'experienced' by the person on different levels: (i) It is 'experienced' on a prereflective level. This prereflective 'experience' of the body reflects the subjectification of the body. The body is, therefore, a subject which is lived through. (ii) The body is also experienced as an object. In turn, objectification of the body can be self- affirming or negating. In other words, we can experience the body as a facilitator or as a burden. The body can facilitate self expression and activity. However, it can also act as a barrier, preventing the person from engaging with the world. Thus, an important aspect of our phenomenological experience of embodiment is of the body as an instrument or a tool. Furthermore, 'having a body' concerns the body as a symbol and as an expression of how we see ourselves and who we believe ourselves to be. The body allows us to engage in our surroundings and to express ourselves. Hence, the way we carry ourselves, to the way in which dress and decorate the body, represents the embodiment of how we see ourselves and our place in society.

Body image refers to the ways in which we think about the body. Body image is affected by a multitude of combination factors including psychological, physical and social influences. Schilder's (1950) conception of body image amalgamates physical, psychological and social domains of bodily

being. The discussion at this point will focus primarily on the physical as well as psychological aspects of body image. Social influences on body image, cannot be avoided in this discussion but will be dealt with in more depth later on. The body image which we hold, can to varying degrees, impact on how we experience our bodies in our everyday lives. Body image can also impact on sense of self, self-confidence and our relatedness to our social environment. Having a physically impaired body due to illness and medical treatment has meaningful repercussions for the person. The participants' body concepts were fundamentally transformed as a result of bodily changes which they experienced. In other words, the physically impairing effects of illness and medical treatment resulted in a more negative body image.

Having a body can be seen allows us to express self to others. That is, the body is an expressive site that enables signification to one's social word. As corporeal beings, we always exist as a body within a specific society. This society causes problems for the body-self by delimiting ways that the embodied being should look and act. However, we tackle the problem of being a body in society through the medium of the body. The dysfunctional body undermines attempts to be a specific type of body which s representative of preferred identities. The participants in this current research, expressed a heightened sense of consciousness of reduced physical capabilities. The physical changes experienced by participants, coupled with changed psychological and emotional status, negatively impacted on the participants' body image. The changes that participants experienced to their bodies and to the natural abilities of their bodies inevitably had a considerable impact on participants. For example, the comment made by *Patrick* below illustrates how diminished physical abilities and loss of confidence on the body can impact on self-esteem. After his treatment for cancer of the throat *Patrick* was left unable to produce saliva and to swallow as the radiation therapy had left his oral muscles and salivary glands damaged as a result he was unable to eat as he considered a 'normal' person would:

> "*And its amazing eating is involved eh, in one's social life and it eh you know its one of the joys of living to be able to eat, eat normally should I say. So eh, that's an ongoing em, problem. Your voice is an ongoing problem because if it's not good one day that you feel that you have to be cautious and eh, careful about it. You know there are limitations that you have to live with*"
>
> Participant 12

Participants held more negative beliefs about what the body is capable of after illness and treatment. Participants, for example reported having to 'cut back' on physical activity or '*slow down*'. A common comment also related to having to be more 'careful'. This extra caution that participants felt they had to take with their body related to reducing physical activity and also being more vigilant with regards their current health and physical status. One female participant treated for breast cancer commented on doing less physically taxing housework such as hoovering or lifting heavy objects because of a fear of developing lymphoedema. Another participant recounted her fear of having to climb the stairs to her apartment after her illness and treatment. This fear related to a fear of falling and a belief that she was less competent physically after her illness and treatment. Another participant recounted her concern about engaging in physical activity such as lifting after her hysterectomy. Participants were clearly less confident in their bodies and felt more vulnerable to physical difficulties and moderated their bodily activities as a result. Changed body image can, therefore, result in changed experience of the body in everyday life. In these instances the relationship between the self and the body can be disrupted. The 'bodily techniques' of the participants have been disrupted. In other words, their typical way of being in the world was interrupted.

The uncontrolled body

The body plays a critical role in shaping the self. Thus, self and body cannot be treated separately. However, we are not creatures that act largely in an unthinking or pre-reflective way. In modern Western society we frequently adhere to the idea of the body as an object. This reflects the divided nature of the body in Western popular and academic cultures. Cartesian discourses in Western culture can be seen to be upheld in the participants' narratives. The body, therefore, is seen as a machine that ought to be controlled. The participants' heightened awareness of the body articulates the social importance of keeping control over one's body.

For the participants, using the body, manipulating the body and having control over the body was no longer as easily done. Suffering physical debilitation has been shown in the previous chapter to give rise to feelings of difference amongst the participants.

> *"I used to joke if I had cancer in some organ that you had two of you know that you could get rid of that would be in some place that would be hidden by your clothes and*

nobody would know and I do think in many ways that might make it easier to kind of forget and go back to a normal life. But, I have an amount of physical restriction now, my ability is different now than what it was. In the most fundamental ways... I mean I've got used to it and I go out and it doesn't usually bother me at all but eh, I look different and sometimes people do stare. It's an effort to speak, it's an effort to eat I have and these are things that you do all the time"

Participant 18

Impairment and physical changes that are experienced by the participants were found to have a significant impact on sense of self. The effects of physical changes on sense of self can be attributed to the disruption of body-self relatedness. However, the disruption caused to the agency of the body-self must also be seen as driving these changes to sense of self. Ultimately, the participants' perceptions of themselves as competent adults were threatened. Threatened or changed bodily competence can be demonstrated to have a significant impact on sense of self. For example, some women were taken aback by loss of periods, and male participants, in turn, were taken aback by loss of facial hair or weight loss as well as generally altered physical sensations. Loss of control over the body had a considerable emotional impact. Reactions to loss of control included frustration to sadness. A changed physical status resulted in changes to the way the participants lived their lives with their bodies. The physically impaired body is seen as a burdensome object and its presence in their lives has to be endured. The body has to be 'carried around' and places restrictions on the person and limits sense of agency.

"So I went home and I felt, I dunno what I felt. It was like everything was against me and I would never even be able to walk on my own two feet again and I was, anyway, I couldn't get up. When I was at home and I was on the sofa, I couldn't even get up to stand without having somebody there in case I fell because I couldn't take my weight. So I couldn't even get myself a glass of water, d'ya know I could do nothing I was really, really helpless"

Participant 18

The excerpt above can be understood in both a literal and a metaphorical sense. The participant's reference to her ability to "walk on [her] own two feet" can be argued to represent the embodiment of her personal struggles in illness. This participant's distress caused by her physical impairment and concomitant sense of loss of self can be argued to be embodied in her physical struggles. Her inability to walk, to be mobile, to 'stand on her own feet' can be seen to reflect her battle to regain a sense of

independence and sovereignity after her experience of illness and treatment. The distress and emotional pain which is experienced by participicants, is accentuated by the physical struggles they experienced. The way the participants talk about their physical struggles can be seen to reveal feelings toward the self, and can also be seen as being illustrative of the experience of powerlessness and vulnerability.

The body is put to particular practical and social uses (Goffman, 1959). Frank (1997) argues that one of the central questions the body confronts when it undertakes an action relates to the issue of control (Frank, 1997). The participants, therefore, can be seen to be constantly confronting issues concerning the predictability of their bodies. The body, which often emerges in the context of illness and healthcare can be experienced as indisciplined. This can result in feelings of being helplessness and worthlessness. Therefore, the body which is 'uncontrollable' can affect sense of self. For participants, the uncontrollable body can overshadow engagement in the daily tasks of life and can give rise to considerable feelings of anger, anxiety, frustration and sadness. Body-control is crucial for presentation of the self. The ability to be perceived and accepted as a competent social actor in modern Western culture requires a level of bodily discipline. The participants' narratives frequently refer to routines to which the body is functionally adapted (walking, talking, acting), and to responsibilities (working, caring for others). Engaging in these routines and resposibilities requires embodied actions that under normal circumstances would allow the participants to establish a self that is valued given his or her sociocultural context. However, illness and treatment changes bodily capacities and loss of bodily control is associated with a loss of social acceptability. The body is an instrument which, to a certain extent, an individual possesses. The pragmatic aspects of embodiment allows us to engage with the world. In particular our embodiment allows us to engage with the world in certain ways, and, therefore, allows us to portray to others aspects of the self which we wish them to see. Loss of control over the body therefore, has broad social implications. Resultant loss of value in social contexts threatens identity and sense of self-worth.

Summary of Part 1

The body in illness and impairment becomes a central aspect of experience. This is testified to by the prominence of the body in the interview narratives. Throughout the interviews, the body, bodily issues and bodily discomfort, featured prominately. This prominence which the body achieves echoes the dominance the body has for participants in their everyday lives. The body and comcomitant disabilities is salient, near to their thoughts. Participants are aware of their bodies. The body is part of self. It is

capable of activity, enaction, purpose, meaning and value. Participants' embodiment however, is threatened as a result of the experience of illness and physical changes incurred by medical treatment. Loss of confidence in the self is resultant. The body is objectified, and can no longer maintain formerly held assumptions about self. Changed self as a result of changed sense of embodiment is common. This is incurred through changed experience of the lived body. That is, that the body is no longer lived through in the same sense as before. The body is no longer part of the background, rather it exerts a dominating force in everyday life. The healthy, taken-for-granted body facilitates action and interaction in the world through automatic, bodily techniques. However, the impaired body can create a sense of opposition between the body and the self. Furthermore, the impaired or indisciplined body can negate former assumptions about self and give rise to more negative perceptions of self.

The body is of the self. As corporeal beings we live through the body. The lived body, therefore, is constituted by body a subjectified relationship with the body as well as an objectified relationship with the body. The body is simultaneously something that we are and that we have and can manipulate. The body-self is a dialectic and is influenced by both embodied factors as well as psychological factors. That is, we are embodied beings and we are also cognitive and social. We can reflect on the body and mould the body. In turn, the body influences how we think. Furthermore, the body-self does not exist in isolation. We live in a social world which also exerts an important influence on embodied life.

PART 2: BEING IN THE WORLD

The Expressive Body

The body expresses to others aspects of the self. Thus, the body is symbolic of self. The symbolic significance of the body for the participants comes to the fore in the narration of their experiences of illness and treatment. The body, therefore, is not only understood in relation to the self, but also as a social representation. For the participants, the body held more negative meaning. This affected the way participants articulated and depicted their own bodies in the interviews. Participants frequently felt that their bodies could not live up to societal standards. This is incurred by the experience of physical dysfunction and by diminished bodily capabilities.

Since their illness and treatment, the participants also held more negative attitudes towards their appearance. More negative identifcations of older, unattractive and less feminine or masculine, were adopted by the participants. For the participants the way in which their body appears to them had radically changed. Thus, the body was no longer experienced as representative of previously valued identities. Participants were evidently more conscious of their bodies, and a significant alienation from the body was manifest. Disruption to embodied experience by the participants can be seen to have some of its origin in the threatened integrity of participants' social role and identities as a result of embodied disruption. Participants experience a discrepancy between desired social identity and their actual physical status which embodies and expresses valued and normative social identities. The body, therefore, is experienced as a symbol. For example, the body can be a symbol of class and gender, amongst a panoply of other social identities. Social identities have to be considered, therefore, to be embodied and to emerge from the body which is embedded in a social setting. How the body is experienced in the social world, therefore, is meaningful and symbolic. The experience of impairment, however, can create an alien and negative meaning for the individual which can undermine preferred self expression.

Being embodied is meaningful. Being a 'normal' body, however, is more meaningful. For participants the meaning of being an impaired body is expressed through changes in embodied actions and the changes in the way they represent the body in talk. Talk about being vulnerable, fragile, emotional, abnormal or marked illustrates changed beliefs about the potentiality of the body. The notion of the "split subject" is frequently used in feminist literature to describe women's experiences of their

bodies. Young (1997), among other feminist academics, argues that women experience contradictory modalities of bodily existence as many women mediate their own relationship with the body by viewing that body from a third person perspective. This can result in problematic bodily experience, as an objectified perspective on the body can supplant a woman's own subjective experiences of her body and her bodily capabilities. The participants in the current study can also be seen as experiencing this splitting of the subject from the object. Participants can be understood as experiencing a conflict between their subjective experiences of the body and objectified experiences of the body. This is illustrated in the case of the female participant who refused to have her photograph taken, or in the instance of participants who no longer socialise to the same extent with their friends, as well as by those who change their dress style to cover up disfigurements. Change in movements and change in actions towards the body also illustrate that former body habits and beliefs which were held have been displaced. Thus, the continuity of the body and its former expressiveness has been altered. Their inner experiences of the body are at odds with the body which is experienced from an objectified perspective. Therefore, the body is not lived, but rather objectified. This identification with an external perspective alienates the subject from the body. Identification with the body which is dysfuntional is experienced as degraded and as undermining the integrity of the self. The body therefore, comes to represent a more negative meaning.

The body is embedded in a social environment and is, therefore, experienced as being constantly on display. Hence the body is an important signifier of a multitude of values which relate to the self and the social world. The experience of physical disruption, therefore, has profound significance. The disruption of biographies, sense of self and the taken-for-granted assumptions we have about our worlds is incurred through physical disruption. Our bodies and our health are typically taken for granted. The slowing down of a body and the ailing body, can give rise to perceptions of a more fragile, vulnerable body and, hence, perceptions of a more fragile, vulnerable self. Hence, a changed sense of embodiment can give rise to more negative meaning for sense of self as the body violates previously accepted values and standards which wer held. The person is split into incongruous personae: normal and abnormal, embodied and disembodied, capable and incapable. Thus, in illness and dysfunction the body is experienced as an expression of a devalued self which transgresses preferred and socially valued mores.

The Social Body

According to Bordo (1993) the individual body is a microcosm of society. In other words, due to the body's immersion in a sociocultural and historical environment, the body has come to be imbued with social significance. The socially constructed nature of the body, therefore, has to be taken into account. Our experience of the body has to be understood as being influenced by sociocultural and historical discourses. Merleau-Pontian theory put forward the notion of intercorporeality to illustrate that our embodiment is always mediated by the way in which we are continually immersed in a social world and continually engaged with human and other material agents in society. The body is the medium for being in the world, of experience and orientation to self and others. But the body is also part of that world and shaped by that world. Frank (1997) argued that the body is positioned at the intersection of institutions, discourses and corporeality. Corporeality refers to the physical actuality of the body, while discourse provides a framework for bodies to understand themselves and institutions provide the context in which actions occur. Thus, our sense of embodiment must be seen as emerging from being a body in a social world. The experience of self, therefore, emerges out of the body and the body's immersion in the world. This implies that bodies cannot be understood as fixed entities. Rathe, they are mutable entities which fluctuate depending on the sociocultural environment. . Sociocultural discourses impose limits on the way in which the physical body is understood (Douglas, 1970). Therefore, bodily characteristics are powerful symbols of social values and norms. Here we shall focus in more depth on the way in which socio-cultural and historical discourses potentially shaped the participants' beliefs, attitudes and experiences of the body.

It can be illustrated from the narratives that societal expectations play a critical role in shaping how we as individuals think about the body. Participants themselves were aware of societal pressures to look a certain way, particularly the female participants.

> *"I don't need to know my weight...because I find especially the way society is, you're supposed to be you know a certain weight ot whatever"*
> Participant 5

The body, therefore, was understood by the participants as a medium of social judgement and having a body that fails to fulfil certain social requirements can result in negative judgements of the self.

"When you encounter other people your face is what they first see of you and how they begin to make their judgements and I didn't know if I'd be able to get past all that. And I was afraid of all that"

Participant 18

The body can be understood as an image of society, or of persons that are valued by society. Thus, the social body can determine our place in society, depending on how it appears to ourselves and to others. This can be illustrated by the impact of physical changes on participants' perception of their respective femininty and masculinity and the resultant emotional impact on the participants. For women, the breast and the womb are laden with social symbolism. Serious trauma is involved in the loss of one's breast or womb, as is witnessed by by the narratives of the women who had experience mastectomies. These bodily aspects are symbolic of womanhood, motherhood, as well as desirability and sexuality. For male participants, the body is also imbued with social significance. The strong, healthy, fit and active male body was understood by participants as indicative of independence, masculinity as well as traditional masculine roles such as that of 'provider'. The ill and impaired body threatens these identities and consequently threatens the individuals' sense of their social standing.

The appearance of the body is symbolic of important social values and is understood as being indicative of a host of personal and social identities. The body is a key representation of social desirabilitity and acceptability. For example, participants' talk about their appearance often reflects social discourse of control and civility. Having a messy, untidy, unhealthy or scarred appearance, being overweight or underweight, or having one breast traverses symbolic body values. Thus, the body transgresses dictates of social order and acceptability and no longer is expressive of these values in society.

Bodily appearance, therefore, can be understood as being representative of self and of value within a specific sociocultural context. The visibility and actuality of the body represents and cements specific social idenities. In other words, the body makes aspects of the self tangible and subject to judgement. Thus, as the body is visible it is subject to social regulation. The body, therefore, is something that can be surveyed, transformed and manipulated by members of particular social groups. Indeed, bodies are increasingly subject to surveillance from various social regulators. This shapes the

way the body is controlled by individuals in a sociocultural context (Foucault, 1977). Bodies, however, that defy control are experienced as objectified and abnormal, even unhuman. Many participants commented on their ability or inability to hide their "scars". Participants who had facial disfigurements, for example, referred the visibility of their scars. This trend is also illustrated in participants' comments on clothing. Participants' commented on hiding their impairments and/or disfigurements behind their clothes. Dressing the body in specific ways, therefore, can be seen as creating a specific visual image of the body and consequently the self.

The actions or techniques of a body, as well as its appearance, are also subject to regulation. Certain body techniques can be seen to be valued over others. One participant who was unable to eat solid food after radiation therapy commented on the distress that this caused. Nourishment is a natural requirement of the body. However, our social embeddedness strips the process of eating of its natural meaning and imbues it with social meaning. The embodied action of eating, therefore, has symbolic implications and becomes part of a social discourse that expresses social status and value.

> *"OK so I'm there but when you feel you can't eat normally. When you feel you have to make special exceptions all the time, you're terrible conscious of your position all the time with your social strata. That em... em that you can't participate in the way that you feel you ought to be participating"*
> Participant 12

The impact of bodily "difference" on the individual and their sense of self, their body image and self-esteem, can be seen throughout the participants' narratives to be considerable. The symbolic properties of the body, mutate the body into a type of "social skin" that informs social and political relationships between individuals (Douglas, 1970: 65). While conventional, healthy, 'unchanging' bodies have social weight within the sociocultural environment in which they are embedded as such bodies explicate and transmit accepted cultural and social values. The body, therefore, is a critical indicator of collective and dominant values, such as engendered identities as well as other personal identities. The body, therefore, can be seen as a type of 'physical capital' (Bordieu, 1977) which can be understood as a potential source of social differentiation and relative devaluation. Bodily worth can be seen as testifying to the individual's social worth. In other words, bodily appearance as well as embodied actions and techniques are key embodied factors of social value and self identity.

The influence of social discourses on the body, is clearly a critical aspect of our experience of embodiment. Given the ubiquity of society, it is understandable that the impact of social influence on experiences of the individual body is considerable. However, while social discourses undoubtedly can change our experiences of the body, in turn the body can change our experiences of our social worlds. Indeed, much of the work that examines the influence of discourse on the body can be criticised for omitting the agency of embodiment from their analyses. The corporeal and physiological reality of the body, which is evident in the narratives which were generated for the purposes of this research, has to be taken into account. Experience cannot be seen as being purely socially constructed. The embodied nature of human life, also has to be seen as playing a role in experience. The body, therefore, confers characteristics on the individual which interact with cultural factors to condition experience. The physical and the sociocultural have to be seen as being mutually interactive and as engaged in a reciprocal relationship.

Bodies cannot be seen as purely symbolic and socially constructed. This is illustrated by the "difference" of bodies[9]. Participants' bodies are different from what they once experienced and knew. Their bodies are also experienced as being different from other bodies in their social environment. Thus, the body itself must be is of importance in explaining the participants' experiences. Indeed, participants' bodies are highly evident in the narratives. The body constitutes a pervasive presence in the participants' stories. The participants' physical reality cannot be ignored or simply seen as being produced as a by-product of socially mediated factors. The participants' experience of physical difference, in terms of difference, in relation to before illness and treatment and in relation to other bodies, illustrates the role of the body in a social context. Thus, focusing on "difference" allows us to examine the dialectical relationship between the body and the world. Forthwith, we shall look at the role the body played in shaping the informants' experiences of their social world. The body is not passive nor a blank slate which social processes writes upon but, rather, can be seen to be an active agent in experience. Changed sense of embodiment was found to significantly affect participants' social relationships. Furthermore, changes to sense of embodiment also found to act upon participants' previously held assumptions about the world.

[9] this approach is used by feminists to avoid both social and biological essentialism

(i) Changed social relationships

The way in which people relate to one another is mediated through embodiment, embodied actions and appearances and our understanding of these states. Intercorporeality describes to the relation of bodies to other bodies in the world (Merleau-Ponty, 1968). The body is perhaps the primary factor that determines group membership. Constraints and possibilities are created for group membership by the corporeal characteristics of age, gender, race, and appearance. The body therefore, plays a key role in our experience of similarity and difference from other people. Thus, the body informs much our relationships with others and our experience of social situations. Radley (1991) references the study from Strodbeck, James and Hawkins (1956) which found that males were more likely than females to be elected jury foremen in artificial juries, to illustrate the way in which the body can create a differential social status between engendered persons. The female body, thus, is judged against the male norm in a patriarchial social system. Similar arguments can be made with regards to the ethnic body in relation to white, Western body norms. Likewise, the ill and impaired body is judged in relation to healthy, 'normal' body. The body in illness and impairment is juxtaposed with normative, healthy bodies. Indeed, bodily differences incurred by illness and medical treatment can in many ways be experienced as acting out against the self. Participants' social experiences were experienced as oppressive to self as a result of self-objectification as well as other-objectification and the stigmatising effects of these processes.

Other-objectification

Many of the participants had experienced negative reactions from others to their illness and medical treatment. Participants at times commented on feelings of lack of support and distance from friends. For example, some participants had experienced shocked or uncomfortable reactions from friends.

> *"there was one day one of my friends saw it. The way she screamed the way she did... I don't want it to happen again"*
>
> Participant 4

Participants also reported a reluctance to talk about their illness with strangers. Staring from others also contributed to participants' sense of objectification. Furthermore, participants often betrayed an emotional reaction to the 'presence' of other bodies. Participants, particularly female participants, commented on getting upset in social situations where bodies were "visible". The implicit messages

which are given to participants in these interpersonal interactions is that they do not constitute the norm. This gives rise to feelings of stigma and isolation. Thus, the experience of intercorporeal relations can be seen to shape experiences of social situations.

In illness and impairment the participants experience a sense of heightened consciousness about the body. The body be experienced as being 'public' in these circumstances and as being even more visible in its frailty and impairment. It becomes, for example, the object of medical investigations and is more likely than ever to be subject to judgement in other social situations. The participants, for example, often commented on others asking about their scars or physical manifestations of illness and treatment. Feelings of bodily differences being on display gave rise to increased perceptions of objectification and changed self perceptions.

Self-objectification

Participants were likely to expect negative reactions from others in relation to their illness and impairments. The expectation of negative reations from others can be attributed to self-objectification as well as the actual experience of other-objectification. Many of the participants presumed other persons to have perjorative perceptions of them. Participants, therefore, feared being judged and measured in relations to their illness and compromised physical status. Participants understand their relationships as being framed in the context of bodily equalities and inequalities.

Participants reported changing their patterns of interaction with their social environments. Participants frequently reduced contact with friends and were less likely to socialise in general. A sense that participants perceived being stigmatised and embarrased as a result of their physical changes and impairments is evident. The physical reality of bodily existence, therefore, can significantly influence interpersonal interactions and intersubjectivity. Despite the body becoming more visible in illness and impairment, participants also felt that illness and disability was a private experience. Participants, for example, felt that unless one had gone through a similar experience then others could not understand their experiences.

> *"... no matter how hard you try, you can't really explain what this is like"*
>
> Participant 7

The embodied experience of illness and physical impairment, therefore, is experienced in individual terms, as well as social terms. This can perhaps be seen as an effort to counteract the objectified and increased self-conscious existence of the body-self in illness and impairment. Indeed, it can perhaps be seen as an effort to maintain a sense of self and reclaim ownership over the body.

The body clearly plays an important role in social situations. The impact of illness and disability on participants personal interactions and experience of social situations illustrates the critical role of the body in identity and relatedness to others. The body exists in a socio-cultural space. Experience and identity is constituted and continually restructed in an intersubjective and intercorporeal space. Overall, changes to sense of embodiment resulted in more difficulty in social interactions. It must be noted that supportive relationships were also discussed by the participants. Such relationships were particularly valued by the participants. Often these relationships helped participants to maintain links with their pre-illness self.

(ii) The body and the experiential world

Merleau-Ponty's theory of perception promoted the primacy of embodiment. For Merleau-Ponty the experience of the world was always embodied. The body, therefore, is the medium through which we experience and interact with the world and the site for meaningful experience. Physically detrimental changes such as illness and impairment, therefore, will not be experienced as just a breakdown of physical functioning, but rather as altering one's ability to live in the world in their usual way. We exist in the world in corporeal form. Through our embodiment we come to understand our world and establish habitual ways of interacting within the world. Changes to sense of embodiment, therefore, can have a significant impact on the embodied person's perceptions of and ways of interacting in the world the world. Indeed, changed perceptions of the world, and changed patterns of interacting with the material world were also evident amongst participants as a consequence of their changed sense of embodiment.

Illness and impairment was experienced as threatening to the participants' sense of bodily integrity. Their sense of bodily competence, for example, was viewed in more negative terms:

"Em, I feel more vulnerable than I did all the time. On all kinds of levels. From a practical physical point of view I'm not as strong as I was. I have to consider things before I do them I have to make allowances for that that I don't have the energy to you know, whatever. That my stamina isn't what it was, em but emotionally too I'm a lot more fragile in some ways"

Participant 18

Participants frequently reported feeling less energetic, as well as feeling more vulnerable physically. This often had an emotional and psychological effect on the participants. Furthermore, increased feelings of vulnerability and uncertainty spilled over into the participants' experiences of their lifeworlds. For example, increased feelings of vulnerability and uncertainty gave rise to increased belief in a more unstable, more uncertain world around them.

"I still know it's like we take something like gravity for granted, you know. You stand up you expect to remain vertical; you expect buildings to remain vertical around you. That s just something we take for granted when we move around. You know, the street horizontal, the buildings will be vertical. The bus will make its way through the town... (pause)... and for me that doesn't apply anymore. (Pause) I know, it's like you have to juggle the two things because I don't live with the expectation that eh this is going to come back everyday but at the same time I know that it's possible that it will"

Participant 18

Bodily disruption had a significant psychological and emotional impact on the participants. Indeed, the experience of bodily disruption has a significant impact on the participants' perspective on the world. The body is a permanent aspect of life and is the constituent of our existence and investment in the world. Thus, bodily stabilty allows us to develop relatively stable assumptions about the self and also of the world around us. Bodily disruption has been shown earlier to evoke disruption to sense of self. However, bodily disruption can also be illustrated to evoke disruption in our experience of the world in which we are immersed. Therefore, when the body and its boundaries are threatened, it becomes for the person a source of instability and uncertainty. Participants often reported being more uncomfortable and unsure in their surrounding enviroments.

"I'm not as outgoing because I used to like going out but now I wont go out of the area...like I want to get home, I want to be at home. I just want to be here. I just want to

be around my own surroundings. And if my friends say are you coming out they say were going across town, I'll say no I have to be in the area... then if, if, if, if that didn't, after the treatment, no, I think I'm a little bit more cautious. I'm a little bit more aware of what's going on around me when before it didn't bother me. Now the house would be on me mind, every ache and pain I get is cancer"

Participant 9

A disrupted sense of embodiment can threaten taken-for-granted assumptions about the world. Above we can see the link between unstable embodiments and a sense of an unstable and dangerous world. Thus, participants' sense of unstable embodiments often gave rise to more uncertainty in their material world. While many participants expressed that they were more physically cautious and tended to take greater care of themselves physically. Many also reported being more cautious socially as a result of their experience of physical disruption. Participants expressed a greater sense of fear and uncertainty in strange and unfamiliar social situations. The body, therefore, or our sense of embodiment plays a critical role in our experience of the world.

Summary

Embodiment is simultaneously physical and social. Our sense of embodiment therefore, is both natually and socially produced. Identities, body-images, our experience of our bodies, and our experience of our social worlds are never solely our own construction. Social discourse plays a critical role in experiences of the body. However, the individual and the body itself also plays a constructive role in these experiences. The interplay between our inherently corporeal and social nature, therefore, is of critical consideration for human sense of self and social experience. This is particularly evident in the case of an individual who has suffered with an illness and physical disruption.

The Medicalized Body

Medical technology has been the subject of considerable debate. Williams (1997) highlights an increasing concern that the body has become a project amidst the substantial growth of technological capabilities in the field of medicine and biology. At the same time there is increasing ambivalence surrounding technology. As a technophilic society expands, it is understandable that medical technology can be seen as simply another positive development (Williams, 1997).

Foucault (1977) argued that self was created and defined by technologies. Foucault identified technologies of production, sign systems, power and of the self. These technologies permit us to produce and signify certain things and they can determine how we behave in relation to one another and objectify the subject. Foucault stipulated that we could effect certain bodily conditions in order to achieve social outcomes. Though Foucault was not referring directly to actual modern technologies such as medical technologies, such theorising has clear relevance to the potential impact of medical technology on meaning and experience. In particular, the forms of production, signification, dominance that can emerge from relations of body-self to medical technologies. Medical technology can inform a particular treatment of the body, training and shaping of the body and in turn training and treatment of the self. Thus, medical technologies can potentially contribute to the meanings and experiences of the lived body-self.

It must also be noted that people or patients do not just experience medical technology in isolation. Technology is always experienced in a certain context. The medical team that carries out treatment, the illness and the person, their broader social and physical environment all need to be taken into consideration. Each of these factors bring with them certain productions, symbolic social signs and power relationships. This is not to say that they technology itself is neutral but that it interacts with numerous other contextualising factors. The physical body is affected by medical technology. The technologies examined in the present study impinged on the body in different ways, ranging from a slow deterioration (dialysis), a gradual build up of effects (radiation therapy) to a sudden, radical and detrimental impact (surgery). Physical changes caused by medical treatment result in changes to embodiment. For participants, this can be shown to have a serious impact on sense of self, identity, and body-image and can also affect social identity.

A disrupted sense of self is evident from participants' encounters with medical technology. During embodied disruption there is a struggle between body and self. The compromised body is intractable and recalcitrant. Medical technology brings the altered, intractable body further into the spotlight. The body which is experienced in light of medical technology is different from the body which was once experienced in typical, everyday life prior to illness. Treatment, therefore, has the potential to reinforce profound disruption of embodied being and can produce an altered sense of self as well as undermining personal and social identities.

On a private or personal level, technology can disrupt sense of self and identity. Perhaps the most salient way in which technology can affect sense of self is the deleterious effect technology can have on body image. Medical technology often had a significant and long lasting effect on participants' body image. In particular, participants tended to feel more self-conscious and to have a more negative body image directly as a result of the effects of technological treatment on the body. There were no instances amongst the participants where technology and its effects on the individual were seen to enhance body image. Disfigurements and other bodily changes tended to inflict distress, anxiety and worry concerning normalcy as well as threatening specific personal identities such as gender identities amongst other social identities. For example, as was recounted in the previous chapter, participants worried that they looked different and were less attractive as a result of the physical consequences of treatment. This disrupted preferred, internalised identities and also created feelings of stigma and social distance.

The threat that treatment technology poses is not to a physiological or mechanical body, but to the person or the body-self. Participants' fear of treatment resided in their fear of the effect it would have on them as beings who are intercorporeal. For example, participants were afraid of the effect treatment would have on their personal, valued characteristics. Participants were also afraid of changes that treatment may cause that would lead to social stigmatisation. The body is subjectively experienced and lived through (Leder, 1990). The relatedness of the body to the self is disrupted by medical technology as medical technology can fundamentally alters phenomenological experiences of the body. For example, increased mistrust of the physical body can be provoked by the experience of medical technology. Participants spoke about a heightened sense of physical and personal vulnerability. Medical technology, therefore, can reinforce objectified feelings toward the body and reify feelings of a compromised embodied status. Feelings of devaluation and negation of self and identities can be attributable to the participants' experiences of medical technology.

Physical changes experienced by participants, such as the loss of a breast, scarring or disfigurement among other physical changes, altered the respective person's embodied subjectivity. This alteration can be understood as a disruptive and negating experience for the participants. In treatment the relationship with the body is fundamentally altered. Persons can feel encumbered with the body in their personal and social circumstances. Medical technology contributed significantly to feelings of objectification, depersonalisation and dehumanisation.

Objectification, depersonalisation and dehumanisation

Threat to identity was incurred not just by physical changes but also by other aspects of the experiences of medical treatment, as well as the experiences of interpersonal relationships in the healthcare environment. Participants often reveal feeling objectified, depersonalised and dehumanised as a result of their experiences. These feelings were linked to each other.

Feelings of objectification were incurred when participants were not treated as social persons but rather, treated as objects. This also incurred feelings of depersonalisation. One male participant, for example, wen describing his experiences of endoscopic tests while receiving treatment, repeatedly referred to scopes as being 'shoved down' his throat:

> *"So he referred me to a Mr. [name] who is specialist in the [hospital] and he immediately took me in and eh under full anaesthetic shoved down a scope"*
> Participant 12

The above quotes illustrates the participant's feelings of being worked on as a 'patient' in a sense that objectifies him rather than treats him as an individual. Implicit in the narrative is a sense of the person being absent from such encounters. Other participants reported having similar experiences. For example, two participants commented on how they felt like a 'pin cushion' due to the large amount of tests that they had to undergo during their treatment.

> *"The little basin beside me, the kidney basin and the needles would be in it and he'd pile them, like I was a pin cushion"*
> Participant 11

These participants, as well as others felt as though they were being "*prodded*" and "*poked*". Such quotations reveal that participants felt like the *object* of medical treatment and examinations. Feelings of being objectified and depersonalised constituted for participants a significant threat to sense of validity and resulted in negative reflections on their experiences of treatment. For example, the male participant quoted above repeatedly referred to not feeling normal, not feeling like himself and feeling inferior to others. Furthermore, feelings of objectification can impact negatively on relationships with medical staff, and result in an unwillingness to receive treatment as well as reduce adherence to medical advice.

Young (1997) argued that medical examinations objectify the body in order to preserve the dignity of the human being. Removing the person from the body, removes them from a 'humiliating' situation where they are tied to a body. However, here the narratives reveal that feelings of objectification and depersonalisation undermined feelings of autonomy and incurred serious questioning of their validity as socal beings, as well as their personal identity. Most medical examinations are "once-off" interactions and objectification of the patient, body or disease is common through the use of gowns and objectified language. In these situations objectification of the patient can help to preserve the self by distancing the person from the examination. However, when treatment requires multiple interactions with medical staff and technologies, objectifying the patient can have detrimental effects.

Feelings of dehumanisation in the context of medical treatment were also common. For example, one participant commented on feeling like a piece of meat:

> *"Like, I felt like a piece of meat on a conveyor belt ...waiting to be picked or rejected..."*
> Participant 9

Again this echoes earlier statements that participants made that indicate feelings of being worked upon. This quote highlights feelings of a lack of autonomy. The participant commented that she felt as if she was 'waiting'. It is almost as if as a patient felt like she was on a production line being monitored by an omnipotent healthcare provider with total responsibility over her life. This illustrates feelings of being in limbo, where the participant feels at a loss, lacking in autonomy and cannot have responsibility for choices made with regard to her treatment. Thus, feelings of powerlessness can instantiate negative

meaning in patients' experiences. Particularly when healthcare providers fail to facilitate the person and their situation and situatedness, thus, failing to facilitate patient empowerment.

The dehumanising potential of medical technology has been subject to much debate. Medical technologies have been accused of being disruptive to the work of medical and healthcare. Haemodialysis places many demands and challenges on the individual. One particular haemodialysis participant commented on perceived dehumanising effect dependency of dialysis had on her:

> *"It makes me feel horrible. It make (sic) me feel as if I am a dead person; I am just still living"*
>
> Participant 4

The quote illustrates how individuals can become trapped and dehumanised by the technology. Haemodialysis is intensive and requires frequent treatments. It is, in some ways, a case of familiarity breeding contempt. The participants' sense of dependency on and being tied to the machine can, therefore, foster resentment. Feelings of living a restricted life can have a negating effect on sense of self. In some ways, the participant sees herself as a 'dead person' or as a corpse that is somehow reanimated by the technology of the haemodialysis machine. The quote is particularly poignant and illustrates clearly the dilemma of living with dialysis. Dialysis sustains the individual but at the cost of living a restricted life where physical as well as psychosocial manifestations of treatment contribute to a sense of dehumanisation.

Similar feelings of dehumanisation were found with participants who had undergone surgery and radiation therapy. For example, this participant commented directly on feeling dehumanised during her sessions of radiation therapy.

> *"And your face such as it is is completely obliterated and you're there like a caricature of yourself and peple are calling out numbers and markers , anatomical markers, to each other and moving the table around. Even though I knew what was happening, I just felt really dehumanised by that"*
>
> Participant 18

This participant describes herself as a 'caricature' of herself. The particpant felt her appearance, and in some way the fibre of her person, was distorted by the technology that surrounded her. Indeed, she commented directly on feelings of dehumanisation which treatment evoked. Once again, feelings of being depersonalised and objecctified are evident alongside feelings of dehumanisation. The participants' comments consistently reflect feelings of being reduced to their anatomy throughout their treatment experiences. Technology, therefore, can create meaning which devalues the individual, in terms of objectification, depersonalisation and dehumanisation. Technology can accentuate feelings of dependence and difference. Participants felt devalued, and inferior to their 'former self'. Medical technology is not just an instrument used by medical staff to treat bodily dysfunction. It is also instrumental in experience; experience of one's self and of how the self appears to others.

While experiences of technology gave rise to feelings of dehumanisation, interpersonal relationships such as interaction with healthcare staff also provided potential for feelings of dehumanisation and depersonalisation.

> *"I did ask to sit up and I asked for a drink of water and nobody looked at me. And I was sitting up on this cold narrow table, this... Em, in my bra with, at the time I was covered in bandages. My hair was..... I mean I was like monster-woman. I was really like monster-woman. If you had seen me. Em I knew it and I felt it, and here were all these professional people avoiding my eye. .....somebody brought me a plastic cup of water and she handed it to me, she didn't look at me and she didn't say anything to me. She didn't even say 'here you are'. She didn't meet my eye. It was as if I wasn't there, you know. That really freaked me out. I hated that"*
>
> Participant 18

This participant describes herself as being like a 'monster'. By using the term monster to describe herself, the participant betrays feelings of being physically grotesque and abnormal. While she felt her appearance made her feel abnormal and felt dehumanised by this, such feelings were reinforced by how she felt she was perceived and treated by medical staff. Once again feelings of being treated like an object and depersonalisation are evident. Indeed, this participant commented a few times that during her treatment, the medical staff did not use her name when talking to her or referring to her. It is evident that these experiences can cause emotional upset.

Despite the alientating potential of technology, communication and interpersonal support can counteract these negative outcomes. For example, the participant quoted above told medical staff of her feelings during treatment and asked them to talk to her while treatment was being administered.

> *"I just said, look, talk to me, just tell me what you're doing... They always you know, they used my name. They told me when they were leaving the room and even when I knew the routine and I could almost have done it for them practically. They would say ok were going out of the room now. They talked to me... it didn't bother me at all because I knew what was happening and I felt some kind of human connection. Even when they weren't in the room that they were talking to me, they were using my name"*
> Participant 18

Feelings of objectification, dehumanisation and depersonalisation were common amongst participants. Such feelings led to feelings of decreased value and loss of self. Thus, negative experiences of medical technology can cause people to lose touch with their very sense of personhood, validity and normality. Certainly, individuals experience significant emotional reprecussions as a result Most participants commented on the uncertainty and emotionality of the situation they faced and were embedded in. for example, participants referred to 'hard' and 'difficult' times they experienced. One participant likened the experience to hell. Other participants commented that they experienced increased negative affect such as sadness, anxiety and depression. Overall, experiences of treatment constitute a significant threat to identity. However, these negative outcomes can be avoided if sufficient emotional and interpersonal understanding is provided for the individual as is illustrated in the above excerpt.

Powerlessness

Contradictorily, to get illness under control a patient must, to some extent, surrender control over the body. The experience of powerlessness was common amongst the participants. However, feelings of powerless arose from a variety of different sources. In other words, there were many different situations in which disempowerment occurred. For example, in some cases feelings of disempowerment were prompted by medical and treatment related issues. Participants also felt that they had lost control over decision making in their lives, particularly in relation to medical factors. However, other sources of

powerlessness included feelings of loss of control over the body. Significant feelings of insecurity were caused by feelings of powerlessness.

(i) Medical and treatment related issues

Many of the participants commented on how they felt they had little control over medical issues and treatment issues in their lives. Frequently, participants referred to medical staff ignoring their concerns about treatment, feeling insufficiently informed about their illness and treatment. Some participants also commented on medical staff talking over them or about them while not addressing them directly. This resulted in feelings of powerlessness.

> *"because I was worried about how I was going to look but nobody gave me, said like, if they had said 'Look [name] this is what you are going to look like a week after, this is what going to look like after three months'.... Fine, I'd have had a choice... but I wasn't given a choice"*
> Participant 9

Participants often felt that they were forced into a particular course of treatment. This contributed to feelings of of restricted options and a loss of autonomy.

> *"I just felt that I was being totally invaded and bombarded and bullied and em, and I know that everyone had my own best intentions at heart but I just felt that I was totally out of control at what was happening to me and everyone was pushing me around the place and I had no say in what was happening to me and it was, it was an awful time"*
> Participant 11

All of the participants to some extent held positive representations of medical professionals and thought of medical personnel as caring, knowledgable and expertly skilled. Although some participants had experienced occasional negative encouters with doctors and other medical staff, they also had positive and trusting relationships with healthcare providers. Many participants also reported perceptions or beliefs regarding the doctor as an expert and that 'the doctor knows best'. Frequently, this was a positive way of thinking and way of coping for participants. For example, for participants whose

conditions were highly uncertain and who faced dangerous treatments, allowing the healthcare staff (most frequently the doctor) to assume control of the illness helped participants cope in the face of uncertainty and fear. However, other participants felt that such treatment decisions were enforced on them and experienced this lack of input into the decision making process as distressing. Medical authorities are seen to lay claim the status of controller of treatment and illness. Thus, the doctor/medical staff claims authority over the illness, and implies that they have greater authority on these issues than the sufferer. The patient, therefore, is seen as the object of medical treatment. However, for the *subject*, experiences of such treatment can be radically different from objective understandings of same. Feelings of powerlessness can have a significant emotional impact on the person and can give rise to feelings of distress. Two participants commented on how close they came to 'giving up' during their treatment as a result of ther experience of disempowerment in the context of their lives and bodies. Loss of control over the situation which was faced was, therefore, experienced as distressing.

> *"I literally just wanted to...I remember in the bed...I remember thinking I wanted to jump out this window. I'm not going to be able to cope with this, I want to get out of here, I want all of this to stop... and I just felt if anyone was coming near me again with a needle I would just run out. I would just stop everything"*
> Participant 11

Disempowerment in the context of medical care and decision making can have different meaning for different participants. In some cases, disempowerment was experienced in a positive sense, allowing participants to cope and to accept the possibility of negative and even fatal outcomes of treatment. However, disempowerment and feelings of loss of control over the situation can contribute to feelings of distress. For example, the quote above illustrates feelings of being under seige and invaded.

(ii) Loss of control over the body

Disempowerment was not prompted solely by loss of control over medically related isues. Loss of control over bodily functions also contributed to feelings of disempowerment. For the participants, loss of bodily functions, which ranged in terms of severity, sparked feelings of disempowerment and an emotional reaction. The experience of loss of control over the body resulted in fear, frustration, as well as irritation.

"it just...I just couldn't eat, I couldn't drink, it was sore to swallow, it was sore everything...was like trying to get even a tablet, a small table down the throat was a fear in itself"

Participant 9

Fear is evoked when participants felt powerlessness to avoid feelings of pain and discomfort. Knowledge that pain is unavoidable for the participant quoted above gave rise to feelings of distress. Many other participants experienced similar levels of distress. Others also experienced frustration and irritation at the loss of control over the body. One participant reveals the frustration he felt with being incapacitated after treatment for oral cancer. After treatment, the participant was unable to eat and was receiving nourishment through a peg tube.

"Anyway I finished my radiation and they told me I did super and eh I believed them and I went back to my peg feed and... eh, terrible few months. Again just lying on my bed with this drip, drip, drip and again people calling to see you and I wasn't n the humour to see anybody. And then I had that thing that goes over my teeth sort of a like ....from the radiation. All sorts of things. Eh got a bit cranky I believe"

Participant 10

The frustration and boredom experienced by participants at being incapacitated is apparent. Loss of control over the body had a significant impact on the participants, emotionally and personally. Above, illustrated is a sense of loss of self experienced as a result of feelings of powerlessness. Loss of control over the body impacted on the participant's sense of self as well as their interpersonal relationships.

"And I couldn't eat anything and eh, it was just a tube going into my stomach keeping me going and em, lots of em tubes and wires coming out of me you know. It was a bit strange not being able to talk or you know, not being able to eat, not being able to walk. Just being kinda helpless"

Participant 13

The experience of powerlessness lends itself to feelings of dependence. Indeed, at times participants felt that not being in control of oneself, in terms of capability and decision making resulted in feelings of infantilisation. For example, this participant commented on how she felt during her treatment:

> *"I was just... it's like a child, learning to walk... it was just learn it, fall, pick yourself up, fall, pick yourself up"*
> Participant 9

Powerlessness, in the case of the participant quoted above, led her to liken herself to being like a child, vulnerable and dependent. Also the sense of falling she felt indicates the uncertainty and fear the participant was experiencing. For many other participants, feelings of powerlessness gave rise to increased feelings of dependence, helplessness and restriction.

The experience of medical technology and its concomitant effects and implications can exert a significantly alienating effect that disturbs embodied subjectivity. The experience of objectification, dehumanisation and depersonalisation and well as powerlessness reveals a body-object. In medical treatment, the body is constituted in the gaze of the other. Ownership of the body is brought to question. Medical technology and treatment, therefore, removes 'self' from the body and essentialises the body. This threatens to undermine the normative symbolic properties of the body and can impinge on experiences of social personae and experiences of the social world.

Medical techology and being in the world

The body can be understood as an expression of socially valued norms. The body is an object in the world, a world that demands dictates that we should have a specific type of body. The body allows us to engage with our worlds through cultivated bodily attitudes which testify to us being valued members of our specific societies. However, medical technology and its ramifications for the body-self can undermine the person's abiltiy to engage in the world in socially acceptable ways.

The physical changes caused by treatment, therefore, have symbolic repercussions for the individual. This can be clearly seen in the participants' narratives. The physical changes caused by treatment gives rise to participants' feelings of stigma and difference. Furthermore, participants felt that

they were unable to engage with the world in preferred ways. For example, participants' ability to engage in normal everyday activities was undermined due to loss of control over the body and the instrumentality of the body was shattered by constraints placed on the body. Agency and competency were brought to question for the individual. The biological changes caused by treatment reached out into the participants' lives and into their social relationships. For example, disfigurements and other bodily changes placed strain on the participants' social interactions and their patterns of engaging in social scenarios were also experienced as being more difficult.

Changes to embodiment caused by medical treatment can influence participants' ways of living. This is perhaps most evident participants who were dialysis. For these participants their lives and time were very clearly centred around receiving treatment. One participant for example described how she went on holidays while receiving dialysis:

> *"Emm I'm going to France now in November and I can change my dialysis to get dialysis on the Friday and I can change my dialysis on the Monday morning to Monday night instead of Monday morning so I get the three nights away. So it's a nice long weekend, Friday, Saturday, Sunday, Monday. You know and I kinda, I do a couple of weekends throughout the year. Keeps me going, keeps me ticking over."*
>
> Participant 1

The same participant described how dialysis disrupted holiday which she goes on and also described having to fit treatment in around going away:

> *"I'm on my holidays and I've done my three days over there in the week in X and it's a nice little unit and yeah, I was there for two weeks that was 5 days out of the two weeks were gone, that way now it was difficult it was one o clock during the day sessions that was a whole day gone and I had to be ready by half 11 and I didn't get back until half 5 ...so the whole day was gone. That way it was a bit no day in the sun today, but at least I can get away. Then I have to turn and say 'look there's not that many people that can do that, at least I can get away'."*
>
> Participant 1

Despite the positive attitude offered by the participant, structuring activities and life around treatment was experienced as restricting. Conversely, the same participant illustrated how being on dialysis influenced her life in positive ways and prompted her to start travelling in the first place:

> *"I had never been abroad so I'm going to start doing these things, I took my kids away which I had never done before things like that that changed me, definitely"*
> Participant 1

Other technologies experienced by other participants were also experienced as changing ways of living, though in a more indirect way. While dialysis directly affected how participants structured their day-to-day lives, the side effects of other technologies affected the participants' ways of living. For example, participants who experienced side effects of surgery or radiation therapy talked about how it structured their behaviour in social settings and sometimes prompted their abandonment of certain social interactions. For instance, one participant whose voice was damaged by his treatment for example, avoided using the phone and felt he had to be come "careful" with his voice in interactions.

> *"So eh, that's an ongoing em, problem. Your voice is an ongoing problem because if its not good one day that you feel that you have to be cautious and eh, careful about it. You know there are limitations that you have to live with."*
> Participant 12

Medical technology, therefore, shaped ways of living. In the main this was negative and was experienced as a curtailing of activities. However, technology can also be seen as potentially prompting expanded ways of living.

Summary

Levels of understanding of technologies varied. While some participants involved themselves heavily in the treatment, researched their treatments and had a good understanding of treatments, other participants distanced themselves from the treatment and did not attempt to develop an in-depth understanding of treatment. Overall negative perceptions of treatment technology were salient. Technologies were seen as being frightening and fear of the effects of treatment on the person was

apparent. Despite negative thoughts about treatment, positive perceptions of treatment were also salient. Meanings ascribed to treatment, therefore, were frequently ambivalent. For example, dialysis was seen as a 'life support' and as restorative but also seen as having significant costs and drawbacks. More so than other technologies investigated, participants undergoing haemodialysis could be said to have developed a relationship with the technology or the dialysis machine. However, in contrast to previous studies in this area, embodiment of the technology where the machine is seen as an extension of the person was not found. Personification of the dialysis machine by participants was evident (see chapter 5 of this thesis) but negative perceptions of the machine also prevailed. Negative perceptions of surgical intervention and radiation therapy were also apparent. Ultimately, much of the way technologies were thought about centred around personal issues and circumstances. The necessity for treatment was paramount and treatment was seen as necessary evil. Also, drugs and other medicines were perceived in a positive sense. One female participant felt that taking preventative medicines gave her a sense of reassurance and protection. However, she also expressed some regret at having to take medication for the rest of her life and she did feel it to be a nuisance in some respects.

Overall, medical technology can create anxiety for those who experience it. The impact of technology can be seen as being attributable to interactions with others such as medical professionals, and others with whom the individual interacts. For example, negative interpersonal interactions can create negative meanings concerning the experience of medical technology. The social context of medical care plays a critical role. However, the technology itself is not innocent but rather plays a role in the meaning and experience of the lived body-self. Technologies can intensify symbolic and physical anxieties which relate to the experience of a disrupted embodiment. Disruption of participants' sense of self and social experiences as a result of the experience of medical technology is evident, treatment can be experienced as threatening and emotional and can exacerbate a feelings of uncertainty and vulnerability. The self, body and worldly experiences are intimately tied up with one another. What happens to one affects the other. Technology and treatment affects the body-self and in turn the body-self can affect understandings and experience of technology. Furthermore, adjusting to physical changes and re-orienting self to one's lifeworld after the experience of embodied disruption involves corporeal, psychological, emotional and discursive adjustments.

Realigning the Body, Self and World

The impact of changes to physical body and to participants' embodiments on sense of self and experience are considerable. Sense of self is radically undermined and how persons view and experience the world through the body is significantly altered. Changes to participants' embodiment have been illustrated. Participants were found to experience their bodies differently. What their bodies mean to them, therefore, was seen in more negative terms. The consequent impact on sense of self was destructive; loss of self, heightened consciousness and negating affects on identities have been illustrated. Furthermore, participants assumptions about their lifeworlds were also shattered. Frequently, therefore, illness and physical changes which constitute changes to embodiments, are experienced as negating.

However, though participants' identities were threatened by illness and dysfuntion and participants saw themselves as changed as a consequence, efforts to maintain previous sense of self and lifepath were also evident. Participants themselves saw themselves as coping very well with their experiences of illness and medical treatment. Furthermore, evidence of benefit finding and perceived positive changes to sense of self and life also emerged in the participants' narratives.

Participants spoke about questioning themselves, their 'self' and lifestyle as a result of the experience of illness. Many participants therefore, engaged in considerable reflection as a result of their experiences. Participants often saw themselves as changing aspects of themselves or their lives which they disliked prior to illness. Thus, participants described what they say as positive consequences of their experiences. For example, as discussed in the previous chapter, participants talked about the closeness that they had developed with family members as a result of what they had gone through together as a familiy. Positive changes in lifestyle were also made by the participants. In particular participants' commented on a change in their perspective on life and and the way in which they lived their lives. The participants, therefore, were capable of responding to and adjusting to the exigencies of illness and medical treatment. How people respond to the problem of changed embodiment, how they adjust and become re-embodied and establish a meaningful sense of self as well as re-insert themselves into their lifeworlds is an important question.

Reconstructing experiences of the body.

Elaine Scarry (1985) gave an account of pain which highlights the ability of pain to 'deconstruct' self and world. The experience of pain has been much investigated and is undoubtedly an arduous and destructive experience. Leder (1990) acknowledges the destructive aspects of pain, yet also interprets the experience of pain as having the potential to evoke positive interpretations. Leder argued that the experience of pain can serve to produce 'authentic recognition' of personal limitations and possibilities. Thus, the experieince of pain can serve to create recognition and understanding of self. In other words, disruption to embodied experiences can serve as the catalyst for emotional and personal growth. The experience of chronic illness and bodily dysfunction can also be seen in this light; illness and consequential impairment of the body can potentially germinate positive changes in self and lifestyle, as well as causing negating changes.

The body, or embodiment, is understood by the participants as being of value to the self. The participants recognise their embodiment as an integral part of as well as an expression of self. Thus, changes to sense of embodiment resulted in changes in subjectivity. Many of these changes in subjectivity were negative. Participants' experiences of objectification, powerlessness, restriction or depersonalisation, for example, illustrates the invalidation of the participants' previously held subjectivites. Changes to embodiments can have negative effects when such changes are regarded as symbolic of devaluation. However, changes can also have positive meaning when such changes are regarded as the symbols for value. For example, participants' experiences and changes to embodiment were regarded symbols of survival and inner strength. Many participants commented on how well they coped with their illness and that they had the strength to get through the ordeal. Many participants commented that they were "stronger" as a result of experiences. Thus, changes to embodiment can also have positive consequences for sense of self.

Participants' change in perspective on the world can also be seen in this light. Frequently, participants' previously held assumptions about the world were shattered as a result of their experiences, giving way to increased feelings of vulnerability and perceptions of an unstable world. Participants perspectives on the world, however, were also subjectively changed for the better. The participants, for example, commented on adopting a more relaxed lifestyle subsequent to the experience of illenss. A common feeling amongst the articipants was that they had learnt to life "one day at a

time", or that they have learned to appreciate life more. As a result participants commented that they were a "better" person.

Discourse and the body

Discourse plays an important role in building, or rebuilding one's sense of self as normal and valued. The process of narrating self throughout the course of the interview allowed the participants to construct, or reconstruct, a coherent sense of self and a coherent sense of the world. Through the interview, a meaningful story of the experience of embodied disruption can emerge. Many discursive actions can be seen to be used by participants in an effort to to reclaim self and to re-align the body, self and society into a meaningful whole. Creating a coherent narrative, where the indvidual is seen as being in control, and changes are seen as normal and valued, thereby allows the participants to repair ruptures between body, self and world by linking up past and present body-self with society. The experience of loss and bodily disruption are thereby rendered coherent by the narrative process of reflection and reconstruction. This allows participants to understand their experiences as being coherent as well as having meaning.

The process of creating a narrative allows informants to reshape the body and cast the body in a positive light, conferring the disrupted, objectified body-self with positive attributes and value. For example, many participants commented that they were energetic, in spite of their illness and impairments caused by treatment.

> *"I'd be a great person for get up and go"*
> Participant 7

Therefore, though the informants had experienced illness and dysfunction, narrating the experience served to create an image of a healthy, energetic and fully embodied person. The body in this discourse is lived and confers on the individual vitality and control. Other discursive tactics used by the informants to serve similar ends included highlighting a lack of 'apparent' differences between themselves and others. Participants commented on the fact that other people could not tell if they were sick/impaired unless they told them. Furthermore, participants often commented that other people were "worse off" than themselves. This often alluded other people who were suffering from similar illnesses.

However, other individuals suffering from various misfortunes such as poverty or tragedy were also alluded to. Another discursive tactic used by participants was creating a shared sense of vulnerability. Participants, for example, highlighted that anyone could get sick. Indeed, anything could happen to anyone, for example, one could be involved in a car crash. Thus, participants de-emphasised or attempted to detract from their illnesses and bodily disruptions, firstly, by arguing that their bodily status was normal and their status as embodied beings relatively unmarred and secondly, by normalising the experience of illness and dysfuction and depicting illness and dysfunction as relatively insignificant.

> *"Once you're in a hospital you'll always find people that are worse off than you are, you know"*
>
> Participant 13

> *"That's life... anybody could go, you could get knocked down in the morning"*
>
> Participant 1

The process of creating such narratives, therefore, allow participants to recast their embodied experiences in a more preferential, more positive manner and which allowed conservation of self. The body and the self, therefore, are remade in narratives. Such processes play an important role in coping. Recasting the body, in terms of 'normalisation' or de-stigmatising illness and dysfunction allows the embodied person to create positive meaning in their experiences. The body is the existential ground and an expressive site of culture and self. Thus, recreating the ill or impaired body in a more positive and meaningful way, recreates the self in a more positive and meaningful way. These discursive practices allows the participants to regain some level of control over the body and to reinsert a meaningful and valued self into the body. Hence, allowing the body to retain a sense of meaning and symbolic significance.

The Healing Body

The body is remade in narratives to recreate symbolic value and significance. However, as has been emphasised througout this thesis, the body is not merely passive. Therefore, though discursive factors can be seen to shape experiences of the body, the body itself has to be seen as playing a critical role in realinging the body-self and lifeworld after illness and physical dysfunction. Firstly, the body cannot be

completely shaped by discursive tactics. Narrating the body does not allow it to become something which it is not. Thus, narration cannot ignore physical disability. However, first I will focus on the role in which the body plays in coping with illness and dysfunction. As discussed earlier the body is something that we are, as well as something that we have. Thus, materiality plays a huge role in feelings of competence and instrumentality. The body in illness and dysfunction is restrictive and places limits on the self. However, the recovering or healing body is experienced as physically enabling and and has positive implications for reconstructing self. Adjusting to the experience of illness, as was outlined in the previous chapter, was mental in that participants' state of mind enabled them to reframe their experiences often in a more positive light. However, adapting was also embodied. Adapting is bodily in that adjusting to life after illness and impairment involves engaging with the body and with the world through the body.

Restriction in corporeal terms can have a significant impact on participants and sense of self. Physical impairment and restriction had a significant impact on participants' relatedness to their body, biography, identity, social relatedness and social experiences. Restricted bodily instrumentality can cause a breakdown in experiences of body/self and world. Limitations of the body can cause loss of self. Reclaiming the body, however, helped participants regain a sense of purpose and of self as valued and meaningful. For example, regaining bodily functions that were impaired as a result of illnesss and treatment had a hugely positive impact on participants and their sense of embodiment. Returning to work and maintaining routine activities was also experienced as positive. Adjusting to illness can be understood as a product of embodied engagement in the world. Regaining control over the body and engaging with the world through the body is important for adjusting to life after illness and medical treatment. Rebuilding one's embodied existence allows the individual to maintain or re-establish a sense of instrumentality and value.

Changed embodied habits also helped participants to regain control over the body and realign body, self and world. Some participants, for example, turned to the use of holistic and alternative medicines. Taking care of the body and other efforts to enhance health can be understood as helping participants to feel connected to and in control of their bodies. Furthermore, many participants commented on "slowing down". Slowing down was sometimes a negative experience and indicative of loss of self. However, slowing down was also experienced as positive when it represented for participants a choice and a positive change in embodied engagement with the world. Rebuilding embodiment and changing embodiment, thus, is important for adjustment in the context of illness and

physical disruption. Additionally, participants also commented on learning new skills, and taking up new activities as a positive step in coming to terms with illness and disability. Thus, finding new ways of using the body and engaging through the body abates feelings of powerlessness and loss incurred by embodied disruption.

Summary

Managing changed embodiments involves complex discursive negotiations. The body also plays an important role in managing embodied disruption. In other words adjusting to illness and bodily dysfuntion can be seen as a process that involves realigning the self, the body and the world. Language has an important bearing on materiality and can shape embodied being. Nevertheless, limitations are imposed on narratives by material constrictions (Butler, 1993). Materiality, therefore, can have an important bearing on language. Thus, language and materiality must be seen as being heavily interlinked. In short, language and materiality influence each other. The body has to be seen as ontologically real. Whether the body is impaired or diseased or otherwise, it has independent structures that are generative regardless of how they are perceived and discussed.

The inter-relatedness of discourse and materiality

The corporeal and the social are inherently interlinked. Thus, narratives have to be seen as being the product of both social and material influences. Thoughout the interviews, the use of narrative techniques, such as the participants search for meaning, together with the different processes in adapting and ways of adjusting, such as an individual's frame of mind can allow individuals to approximate former states of embodiment. However, continued physical dysfunction can undermine these attempts at re-embodiment. Thus, physical materiality has an important formative influence on experience and discourse. Below is a statement from a male participant relating to his adjustment after surgery for oral cancer. Speaking of his adjustments to the disfigurements and dysfunction he had experienced as a result the participant commented:

> *"I almost accept it now, it's part of me"*
> Participant 10

The above statement orients the participant towards a discourse that aims to convey adjustment to changes. The participant aims to convey that he has incorporated physical changes into new sense of self. However, it is also evident that materiality plays an important role in this process of coping and adjustment. Self is reclaimed, however, this is not done simply through narrative reconstruction. The body plays a critical role in self and has to be assimilated into ones' sense of self. For example, the participant's emphasis on *almost* illustrates the potential of the corporeal status of the individual to frustrate and constrain self. Thus, constraints on self and self-narration can be imposed by the body. There are limitations on the 'self' establised by the obdurate status of the individual's embodiment. Embodiment, therefore, can limit and constrain the use of certain discourse. Similarly embodiment can create possibilites for other discourses. For example, discourse that aims to 'normalise' the impaired or diseased body-self can used if illness and impairments are not physically visible. Thus, the material staus of the body can allow for certain discourses to be employed while closing off others.

Conclusion: The Ambiguous Body

The body and the embodied nature of human life informs the essential background to this analysis. The central purpose of this analysis was to elucidate the role of embodiment in the construction of self and experience within the context of illness and medical treatment. Throughout the course of this chapter, we have highlighted change to identity and change to lifeworld. While much of this analysis has focused on disruption, attention has also been given to coping, adjustment and positive changes in the lives of individuals who experience illness and medical treatment. Accordingly, transmutations in identities, embodiments and lifeworlds have been identified. The role of embodiment in these transmutations has been highlighted. Embodiment can be understood as being inherently ambiguous. As Williams (1999) states the body is "...a fleshy organic entity and a natural symbol of society; the primordial basis of our being-in-the-world and the discursive product of disciplinary technologies of power/knowledge; an on-going structure of lived experience and the foundational basis of meaning, imagination and reason" (ibid: 798). This serves to highlight the multifaceted nature of embodiment. Thus, the ambiguity or indeterminacy of the embodiment has to be elaborated.

Embodied experiences are constituted by a dynamic interaction between the body, the self and the world. These relationships encompass the diverse ways in which the body, identity and world are both connected to and disconnected from each other. That is, the body, self, and world are intimately tied up with one another. However, the unity between body-self-world is profoundly disrupted in the context of illness and medical treatment. Firstly, the body is both connected and disconnected from identity, and secondly, the body is simultaneously a constraint on self and experience as well as opening up possibilities for self and experience.

Bodily dysfunction as a result of illness and medical treatment undoubtedly impresses itself upon identity. Participants struggle to keep a "different" identity at bay and strive to maintain a "normal" identity or to reconstruct a meaningful identity. The self, body and world are typically interfused. The body, therefore, is largely unnoticed and pre-reflective in the course of typical everyday life. It is the body that allows us to feel alive, real and substantial, engaged, efficacious, and socially valued. However, this melding of mind and body is thrown into sharp relief when the body becomes problematic in disease and impairment. The lived experience of illness and medical treatment fundamentally alters one's relationship to the body and changes to self and to being in the world frequently ensue. In illness and dysfuntion, self and world is disconnected from the subjective,

prereflective body. Thus, the body is objectified and is experienced in its alterity. The body, however, can never be seen as being completely disconnected from self. Indeed, embodied activities and engagement continue to play an important role in creating meaningful experiences and continue to help to indivduals construct a coherent sense of self. The body is both self and other. That is, we are not simply living with a body, nor simply dissociated from the body. Embodied existence exists on a continuum, which can allow for qualitative differences in terms of subjective experiences of connection/disconnection to the body.

Not only does the experience of embodiment range along a continuum of connectedness, embodiment can also range along a continuum of contingency. That is, the body can impose restrictions on self and lifeworld; however, the body can also create possibilities for self and lifeworld. Through the disruption of embodiment, the existential possibilities inherent in the lived body are diminished. The body is experienced as a constraint on self and experiences. The impaired body curtails activities and projects, and is a source of uncertainty. Loss of self, vulnerability and uncertainty are illustrative of this non-determinacy. Participants' bodies disrupt their lives and constrain their engagement with the world. Participants' future projects, and goals may be made unattainable and relationships can be constrained. Thus, self and lifeworld have to be renegotiated. Despite the body being perhaps the primary root of curtailed self and lifeworld, new ways of being in the world can also be negotiated through the body. The body thererfore, closes off certain possibilities and yet plays a central role in reconstructing self and realigning self, body and world.

As social beings, identity and experience can never be seen as being entirely contingent on the body and embodiment. Social discourse plays an important configurative role in embodiment. However, the body reciprocally influences the social self. The body, therefore, is an active agent in our social life. The body, self and world exist in a "chiasmatic" relationship (Merleau-Ponty, 1968: 136). It is essentially impractical to attempt to determine where one starts and the other terminates. The body illness and dysfuntion disrupts an individuals' lifeworld and relationships. However, in turn bodily disruption is encountered within a particular cultural context which can have a major influence on the experience of embodiment. Socio-cultural environments, for example, medical sciences specify values for the body. The diseased or impaired body flouts these specifications. Thus, the body, self and the world can be in opposition with one another, despite their primordial co-engagement. Embodied self and engagement with the world, the social and the material are, thus, inseparable. Nevertheless, the body-self and engagement in the world can also be seen to exist in a dialectical relationship.

The experience of the body, therefore, is fundamentally ambiguous. It has not been the main aim of this analysis to investigate the nature of embodiment or what bodies are. Rather the aim was to explore what it means to be embodied and the impact of embodiment on human subjectivity. The emphasis of this chapter, therefore, has been on the experience of embodiment and the often incommensurate experiences that arise out of embodied existence. Embodiment plays an important role in identity and experience on a variety of different levels. To conclude, living in and through a particular body can impact on subjectivity, relationships, and lifeworld.

~ CHAPTER SEVEN ~

CONCLUSIONS

The Role of Embodiment in Human Experiences

I shall first take this opportunity to recapitulate on the central arguments and findings from this research. At the heart of this thesis is an exploration of the experience of illness and medical treatment. This examination of personal experiences of chronic illnesses and medical treatment proved a fertile space for debate concerning the role of the body in human life.

The experience of illness and medical treatment is meaningful and consequential for the person because of their embodied existence and relationships with the world. In the present research, embodied disruption was found to result in fractures in the participants' sense of self and their experiences of their everyday lifeworlds. For example, when participants experienced disruptions to fundamental abilities such as walking, talking and eating, among other physical changes, these disruptions in bodily experiences and functioning resulted in feelings ranging from changed self to the exacerbation of feelings of powerlessness and vulnerability. Body image was also negatively affected, and physical changes and disfigurements whether tangible or perceived, obvious or concealed, adversely affected confidence and self-esteem. Frequently, social relationships and participants' experiences of their taken-for-granted worlds were undermined. The body, therefore, plays a critical role in the experience of illness and medical treatment. This role is highlighted by the participants' narratives. In the interviews conducted for the purpose of this research, few direct questions about the body were posed to the participants. However, bodily issues emerge as prominent throughout the participants' narratives. Furthermore, narrativisations themselves must be understood as being essentially embodied. Narratives can only be created through the body and as such are inherently influenced by embodiment. This issue was made salient by the difficulty some of the participants in the current study had in speaking. Difficulties in creating narratives and barriers to communication were, therefore, established by the body. The body can also be understood as shaping the participants' narratives in less tangible ways. For example, continued physical impairments and bodily dysfunction could disrupt or derail the participants' narrative attempts at adjustment to physical changes. The physical reality of the person, continued illness and disability, and other physical flare-ups can be understood as making certain narratives more or less attainable. Furthermore, the relationships within the context of the interview

must be understood as being embodied relationships. That is, the interviews must be interpreted in light of the intercorporeal situation which they created. The interviews were conducted between a fully embodied, healthy interviewer and an individual experiencing a distrupted sense of embodiment. These intercorporeal relationships may have shaped the content of the interviews and informants may have been placed in a position where they felt they had to defend themselves and portray themselves and their experiences in certain ways.

Embodiment can be understood as an important factor in shaping how people think about themselves and their lifeworlds, and how they attempt to engage with these worlds. However, the embodiment of human life is also inherently ambiguous. That is, the body is generally not experienced, rather, the possibilites and limitations inherent in the body are experienced. In illness the physiological and material features of the body are modified, and the attitudes or techniques of the body are forced to digress from those previously adopted by an individual. Not only does the body feel different to the person, but their ways of interacting with the world are altered. Experience of the body, therefore, is not understood in physiological terms but in meaningful terms. In a sense, the person does not experience illness (Radley, 1997). That is, a person cannot know a disease, or experience a disease. For example, kidney failure or the growth of a tumour is not experienced, rather, the person experiences the embodied implications of such disease and illness. In illness people experience pain, discomfort, changed relations to the world, an inability to walk, difficulty talking and changed functioning. Thus, illness is not an objective experience. They are experiences which are meaningful to the person. Therefore, to have a body is not to come to the conclusion that one is in possession of an object but that there is a self or a being and what happens to the body affects this being.

To be a body, therefore, is to be a person. Disruption to the body originates changes in selfhood and experience. Embodied disruption leads to the dysfunctional state of dysembodiment. That is, embodied sense of self is disrupted and the body-self becomes disjointed. Hence, the body and the self are placed in opposition to one another. The lived-body, which provides the person with the capacity to act, to engage with the world and is an unobtrusive aspect of self, is disrupted. The body comes to the fore and is experienced as acting out against the self, which is shattered by the constraints imposed by the body. The lived-body becomes conscious of ineptness and weakness. Hence, feelings of agency and competence are replaced with feelings of vulnerability. The body as a medium and instrument which conveys self is problematised. Hence, the body becomes a thing that is alien to the self. The body which

is compromised or impaired is experienced in its corporeality, rather than as an inherent part of the subject. As such the body is experienced as an object, rather than as an instrument.

When the body is deselfed and experienced in its alterity, it can be experienced as marginalised or even threatening. That is, the body is no longer reconcilable with preferred self-identifications and is threatening to the self. The body that has a presence, therefore, has a negating personal and social weight. 'Inner' or private experiences of the body are disrupted, but so too are 'outer' or social experiences of the body. The object-body is experienced in terms of negative interpersonal meaning, or in terms of being an unwanted or unpreferred expression of self to others. Thus, social experiences of the body are problematised. Issues of meaning and legitimacy and the symbolic significance of the body come to the fore. Internalised and socially valued self-representations are no longer able to be maintained and the physically damaging effects of illness and treatment can also contribute negatively to a person's ability to live in their lifeworld. The ill or physically compromised individual can often experience a restriction in social activity and interpersonal interactions in social settings can be placed under strain. Patterns of engagement with the world, therefore, are often changed. Physical changes are affected by socially mediated structures of knowledge, however, they are also embodied. That is, the body itself is a communicative medium and plays an important role in shaping experiences of the social world. Ultimately, a sense of embodied normality must be seen as an interaction of bodily processes with feelings, thoughts, and worldy experiences. Therefore, it must be acknowledged that in spite of social influences, identities and social experiences also can be contingent on bodily experiences. Experiences of corporeality, therefore, are always relational and to understand these experiences is to describe them as being both social and embodied.

We know ourselves through our perceptions, experiences of, and our existence in, the world. Both the body and the world always play a role in these processes. Thus, the body-self and the world can be seen as co-constitutive of each other. As previously stated, human experience of the body-self and of the world is relational. The body and the agency it confers in the ability to carry out work and to conduct personal and social relationships, is often sufficient to feel healthy and to also appear healthy to others. This facilitates the maintenence of a valued sense of self. The body's role in illness is its disengagement from everyday life and its failure to constantly permit engagment. The body has a key role in illness not just in conferring an 'ill' status, but also in recovery and in living with the long-lasting physical compromises that can be caused by illness and medical treatment. Continuing with life as normal requires a re-assertion of the body. Bodily being is witnessed in the carrying out of actions

and activities in a social world. The body is, therefore, a constraint. However, it is also the medium which enables us to achieve desired everyday objectives. Thus, self is both embodied and socially meaningful. People do not see themselves as being wholly defined by their embodiment. Social experience and embodied engagement with the world are also important.

Summary

This research hightlights issues of embodiment and phenomenological concerns. Self can be seen as being known and understood through embodied experiences which are embedded in a social world. The embodied nature of human life is both corporeal and social, material and representational. The body is corporeal. The natural capabilities of the body provide the basis for human experience; there can only be experience if there is in turn a world with which to engage. Thus, the body is both of the self and of the world, personal and public. However, too much emphasis on social shaping of bodily experience has been evident in the extant literature on embodiment. Embodied disruption cannot be seen as a disruption of purely social meaning. Rather it must be understood as the disruption of process and engagement as well as of social disturbance. The body, therefore, plays a vital role in the experience of selfhood and social engagement. True, the body needs to be managed and can be done so successfully through discursive and social practices. Williams (1997) argues that the process of narrativisation, where the individual turns the imposition of bodily compromise into a meaningful story can function to realign body, self and world. In other words, biographical work can counteract dysembodiment and affect a reembodiment of sorts. Thus, the repairing of the embodied relationships between the self, body and world can be achieved through narratively recasting the body. However, the maintanence of the body also involves embodied activities and processes. For the participants, for example, embodied experiences and activities played a critical role in their adjustment to illness and physical impairments caused by medical treatment. That is, re-engaging with the world through the body helped to establish a renewed sense of self and to reconstitute the relationships between self, body and world.

Experience as Relational: Implications for Theory in Psychology

The appeal of this thesis is to put persons into the body, experiences into the body and body into experiences. We are embodied beings. Thus, bodies are part of the self and part of experience. Indeed self and experience are often contingent on the body. The body therefore can be understood as

fundamental to the constitution of subject and subjectivity. We live in and through our bodies and the body can be understood as a constitutive aspect of self. The body shapes much of how we think about ourselves, it informs fundamental identities and is also critical to our investment in the world.

Biological reductionism must be avoided. Psychological theories cannot continue to reproduce a functional, physiological body and espouse dualist doctrines. The body is experientially meaningful and is an agentic force in human life. Indeed, Merleau-Ponty (1962) argued that biological reductionism is unthinkable and unworkable in terms of a holistic psychological understanding of human experience. Reductionism, in scientific terms, connotes a purification of an object. In the case of the body, reductionism attempts to lead us to some characterisation of the body that is more simple, but more essential. Reductionism of the body in psychology, however, is reflected in the conceptualisation of the body as an automaton or a substrate for a diaphonous mind. While this approach may be appropriate for the biological sciences, it cannot be for a psychology which takes into account the embodied nature of human life. The human body, treated in a reductionist manner, is not seen as being phenomenologically meaningful. It is a machine or thing which is not involved in subjectivity. Reductionism essentialises the body and cannot allow for a body which plays a meaningful role in everyday human life. However, as human beings, we imbue the body with meaning. We treat it with respect and are offended when others do not. Moreover, the body itself is meaningful and is central to subjectivity created by human beings.

Social constructionist approaches cannot continue to ignore the body's meaningful imput to human life. Just as a mechanistically reductionist understanding of the body is inappropriate for psychology, so too is conceptualising the body as completely coordinated by the social world. Many studies illustrate how self and experiences are socially constructed and demonstrate embodied experiences as similarly constructed. However, if social constructionism is to truly contest biological reductionism and determinism, constructionism needs a view of the body that is more than merely narrated constructions. Understanding bodily experiences as being mediated by social forces fails to recognise the agentic influence of the body. The significance of physical experiences are not just a matter of discourse and language. One's relationship to society is realised through embodied being. Disturbances of the body clearly illustrate how the body can shape social experiences. While bodily disturbances can also be defined and limited by social interpretations, the body cannot be seen to be purely socially defined. Dysfunction, no matter how we choose to describe it, has a material reality which is meaningful and agentic in human experience.

The body is not passive and docile. Nevertheless, socially mediated discourse can cause problems for the body. That is, certain types of bodies are more valued than others in certain cultures. However, the body itself plays a critical role in resolving the problems inherent in the relationships between the body, the self and the world. The body confers the ability to carry out actions, and to engage with the world which allows the person to establish a certain identities. Thus, embodied action can potentially allow the person to establish a valued and preferred identity and communicate this identity to others. However, bodies can also prevent people from engaging in certain activities and, hence, limit identity and the representation of identities to others. Bodies are, therefore, both material and representational and these modes of bodily being continually interact. For example, individuals in the current study use bodily practices to reformulate and attain hegenomic social identities. Physical experiences, therefore, enter into and influence social conditions and interpersonal interactions in which embodied beings are engaged. Embodied beings are always embedded in a social and physical environment and reciprocally and relationally influence each other.

The body-self and the social world are inseparable, yet they are not identical. Thus, the body-self and society constitute a dialectic. In other words, social conditions, psychological conditions and embodied conditions each have an important bearing on human life. A focus on each at the same time is required and can help to clarify the real though often veiled inherent relationships between these conditions. We must, therefore, aim to form a synthesis between the social, material and psychological aspects of human life. Such an encompassing approach can only assist in our attempts to explain the human experience and to capture the meaning in such experience. There is, therefore, a need to include phenomenal and material experiences within a constructionist outlook.

Does this call for a focus on embodied features of human life overstate their importance? The significance of embodiment is apparent in the lives of individuals for whom embodiment is an issue. Undoubtedly, accounts of the experience of chronic illness and medical treatment illustrate the impact of embodied disruption on subjectivity. However, it could be argued that such experiences constitute an extreme example of embodied disruptions and insights from such studies cannot be extrapolated from nor be taken to apply more generally outside the realm of illness and treatment. However, I contend that people are ever more likely to experience unhappiness and dissatisfaction with their bodies in current, modern Western societies. The body as a commodity is ever more ubiquitous and more and more people are becoming estranged from the body. The perfection of commercial 'bodies' often stands in stark contrast to real and fleshy bodies highlighting their inadequacies and imperfections. The elevated

prevalence of eating disorders such as anorexia nervosa, the explosion of cosmetic surgeries and the expansion of a fitness culture, is illustrative of people's increasing alientation from the body. In a "somatic society" and consumerist culture, few people can afford to take their bodies for granted (Turner, 1992). Indeed many contexts are common to everyday life where the body can become the object of attention. Processes of objectification can be seen to exist at large in society. These processes have the ability to exacerbate anxiety and conflictual experiences of self. For example, a consumerist culture has exacerbated this objectification of bodies. Furthermore, the context of a risk society (Beck, 1992) and increasing medicalisation brings the body even further into focus. Few people cannot pay heed to the body. Thus, an understanding about experiential and lived aspects of embodiment is ever more necessary and can help to provide insights into these social and psychological developments.

To develop a thorough understanding of embodiment, however, is a difficult undertaking. As Radley (1995: 5) states the body is "elusory". The body encapsulates the person. However, embodiment cannot be fully understood by solely considering individual bodies. Yes, the body forms the boundary which delineates subject from other, forms the basis for experiences, the formation of identities and internalised representations of self and many of our assumptions about our worlds. As source of agency and competence they allow us to build our own worlds and shape our own lives. Thus, bodies impact on on the world and on our relationships. However, bodies are also part of the world and are, therefore, influenced by the world. Embodied experiences can be understood as the site where multiple forces come together. For example, the influence of illness and medical technology on the experience of embodiment, illustrates how the body is multifarious. Experiences of the body in the context of illness and healthcare are shaped by physiological, psychological and social factors. Exploration of the body therefore, requires sensitive investigation.

The scope of this thesis was to examine the body as a 'problem'. It is necessary to revisit this idea. By considering the body as a problem, this work begins to show how experiential embodiment can often be difficult for individuals and outlines the impact of embodied disruption of selfhood and experiences of lifeworld. However, it also allows scope for understanding how the body can reinforce positive representations of self and allow for expanded ways of living. Experiential embodiment can be seen as a site where various processes of recognising and understanding self can occur and interact. Emergent physiological processes, representations and social experiences combine to produce effects on sense of self and identity. Furthermore, illustrated are the relational and instrumental links between people and their bodies, and ways in which the body-self engages with the world. The thesis therefore,

can be characterised as theorising *from* the body, rather than *about* the body. Thus, many messy arguments about what the body definitively is are sidestepped. This approach allows for flexibility and openness to new possibilities and can complement theoretical work on embodiment theory as well as general scientific enquiry about the body. Furthermore, it demonstrates importance of an empirically informed approach to embodiment.

Summary

The body is an important part of human life. The findings from the current study illustrate how the body can be seen to have an agentic role throughout the experience of illness and medical treatment. Traditionally, the body's role on the in illness and medical treatment has been neglected in psychological models and theories. Therefore, the body has been treated in a reductionistic manner. The danger of this approach, however, is that it fails to counteract hegemonic biomedical discourses that in the field of healthcare. The body's role in illness however, is not just physiological. Rather the body can be seen to play an important role in the person's sense of self and their everyday interactions in their social and physical environments. A holistic understanding of the experience of illness cannot continue to ignore the body. Recognizing a role for embodied being in the experience of illness and healthcare does not invalidate other approaches. Rather, an understanding of the role of embodied being can augment our understanding of what it means to live in the world of illness.

A focus on embodied being does not necessitate a neglect of psychological and social aspects of the experience of the illness and treatment experiences. The findings from this study illustrate how the experience of illness as treatment can be seen as both relational and dialectical. That is the embodied person must be seen as simultaneously physical, mental and social, and cannot be separated from his or her environment. While body, self and world relationally and reciprocally shape and build experiences, each of these factors can still be seen to have a distinct and important influence on human life. To gain a thorough understanding of the experience of illness and medical treatment we should see the person as both embodied and cognitive and as embedded in a social world.

As body dissatisfaction becomes ever more prominent and our capabilities for altering and reproducing bodies advances, the body has never been more in the spotlight. An understanding of embodiment is more and more imperative. However, developing an understanding of embodiment is a

difficult undertaking. The results from this research contribute to an understanding of the experience of embodiment. However, I have not attempted to theorize about what the body is or what it is to be embodied. Rather the study focuses on experience. The phenomenological perspective is particularly amenable to this approach. In phenomenology, experience, including bodily experiences, is taken as foundational. This allows for the exploration of social, psychological and embodied aspects of experience. This research, therefore, provides important empirical research into the experience of body, self and world relationships in the context of illness and medical treatment.

A Real Body and a Social Outlook: Methodology in Psychology

The body is socially constructed to a certain extent. As Foucault postulated, the modern human body came to be discerned through the techniques of modern medicine. Therefore, the body exists as a construction of modern medicine. However, the body cannot be holistically conceptualised as purely discursively produced. Taking the ailing body as an example illustrates how disease and illness concepts can be discursively produced within the medical sciences. However, the physical impairments of disease and illness are none the less real regardless of how they are described. Thus, thinking of the body solely in discursive terms can create a barrier to understanding the body.

Excessive concern with methodology has had a pernicious effect on psychological inquiry and its methodological fetishism has been criticised (Michell, 2003). However, methodological issues must be dealt with and in this case the argument is not for proposing a proscription on specific methodologies, rather the expansion of current discursive approaches. As mentioned earlier, investigating the body is difficult and teasing out the role of the body in human life is certainly a laborious undertaking. So how does one examine embodied experiences? I acknowledge my theoretical sympathies coincide with the majority of doctrines that form the social constructionist project. The examination of embodied experiences as being meaningful to the person is arguably more suited to qualitative discursive approaches than otherwise. This research endeavours to undertake a critical look at the experience of illness and healthcare. Any talk of illness and medical treatment that cannot and does not recognise the body is accordingly seen as deficient and inadequate. The body is the source of illness and is the object of medical treatment. Thus, the subjective experiences of illness and treatment are undoubtedly shaped by embodied events. After all, if the body wasn't impaired in illness then an individual's subjectivity would not have to be adjusted. Thus, corporeal features are important factors in

determining meaning and actions in illness and healthcare. There is perhaps danger of getting into a circular argument as to which, the body or discourse, is the primary driving force in the participants' narratives. Many social constructionists would argue that all narratives have to be seen as mediated by discourse. That is, human experience can only be understood from a relativist position. While it is accepted that psychological phenomena can be usefully examined from a relativist position which can allow for the elaboration of hermeutic issues. However, it is argued that additional and beneficial insights can be gained from accepting the existence of, and examining, factors that are material in nature which have an ontological status independent of, and which can potentially influence discourse.

The distinctions between phenomenological and discourse analytic approaches in accounts of illness experiences is salient to how the body is understood, as well as how illness and healthcare are understood. Discourse analyses elaborate sociocultural discourses and their relationships to the structure of talk and meaning. Phenomenological approaches, however, elucidate the experience behind accounts of events or phenomena which are offered by persons. Therefore, in phenomenological approaches, descriptions of the body *are* people's experiences of the body and are key to understanding their situations. In other words, accounts of the body are understood as revealing bodily experiences. They are not just descriptions which are no more significance than any other part of the story. Narratives are not just rhetorical. Hence, a phenomenological approach allows for the exploration of how narratives exist in a real context such as that of the body. Such an approach can help to provide alternative theoretical explanations for human phenomena, arm us with a different way of seeing the world and provide a starting point for reflexively questioning our assumptions about self, body and the social world.

In the current research a phenomenological approach is used to investigate the role embodied features play in shaping experiences of illness and healthcare. The point of departure for the analysis is that embodied experience is a reality for individuals and should be investigated in psychology. The phenomenological approach constitutes an attempt to understand phenomena from the contexts in which they have meaning. That is illness and medical treatment have to be understood from the context of embodied existence. As embodied beings, we live in the context of bodies, our own as well as other people's bodies. Taking the body as a context in which human experience is played out allows for an investigation of the possible ways in which the body can shape meaning, and enable certain discourses and disable others. Thus an agentic role for the body is provided for. For phenomenologists, therefore, the body needs to be taken seriously as a contextual aspect of self and experience. A phenomenological

approach, therefore, represents an attempt to examine the lived world of human beings. Embodied existence can, therefore, be examined as meaningful.

The phenomenological perspective in the current study represents a material discursive approach that takes as its foundation a critical realist ontology. A critical realist approach allows us to return the body to psychology and affords an opportunity to relate the body to the person and the world in a relational way. Such an approach allows us to "*rethink questions of identity, difference and ethics of care through a committment to real bodies and real selves, real lives and real worlds*" (Radley, 1997: 182 – 3). A phenomenological, critical realist approach allows for understanding of how people experience their situations as well as allowing for an illustration of how the body is interwoven with social meaning and can help us to rethink theory that defines the significance of human experience, self and identity.

Summary

The social constructionist approach to the exploration of the experience of health and illness has been recognised throughout this thesis as having many benefits. However, the drawbacks inherent in relativism impose limitations on social constructions when it comes to understanding and examining the body and embodied experiences. The influence of social factors on how the experience of illness and medical treatment is structured is certainly considerable. However, the body must be accorded a status that is independent of social influences. How we think about the body and how we experience our embodiment cannot be understood as being entirely socially constructed. Rather the body or embodiment must be seen as having a status and an agency which is independent of social influences.

To this end a critical realist phenomenological approach has been promoted. This approach has been argued to be able to maintain a focus on both material and social aspects of experience. According to this approach, experience can be seen as being influence by social factors. However, social factors are understood as occurring in certain material contexts. These material aspects of human life must be understood to constitute an important structuring influence on human experience. In order to appreciate how experience and meaning is shaped, body material and social factors have to be examined without treating either in a reductive manner.

Bodies, Persons and Healthcare

The idea of human embodiment has clear theoretical and methodological implications. However, research must also have practical applications. Firstly, embodiment theory has critical implications for how psychological practices can be improved. A notion of the embodied person can guard against the idea of biological determinism (Cromby & Standen, 1997). By allowing for a notion of the embodied person can counteract the increasing primacy which is granted to biological machinery and genetics. Thus insight into embodiment can help to redress the impoverishment of medical systems that promote reductionism and dualisms.

Thus, on a practical level, the investigation of embodied experiences can have implications for how healthcare can be improved as well as practical suggestions for how healthcare staff can help people who experience undergo medical treatment and physical disruptions. Medical treatment can be disruptive in nature and can mediate a person's relationship with his or her body. As has been argued, the impact on the individual can include feelings of an estrangement from self and body and objectification, dehumanisation and depersonalisation. Such experiences can be avoided if the context in which it is provided is personalised and an ethic of embodied care is developed. That is, healthcare systems need to care for the embodied person and recognise the significance of embodiment for identity and experience. Modern medicine, however, promotes the need to objectify the patient and a reductionistic view of the body. That is the body as the object of medical examinations is seen as a physcial thing. However, the body that is a product of medical treatment is passive and objectified. As Radley (2007) points out one of the key aims of treatment is the displacement of self, feelings and other responses that would interfere with the treatment of the disease. "Medicine is constituted in difference" (p. 299) in that the separation of doctor from patient and the body from self is an inherent part of medical interactions. This directs attention away from concerns such as mortality, vulnerability, preserving the self and dignity of the person (Young, 1989). However, as experienced by the patient, such objectified interactions create feelings of disempowerment, uncertainty and anxiety and, hence, can have significant emotional and psychosocial reprecussions for the individual.

Healthcare staff as well as others can help people overcome the negative repercussions of embodied disruptions. Embodied experiences, if given full weight, can help us gain a better understanding of how people who experience an illness as well as medical treatment cope with suffering and vulnerability. Embodiment is not just a feature of the person but also a part of process and

engagement and as such can be a critical aspect of healing. By understanding how people experience their bodies in recuperating from illness and in rehabilitation after bodily compromise, embodiment theory can be involved in the allieviation of suffering and reconstitution of identity as well potentially assisting new and expanded patterns of engagement in the world. Being embodied and reliance on the body is meaningful. Repairing biographical disruption involves embodied practices. Healthcare staff can assist in this process. Engaging with the patient in meaningful embodied interactions can allieviate feelings of dysembodiment, objectification and depersonalisation. Simple intercorporeal actions such as covering the patient and making eye-contact with the patient are meaningful because people are embodied and can help to avoid situations which can fracture the relationships between body, self and world.

Treatments necessarily involve embodied exchanges. Caring for the patient in an embodied sense is important and can help patients to recover, indeed maintain, a sense of dignity and a sense of worth in illness and medical treatment. Undertaking to engage with patients in an embodied sense may help to improve patients' treatment experiences and their satisfaction with treatment. If the potentially objectifying aspects of medical treatment are recognised and attempts are made to counteract this, then the distressing experiences of powerlessness and dehumanisation can be minimised. Embodied strategies which resignify the body may also be useful for patients after treatment in coming to terms with physical changes and pain management. Futhermore, patients themselves can be encouraged to recognise experiences which evoke dysembodiment and to strategise to minimize the impact of these experiences on sense of self. Patients may also need help to re-connect to and work with their bodies. However, considerably more research into how best to help patients to rediscover meaning in their bodies would be needed before any reccommendations can be made. Furthermore, consideration of who would be best placed to advise patients to such an effect is also necessary.

Summary

Understanding human life as embodied has considerable theoretical and methodological implications for the exploration of the experience of illness and medical treatment. However, an understanding of the embodied aspects of illness and medical intervention can also have important practical implications for healthcare. The body is implicit in illness and medical interventions. Interactions between patients and healthcare providers can be understood as embodied interactions. As has been illustrated in the current study, experiences of medical treatment frequently disrupt embodied experiences and consequently

results in the fracturing of self-indentities and disruption of everyday life. Embodiment theory, therefore, can help us to rethink healthcare delivery and to devise ways which allow individuals to remain embodied throughout their experiences of healthcare, thereby, improving their experiences of illness and medical treatments.

EPILOGUE

Strengths of the research

This research was conducted with participants from a wide variety of different backgrounds and who had a wide variety of different experiences, such as different illnesses and different treatments. Despite these differences, similar themes can be elaborated from the narratives. This reinforces the potential for transfer of the findings to others who also experience illness and medical treatments. Furthermore, while I have confined empirical inquiry to the experience of illness and healthcare, insights from this research may extend beyond the area of health and medicine to other persons who more generally experience dissatisfaction with the body.

How the materiality of the body contributes to the experience of illness and treatment was explored in this research. Incorporating embodied factors into the investigation of experiences avoids the pitfalls of social constructionist approaches. Despite a focus on embodied materiality social constructionist insights into the body are not precluded. Indeed, this research deals with how the body can at times be subject to social constructions. However, by adopting a phenomenological approach the study does not accept that the body does not exist outside of a realm of social discourse. Thus the body is theorised as being real as well as social. The participants' who were interviewed can be understood as being implicitly aware of the body as a fleshy and finite entity. Indeed, many recognised that the body, even the most basic of physiological processes, is often taken for granted. Participants, however, were also aware of the representational nature of human bodies. Thus, we can experience the body as both inner and outer, private and social. These views, the body as material and the body as social, do not need to be opposed to one another. This research, therefore, illustrates how the body can be explored as both a lived entity and a social entity.

Questions Arising from the Research

This research explored the experience of embodiment in the context of illness and medical treatment. The experience of the 'healthy body' was not investigated. Thus, care ought to be taken in extrapolating findings from the current research to times and situations where the body becomes an issue for the healthy person. Furthermore, despite the diversity amongst the participants, they were drawn from a

similar age group. It is possible that participants' relatively older age exacerbated feelings of embodied disruption and contributed to the continued feelings of dysembodiment that participants reported.

Embodied factors were the primary focus of this research. However, there are many other material factors that could also be playing an important role and are omitted from this inquiry. Aspects of the physical environment and institutional power were identified by Cromby and Nightingale (1997) as material factors which can influence discourse. These factors constitute important factors in experience. Indeed the experience of illness and medical technology, certainly would be influenced by such factors. For example, financial factors, and the status differentials between patients and medical staff may play critical roles in patients' stories about illness and treatment. Thus, not including such factors limits the explanatory framework of this research. It could be argued that this research does not go far enough to counteract some of the limitations of the extant research.

Areas for future research

The findings generated from this research may have important implications for theorising about the body and human practices in the context of illness and healthcare. One such finding suggests that the body is an integral part of the establishment of socially valued identities and that it assists individuals to conform to established social exigencies. Further research into whether there are similar processes used by persons in more general, everyday situations is needed. For example, do healthy individuals use similar bodily practices to attain or represent socially valued norms? Furthermore, what of healthy individuals who engage in 'unorthodox' bodily practices such as tatooing and piercing? Though some may take issue with this, extreme or excessive tatooing and piercing can be considered to be unorthodox in the context of modern Western society. Such practices appear to have the function of subverting hegenomic social identities. Thus, physically compromised indivduals appear to desire a 'blending in' of the body both in terms of social and phenomenological experience. Others, however, can be argued to engage in bodily practices with the express purposes of 'standing out'. More empirical research into the different ways in which healthy persons engage with and through their bodied is needed. However, given the phenomenological absence of the body under the normal circumstances of everday life, this will be a difficult project.

Summary

In this thesis I have attempted to bring together academic and empirical investigations of embodiment in order to glean new insights into embodied experiences and the role of the body in illness and medical treatment. The philosophy of Merleau-Ponty, among many other academic accounts such as those postulated by Williams (1997) and Radley (2000), were found to be useful in developing an understanding of the body. Furthermore, the experience of physical or embodied changes in the context of chronic illness and medical treatment was investigated empirically. Empirical accounts are important to reinforce theories. Academic accounts are undoubtedly useful. However, empirical accounts represent a grounding of theory. Embodiment theory after all promotes the grounding of psychological life in the embodied person and his or her life world. Therefore, a perspectival nature of human life is promoted. Empirical research has to be seen as central to this endeavour and can help to maintain a focus on the person and his or her experiences. Psychological life can be investigated in both the embodied and embedded contexts in which it occurs and we can related these contexts to each other in a non-deterministic, relational manner.

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APPENDIX A: INFORMATION SHEET FOR RECRUITING PARTICIPANTS

INFORMATION SHEET

My name is Gráinne Ní Mháille. I am a postgraduate student in the School of Psychology, Trinity College Dublin under the supervision of Dr. Jean Quigley. I am conducting research into the experiences of individuals suffering from a serious illness, their experience of the medical treatment they receive, and how the treatment contributes to the experience of their illness.

Individuals who have just undergone a surgical intervention and who are willing to discuss their experiences are invited to take part in a face-to-face interview. Some of the topics that will be discussed are your experience of your illness, the process of receiving the treatment, worries and feelings felt before, during and after your treatment, experiences of side-effects of the treatment and lifestyle changes due to illness and treatment.

The interviews will last approximately 45 minutes to an hour and will be audio-recorded. Participants will be allowed to take at least one break during the interview. All findings from the research are completely anonymous and confidential and participants are free to withdraw from the study at any point if they wish to do so.

This study will be of help to the understanding of the experience of medical technology and how it interacts with an individual's illness experience. It will also provide you with an opportunity to share your own treatment experiences. If you wish to participate in this research or are interested in finding out more about this research, please contact me.

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APPENDIX B: CONSENT FORM

CONSENT FORM FOR PARTICIPANTS

I _____ agree to participate in this study. I have been advised about confidentiality and anonymity. The researcher's contact details have been made available to me. I do not have to discuss any particular information which I feel uncomfortable with. I am free to withdraw from this study at any point if I wish to do so. I am also free to withhold my consent for data gathered from this interview to be included in this research.

SIGNED: _____

DATE: _____

APPENDIX C: DEBRIEFING SHEET FOR PARTICIPANTS FROM THE HAEMODIALYSIS GROUP

DEBRIEFING LETTER FOR PARTICIPANTS

This research was investigating patients' experience of treatment technology. You are free to withhold your consent for data generated during this interview to be included in the research. The material from your interview and findings from this study will be made available to you. I would like to remind participants that all information collected during the interview is completely anonymous and confidential and no identifying characteristics will be made available in any written aspects of the research. A copy of the transcription will be made available to you and you will be informed of findings generated from the study.

If you wish to talk to a professional counselling service following participating in this interview please contact the Irish Kidney Association (telephone Number: 01-668 9788).

If you require any further information please do not hesitate to contact me. Contact details are provided below.

THANK YOU FOR YOUR PARTICIPATION

Grainne Ni Mhaille

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Debriefing sheet for Participants from Surgery and Radiation Therapy Group

DEBRIEFING LETTER FOR PARTICIPANTS

This research was investigating patients' experience of treatment technology. You are free to withhold your consent for data generated during this interview to be included in the research. The material from your interview and findings from this study will be made available to you. I would like to remind participants that all information collected during the interview is completely anonymous and confidential and no identifying characteristics will be made available in any written aspects of the research. A copy of the transcription will be made available to you and you will be informed of findings generated from the study.

If you wish to talk to a professional counselling service following participating in this interview please contact the Irish Cancer Helpline on 1 800 200 700

If you require any further information please do not hesitate to contact me. Contact details are provided below.

THANK YOU FOR YOUR PARTICIPATION

Grainne Ni Mhaille

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APPENDIX D: INTERVIEW SCHEDULE

INTERVIEW SCHEDULE

So just to get started, would you mind if we discussed your background briefly,
OK…you are female/male and you're in your twenties/thirties?
How long is it since you were first diagnosed with kidney problems/cancer?

ILLNESS BACKGROUND

- Can you tell me the brief history of your problem from when it started to you beginning treatment?
- Had you ever heard of it before you were told that you would need this treatment?
- How was the treatment described to you?
- Did you start receiving treatment straight away?
- Was treatment a major concern for you, or were you preoccupied with other worries?
- Did treatment have an impact on your coming to terms with your diagnosis?
- Do you remember how you felt in the early stages of your illness and treatment?
- Can you think back to your first treatment? Can you remember it clearly? How prepared were you for the experience?

Part2: I would like you to tell me a little about how you think about your treatment. Can you describe what happens during treatment, in your own words?

- What is a typical day when you receive treatment like? Where does treatment happen? When? Are you alone? What do you wear?
- Has the experience changed much from the first time you experienced treatment to now? Have your worries changed or do you feel more relaxed?
- How does the treatment work?
- What do you do when you are having treatment?
    - What do you think about?
    - How do you feel when you are having treatment?

- Physically, emotionally, mentally - What does it feel like when you are receiving treatment? Do you get any physical sensations?

- How do you usually feel afterwards?
- Do you ever think about what the treatment is doing to you?
  - What is the impact on your body/physical self?
- You know, when people get surgery or a transplant for example, they often feel like their body has changed – I know this is not the same but do you feel anything like this?
- What did you think of the technology?

Part3: How does (did) treatment affect your everyday life?

- Have you experienced side-effects? Are you worried about side-effects? How do you think the treatment affects you body? Do you feel in control of your body during treatment?
- Social side-effects? I mean have you had to adjust your life-style much?
- Does receiving treatment take up much of your time?
- If you had to describe what the treatment means to you, what would you say?
  - So is there a particular way in which you think about the machines? Does this reflect the anything in particular about the way you feel about the treatment?
  - In some cases, people come up with nicknames for machines, particularly if the spend a lot of time with them, do you ever refer to the machines in this way?

Part 4: So how would you describe yourself as a person?

- What are your most valued characteristics?
- Has having treatment made a difference?
  - How would you say you have changed?
  - What about the way others see you?

Part 5: Coping with treatment

- Do you see yourself as being ill?
  - Do you worry much about your health?

- On a day to day basis, how do you deal with all that's been going on?With your illness and treatment

APPENDIX E: PARTICIPANT VIGNETTES

Each participant has been given a number and a pseudonym. Background details that were particularly identifying were omitted. Participants are listed below in the order in which they were interviewed.

1. *Louise*, 42 was divorced and had three children. She was a homemaker while her children were young and at the time of interview was conducting a FÁS course. Her diagnosis of kidney failure eleven years previously, came after donating a kidney to her brother who also had kidney failure. Initially she received haemodialysis and then changed to home dialysis. She had received a transplant however; it had never worked and subsequently discovered that she was not suitable for transplantation due to the blood disorder that caused her kidney failure. She shared this condition with her brother and the kidney she had donated to him did not work either. She returned to dialysis treatment in hospital as she felt it suited her lifestyle more. Throughout the interview she generally expressed an optimistic attitude towards her illness and treatment. However, she did admit to periods of depression and sadness regarding her illness and treatment.

2. *Andrew* was 60. He was married and had three adult children. He had taken early retirement from his previous job as a manager and how worked for a retirement consultancy group. He had been diagnosed with prostate cancer. He chose not to have surgery for the cancer due to fear of possible impotence caused by surgery. He opted for radiation therapy. The radiation therapy lasted 12 weeks and was administered on an outpatient basis. He endeavored to learn as much as he could about the treatment and felt that this helped him cope with his treatment. Once finished treatment, he did not experience side-effects and considered himself to be currently in good health. Despite his initial reluctance to talk about his illness and treatment with family and friends, after treatment he had joined a support group and continued to assist in campaigns to promote awareness of prostate cancer in men and encourage screening.

3. *Rachel* was 59 and had been diagnosed with breast cancer 16 years previously to the interview. She was widowed and had three sons. Her husband was still alive when she was diagnosed with breast cancer and her children were young. She was now retired however, at the time of her illness she ran a nursery and worked part-time throughout her illness and treatment. She was

treated for her breast cancer with a complete mastectomy of the affected breast. She told of how she removed her bandages quite soon after her surgery to see her scars and felt that this helped her to come to terms with the loss of her breast. After surgery, she received radiation therapy for residual cancerous cells. This lasted 8 weeks and was administered on an outpatient basis. She did not feel her experience of radiation therapy was very difficult. However, she did find her initial treatments very difficult and invasive. After treatment she had some difficulty with lymphoedema. This hindered her in many daily tasks such as housekeeping. She went for regular check-ups but had been told that the likelihood of reoccurrence was low. Her husband had passed away since her illness but she commented on how supportive he had been along with her sons.

4. *Catherine* was in her late thirties and had been diagnosed with kidney failure three years prior to the interview. She was married with three children and unemployed. Her diagnosis came while she was expecting her third child. Kidney failure had been caused by chronic hypertension. Her son was induced prematurely. The birth did not have any complications and the baby was healthy. She was currently receiving dialysis and was on a waiting list for a transplant. She was unemployed and lamented that due to her treatment she was unable to find employment. She felt her family were very supportive and felt she was coping well with her illness and treatment. However, at times she mentioned struggling emotionally with the illness and treatment.

5. *Alison*, 47, lived alone and had been diagnosed with kidney failure 12 years prior to the interview. She had started to experience symptoms such as hair loss, fatigue, and was unable to pass urine. She was subsequently hospitalized. Within 6 weeks she was told that she had renal failure and began dialysis immediately. She felt that she was unprepared for treatment at this time and also commented that she continued to feel very sick for a long time, was frequently hospitalized and receiving dialysis everyday from bed. After two years she received a kidney transplant which failed. She expressed relief that the transplant had failed as she was uncomfortable with a "dead person's organ" in her body. She had conflicted attitudes towards treatment, referring to treatment as her "best friend" but at the same time "it doesn't give a shit [about me]". Illness and treatment interfered with her desire and ability to engage in preferred activities. However, she did voluntary work in a hospital and felt this helped her to get on with life.

6. *Rachel*, was in her early thirties a wheelchair user had been born with Spina Bifida, a congenital condition regularly associated with kidney problems. Rachel's kidney functioning was being monitored and eventually she reached a stage where her kidneys were failing and dialysis was required. She found her initial dialysis treatments quite intimidating and disliked the catheter through which dialysis was carried out. Having Spina Bifida, she felt she was well accustomed to hospitals and this helped her to cope with her treatment. She underwent dialysis for a number of years before receiving a transplant. The transplant was accepted and still operational at the time of interview. She regarded herself as being very healthy despite having to go for regular checkups. She had married after her transplant and worked as an administrative assistant.

7. *Rita* was 48. She had been diagnosed with breast cancer 12 years previously and had a relapse 5 years previously. She also experienced secondary tumours in her back and womb. In the first instance of breast cancer she underwent a partial mastectomy and subsequent radiation therapy. The second time she was diagnosed with breast cancer she underwent a mastectomy again followed by radiation therapy. She also had radiation therapy for the secondaries in her back and womb and her ovaries ablated with radiation therapy. She found the loss of her breast very difficult and described it as being like a grief. She also found the radiation therapy intimidating and described her treatment as a very emotional time. She was married and had two sons and was a full time home-maker, enjoyed playing golf and described herself as being great for "get up and go". She also talked about having to slow down as a result of her experiences. She had a lot of responsibility from a very young age. Her mother died when she was 19 and her father when she was 23. She had married six months previously and she subsequently cared for her younger brother who was eleven years old at the time.

8. *Anne*, 47 was unmarried and had one son. She had been diagnosed with kidney problems when she was young, and described herself as having always been in and out of hospital during her youth. She was currently on home dialysis to treat her kidney failure. Many years prior to the interview being conducted she had a thyroidectomy to assist with her treatment for kidney failure. However, she felt that this had caused many health complications subsequently. Overall, she found dialysis difficult and lamented the side-effects such as weight gain and bloating. These side effects had a diminishing effect on her body image. In particular, she felt that it affected her sense of femininity. She had received a transplant 6 years previously,

however, after a few years she stopped taking the anti-rejection medications. Despite being encouraged to continue to adhere to the anti-rejection treatment plan she refused to do so. Three years later, the kidney failed and she began receiving dialysis again. She was currently not on a waiting list for transplantation. In general, she found the restrictions; both diet and lifestyle, associated with dialysis difficult to bear and her relationships with healthcare professionals were often strained. She described herself as "non-compliant". She stated that her kidney failure was her disease and that she was responsible for her own body, and what goes into it. Therefore, she regularly ignored diet and medication advice.

9. *Eibhlis* was 52 and lived alone in social housing. She was unmarried and her former partner had died from lung cancer several years previously. She became suspicious of what she thought was a cold sore on her lip when it refused to heal and subsequently went to the doctor and was sent to a specialist immediately. She was subsequently diagnosed with oral cancer. After being hospitalized she refused surgery as a treatment option fearing the resultant affects on her appearance. Instead she received chemotherapy and radiation therapy after discussing her treatment options with her niece who was a nurse. She found her experience in hospital difficult and felt she was scared of doctors as a result. She commented that she felt that she had been spoken down to and had not been well informed about her illness and treatment. This contributed to her negative interactions with doctors. Her course of chemotherapy and radiation therapy lasted 24 weeks. She described her experience of radiation therapy as frightening and was concerned about the side effects of the radium. After her treatment she went to a respite centre for convalescence. However, she left after a week as she did not like the environment and felt that she would prefer to be in her home surrounded by her own possessions. At this time she was emotionally and physically stressed and was suffering side effects of the treatment. She experienced considerable pain and developed deep vein thrombosis as a result of the chemotherapy. She described herself as having developed a phobia about climbing stairs which she attributed to the difficulty she had in her legs after chemotherapy. She also described a phobic response to showering after her treatment which she attributed to her treatment during radiation therapy and the mask which was necessary. She had returned to work and commented that she did not tell her work colleagues about her illness. She was unhappy with her current housing situation as did not like having to climb stairs to get to her apartment.

10. *Bernard,* was a retired 62 year old who was married with two children. His wife suffered from Multiple Sclerosis. Three years previously he had been diagnosed with cancer in his throat and tonsils. He had originally been suffering from a sore throat and later found a lump in his neck. He went to a GP and was prescribed antibiotics for his throat. However, he was unhappy with this and sought a second opinion from his daughter who was also a GP. He was subsequently referred to a specialist and diagnosed with throat cancer. He described himself as being shocked by his diagnosis as he had not felt particularly ill beforehand and had been playing golf before. He became quite emotional upon diagnosis. He underwent immediate surgery and had a tracheotomy. As a result he could not talk for 2 weeks and eat for 12 weeks. He did not want his wife to visit him in hospital, as he did not want her to see him while he was ill. He received radiation therapy for 8 weeks, which damaged the salivary glands in his mouth. This caused subsequent damage to his jaw bone which may need to be removed in the future. After his treatment he was unable to eat and was fed through a peg tube for 3 months. He found this period very difficult and described himself as being tired, weak and irritable. The restriction in activity, which was caused by his need for a peg tube, affected him and he described these months as being extremely boring. However, overall he felt he had coped very well with his treatment. In fact he said he had amazed himself with the strength he had to overcome the experience. He felt his recovery was going well and he had started playing golf again, attended support groups regularly and had taken up piano lessons. He had experienced some continued side effects. In particular, he lost his facial hair which he said bothered him. However, he also said that his appetite was better than it had ever been. He had given up drinking alcohol as a result of his illness and treatment and was considering starting to drink again. Though he feared drinking alcohol could risk reoccurrence, he missed socializing with his friends.

11. *Mary* was 48. She was married with three children. She was a trained nurse and had specialized in cancer nursing. She discovered a lump in her breast through a self examination while she was on holiday. She subsequently went to her doctor for test and was referred to a breast care clinic. After the lump was biopsied she was diagnosed with an invasive duct carcinoma. The cancer had been caught early; however, it was in a gland which necessitated chemotherapy. She had breast conserving surgery to remove the tumor followed by chemotherapy and radiation therapy. She experienced several side-effects of the chemotherapy and lost her hair, eyebrows, eyelashes, fingernails and toenails. She described her treatment as very difficult and worried about the effect it had on her children who were still young. In particular, he daughter was entering adolescence and starting secondary school at the time. She felt her illness had affected

her relationship with her daughter at the time. She described the radiation therapy as being very different, however, found radium treatment as very uncomfortable and had burned her skin. In subsequent years she had broken two ribs on different occasions and attributed this to the radiation therapy. She had undergone a hysterectomy and was receiving continued hormonal treatment to reduce the risk of reoccurrence. Her own mother had died of breast cancer and she was now considering undergoing genetic testing to discover whether she had the Breast Cancer 1 gene. She felt this would help her daughter protect herself in the future.

12. *Patrick,* was a 60 year old married man. After having a sore throat for a number of weeks he went to his GP for antibiotics, however, the sore throat did not clear. After several visits to his GP he was sent to a throat specialist and was given the all clear. However, his sore throat continued and he became increasingly unhappy with his GP's advice and insisted on being sent to another specialist. He referred to a stomach specialist who performed a gastric scope and upon removing the scope discovered a tumor behind Robert's larynx. At this stage the tumor was advanced and could not be removed via surgery as it would have necessitated removing his larynx and receiving a mechanical voice box which Patrick felt would "have been a disaster" in his life. He received chemotherapy and radiation therapy for 32 weeks. He described the effects of radiation therapy as having burnt his mouth. His salivary glands were damaged and for many months he was fed through a PEG tube. He was still unable to eat solid foods and he felt that this left him unable to go out socializing. He commented that he would not eat food that had been liquidized simply for the sake of it. He limited his food intake to foods which were easy to swallow such as yogurt and mashed potato and said there was no point in eating a liquidized steak simply to have one. His voice had also been affected by his radiation therapy. Functioning had returned, however, some days he was unable to talk above a whisper and this bothered him. Overall, he felt that the side effects of treatment had left him with "visible scars" which had left him "marked". He showed considerable regret that the cancer had not been caught earlier which he attributed to the neglect of his GP and the first specialist he was sent to.

13. *Brendan* was 40, unmarried and lived with his parents. He worked as an accountant. He had been diagnosed with an adenoid carcinoma in his neck four years prior to the interview. He had a serious and complicated surgery to remove the tumour from his neck. This involved removing a considerable amount of tissue from his neck, which was replaced with tissue from his arm. The tissue from his arm was replaced with tissue from his leg. He described his surgery as

being like musical chairs with body parts. He described the effect of surgery as like he was hit by a bus. It left him physically weak for a considerable period of time. After surgery he received radiation therapy for 8 weeks to remove any remaining cancer cells. He returned to work when receiving radiation therapy, which helped him to cope with treatment as he felt it restored normality to his life. The surgery had taken away a considerable amount of tissue from the side of his neck and he was self-conscious about this visible change. However, he also commented that people generally did not comment on any difference so this reassured him that he did not look "really ugly". He described himself as a spiritual person and felt his faith helped him to cope with illness. In particular he commented that are always others who are worse off and, therefore, minimized his illness.

14. *Yvonne*, 61, was married with four children and was working as a primary school teacher. She was diagnosed with breast cancer. Describing her illness background she said that she had been developing microcalcifications for several years. She later discovered when a relative was diagnosed with breast cancer that microcalcifications were a risk factor for developing breast cancer. This caused her some concern and she decided to go for a check up in a breast care centre as she had been experiencing some cyclical pain in her left breast. She received a mammogram that revealed a spot which the radiographer was concerned about so she was sent for a biopsy. The biopsy revealed a ductal carcinoma. The carcinoma was still in a very early stage, as had not spread into any of the tissue. Therefore, a relatively non-invasive surgery was required. As the surgery was breast conserving she did not feel overly preoccupied with the effects of surgery, however, she did describe many of the preparatory procedures as uncomfortable. The wound from the surgery had subsequently developed an infection which had left a significant scar, which she felt was worse than the surgery itself. Overall, she felt grateful that it had been caught early, which she felt was largely due to her own initiative. She felt that women in general needed to have greater awareness of the risks and should regularly go for mammograms.

15. *James*, (58) was a successful business-man. His role as a managing director of a company required him to spend several weeks at a time traveling. While traveling he began to feel particularly tired and suspected that this tiredness was due to some other factor than jet lag. He consulted his wife who was a nurse and they decided he should get a check up. A subsequent check up revealed abnormal blood results and after being sent for further tests a cancerous

growth in the colon was discovered. The cancer had been detected early, however, it was described to him as being aggressive. He said that if had been even a five week delay in detection, the tumour would have broken through the wall of the colon and spread. He required surgery to remove the growth. He described himself as being extremely lucky that the cancer had been caught early and attributed this to his own belief in the importance of regular health screening and having private health insurance. He described himself as a recovering alcoholic and had ceased drinking 16 years previously. He also had had an angiogram in the past to correct narrowing of the coronary arteries. He, therefore, described himself as having been given three major chances in life.

16. *Sinead* was 68 and was a married, homemaker with four children. She had been diagnosed with oral cancer 16 years previously. She originally had been born with a birthmark on her upper lip, which had been removed. She described the process of the birthmark being removed as feeling like she was being branded as the lasers which were used to remove the birthmark had left her skin considerably burnt and the process had been extremely painful. Her problem with the lip began to resurface when a 'cold sore' appeared which would not heal. A relative of hers commented one day that she did not like the look of it and encouraged Sinead to get it checked out. She subsequently visited the doctor and it was biopsied which revealed a tumorous growth. She received chemotherapy and radiation therapy for 12 weeks. She originally was hesitant about the radiation therapy due to her earlier experiences of having her birthmark removed. However, she said she quickly became accustomed to the treatment and that it was not nearly as bad as those earlier experiences. She felt that she had not been affected by her treatment to a great extent and described herself as being still very active and enjoyed being part of and organizing a retirement club. However, she commented that she did not like to have photographs of herself taken, often refusing to be in photographs. She commented that when she looks in the mirror that it was not herself looking back, although she attributed this as much to aging as to her illness. She was very grateful to have been free of illness for so long. Her husband had died several years previously when her children were young so she was grateful that she was still around to see her grandchildren.

17. *Peter* (75) was a married, retired school teacher. Although Irish he had lived abroad for several years teaching mathematics. Four years prior to the interview, he was experiencing soreness in his gums and sought advice from his dentist. His dentist pulled a tooth and subsequently

discovered it was more serious than he originally thought and referred him to a specialist. He was diagnosed with head and neck cancer which required a part of his jaw to be removed as well as part of his ear. Recuperating after the surgery was experienced as difficult. He was unable to eat or talk for a considerable period of time. He was fed through a peg tube for several months which he described as being difficult. Furthermore, he described himself as almost having to learn to walk again as a bone from his leg was removed to reconstruct his jaw. He described this as the worst part of the treatment. He continued to experience side effects in terms of his ability to eat. He commented that it took him a considerable amount to time to eat. However, he didn't let this stop him from going out or going to a restaurant. However, he was no longer able to drink wine which he believed burnt his mouth. He commented that he always felt that he would come through the experience.

18. *Rebecca* (59) was married, had two daughters and worked as a writer. Three years prior to interview, she had been going to the dentist for a considerable period of time as she had a wisdom tooth overcrowding her bottom teeth and she was grinding her teeth. She later developed a sore spot on the inside of her cheek that was like an ulcer. The dentist told her that she must be biting her cheek in her sleep. The condition continued to worsen, began to cause her considerable pain and interfered with her ability to eat. After repeated trips to the dentist she was diagnosed with erosive lichen planus and referred to a specialist, however, she would be on a waiting list for several months. She was now in considerable pain and became increasingly unhappy with the condition. After looking up the condition she discovered that it was a precancerous condition which concerned her. Furthermore, it recommended seeking medical advice. She returned to her dentist and asked whether she should see a GP. The dentist recommended she wait until her appointment with the dental specialist was set. However, the pain she was experiencing continued to worsen and she went to her GP who immediately referred her to a head and neck clinic. There was a history of cancer in her family and both her sisters were diagnosed with breast cancer, one of whom had passed away as a result. After a period of tests she was diagnosed with oral cancer. She received major surgery which required the removal and reconstruction of her jaw bone and she was left with some facial disfigurement as a result. A bone from her leg had been used to reconstruct her jaw which resulted in her experience complications when she experienced a fracture in her leg as a result. This caused her considerable pain and resulted in a lengthy period of immobility. After surgery she received radiation therapy for 9 weeks. She experienced several physical side effects including diarrhea, fatigue and nausea.

19. *Joseph,* 50, was an unmarried business man and ran his own consultancy company. Six years previously, during a particularly busy period in work, he began to experience an "exceptional tiredness". He later discovered a lump in his neck and one day asked a doctor who he was working with to have a look at it. This doctor referred him to hospital. He was later diagnosed with an adenoid carcinoma in his neck. He had surgery to remove the lump and then received radiation therapy for a period of 2 months. He experienced some side effects, however, he did not feel frightened of the machines. He felt that they were very advanced technologically and described them as fascinating. He commented that the atmosphere in hospital had a considerable effect on the experience of treatment. He received treatment for his condition in a number of hospitals and felt that the differences in the respective environments result in more or less positive experiences. In particular the medical staff had a considerable effect on the experience. During the experience of treatment he did not tell his work colleagues of his illness and continued to work as much as he could. He likened the experience of illness to being a personal journey for him and described himself as a more patient person as a result.

20. *Theresa*, 61 was a married mother of four and had worked as a teacher. Three years previously she experienced bleeding, despite being post-menopausal, as well as some discomfort and pain. She was subsequently diagnosed with type 1 endometrial cancer which was minimally invasive and she got a good prognosis. She had a hysterectomy to remove her womb and the cancer. She found the hysterectomy difficult. In particular she commented that it was part of her being a mother and that she felt that it in some way affected her relationship with a child she had miscarried many years previously. After recuperating from surgery she began to feel well again and felt that she coped well with the treatment. However, she commented that she had to make adjustments to her movement and reduce physical exertion. She was considering retiring as she began to feel that her job was too stressful and physically fatiguing.

APPENDIX F: WORKED EXAMPLE OF ANALYSIS:

Transcripts were coded in two phases. Initial coding included paraphrasing and integrating statements. In the second phase, interpretation of statement began

Excerpt from Participant 18

I… Em, and I didn't know if I'd come out of it. I didn't know what was waiting for me on the other side in terms of quality of life or anything like that. There was the whole concern about the effect the surgery would have on me. On how I look, for a start, which was one thing. But funnily enough my biggest fear was that I would lose my voice because that was a possibility eh, and [pause] its something that I used in work, I mean I don't know how much to say without identifying myself. No matter how you cloak this, but you know I taught, I gave workshops, I did readings. All of that is very important

G: Emhm

I: besides just the personal thing. There is a personal thing about a voice; there is a personal thing about a face. When you

Unsure of what would happen

afraid of the effects of surgery

concern about effect on appearance

Fear of losing voice

Importance of Voice

Using voice

Voice important for work

Voice = personal

Face = personal

Uncertainty caused by diagnosis

Fear of the effects of treatment

Fear of effects of treatment

On appearance, voice and abilities

Disruption in life

Disruption to self

Encounter other people your face is what they first

see of you and how they begin to make their judgments and I didn't know if I'd be able to get past all of that. And I was afraid of all of that, you know. [pause] There was the whole issue of mortality to deal with and actually that was the big thing. That was the kind of reverberating theme of the whole. It was such a shock it was a real shock that someone could just say 'that is, your times up now' and pull you out of the game and that's it it's over. And there was no bargaining with it, there was no arguing with it. I couldn't talk my way out of it, I couldn't pretend it wasn't happening, this was something real that I couldn't avoid that was the real shock and it changed the way that I feel about everything. It changed the way I see everything. Just that one thing, all of the rest is stuff you know. Like noise in the background

Other people see face

Make judgments of you

Afraid of change

Aware of mortality

Continuous Shock

Fear of death

Mortality

Illness couldn't be avoided. It was an actual event in life and she couldn't get our of it

Massive effect on life changed the way she saw life

Made other things seem insignificant

Affect social relationships

Social objectification

Fear of treatment

Facing mortality

Disruption and fear, uncertainty

Life disrupted

Change in life direction

Loss of control over life

Major change in life

Changed perspective on life

G: Would you say the experience has really changed you?	*Changed but not changed. On a superficial level not changed But won't ever be the same again.*	Changed self
I: [pause] Again yes and no [pause], but yeah more than no. Superficially I think I'm fairly back to normal but I don't think I ever will be the same. [pause].		

(ii) Establishing Final Experiential Themes

Codes were grouped appropriately, amalgamated into initial concepts which were then used as the basis for the final themes. From the example given three themes can be illustrated: *Disorder in Illness*, *Disorder in Treatment* and *the Wayward Self.*

	INTEGRATION OF CODES	EMERGING CONCEPTS	FINAL THEMES
1	Uncertainty caused by diagnosis Fear of the effects of treatment Disruption in life Disruption to self Disruption and fear, uncertainty Life disrupted Change in life direction Loss of control over life Effects social relationships Social objectification	Illness affects life in many ways Affects activities, social relationships, change in way of understanding self and seeing one's self. Causes fear and uncertainty Causes life disruption - personally and socially	**Disorder in Illness**
2	Fear of effects of treatment Fear of treatment On appearance, voice and abilities	Treatment can cause fear and uncertainty and disruption to the person life. Fear of the effects of treatment would have on appearance and functioning caused considerable upheaval emotionally, personally and psychologically.	**Disorder in Treatment**
3	Major change in life Changed self Changed perspective on life Facing mortality	Changed sense of self in illness. Not the same as their former self and this has many negative consequences. However, the experience of illness and treatment prompted considerable existential questioning and consideration mortality and vulnerability. Positive changes to self and to life as well as a changed perspective on the world.	**The Wayward Self**

(iii) Integrating Findings across the Transcripts

All transcripts were coded and analysed. Themes which were common amongst all of the transcripts were maintained. Themes which were not common across the transcripts were collapsed into other themes where appropriate or discarded.

Example Theme 1: Disorder in Illness

Illness is a disorder of the body, however, it also can throw the individuals' sense of self and lifeworld into disarray. *Disorder in illness* captures the effect that illness had on the participants personally and socially. The experience of disrupted self, disrupted work and family environments is also included in this theme. The emotional impact of illness on the participants, such as the experience of shock, uncertainty, sadness, anger and confusion, is also included.

Illustrations of quotes from other transcripts which are indicative of *disorder in illness* are listed below:

PARTICIPANT	QUOTE
18	*"there was no bargaining with it, there was no arguing with it. I couldn't talk my way out of it, I couldn't pretend it wasn't happening. This was something real that I couldn't avoid. That was the real shock"*
19	*"That worried the life out of me"*
11	*"God....I've have a really bad time".*
7	*"Coming to your life style or your family life style as well. It was terribly upsetting in that kind of way"*
10	*"He said 'I have to tell you now [name] that you've got cancer'.....and I said 'Jesus' and I sat there and I think, not that I think, the tears came into my eyes and then...(pause)"*
12	*"It was a terribly traumatic time in my life".*
1	*"I've had depressions and stuff but I'm not that type of person. I do try to snap out of it, you know"*

Example Theme 2: Disorder in Treatment

Treatment aims to correct physical disorder, however, medical treatment can also give rise to disruption. Disorder in treatment captures the considerable feelings of uncertainty and fear which the prospect of treatment caused. The way participants make sense of or think about their treatment and how it affects them, as well as fears regarding the effects of their treatments are also subsumed in this theme.

Illustrations of quotes from other transcripts which are indicative of *disorder in treatment* are listed below:

PARTICIPANT	QUOTE
18	*There was the whole concern about the effect the surgery would have on me. On how I look, for a start, which was one thing. But funnily enough my biggest fear was that I would lose my voice because that was a possibility*
6	*, it is...I think it is a big shock when you see them for the first time, like you know, and you see people on it and you kinda go 'oh God, that's... your life is over', you know what I mean. Because it does look very, ah, intimidating. The actually reality of it"*
9	*"all I could see was the neck open and the eye drooping and I said I'm not having that...rather than have the surgery, I said, I'm going for that (chemotherapy and radiation therapy)*
1	*"(I) try not to think about it. It is wearing me out. I do get tired. I know the effects it's going to have on my heart. I think in the long term, I think 90% of people of kidney patients die of heart failure... it makes the heart weak"*
8	*"I don't have a nickname for it. I don't because I despise it because it's in the room... and in everyroom in the house twas Baxter, that's the company that makes the products. So everywhere you go in the house, there's something belonging to Baxter in it. So you're not actually getting away from it. Everywhere you go there's Baxter, so you've this little, em, yeah flashing light to remind you that you're on dialysis"*
20	*"I found it quite scary. Especially the first time I went in. I thought it was like...the first thought that I had was 'oh this is what it must be like to be in a coffin' because youre lying down on this thing and you have to stay still and all these things around you..... I did find it quite frightening"*
12	*"Ok it's a short burst but its, it could be very frightening to some people because eh you are strapped down. And you have this mask. In my case, I had this mask down over my head and shoulders, em, to prevent movement"*

Example Theme 3: The Wayward Self

Illness and treatment prompted considerable changes in the participants sense of self and their experiences of their lifeworld. *The Wayward Self* captures the changes that people experience in sense of self in illness. Participants felt that they were not the same as their former self and this has many negative consequences. However, *the wayward self* also captures how the experience of illness and treatment prompted considerable existential questioning where participants are considering their mortality and vulnerability. Therefore, illness prompted questioning of the participants' identities and lifepath. Often this resulted in participants experiencing positive changes to self and to life as well as a changed perspective on the world. Therefore, the wayward self captures how participants sometimes felt that their illnesses and experiences had positive effects on their lives.

Illustrations of quotes from other transcripts which are indicative of *the wayward self* are listed below:

PARTICIPANT	QUOTE
18	*"There was the whole issue of mortality to deal with and actually that was the big thing. That was the kind of reverberating theme of the whole. It was such a shock it was a real shock that someone could just say that is your times up now and pull you out of the game and that's it its over. And (pause) there was no bargaining with it, there was no arguing with it. I couldn't talk my way out of it, I couldn't pretend it wasn't happening, this was something real that I couldn't avoid that was the real shock and it changed the way that I feel about everything. It changed the way I see everything. Just that one thing, all of the rest is stuff you know. Like noise in the background"*
12	*"Yeah I would have. Would have. Because I can't (pause) I can't do, I can't do a lot. I eh, run things, I took early retirement and I run a pensioners club and that partially involves eh, a few lunches a year or what have you. OK so I'm there but when you feel you can't eat normally. When you feel you have to make special exceptions all the time, you're terrible conscious of your position all the time with your social strata. That em... em that you can't participate in the way that you feel you ought to be participating"*
1	*"I used to be always going out and everything, which you know I was younger then obviously...but that slowly went. I'm not able for that anymore...yeah I hardly go out at all anymore you know that sort of way. And financially as well, things have gone so bloody expensive anyway but no, I don't have the same energy, you know I'm older now"*
11	*"It was a harrowing time and you are facing... and I faced my own mortality. I had to look at the fact there is a possibility that I am going to die"*

10	*"I must say I pray quite a lot now, but I do pray, pray a lot now. Don't take things for granted that much and eh, I think I'm a better person... that eh may sound strange"*
7	*"Oh I changed, oh yeah, I had to slow down. My mother had died when I was nineteen, my father died when I was twenty-three, six months married. My brother was an orphan like at eleven years of age so he came to live with me. So like, and I was working and all that, you know, I was constantly going, going, going. I had to come up with the mother role in the house. I was always going... Like, I had to look at my life and I was kind of saying 'Just slow down, you just say no' and I did and I kind of like, I didn't take life as seriously, you know what I mean. I kind of like, I started enjoying life then. I kind of started going out more with the girls and all this sort of thing. I did, you know what I mean?"*

APPENDIX G: ILLUSTRATION OF ANALYSIS OF THE MEANING PARTICIPANTS ATTACH TO THEIR EXPERIENCES

Step 2: Analysis of meaning participants attach to their experiences.

(i) The themes which emerged from the experiential analysis detailed above were subsumed into conceptual categories.

Experiential Theme	***Quotation Example***	**Conceptual Theme**
Disorder in illness	*".. what matters to me is how it feels; it feels different, takes much more of an effort and is tiring to talk. I am constantly aware of how the changes feel"*	Being a body The alterity of the body
Disorder in treatment	*I'm living with all the time, my leg (pause) so I have to carry all of that; it's a lot to carry round with me all the time."*	Having a body The uncontrolled body
The inconsistent self	*"I don't need to know my weight...because I find especially the way society is, you're supposed to be you know a certain weight ot whatever"*	The expressive body The social body
The limited self	*"Yeah I would have. Would have. Because I can't (pause) I can't do, I can't do a lot. I eh, run things, I took early retirement and I run a pensioners club and that partially involves eh, a few lunches a year or what have you. OK so I'm there but when you feel you can't eat normally. When you feel you have to make special exceptions all the time, you're terrible conscious of your position all the time with your social strata. That em... em that you can't participate in the way that you feel you ought to be participating"*	Changed social relationships

Threatened Stability	*"I still know it's like we take something like gravity for granted, you know. You stand up you expect to remain vertical; you expect buildings to remain vertical around you. That s just something we take for granted when we move around. You know, the street horizontal, the buildings will be vertical. The bus will make its way through the town... (pause)... and for me that doesn't apply anymore. (Pause) I know, it's like you have to juggle the two things because I don't live with the expectation that eh this is going to come back everyday but at the same time I know that it's possible that it will"*	The body and the experiential world
Disorder in treatment	*"there was the whole concern about the effect the surgery would have on me; on how I look for start, which was one thing"*	Medical treatment and the body-self Objectification, depersonalisation, dehumanisation
	"I just felt that I was being totally invaded and bombarded and bullied and em, and I know that everyone had my own best intentions at heart but I just felt that I was totally out of control at what was happening to me and everyone was pushing me around the place and I had no say in what was happening to me and it was, it was an awful time"	Powerlessness
	So I went home and I felt, I dunno what I felt. It was like everything was against me and I would never even be able to walk on my own two feet again and I was, anyway, I couldn't get up. When I was at home and I was on the sofa, I couldn't even get up to stand without having somebody there in case I fell because I couldn't take my weight. So I couldn't even get myself a glass of water, d'ya know I could do nothing I was really, really helpless"	Medical treatment and being in the world
	"I feel as if I was sleepwalking before, and I'm awake now. I understand	The reconstructed body

The adapted self	*something urgent and crucial and as basic as air, that I just didn't get before. I was oblivious."*	The discursive body
⇨	*"I'd be a great person for get up and go"* ⇨	The healing body

(ii) The themes listed above were amalgamated into overarching themes which described the participants' experiences of embodiment in the context of chronic illness and medical treatment.

Sub-themes		**Overarching themes**
Being a body The alterity of the body Having a body The uncontrolled body	⇨	**The inseparability and duality of the body self.**
The expressive body The social body Changed social relationships The body and the experiential world	⇨	**Being in the world**
Medical treatment and the body-self Objectification, depersonalisation, dehumanisation Powerlessness Medical treatment and being in the world	⇨	**The medicalised body**
The reconstructed body The discursive body The healing body	⇨	**Realigning the self, body and world**

APPENDIX H: EXAMPLE TRANSCRIPT

Participant 1: Louise

I: OK, would you mind telling me a little bit about your background

P: I was married. I'm not married anymore, separated and I've got three kids…grown children, 25, 21 and 17 and…they're all healthy, they're fine

I: Yeah

P: Yeah

I: so you said its eleven years since you started getting kidney trouble

P: eleven years, yes….well I didn't have to. I never had kidney problems. My brother was always on dialysis and he's in England, 16 years on dialysis, and I actually donated a kidney to him

I: Emhm

P: and four months after I donated a kidney to him, I got kidney failure

I: Oh, really?

P: and he only got 6 months out of the kidney I gave him, so the two of us are on dialysis. And this happened in England, it didn't happen here. It was in hospital in England.
And I've never been sick really before that you know

I: so was it hard for you to get used to that?

P: well, yeah, well I was used so much to Thomas* being sick [1] and when I first came home after the operation, I never recovered I was always sick. But I just thought it was my body getting used to having one kidney, I didn't realise that the kidney was actually failing and it was only when I was very very sick that I went to the doctor and he got me straight to *Hospital A* and I went in…obviously I couldn't pee and when I did I'd have creatine in the urine so straight to *Hospital A*

I: Emhm

P: and I went to *Hospital A* and I went on drugs and I used to ring Thomas and he told me oh your creatine levels they're going up, that's not a good sign, that's a sign of kidney failure. So, then I started asking questions which was obviously that the kidney might not be good and eventually they done a biopsy and eventually it failed and I was in two months and I can home doing home dialysis. And at the time my kids were a hell of a lot younger you know so it took a lot of getting used to at the time and I opted for the home dialysis thinking it would be better if I was home all the time

I: Emhm

P: 7 days a week, four times a day. And very time consuming.

I: right

P: so I done that for a year and a half and there was a line then in my stomach and I got an infection so they had to take it out and put me on haemodialysis which I found a million times better.

I: OK

P: it was just three mornings a week and you've had your days in between so I find I've a four day week. I've four full days with no hospital or anything and I just find it a lot better

I: right

P: :...in…..in …..in the long run I know that it wasn't something I was doing, I would have to be home all the time and bring stuff with me everywhere I went, you know. I could get away for weekends, it would be a break away from…I have more of a life doing the CAPD (correction) or the haemodialysis than I did with the CAPD

I: right

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[1] *name has been changed

P: I think that might be more of old people…older people that would be staying home a lot

I: Okay….so could you describe what happens during treatment, you go into hospital I presume and?

P: I go in very early in the mornings now. I get collected at 5 o clock in the morning, and I have a graft in my arm at the moment and I'm on the machine, I do three and a half hours of haemodialysis, three days a week – Monday, Wednesday, Friday and I get into bed and I have treatment, drain the fluid, I fall asleep and then they wake me up and its time to go home grand…and the taxi is organised to go home…..it is very time consuming, the night before I'm in bed early emmmm…not so bad...you see its not so bad now the kids are reared but when they were younger and school and stuff like that and making sure that they were ready for school the night before...then it you know, it took an awful lot out of me but now as they are older, they all pitch in at home, you know...emm but it is very time consuming and I get tired and its very restricted and work wise you get tired a lot. And very time you get quite a lot. Like I was up this morning, I'm in here today. I was up since half 3 this morning. I'm ready for bed now you know that sort of way….you know

I: right…right…so would you think the experience has changed a lot?

P: ah…how do you mean?

I: well from the first time you had dialysis to now?

P: well I'm more used to it now…I mean, I did go through a bit of depression. Not wanting to go in and refusing to go in and as I'm not actually suitable for a transplant

I: yeah

P: I did have one 5 years ago…and I when I was on the transplant list it gave me something to hope for, you know. But it didn't work and I was very disappointed by that you know...then I was told that I'm not actually suitable. I've got a blood disorder

I: ok

P: then that just shattered me and ah....that just got to me like this is it for the rest of me life coming in here for three days a week and you know… and I went through a bit where I just refused to go in for dialysis and I cancelled and *Hospital A* were very good for that and my counsellor and my consultant was sent over to talk to me and you know kinda stuff like that and you know medicine you know and in the next few years but it was very daunting and when you don't have that kind of hope in the end….it was very daunting

I: right

P: but as I said and I'm enjoying my 40s you know and I go on holidays now. So that's something I have to look forward to and that kinda keeps me going, do you know what I mean. I always have to have something to look forward to and that makes me to go on you know

I: OK

P: but yeah…God...I've had really bad time, I've had depressions and stuff but I'm not that type of person I do try to snap out of it, you know

I: yeah..

P: it's been a while now and I have… I have been ok

I: OK...so do you think much about how the treatment works at all?

P: Yeah…well I try not to because my access is running low I'm running out of places to go for access for dialysis you know emm… and I know that it plays havoc on your heart, your heart suffers from of it but I try not to think too much about the future you know that sort a way so…that's the way I used to be like oh what if this goes what am I going to do…now I'm just if it happens it happens and I'll deal with it when it happens, you know...I think they are improving all the time emm I mean I know people that kinda had thyroid problems and stuff and my thyroid, you know, was going very high but I'm on the medication to reduce that so I don't have to have the operation on that and I know loads of people that have had that done and I'm saying you that I don't need that done so medication, you know, its coming on a hell of a lot, emm for phosphates and kinda calcium residue, they can give you something to bring that

down a bit when it goes too high. you know little things like that you know, they are all the time coming up with something newer you know, since I was first on dialysis

I: right

P: the diet has loosened up a little bit its not as strict. Fluid would be but fluid wise it wouldn't be as strict as when I was first on it

I: emhm

P: yeah, which its all an improvement, obviously…emmm. I don't know how much further it can go,…ya I find as it cause I'm so long on it now and even like with Thomas, 16 years so kinda dealing with it with him, you know it has changed a lot, and he kinda gives me information from England and I give him information from here.

I: right

P: do you know what I mean?

I: yeah

P: and I'll tally it up and ill ask questions here of the doctors and he'd be the same over there, you know

I: emhm

P: so it's good to have somebody else in the family to discuss, ah ah, cause he understand, you know, more so than anyone else..

I: so ye support each other?

P: ah yeah…well this is it I know exactly what he's talking about when he's on the phone, do know what I mean, and he kn…so its great to have a chat with him when you know, if you're feeling a bit down cause he actually understands what you are talking about, you know. I suppose as good and all as *Hospital A* is and the girls are lovely, they don't actually know what…you know…

I: yeah

P: what…you know…what they…and at home do you know what I mean?

I: yeah

P: so it is nice to have that bit of support there, it is

I: grand, so, do you spend much time with medical staff?

P: no not really, just when I'm in the hospital, I see them…you know and talk to them. Doctors no I don't see very often. I'm not one of the sicker patients there you know what I mean. I run when I see a doctor (laughs)..no no I'm really, normally they just come down if my medication is being changed and just check the bloods and you know come down for a chat every now and again but I'm having a few problems now in the ovaries so I'm getting that seen to now but I think that's just normal. Anybody could got that but that's the best again *hospital A* treat all that, do you know what I mean

I: ok

P: and I get looked after quite quickly in there so anything that wrong with me you know, the doctors get sent down they do sort it, well with me anyway, pretty quick. But this just happens throughout the year but you know..

I: OK, so if you had to describe what the treatment means to you, what would you say?

P: oh I wouldn't survive. I wouldn't be alive you know, if I hadn't gotten dialysis over the years I'd be dead along time ago you know, so yeah that's you know, I'm separated so for me kids I'm here even if I'm home in bed I'm here. Oh yeah…I wouldn't do with out it so it's the lesser out of an awful lot of evils, really

I: so what kind of person would you describe yourself as?

P: I am quite outgoing I think. I'm not one for moping around being sick all the time. I have had times when I did but I do snap out of it, but it is hard. Its taught me a lot and I'm a hell of a lot more easier going and I appreciate more, do you know what I mean

I: there are positives

P: oh yeah definitely, because I've seen an awful lot of people passing away, young and old, you know, and friends and they've had problems as well so yeah I do appreciate everything down to

the taxi man that collected me in the morning you know, 5 o clock,, bringing me home and I do I appreciate everything, you know

I: emhm you don't ever think about what the treatment does to your body?

P: well that's what I was saying, try not to think of it. It is wearing me out. I do get tired. I know the effects it's going to have on my heart. I think in the long term, I think, 90% of people of kidney patients die of heart failure it makes the heart weak but I try not to think that far ahead because at the moment I'm not bad

I: ok

P: and anything could hit you tomorrow, you could be gone. You know nobody could live like that sure you wouldn't live

I: so on a day to day basis

P: I don't think about it no, no. every now and again, as I said, if I was to go very deep into it and really think about it like I used to do, yeah. But sure you'd go crazy, it would, it would drive you crazy, that this is it you know. You know there was one time I did have a row with one of the girls from *Hospital A*, and it was along long time ago and we were always friends, one of the nurses and I slept it out one morning over a taxi I had been out the night before and I didn't want to get it and then I did , she sent me one an hour later at 6 o clock and I got that one and she ate me when I got into *hospital A*, and she was real "do you know what this is costing the government with taxis and all that" and I said if its that much of a problem then I'll pay and she said but sure you're delaying everyone else now on the machines for the rest of the day" and I just stood up and I said fine well I'm very sorry for being an inconvenience, I said have you never slept it out for work. I said you can take your holidays, she had gone to Australia for six months or something, and I can't do that this is it and I started roaring crying. I did I pulled out my line I said 'I'm not being dialysed today you can send me home', you know. That kind of attitude and she came over and she couldn't stop apologising but to me it was too late she had said it and that I was costing the government money and that really really hurt me, you know. And the next day I was in and she came over and was crying and she said "I haven't stopped thinking about you" and she was so wrong, which she was wrong you know, it wasn't coming out of her pocket, she was just after coming back from Australia you know she was settling back in to work, you know. I mean since then she is married with kids and everything she was only young but I think that hurt me

I: Emhm

P: you know and I stood up and said don't bother dialysing me and you know eventually they got me on a machine and I said just do me for two and a half hours instead of three and a half hours, I said well I'm not going to be delaying everyone for the day so this way it can be very restricting

I: So you feel you've had to adjust your lifestyle?

P: Oh very much, very much I mean completely. I used to be always going out and everything, which, you know I was younger then obviously but you know *hospital a*, the taxi used to pick me up from town, not from home, oh I'm still in town in 'Abrakebabra' I'm not going to make it home in time for the taxi could you pick me up on such and such a street and they would, they used to get a great laugh out of me you know, but that slowly went I'm not able for that anymore

I: so you get physical side-effects

P: Yeah yeah I hardly go out at all any more you know that sort of way. And financially as well, things are gone so expensive anyway but no I don't have the same energy but when I first went to *hospital a*, you know I'm 44 now, I was only 32, 33, you know all in all, no I wouldn't have the same energy.

I: So you see a big change?

P: Big change, oh I had never been abroad before in my lifetime and that time I started you know there were times when I did nearly die in *hospital A*, and I didn't go home for a few days and I've had a few nasty shocks with the family you know, my mum and dad I've had priests and

everything you know, I think this is why I kinda appreciate the things. I had never been abroad so I'm going to start doing these things, I took my kids away which I had never done before things like that that changed me, definitely

I: Well do you think about the machines themselves much in any particular way?

P: no, not really no

I: no?

P: I just want it to be over, I have said to the girls a couple of time 'I must learn to use one of these' because my brother has his own machine and he dialyses at home a haemo machine and he's able to do the whole thing himself. I should, I should really know a bit more about the machines. I just know they clean me out, they take the fluid off me. I know an awful lot about dialysis you know, obviously I do know the benefits of everything. I could teach people about lines about , about everything, the diet but ya the machine, why it work and how it works but I know the longer you are on it its not doing you any favours really.

I: Right and do you worry about your health much, you wouldn't?

P: em...I don't, I try not to dwell on it because as I'm only a couple of weeks in here (IKA) and its bringing it more home to me because when I'm in *hospital A*, as soon as I finish I go home and I don't think about the hospital anymore. But here is a constant reminder all to do with organ donation and and sending out donor cards and there's an Ad on the radio at the moment and its plugging donation and the sick people in here is a bit of a reminder. I have worked before and it's great to work but I haven't worked for 5 years but I haven't been well for five years since the transplant and when I did work before it was an escape from everything. Here isn't it's a reminder, it's only a six week course you know but here is a constant reminder, which wouldn't be doing much good really to be honest. It should really cause you know, because it's so important but just because you know

I: yeah, yeah

P: not to be constantly thinking about it as I said on the Friday I finish dialysis and I'm not back in again till the Monday morning and I don't even think about the hospital and ok if I'm eating I have to take a couple of tablets and night-time before before I go to bed four or five drops of tea, that's it. I'm so used to the diet and the fluid restrictions it doesn't bother me anymore, you know. Emm, ya I just don't like being constantly reminded and I go out and meet new people and I don't talk about it or anything like that you know?

I: yeah

P: I wouldn't be like there I was away on a two week holiday. I had a great time. I was a bit sick now. I'm not good at eating out now, I throw up quite a lot but emm, but I wouldn't tell anybody that I'm sick, I don't if people ask ill say oh it was just and accident' and I'll push it off

I: you wouldn't tell them

P: no its such an old story, and who needs to know. Everybody has their problems and I don't want to be talking about it all the time constantly so when it gets into conversations about bloody hospital and I'm on my holidays and I've done my three days over there in the week in Palma and it's a nice little unit and ya I was there for two weeks that was 5 days out of the two weeks were gone, that way now it was difficult it was one o clock during the day sessions that was a whole day gone and I had to be ready by half 11 and I didn't get back until half 5

I: Right

P: so the whole day was gone. That way it was a bit no day in the sun today, but at least I can get away. Then I have to turn and say 'look there's not that many people that can do that, at least I can get away'. Emm I'm going to France now in November and I can change my dialysis to get dialysis on the Friday and I can change my dialysis on the Monday morning to Monday night instead of Monday morning so I get the three nights away. So it's a nice long weekend, Friday, Saturday, Sunday, Monday. You know and I kinda, I do a couple of weekends throughout the year. Keeps me going, keeps me ticking over.

I: So that's important?

P: Yeah, how I do it, that's how I cope anyway. I don't know how other people but that's how I do it

I: OK so is there anything else you would like to add

P: Emmm…I suppose I'm giving a real light hearted kinda view on it its not cause…I mean it is tough. It is tough going and there's a lot of people that wouldn't have the same attitude as me. My brother now if he was here talking to you would be here for 10 hours, d'you know what I mean? He's… oh he would moan and groan and give out and 'my life is unfair' and 'oh my life is over'. I feel you see he was only 26 and he hadn't got kids. I feel like I had my kids, I had my house. I had a lot before this happened me. I'm kinda one of the luckier ones. I had a best friend that was a kidney transplant patient and she's 42 now and she would love to have kids but she's not going to now, you that sort of a way. So you know, I think that's how I kinda got over it, you know, at least I had my family and I had a lot done, you know, and its just things that I'd never done that I've started to do now. And I think for my kids as well it's been a learning experience. You know they had to grow up a little bit quicker, be a bit more independent. They all iron for themselves, they all cook. Do you know what I mean? Well it didn't do them any harm. Well I know they missed me a lot and they got thrown around a bit now and I was very sick and I felt it more for them, they found it tough. But they've come out of it. On a good end, not on a bad end which is good. But at the time it wasn't, I felt that they were missing out on a lot, their dad wasn't around and I was sick a lot. Their grandparents were looking after them, neighbours were looking after them, they did suffer a lot, but as I said it has made them stronger now. I didn't see it at the time but now and

I: And ye are close

P: Close, very close, well me daughter now not as close as the two boys, but the boys very close. Which is nice to see, which is nice to see. But it was tough on them. But I wouldn't bother them with an awful lot of stuff if I was in hospital when I come home I say 'no, I'm fine, I'm fine' and id be really bad.

I: They help you a lot so

P: Yeah, it's great to see them now, happy in themselves and settled now and we're all quite close, which is goods there is a reason in life for me for everything. What my reason is I don't know but I got sick. I can say now, with the kids grown up, it's not as bad as few years ago and I was working as well and it was a hell of a lot more tougher then. But now its just (inaudible)

I: You mentioned your parents, and how have they coped?

P: Ya, well they are getting on into their seventies now. Ya my mam, they don't understand the illness really, they never really did. They don't understand the diet, you know I still go for dinner now, you know and mashed potato and gravy and after so long being sick and she tries but of course its all fluid and it's genuine. She's never really tried to understand, she's never read a diet book, she's never really read up

I: Ok

P: Emmm.. ya they wouldn't be very well up and it's an awful shame they should have you know, and this is where my brother would feel it more. When he comes home for a weekend he goes mad you know, 'do you not know now what I'm allowed' and just don't eat it, leave it on the plate what you cant eat type of thing. But they should have, they should have taken a bit more interest and learned more, and I've given them the support magazines and they didn't even read them

I: Right

P: So they wouldn't be that interested. I'm the oldest in the family and two others are younger and living in England so they actually rely on me an awful lot as well

I: So it's a strain

P: Oh ya they do, they depend on me quite a lot. So kinda even for the boys now they would contact me, they wouldn't really ring my mother but me. But I was always the oldest sister; I always had that kind of a role anyway. So ya I've good friends and they are good to me now so. They try they do try.

I: OK so well I think we've covered everything.

P: I don't know of I was any good to you

I: oh no, no, no. thanks this is great. Is there anything else you would like to add?

P: well, what you were saying there about the effects of the machine, do you have, do you know what all the effects are?

I: well I have read up on it but really articles are very technical, what I am interested in is the general experience, you know the person's story

P: oh yeah, no I just thought you had information. You know I learnt from the nurses in *hospital A*, and I ask question and I know that I was on the CAPD and they would prefer me to be on the CAPD than the haemodialysis, because it's kinder, it's a milder dialysis for the heart but its very time consuming, you know. And I think each individual would be different in the way they want their treatment done. I mean if it came to the crunch, that I lost my access or if they say 'you know, the old heart, to go back on the CAPD' I would go back on it. Emmm, I won't say quite happily but again give me another few years and you know that sort of way. But I think the way I'm doing this at this moment in time does suit my way, you know I'm so long doing it this way I got myself into the routine. But that girl there she's only two years into it and she's got a young baby and you know I feel I listen to them and I think oh god its hard but you have to you have to. You have to think, you're lucky, you have to. I'm lucky in a lot of ways and unfortunate, just unfortunate that it happened, just unfortunate the way it happened, as I said. I was in the full of my health and it just happened. They discovered I had the same blood disorder as Thomas after the transplant. They have done loads of research into it now, which is great so myself and Thomas and Martina, my parents all gave blood for the doctors in *Hospital A* who sent them over to the guys who were doing all this over in England. You know kinda to find if there could possible be a cure you know emmm ya so they're working it was unfortunate it happened. It took me a couple of years to get used to it, as I say, and I still it's been a while since I've been down, but ya I get done

I: yeah

P: yeah but everyone gets down at some stage.

I: Emhm

P: so ya, OK

I: thanks very much for talking to me today

P: is that ok for you?

I: Ya