Paediatric Palliative Care - describing patient needs and the experiences of caregivers and health care workers in a Cape Town Paediatric Intermediate Care Facility.

DISSERTATION IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE

MPHIL IN PALLIATIVE MEDICINE

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DECLARATION

I, Alexandra Jacqueline Daniels, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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LIST OF ABBREVIATIONS AND ACRONYMS

ACT	Association for Children's Palliative Care
ALOS	Average length of stay
CHT	Children's Hospital Trust
CPC	Children's Palliative Care
DOH	Department of Health
FGD	Focus group discussion
HAART	Highly Active Antiretroviral Therapy
HPCA	Hospice Palliative Care Association
ICF	Intermediate care facility
ICPCN	International Children's Palliative Care Network
ICPF	Intermediate Care Policy Framework
IPPCU	In patient palliative care unit
LL	Life-limiting
LLC	Life-limiting condition
LTC	Life-threatening condition
LMIC's	Low- and middle-income countries
NPO	Non-profit organisation
PPC	Paediatric palliative care
PPM	Paediatric palliative medicine
PC	Palliative care
RCPCH	Royal College of Paediatrics and Child Health
RCWMCH	Red Cross War Memorial Children's Hospital
RVD	Retroviral Disease
SA	South Africa
SFCCH	Sarah Fox Convalescent Children's Hospital
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organisation
WHA	World Health Assembly

Abstract: Paediatric Palliative Care - describing patient needs and the experiences of caregivers and health care workers in a Cape Town Paediatric Intermediate Care Facility.

Introduction:

Palliative care has the potential to improve the quality of life for children living with LL or LTC's and their families. However, in the South African context, little is known about the specific care needs of these children and the experiences of caregivers and health care workers during the child's stay at an intermediate / step down facility.

Aim:

The study describes the population (and care needs) of children admitted to the facility, the experiences of their primary caregivers and the health care workers caring for them.

Methodology:

This was a descriptive study that utilised elements of both prospective and cross-sectional design. The health records of 25 patients were reviewed and matched caregivers partook in a three-part questionnaire. Focus group discussions were conducted with 15 health care workers at a single point during the study.

Results:

The majority (48%) of patients were referred to the facility for transitional care, the average length of stay was calculated at 97 days and pain was identified as the most prevalent symptom. Despite significant degrees of worry, most primary caregivers derived emotional strength and spiritual meaning from the experience of caring for their child. Health care workers valued access to training, appropriate resources and support to meet the challenge of caring for children and families with specific care needs.

Conclusion/Recommendations:

These results conclude that children living with LL or LTC's and their families have complex holistic care needs that require a comprehensive approach. In order to best meet these needs, at ICF level, health care workers need to be assured access to a range of skills, resources and support.

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Chapter One: Introduction and Literature review

Children living with life-limiting conditions (LLC's) and life-threatening conditions (LTC's) have specific needs and access to expert care and support can impact significantly on the quality of their lives (1).

Caregivers need to be adequately equipped and supported to navigate the often-unpredictable path along the child's disease trajectory. Increased care needs at the end-of-life place further demands on families and suboptimal management of terminal care may contribute to the risk of complicated grief for families. The strain of caring for a child with high care needs weighs heavily on family structures and families can benefit from accessing respite care (1, 2).

Health care professionals attending to this group of children and their families need to be skilled and proficient so as to respond appropriately to their unique requirements (3) .When the diagnosis of a child's LLC or LTC is made, often against the backdrop of economic, family, community and political challenges, this may cause a significant increase in stress levels and families. Families require culturally sensitive supportive care to manage this complex situation. Palliative care holds at its core the potential to improve the quality of life of beneficiaries and in the context of a child with a life-limiting (LL) or LTC, this is essential not only for the child, but also for their families (4, 5).

1.1 Definitions:

The WHO states that palliative care is an approach to care that focuses on prevention, early identification, and thorough assessment. Holistic care that incudes pain management and relief of other distressing symptoms improves the quality of life of people living with life-threatening illnesses. It acknowledges care for children as related to adult care with distinct differences.

WHO further states that palliative care for children should begin from the time of diagnosis, proceed alongside aggressive treatment e.g.: chemotherapy, continue throughout the disease trajectory till the end-of-life phase and extend to the bereavement period. Health care providers are required to evaluate and alleviate the holistic care needs of the child. WHO acknowledges the child’s family as an integral member of the broad multidisciplinary team, community resources are recognized assets and even when resources are limited, this approach to care may be practiced at all levels of health care service delivery including children’s homes (1). The Association of Children’s Palliative Care (ACT), (since renamed Together for Short Lives), adds to the WHO definition by focusing on the enhancement of quality of life for the child / young person and recognizing the need to support families with respite breaks (6).

Internationally, the Association for Children with Terminal conditions (ACT) Categorisation System is used to identify which life-threatening and life limiting conditions in childhood would require palliative care. These are:

- ACT class 1: Conditions for which curative treatment is appropriate but may fail: E.g.: acute lymphoblastic leukaemia.
- ACT class 2: Conditions where premature death is inevitable, but quality of life can be maintained with long-term treatment E.g.: HIV on HAART
- ACT class 3: Progressive conditions in which treatment is exclusively palliative after diagnosis E.g.: Progressive metabolic disorders
- ACT class 4: Conditions involving severe, non-progressive disability causing extreme vulnerability to health complications E.g.: Severe cerebral palsy (6).

1.2 Public health strategy:

In 1990, the WHO recommended a public health strategy to integrate palliative care into health care systems. The strategy outlines four essential elements to achieve palliative care for all: appropriate policies, adequate drug availability, and education of public and health workers, policy makers and implementation (7).

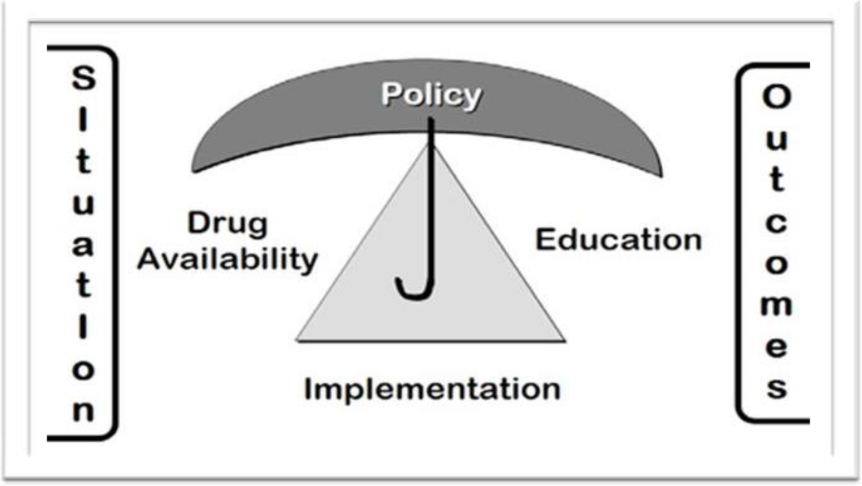


Figure 1: WHO Public Health model (7)

The public health strategy emphasises the value of community participation and ownership in the implementation of palliative care initiatives across settings.
This is a prerequisite to promoting pain relief and palliative care provision that impacts on the quality of life of members of society. It is ***as*** important to mobilise communities through education, training and advocacy as it is to lobby governments to establish policies and programmes that encourages the framework for a palliative care approach(7).

1.2.1 World Health Assembly (WHA) resolution WHA67.19

In 2014, the first ever global resolution on palliative care, World Health Assembly resolution WHA67.19(8) called upon WHO and Member States to improve access to palliative care as a core component of health systems, with an emphasis on primary health care and community/home-based care.

The WHO undertook to support member states to strengthen the integration of palliative care globally by:
- promoting increased access to palliative care,
- promoting adequate resources for programmes,
- developing models for care,
- supporting the development of palliative care guidelines and tools,

- supporting national processes around accessing palliative care medicines,
- monitoring and evaluating progress made in global palliative care programmes,
- encouraging research especially in low middle-income countries (LMIC's) (8).

1.3 Estimating the need for Palliative care for children

Evidence of an increase in Children's Palliative Care (CPC) related research (over the last decade) was demonstrated in a Delphi study (9) undertaken by the International Children's Palliative Care Network (ICPCN) in 2015. The study revealed that research is being done in developed countries and not in areas such as sub-Saharan Africa (SSA) where the burden of disease is higher. Notably though, the second highest group of respondents was from SSA and consensus was reached around 26 areas of research following two rounds of questionnaires conducted via the internet. Global research priorities identified by the study included the following topics: children's understanding of death and dying, managing pain in children when there is no morphine, funding, training, models of care for children's palliative care CPC and integration of CPC into core health curriculum(9).

In 2013, a joint three country study with United Nations International Children's Emergency Fund (UNICEF) and ICPCN (10) assessed the need for CPC and the country's ability to deliver a service in three sub-Saharan countries namely Zimbabwe, Kenya and South Africa (SA). The need to integrate paediatric palliative care (PPC) into the public health system emerged as essential. In addition, the need to develop policy as well as palliative care indicators within the current health care system was recognised. In a sub-report on the South African component of the study, Connor et al (11) identified the need for more research so as to provide insights as to which children would benefit from PPC, at which points of their disease trajectory as well as where they should receive this care. The need for gathering this data and bringing it to the attention of policy makers and others is by no means specific to SA but to all countries so that this largely unmet need may be addressed.

A representative sample of countries from all regions of the world and across all World Bank income groups were included in a 2017 study aimed at estimating the need for CPC globally (12). The study's findings reveal that more than 20 million children worldwide would benefit from a generalist palliative care approach and 8 million children required specialist palliative care. More research would be required to retrieve essential data about specific needs of the paediatric population and the capacity of countries to deliver a service in response to the need. The study recommended a move to integrate palliative care services into primary health care and paediatric sectors in an attempt to address this large unmet need (12).

Based on a 20% incidence of chronic illness in children in SA, the midyear (2011) census estimated that 398 562 children were living with a chronic illness in the Western Cape based on Robertson's review (13) and approximately 79 712 of these children (20%) could potentially benefit from a palliative care approach (13). Extrapolated to the Western Cape, (11.4% of the total population: Stats SA 2013) this translates to 91 332 children needing generalist care with 34 706 needing specialist care in the province. These figures draw attention to the significantly high number of children living with LL and LTC's in the country. In the paediatric population communicable, non-communicable, peri-natal, and maternal and injury- related disorders (14) collectively contribute to the spectrum of conditions that make up this group.

In the Western Cape, the diagnosis of children with LL and LTC's is usually confirmed by specialists at tertiary centres and families make several trips to these centres for treatment and to access chronic medication. In addition, these children are required to spend a disproportionate amount of time in hospital and this impacts on their ability to perform optimally academically as well as interact socially with their peers. The impact of hospitalization affects the family's ability to function with one parent often spending extended periods in hospital and not being accessible to the remaining spouse and other children.

For many children living with LL and LTC's, the tertiary hospital may also be the place where they experience their end-of-life event. Tertiary care facilities operate primarily as acute care centres and as such are cure focused and thus not ideally positioned to manage terminal care. Caring for children with LL and LTC's especially but not exclusively at the end of their lives, requires a nurturing environment, resources, professional expertise, and time.

The motivation for this study arose from my experience as a community liaison nurse for a donor funded tertiary located PPC programme based at Red Cross War Memorial Children's Hospital (RCWMCH) in Cape Town. The hospital acted as a base for the palliative care service and later became the primary feeder for Sarah Fox Convalescent Children's Hospital (SFCCH). The PPC team worked alongside primary care teams and offered children and their families' in-hospital care and support. Access to a palliative care approach post discharge however was not assured thus causing a disruption to the continuum of care.

At the time, I was responsible for referring discharged patients to non-profit organisation (NPO) operated, Department of Health (DOH) supervised, home based care services across the Cape Metro. Challenges with this service included the lack of training and experience of care workers in managing complex holistic care needs of children and their families at home and in some instances institutional care was necessary. Adult hospice inpatient units were few and far between and regulated by restrictive policies and thus unable to admit children under the age of 12 years. In addition, the adult home-based care programmes were overextended and offered limited support to children and their families.

Caring for a child with a LL or LTC often impacts on how effectively family's function and affects the wellbeing of families. These families need care and support to get them through challenging times when the burden of care may increase e.g., managing distressing symptoms or during the terminal phase. Experienced adult palliative care colleagues acknowledge their difficulty in dealing with the emotional demands of caring for a child and their family. Many feel ill equipped both clinically and emotionally to take up the challenge of providing holistic care to children.

1.4 Opportunity for integration:

The Sarah Fox Convalescent Children's Hospital (SFCCH) is a provincially aided intermediate care facility (ICF) located in the Cape Metro. SFCCH was opened in 1965 with funding from a trust established to commemorate Sarah Hilda Fox, a young Irish woman who immigrated to South Africa in the 30's. Initially catering for children with gastroenteritis and malnutrition, the hospital expanded its scope to care for children with HIV, Foetal alcohol syndrome, Cerebral Palsy, burns and non-accidental injuries.

The Department of Health (DOH) in the Western Cape Government’s newly drafted Intermediate Care Policy Framework (ICPF) (15) aims to provide guidelines on the role of ICF’s in supporting patients including those with palliative care needs. ““The core goals of intermediate care are both to ensure a successful discharge of users into the home or other appropriate environment and to prevent the need for further hospitalization”” (15) Pg 4. Integral to care packages offered at SFCCH, as well as other ICF’s, is for the patient’s stay to contribute positively to the continuum of care, thereby improving the patient’s experience.

Admission to an ICF was based on functional need not diagnosis. Eligibility criteria include patients who had ‘“experienced a recent decline in functional status due to long term conditions, terminal illness or disability, requiring a short period of enhanced care”’ (15) Pg 9. Patients who were actively dying and patients with an expected average length of stay (ALOS) of more than 6 weeks were excluded from admission. Key outcomes in providing a package of care for patients requiring palliative /end of life care were ‘“adequate psychological and social support, patient and family prepared for death and dying and symptom control and treatment/prevention of avoidable problems”’ (15) Pg 10. A multi disciplinary team consisting mainly of ““nurses, rehabilitation, social and care workers that are competent were to provide care including “end of life care”” (15) Pg 11.

An opportunity arose at SFCCH for PPC to be integrated into the care packages of patients. Committed to the broader vision of integrating PPC at all levels of care, the Children’s Hospital Trust (CHT), the fund-raising wing of RCWMCH, agreed to support the establishment of a ten bedded inpatient paediatric palliative care unit (IPPPCU) at the SFCCH. The unit aimed to offer symptom management, respite and terminal care to children and their families. Children and their families would have the opportunity to access palliative care in a child /family friendly ‘home from home’ setting.

This study of a novel service aims to contribute towards a body of work focused on addressing the specific needs of children with LL and LTC’s and their families and more specifically how these often-complex care needs can be effectively delivered at intermediate care level within the public health care system in South Africa. The study further sets out to describe primary caregiver’s experiences of caring for their children as well as health care workers experiences of providing care.

1.5: Operational definitions:

Intermediate care, as defined by ICPF.

Inpatient transitional care, which facilitates optimal recovery from acute illness or complications of a long- term condition enabling patients to regain skills and abilities in daily living with the ultimate discharge destination being home or an alternate supported living environment. Intermediate care constitutes only one part of the patient’s overall care pathway (15).

Life-threatening condition

A life-threatening condition is a disease that is potentially fatal, likely to result in imminent death (16).

Life-limiting condition

A life limiting illness is an illness which may not be immediately life-threatening, but which imposes limits on a person’s quality and/or quantity of life (16).

Primary caregiver

A primary caregiver is a parent (or surrogate) who primarily takes care of the child (17).

Child

The South African Bill of Rights and the Children's Act define a 'child' as 'a person under the age of 18 years'. This means that all people under the age of 18 years are entitled to the protection guaranteed by section 28 of the Bill of Rights and the provisions of the Children's Act.

1.6: Literature review

A comprehensive search of literature was done using various databases including CINAHL, PUBMED, Africa - Wide information and Psych INFO, using the following key words: paediatric /children's palliative care, models, policies, services, children's hospice, and inpatient units.

1.6.1: Policies

Health policies relate to the process of reaching a specific health care goal whilst focused on a vision for the future and may include targets and points of reference, both short and medium term.(18) Health policies have the potential to build consensus amongst people as well as inform them.

Walt and Gilson (19) developed a policy analysis triangle as a means of assisting researchers to systematically analyse health related policies. The four elements examine the range of factors that affect policy making and refers to the relationship between these factors. The four core elements described are context, content, process and actors. Policy actors are those who are involved in the initiation, development, implementation and monitoring of policies.(19)

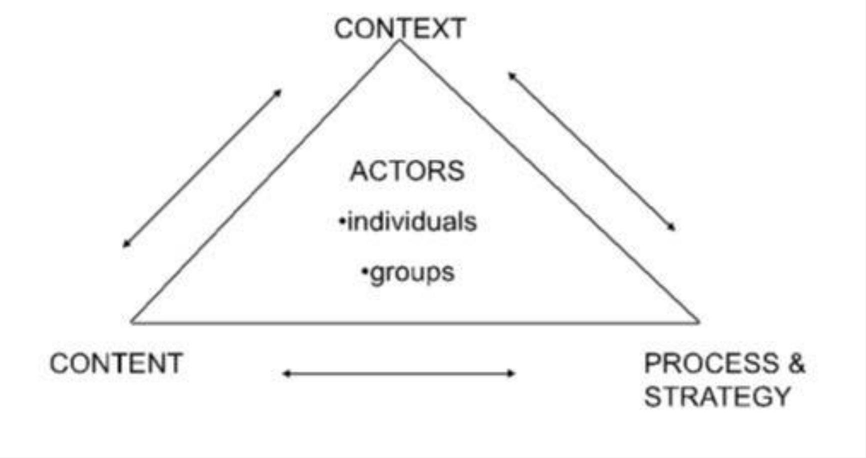


Figure 2: Policy triangle (13)

Policy content refers to what has been agreed to in the policy and is the essence of policy. The context refers to the backdrop against which policies occur e.g., global need for palliative care and the WHA resolution 67.19(8) pressuring member states to incorporate palliative care into public health systems. Policy processes take place over time and are ever changing.(19)

Within the context of the WHO public health model, Stjernsward et al(7) outlines policy as fundamental to the integration of palliative care into national health care plans. It is recommended that the process commences with the identification of national and regional policy makers and regulators in government. Policy and drug availability are prioritised above education and implementation in the process. Stjernsward et al suggests training without securing policy and drug availability will only act as a source of frustration for all (7).

One of the WHO's core responsibilities is to support and improve policy making and together with the Alliance for Health Policy and Systems Research (established 1999) a new programme focusing on LMIC's, to strengthen capacities for health policy analysis, was launched (20).

1.6.2: Specific needs in paediatric palliative care

Stevenson et al (21), in their meta-summary analysis, selected twenty-one qualitative and survey-based studies on the needs of children and families receiving palliative and end of life care in Canada and the United States. In all the studies the perspectives of patient's, parents, siblings, and heath care practitioners were considered. Findings were grouped into 10 thematic domains that relate to the needs of patient and families. These are interactions with staff, information needs, psychosocial needs, pain and symptom management, decision making, health care delivery and accessibility, bereavement needs, spiritual needs, cultural needs, and the needs of siblings (21) . These specific needs have been extensively described in table 1.

Thematic domains	**Needs**
Interactions with staff	Continual and ongoing relationships between staff and families in their care. Families need a familiar person to deliver difficult news with sensitivity and compassion. Parents need honest and straightforward communication.
Information needs	Parents need to be prepared for what to expect along the course of their child's disease trajectory. Parents felt information was withheld or presented in a contradictory or confusing manner especially to non - English first language speakers. Parents need to be updated regularly and be provided with clear information in a language they understood.
Psychosocial needs	Patients and families need emotional support. An important need for patients was to be treated with dignity and respect and to have access to information to inform their decision making. Patients need to connect with peers and engage in developmentally appropriate activities. Patients need access to peers who have had similar experiences.
Pain and symptom management	Pain and other symptoms to be assessed and managed with consistency and effectively. Discrepancy between parents and patients reporting high degrees of pain and HCP's perception of pain being well-managed. While parents wanted their children's pain to be well-managed, they needed to have their children awake enough to communicate with them.
Decision making	Patients and families need to be treated with respect and need to be included in decision making process.

Health care delivery and accessibility	Continuity, consistency, and coordination of care includes care outside of the hospital. Home visits were considered essential. The need for competent professionals trained in caring for paediatric patients was emphasised by parents and HCP's.
Bereavement needs	Support for parents from time of diagnosis through to bereavement period. Parents want mementos and staff to remain in contact after the child's death eg: attend memorial service, send cards etc Parents need help to prepare for their child's death. Families need access to flexible and consistent bereavement support from immediately after their child dies.
Spiritual needs	Parents want their child to be remembered after death. Parents strive for hope and maintaining hope while accepting the child's prognosis. Parents search for meaning from their child's death. Access to spiritual counsellors or clergy.
Cultural needs	Need for culturally sensitive information. Translators and interpreters need to be available.
Sibling needs	Care needs to be family orientated and include the patient's siblings. Parents need information on how to support the needs of siblings. Available services for siblings.

Table 1: Thematic domains and needs (21)

In 2001, Hain commenced a cross sectional study that aimed to establish the incidence and prevalence of children needing PC. This Welsh study was conducted over a period of two years and 226 children were identified through paediatricians, specialist paediatric palliative medicine referral and children's hospice services. The study foregrounded the holistic nature of care children living with LLC's required in terms of their medical and nonmedical care and highlighted a range of settings that included public health hospitals, hospices, schools, and children's own homes (22). Notably this study did not include children receiving PC at intermediate care facilities.

1.6.3: Models for palliative care

Cecily Saunders first began her work with terminally ill patients in the late 40's and trained as a nurse, social worker, and a doctor in London before opening St Christopher's Hospice in 1967(23). Dame Cecily Saunders is regarded as the founder and the inspiration of the modern adult palliative care movement. Palliative medicine first became recognised as a full medical speciality in the United Kingdom in 1989(24). However paediatric palliative medicine was only recognised as a subspecialty 20 years later in 2009(24).

Paediatricians recognised the need for PC in children in the 70's and Helen House, the world's first children's hospice was opened in Oxford in the UK in 1982(24). The function of charity funded children's hospices in the UK has primarily been to provide respite care and some terminal care. Although hospices have received some government support, their sustainability has been largely dependent on a donor pool that has been challenged by the current economic climate. A range of models of PPC service provision have developed in the UK over time, often driven by a group of highly motivated and enthusiastic individuals. More recently with increased collaboration and networking there has been a shift: the focus of care within PPC from end-of-life care alone to include support for children and families through life, death and into bereavement (24).

The Footprints model of paediatric palliative care was developed in the US out of the need to shift from the disease focused hospital-based model to hospital and community-based services in order to improve continuity in care (25). This best practice model focuses on education, research, and advocacy and makes provision for advance care planning; it promotes quality of life of the child and family and includes the health care professional's satisfaction with care.

Partners for Children (PFC) (26) is a Californian based three-year pilot programme that demonstrated participation in a community based palliative care programme, improved quality of life not only for the child but also their family. PFC makes use of hospice care to assist with coordinating palliative care for children. The average length of stay (ALOS) in hospital is reduced by 1/3 and the result is a substantial decrease of cost factors in hospital (26).

In Florida, Partners in Care, Together for Kids (27) model illustrates the effectiveness of collaboration with partners in improving quality and access to PPC. This programme developed a partnership between care coordinators employed by the state and staff at the local children's hospice.

In a review of PPC programs from 1995 to 2004, Himelstein et al (28) reviewed the growth of various PPC programs that attempt to address the gap between hospital and community-based care. This study alludes to the idea of palliative care teams providing specialist palliative care to children and their families across various settings, as the ideal. However, in LMIC's, access to specialist palliative care is often a luxury with teams ill equipped to manage specialist needs. In SA, care for children and families is compromised by several factors including the lack of recognition of palliative medicine as a specialty, no existing government funded PPC service and the scarcity of healthcare workers trained in PPC.

In a study conducted from Boston's Children's hospital in 2005, Graham (29) focused on the benefit of integrating a palliative care approach to the management of children with severe neuro developmental disabilities and complex medical conditions and demonstrated the resulting improvement not only in the child's quality of life but also in the quality of their death.

1.6.4: Palliative care in the developing world

In many resource poor settings, home based care programmes have been seen as the most cost-effective way of providing palliative care and have been supported by some governments. However, in South Africa home base care programmes often provide services to children without support from professionals trained in palliative care (30). Hence children are generally not able to access opioids through community services and due to lack of training may not be referred for hospital-based care when needed. The literature identified a need to provide continuity of care between hospital and community as well as the provision of respite and bereavement care (11).

In 2006, Amery et al (31) undertook a study focusing on children’s access to palliative care with reference to the provision of this in resource poor settings in Sub-Saharan Africa. This study utilised a mixed method approach and noted an increase in the general number of referrals to the service during the study period. In addition, the study revealed an increase in those accessing medication to manage symptoms and other basic needs including psychological support provided by staff with increasing competency. However, several challenges were also noted and some of the recommendations included the need for i) the provision of a more accessible service, ii) improved systems for patient education, communication and follow up and iii) more education and training of staff members caring for these children and their families.

Jagwe and Merriman (32) foreground the need for palliative care as an urgent public health care problem in the developing world with reference to addressing this need in patients suffering from HIV and cancer. Based on their experiences in Uganda, the authors advocate for a collaborative approach between stakeholders to break down barriers that include the lack of political will, training and the availability of drugs that were identified as the main hindrances to the spread of palliative care worldwide (32).

1.6.5: Paediatric Palliative Care in South Africa

In her book, that aimed to provide a global perspective to PPC, Knapp et al (33) drew on information from countries with diverse systems in relation to health care provision, socio-economic, political, economic, and geographic factors. Marston outlined the history of PPC in SA, “” Hospices in South Africa have been caring for children within traditionally adult focused programmes for the past 30 years’’” (33) Pg 27. In South Africa, adult hospices had opened their doors to children in response to the HIV pandemic and poverty issues prompting the Hospice Palliative Care Association

(HPCA) the national palliative care structure, to act. In 2007, HPCA created a paediatric portfolio to support the development of PPC in the country and later the same year an appraisal of services identified only seven children’s palliative care programmes.

By 2010, HPCA had provided PPC training to over 100 health care professionals and training had extended to Uganda and Tanzania. Four clinical placement cluster sites were created. ‘“The cluster sites consist of a hospice or hospices with an inpatient unit, home-based care, day care and bereavement services; a hospital; clinician with children’s palliative care training and/or experience; and a university link”’ (33) Pg 33.

Bigshoes Foundation, a national NPO operating in three of SA’s nine provinces, were committed to improving medical care for various categories of vulnerable children including abandoned babies, orphans and especially those affected by HIV and AIDS. By 2012 Bigshoes was providing hospital based consultative paediatric palliative care for a total of 15 hospitals located across three provinces in the country.

1.6.6: Principles of care

Family centred care

Gans et al (34) used a questionnaire to measure the impact of California’s PFC program to determine caregiver stress in relation to experiencing difficulty sleeping and worry about their ability to manage their child’s health. The tool addressed areas of support from significant others, the child’s grandparents, family members and friends as well as the caregiver’s perception of the HCP’s ability to manage their child’s pain. Hence an integral component of care planning involved the inclusion and supportive care of family in the care of their child whilst providing access to around the clock nursing support. It will be interesting to know whether this study population will reveal similar findings.

In an interpretative qualitative study conducted by Verbene and colleagues (35), parents expressed appreciation and felt supported by the PPC teams they dealt with. The study identified three core elements in achieving these outcomes: process-related aspects relating to coordination and continuity in care, practical support, and team member's attitude (35).

Eaton (36) used semi structured interviews in his qualitative study to examine the experiences of families including the need for access to respite care for children with LL and LTC's. Adequate referral systems, regular assessment of the child and family's needs, continuity in care and acknowledgement of the difficulties these families experience when having to hand over care of their child to professional caregivers all emerged as points to consider when planning respite care.

De jong et al (37) further highlighted the importance of bereavement care as additional support for families to assist them with the difficult process of grieving the loss of their child. Due to a range of genetically linked conditions in PPC, losing more than one child to the same illness is an unfortunate reality for some families and increases their risk of complicated grief.

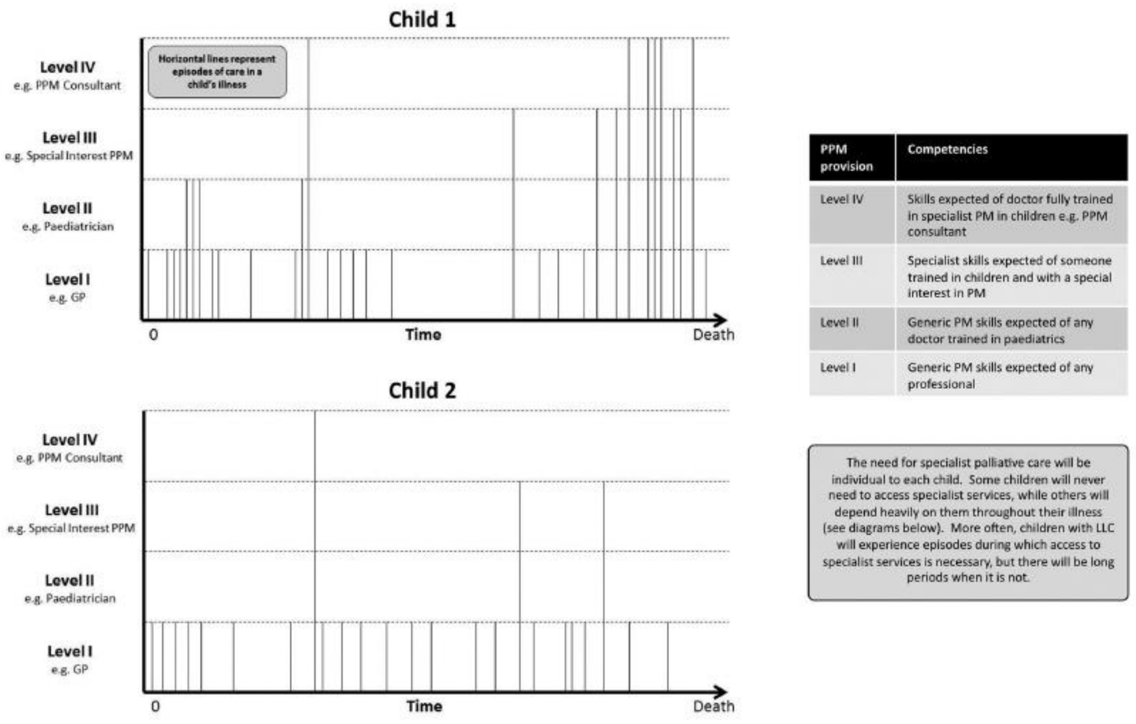
Respite care

In a literature review conducted in New Zealand in 2002, Horsburgh et al (38) reviewed respite services for children who are dying and their families. The need for families to have a break from care is clearly indicated and further research in the area is suggested so as to determine exactly how this should be structured. There are various kinds of respite care to consider including structured /planned breaks or emergency breaks such as when a family crisis occurs or in the case of the older child, recreational breaks. The need to explore the experiences of families across a diverse cultural range is required in order to develop appropriate respite options for families. However, recognising the need for respite care in the care of children with LL or LTC's is the first essential step. In South Africa, despite families requesting respite care, there were no known paediatric palliative care services offering patients and families opportunities to access respite care.

Staffing

Paediatric Palliative Medicine (PPM) recognises the contribution doctors bring to the world of PPC. In the UK, PPM was recognised as a subspecialty in 2009 and practitioners working in the field are required to have the following skills: complex pain and symptom control skills, an understanding of the disease trajectories of often rare life-limiting conditions in children, knowledge and experience of death and the dying process, skills for planning and facilitating family choices about care (including care outside the acute care setting), advanced communication skills, and knowledge and experience of managing complex ethical dilemmas(24). Recommendations were made for each region of the UK to have a paediatrician with a special interest (PWSI) as well as a tertiary consultant in PPM.

The main professionals responsible for care of the child are the primary practitioners (GP or Paediatrician) with the need for specialist PC input based on the complexity of the child’s condition. The following diagram (24) illustrates the fluctuating needs of a child over time and the various levels of care providers and their competencies.



PPM provision	Competencies
Level IV	Skills expected of doctor fully trained in specialist PM in children e.g. PPM consultant
Level III	Specialist skills expected of someone trained in children and with a special interest in PM
Level II	Generic PM skills expected of any doctor trained in paediatrics
Level I	Generic PM skills expected of any professional

The need for specialist palliative care will be individual to each child. Some children will never need to access specialist services, while others will depend heavily on them throughout their illness (see diagrams below). More often, children with LLC will experience episodes during which access to specialist services is necessary, but there will be long periods when it is not.

Figure 3: PPM competencies - illustrating fluctuating needs over time (18)

WHO outlines minimum staffing requirements to provide a paediatric palliative service in resource limited as well as better resourced settings (39) . Minimum standards would include “a nurse and doctor supported by a team of community health care workers, all who have paediatric palliative care knowledge and competence”(39). Whereas in better resourced settings, the team could include allied health care therapists, psychologists, social workers, and a paediatrician. Nurses often lead the team in many settings (39).

In a UK audit conducted in 2014, Maynard and Lynn (40) highlighted the effectiveness of clinical nurse specialists, supported by a network of professionals, in delivering around the clock palliative care to children and their families. The team consisted of five clinical nurse specialists, an administrator, specialist support provided by a part time children’s palliative care consultant and four PWSI in palliative care. A service of this nature successfully fulfilled a gap in service provision and families felt empowered and supported by an accessible service.

Rallison and Moules (41) explores the unique opportunity for the nurse to facilitate the experience of illness and dying for families. The very subject of children dying is often “unspeakable” but within the relationship of nurse with the child and their caregivers lies an opportunity to engage and embrace the unspeakable “not in a cloak of secrecy and silence but rather with great sensitivity, respect and curiosity as a blanket of comfort and security” (41).

In 2005, Rushton used case studies to illustrate the role paediatric nurses have in advocating for the integration of palliative care for children and families in their care (42). The researcher illustrates the value of an integrated approach to palliative care in the care of two children: in the case of the first child, all interventions were cure driven and focused on increasing the child’s chance of survival whereas in the case of the second child, care was directed at improving quality of life and emotional healing. Undoubtedly in the case of the second child, managing distressing symptoms and having difficult conversations were all key measures directed at improving the child’s quality of life thus demonstrating the value of a more comprehensive and compassionate approach to care.

Hain points to guidance offered by the Royal College of Paediatrics and Child Health (RCPCH) in the provision of providing specialist PPM at regional and district level. He promotes clinical nurse specialists as key players in addressing palliative care needs of children and their families and raises the issue of paediatricians developing a special interest in the field and undertaking training in palliative medicine (43).

Liben et al's(5) review in 2008 suggests that all dying children would benefit from the basic principles of PPC and some of the challenges to the provision of PPC were reviewed in this study. In terms of grief related challenges, professionals caring for children with LL and LTC's face and the complex and varied grief responses and coping mechanisms when their young patients die."" Some health-care professionals might grieve over the loss of a personal bond they have developed with a child, some over the non-realisation of their efforts to cure or control the disease, and others over unresolved personal loss that surfaces with the death of a child""(5). Page 859. It is recommended that professionals working in a PPC care setting receive formal and informal support to prevent compassion fatigue and burn out. Little is known about the long-term effects on professionals working in this field and the authors recognise this as an important area for future research.

In conclusion, most of the literature reviewed for this study were from high income countries (HIC's) which is informative though not always helpful when applied to other settings such as the context for this study. In these settings country level palliative care policies exist, the discipline is recognised as a specialty and services have been in existence for several decades. There is a paucity of literature regarding PPC in the developing world, and even where this exists the focus is more on HIV and cancer and does not include the full spectrum of paediatric conditions that would benefit from palliative care.

There are few studies describing CPC programmes in SA and especially those that have been developed in the intermediate care setting which is a unique level of public health care in-between the hospital and the child's home.

This study sets out to address these gaps in a South African setting by describing the spectrum of conditions for which children were referred, the needs of these children and their primary caregivers as well as the skills and resources required by the healthcare professionals caring for them.

1.6: Rationale for the study

In SA, the spectrum of childhood conditions that require PC include communicable, non- communicable, and peri-natal related conditions. In the past, PC services were predominantly provided by NGO’s and HIV was the main condition that required PPC with programmes like the President's Emergency Plan for AIDS Relief (PEPFAR) catering mostly for children with HIV, to the exclusion of other paediatric conditions. However, with the positive impact of prevention of mother-to-child transmission (PMCTCT) and ARV roll outs, HIV funded children’s hospices closed and no government PPC services were being provided at intermediate/subacute level in the province or in the country at the time.

In the Western Cape, the establishment of a donor funded PPC unit at SFCCH (a government funded facility) coincided with the roll out of a new ICPF

, that included palliative care. For the first time palliative care for children was being considered at ICF’s in the province/country. This created a unique opportunity to evaluate the population of children accessing this service by describing their needs and the experiences of caregivers and professionals caring for them. The research study sought to conduct evidence-based research and aimed to describe the population of children and the experiences of primary caregivers and health care professionals admitted to an intermediate care facility. This was a gap in the literature with none of the studies settings examining an intermediate care facility in a lesser resourced setting where PC was not a recognised specialty.

1.7: Research question

A research problem is the issue being addressed. It helps in narrowing the topic down to something that is reasonable for conducting a study. Creswell defined research problem as “’a general educational issue, concern, or controversy addressed in research that narrows the topic’”(44) Page 60.

What do the population and care needs of children admitted to an intermediate care facility consist of, what are the experiences and caregiver burden of their primary care givers and what are the experiences of health care workers providing care to these children?

1.8: Objectives of the study

1.8.1 To describe the population (and care needs) of children admitted to SFCCH.

1.8.2 To describe primary caregiver's experiences and care burden of caring for their children.

1.8.3 To describe the experiences of health care workers providing care.

Chapter 2: Methodology

2.1: Study site /setting

SFCCH is a provincially aided intermediate care facility supported by the Western Cape Government 's DOH as well as various private donors. In 2014, an opportunity arose for palliative care to be woven into the care packages of children and families admitted to SFCCH through funding from the CHT and the development of the Western Cape's ICPF. Committed to improving outreach care for RCWMCH patients, the CHT agreed to finance the setup of the IPPCU - this included initial alterations to one of the two wards at the hospital, the cost of equipment, training of all staff members, recruitment of four registered nursing staff members and unit manager. It was hoped that in the period following the two-year CHT funded period, operational costs for the IPPCU would be supported by the DOH.

A novel service was planned in that the first PPC service was to be established within an ICF in South Africa. SFCCH is a 60 bedded facility and a section of the hospital had been refurbished to accommodate a 10 bedded palliative care unit. The IPPCU aimed to offer symptom management, respite and terminal care to children and their families in a child /family friendly “home from home” setting.

The IPPCU at SFCCH

The IPPCU was officially opened on 11th June 2014 and the study was commenced eight months later. The study ran for a period of six months however five months into the study, in July 2015, the management of SFCCH closed the IPPCU. Children and their families at the hospital continued to benefit from a palliative care approach beyond this period. This ongoing integration was largely due to the commitment of nursing staff to adopting a palliative approach to their patient's care. The nurses were supported by a small team of palliative care doctors, no longer employed by the hospital, who remained accessible through telephonic support.

2.2: Study design

This study is descriptive in design and used different methods to describe three populations within the study site: the patients, their primary caregivers and health workers caring for them. A descriptive study examines the characteristics of a population (or phenomenon) and then organizes, tabulates, depicts, and describes the data collection (45).

Data describing the population were collected prospectively over a 6-month period. Cross-sectional data was collected on the caregivers and professionals by interviewing them at a single point during the study. A *cross-sectional* study provides information about the situation that exists at a single point of time. These could be on disease or symptom description or process (46).

2.3: Unit of analysis

There were three distinct study populations: the health records of patients admitted to the hospital, their primary caregivers and health care workers who cared for the patients.

2.4: Inclusion criteria

2.4.1: The health records of paediatric patients admitted to IPPCU

- Health records of patients (aged 0 - 18 years) admitted, during the six-month study period, whose primary caregivers had consented to the study.
- Health records of all patients (with LL or LTC's) who met the hospital's admission criteria for a palliative care admission to the IPPCU.

2.4.2: Primary care givers

All primary caregivers of patients (with LL or LTC's) admitted to the IPPCU / SFCCH over a six-month period who had consented to the study.

The health records of 25 patients were matched with 25 consenting primary givers.

2.4.3: Health care workers including allied health professionals and complimentary health practitioners

Health care practitioners who worked in the IPPCU/ SFCCH over the six-month study period. Categories of health care workers included professional nurses, doctors, a care-worker, social worker, family counsellor as well as therapists. The therapy categories included complimentary health practitioners e.g. aromatherapy massage and music therapists, allied health practitioners including occupational and speech therapists as well as a dietician.

2.5: Exclusion criteria:

2.5.1: Health records of paediatric patients admitted to IPPCU

- Non-palliative care patients and overflow general patients.
- Patients above 18years old.
- Patients whose primary caregivers had not consented to the study.
- Patients who did not have an accompanying primary caregiver.

2 .5.2: Primary care givers:

Non-primary caregivers or relatives who interacted with the patient and staff were excluded from the study.

2.5.3: Health care workers including allied health professionals and complimentary health practitioners.

Short term professional volunteer staff or health care practitioners doing clinical placements in the IPPCU were excluded from the study.

2.6: Sampling method

2.6.1: Health records of patients

All available health records where the primary caregivers had provided consent for were included. Where consent was unobtainable, or the primary caregiver was not traceable the child's health records were excluded from the study.

2.6.2: Primary care givers

All available primary caregivers who consented to participating in the study were included.

2.6.3: Health care workers including allied health professionals and complimentary health practitioners.

Purposive sampling is a technique of obtaining information rich resources from a small target group (47). Health care practitioners were recruited by a process of purposive sampling to ensure representation from all disciplines involved in the care of the children. A total of twenty-seven health practitioners representing a range of disciplines were approached. Four professional nurses, two enrolled nurses, two enrolled nursing assistants and nine caregivers were approached. In addition, a music therapist, occupational therapist, speech therapist, dietician, two rehab care workers, two doctors, a social worker and a family counsellor were approached to partake in the study. Of this group, 15 health care providers agreed to partake in the study.

2.7: Data collection tools

2.7.1: Case report form

The researcher extracted information from health records using the case report form (designed by the researcher) and no structured observation was used for the study. Field notes collected in this process were also incorporated into the research findings. The case report form was used to collect information to describe the patient population, their needs and multidisciplinary care received. Data was collected longitudinally, at several points hence it was possible to view a range of needs and care requirements during the patient's stay in the IPPCU and data was collected from 1 March 2015 till 30 August 2015. Data included patient demographics, primary diagnosis, ICD codes, reason for admission, medical and psychosocial interventions and outcome.

Various types of counselling were available:

Medical counselling sessions refer to doctor led sessions with or without another staff member present, the primary focus of these session related to medical issues.

Nursing counselling sessions refer to professional nurse led sessions and a mixture of psychosocial and medical issues were discussed.

Psychosocial sessions refer to social worker led sessions with one or more family members and dealt exclusively with psychosocial issues.

Family counselling sessions were facilitated by a doctor, family counsellor or professional nurse and a range of issues were usually addressed.

Bereavement counselling sessions were conducted by a family counsellor with or without another staff member present and the number of family members attending varied. See Appendix 3 for more details.

2.7.2: Primary care givers questionnaire

A three-part questionnaire was used to suit the local setting and translated into two widely spoken languages in the region i.e: Afrikaans and isiXhosa. Section A of the questionnaire obtained the primary caregiver's demographic data, in Section B the the Brief Assessment Scale for Caregivers of the Medically Ill (BASC) was adapted to determine feelings for example worry, fear and distress and Section C explored their experiences of caring for their child using open ended questions.

The researcher created Section A and C of the questionnaire. Section B was adapted from the BASC. Written permission to use and adapt the BASC, for purpose of the study, was obtained from the author, Dr Myra Glajchen. Most of the questionnaires were self-administered and in the case of three illiterate respondents, the researcher administered the questionnaire. Once complete, questionnaires were stored in a locked filing cabinet and later data was transferred to a password protected personal computer administered by the researcher. See Appendix 13.

2.7.3: Professionals demographic sheet

Demographic data sheets were used to assess level of training and experience of HCP's. See Appendix 6

2.7.4: Focus group discussions

Two semi structured focus group discussions took place in the seminar room at RCWMCH and the third was held in a neutral venue close to the hospital; all FGD's were facilitated by an independent social worker. The first two groups had 7 and 6 respondents respectively and due to staff shifts the third focus group discussion had two respondents. Focus groups discussions lasted for 1 ½ - 2hrs at a time and discussion guides were used to facilitate discussion. See Appendix 7. A voice recorder machine was used to record responses from the discussions which was later transcribed verbatim. Field notes were used to capture the subtleties of the conversation as well as nonverbal cues.

2.8: Data analysis

2.8.1: Quantitative data

Quantitative data refers to any data that is in numerical format such as percentages or unit measurement (49). This study obtained quantitative data from case report forms and the demographic sections of caregiver and health care worker questionnaires. Data was captured, stored, and analysed in Access and then transferred to Excel for further analysis.

2.8.2: Qualitative data

Qualitative data focuses on text and through the analysis of what participants really think or feel and say, the richness of their experiences may be revealed. Data retrieved from focus group discussions (FGD's) was analysed using a thematic framework analysis. Thematic analysis is a technique used to identify, analyse and interpret patterns of themes within qualitative data. The process of thematic analysis began with the researcher actively immersing herself in the data obtained from the transcripts of the FGD's, thus increasing understanding and familiarisation with all aspects of the data. The data was then coded as key aspects/issues were identified in the transcripts. The coded data was then grouped into categories. The categories were then sorted and collated according to overarching emerging themes (50).

2.8.3: Rigour

Cypress defines rigor as a state of being thorough and accurate and the study used various elements throughout the process of planning, data collection, analysis and reporting to ensure information was precise (51). In order to maintain neutrality and validity, an independent, experienced, compassionate social worker facilitated all three focus group discussions. The researcher assumed the role as silent observer and recorded field notes throughout the discussions. Validity indicates trustworthiness thus increasing transparency and reduces opportunities for researcher bias (52). Reliability relates to consistency and this was achieved by the use of a standardised question guide for the focus group discussions, facilitated by a consistent facilitator. All respondents were provided with the same information prior to discussions.

2.9: Ethical considerations

The study commenced once approval from the UCT's Faculty of Health Sciences Research Ethics Committee (HSREC), the Western Cape Provincial Department of Health and the board of Sarah Fox Convalescent Children's Hospital was obtained. Primary caregivers were issued with an information sheet that clearly outlined what the researcher was wanting to do - this referred to a file review and obtaining a caregiver questionnaire. Only once the primary caregiver agreed to participate were, they then supplied with a consent form. The clause in the information sheet reads as follows "If you agree to participate, you will be asked to sign a consent form, which shows that you have agreed to the file review and questionnaire". See Appendix 1

Consent was obtained from all participants and participation in the study was voluntary. The voices of children were not included in this study. Age-appropriate assent was not possible because none of the children aged 7 to 13 years were able to provide assent due to their condition with many of them being non-verbal.

Participants could withdraw from the study at any time with no explanation and no compromise to the quality of care of their child (in the case of caregivers) or risk to their job (in the case of a staff member). The researcher was responsible for handling audio and written data and transcribing interviews. Interviews were stored on a password protected computer and recordings were deleted from audio recorder post interview and transcription. Records are kept for five years.(53)

Chapter 3: Results

3.0: Introduction

A total of 28 primary caregivers were screened and 25 primary caregivers and matched health records of patients were enrolled on the study. Three primary caregivers and matched health records were excluded from the study because informed consent was not obtained from the primary caregivers. These primary caregivers did not turn up for scheduled appointments and the researcher was unable to reach them.

A total of 27 health care workers were invited and 15 health care workers were enrolled on the study. Twelve health care workers chose not to be included and reason for refusal was requested or offered by those who declined. However, the study was conducted at a time when there was a lot of uncertainty about the future of the unit and this may have influenced some of staff member's willingness to participate in the focus group discussions.

The results of this study are presented in 3 parts:

A. Health records of patient population: results of data obtained using a case report form.

B. Primary caregiver population: results of data obtained using a three-part questionnaire.

C. Health Care Worker population: results of data obtained using demographic data sheets and from semi-structured focus group discussions.

3.1: Health records of patient group

A total of 25 children were enrolled in the study of which (60%; n=15) were female and (40%; n=10) male. The age of patients at the time of admission is presented in the graph below:

n=8).

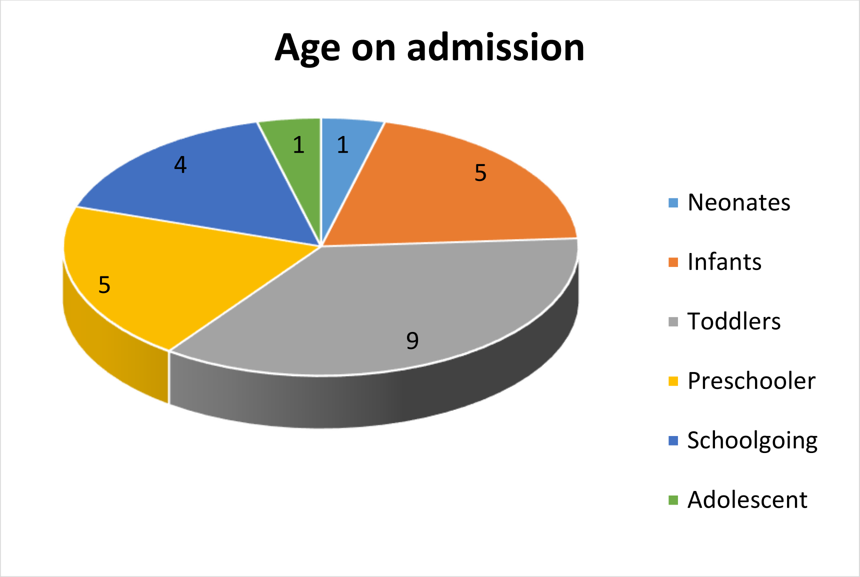


Figure 4: Age on admission

The following graph describes the length of care of primary caregiver.

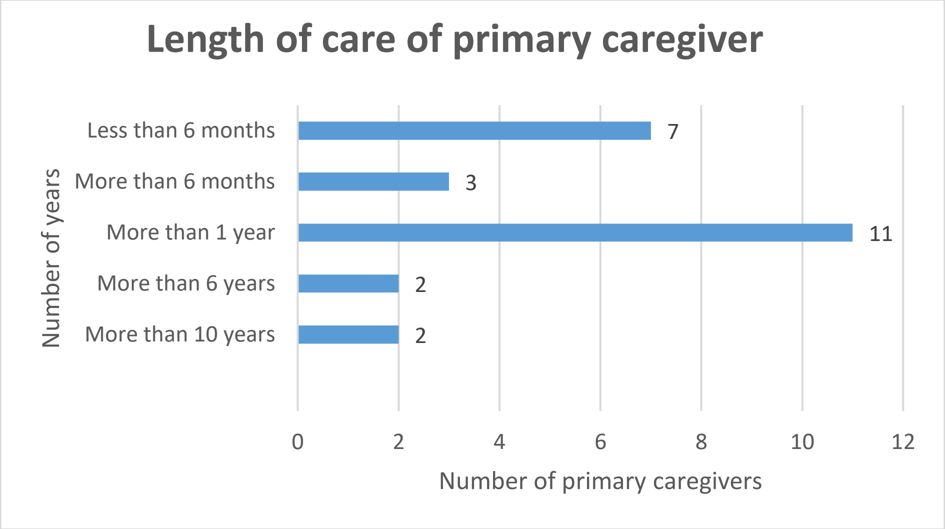


Figure 5: Length of care of primary caregiver

The following graph represents the range of primary diagnoses patients were admitted to SFCCH with. The most prevalent diagnosis was Retroviral Disease (RVD) on Highly Active Antiretroviral Therapy (HAART) (36%; n=9) followed by Cerebral Palsy (32%; n=8).

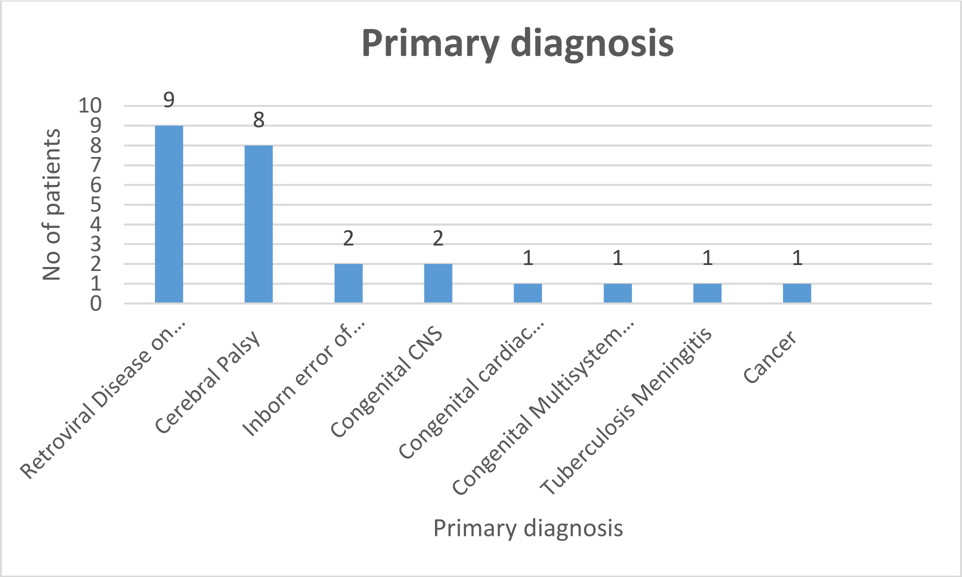


Figure 6: Primary diagnosis

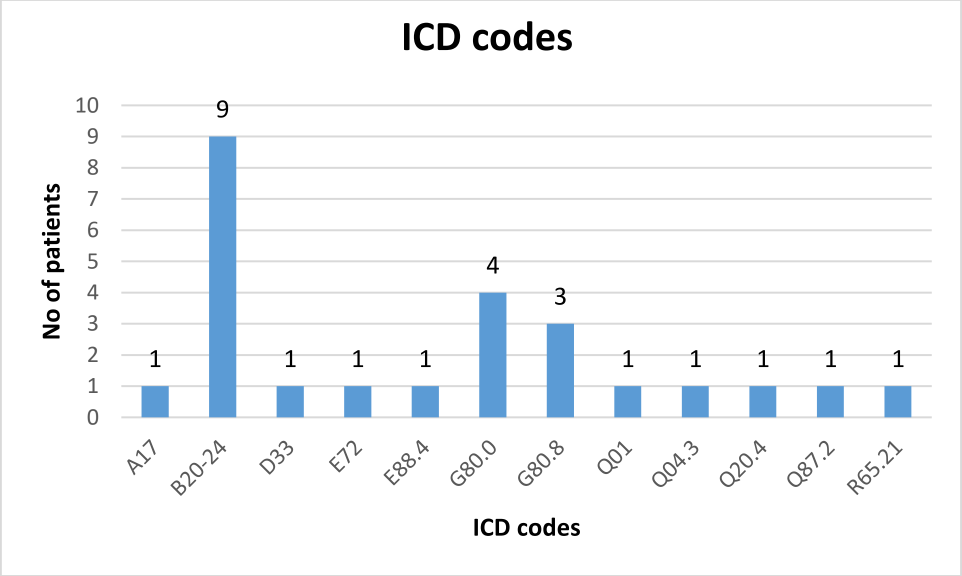


Figure 7: ICD codes

In terms of the categories of palliative care patients (ACT Classification), all categories were represented although most patients were in ACT Class 2 and 4.

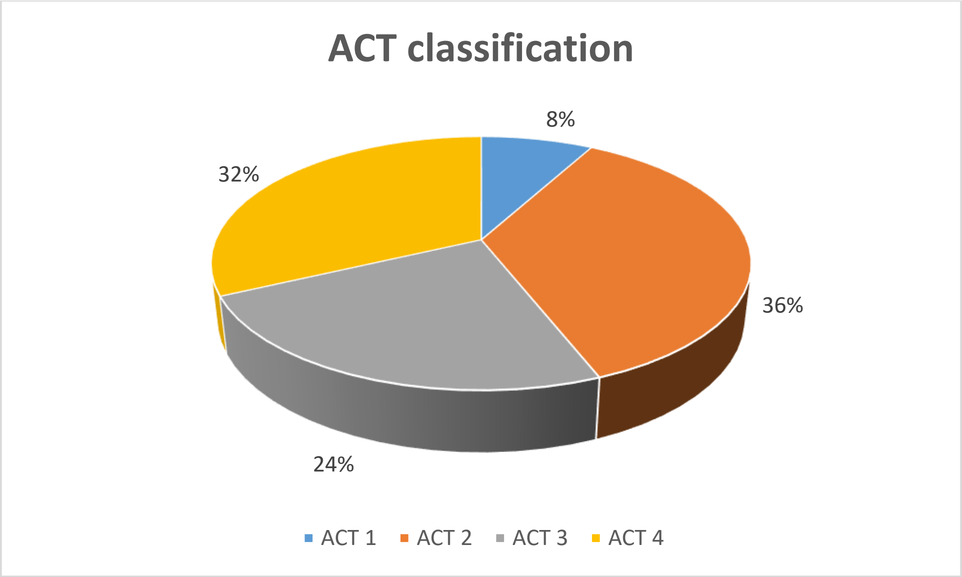


Figure 8: ACT classification

Reason for admission: (8%; n=2) patients were referred to the facility for symptom management, (48%; n=12) patients for transitional care, (16%; n=4) for respite care and (28%; n=7) patients for terminal care.

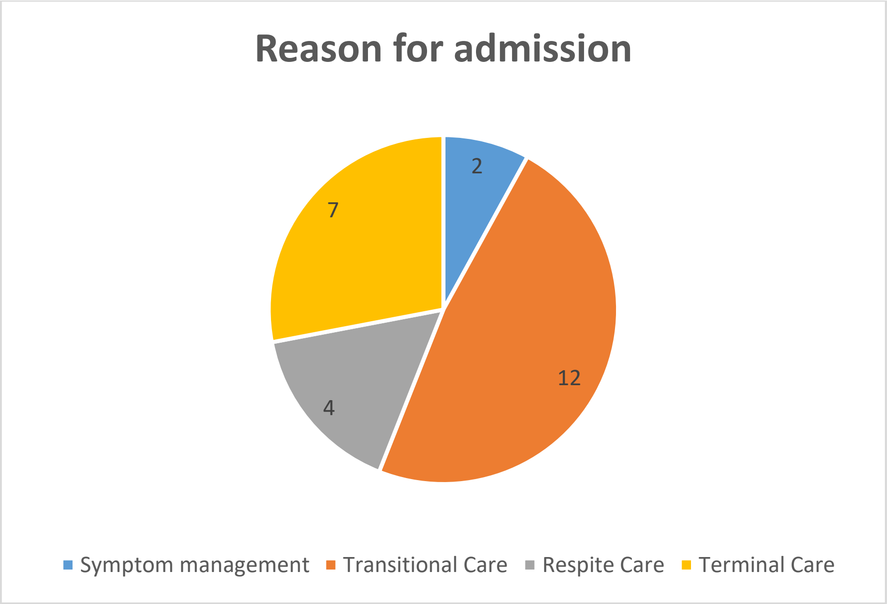


Figure 9: Reason for admission

Length of stay: the average length of stay was calculated at 97 days. (40%; n=10) stayed for less than the prescribed 42 day stay as set out by the ICPF with (60 %; n=15) staying at the facility for between 48 and 183 days.

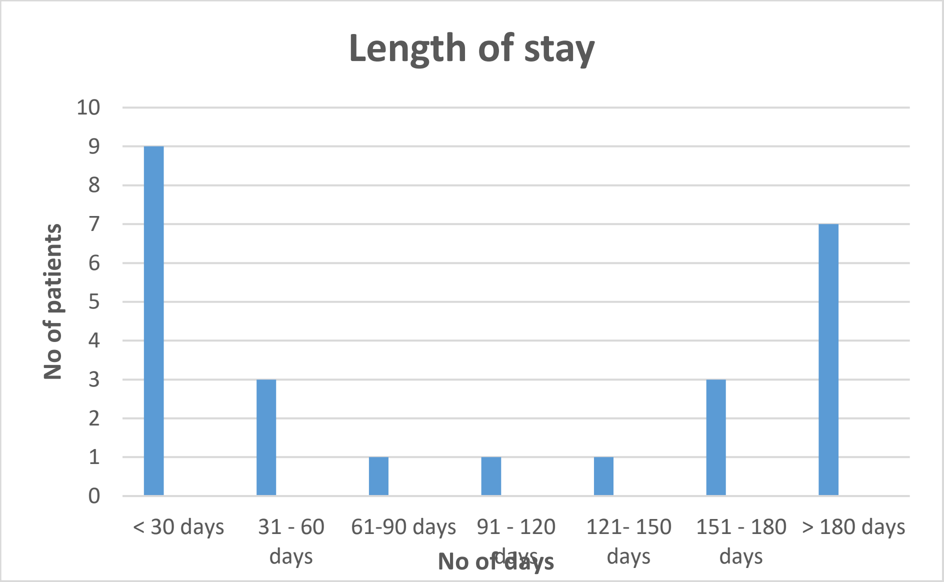


Figure 10: Length of stay

The following graph represents symptoms children experienced during the study period. These symptoms either presented at the time of admission or during their stay in the IPPCU. Pain was the leading symptom managed (44%; n=11), followed by secretion management and (28%; n=7) required seizure management.

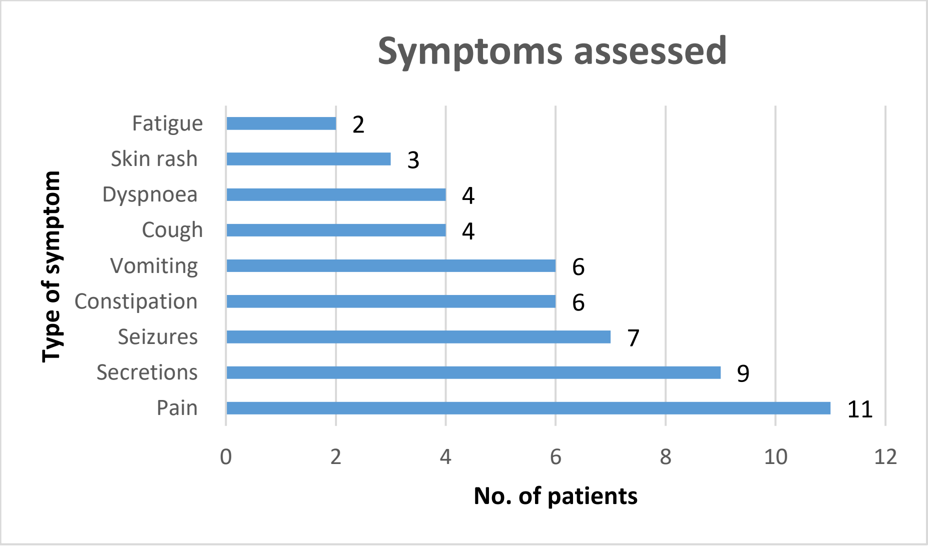


Figure 11: Symptoms assessed

The following table represents the range of drugs used including the route these drugs were administered by and how frequently they were used. Information on drugs usage were retrieved from retrospective file review.

Drugs and route of administration

Name of drug	Route of administration	Frequency
Paractemol	Oral	n=17
Sorbitol	Oral	n=10
Gabapentin	Oral	n=4
Baclofen	Oral	n=1
Morphine	Oral	n=9
Morphine	Subcutaneous	n=4
Atropine drops	Sublingual	n=8
Buscopan	Subcutaneous	n=6
Furosemide	Nebulised	n=2
Dormicum	Subcutaneous	n=1
Valium	Rectally	n=1

Table 2: Drugs and route of administration

An average of 12 clinical examinations were conducted by a doctor per patient.

Weekly multidisciplinary team meetings were held, and the following graph represents the number of times a patient was discussed at these meeting. Some patients were discussed extensively (particularly shortly after admission if there was a deterioration in their condition or during the terminal phase) and sometimes the discussion was a considerably briefer e.g.: when team members provide updates to existing plans. Unfortunately, the duration of these meetings was not recorded therefore this information was not collected as planned.

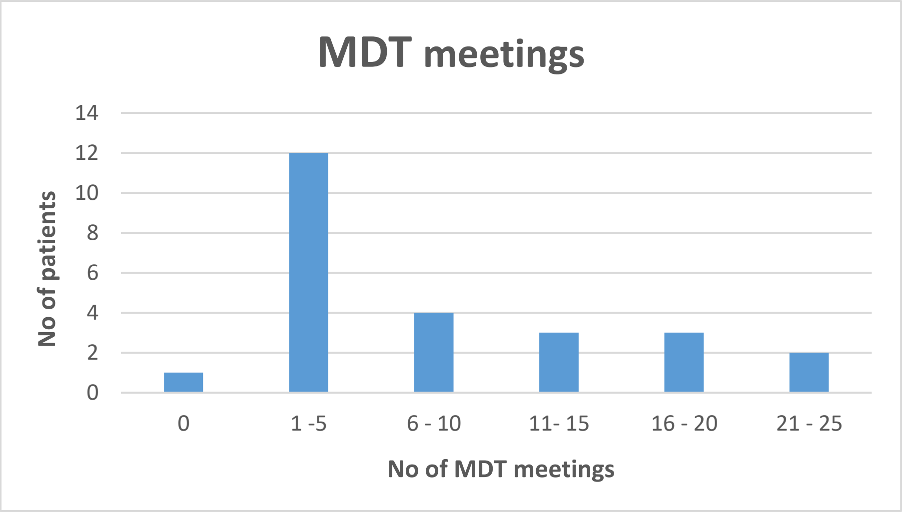


Figure 12: MDT meetings

The following graph depicts counselling sessions held by various staff members with family members.

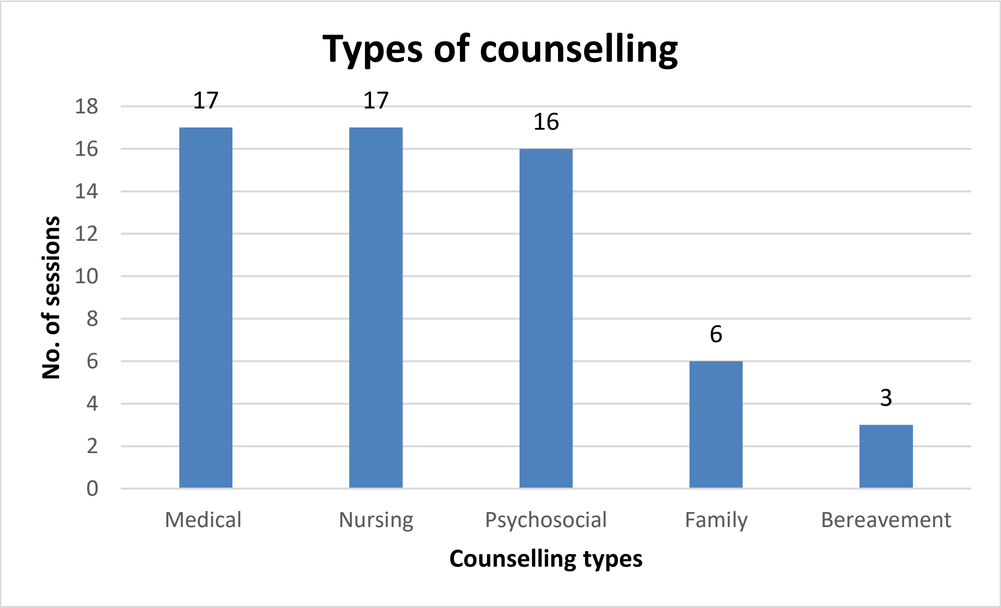


Figure 13: Counselling types

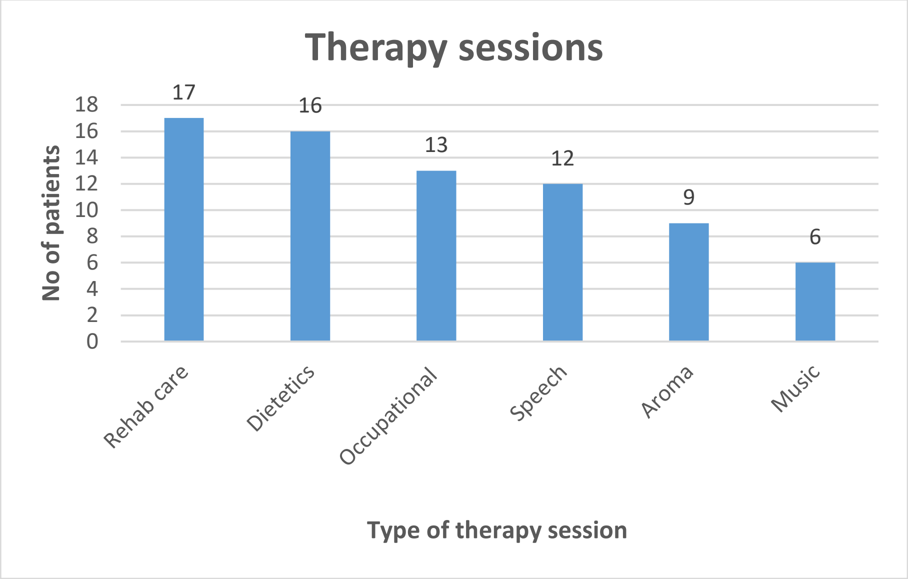


Figure 14: Therapy sessions

The following graphs represents outcome: One patient (4%) was discharged back for acute care and one patient (4%) died, eight patients (32%) were discharged home and fifteen patients (60 %) remained at SFCCH. Of the latter group, three patients died within twelve weeks following the study with one of these patients having been at the facility for a period of 9 months prior to her death. The patient who died during the period of the study died 30 days following admission.

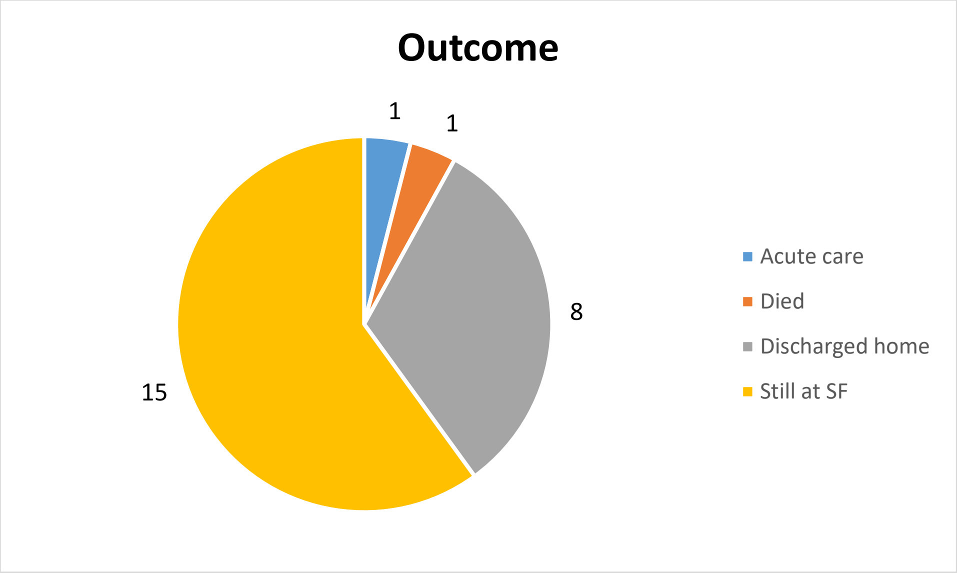


Figure 15: Outcome

The following graph represents referral destination for (32%; n=8) of patients who were discharged home. Only one patient was referred to home based care services, one patient was referred on to another step-down facility and remaining six patients were referred to clinics based at referral hospitals.

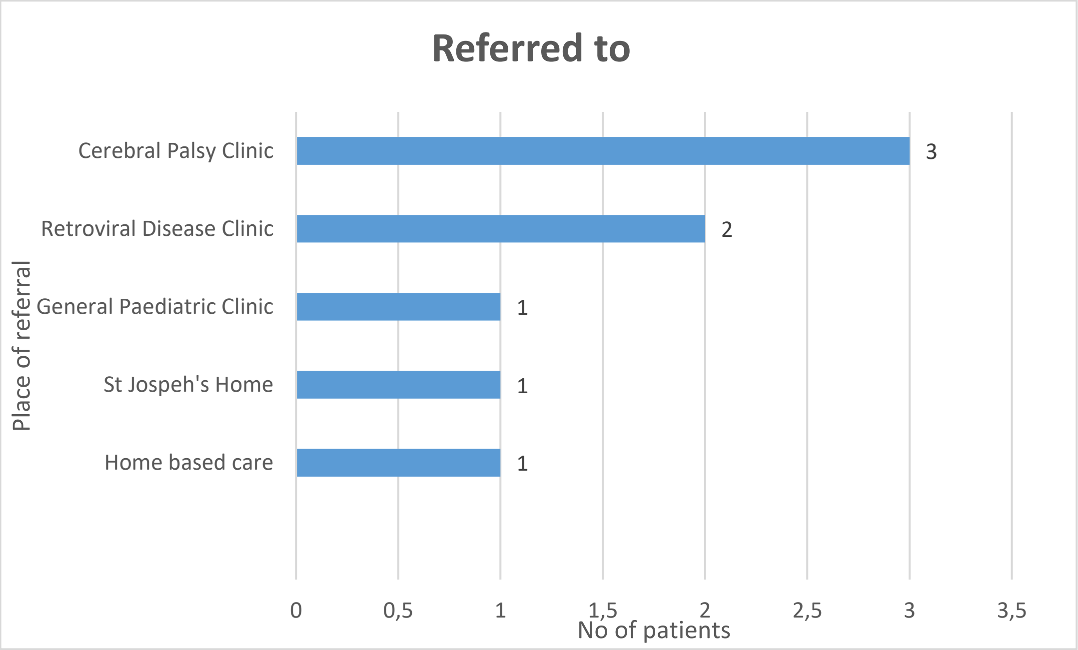


Figure 16: Referred to

3.2: Primary Caregiver Group

A total of 25 caregivers were enrolled in the study.

Section A

Twenty-one caregivers (84%; n=21) were the biological parent of the patient, (12%; n=3) were grandmothers and one aunt undertook the role of primary caregiver.

Eighteen caregivers (72%; n=18) were unmarried and (28%; n=7) were married.

Most caregivers (76%; n=19) had children and (24%; n=6) reported they did not have children.

The following graph represents the number of persons living in each household.

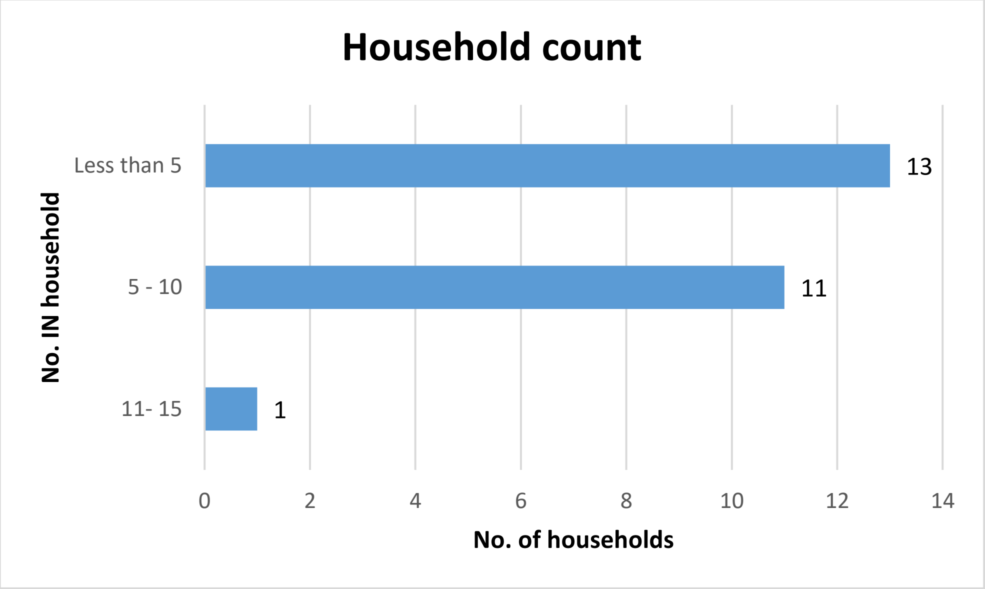


Figure 17: Household count

Most caregivers (64%) reported having some form of assistance with caring for their child. The majority of primary caregivers were unemployed (64%; n= 16) and (36%; n = 9) were employed.

Fourteen families (56%) received a monthly income of less than R 2500 /month, six families (24%) received less than R1000/month and four families (16%) received between R2 500 - R5 000/month.

Section B:

Because of the illness, how much have you:	**Not at all**	**A little**	**Some**	**A lot**
Worried about …………., even when you not with him/her.	1	1	0	23
Felt depressed because of …………..'s illness.	3	3	5	14
Felt upset because of not having enough time for yourself because of caring for………………	8	0	7	10
Felt overwhelmed because of the responsibility of caring for………	3	3	5	14

Please rate your distress during the past month:	**Not at all distressed**	**Little distress**	**Some distress**	**Lots of distress**	**Does not apply**
Distress over seeing ………… in pain and discomfort.	3	2	5	10	5

Distress at not having enough time to do a/ attend to other responsibilities or chores.	7	2	6	5	5
Distress about having to make decisions about hospitalizing……………..	5	4	5	8	3
Distress at thinking/talking about medical procedures what ………….. would / would not want if his / her hear or breathing would stop.	5	1	1	9	9
Distress at having strained relationships with other family members about taking care of…………..	2	1	6	7	9

Please rate whether you agree or disagree with each statement as it applies to you in the care of …………….in this month.	**Agree a lot**	**Agree a little**	**Disagree a little**	**Disagree a lot**	**Does not apply**
Taking care of ………….. has drawn the two of us together.	21	1	0	0	3
Taking care of ………………. has brought meaning to my life.	24	0	0	0	1
Caring for ………………… has brought members of our family closer.	16	2	4	2	1
Taking care of ………………….makes me feel good about myself.	21	0	2	1	1

Table 3: Results of Primary Caregiver's questionnaire

Section 3

The final part of the caregiver's questionnaire comprised of two open ended questions to determine caregiver's experience of caring for their child at home as well as at SFCCH, as expressed in their own words. The results of the open-ended questions were analysed using quantitative content analyses which led to frequencies. Quantitative content analysis is a method used to identify patterns through a process of categorizing words, themes and concepts by counting and measuring text (54).

Theme	**Sub theme**
1. Caring for the child at home.	1.1 Difficult tasks - Ten respondents experienced caring for their child in their home environment as a difficult task.
	1.2 Increased worry and anxiety - Three respondents indicated that caring for their child at home caused increased anxiety and worry.
	1.3 Easy/pleasurable - Five respondents expressed having positive experiences around

	caring for their child, with special needs, in their home environment.
	1.4 Concern for future needs - One respondent expressed concern around future needs including her child’s special learning needs.
2. Caring for the child at SFCCH	2.1 Nursing support - Twenty-one respondents appreciated nursing support and the manner in which the nurses cared for their children. Respondents indicated that learning from the nurses prepared them for caring for their child at home.
	2.2 Positive outcome/impact on child & caregiver - Seven respondents indicated that the therapeutic environment at SFCCH had impacted on their child’s quality of life. Their children appeared to thrive, were stimulated and happy, thus impacting positively on their own happiness.
	2.3 Better place for care - Two respondents expressed their assessment of the hospital as a better place of care in comparison with their home environment.
	2.4 Financial challenges - One respondent raised the impact of cost of traveling to hospital.
	2.5 Concern for future care - Two respondents expressed concern for their child’s future care needs in relation to options for alternative care.
	2.7 Staff attitudes - Two respondents alluded to attitude of nurses on some shifts as having a negative impact on care of their child.
	2.8 Accommodation for caregivers -Three respondents raised the issue of access for

	caregivers to stay over with their children. Due to the facility's limited arrangements for caregivers, their wish to remain at their child's bedside was not always granted.

3.3: Health Care Worker's group

3.3.1: The Participants

Four broad categories of staff participated in the focus group discussions. The counselling category included a family counsellor and social worker; nursing category included professional nurses and one carer, and the therapy category included allied health care workers as well as complimentary health care practitioners. The following graph represents the four categories of staff.

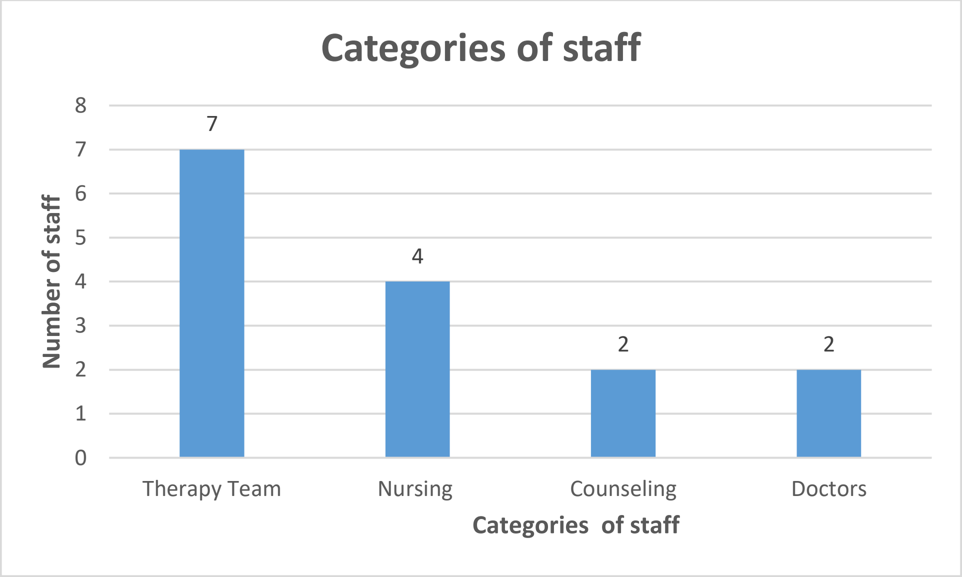


Figure 18: Categories of staff

The following graph represents terms of employment of HCW's participating in focus group discussion.

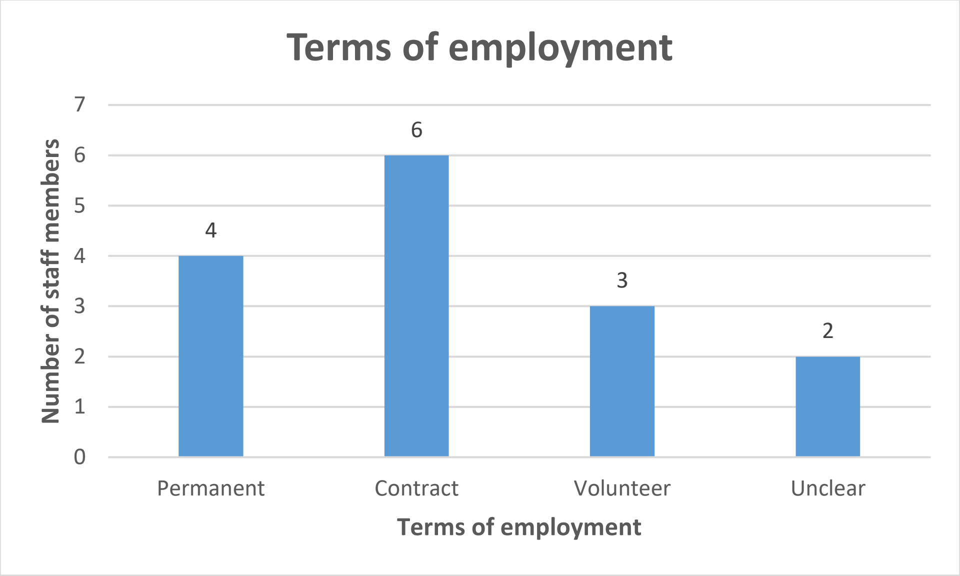


Figure 19: Terms of employment

The following graph represents the age of HCW's with those in the age group 30-45 years making up the largest group (40%) and 27% of HCP's > 45 years. All participants were female.

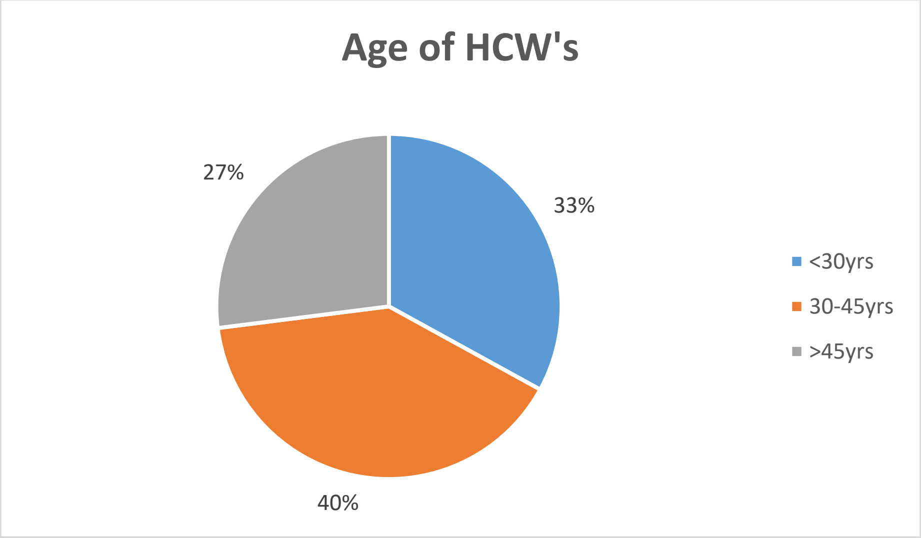


Figure 20: Age of HCW's

Most HCP's (60%) had received some form of palliative care training ranging from one day course in palliative care to a 5-day introductory course and 5-day practical course in PPC. The practical 5-day training courses focused on paediatric conditions that would benefit from a palliative care approach. Two respondents were enrolled on the postgraduate Diploma in Palliative Medicine at UCT at the time of the study.

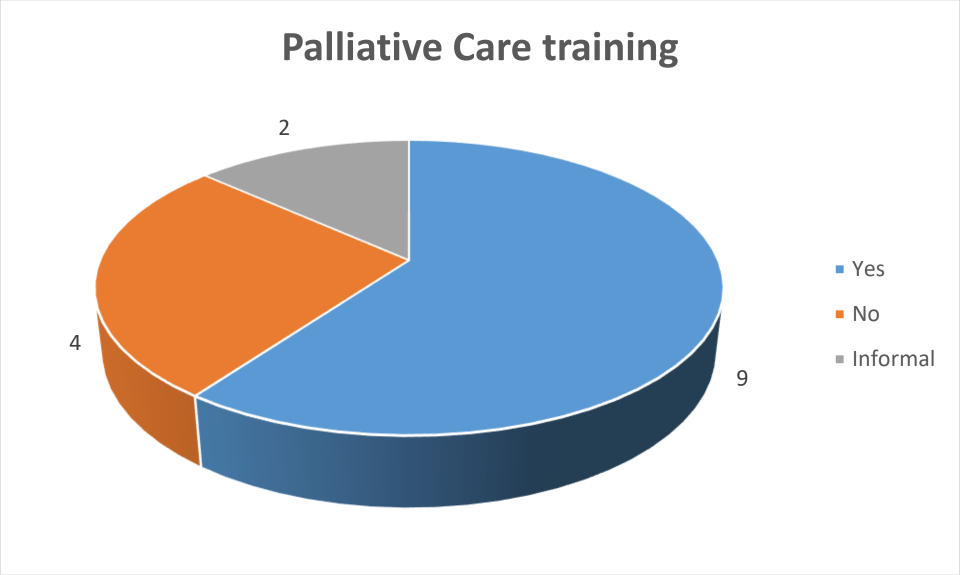


Figure 21: Palliative Care training

Participants were a mixture of newly qualified health care professionals, those with little working experience and some with extensive experience working with adults and children in the area of palliative care. Five respondents had worked with children or adults in a palliative care context prior to their experience at SFCCH.

3.3.2: Themes and categories arising from the data

Six broad themes and 16 categories arose from analysing the data retrieved from the focus group discussions by using a thematic framework. Through the process of thematic analysis, numerous codes were identified, and data was subsequently sorted and collated till overarching themes emerged. Further classification and organization led to key themes and emerging categories (50). The themes relate to the HCW's experience of caring for children and their families and are outlined as follows: professional impact, personal development, working with families, teamwork, support and institutional issues.

Theme	Categories
Professional impact	- Different way of working - Increasing confidence with new skills
Personal development	- Emotionally demanding work - Feelings in relation to the death of a child - Debriefing
Working with families	- Time factor - Different types of families - Family responsibilities
Teamwork	- Strengths - Source of support - Emotional readiness of team members
Support	- PPC training - Mentorship
Institutional issues	- Lack of support for PPC - Lack of resources - Closure of the unit

Professional impact:

Respondents acknowledged that caring for children with palliative care needs had introduced them to a different way of working as professionals. Their experiences in the IPPCU extended beyond caring for the physical needs of their patients but embraced more holistic aspects that incorporate psychological, social and spiritual components of care. In a hospital context, where the primary focus was on providing acute care, attending to the often-complex holistic care needs of the child living with a LL or LTC was not prioritised. Furthermore, acute settings placed (time) restraints on time spent with patients and in addition there was a general lack of understanding among health care workers in terms of what a palliative care approach had to offer. Holistic care provided in the IPPCU had demonstrated the benefits of the professional's wholehearted attendance throughout the child's disease trajectory and particularly at the end of life.

P06: "… from the world I come from a patient is resuscitated, transferred to ward and a few days later discharged home, so PC was different, it was not only about *stabilising, (making the patient) comfortable if terminal, peaceful and comfortable, making patients comfortable and families at peace … “*

P13: “I come from a paediatric hospital, I worked with children in tertiary settings, working at SFCCH was sort of a dream come true, I tried to get doctors at paediatric hospital to think about PC but was sort of a losing battle…. “

Health care workers reflected that working with patients in this different way required the acquisition of new skills that many were not prepared for. Despite extensive undergraduate training, HCWs stated that they were ill prepared (for) when they first commenced work in the IPPCU. However, with regular exposure and experience, new skills had been acquired and the confidence HCW’s experienced in caring for children with PC needs, was increasing.

P15: “I feel a lot more equipped now than I did before, I do feel because each child has a different end of life experience symptom. You will never know it all ….I will be able to deal with a lot of the issues, I will still need to call someone up with regard to something more complex”

Personal development:

Several of the respondents mentioned that caring for children with palliative care needs had impacted them personally. While their experiences of caring for these children was gratifying, some of the younger HCW’s, particularly those who had young children of their own, experienced the work as taxing, difficult and emotionally demanding.

P11: “I see the value of little things, e.g: touch, small interactions with the child, with PC children you become more in tune with the little things like getting nails painted.”

P5: “It’s like your heart is there, hey… something you can’t explain to someone else; they wouldn’t understand, it has become a passion.”

P6: "At present I have a small baby, when something happens to these babies, it stays with me a long time…what will I do if my baby dies, how will I cope? It stays with me for a very long time, sometimes I even have dreams about them".

Health care workers proceeded to describe their feelings in relation to the death of a child in their care and how they dealt with the death as individuals. It helped some HCW's to know that everything possible had been done to provide the absolute best care for the child and their family. In addition, HCW's acknowledged the value of a debriefing space, as essential to the process in helping them deal with the impact of loss on the individual and the team and expressed regret that a space for debriefing was no longer available.

P11: "I sometimes feel who am I for being so emotional? I have only known the child for two weeks".

P13: "When PT XXX died, it was 18h55, he had his meds at 18h30, took it well, at 18h55, he was dead, no warning. I almost wanted to resus (resuscitate) him. His mother knew, she went out for a smoke break, I was in shock. I was the only sister on duty. It was almost as if the mother wanted to make me feel better. The father came, got into bed with the child, I dealt with everything professionally, I got into the car and cried like a baby."

P4: "…time to debrief, there was space that fell away. It is a hiatus at the moment, whole thing is precarious".

Working with families:

Health care workers reported that working with and developing relationships with families of children with palliative care needs required time, skill and improved with experience. In addition, families presented with different levels of knowledge and understanding in relation to their child's illness and disease trajectory. They acknowledged that all families were unique in that they presented with different experiences that impacted on their ability to cope with adversity and this influenced their current situation.

P14: “The families are similar to families all over SA with sick children: angry, scared, sad, confused and uncertain.”

P4:” Many people come with fear and apprehension that needs to be understood and respected, to see the change into trust, it becomes trust as they become part of the team”.

Journeying with families entail providing different levels of support - there was no one size fits all approach. In addition, families of children with LL and LTC’s were often complex in that they needed to juggle several competing responsibilities outside of the hospital environment including caring for other family members, work commitments, economic pressures etc.

P10: “I am not there every day, my view is different, and parents are not able to get there all the time, torn between children and home. Terribly hard for parents to juggle choices continually”.

P8: “Parents become very comfortable with the fact that their child is at SF (SFCCH), so often they do not care, that they do not visit very often, we are eager to intervene, explaining PC to parents is very difficult and tricky.”

Teamwork:

Health care workers agreed that providing PC for children and their families could not be provided by one person and a team approach was essential. The benefits of working as a team in addressing the holistic care needs of the child and his /her family was repeatedly acknowledged and appreciated by most HCW’s.

P1:” …. especially recently there is a big team, all this big organism, with the aim to settle the child and to provide support and kind of a container for them, I can’t be doing this in isolation”.

P 10: "XY was a case in point……if you think of the resources that were used - OT, Play therapy, SLT, rehab, family care - social workers and siblings came in. The thing that struck me, with all the children who had PC… he was pinnacle, had everything that we could possibly give him, whatever caring he needed…."

The strength of the team and ability to work collaboratively helped to address and optimise the quality of life of beneficiaries. HCW's appreciated the support team members offered each other particularly at challenging times and felt this contributed towards team morale.

P14: "The fact that looking after these children involves an MDT approach, I enjoyed - working with colleagues making decisions as a team."

P4:" Seeing the difference that's it made with a team approach that includes families and patient" ". Commitment from them (staff) and enthusiasm and hunger and get to grips with the big challenge of working with a PC approach and delivering very good PC, which is often instinctive or intuitive in people but to see it overtly practised".

Some expressed concern in relation to the emotional readiness of team members to meet the challenges of work with dying children and families.

*P5**: "**There was a young one, she was very proactive in everything and when this situation arose she just got herself missing and I knew she does not like to deal with this situation (child dying). Then on the other one there is the other side where there is the carer that will sit there with music without being asked, can be various factors that impact. I don't blast, I sort of reason, I let it be".*

Support:

All respondents affirmed the importance of HCW's being proficient in PPC skills and knowledge. They valued formal and informal training they had received and acknowledged the need for ongoing training and support. Some respondents identified specific gaps in knowledge where more training was needed eg; communicating with families around the death of a child.

P6: "You need to have the right information and training, for now I am competent, in order to be 100%, I still need more training. I am competent in self - acquired skills and little training I got last year. Otherwise I would like to do more PC training."

P7: "I want to learn more about working with families, I would not know what to do if I were to be in P12's situation…."

Some expressed concern around the lack of mentors in the field of PPC and the implications of this for the region going forward.

P14:" What does concern me is that there are not that many senior people /expert opinions. If it wasn't for Dr X, there is not that much paediatric published data. I worry service so reliant on Dr X".

Institutional issues:

While most HCW's appreciated the valuable contribution and difference adopting a PPC approach had made to the lives of children and families admitted to IPPCU at SFCCH, they raised several concerns in relation to the institution that impacted on the future. The perceived lack of support for PC at SFCCH was attributed, by some HCW's, to a lack of understanding of what PC (PPC) is with the unfortunate repercussion of compromising the quality-of-care children living with LL and LTC's were to receive at ICF.

P8:" I think management do not want to understand (PC) if they cannot see the value, they are never going to motivate it or feel for it, I will (continue to) give it my everything. They see it as an experience, maybe we should educate management… they don't understand what and why - goes right up to DOH".

P15: "Any place has ups and downs, politics get in the way, perhaps there is a lot of reluctance from management to come on board with PC because whether it is financial burden that PC places on the SF budget or fact that management does not understand PC, seems like a lot of blocking."

P6: "It's kind of sad: I don't know whether it is the DOH or management is not acknowledging PC…it's kind of sad not a common practice, it is so rare to find one (PPC IPU) I am feeling sad we do not have much support for that".

The lack of understanding extended to the availability of appropriate equipment needed to optimise quality of care. The lack of essential equipment placed HCW's under pressure to problem solve at times and make do with suboptimum equipment that compromised the quality of care they provided.

P5: "I get frustrated about supplies, that part I can't handle, I get bottled up about it."

P6:" Supply issue I am able to improvise eg: blocked (gastrostomy) tube, when the driver is taking (too) long, I think fast – one of my specialities is being a mechanic, I like to fix things."

*P4**: "**Challenge and frustration trying to work with management who have seemed resistant, not understanding PC who have seemed either paralysed or unmotivated to support the unit and try to advocate for what the ward needs".*

Several HCW's acknowledged the profound impact closure of the unit had on them as professionals as well as the implications for children and families requiring palliative care. They expressed a range of emotions in terms of feeling uncertain about what the future holds.

P1: "Shocking coming into the ward yesterday I did not know it was closed, hope it will be reopened".

P13: "If the unit does not open again what do I do??"

P6:" I am worried if SF PC is no more there is no other PCU then those children will have to suffer through there process of death and dying…. So that's my only problem."

P14: “People have remained positive there are a good staff that have stayed there - it is a difficult place to work. People should be encouraged to practice their passion you can’t keep them in their place. We have accomplished so much despite what has been thrown in front of us, sad for what could have been…”

Chapter 4: Discussion, Conclusion and Recommendations

4.1: Discussion

4.1.1: Health records

The number of children (n=25) that were enrolled on the study may be attributed to the relative low patient turnover at the time of the study. Of those referred for care, the majority (48%) of patients were referred for transitional care, 28% for terminal care, (16%) for respite care and (8%) for symptom management.

The significant demand for transitional care confirmed the need for care provision between acute hospital care services and the patient’s home. Intermediate care facilities (ICF’s) are considered halfway points between hospital and home and aim to prepare/equip patients and their families for home care / discharge (15). However, this goal is often unrealistic in the case of children living with LL and LTC’s. For example, when managing complex distressing symptoms which require access to specialised care and resources or in the case of providing oxygen to a patient in less resourced settings. In the case of the latter, oxygen may be administered via an oxygen concentrator only if the child’ s family have access to electricity and in many instances this basic need was not available. Hence an oxygen dependent child may well become ‘stuck’ at intermediate care. This study highlighted the gap in service in terms of providing alternative places of care where home care was not an option and supports Verbene et al’s findings that emphasises the importance of process-related aspects of care in relation to coordination of services to ensure continuity in care. (35)

Integral to the provision of any PPC service is the care and support of children and their families through the terminal phase of the child’s life with the aim of achieving a ‘good death’. In order to achieve a good death experience several factors need to be considered including preparation of the child (if appropriate) and their family for disease progression and dying, development of a clear plan that includes a realistic goal of care, that the child’s symptoms are optimally managed, and opportunities created for closure, legacy making etc. The IPPCU set out to offer this special kind of care in a home from home setting however to achieve this, several factors including appropriate resources, professional expertise and sufficient time to provide specialist care need to be ensured. The low death rate amongst the number of children referred for terminal care during the study period suggests the unpredictability of death in childhood and the need for staff and caregivers to constantly adapt to the changing healthcare needs of the child. This supports Stevenson et al’s (21) finding in terms of interactions with staff; families need to be prepared for what to expect throughout the course of their child’s disease trajectory and including the end -of -life phase.

Interestingly while symptom management was cited as a reason for admission in only 8% of patients; pain, secretion and seizure management emerged as significant symptoms. Pain was the most prevalent symptom, (44%) reflecting the underassessment and management of pain in children in referring institutions. Himmelstein (28) emphasises the importance of assessing and managing symptoms in children with PC needs. The reason for the significant number of symptoms assessed and subsequently treated may be attributed to the holistic nature of palliative care and the focus on impeccable assessment (1). Thus, symptoms that may have previously been missed, were identified during the patient’s stay at SFCCH and subsequently treated hereby improving the patient’s quality of life. The need for effective and consistent assessment and treatment of pain and other symptoms is further supported by Stevenson et al (21). Thus, access to drugs for oral, subcutaneous, nebulised, and rectal administration is essential to manage symptoms effectively. The lack of a formal plan / arrangement with District services to accommodate the change in quality and quantity of drugs required to provide effective symptom management at ICF level, made accessing drugs challenging.

The relative high number of children with a diagnosis of Cerebral Palsy (32%) accounted for the greater percentage of ACT Class IV represented. This non-progressive disability that rendered patient is vulnerable to health complications, required specialised attention and with limited permanent placement options contributed to the protracted length of stay. In addition, these children contribute to the group admitted for respite care and highlighted a notable gap in available services to meet this particular need. Horsburgh (38) raised the issue of the need for family caregivers to be given a break from caring for their child even if this be a scheduled and or emergency break. However sadly in the South African context, due to the lack of respite care services for children, it is virtually impossible for families to have time off from caring.

The study revealed that families benefited from equal amounts of medical and psychosocial counselling sessions alluding to the holistic nature of PPC provision. Considerably less family counselling sessions were conducted which may speak to the challenge of getting family members to the hospital due to financial pressures or work commitments. Stevenson et al (21) emphasised the need for information sharing sessions between family caregivers and a range of professionals as an important component of care. Therapy interventions alluded to the value of non-drug interventions with rehab, occupational, aroma and music therapy interventions primarily adopting this approach. Stevenson alludes to the need for patients to be soothed and comforted when managing pain and other distressing symptoms (21). All disciplines may integrate non - drug measures in their practice e.g., providing a warm soothing bath or and massage to manage a child presenting with constipation. It is important to note that the occupational therapist, speech therapist, dietician and four rehab care workers were new appointments and were shared between the rest of the hospital and the IPPCU. However, the aroma/massage therapist and music therapists were volunteers and visited the hospital once a week. Shafto et al acknowledged the contribution adopting an integrative approach made in reducing symptom burden for patients and their families (55).

Despite the stipulated LOS (15) of 42days, 60% of patients remained at the facility for between 48 and 183 days which reflects the challenges in placement of seriously ill children. The discharge of eight patients (32%) back into their home environment implies successful transitional care. However, only one patient was referred to home based care services which speaks to the lack of capacity of the HBC sector to accommodate the needs of paediatric patients in local communities as Campbell demonstrated in her study (30).

4.1.2: Primary Caregiver Group

The study revealed that despite most children being cared for by their biological parent/s, 64% of caregivers were single unemployed mothers. 56% of families received a monthly income of less than R 2500 /month and 24% of the families on the study received less than R1000/month. This is of particular significance since chronically ill children require a lot of resources and support and this task becomes increasingly more challenging in the absence of economic resources and family / social support networks. Himmelstein reminds us to consider the financial burden a child's illness may have placed on the family (28). Gans stressed the importance of family centred care and recognised the need *to include and support the family*, as integral components of caring for a child living with a long-term health condition (26).

The emotional and financial impact of caring for an affected child places significant strain on an already overstretched family dynamic and tests the primary caregiver's ability to respond adequately to the needs of other family members. Often the chronically ill child become the focus of attention, with the primary caregiver spending extended periods at the hospital bedside, away from the rest of the family.

The challenges primary caregivers of children with LLC's face in their day -to- day life, reflected in the significant levels of worry they report, even when they were not with their child. Another consideration in this respect is the impact that limited caregiver accommodation at the facility had causing the unnecessary separation of primary caregiver and child, resulting in further anxiety in both parties. Claasen argued that separating the child from their parents was a trauma and caused grief in the child thus motivating for rooming in facilities for caregivers to be common standard(56).

The fact that primary caregivers also derive spiritual and emotional strength from the experience of caring for their child, suggests that families possess an inherent sense of resilience that supports them through difficult times. Limardi et al referred to resilience as the ability to adjust to adversity or at particularly at times of stressful events(57). Primary caregivers experienced significant distress when seeing their child in pain affirming the need for parents to have their child's pain well-managed as described by Stevenson (21).

While 40% of primary caregivers from this study findings described caring for their child in the home environment as difficult, a significant number (84%) valued support and learning gained from nurses at the facility as it enabled them to take better care of their children. This speaks to the integral role nurses play in supporting the process of equipping family caregivers to respond to the care needs of their child as highlighted by Rallison and Moules (41). Rushton further emphasised the invaluable role paediatric nurses play in the successful integration of palliative care for children and families particularly during the terminal phase (42).

4.1.3: Health Care Workers Group

Findings from this study highlighted the importance of HCW's proficiency in PPC skills and knowledge, suggesting the need for ongoing education and training to be provided. Education has been foregrounded as key to the successful integration of palliative care into the public health sector and in 2014, the WHO member states initiated a global move to strengthen efforts in this respect (7,8). However, in South Africa, PPM is not a recognised specialty, as described by Hain (24) and although PC and PPC has been integrated into the curriculum of medical students, it has been slow to infiltrate other professional disciplines. Despite the absence of PPC education at undergraduate level, the majority (60%; n=9) of health care workers who took part in the focus group discussions had received formal PPC training at SFCCH, two HCW's were actively pursuing postgraduate studies in PPC and two HCW's had received informal training. The study highlighted the unique opportunity the experience of caring for children with PC needs provided HCW's with in terms of expanding their skill set as well as the need for ongoing palliative care training, supporting the recommendations made in a study conducted by Amery (31). However, in addition to formal training, consolidated by practical skills and experience, individuals needed more mentoring and support to optimise competency in the field.

The study revealed the strength and resilience of an experienced team who despite considerable uncertainty continued to acquire new skills and raise their standard of professional practice. In keeping with the WHO definition of PPC, the broad multidisciplinary team represented in the study reflect the diverse skill set required to provide holistic care for children living with LL and LTC's (1). HCW's spoke candidly about the personal challenges they experienced following the death of a child and while little is known about the impact of PPC on HCW's, studies suggest they may be at risk of burnout and compassion fatigue(5). Therefore, access to a reflective space that serves to contain the often complex and varied grief responses and coping mechanisms HCW's experience when their young patients die, is an essential step for team wellness (5).

The study highlighted the need for families to be treated with respect and to receive personalised culturally appropriate care and support. These key observations from families support the findings of a study Verbene and colleagues (35) conducted where families expressed appreciation and felt supported by paediatric palliative care teams they dealt with. In keeping with the WHO definition of PPC (1), families are important members of the caring team that support their child's holistic care and need to be included in their care.

The study revealed how difficulties in accessing essential resources (equipment and medicine) required HCW's to draw on their resourcefulness, creativity, and ingenuity in order to problem solve. Problem solving in this respect was not only time consuming but placed staff under pressure and compromised the quality of care offered to their patients because the HCW's attention was focused on solving the problem and away from the child and his /her family. Furthermore, despite policy provision for PPC delivery at ICF through the ICPF (15), a perceived lack of understanding of the fundamentals of PPC by management was considered a major stumble block to successful integration. WHA resolution (WHA67.19) speaks to the issue of adequate resources as an essential area of focus if palliative care services are to be strengthened and integrated into public health care systems (8).

Hence the CHT's broader vision of integrating paediatric palliative care at intermediate level was short lived in that the IPPCU closed its doors in June 2015, six months after the end of the CHT funding cycle. The service was withdrawn because the SFCCH's management and Board failed to convince the WC health authorities of its ability to sustain the service. This took place against a backdrop of mismanagement at the hospital that significantly compromised the integration of a PPC approach. The closure of the IPPCU resulted in beneficiaries being deprived of a service and once more left a gap in service provision.

However, in South Africa in May 2016, a national steering committee was appointed by the Minister of Health to assist the DOH to implement, monitor and evaluate progress towards achieving the WHA resolution. By April 2017 the National Health Council had approved the Policy Framework and Strategy for Palliative Care (NPFSPC). This shift on PC policy may have paved the way for a new opportunity to integrate PPC at intermediate level of care.

4.2: Conclusion

4.2.1: Health records

The review of health care records of children during the study period showed that children with a broad range of conditions were referred for palliative care. These included several conditions other than HIV and cancer as mostly cited in the literature from the developing world. The second highest group of children admitted had Cerebral Palsy requiring specialised care and support.

Health records further revealed that children had a range of symptoms and while pain emerged as the most prevalent symptom, in addition seizures, excessive secretions, gastro-intestinal and respiratory symptoms needed to be addressed. Trained health care workers assessed symptoms and included pharmacological and non-pharmacological measures in their management. Music therapy and aromatherapy massage are examples of non-pharmacological interventions that helped minimize symptoms and alleviate the child and family’s suffering. Furthermore, health records revealed a high number of therapies provided by allied health care providers that speak to the need for rehabilitative support for children with palliative care needs. These therapy interventions contributed towards the child’s holistic well-being and resulted in an improvement in their quality of life.

A significant number of counselling sessions took place during the time of the study which speaks to the need for regular and sustained communication between the team, the child (when appropriate) and his/her family. While families of children with

LL and LTC's need access to information about their child's diagnosis and prognosis, it was equally important to address their accompanying psychosocial and spiritual needs. Hence a broad team of health care workers that include nurses, doctors, psychosocial, allied health care professionals, and complimentary health practitioners are best suited to address the complexity of issues that require attention. It is important to attend to these unique set of care needs to relieve suffering and optimise quality of life for the child and his/her family.

In order to optimise response to the child's holistic care needs, adequate resources need to be available and consistently accessible. When essential resources are not readily available, the quality of response to the child's care needs may become compromised and this has the potential to exacerbate suffering and impact negatively on the child's quality of life.

The review of health records of children at the time of the study further revealed a number of long stays of children who were not able to be discharged due to poor social circumstances and a lack of community-based care. This speaks to the gap in support for this subset of children with specialised holistic care needs and to the need to optimise services to address this specific challenge.

In addition, health care workers must be mindful of the child's changing needs in relation to age and stage development and be ready to meet the child and their family at different levels of public health care service points, including at intermediate care. The latter is an important consideration and of particular significance for children and families living with LLC's as they transition between acute and community services.

4.2.2: Caregivers group

Primary caregivers shared experiences that highlighted some of the challenges they encounter when caring for the complex care needs of their children. The experience of caring for a child with a LL or LTC inevitably impacts on the caregiver's personal journey and in the study, they rose to the challenge cultivating resilience and remaining committed to ensuring that their child receive the best possible care.

However, caring for child with a LL or LTC came with significant stresses, reflected in the degrees of worry and anxiety primary caregiver's experience and some of the challenges experienced were around their emotional and financial burdens. What came through in this study's findings is congruent with available literature on the significant emotional burden caregivers carry. Experiences shared in this study suggested that to optimise their role in their child's care, primary caregivers need to be supported and affirmed. The significant number of single unemployed parents further emphasized the need for support after their child was discharged from the facility.

4.2.3: Health care worker's group

HCW's need to be assured access to PPC training and support and if this is not secured, quality of care may be compromised. For children living with LL and LTC's and their families to receive appropriate care at all points along the disease trajectory, HCW's need to be equipped with special skills and knowledge. These include the ability to assess and manage pain and other distressing symptoms, manage end of life care and to support the child and family's emotional, psychosocial and spiritual needs. The study affirmed the need for debriefing, supervision and mentoring as key components of this process.

In a PPC context, a team approach is essential and, in the study, HCW's benefited from working in a collaborative way and emerged as a committed team. To accommodate the multidimensional complex needs of child and his /her family, a diverse team was best able to provide individualised culturally sensitive care and support. In the study, team members, across disciplines, drew strength and learnt from each other and were thus able to provide the best care possible.

However, in order to support the HCW’s focus on the provision of quality care, access to essential resources must be ensured and the importance of this has been raised in the section under health records.

4.3: Recommendations

Findings of this study support the need to adopt a holistic approach when caring for children living with LL and LTC’s and their families. Primary caregivers are key role players in their child’s care and all efforts to acknowledge their value and support their endeavours to want the best care for their children must be prioritised. This includes minimising separation from their children. To provide specialised care, a diverse group of healthcare workers, equipped with appropriate skills and knowledge is recommended. Most importantly, resources must be secured for this to happen.

Further research is recommended to provide greater insight into the cost implications of caring for children living with LL and LTC’s across care settings. For example, it would be helpful to compare costs when providing terminal care within an acute hospital context vs an ICF especially considering unpredictable disease trajectories. This is important when considering the best suited location for addressing the holistic care needs of children within public health structures and has implications for planning budgets across provincial departments.

Further research is also recommended in terms of determining placement centres for children with long term health conditions unable to be discharged into their home environment.

Key to the successful integration of high quality PPC is securing support from strategic role players. This would include buy in from management as well as support from government so as to ensure sustained supportive care for children living with LL and LTC’s and their families.

4.4: Limitations of the study

Health care records: The small sample size of 25 patients was a limitation of the study and a result of low patient turnover during the 6-month study period. In addition, the number of children needing permanent placement staying for long periods of time at SFCCH due to lack of available beds in long term care facilities impacted on low numbers.

Primary caregivers: The study was limited in that primary caregivers who were not available to participate may have biased the research to include the more involved and possibly less socially or psychologically affected parents/caregivers. The researcher was not based at the study site and thus relied on staff members to assist with the coordination of meetings between primary caregivers and the researcher. These meetings were often not honoured by the primary caregiver further compromising time the researcher was able to spend with primary caregivers. The caregiver burden tool could have been clearer e. g: the question on whether the primary caregiver had other children could have been better phrased.

Health care workers: Although the health care workers were purposively sampled, there was also self-selection as many junior staff members declined to partake in the study. However, the study was conducted at a time when there was a lot of uncertainty about the future of the unit and this may have influenced some of staff member's willingness to participate in the focus group discussions. Possibly those who did not participate did not have as positive an experience as those who did partake in the study. Results may differ if HCW's were interviewed more than once or one on one and not as a group.

4.5: Strengths of the study

During the literature review for the study, the researcher discovered a paucity of literature on the subject in South Africa. Thus, this is the first known study that set out to describe holistic care needs of children and the experiences of their families and health care workers at ICF level in SA. A key strength of the present study is that it could serve as a guide for regional case workers and policy makers interested in developing PPC services at this level.

REFERENCES:

(1) Muckaden M, Dighe M, Balaji P, Dhiliwal S, Tilve P, Jadhav S, et al. Paediatric palliative care: theory to practice. Indian J Palliat Care 2011 Jan;17(Suppl): S52-60.

(2) 'Koch K JB. Supporting Parent Caregivers of Children with Life-Limiting Illness. J Children (Basel) 2018 July 2018;5(7):. Published online 2018 Jun 26. doi: 10.3390/children5070085 PMCID: PMC6069074.

(3) "Downing Julia, Ling J, Benini F , Payne S, Papadatou D". Core competencies for education in Paediatric Palliative Care. 2013 November 2013.

(4) "Knaul FMea. **Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the report.** Lancet Commission 2017 October 12, 2017.

(5) 'Liben S, Papadatou D, Wolfe J'. Paediatric palliative care: challenges and emerging ideas . Lancet 2008 March 8, 2008;371(DOI:10.1016/S0140-6736(07)61203-3):852-864.

(6) 'Chambers L editor. A Guide to Children's Palliative Care. Fourth Edition ed. England.: Together for Short Lives; 2018.

(7) Stjernswärd J. Palliative care: the public health strategy. J Public Health Policy 2007 01/01;28(1):42-55.

(8) WHO. **World Health Assembly (WHA) resolution WHA67.19** Available at: http://www.who/int/mediacentre/factsheet/fs402/en/. Accessed October 9, 2015.

(9) 'Downing Jea. Priorities for global research. Research gate Aug 2015.

(10) Connor SS, C. UNICEF / ICPCN Assessment of the Need for Palliative Care for Children: Three Country Report: South Africa, Kenya and Zimbabwe. ;November 2013.

(11) Connor Sea. Assessment of the need for palliative care for children in South Africa. International Journal of Palliative Nursing 2014;20(3).

(12) Connor, S. Downing, J. Marston, J. Estimating the global need for palliative care for children: A cross-sectional analysis. Pain Symptom Management 2017;53(2):171.

(13) Robertson A. Chronic conditions in children. South African Health Review 2006;2006(1):257 - 270.

(14) Mayosi B. The burden of non-communicable diseases in South Africa. The Lancet 2009 September 2009;374(9693):934-947.

(15) Western Cape Government. Intermediate Care Policy Framework. Department of Health 2012 September 2012.

(16) 'Meiring M. Caring for children with life-limiting and life-threatening illnesses: what the gp should know. . J Continuing Medical Education 2011;29(7).

(17) Legal wise. Parental rights and responsibilities. Available at: https://www.legalwise.co.za/help-yourself/legal-articles/parental-rights-and-responsibilities.

(18) WHO. https://www.who.int/topics/health_policy/en/.

(19) Walt GG, L. Reforming the health sector in developing countries: the central role of policy analysis. Health Policy and Planning 1994;9(4):353-370.

(20) Ghaffar , A et al. Where is the policy in health policy and systems research agenda?

Bull World Health Organ. 2016 Apr 1; 94(4): 306–308. Published online 2015 Mar 2. doi: 10.2471/BLT.15.156281. Bulletin of World Health Organisation 2016;94(4):306-308.

(21) Stevenson.M. Achille, M. Lugasi, T. Pediatric Palliative Care in Canada and the United States: A Qualitative Metasummary of the Needs of Patients and Families Palliative Medicine 2013;16(5):566-576.

(22) Hain R. Palliative care in children in Wales: a study of provision and need. Palliat Med 2005 03;19(2):137-142.

(23) Biography.com Editors. Cicely Saunders Biography. February 5, 2016; Available at: https://www.biography.com/people/cicely-saunders-9472419. Accessed November 7, 2018.

(24) Hain R. Paediatric palliative medicine in the UK:past, present and future. Arch Dis Child 2012;12:November 8, 2014-381-384.

(25) Toce SC, M. The FOOTPRINTS model of paediatric palliative care. Palliative medicine 2004;6(6):989-1000.

(26) Gans D, Kominski GF, Roby DH, Diamant AL, Chen X, Lin W, et al. Better outcomes, lower costs: palliative care program reduces stress, costs of care for children with life-threatening conditions. Policy Brief UCLA Cent Health Policy Res 2012 Aug;(PB2012-3)(PB2012-3):1-8.

(27) Knapp Cea. Partners in Care: Togetther for Kids: Florida's Model of Paediatric Palliative Care. Palliative Medicine 2008;11(9):1212 -1220.

(28) Himelstein BP, Hilden JM, Boldt AM, Weissman D. Pediatric palliative care. N Engl J Med 2004;350(17):1752-1762.

(29) Graham RJ, Robinson WM. Integrating palliative care into chronic care for children with severe neurodevelopmental disabilities. J Dev Behav Pediatr 2005 Oct;26(5):361-365.

(30) Campbell L. Children’s Palliative Care in South Africa: An urgent need for an evidence base. . J South African HIV medicine 2011 April 2011.

(31) Amery Jea. The beginnings of children's palliative care in Africa: Evaluation of a children's palliative care service in Africa . Palliative Medicine 2009;12(11):1015-1021.

(32) Jagwe JMA. Palliative Medicine, an Urgent Public Health Need in the Developing World JACK JAGWE and. Public Health Policy 2007;28:40-41.

(33) Knapp, C. Fowler-Kerry, S. Madden, V editor. Pediatric Palliative Care: Global Perspectives. New York: Springer; 2012.

(34) Gans Dea. Impact of a pediatric palliative care program on the caregiver experience. Journal of Hospice and Palliative Nursing 2015 01-01-2015;17(6):1-12.

(35) Verbene Lea. Parental experiences with a paediatric palliative care team: A qualitative study. Palliative Medicine 2017:1-8.

(36) Eaton N. 'I don't know how we coped before': a study of respite care for children in the home and hospice. J Clin Nurs 2008 12;17(23):3196-3204.

(37) deJong-Berg MA, deVlaming D. Bereavement care for families part 1: a review of a paediatric follow-up programme. Int J Palliat Nurs 2005 Oct;11(10):533-539.

(38) Horsburgh M, Trenholme A, Huckle T. Paediatric respite care: a literature review from New Zealand. Palliat Med 2002 Mar;16(2):99-105.

(39) WHO. Planning and implementing palliative care services: a guide for programme managers. 2016; Available at: http://www.who.int/iris/handle/10665/250584. Accessed November 9, 2017.

(40) Maynard LL, D. Innovative approach to providing 24/7 palliative care for children. Nursing Care and Young People 2014;26(6):29-34.

(41) Rallison LM, N. The Unspeakable Nature of Pediatric Palliative Care: Unveiling Many Cloaks. Family Nursing 2004;10(3):March 2018-287-301.

(42) Rushton CH. A Framework for Integrated Pediatric Palliative Care: Being with Dying. Paediatric Nursing 2005;20(5):311- 325.

(43) Hain RDW. Paediatric palliative medicine: a unique challenge. Pediatr Rehabil 2004 04/20;7(2):79-84.

(44) Creswell JW editor. Educational research: Planning, conducting, and evaluating quantitative and qualitative research. 4th Edition ed. Boston, MA: Pearson; 2012.

(45) Glass, Gene V, Hopkins,Kenneth D.,. Statistical methods in education and psychology. Englewood Cliffs, N.J.: Prentice-Hall; 1984.

(46) Aggarwal R, Ranganathan P. Study designs: Part 2 – Descriptive studies**.** Perspectives in Clinical Research 2019.

(47) Teddlie C, Yu F. Mixed Methods Sampling: A Typology With Examples. Journal of Mixed Methods Research 2007; 1:77 -99.

(48) Glajchen M, et al. Development of a Brief Assessment Scale for Caregivers of the Medically Ill. Journal of Pain and Symptom Management 2005; 29:245-254.

(49) Ingham-Broomfield R. A nurses' guide to Quantitative Research. Austrian Advanced Nursiung ;32(2):32-38.

(50) Clark V, Braun V. Thematic Analysis. J Positive Psychology 2017;12(3):297-298.

(51) Cypress B. Rigor or Reliability and Validity in Qualitative Research: Perspectives, Strategies, Reconceptualization, and Recommendations.
. Dimensions of Critical Care 2017;36(4).

(52) Middleton F. Reliability vs validity: what's the difference? 2020; Available at: https://www.scribbr.com/methodology/reliability-vs-validity/. Accessed 7/2020, 2020.

(53) Deakin University. What do I need to keep and for how long? Available at: https://www.deakin.edu.au/library/research/manage-data/store/what-data-do-i-need-to-keep-and-for-how-long. Accessed 08/2020.

(54) Luo A. What is content analysis and how can you use it in your research? Date published July 18, 2019 by Amy Luo. Date updated: June 19, 2020; Available at: https://www.scribbr.com/methodology/content-analysis/. Accessed 15 July 2020, 2020.

(55) Shafto, K. Gouda, S. Catrine, K. Brown, M. Integrative Approaches in Pediatric Palliative Care. Children 13 June 2018;5(75):2-12.

(56) Claasen C. Pediatric palliative care - The role of the patient's family
. World J Clin Pediatr 2012;1(3):13-19.

(57) Limardi S, et al. Caregiver resilience in palliative care: A research protocol
· .Journal of Advanced Nursing 2015 October 2015;72(2).

Appendix 1

INFORMATION SHEET (for primary caregivers)

Is the Western Cape Government's Health Intermediate Policy Framework sufficient to meet the needs of paediatric palliative care patients and their families at Sarah Fox Children's Convalescent Hospital?

Thank you for giving your time to hear about this study. This study is organized by Sister Alex Daniels as part of a Master's Degree in Palliative Care at the University of Cape Town, South Africa.

The study would like to find out whether the Western Cape government's plan to have Sarah Fox Convalescent Children's Hospital look after sick children considers all factors required to offer this kind of care. The study will explore some of these factors by 1) finding out about the kind of illnesses the children have and what their particular needs are and 2) finding out from primary caregivers about their experiences of caring for their child.

The researcher seeks to:

i) conduct a file review - record information from the patient's file to learn more about what kind of care the child received while at the hospital e.g.; what kind of care was required, which medicines were used, what kind of service was offered

ii) request that primary caregivers complete a three-part questionnaire with questions asking about the experience of caring for their sick child.

If you agree to participate, you will be asked to sign a consent form, which shows that you have agreed to the file review and questionnaire.

All the information which is collected during the file review and questionnaire will be kept confidential. You will not be identified in any way, and your personal details will be kept separate from the information you give. No-one other than the researcher will have access to the information you give.

There are no direct benefits to the study for participants. The anticipated benefit is that the study outcome will assist in identifying best practice, skills and gaps in the care of children and families with palliative care needs at an intermediate care facility.

Feedback on the study outcome will be given to participants, the management of Sarah Fox Hospital, Children' s Hospital Trust and Western Cape Government Health. The study will be presented at training institutions and conferences and submitted for publication.

Contact details:

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Appendix 2

CONSENT FORM (Primary caregiver)

Is the Western Cape Government's Health Intermediate Policy Framework sufficient to meet the needs of paediatric palliative care patients and their families at Sarah Fox Children's Convalescent Hospital?

1. I confirm that I have read the study information or the study information has been explained to me and I have had an opportunity to ask questions.
2. I understand that there will be no way of linking my consent form to the questionnaire I will complete and my answers will remain confidential.
3. I understand that my participation is voluntary and I am free to withdraw at any time during the study without giving any reason.
4. I have been provided with a telephone number of a person to contact should I need to speak about any issues that may arise whilst completing this questionnaire.
5. I agree to take part in this study.

____
Participants name

________________________ ________________________
Signature of Participant Date

____
Signature of Researcher

Appendix 3

CASE REPORT FORM

Case number:	
Age:	Gender:
Primary caregiver’s relationship to child:	Length of care of primary caregiver:
Primary diagnosis:	ICD code:
Reason for admission:	
Admission date:	Discharge date:
Medical interventions: • Acute care • Symptom control: • Pain management • Symptoms other than pain: ○ Dyspnoea ○ Nausea ○ Constipation ○ Fatigue ○ Irritability ○ Seizures ○ Diarrhoea ○ Oral thrush Clinical examination time: Telephonic consultation time:	Psycho social interventions: 6Bereavement counselling: How many minutes? 1Medical counselling (Dr +another team member): How many minutes? 2Sibling support: How many minutes? 3Counselling session (caregiver with S/W: How many minutes? 4Counselling session (child with S/W: How many minutes? 5Family meeting: How many minutes? Aromatherapy: How many minutes? Music therapy: How many minutes? Art therapy: How many minutes?
MDT time:	
Symptom control drugs used:	Total amount of Opioids used:
Outcome:	Referred to:

Comments:	

Appendix 4

INFORMATION SHEET (health care professionals)

Is the Western Cape Government's Health Intermediate Policy Framework sufficient to meet the needs of paediatric palliative care patients and their families at Sarah Fox Children's Convalescent Hospital?

Thank you for giving your time to hear about this study. This study is organized by Sister Alex Daniels as an undertaking of a Master's Degree in Palliative Care at the University of Cape Town, South Africa. The study seeks to assess the Intermediate Care Policy Framework's ability to meet the needs of children and their families admitted to the new inpatient palliative care unit at Sarah Fox Convalescent Children's Hospital. The study will focus on the profile of patients and their needs; explore the experiences of caregivers in the care of their child and explore the experiences of staff providing care at the facility.

The researcher requests that staff members complete a demographic sheet and partake in focus group discussions. If you agree to participate, you will be asked to sign a consent form, which shows that you have agreed to the demographic sheet and to partake in the focus group discussions.

All the information which is collected from the demographic sheet and focus group discussions will be kept confidential. You will not be identified in any way, and your personal details will be kept separate from the information you give. No-one other than the researcher will have access to the information you give.

There are no direct benefits to the study for participants. The anticipated benefit is that the study outcome will assist in identifying best practice, skills and gaps in the care of children and families with palliative care needs at an intermediate care facility.

Feedback on the study outcome will be given to participants, the management of Sarah Fox Hospital, the Children' s Hospital Trust and Western Cape Government Health. The study will be presented at training institutions and conferences and submitted for publication.

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Appendix 5

CONSENT FORM (HCP)

Is the Western Cape Government's Health Intermediate Policy Framework sufficient to meet the needs of paediatric palliative care patients and their families at Sarah Fox Convalescent Children's Hospital

1. I confirm that I have read the study information or the study information has been explained to me and I have had an opportunity to ask questions.
2. I understand that there will be no way of linking my consent form to the questionnaire I will complete and my answers will remain confidential.
3. I understand that my participation is voluntary and I am free to withdraw at any time during the study without giving any reason.
4. I have been provided with a telephone number of a person to contact should I need to speak about any issues that may arise whilst completing this questionnaire.
5. I understand that although focus group discussions will be recorded, participants contributions will remain anonymous and confidentiality cannot be guaranteed
6. I agree to take part in this study.

____
Participants name

_________________________ _________________________
Signature of Participant Date

____
Signature of Researcher

Appendix 6

DEMOGRAPHIC SHEET FOR STAFF MEMBERS

Case number:		
Category of staff:		
Permanent:	Contract:	Volunteer:
Age:	Gender:	
Qualifications:		
Additional experience:		
Palliative care training:		
Additional comments		

Appendix 7

FOCUS GROUP GUIDE

Is the Western Cape Department of Health's Intermediate Care Policy Framework sufficient to meet the needs of paediatric palliative care patients and their families at Sarah Fox Convalescent Children's Hospital?

Preamble: Caring for children with palliative care needs is a new experience at Intermediate level of the public health system. Health care professionals placed at this level of care are ideally placed to gain insight into the care needs of this group of children and their families. The experience of accompanying children and families on their journey might prompt the professional to embark on a personal journey of their own. This group discussion therefore provides an opportunity for each individual to share and explore with others their own experiences. Please use whatever language you prefer in this discussion.

Questions:

I would like to start by inviting each of you to reflect on the work you do here at Sarah Fox, the children and their families you care for and your experience relating to your work.

1. What has been a highlight in your experience in working with children with palliative care needs? (Objective 1)
2. What do you notice about families of children admitted to the palliative care unit? (Objective 4 or 5)
3. What are the pros and cons of working in the palliative care unit? (Objective 3 or 4)
4. How equipped do you feel in your ability to care for children with palliative care needs? (Objective 2 and 3)

5. How equipped do you think the team is in caring for children with palliative care needs? (objective 2 and 3)
6. How did you feel when a child you cared for died? (Objective 3 and 4)

7. Is there anything more you would like to say about your experience in caring for children and families with palliative care needs?
   (Objective 3 or 4)

Appendix 8

SARAH FOX CHILDREN'S CONVALESCENT HOSPITAL

CAPE CHILD HEALTH ASSOCIATION - W. O. No. 2433
FR No. 088001560004

SARAH FOX KINDER HERSTELLINGSHOSPITAAL

KAAPLANDSE KINDERGESONDHEIDSVERENIGING - W.O. No. 2433
FR No. 088001560004

Tel: 021 637 1302
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REG. no.: 003 - 036 NPO

6 PETUNIA ROAD
SILVERTOWN
ATHLONE 7764
CAPE/KAAP

INTERNAL MEMORANDUM

To	To whom it may concern
From	Mrs F Marola Hospital Administrator
CC	Mr Peter Pienaar Chairperson of board
Subject	Permission to conduct research - Access to patient files, participation of primary caregivers and staff members
Date	30 October 2014

Permission is hereby granted to Sr A. Daniels to conduct research in the In patient palliative care unit at Sarah Fox Children's Convalescent Hospital.

The research study is entitled : Is the Western Cape Department of Health's Intermediate Care Policy Framework sufficient to meet the needs of paediatric palliative care patients and their families at Sarah Fox Convalescent Children's Hospital?

The research proposal was submitted to the Human Research Ethics Committee (FHS - HREC) at UCT for research approval.

Informed consent will be signed by all participants and confidentiality will be observed by all means.

Kind regards

Mrs F. Marola
Hospital Administrator
(Sarah Fox Convalescent Children's Hospital)

APPENDIX 9

ASSENT FORM FOR CHILDREN (< 13years)

Read and explain the following to the child in a language s/he can understand when s/he has assented to talk:

- **What is the aim of the study:** The aim of the study is to find out if you are receiving all the care that you need for your illness.
- **Who is doing the study**? This study is organized by Sister Alex Daniels as part of a Master's Degree in Palliative Care at the University of Cape Town,
- **Why is this study being done?** This study is being done so that we can find out more about the care you need for your illness and identify areas where we need to give better care to children like you and their families.
- What will happen during the study? I will examine your hospital folder and write down information about your illness and details about your stay in the hospital eg; what kind of medicine you need.
- Who will know about what I did in the study? No one will know apart from your parent/ legal guardian and the few people doing the study; no else will know that you are involved.
- Can I decide if I want to be in the study? You can decide to be in the study or not. Nobody will be angry or upset if you do not want to be in the study. I will ask the person caring for you (parent/legal guardian) for permission to partake in the study. I will be asking them to complete a questionnaire about their experience of caring for you.
- Are there good things and bad things about the study? The good thing about the study is that we will learn more about the care you are receiving and find out what care you are not receiving. Some of the questions I ask your caregiver, may be hard to answer. If your caregiver is sad and does not want to talk, this is fine. The caregiver will not be forced to talk, we will stop and someone will comfort / take care of him/her.

NB: This assent form will be used for verbal children aged 7 years to 13 years.
Adapted from assent form used by the African Palliative Care Associations Palliative Care Outcomes Scale validation study 2012.

Appendix 10

ASSENT FORM FOR CHILDREN (> 13years)

Allow the child to read and clarify the following to the child in a language s/he can understand when s/he has assented to talk:

- **What is the aim of the study:** The aim of the study is to find out if you and your family are receiving all the care that you need for your illness.

- **Who is doing the study**? This study is organized by Sister Alex Daniels as part of a Master's Degree in Palliative Care at the University of Cape Town,

- **Why is this study being done?** This study is being done so that we can find out more about the care you need for your illness and identify areas where we need to give better care to children like you and their families.

- What will happen during the study? I will examine your hospital folder and record information about your illness and details about your stay in the hospital e.g.: what kind of medicine you need?

- Who will know about what I did in the study? No one will know apart from your parent/ legal guardian and the few people doing the study; no else will know that you are involved.

- Can I decide if I want to be in the study? You can decide to be in the study or not. Nobody will be angry or upset if you do not want to be in the study. I will ask the person caring for you (parent/legal guardian) for permission to partake in the study. I will be asking them to complete a questionnaire about their experience of caring for you.

- Are there good things and bad things about the study? The good thing about the study is that we will learn more about the care you are receiving and find out what care you are not receiving. Some of the questions I ask your caregiver, may be hard to answer. If your caregiver is sad and does not want to talk, this is fine. The caregiver will not be forced to talk, we will stop and someone will comfort / take care of him/her.

NB: This assent form will be used for verbal children aged 13 years to 17 years.
Adapted from assent form used by the African Palliative Care Associations Palliative Care Outcomes Scale validation study 2012.

Appendix 11

INFORMATION SHEET (for major participants 18 years)

Is the Western Cape Government's Health Intermediate Care Policy Framework sufficient to meet the needs of paediatric palliative care patients and their families at Sarah Fox Children's Convalescent Hospital?

Thank you for giving your time to hear about this study. This study is organized by Sister Alex Daniels as part of a Master's Degree in Palliative Care at the University of Cape Town, South Africa.

The study would like to find out whether the Western Cape government's plan to have Sarah Fox Convalescent Children's Hospital look after sick children considers all factors required to offer this kind of care. The study will explore some of these factors by 1) finding out about the kind of illnesses the children have and what their particular needs are and 2) finding out from primary caregivers about their experiences of caring for their child.

The researcher seeks to:

iii) conduct a file review - record information from the patient's file to learn more about what kind of care the child received while at the hospital e.g.; what kind of care was required, which medicines were used, what kind of service was offered

iv) request that primary caregivers complete a three-part questionnaire with questions asking about the experience of caring for their sick child.

If you agree to participate, you will be asked to sign a consent form, which shows that you have agreed to the file review and questionnaire.
All the information which is collected during the file review and questionnaire will be kept confidential. You will not be identified in any way, and your personal details will be kept separate from the information you give. No-one other than the researcher will have access to the information you give.

There are no direct benefits to the study for participants. The anticipated benefit is that the study outcome will assist in identifying best practice, skills and gaps in the care of children and families with palliative care needs at an intermediate care facility.
Feedback on the study outcome will be given to participants, the management of Sarah Fox Hospital, Children' s Hospital Trust and Western Cape Government Health. The study will be presented at training institutions and conferences and submitted for publication.

Contact details:

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Faculty of Health Sciences
Human Research Ethics Committee
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Appendix 12

Informed consent (major participants)

I have read this information (or had the information read to me) I have had my questions answered and know that I can ask questions later if I have them.

I agree to take part in the research.

OR

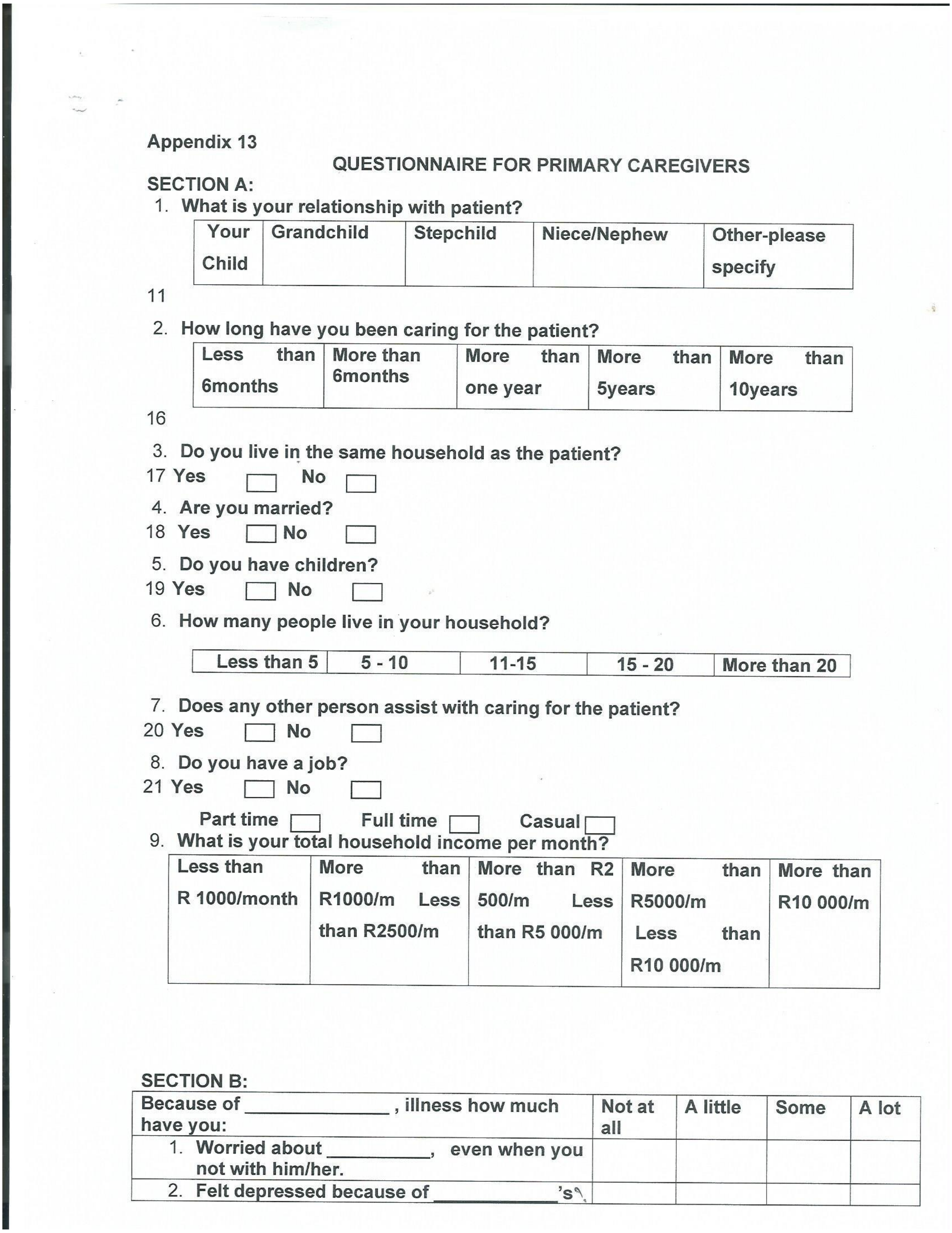
I do not wish to take part in the research and I have not signed the assent below.___________ (initialled by child/minor)

Only if child assents:

Print name of child ___________________

Signature of child: ____________________

Date: ________________



Appendix 13

QUESTIONNAIRE FOR PRIMARY CAREGIVERS

SECTION A:

1. What is your relationship with patient?

Your Child	Grandchild	Stepchild	Niece/Nephew	Other-please specify

11

2. How long have you been caring for the patient?

Less than 6months	More than 6months	More than one year	More than 5years	More than 10years

16

3. Do you live in the same household as the patient?

17 Yes ☐ No ☐

4. Are you married?

18 Yes ☐ No ☐

5. Do you have children?

19 Yes ☐ No ☐

6. How many people live in your household?

Less than 5	5 - 10	11-15	15 - 20	More than 20

7. Does any other person assist with caring for the patient?

20 Yes ☐ No ☐

8. Do you have a job?

21 Yes ☐ No ☐

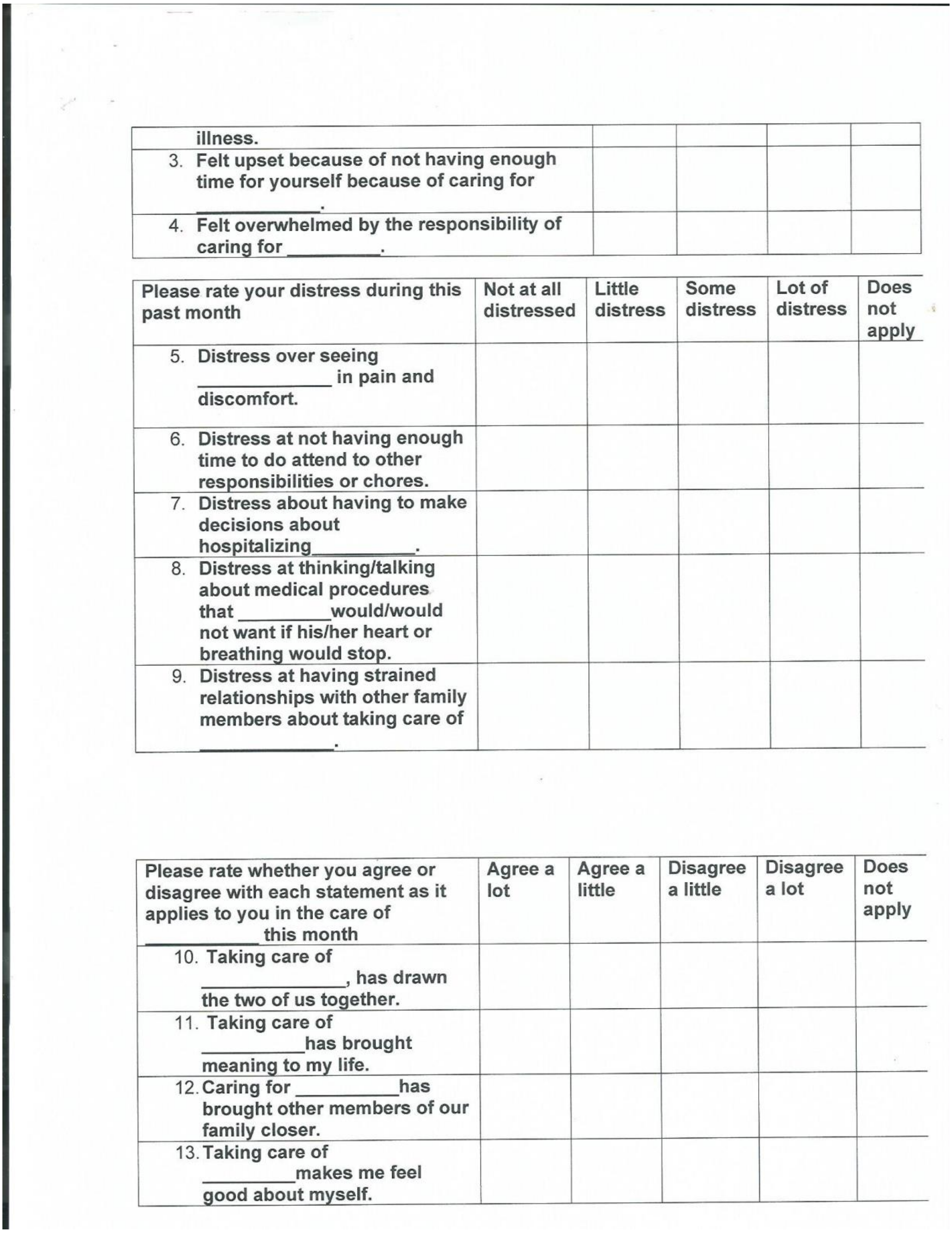
Part time ☐ Full time ☐ Casual ☐

9. What is your total household income per month?

Less than R 1000/month	More than R1000/m Less than R2500/m	More than R2 500/m Less than R5 000/m	More than R5000/m Less than R10 000/m	More than R10 000/m

SECTION B:

Because of ____________, illness how much have you:	Not at all	A little	Some	A lot
1. Worried about __________, even when you not with him/her.				
2. Felt depressed because of ____________'s				



illness.				
3. Felt upset because of not having enough time for yourself because of caring for ____________.				
4. Felt overwhelmed by the responsibility of caring for __________.				

Please rate your distress during this past month	Not at all distressed	Little distress	Some distress	Lot of distress	Does not apply
5. Distress over seeing ______________ in pain and discomfort.					
6. Distress at not having enough time to do attend to other responsibilities or chores.					
7. Distress about having to make decisions about hospitalizing___________.					
8. Distress at thinking/talking about medical procedures that _________would/would not want if his/her heart or breathing would stop.					
9. Distress at having strained relationships with other family members about taking care of ______________.					

Please rate whether you agree or disagree with each statement as it applies to you in the care of ____________ this month	Agree a lot	Agree a little	Disagree a little	Disagree a lot	Does not apply
10. Taking care of ______________, has drawn the two of us together.					
11. Taking care of __________has brought meaning to my life.					
12. Caring for __________has brought other members of our family closer.					
13. Taking care of _________makes me feel good about myself.					