Technology Used at Home

for

Children with Complex Needs

The Identification of the Types of Technology used by Children with Complex Needs at Home.

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Acknowledgements

Executive Summary

This exploratory mixed method study was undertaken to identify the types of technology used in the care of young children with complex needs at home.

A number of major factors underpinned the need for this study. Internationally and nationally there is an increasing emphasis on providing children's palliative care services and on sustaining their excellence and quality (European Association of Palliative Care (EAPC) (2009) & Department of Health and Children (DoH&C) (2010)).Children's palliative care includes providing care for children with complex needs and life limiting illnesses in which technological care giving forms part of mother's caring roles (Nicholl 2008). However the exact nature of this technology and its use in the family home is under researched.

The aim of the study was:

- to identify the types of technology used by children with complex needs receiving their care from their parents at home.

The study's objectives were:

- to identify the equipment used at home in the children's care.
- to identify parents' concerns regarding equipment used in the home.

The study was conducted in two phases. Data was collected from nurses and parents caring for their children at home. In Phase 1 registered children's nurses (RCNs) were invited to participate in a focus group interview and in Phase 2 parents were invited to complete a questionnaire.

In Phase 1 nine expert Registered Children's Nurses (RCNs) participated in the focus group interview. The findings from this interview informed the development of the questionnaire.

One hundred and seventy seven (177) families and (178) children took part in Phase 2 of the study. One hundred and seventy-seven families completed the questionnaire either by face to face or telephone interview.

The questionnaire results identified a large number and range of technology that are used and managed for the children's activities of living. Results show that on average (22) pieces of equipment are used in the daily care of each child with additional equipment being used in physiotherapy and occupational therapy. Additional significant findings relate to parents difficulties in accessing and procuring the required equipment along with issues relating to the assessment, sanctioning, funding and delivery processes of equipment and the management of the equipment and its impact on the family home.

Recommendations

A strategic review should be undertaken into the:

- needs of children receiving care at home
- technology used in their care
- personal, financial and practical implications on parents of the high levels of equipment used.

Abstract

The aim of this mixed method exploratory study was to identify the types of technology used for children with complex needs receiving care at home. The objectives were to identify the range of technology used and the issues encountered by parents in using this technology.

The study was conducted in two phases:

- In Phase 1 data were collected from a focus group interview with Registered Children's nurses (RCNs). The data collected informed the development of the study's questionnaire.

- In Phase 2 the questionnaire was administered to families either by telephone or during visits with them. One hundred and seventy seven (177) families completed the questionnaire.

The study's results indicate that children with complex needs require the use of high levels of technology to maintain their health and well-being. On average, families identified (22) pieces of equipment used by them in the care of their child. In relation to equipment to assist with activities of living the equipment most frequently identified is that used to maintain mobility. The study also shows a substantial number (95%) of children used nappies and pads, this is particularly interesting considering (33%) of children were aged (5) years or over. Figures further indicate that of the (33%) aged (5) years or over, (92%) of them wore nappies.

In relation to medication equipment a high proportion of parents (69%) used equipment such as syringes and tablet crushers and (67%) used a medication box or cupboard for storage. Thirty-eight percent (38%) of children regularly used nebulisers (26%) used inhaler medication devices to deliver medications such as Salbutamol (Ventolin) or Beclomethasone (Becotide).

Perhaps some of the study's most significant findings are the parental reports of their difficulties in accessing and procuring equipment. This includes issues relating to the assessment, sanctioning, funding, delivery processes and the training required for managing the equipment and its impact on the family home.

The study recommendations are that a strategic review into the needs of children receiving care at home, the technology used in the children's care and the personal, financial and practical implications in the use of high levels of equipment on their parents and families be undertaken.

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Glossary of Terms

For the purpose of this report terms used are defined as:

(1) Technology and Equipment

The terms equipment and technology are used interchangeably.

Technology and equipment is any piece of equipment used by parents in the day-to day care of their child. These range from complex life-saving resuscitation equipment to less technical equipment such as equipment for feeding and communication.

(2) The Jack and Jill Children's Foundation

The Jack and Jill Children's Foundation (J&JCF) established in 1997 by Jonathan Irwin and his wife Mary Ann O'Brien "helps young children" in Ireland who are born with or develop brain damage and who suffer as a result severe intellectual and physical developmental delay.

J&JCF provides financial funding for the provision of direct care services and home supports which includes assistance with various services, including respite services and the provision of information and emotional support. Services are provided to children up to age four years who are identified by a service provider as requiring early intervention home respite. Children receiving J&JCF services are termed "active cases". These services are normally terminated when a child reaches four years however very occasionally services for specific reasons can be continued. Children no longer in receipt of services are termed "closed list".

(3) Complex needs and Life-limiting

The children in this study are children born with, or develop brain damage and who as a result suffer severe intellectual and physical developmental delay. Most have a shortened life span and a significant range of complex needs.

Professional terminology used for the children can include 'life-limited' (ACT & RCPCH 2003 Categories), life-threatened and complex needs. These terms are used interchangeably throughout this study.The diagnoses of the children as reported by participants in the study are in Appendix 1.

(4) Children Requiring Palliative Care

In this study Children Requiring Palliative Care refers to those children perceived to need end of life care.

(5) Nurses

Refers to Registered Children's Nurses (RCNs).

(6) Parents

Refers to, and includes, parents caregivers and families.

Chapter One: Background

1.1 Introduction

Internationally and nationally there is an increasing emphasis on providing children's palliative care services and on sustaining their excellence and quality (European Association of Palliative Care (EAPC), 2009); Department of Health and Children (DoH&C) (2010). Children's palliative care includes services for children with complex needs and life limiting condition. Technological care giving forms part of care giving for children with these children (Nicholl, 2008), however the exact nature of the technology, and its dependency, is under researched.

Children who are technology dependent vary according to their disease, its cause, the age of onset, the duration of the dependency, the incidence of associated disability and other factors including the frequency in the use of this technology (Glendinning et al 2001). Anecdotally, it is reported by health professionals that the specific equipment used by children and families at home is becoming increasingly extensive as the children live longer and their needs become more complex.

In Ireland no literature exists to identify the equipment used in the care, support and development of children with complex needs at home and on the demands the use of this technology places on parents and families.

This collaborative study is the first Irish study to identify the technology used by parents in the care of their children at home.

1.2 The purpose of this study

The purpose of this study was to identify the technology used by children with complex needs at home; to contribute towards a picture of contemporary home life for parents caring for children with complex needs at home; to provide a baseline for further investigation and to contribute towards the development of future services.

1.3 The aim of the study

The aim of this study was to identify the types of technology used by children with complex needs cared for by their parents at home.

1.3.1 Objectives

The principal objective:

- to identify the equipment in use within the home in the care of children with complex needs.

The secondary objective

- to identify medications children receive.

1.4 The literature

A brief synopsis of the literature on children's palliative care which includes children with complex needs and life limiting illnesses is provided.

1.4.1 Technology dependence

On-going developments in health care knowledge, technology and medications have improved the survival of many children with complex needs and serious illnesses. Children, who are technology dependent including those who are life-limited, vary according to their disease, its cause, the age of onset, the duration of the dependency and the incidence of associated disability (Glendinning *et al* 2001).

Survival has resulted in many children living longer and becoming dependent on technological devices which "… sustain life or optimize health and [where children] have the need for substantial and complex care for substantial parts of the day or night" (Glendinning, 1999:35). There is no Irish literature to support the equipment used in the care of the children at home and the demands placed on families.

Dependence on technology can involve a myriad of equipment including mechanical ventilation, oxygen therapy, enteral and parenteral nutrition (Glendinning *et al,* 2001; Heaton *et al,* 2003; Teare, 2008). Heaton *et al* (2005) developed this definition to include the technical skills involved in the use technological care. Definitions however can also change over time as children's diagnoses become clearer, and they are also influenced by the complexity of the child's condition which can change during the child's lifetime. There is no acceptable internationally recognised definition for technology dependence. Nicholl (2007) in an Irish study also acknowledges the vagueness of the definitions used in caring for children with complex needs and the multiple perspectives that are adopted and their impact on service provision.

1.4.2 Life-limited, complex needs and palliative care

Internationally and nationally there is an increasing emphasis on providing children's palliative services with sustaining excellence and quality (EAPC), 2010; DoH&C 2010) for children with a range of life-limiting illnesses (Kirk & Glendinning 1999, 2002, 2004). Palliative care as a continuum of care, and not purely end of life care for children has, in Ireland, and in keeping with international developments undergone considerable change in recent years in terms of care and service provision for the children and their families. These changes have been greatly influenced by the associated complex care particularly required by children with non-malignant conditions (Nicholl & Price, 2011). This complexity of care with increasing emphasis for technological support (Reeves Timmons & Dampier, 2006)

is recognised as requiring specialised nursing and health care supports (Teare, 2008).

1.4.3 The impact of caring at home

Historically children with complex needs and life-limiting illnesses remained long term in hospital. It is now recognised that care at home improves children's physical health (Jardine, 1999) and that long term hospital care is not beneficial psychologically, socially and educationally to their wellbeing (Boosfield & O' Toole, 2000).

While current policy directs the preferred option towards care of the child at home, (EAPC 2009), there is however available evidence on the impact of this transfer of care onto parents, family and on the general home environment. Training in the use of equipment and its impact on parental roles has been explored and Kirk and Glendinning (1998) suggest there is a blurring of the boundary between lay/parents (non- professional) and professional care.

As technical care-givers as well as being parents, gives rise to challenges and conflicts between the caring, mothering and parenting role within a highly medicalised home environment (Kirk 2001, Kirk *et al,* 2004). Moore *et al* (2010) also acknowledge the intrusive role of living with technology in the home, for example where portable medical devices are used and operated by trained parents.

Reporting on family pressures While *et al* (1996), Kirk & Glendinning (2003) and Kirk *et al* (2004) amongst others report parents as experiencing sleep deprivation, isolation and depression on a daily basis. In addition Hewitt-Taylor (2005, 2010) writes on family consequences and the lack of opportunities for both the child and family to engage in social activities, often due to the child's need for assisted feeding or ventilation requirements. Others have also highlighted a lack of community supports for these families.

1.4.4 The Irish Perspective

In Ireland technical care-giving has been identified as one of the four components of care-giving of children with complex needs at home (Nicholl, 2008). The burden experienced by parents caring for their technological dependent children in relation to social, emotional and financial pressures is reported by Redmond *et al* (2000) and Richardson (2001). Families suffer financial losses from home caring and lack opportunity to gain employment while undertaking full time carer roles as (Normand & Revill, 2010) identified the enormous strain placed on families of children with life-limiting illnesses. However the care provided by parents to their children at home and the issues they face remains under-investigated.

1.4.5 Irish Policy Directives

In response to international service developments, Irish policy makers are responding to the needs of children with life-limiting illness and complex needs by developing community care services and specific training for professionals involved in the delivery of the care of the children and their families (DoH&C 2005, 2010).

The recent national policy for the delivery of palliative care for children with life limiting conditions (DoH&C 2010) identified key principles for service direction. Key principles and developments include the construction of a children's hospice and funding for specialists and education. This funding has been released to appoint eight community specialist children's clinical nurses "outreach nurses" and a children's palliative care consultant. Educational training programmes to support excellence in practice in the principles and practices have been developed. There is further requirement for a third level specialist educational programme in children's palliative care.

1.5 Conclusion

The numbers of children with complex needs and life limiting illnesses are increasing but little research exists into the technology required. It is reported that

the technological care for children at home is extensive and as the children live longer their needs for supportive equipment can become increasingly more complex (Nicholl, 2008). However the exact nature of what equipment is involved, and the issues it raises for parents, is under researched.

Chapter Two: Methodology

2.1 Introduction

This chapter outlines the research design of this mixed method exploratory study and includes the aim, objectives, methods of data collection, the sample, the inclusion and exclusion criteria and ethical approval**.**

2.2 The aim of the study

The aim of this study was to identify the types of technology used by children with complex needs cared by their parents at home.

2.2.1 Objectives

The principal objective:

- to identify the equipment in use within the home in the care of children with complex needs.

The secondary objective:

- to identify medications children receive.

2.3 Data Collection

Data for the study was collected by two methods and in two phases. In phase (1) a focus group interview with expert nurses was undertaken. In Phase (2) a survey using a specifically designed questionnaire was administered to parents.

2.3.1 Phase 1 Focus Group Interview

In phase (1) data were collected from a focus group interview with nine expert nurses employed by J&JCF. The interview guide for this focus group was drawn from the literature.

2.3.2 Phase 2 Questionnaire

A structured questionnaire was developed from the focus group findings and was administered either by telephone interview or by personal contact with parents.

2.4 Recruitment of the Sample

Two groups of participants were recruited. One group contributed to Phase (1) and the other group to Phase (2).

2.4.1 Expert Nurses

Expert registered children's nurses (RCNs) were recruited and all had at least (5) years career experiences with J&JCF. This involved providing home respite services to families with children aged up to four years who have severe developmental delay and required extended care at home. These nurses provided a purposive sample in that they had expert knowledge of the topic under investigation.

The nurses were informed about the study at their monthly meeting. An information pack which contained an information leaflet, an invitation to contribute to the focus group and a consent form was distributed to all.

2.4.2 Parents

Parents on the J&JCF database were informed of the study by a notice placed on its website by the nurse manager. The nurse manager acted as a gate keeper to protect families' personal data and distributed the study information pack by post to families. One follow up reminder was sent to those who did not respond to the first information pack. The information pack contained a letter of invitation, an information leaflet, a consent form and a return envelope. Following return of the completed signed consent form, parents were contacted and invited to complete the questionnaire.

2.5 Inclusion and Exclusion Criteria

2.5.1 Inclusion Criteria

Nurses:

- J&JCF expert RCNs currently involved in service provision.

Parents:

- Parents on the J&JCF "active cases" family database that is, those in receipt of services,
- Or those on the J&JCF "closed list" family database, (that is those no longer in receipt of service but who had received services) and whose current circumstances were known to the nurse manager and to the other nurses.
- Parents having (1) or more children with complex needs.

2.5.2 Exclusion Criteria

Nurses:

- Not signing the consent form.

Parents:

- Any invited parent who did not wish to take part in the study.
- Any invited parent who did not wish to respond at the time of the questionnaire interview.
- A parent on J&JCF "closed list" data base whose current circumstances were not known to the nurse manager and to the other nurses. [Their contact details may have been inaccurate and their child's current circumstances unknown.]

2.6 The Questionnaire

No questionnaire on the technology used by children with complex needs receiving their care at home was found in the literature. As a result the questionnaire for this study was developed from the focus group findings and in consultation with four

experienced RCNs to ensure its relevance, consistency and the validity of the questions. In order to reduce to error and bias written instructions for data collectors were also developed. These were similarly reviewed. Minor changes were made to both documents based on feedback from three reviewers. Before the administration of the questionnaire discussion took place with all data collectors and their queries were answered.

2.6.1 Questionnaire Structure

The questionnaire comprised of 8 sections. In each section the respondent was provided with a forced choice pre-coded "Yes/No/Not" applicable response. Section (1) elicited basic demographic and biographical data including the date of birth and gender of the child and the county in which they lived. The seven subsequent sections focused on the technology used for a range of seven activities of living - sleeping, hearing/vision and communication, mobilising, elimination, eating and drinking and breathing. For each section the "Yes" response indicated the parent had technology in the home and after every question the parent was given the opportunity to include additional relevant information on the item.

Data in each category included 'simple' technology (glasses, adapted cutlery or nappies) to more complex equipment (intravenous feeding tubes, powered mobility devices and ventilation assistive technology).

Information on additional technology, medication technology and medication was also gathered as was information on general equipment provided by physiotherapists or occupational therapists. In the final part parents were asked to identify three key issues related to managing the technology and were also given the opportunity to add any additional comments or questions.

While the questionnaire was developed primarily to collect data from parents it also included a sub-section which allowed for a subjective assessment of the child's

level of need for care by the data collector. This included the assessment on the complexity of child's needs and perceived need for 'palliative care' or 'end of life' care at the time of data collection.

2.6.2 Questionnaire Administration

The expert RCNs who agreed to take part in the focus group interview were also invited to collect data during a routine home visit; otherwise the data were collected by the research assistant. The research assistant did not have a nursing background and parents were informed of this.

The questionnaire was completed with each parent in one of two ways:

- During a routine home visit with the J&JCF nurse
- Via a telephone interview

Telephone interviews or home interviews were arranged at mutually agreed times. The home interview generally took place when a family visit was due. Before the start of each interview the aim and objectives of the study and the format of the questionnaire was explained and consent was again confirmed. The data collector checked the respondent had time to complete the questionnaire. Respondents were given the opportunity to clarify any issues during the interview and to ask for explanations if necessary. The questions were asked in a structured, informal manner so that the interview appeared more like a discussion or conversation (Mathers et al, 1998). Each respondent was thanked for their contribution.

2.7 Ethical Approval

Ethical approval was obtained from the Faculty of Health Sciences Ethics Committee, Trinity College Dublin.

The study adhered to the principles of good ethical practice in research as identified by the International Council of Nurses (2006). Steps were taken to

protect respondents' rights to information and confidentiality. The use of codes and the removal of potential identifiers were used to protect the respondent / participants' identities. No individual respondent / participant or their family is identified in the report. Data were stored on a password protected computer and paper records were stored securely and access to raw data was restricted to the research team. Data protection legislation within the university was adhered to and original data will be destroyed as required by this legislation.

In Phase (1) each nurse was provided with an information pack about the study which included a consent form, details of voluntary participation and withdrawal from the study. Two of the research team members met with the nurses at their monthly meeting and provided information about the study. These nurses signed and completed consent forms prior to participation in the focus group interview and completion of the questionnaire.

In Phase (2) J&JCF nurse manager acted as gate keeper and each family on the J&JCF "active cases" family data base was sent by post an information pack containing a letter of information and two consent forms. Before recruitment of families on J&JCF "closed list" data base, families were reviewed by the nurse manager and those whose current circumstances were known to her and to the other nurses were invited to participate but those whose current situation was unknown were excluded as their contact details may have been inaccurate and their child's current circumstances was unknown.

The information letter sent to families gave details of the study's aim, rationale and the method of data collection, as well as the right and how to withdraw from the study without prejudice at any time. Following return of a signed consent form the family was included in the study and data were collected, either by a telephone interview or during a routine home visit. At the outset of each interview consent was again confirmed and any questions answered.

Chapter Three: The Findings

3.1 Introduction

This mixed method exploratory study was conducted in two phases. In Phase (1) data were collected from a focus group interview with Registered Children's nurses (RCNs). This data informed the development of the study's questionnaire.

In Phase (2) the questionnaire was administered either by telephone interview or during direct home contact with families.

3.2 Phase 1 Focus Group Interview

The themes which emerged from the focus group interview served towards the development of the questionnaire, medication and the identification of equipment in home use.

The group identified the use of eighty-seven (87) pieces of technology and these were divided for use by six (6) categories of activities of living:
1. Sleeping;
1. Hearing/vision/communication;
2. Mobilising;
3. Elimination;
4. Eating and drinking;
5. Breathing;
6. Additional equipment.

The use of additional equipment and equipment for physiotherapy and occupational therapy were also identified. In addition to the medication the children take and the equipment used to administer that medication.

3.3 Phase 2 Questionnaire Respondents

One hundred and eighty (180) families agreed to participate in the study. Of these, data were collected from one hundred and seventy-seven (177) and one hundred and seventy-eight (178) children because in one family two (2) children had complex needs.

Of the one hundred and eighty (180) families who agreed to participate (1) family was excluded as their child had sadly died during the study and (1) parent was unable to complete the questionnaire due to his/her child's ill health. One (1) further parent who consented to participate had two children with neuro-behavioural and psychological development disorders (Asperger Syndrome and self-harming Attention Deficit Hyperactive Disorder) and was therefore not considered eligible for the study.

Of the one hundred and seventy-eight (178) children, (63.5%) were on J&JCF 'active cases" with the remaining (36.5%) on the "closed list" databases.

Data were collected over a three month period. Questionnaires were completed with families either by telephone interview or in the family home. Interviews lasted between twenty minutes and one hour. Ninety percent (90%) of the data were obtained from mothers and ten percent (10%) from fathers. Parents from all regions of the country took part in the study.

3.3.1 Questionnaire Analysis

Simple descriptive analysis was undertaken using frequencies for categorical variables using SPSS V. 17. Simple thematic analysis was used to analyse qualitative data.

3.3.2 Biographical Data

The greatest proportion of families who took part in the study live in Dublin (n=47), followed by families in Cork (n=20) and Galway (n=13).Figure 3.1 illustrates the general geographical profile by province.

Figure.3.1: Geographical profile of families by province
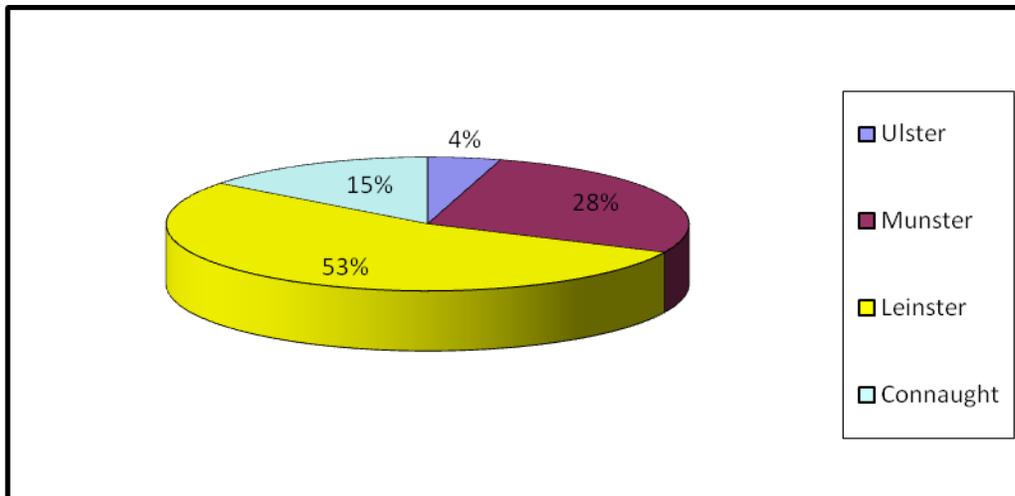
3.3.3 Age of the Children

Children's ages ranged from four (4) months to (10) years with a mean age of just over (4) years. Sixty-six percent (66%) of children were aged (4) years and under with (34%) of children aged (5) years and over. Fifty-seven percent (n=102) were boys and forty-three percent (n=76) were girls *(Table 3.1).*

3.3.4 Active Cases and Closed List

J&JCF services are provided to children and families up four years of age. Children receiving services are termed "active cases". Normally the services are discontinued when a child reaches four years however on rare occasions, services are, for very specific reasons, continued. Children no longer in receipt of services are kept on file as a "closed list".

Sixty-six (66) "active cases" children and thirty-four (34) "closed list" children were represented by their parents in the study *(Table 3.1).*

Table 3.1: Ages of children categorised according to active/closed cases

Ages of children		Active cases (%)	Closed cases (%)
10 months- 4 years	(n=118)	92%	8%
>4years -10 years	(n=60)	7%	93%

3.3.5 The Diagnoses of the Children

Many of the children in the study had multiple diagnoses and co-morbidities. There was a significant range of diagnoses and these were grouped according to broader diagnostic categories (Appendix 1).

The main diagnostic groupings identified were syndromes (19%) cerebral palsy (17%) and congenital abnormalities (16%). Six percent (6%) of parents reported having not received a formal diagnosis for their child. The reminding children (42%) had a range of medical diagnoses. The diagnostic categories of all one hundred and seventy-eight (178) children are represented in *Figure 3.2.*

Figure 3.2: Diagnostic category of the children in the study

Diagnostic category

Legend:
- syndrome
- cerebral palsy
- congenital
- global dev delay
- chromosome
- down's syndrome
- no diagnosis
- spina bifida
- tumour
- brain disorder
- premature
- metabolic
- neurologic post-virus
- cardiac
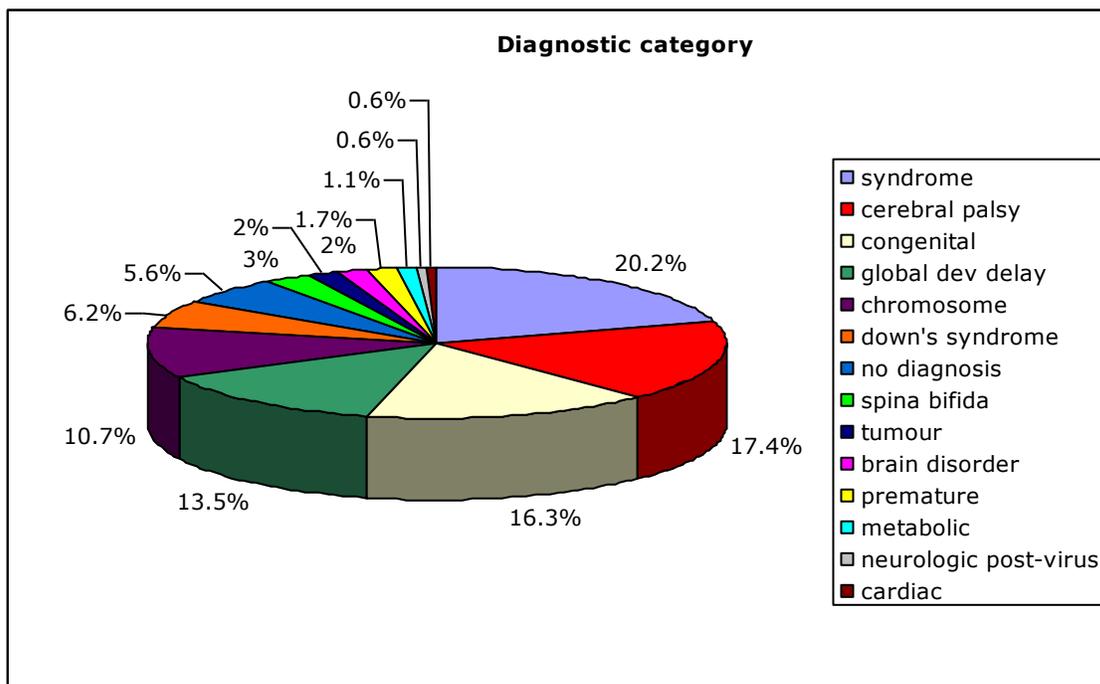
3. 4 Equipment Used

This section identified equipment used to assist children and their families in six identified activities of living. Information on additional equipment [including medication administration] and equipment used in physiotherapy and occupational therapy was also included.

3.4.1 Activities of Living Equipment

Of all identified equipment used in the six activities of living, mobilisation equipment was the most commonly reported one thousand and forty-two (1042) pieces of equipment were identified. Eighty-six (86 %) of parents reported using a car seat for mobility. The total number of pieces of equipment identified in each of the six activities and those in additional equipment is presented in *Figure 3.3.*

Figure 3.3: Total number of equipment identified in each of the seven categories.

Total equipment use
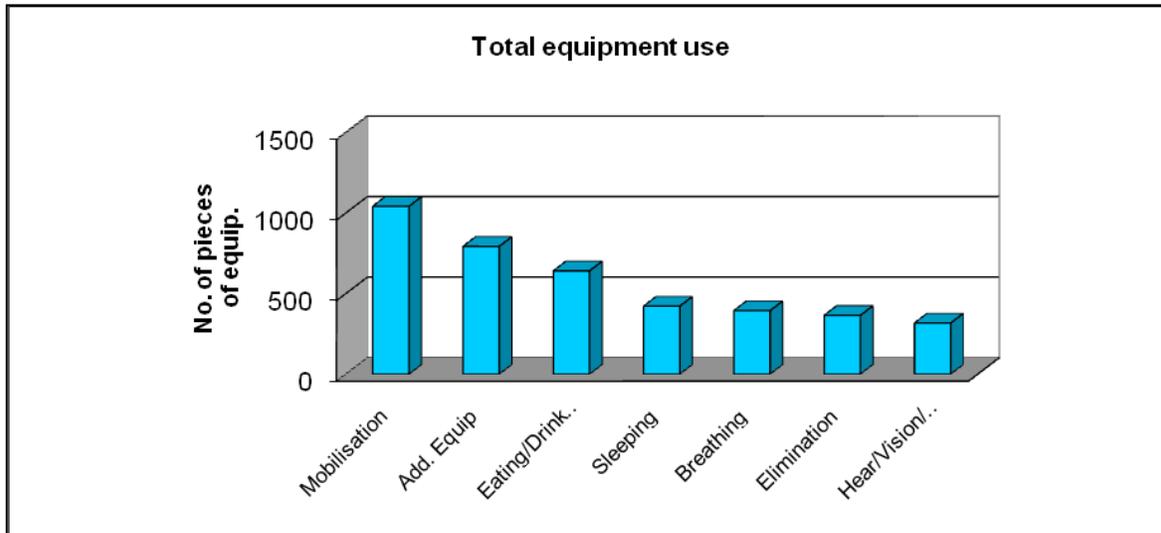
On average families identified twenty-two (22) pieces of equipment with the least number relating to equipment used in hearing/vision/communication. Elimination equipment including nappies/pads was used by (95%) of children. In addition (69%) of parents reported that medication equipment devices, such as syringes, tablet crusher and soother, were used.

The findings related to specific equipment use by parents are reported individually in each of the six categories and additional equipment *(Table 3.2).*

Table 3.2: Most commonly identified pieces of technology in each individual category

Category	Technology	(%)
Elimination	Nappies	95
Mobilising	Car seat	86
Additional equipment	Medication equipment devices	69
Eating/Drinking	Adapted seating/tables	66
Hearing/Vision/Communication	Special toys/multi-sensory equipment	60
Sleeping	Adapted cot/bed	56
Breathing	Nebulisers	38

The following provides an overview of the equipment identified in each of the six categories.

3.4.1.1 Sleeping Equipment

In the category sleeping equipment (56%) of children used some kind of adapted cot, bed or sleep system with mattress and side rails with a further (45%) using positioning devices or bumpers. Over half of the children (56%) used lighting at night time. Just over a fifth of children (21.5%) used some form of daytime sleeping equipment mainly in the form of sleep systems, mattresses or buggies. Forty-one percent (41%) of parents also reported using a baby monitor *(Table 3.3).*

Table 3.3: Use of Sleeping Equipment

Sleeping equipment use	n	(%)
Adapted cot/bed/sleep system/mattress/side rails	100	56
Nightlights/bedside lights	100	56
Positioning devices	80	45
Baby monitor	73	41
Daytime sleeping equipment	38	22
Seating devices for daytime sleeping	31	17

Additional pieces of equipment identified by parents to assist their child with sleeping included oxygen and its associated equipment such as BiPap systems and music including IPod and compact discs.

3.4.1.2 Communication Equipment

A significant proportion of children (60%) used multi-sensory equipment/special toys. Just over a third (35%) of parents reported using some form of alternative communication such as voice, eye or touch activated equipment. Thirteen percent (13%) of children used the Big Mac switch. Other communication devices identified included Picture exchange communication systems (PECS) and laptops. A quarter (25%) of parents used flash cards to communicate with their child. Twenty-nine percent of children wore glasses and fourteen percent (14%) of children used hearing aids. Six percent (6%) of parents reported their child had had a cochlear implant. For observational purposes fourteen percent (14%) of parents used video monitoring such as a Teddy Cam *(Table 3.4).* Forty-one percent (41%) of parents also reported using a baby monitor *(Table 3.3).*

Because of the numerous pieces of equipment used, almost a third of parents (32%) used additional batteries, extension cables and extra plugs.

Table 3.4: Use of Hearing / vision /communication equipment

Hearing / vision / communication use	n	(%)
Special toys/multi-sensory equipment	108	(60)
Alternative communication; voice/eye/touch activated	61	(35)
Glasses	52	(29)
Flash cards	44	(25)
Hearing aids	25	13
Cochlear implants	10	(6)
Eye patch	7	(4)
Low vision aids	6	(3)
Speaker valves	4	(2)

3.4.1.3 Mobilising Equipment

Of all equipment used, mobilising equipment use was the most frequently identified by all parents. This included both standard shop purchased and specialised equipment. Analysis of this finding indicates that a high proportion (73%) of children used buggies and (86%) used car seats. Of the (73%) of children using buggies, almost one-fifth (19%) of them were aged 5 years or more.

Play mats or gyms were used by (63%) of all children. Half of the children used a standing frame/bar with just over a fifth (23%) using a walker/rollator. Thirty percent (30%) of children used a wheelchair and thirty-six percent (36%) of those used positioning devices, the majority of which were posture supporting chairs such as Heathfield/Jenx/Leckey/Squiggles. Splints were used by (35%) of children and over half (53%) used some kind of shoe adaptations such as orthotics / boots including Pedro boots. Just over a fifth (21%) used a type of supportive brace or cast [hip/ spica /body brace].

Over half of the respondents (53%) had made bathing/shower adaptations in their homes. Fourteen percent (14%) had had a hoist fitted in their bathroom. One fifth (20%) had installed lift/ramps and a further (16%) hand installed ramps in their cars to cater for wheelchairs (*Table 3.5).*

Table 3.5: Use of mobilising equipment

Mobilising equipment.	n	(%)
Car seat	153	(86)
Buggy	129	(73)
Play mats/gym/floor mattress	112	(63)
Shoe adaptations – orthotics/boots	95	(53)
Bathing shower adaptations	95	(53)
Standing frame/bars	88	(50)
Positioning devices	64	(36)
Splints	63	(35)
Wheelchair	54	(30)
Walker/Rollator	40	(23)
Hip brace/spica/casts/body brace/second skin	38	(21)
Lift/ramps	37	(21)
Car ramps	29	(16)
Hoist	25	(14)
Adapted bicycle	19	(11)
Crutches	1	(1)

3.4.1.4 Elimination Technology

Nappies and pads were used by a substantial proportion (95%) of children. This percentage is particularly significant considering (33%) of children were aged (5) years or over. Forty-two percent (42%) of children required the need of equipment used in bowel medications including enemas and suppositories. Just

over a third (34%) of children use waterproof bedding and (19%) of parents had toilets adapted (potty, seating, risers) for their children's use *(Table 3.6).*

Table 3.6: Elimination technology

Elimination technology	n	(%)
Nappies/pads	169	(95)
Bowel medications	75	(42)
Waterproof bedding	60	(34)
Adapted toilets; potty/seating/risers/handrails	34	(19)
Temperature control mattress	8	(5)
Urine testing equipment	5	(3)
Intermittent catheterisation equipment	4	(2)
Bowel washout equipment/ACE management	3	(2)
Colostomy/stoma	2	(1)
Urinary catheter & equipment	4	(2)
Renal dialysis equipment	1	(1)
Rectal dilations equipment	0	0
Urostomy equipment	0	0

3.4.1.5 Eating and Drinking Equipment

Sixty-six percent (66%) of parents have adapted seating or tables for their children use. Thirty-one percent (31%) of children used adapted cups/bottles/feeders, (23%) used adapted cutlery/plates/non-slip mats and (44 %) used some type of protective clothing at mealtimes.

Thirty-seven per cent (37%) of children used percutaneous endoscopic gastrostomy (PEG) feeding equipment. Forty percent (40%) of parents used a feeding pump, (32%) and liquidisers and (14%) of children required suctioning at

meal times. Almost half of the children (47%) consumed thickened feeds/special diet such as Nutrini. No child received total parenteral nutrition *(Table 3.7).*

Table 3.7: Use of Eating and drinking equipment

Eating & drinking equipment use	n	(%)
Adapted seating/tables	117	(66)
Thickened feeds/special diets	83	(47)
Protective clothing	79	(44)
Feeding pump	70	(40)
PEG feeding equipment	65	(37)
Liquidiser	56	(32)
Adapted cups/bottles/feeders	55	(31)
Adapted cutlery/plates/non-slip mats	41	(23)
Sterilising equipment	32	(18)
Suction at feeding time	25	(14)
Nasogastric/ nasojejeunal feeding equipment	12	(7)
Weighing scales for food	6	(3)
Total parenteral nutrition equipment	0	0

3.4.1.6 Breathing Equipment

Oxygen (O2) cylinders and associated equipment (O2 masks/ nasal prongs/ artificial airways/tubing) were used by a fifth of all the children; seven children (n=7) had had a tracheostomy. Eight percent (8%) of children used multiple cylinders that is they were using at least 2 or more cylinders. Fourteen percent (14%) of parents used an O2 saturation monitor, (11%) used an apnoea monitor and over a quarter (26%) used suction machines and related equipment. A substantial proportion of children used equipment related to the administration of respiratory medications including nebulisers (38%) and (26%) using inhaler

devices for administering Salbutamol (Ventolin) or Beclomethasone (Becotide) *(Table 3.8).*

Table 3.8: Use of breathing equipment

Breathing equipment use	n	(%)
Nebuliser and equipment	68	(38)
Batteries/extension cables/extra plugs	56	(32)
Inhaler devices	46	(26)
Suction machine/catheters/tubing	46	(26)
O_2 cylinders/valves	37	(21)
O_2 mask/prongs/airway/tubing	35	(20)
Video monitor	25	(14)
O_2 saturation monitor	24	(14)
Apnoea monitor	19	(11)
Humidifier and equipment	12	(7)
Emergency resuscitation equipment	10	(6)
Ventilation support equipment/overnight ventilation.	9	(5)
Tracheostomy and related equipment	7	(4)

3.5 Additional Equipment

In addition to the equipment used in the six activities of living, the use of additional equipment was also reported. Sixty-seven percent (67%) of parents used additional equipment to maintain their child's safety such as harnesses or straps for a buggy, wheelchair or car strapping and (24%) reported having installed specific safety devices around the home including stair gates, locks for cupboards, windows and fireguards *(Table 3.9).*

A high proportion of parents (69%) used medication equipment devices such as syringes and tablet crushers; (67%) had a medication box or storage cupboard and thirteen percent (13%) had a sharps box for the disposal of sharps and needles. Thirty-two percent (32%) regularly used gloves, dressings, tapes or bandages. *(Table 3.9).*

Table 3.9 Additional equipment

Additional equipment use	n	(%)
Medication equipment devices (for example syringes)	123	(69)
Harness/straps for buggy/wheelchair/car	119	(67)
Medication box/cupboard(press)	120	(67)
Dressings/tapes/bandages/gloves	57	(32)
Specific safety devices	42	(24)
Sharps box	23	(13)
Fridge for storage of extra feeds/drugs	21	(12)
Injection equipment	14	(8)
Helmet	13	(7)
Restraints	8	(5)
Blood glucose monitor equipment	6	(3)
Syringe driver and equipment	5	(3)
Central line/Portacath equipment	2	(1)
Intravenous equipment	1	(1)

3.6 Physiotherapy and Occupational Therapy Equipment

Parents also reported on equipment used in physiotherapy and occupational therapy by their child. Over half of all children (53%) used both physiotherapy and occupational therapy equipment. Three quarters (75%) of parents reported having

physiotherapy equipment and (60%) having occupational therapy equipment *(Figure 3.4).*

Figure 3.4. Physiotherapy and Occupational therapy equipment

Physiotherapy   Occupational therapy
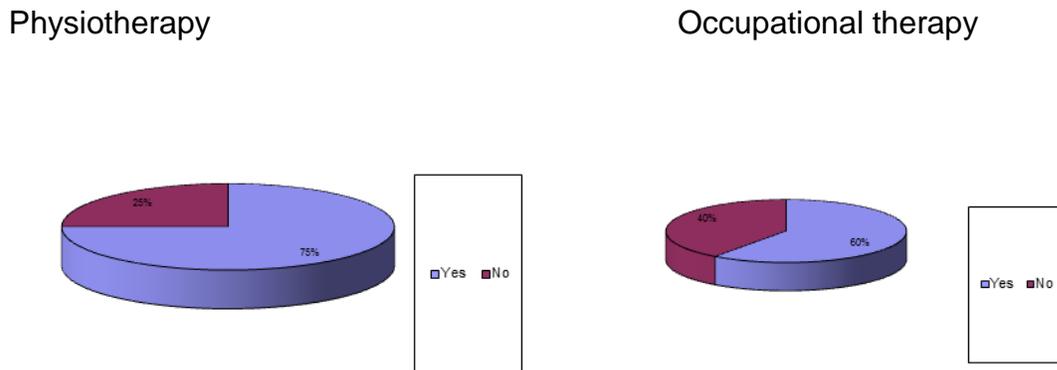
3. 7 Medication

Medication emerged as significant when in discussion parents spoke about the medication their children were receiving for the treatment and management of their illnesses or conditions and the equipment/technology used in its administration. Data collected on this theme provides an additional insight into the complexity of the children's needs and their care. Findings indicate (30%) of children were taking (1) to (2) daily medication, (18%) were taking (3) to (4) daily medications and (6%) were taking (11) or more daily medications while three (3) children were taking up to (19) medications per day however one fifth (20%) of all children were not taking any medication. The number of daily medications taken is illustrated in *Figure 3.5.*

Figure 3.5 Number of medications taken by children daily
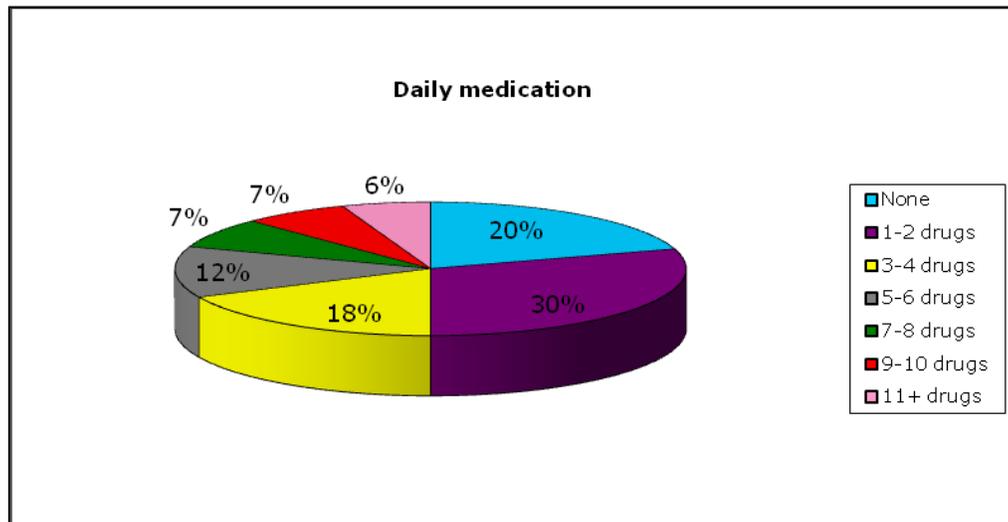
3.7.1 Categories of Medications

Medications identified were for the management of epilepsy, (23%) of children were taking anti-epileptic medication. Respiratory disorders and respiratory medication accounted for (12%) of all daily medications, (18%) accounted for gastro oesophageal reflux and gastro-reflux medication. In relation to bowel management (21%) of children were taking laxatives as illustrated in *Figure 3.6.* Other medications included analgesics, extended release pain medications 'Oromorph' and medication to promote sleep as well as antibiotics and nutritional supplements.

Findings indicate there exists, considerable overlap between all categories of medication with many children taking a range of medication. The most common occurring overlap found, was between anti-epileptic medication and laxatives.

Figure 3.6 Breakdown of daily medication by category
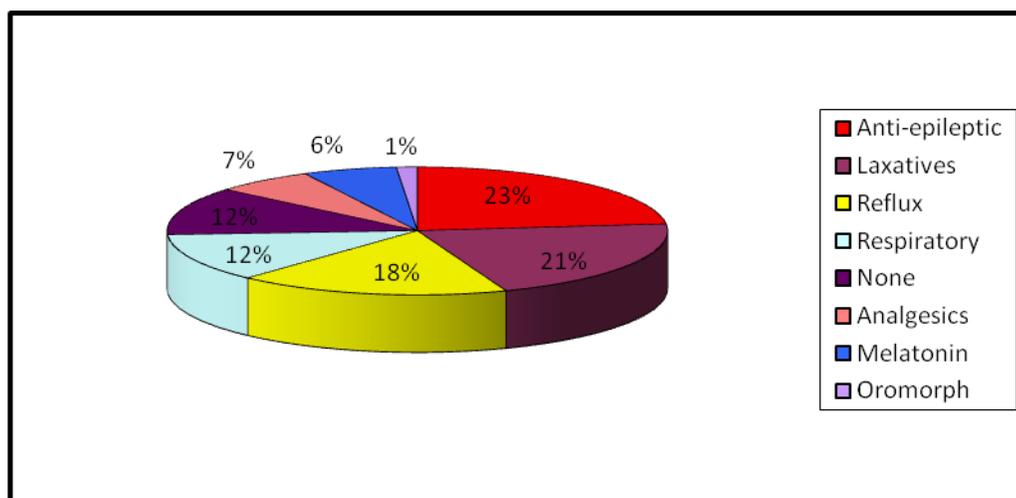
3.8 Qualitative Findings

The questionnaire allowed parents to express their views. The data gathered was analysed using simple thematic analysis. Three key themes were identified.

3.8.1 Key Themes

The significant issues reported by parents were related to difficulties in accessing and procuring of equipment for their child which included concerns in relation to the assessment, sanctioning, funding and delivery processes and also about managing equipment and its impact on the family home.

3.8.1.1 The Procurement Process

Parents reported difficulties obtaining equipment, in particular, on the length of time involved in acquiring devices. One parent described the procurement process as a 'constant battle'. Parents emphasised the long waiting times between ordering and delivery of equipment with some waiting up to one (1) year for equipment to arrive and in one instance the child had outgrown the device. Another parent reported waiting three (3) years for a sleep system, while another reported a delay while waiting for the company representative to

set up the equipment. Although most parents relied on health care professionals to procure equipment, some parents dealt directly with suppliers this proved to be inconvenient and time-consuming. For many having to ensure adequate stock supplies at all times caused undue stress and worry.

The acquisition of equipment was reported by many parents as a lengthy process, compounded by lack of funding and delivery delays. They reported on how the current adverse economic climate is impacting, most notably for physiotherapy and occupational therapy equipment.

3.8.1.2 Managing Equipment

For parents the second issue of concern was the management of equipment and the increasing number of complex tasks they have taken on. They expressed worries regarding the correct use of equipment and the constant need to adjust it to ensure both comfort and safety for their child. Many devices required resizing in accordance with the developmental stage of the child and some needed two people to manage the equipment and the child.

Difficulties were further encountered regarding the operability of some devices, for example suction machines, hoists, feeding tubes and specialised buggies were frequently mentioned as difficult to manage. Servicing of equipment was also a concern for many as well as the need for back up devices. These concerns were further exacerbated by the lack of appropriate instructions, training and support. One parent commented that equipment was delivered by courier and she was left to set-up and operate the device on her own. Another parent spoke of difficulties in managing a nasogastric tube and intravenous catheter despite being a trained nurse. Importantly, parents believed too much responsibility was being placed on them to manage the equipment effectively.

3.8.1.3 Impact on the Home

For parents the physical impact of equipment in the home environment was of great concern. They reported that equipment and supplies needed to be stored as unobtrusively as possible so that the home environment did not resemble a hospital setting. As a result with inadequate storage space and the intrusion of medical devices, some parents had renovated or extended their homes, or were planning to do so. The noise made by equipment was also problematic as was the lack of portability and mobility of larger devices.

Transportation of equipment such as respiratory devices or special buggies was particularly challenging due to their bulky or cumbersome nature. Some reported having upgraded to a larger car in order to transport bulky equipment and supplies. Furthermore, parents also admitted to limiting unnecessary travelling/journeys and family activities on account of the equipment. Another parent restricted visiting children playing in the home on account of the safety risks posed by certain devices.

3. 9 Data Collectors

In addition to information gathered from parents. The data collectors were also invited to give their views on the levels of support each family required in the home. These views were gathered using three indicators. These indicators were:
- The child's needs are:
    - Complex requiring moderate level of support. Managed by mother.
    - Complex requiring moderate levels of support.
    - Highly complex requiring high levels of support.

Results from their subjective assessments during data collection indicated that forty percent (40%) of children required moderate levels of support, (36%) of the children's needs were complex needing moderate levels of support and twenty four

percent (24%) were considered highly complex requiring high levels of support (*Table 3.10*).

Table 3.10: Child's needs according to levels of support

Support levels	n	(%)
Complex requiring moderate levels of support. Managed by mother	71	(40)
Complex requiring moderate levels of support	65	(36)
Highly complex requiring high levels of support	42	(24)

While the majority of care identified in the study and supported by Liben Papadatou and Wolfe (2008) was to improve the quality of life of children with complex needs or life threatening illnesses however data collectors also viewed that approximately (10%) of children required end stage palliative care.

Figure 3.7 Level and type of care required
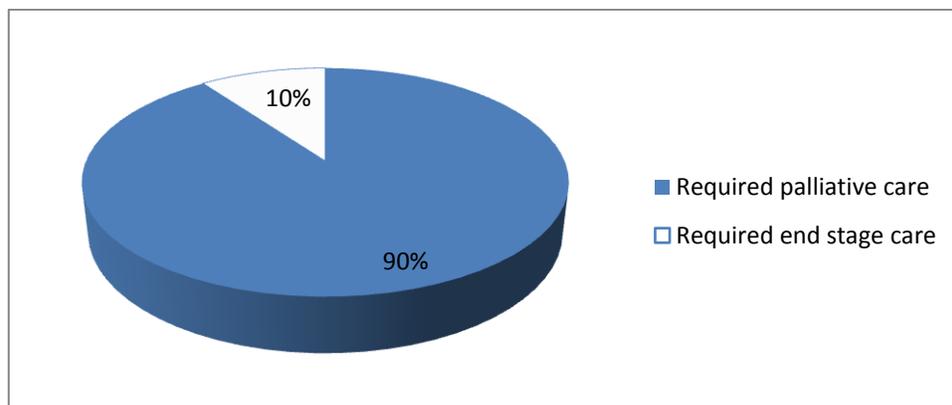
While the information gathered in this section reflects the views of the data collectors only it is considered valuable as it provides additional insights into the level and type of care children required.

Chapter Four: Discussion, Conclusion and Recommendations

4.1 Introduction

The aim of this study was to identify the types of technology used by young children with complex needs receiving care at home. The study's objectives were to identify the range of technology used and parents' views in relation to using these technologies. Data for the study was collected in two phases. Phase (1) involved a focus group interview with nine expert RCNs the purpose of which was to gather data towards the development of the study's questionnaire. Phase (2) involved the development and the administration of the questionnaire.

4.2 Discussion

This discussion focuses on the Phase (2) of the study's findings because of Phase (1) purpose was gather data from the focus group interview to assist in the construction of Phase (2) questionnaire.

4.2.1 Phase 2

Phase (2) provided for parents' identification of the types and range of equipment they use and manage for their children at home. Technology required for the identified six activities of living was itemised. These activities relate to sleeping, hearing/vision and communication, mobilising, elimination, eating and drinking and breathing and additional equipment including equipment to manage medication administration and that required for physiotherapy and occupational therapy. Key issues in relation to technology used and its impact on the family also featured.

4.2.1.1 Parental Findings

Findings indicate that technology plays a significant role for parents in caring for their children at home. As does the reliance on a large range and number of technology used in relation to their children's activities of living needs and other needs. The technology identified includes both low and high-tech equipment. This reliance is supported by Lowson et al (2007).

The technology identified to assist children with their activities of living included technology to assist with sleeping, mobilising, elimination, eating and drinking and breathing. The findings are in accordance with the expected needs, and complex and degenerative nature of some of the children's illnesses, reported by Nicholl (2008) and others.

The use of mobilisation equipment was identified as the highest level use of all equipment and included the use of orthotics, splints and mobilising aids. Technology required for feeding was also identified as high level use. This included feeding pumps and nutritional supplements with (37%) of equipment required for PEG feeding reflecting the complexity of the children's conditions and the care-giving required. In relation to technology used to assist with communication (29%) of children wore glasses and (6%) had had cochlear implants.

While the study set out to identify the type and range of technology used another interesting finding emerged. This finding relates to the number and types of medications administered to the children as was also found by Rehm and Bradley (2005). Forty-two (42%) of children were identified as taking bowel medication, this included medication such as enemas and suppositories. Forty-seven percent (47%) of children were receiving nutritional supplements. The study also identified that parents are assuming an increasing level of responsibility for medication management and for the equipment used its

administration. These findings provide further data on the complexity of equipment and care management required in the home and adds to Nicholl (2008) findings on the need for parents to deliver technical care-giving including medication management in the home and are further supported by those of Kirk and Glendinning (1999) who identified that highly technical procedures are performed by parents at home and Kirk and Glendinning (2004) indicated that parents assumed responsibility which would previously only have been undertaken by professionals.

Thematic analysis identified parental concerns on issues related to sourcing and managing equipment within the home. Three (3) key issues emerged, these were the management of equipment; the impact of the equipment on the family home and the accessing and procuring of the equipment.

The study's findings provide evidence of the abundance of equipment and supplies which need to be accommodated. The practical, physical and financial concerns involved as reported in this study are potentially considerable for many families with some having to modify rooms or extend the home. In addition parents have to manage specialist occupational and physiotherapy equipment. Literature and international studies have highlighted the impact of equipment use on the carer, family and the family home and show that families experience considerable stress whilst caring for technology-dependent children. While some literature indicates that home care can provide families with a sense of security, privacy and control (Hynson *et al*, 2003) the subsequent medicalisation of the home environment alters the family structure and is likely to have negative effects on the emotional well-being of the caregivers (Moore *et al*, 2010). Similar findings on the social and emotional impact of care-giving within the home environment are also reported by (Plauche Johnson *et al*, 2005).

Kirk and Glendinning (1999) suggest that the impact on carers should not be underestimated particularly given the technological advances which are allowing children a greater life-span. Himelstein *et al* (2004) also report on the complex medical tasks and round the clock caring that parents are involved in when providing palliative care for their children and from which they have little relief. The potential long-term consequences of caring for a child with complex needs at home identified in the literature includes psychological and emotional stress, social isolation, curtailment of family activities and financial strain (Farasat & Hewitt-Taylor 2007). Redmond and Richardson (2003:206) support this but also indicate that mothers are required to take on a "quasi nursing" role to meet their child's specific medical needs at home. The volume of equipment identified in this study adds to the understanding of the impact of care giving on the carer and family home.

Parents additionally raised their concerns about their roles and responsibilities in procurement, use and maintenance of equipment and also identified sourcing as part of their role. Nicholl (2008) reported that paperwork and administration related to equipment were key aspects in this phenomenon. Concerns related to the accessibility and management of equipment for parents concurs with similar research by Kirk and Glendinning (1999) who indicated that procurement difficulties are problematic for parents. This study's findings concur as parents reported responsibility for accessing, procuring and managing equipment and this responsibility for some also serves to cause them unease and anxiety.

Parents also reported on insufficient funding and additional costs associated with resourcing and using the devices. Mitchell and Sloper (2001) and the Audit Commission in the United Kingdom (2003) have reported similar concerns in parents about accessibility to equipment and services. Additional expenditure on equipment was reported and included maintenance and repair costs, purchasing assistive learning devices, special clothing and supplies for incontinence as well

as increased transportation, fuel and electricity costs. In addition parents reported the need to undertake home renovations including adaptations for bathrooms and storage facilities. Over the course of their child's lifetime, such costs may represent a considerable financial burden for families which warrants further economic investigation. Financial issues are recognised as stressors for parents caring for sick children in the home and the added costs for families are numerous.

4.2.1.2 Data Collectors

In addition to data gathered from parents, data collectors were also asked using three indicators to provide their views on the levels of support each child required in the home. Results show that forty percent (40%) of children's care was complex but managed by the mother, (36%) of the children's needs were complex needing moderate levels of support and (24%) were considered as highly complex requiring high levels of support. Further results indicate that data collectors viewed that approximately (10%) of children required end stage palliative care at the time of data collection indicating the complexity of the children's illness trajectories that may be interspersed with periods of wellness. In addition the study also identifies the reported diagnoses of (178) children in Ireland who are, or who have, received care from the Jack and Jill Children's Foundation. In the absence of a data base for children with rare disorders this in itself is an important finding.

4.3 Conclusion

The study serves for the first time in Ireland to identify the range and nature of equipment used, managed and stored by parents when caring for their children with complex needs at home.

The study also serves to identify the type of care activities parents undertake and the responsibility they assume when care-giving for their children at home. It further identifies the practical impact on parents on the use and management of sophisticated equipment for which many reported feeling ill-equipped to handle. In addition the study provides evidence on the financial implications and the delays experienced in the acquisition of required equipment. It also provides insight into the types of medication children are taking and the resultant increasing number of complex tasks required in the administration of these medications.

In addition the subjective assessment data included also suggested that (40%) of the children had care that was complex but managed by mothers alone. Twenty four (24%) however, were viewed as needing highly complex care requiring high levels of support which suggests the complexity of the children's needs at the time of the study.

This study also identifies the need to develop appropriate supporting mechanisms to effectively meet the needs of parents and children with complex needs in their home. It is significant in identifying equipment currently in use in the home and highlights associated issues concerning the use and management of this equipment for families. It provides a baseline for future research and the urgent need to address the gaps in funding for equipment in the home.

4.4 Limitations

4.4.1 The Sample

Phase (2) sample comprised of parents of children on J&JCF family data bases aged four (4) months to ten (10) years of age only.

4.4.2 Survey Method

Questionnaire data collection was by parents' self report. This carries with it the risk that the respondent may respond in a socially desirable manner or may not include certain information.

Data collectors, other than the one research assistant, were RCNs known to the parents which could influence responses.

4.4.3 The Questionnaire

The questionnaire designed specifically for this study needs to be tested in other populations. While it was reviewed for content and face validity its reliability and validity warrant further testing.

4.4.4 The Findings

No account was made for additional equipment used outside the home. Some parents, for example, had duplicate sets of equipment for home and school and therefore the number of devices used could be potentially greater than was reported.

The study's findings are a record of identified technology but may not reflect the level of care involved, or the frequency, currency and appropriateness of the technology is used.

4. 5 Recommendations

The study's recommendations are directed to:

4.5.1 Strategic planners

- Review of the needs of children with complex needs cared for at home.
- Review of the needs of children with complex needs and their technology support at home.

- Review the personal, financial and practical implications on the high levels of equipment used, on parents and the family.

4.5.2 Service Providers

- Provide a collaborative approach in discharge planning between hospital and community services to ensure that equipment required at home is resourced, restocked, resupplied and replaced on a planned needs basis.
- Provide parental training programmes implementing a flexible, responsive and needs focused programmes.

4.5.3 Practitioners

- Ensure specific and focused discharge planning occurs to ensure that, adequate resources are in place at home before the child is discharged.
- Participate as required in the parental needs focused training programmes.

4.5.4 Research

- Confirm and extend findings to other groups of children with complex needs.

- Explore patterns of long-term technology use and the emotional and psychological impact on families in technological care-giving at home.

- Measure the financial costs of equipment use to families.

4.5.5 Education Providers

- Improve professionals understanding of the implications of providing care for children with complex needs at home by developing appropriate curriculum content.
- Develop community care programmes for nurses and other health professionals.

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Appendix 1 The Study's Reported Diagnoses

Syndromes

Allan Herndon Dudley Syndrome

Angelmann Syndrome (3 children)

Bardet-Biedel Syndrome

Charge Syndrome (2 children)

Di George Syndrome

Down's Syndrome (2children)

[Acute Lymph Leukemia &] Down's Syndrome

Down's Syndrome with cardiac problems

Down's Syndrome, Congenital Heart Defect, Imperforate anus

Down's Syndrome, Laryngomalacia, Interventricularhaemorrhage, epilepsy

Down's Syndrome, Epilepsy, Severe Developmental Delay, cardiac complications,
bowel surgery x 2

Down's syndrome (with metabolic problems, GI problems, PEG tube in-situ)

Down's Syndrome, complex cardiac condition, moderate/severe developmental
delay

Down's Syndrome with complex cardiac condition

[Brochiolitis Obliterans&] Down's Syndrome

Hypomyelination Syndrome

Masa Syndrome & Hydrocephalus

Microdeletion of 12P Chromosome Syndrome

Miller-Dieker Syndrome (2 children)

Moyamoya Disease

Mowat Wilson Syndrome

9P Minus Syndrome

Noonan Syndrome

Ohdo Syndrome [2]

Pallister Killian Syndrome [2]

Patau Syndrome

Prader Willi Syndrome [2]

Retts Syndrome

Rubenstein Taybi Syndrome

Short Bowel Syndrome

22q11 Deletion Syndrome with cortical dysplasia

Treacher Collins Syndrome; Grade 2 brain haemorrhage

Velo-Cardio-Facial Syndrome (VCFS)

West Syndrome with Developmental Delay

Wolf-Hirschhorn Syndrome

Cerebral Palsy

Cerebral Palsy [14]

Cerebral Palsy & Deaf

Cerebral Palsy Quadriplegic

Cerebral Palsy Spastic Quadriplegic & Hydrocephalus

Quadriplegic Cerebral Palsy

Severe to profound Cerebral Palsy

Cerebral Palsy, Epilepsy & Severe Developmental Delay

Cerebral Palsy, Visual Impairment, Epilepsy

Cerebral Palsy, Microcephaly & Epilepsy

Cerebral Palsy Quadriplegic

[Acquired Brain Injury &] Cerebral Palsy

Disconnect Cerebral Palsy

Mild Cerebral Palsy, autistic with moderate intellectual disability

[Microcephaly &] Cerebral Palsy

Quadriplegic Cerebral Palsy

Quadriplegic Cerebral Palsy & Epilepsy

Cerebral Palsy Spastic Quadriplegic

[Microcephaly &] Cerebral Palsy [Quadriplegic]

[Microcephaly &] Cerebral Palsy [& Epilepsy]

Chromososomal Abnormalities

Chromosome Ring 18

Chromosome 10

Depletion of Short Arm of Chromosome 17 & Developmental Delay

3 way chromosome disorder

Inverted Duplication of Chromosome 15

Chromosome 7p deletion

Chromosome Mosaic Partial Trisomy 8

Unbalanced Translocation of Chromosome 14 & 21 [T1421]

Unbalanced translocation - genetic

Trisomy 9

Tetrasomy 18p

Trisomy 17p

Trisomy 21, Cho-anal Atresia

Trisomy 21 & Complex Cardiac Disorder

Trisomy 22

Chromosomal Abnormality, Trisomy 9 & Monosomy 10q

Chromosome Ring 18

Undiagnosed

Chromosome 2 possibly but not confirmed

Undiagnosed [2]

Undiagnosed Spinal Muscular Atrophy [SMA Type II]

Ventilation - no diagnosis

Undiagnosed Severe Developmental Delay with Epilepsy

Undiagnosed Global Developmental Delay

Undiagnosed - Global Developmental Delay

Suspected mitochondrial defect but not confirmed [2]

Undiagnosed Severe Developmental Delay with Epilepsy

Undiagnosed but mental and visual disorders

Developmental Delay

Developmental Delay

Global Developmental Delay associated with hypotonia and bulbar palsy

Developmental Delay, airway obstruction leading to Tracheostomy and 24 Nippy

Global Developmental Delay [5]

Severe Developmental Delay plus hypotonia& epilepsy

Global Developmental Delay & Seizures

Severe Global Developmental Delay with Epilepsy

Global Developmental Delay, Ataxia & Arachnoid Cyst in the Internal Fossa

Global Developmental Delay & Cerebral Palsy & Epilepsy

Global Developmental Delay & Epilepsy[2]

Global Developmental Delay with seizures

Severe to Profound Developmental Delay plus Migrating Epileptic Seizures

Globally medically developmentally delayed

Laryngomalacia, Global Developmental Delay &Stiklo Type Collagen Disorder

Severe Global Developmental Delay

Severe Developmental Delay, Mitochondrial Disorder, Visual Impairment &
Epilepsy

Global Developmental Delay assoc. with Epilepsy, Autism,

Control Seizure Disorder with Global Developmental Delay

Congenital Disorders

Congenital Hydrocephalus

CongenitalHypotonia

Congenital Cytomegalovirus [4]

Congenital heart disease & Interrupted aortic Type B

Tumours

Brain & Spine tumour - unusual neurological tumour

Brain tumour

Chorid Plexus tumour on third ventricle

Others

Achondroplasia, chronic obstructive sleep apnoea

AdenylosuccinateLyase Deficiency ASDL

Agensis of the Corpus Collosum

Arthrogryposis with Severe Developmental Delay

Bilateral Schizencephaly, severe developmental delay, epilepsy, visual impairment

Cardiomyopathy plus feeding difficulties, Erbs palsy and stunted brain development

Chronic lung disease plus heart condition

Chronic Lung Disease, Congenital Heart, Pulmonary Hypertension, Tracheostomy

Congenital Heart Defect, severe intracerebral damage, secondary to cardiac surgery, Severe Developmental Delay, Epilepsy

Dystonic Quadriplegic

Epilepsy & general delay

Hypoxic Ischemic Encephalopathy

Hydrocephalus & Stroke

Idopathic Pulmonary Arterial Hypertension

Intractable Epilepsy

Lissencephaly [2]

Lissencephaly, Severe Developmental Delay & Epilepsy

Microcephaly

Microcephaly &Spina Bifida

Mitochondrial Disorder 3 & 4

Macrothrombocytopenia, Mitochondrion

Mitochondrial Disorder (HOCM)

Neuronal Migration Disorder

Osteogenesis Imperfecta Type 3

Polymicrogyria Arthrogryposis

Polystic kidneys & learning difficulties

Premature [2]

Premature Post-viral encephalitis

Rudimentary RH & AFC in left ventricle

Septo-optic Dysplasia, Diabetes Insipidus & Epilepsy

Severe Intellectual Disability

Spastic Quadriplegic & visually impaired & PEG tube

Spina Bifida

Spina Bifida & Hydrocephalus [4]

Spinal Muscular Atrophy Type 2

SSADH (succinic semialdehyde dehydrogenase deficiency)

Tracheo Oesophageal Fistula Atresia