University of
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“We matter too”:
Needs of parents caregivers of children with disabilities and their experiences with the healthcare system.

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Abstract

Due to a decrease in manpower, the Norwegian healthcare system has been plagued with a shortage of healthcare professionals which puts parents as the front runners for the long-term care of their children with disability. Yet their expertise and significant contribution in the field of informal caregiving has gone unnoticed by the healthcare system. This new role placed on parents has created a burden which has caused physical, psychological, and emotional burden and has been left unmet by the healthcare system. This study explores the needs of parent caregivers, their experience with the healthcare system and the coping mechanisms used in their caregiving role. An inductive qualitative research approach was taken, using an in-depth semi-structured interview guide on eight parent caregivers who had children with disability. Thematic analysis was used in analyzing the interview data and was divided into themes and sub-themes. Findings from the study show that parents caregivers, as much as the children they cared for, need physiological and psychological support to cope with the continuous but difficult tasks of caring for their children with disability. Although, some of these parents have been able to develop some form of coping mechanisms through social networking and supports from families and friends. Nonetheless, the research posits for the possibility of a joint effort between the healthcare system and the parents' caregivers to find better ways to support each other.

Abbreviation List

AAP - Work Assessment Allowance (in Norway)

ADHD - Attention Deficit Hyperactivity Disorder

PKU - Phenylketonuria

SFO - Skole Fritids Ordning (After child care in Norway)

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CHAPTER ONE

INTRODUCTION

This chapter will begin with a background on parent caregivers and a definition of disability, looking at why the study on parent caregivers should be conducted, the significance of the study, research aim, research question, scope of the study and lastly the organization of the study.

1.1 Background

Globally, it has been estimated that over 93 million children are living with one form of disability or the other (UNICEF, 2013) and the number increases due to population growth. Of the 5.3 million population in Norway, over 800,000 people are caring for the sick, disabled and/or old and dependent family members and friends (Eurocarers, 2019). Twenty percent provide regular informal care, while 4.4 percent participate in unpaid voluntary work in long-term care to a person with disability who requires special care while (Skinner et al., 2020). For a welfare model which has been characterised with universal rights and service and benefits to all, there has been a decline in healthcare workers and manpower due to the decrease in birth rate and the increase in growth of the elderly population, thereby making family members and friends take up the responsibility to be sole providers of about 50% of the care (Norwegian Ministry of Health and care services, 2018). As of the time of this research, there was no data on the number of children with disability in Norway.

Disability is defined as an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations (Sharma, 2014; World Health Organization & World Bank, 2011) . Most individuals born with the disability and are diagnosed at birth while some are discovered during early childhood stage, some individuals became disabled later in life due to an illness or injury (Disabled-world, 2020). A child’s disability is not only experienced by the child and their immediate family or environment, but all other factors and variables surrounding them are affected by the disability. Though caring of these children with disabilities are usually with family members or close kin, especially their parents, but children are naturally dependent on their primary caregivers for survival, growth and development; therefore, a child with a disability will place more burden and dependency on their caregivers due to the burden affecting their health (Schulz et al., 1990; Marks, 1996; Wong et al., 2004).

In the early days, parents who were primary informal caregivers were assumed to be inexperienced and ignorant when contributing in the responsibility of professional medical care while the professionals were reserved the mantle of experts in the field of providing care (Beltman, 2001), research has proven that parents have gained more knowledge and experience during the cause of their care to their children and their assistance and cooperation is essential to the growth and development of the child/children (de Geeter et al., 2002). The parents' caregiver's role in the healthcare system is of significant importance to both the recipient and the system; but these parents are made less visible by the overall healthcare system by being characterized as "hidden healthcare system" (Verbakel et al., 2017). Caregivers may be characterized as hidden care system because they are mostly not certified and lack properly formal training. However, Stajduhar et al. (2010) wrote on the role they play in the health system and points to the fact of caregivers being the backbone of healthcare and permanent informal caregivers to family members, and also they provide social care services to the recipient. The society will be doing some justice if the healthcare system becomes aware by recognising and placing value on the expertise of these parents (Thwala et al., 2015). On the 31st of October 2019, President Donald Trump of The United States of America declared the month of November as a National Family Caregivers' month. He acknowledges that caregivers have played a vital role in the country through their enormous sacrifice in taking care of family members and further pledged support to their course by providing resources for their wellbeing while equipping them with the tools needed to take care of their loved ones (Trump, 2019).

The state of shock, denial, grief, anger, depression, sorrow and more stress are emotions parents feel when caring for a child with a disability when compared to families without children with disability; these emotional effects are a problem to the family dynamics (Degeneffe et al., 2018; Johnson, 2000). Families of children with disabilities are usually faced with numerous challenges and difficulties at different stages of their lives when compared with other families. They are usually faced with the needs for assistance and economic support to enable them to give their children the best life has to offer (Gundersen, 2012). Research has shown that the lifelong care of a child with disability places parents caregivers in poor emotional, physical and psychological health (Murphy et al., 2007). Taking care of a child with a disability is lifelong care, which requires the caregiver being in a good state of mind. Caregivers place a great deal of energy and effort toward the health and well-being of the care recipient (Kvarme et al., 2016), likewise, when they lack basic support and resources necessary for care, it creates huge financial, physical, emotional and psychosocial effects on them (Zarit & Whitlatch, 1992) and this can impact the health and quality of life of the caregiver and the care they provide (Bastawrous, 2013; Kvarme et al., 2016). Most parents engage in multiple roles in their lives (parent, partner, taxi driver, diary keeper, nurse, physiotherapist), but the roles of parent caregivers of children with disabilities are usually additional (administering enteral feeds, giving medications, and clinical care), which requires one to be in a good state of mind for the benefit of those under their care (Whiting, 2014).

Parents who cared for children with disability were reported to require information, support (from both family and healthcare practitioners), accessible community services and finances. These needs were related to other variables such as the age of both the child and parents, the education received by the child, the number of siblings, marital status of parents, family income, parents' level of education and family's participation in support services. Families who had younger children with disabilities had more pressing needs than those whose children were older (Ellis et al., 2002). However, parent caregivers' needs are multidimensional and can be affected positively and negatively by these variables (Fletcher et al., 2012; Yuen et al., 2016).

Caregiving is no doubt a complex long-term process which requires that most caregivers need to be constantly motivated in order to continuously adapt to the experience of providing care and support for the recipients (Dombestein et al., 2019; Quinn et al., 2010).

1.2 Problem statement

The United Nations Convention on the rights of persons with disabilities to which Norway is a signatory places the rights and interest of persons with disabilities as that which is of utmost priority, and the state shall also respect the rights and obligations of their parents or guardians to provide the person with the guidance in asserting the rights of the convention; both parents have the responsibility for the child's care and development according to what is best for the child. The state shall also provide support and ensure the development of institutions, services and measures for the care of children, including taking into account working parents (United Nations, 2006). The needs, experiences and encounters of parents caregivers have been studied by previous researchers, but despite everything that has been written about supporting families over the past decade, their needs are still not met (Carpenter, 2000).

Family caregivers play much roles in the lives of their children, the health care system, and especially long-term health care, but the focus in research has been on children and persons with disabilities, and there has been limited research in their caregivers; therefore it is important to recognize and address the experiences and needs of these caregivers to establish a good quality of life (Reinhard et al., 2008). According to Blum & Sherman (2010), caregivers should also be seen as “care recipient” and should be treated as patients. The author also states that family caregivers have the right to support and assessments of their needs. However, research shows that when it comes to disabled children, there is a huge gap between caregivers’ expectations and what the community health care services can provide despite unlimited resources (Dybwik et al., 2011). The question becomes: why such disparity? While research have shown that the resources available for caregivers are in limited supply, however for these resources to be utilized effectively and for improved intervention to be made on behalf of caregivers there should be a comprehensive understanding of their needs and experiences (Blum & Sherman, 2010). Also, health professionals who have worked with parent caregivers, who are supposed to know when they are in need, have proven not to acknowledge the existence of the caregiver’s needs; therefore failing to help create an intervention plan (Guberman, 2006). For parent caregivers to have and create a balance in their lives and environment, understanding their needs from different aspects of their lives, understanding and learning about their experiences can provide more knowledge on how these needs can be met and plans can be put in place for all sectors to provide essential support.

1.3 Significance and aim of the study

Of the large percentage of informal caregivers who offer care in Norway, it is important to understand their needs in their daily lives and encounter with professionals; but the knowledge behind these have not been duly studied and understood (Nolan et al., 2003). The effect of full-filling these needs and understanding their wants and roles is the fact that it energizes behaviour, initiates, generates and increases task engagement and directs actions towards certain goals, therefore encouraging and enabling a good and healthy environment for the parents and others involved both all internal and external factors which will help towards the individuals' sense of well-being, psychological growth and resilience over the long-term (Weinstein & DeHaan, 2014).

This research will add to existing knowledge already provided to the field of care, health and social sciences and continue creating awareness on the unmet needs of parent caregivers and their experiences with the healthcare system. Furthermore, the findings from this study will help policymakers understand what parent caregivers need and implement policies which will improve social policies. The society can also learn more about the role parent caregivers play in the household and find ways of assisting. Therefore, this paper is to apply qualitative analysis through a descriptive interview, to explore the needs of parents parenting a child with disability by (a) understanding those needs; based on their roles as parents to the child with disability (b) provide suggestions of how a better and more flexible healthcare system should look like (c) identify parents coping mechanisms.

1.4 Research question

The questions this research wants to investigate is the needs of parent caregivers, but we do not want to research on their needs only but on how to help them address these needs and the role of the health care system. The specific questions we need to know are:

- What are the needs of parent caregivers of children with disability in Norway?
- From the perspective of parent caregivers, what were the experiences with the healthcare system?
- What coping mechanisms do parent caregivers use in their caregiving role?

1.5 Scope of the study

The research is not limited to parent caregivers of a specific disability but different forms of disability. The focus of the study is not on the child with a disability but on the informal parents' caregiver who takes up the role and task of life-long care for a child who requires special attention. Theoretically, the research should have focused on parents' caregivers of children with a specific form of disability, but practically it proved difficult due to the time frame of the study. The experiences or perspective of the needs of the child cannot be included in this study due to comprehensive unlimited research in this field.

1.6 Organization of the study

This section shows the structure in which the study will follow. The study is organized into seven chapters. The literature review combining the contributions of previous research will be discussed in chapter two. Chapter three will be the theoretical framework used in the analysis of the study. The next chapter, chapter four, will have the methodology, data collection, ethical consideration and recruitment and limitation to the study. Chapter five will be the detailed presentation of the transcribed results of the interview. Chapter six will focus on the discussion of the results which connects to the theoretical framework and summarises the research question, solutions to findings and implication to practice will come along each discussion. Finally, the last chapter will be a conclusion on the research and suggestions for further studies.

CHAPTER 2

LITERATURE REVIEW

Introduction

This chapter provides a literature review of studies related to parent caregivers, their children with disability, and the healthcare system that caregivers have to deal with. A brief introduction of caregiving and the general overview of how caregivers are defined will be discussed. The chapter will also try to give an understanding of children with disability and how life revolves around these children. Parenthood will also be discussed, especially the difference between being a parent and being a parent caregiver to a child with a disability. Gender role of parents when caregiving is presented. The effects of caregiving on parent caregivers will be broadly discussed. Lastly, health and social policy within Nordic and Scandinavian countries which concern parent caregivers will be presented.

2.1 The concept of Caregiving

The concept of caregiving comprises of different definitions. One common general definition is that a caregiver is one who provides formal or informal care to a person in need. Most researchers have described caregivers to be either family members, neighbours, friends who volunteer or healthcare officials who are paid (Brown & Brown, 2014; Lindstrom et al., 2011). Totsika et al. (2017), described informal caregivers as people who provide unpaid services to individuals (not limited to family members) with disabilities and/or long-term illness or condition. A study in the United States of America shows the average working hours that caregivers spend in providing care to dependent ones, which is up to 24.4 hours per week (National Alliance for Caregiving & AARP, 2015). Most of the assistance they provide is in the form of monitoring children and their health. Moreover, they deal with health professionals, schools, social services and make appointments for therapy and treatments (DeRigne & Porterfield, 2010). There are two forms of carers: primary and secondary carers. Primary carers are spouses/partners, parents, siblings and grandparents who provide care on a daily bases while secondary carers are mostly professionals who help primary carers by the hour (Corry & While, 2009). Caregiving includes having feelings and obligations towards caring for the wellbeing of another, which can affect the caregiver both physically and psychologically (Waerness, 1984). For the purpose of this study, parents are primary caregivers who have taken up the task of an unpaid role to care for a child or children with disability. The children lived with them in their homes, and the caretaking is meant for a lifetime.

Caregivers importance in both the healthcare system and family life goes a long way in benefiting the care recipient and the system due to their intermediary role in providing care (Dombestein et al., 2019)

2.2 Parenthood

Life changes when people bear children, they decide ways to navigate their lives in order to determine if the changes will be negative or positive. The arrival of an infant into a family not only brings changes to the parents but every aspect of their being will be changed (Cowan et al., 1985; Nyström & Öhrling, 2004); everything is learnt new, new relationships are made while already existing ones are made stronger (Cowan & Cowan, 1995). The transition into parenthood has been defined as "an ongoing process of planning, implementing, evacuating, and balancing the details of parents lives with the details of their children's lives to achieve an integrated quality of life for the entire family" (Ankeny et al., 2009, p. 28). Men and women have a different perspective on parenthood, and their transition process is usually different (Cowan et al., 1985). Research has mainly investigated mothers' perceptions and experiences of motherhood while father's perspective on fatherhood has been under-researched. Fathers experience challenges in settling into the new role and demands of caring for a little being. The experience may result in frustration, anger, low self-esteem, and in decline in their physical, emotional and psychological wellbeing (Nyström & Öhrling, 2004). Also, education and acquiring knowledge in the classroom will not give a parent the necessary skills needed to care for a new-born infant. While courses in developmental and behavioural psychology can educate one, they cannot facilitate practicalities. Most people, before becoming parents may have experiences in child-care through; baby-sitting and caring for siblings, but these do not prepare them enough for the journey into parenthood (Rossi, 1968). From pregnancy to delivery through to the early years of parenthood, parents need to be trained, guided, given information, taken care and given advice of things they should do in the cause of their new life (Deave & Johnson, 2008; Rossi, 1968).

However, mothers have been found to be the primary caregivers of infants and experience of pregnancy, birth of a new baby, sleep deprivation, feeling of powerlessness and so on, affects their general health and most times puts a strain on their relationship with their partners or other family members (Nyström & Öhrling, 2004). With the arrival of the baby to the house, the attention usually shifts to the newborn who demands all-round attention from the adults. Also, mothers have been said to need attention too, and they sometimes felt that children take all the energy and attention in the home (Kluwer, 2010). For a child to be born into a conducive environment means to have parents who are physically, emotionally, and psychologically capable of bringing the children up. The environment and all elements within it have to work together to assist parents transit into parenthood smoothly (Nyström & Öhrling, 2004)

2.3 Parenting a child with disability

Marriage is beautiful, having a baby adds more beauty to the union, the onset of pregnancy is usually filled with joy, planning and expectations for most couples, but when there is an information or discovery of the possibility of the unborn child having a form of problem, the world of most parents get turned around (Ergün & Ertem, 2012). What will happen to my child, how will people see this child? While some come to terms with the diagnosis of their child others may not. Parents begin to face inevitable life-changing events, from the home to personal space, careers, relationships with friends and family members, which implies that either positive or negative changes have to be made for the benefit of all members of the families (Scorgie & Sobsey, 2000)

At the early stage of the child's life, parents are affected physically due to carrying around the child, especially children who weigh more than an average child of their age. The physical health of most parents deteriorates, mostly mothers complain of pains in some part of their bodies, and most of the pains affect them in their old age. Most parents had physical injuries caused by the attacks of their children. They are also deprived of adequate sleep or rest which results in sleep disorder (Murphy et al., 2007)

Economically, having a child with disability puts a burden on family dynamics and structure. When there is little or no financial support from the government or relevant authorities, families bear more of the 'fair share' of the burden of caring for these children. Caring for a child with disability can drive families into poverty. Due to the demand placed on parents, one has to forego his/ her full-time job to care for their child, therefore burdening their spouses' income.

The uncertainty of the future of the family, their child and the health of the child weighs the parents down, but most parents try to take life one step at a time, as it comes for the family (Nygård & Clancy, 2018). Thinking about the future of the child, coupled with the daily stress of caring for the child can lead to a psychological breakdown of most parents (Hansen & Slagsvold, 2015). Most times parents hoped for the situation to change and everything is going back to normal, hoping it was a misdiagnosis or a specialist will inform them of a cure or possible treatment (Sallfors & Hallberg, 2003). Trollvik & Severinsson (2004), explained that most of the parents relaxed a bit when they acquired more knowledge through the experience as carers on the field with the children. On the other hand, Hinton & Kirk (2016) viewed the parents' ease of concern was that they had to focus on the present by staying positive and hoping for a better future they do not have the power to make or predict, but at the same time treating their child(ren) with disability like they did to the other children without special needs. Sometimes, there comes a time when trust becomes quite a challenge for the parents; hence, they find it difficult to let medical professionals in charge of their children's lives (Nygård & Clancy, 2018). One will wonder if their lack of trust was due to fear of being side-lined or they would feel incompetent. Also, healthcare professionals did not make it easier for these parents because the parents expressed that they felt ignored and mistrusted, thereby being stressed, and wanting to give up. Eventually, parents lost their respect for the professionals (Nygård & Clancy, 2018). Healthcare professionals were not able to provide parents with the essentials skills and education they needed due to the fact that they did not know how to handle and deal with these parents who were confused with the new diagnosis (Hayles et al., 2015; Sullivan-Bolyai et al., 2003)

Parents viewed support from friends, family members, other parents or individuals who had children with similar health-related problems as a source of motivation for them to pull through most of the days without feeling lonely and will make their everyday life less a burden (Nygård & Clancy, 2018). Parents need to be acknowledged for the work of the extra care they provide for their children, especially from professionals who see the work they put into caregiving (Wennick et al., 2009). While parents needed support from family members and friends, most also needed to shield their children and themselves to enable them to stay positive and optimistic about their life and what the future holds. Other parents, however, hid their children from society due to the stigma attributed to having a child with special needs or disabilities (Huang et al., 2010).

2.4 Gender role in Caregiving

2.4.1 Mothers experience of being caregivers

Caregiving has been viewed as a feminine role, which has prompted caring for a family member to be done by women within the family dynamics (Blum & Sherman, 2010; Pelentsov et al., 2015). Traditionally, female children were bound by duty to care for any member of the family who was critically ill or disabled; the society expected them to take up this duty irrespective of the physical, emotional and psychological burden it will place on the individual (Blum & Sherman, 2010). This traditional perspective is based on the idea that women who are the ones giving birth to children are more emotional and intuitive than men; therefore they should be able to play the caregiving role with ease (Waerness, 1984). The Western world has made a shift from the patriarchy system of fathers being the sole breadwinner and providing for the home to a system, in which women began engaging in paid work while they still have to accommodate the family structure and a child with special needs in contrast to their male counterparts (Brekke & Nadim, 2017). This leaves mothers with the decision to forgo full-time work and stay at home for the early and formative years of their children's lives, sacrificing their career, putting it on hold and going into the workforce when the children have begun elementary school or even when they are adults (Porterfield, 2004). The choice made to forgo paid job has been seen as a difficult decision for mothers to make, they would have preferred to work to enable them to acquire more income for the family, using their place of work to forget the stress of their children and avoid being lonely when their children eventually begin elementary school. However, mothers have expressed their dissatisfaction with the way the society viewed them as being 'self-fish' to place their own needs above that of the child who needs special attention and care (Ryan & Cole, 2009; Shearn & Todd, 2000). For those who combined full-time work and care of their children, they were able to gain social networks, a sense of identity, self-worth, value, financial independence (Ryan & Cole, 2009). While engaging in work provided a positive perspective to mothers, they also had its negative aspects, mothers felt 'undesirable' at their place of work due to their lack of full- time commitment to the job which was as a result of frequent visitations to the hospitals for doctor's appointment, impromptu calls from the secondary carer or absence from the job due to ill health (Ryan & Cole, 2009). Mothers do not only feel guilt for trying to provide financially and also empowering themselves in the workforce, but they are also blamed for birthing a child with a disability and possibly being responsible for passing and transmitting the genes which caused the disability to the child (Huang et al., 2010; Trollvik & Severinsson, 2004). For the other children within the family, mothers feared a sense of partiality towards the care they gave to the sick child while unconsciously ignoring the sibling of the child (Huang et al., 2010)

Generally, mothers take a multi-dimensional role within the family and especially for the child with disabilities through not just being their primary caregivers but also being an informal nurse who administers medications, coordinates medical high-tech equipment's and still care for everyone around her next to their pad jobs (Redmond & Richardson, 2003)

2.4.2 Fathers experience of being caregivers

Most studies on caregiving have been focused on mothers and their perspective in caring, while fathers' perspective of caregiving has been less researched (Butcher et al., 2008; Esdaile & Greenwood, 2003). Fathers are tasked with providing basic amenities for the home, but they also engage in caregiving task. They are seldomly present in the home and have been described as 'onlookers' who prefer to use the work in the office to avoid the problem at home and identify their own needs and feelings (Van Hove et al., 2009). An initial study conducted on parent and grandparents caregivers in the United Kingdom showed that fathers' in the study pointed to the fact of facing difficulties in caring for a child with disabilities, but they are also always positive aspects to the role they play (Hastings & Taunt, 2002). Research has shown that most father's do not experience negative outcome from caring for a child with disabilities, that is to say, fathers who had negative effects were those who had severe dependable children who required their full attention and care (Darling et al., 2012). Hornby (1992), reviewed accounts of fathers' experiences, speaking on how emotionally unstable they felt on hearing the news of their child's diagnosis. The author pointed out how these fathers were in denial, shock, guilt, anger on; their spouse, child, themselves for bringing a dependent child into the world and the professionals handling their cases, there was also resentment and disappointment towards the situation. The birth of a child with a disability put a strain in their marriages while most were able to weather the storm; some marriages ended in divorce, which made coping difficult. The fathers were grateful for the support they got from the experiences and communication from families in the same situation. They also felt comfortable that their children were well taken care of during school hours due to the special education institutions they were able to send them to. Also, counselling played a huge role in their parenting (Hornby, 1992). While parents are still dealing with the new diagnosis of their young child and trying to learn more about the disabilities and ways to cope, fathers have been affected with the effect of having a child with disability due to the societal reactions, the way the society viewed and treated their children affected the way in which the fathers saw their children's disabilities, since the society refused to accept the child, the fathers, in turn, viewed the children as burdens (Darling et al., 2012). Between fathers and mothers, the former was found to be less close and affectionate to their children, and they were more affected with their child's ill health, fathers were found to create a bond with their children when the children were in care institutes, and they would not have to continually care for them (Darling et al., 2012).

Fathers who were professionals in the medical fields also had negative experience with their children. They had clear pictures of what other parents went through, such as the need for personal space and time for other things were part of their concern, being unable to travel without worrying about the comfort of their child was also in consideration, most fathers were also concerned about the future of their children and refused to accept that they had become adults and could live on their own with little or no supervision (Hornby, 1992).

2.5 Positive effects of parenting a child with disability

Social model discourse on disability has emphasized disability not being caused by an impairment or a function of the individual but is a result of the oppression of people with disability. The model proposed a non-tragic view of disability as not being a problem but as a positive aspect of individuals who live fulfilled and satisfying lives (Swain & French, 2000). Most researchers do not see a positive aspect of caregiving due to the stress associated with the role (Hansen & Slagsvold, 2015). There has been less research on the positive consequences of having, caring and raising a child with disability (Trute et al., 2012). Most publications on parenting a child with disability have overlooked to present findings on positive aspects (Scorgie & Sobsey, 2000). There have been positive reports of being a caregiver, most of them had a feeling of satisfaction and reward for a role so demanding of any individual especially for one who is not being paid (Haley et al., 2003). Caregivers who had sufficient resources received acknowledgement and encouragement from their environment, engaged in social activities, had positive attitudes towards caregiving and also less likely to fall into depression (Blum & Sherman, 2010).

An analysis by Mullins (1987) on 60 books written by the parent caregivers of children with different forms of disabilities showed their experiences and the positive outcome of caring for children with disability. A good number of parents have been seen to experience the positive aspect of caring for children with disability to have by been transform to be better people. For instance, parents attested to the fact that through their experience, they were able to advocate for the rights of persons with a disability; they have become more outspoken; being protective towards their children; they had also become compassionate towards people; they became better writers, teachers, speaking out more and also found themselves becoming self-less and more attentive to the needs of those around them. Although they lost their friends and social lives, they have gained new friends who are also parents caregivers and these friends had similar stories and experiences to share which made their bond strong (Bayat, 2007; Scorgie & Sobsey, 2000).

Studies have also shown some positive impact in having children with disability in the family. Some family viewed the developmental process as a way of bringing them together, where no one is left out when it comes to caring for the needs of everyone, including the persons with special need. This was achieved by creating a platform and a structure where everyone speaks out on their individual needs while putting into account the need to care for the persons with special need in the family. This way, the family become flexible to their needs while everyone is involved in taking care of each other. In the study, religious families viewed having children with disability as the will of God which in turn makes them spiritually and physically strong by taking care of their children with special needs religiously (Bayat, 2007).

2.6 Coping mechanisms for parents

To Care for a child is not an easy task, but to care for a child with a disability will require extra skills from the parents. Parents find themselves in the caring position whereby a child with a disability is unable to express himself/herself especially in a time of need or pain, they get aggressive and cause worries and concerns for the parent who do not know what to do and how to deal with the situation (Gray, 2006). Furthermore, for children with disabilities who live with their parents for most of their lives, their parents have to employ techniques in coping with the experience in order to live a better life.

There is no outlined or programmed coping mechanism, rather parents and caregivers have been found to generate ways to adapt with the challenges of caring for a child living with disabilities (Glidden et al., 2006; Gray, 1994). Parents have been found to accept their experience as one which exempts them from the crowd and admitting that the best coping mechanism for parents of children with disabilities is to work with whatever mechanism suits both them, their child, their family and environment, living from day to day to avoid sorrow and pain in thinking about an insecure future is part of the coping strategies (Gray, 1994; Jones & Passey, 2004; Marcus, 1977). Eventually, everyone has their own coping mechanisms because they change over time (Gray, 1994; Lazarus, 1996).

Coping mechanisms were categorized into two-part; the problem-focused and emotion-focused, while younger parents tend to lean towards problem-focused coping strategies which are a form of distraction from the particular individual causing the parent to be in a stressful situation. Middle-aged parents use more emotion-focused coping mechanisms by focusing more on praying, withdrawing from their surroundings and most of them expressing their feelings (Lazarus, 1996). For example, using the emotion-focused coping mechanism, parents noticed that getting attached to their chid and appreciating little achievements or milestones the children made gave them a purpose to move on in life. Treatment centres were important in the development of the child's formative years; firstly, children were able to acquire basic skills from the centres; secondly, while children were acquiring and learning in the centres their stay provided respite for their parents; lastly, they were a place of safety for parents should they require any form of assistance and support, but for parents who couldn't get access to these centres they relied on God to take control of their situation (Gray, 1994, 2006; Heiman, 2002).

However, Gray (1994) classified parents coping mechanisms into cognitive and behavioural aspects. Cognitive aspects are how parents perceived their child's disability and how they would create coping mechanisms for themselves. The behavioural coping aspect is family support through assisting parents in living normal lives by helping them in activities, allowing the parents to take care of themselves and rejuvenate. The author also mentions religion as a form of coping mechanism. This was because most parents experienced rejection from the society and felt isolated but got comfort from the church they attended who tried to understand what the disability was and what parents needed. Another form of behavioural coping strategies is individualism, parents have been found to actively get involved in things that provide them with momentary relief from the problems at home, they engage in sporting activities, like hiking, some also focused more on their jobs and also became political advocates for the disability movement. The stare parents get from neighbours or when they are out with their children or the facial expressions people make when children make a scene at the restaurant or the playground has made parent withdraw and shy away from the society; they would prefer to make positive friendships and discuss with other parents of children with disabilities who understand them and who make them feel safe and comfortable (Heiman, 2002). While most parents withdraw from the crowd, they have been found to seek help, gather information, learn more and become experts in the field of their child's disability (Marcus, 1977). Other parents decide to educate friends, neighbours and those around them about the disability of the child. Educating people about the child's disability have helped parent cope with the discomfort (Jones & Passey, 2004).

2.7 Norwegian health and social policies

Nordic countries have been found to have good welfare policies that cater for all members from the day of birth to the day of death. Of the numerous elements of the Nordic model, one of them is the generous social security system which covers and protects the general population against primary risk, for example, unemployment, sickness, disabilities, accidents and old age (Pedersen & Kuhnle, 2017). Social policies within Scandinavian countries have implemented to care for all its citizens and especially for the vulnerable who cannot care for themselves economically (Kissman, 1991). The welfare state model has the responsibility of the state, market and family; the aim of Nordic welfare state model is the universal provision of available health care services for all her members irrespective of social status or class (Esping-Andersen, 1990). The implication is that the state is the sole provider of care and the citizens are in support of this model (Daatland & Herlofson, 2003). "Generous welfare services and benefits reduce citizens dependence on the market to a minimum and ideally reduce the dependence on the family care in long term care"(Christensen et al., 2018, p. 15). Income replacement which is an equivalent of the income earned as of the time of employment is given to citizens who have stopped work as a result of a disability or elderly citizens who have attained the age of retirement (Pedersen & Kuhnle, 2017). This model is founded on an egalitarian system which has placed its goal on creating a good source of living for all (Kissman, 1991) and also providing economic security for its members from 'cradle to grave' (Kuhnle & Sander, 2010). Healthcare is the responsibility of the public (Esping-Andersen, 1990), it is categorized under a two-tier model comprising of specialist healthcare services and primary healthcare service. The primary healthcare system is the long-term care and is run, financed and managed by the local municipalities. Specialist healthcare services are part of the hospitals which are owned and financed by the Ministry of Health and Care services and managed by the regional health organisations (Bragstad et al., 2014). Healthcare under the welfare model is free for all population and also subsidized (Pedersen & Kuhnle, 2017). There are also policies which give next-to-kin and relative rights as important stakeholders to the patient and care recipient and also healthcare system and encourages their active involvement in planning and decision making (LOVDATA, 1999). The welfare state model has been established to create equality and equal distribution of wealth among all her citizens.

CHAPTER THREE

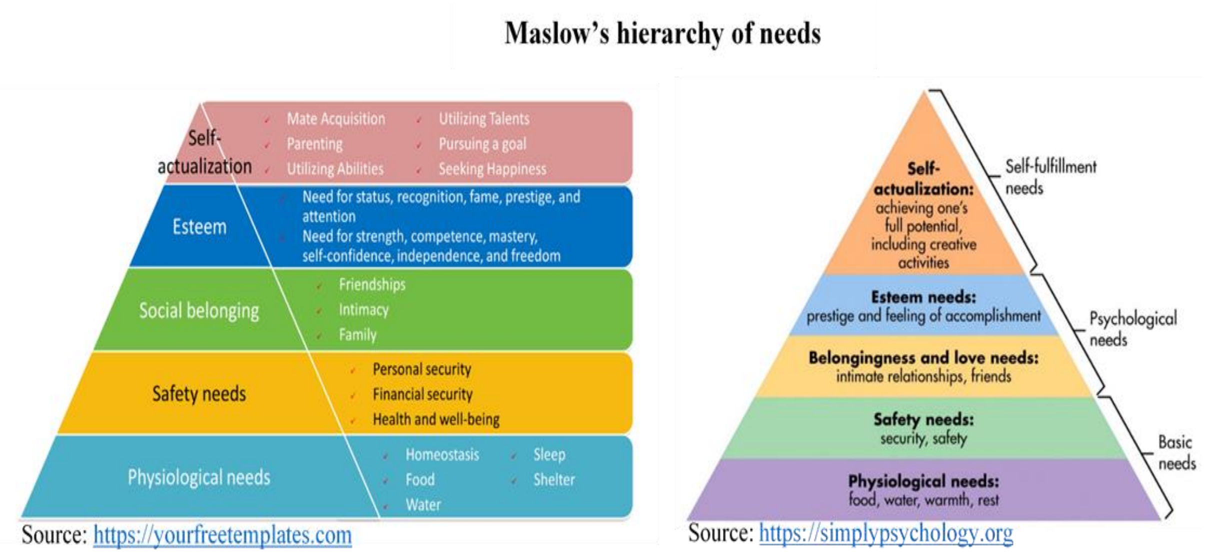
THEORETICAL FRAMEWORK

Maslow’s (1943) theory of need is used as a theoretical framework to establish the link with the findings of the study. The theory is used in understanding and classifying the needs of parent caregivers.

According to Noltemeyer et al. (2012), Maslow, a prominent 20th-century psychologist proposed the ‘hierarchy of needs’ theory. Maslow (1943), argues that there are five basic needs which are linked to human behaviour, arranged in a hierarchical order of prepotency and failure to have these needs met at each level of the hierarchy within the pyramid will lead to negative consequences. The lower level must be satisfied before the individual can progress to meet the next level. This theory explains that while everyone may not be able to satisfy a higher level of needs, but the satisfaction gotten from the lower level enables the individual to satisfy the next higher level of needs. Therefore, when a need has been adequately satisfied, an individual will have sufficient time to satisfy the next higher level of need (Taormina & Gao, 2013).

The theory is represented in a pyramid form which has five stages (1-5) as shown in Fig. 1, illustrating different levels of needs from the basic needs, and climbing up to the growing needs and sub-divided into three needs. The first stages or levels of human needs are physiological, and the second level is the safety needs; these two are grouped under the basic needs, the third and fourth are social belongingness and esteems respectively which are under the psychological needs, while the self-actualization needs are grouped as self-fulfilment needs.

The first is the most fundamental which are the basic human physiological needs such as food, water, homeostasis, sleep, shelter, and air. These very basic needs which every human need in their daily life and if not satisfied the individual’s body may not function to its optimal capacity, may become sick, irritated, feel pain, discomfort. But once they are satisfied the individual can think about other things in life and move to the next need. At the onset of having a child who requires special needs, the parents will become sleep deprived due to the unease the child feels at night or during the day, running around from one appointment to the next may also make parents have lack of rest. Planning and caring for others and forgetting to care for yourself as a parent may lead the parent to skip essential meals of the day which can cause ill health. However, once physiological needs are satisfied and do not hinder the individual from achieving certain goals, the need for safety sets in.



Source: https://yourfreetemplates.com

Source: https://simplypsychology.org

Figure1: Abraham Maslow's Hierarchy

Maslow (1943), explained safety needs to be security, personal security; danger, employment security: during an economic recession and an accident, financial security, retirement, health, medical insurance and well-being. This need is placed higher than the previous one. Adults do not have much awareness of their safety except in times of desperation and danger which puts them in lack of this need (Simons et al., 1987). Safety needs become a necessity when a person encounters a traumatic experience due to a breach in their safety. The gap in information gathering between parent caregivers and healthcare practitioners can cause a breach in the care of the child with a disability which in turn leads to inadequate health care for the child.

The third level of needs which is categorised under the psychological needs is social belonging; the need for friendship, intimate relationships, family and interpersonal relationships. McLeod, (2007) gave some examples of this stage as the need for acceptance, trust, receiving and giving affection and love and also being a part of an intimate group like friends and families. The need for closeness is a universal feeling which is inherent in all individuals and is necessary for human co-existence (Baumeister & Leary, 1995). Due to activities of caregiving, most parents do not have friends or loss contact with people around them and end up being alone and having no one to talk to or share their problems with which can result in an emotional and psychological breakdown, feeling of isolation and rejection. Caring can also create a breach with parents who have partners and they end up drifting away from each other and they, in turn, get lonely.

The next higher level of need after social belonging is Esteem needs which are prestige and feeling of accomplishments, need for status, recognition, fame, competence, mastery, selfconfidence, independence, and freedom. Maslow (1943) categorised this needs into two parts: self-esteem and esteem from others. This is a stage where parents and individuals need to be appreciated and recognised for the work and effort, they put into what they do. They also need confidence in what they do, they need to be in-charge of their home, life, their children's life to care for them the way the children need to be cared for because they know and understand their children more. Parents are also required to have confidence in their parenting and caregiving role.

The highest level of needs is self-actualization which is also known as the growth need, this stage explains the need for personal growth and self-discovery, that individuals growth does not generate from the lack of a particular need but from a desire to grow as a person (McLeod, 2007). Likewise, parents want to develop more not just as caregivers but as individuals who had an existence before the on-set of parenthood or the desire to grow into an informal expert parent caregivers who have acquired more knowledge and relevant skills in the field of their child's disability and can work together with relevant professionals. This need is sub-categorized under self-fulfilment needs which are mate acquisition, parenting and utilizing abilities. Maslow posits that people can be prevented from getting to the stage of self-actualization due to hindrances within the society, giving a solution on how to get the last stage he advocates for individuals to be educated and empowered (Simons et al., 1987).

Maslow's theory of needs was criticised due to his explanation of human physiological needs and was said not to affect individuals of the upper class of the economy but those of the lower class who could not afford basic needs (Taormina & Gao, 2013). The representation of human needs using a pyramid was also criticised, questioning the evidence he used in placing needs in hierarchical order (Wahba & Bridwell, 1976). The quality and authenticity of his theory were questioned. Self-actualisation needs were characterised using a qualitative method called biographical analysis, firstly, the number of participants used in the research for the formulation of this need which was said to be a small sample for research of this magnitude. Alongside, the participants used in the research were educated and prominent males and females who had already fulfilled life and have achieved life's goal, which puts a question to the validity of his findings (McLeod, 2007). The theory has also been viewed as gender bais (Cullen & Gotell, 2002). Researchers analyzed the theory which was on individuals from 123 different countries and it was found out that an individual can have good social relationships and self-actualisation need without having the physiological and safety needs being satisfied (Tay & Diener, 2011). Therefore, the assumption of needs has to be satisfied before an individual can achieve self-actualization has been proven to not always be the case, putting doubt to this research

(McLeod, 2007). While his theory has been criticised to be culture entered (Yang, 2003), research proved that Maslow did not put into consideration cultural needs and aspects of individual before generalising on their needs, since different cultures have different needs and perspectives on how they can be met hence, the Hierarchy of Need is based on a Western perspective (Hofstede, 1984).

Notwithstanding the criticism pointed at Maslow’s Hierarchy of needs, this study found it relevant to understand the needs of parent caregivers and their experience with the healthcare system.

CHAPTER FOUR

RESEARCH DESIGN AND METHODOLOGY

Introduction

This chapter discusses the methodological choices of the study. The beginning of the chapter will be explaining our choice for a qualitative approach; in answering our research questions. The researchers’ position in the field of research will be discussed. Furthermore, the methodological choice of conducting an in-depth, semi-structured individual interview, the process of sample selection, interview methods, ethical considerations, NSD application procedure and the strengths and limitations of the research. Lastly, the choice of data analysis will be concluding the chapter

4.1 Research approach

During the recruitment phase of the research, some difficulties were met, and alternative options were sought. In trying to answer the research questions in a quantitative approach, a systematic literature review was put forth as an alternative by my supervisor, but other methods had to be considered. Firstly, the experiences of caregivers had been widely investigated, but their needs had been under-reported. Using a quantitative approach would have been researcher-led questions which will generate monotonous answers, therefore failing to represent the views and will mostly produce generalisation on the findings. Secondly, the research aimed to explore the parents' experience with the healthcare system in different municipalities in Norway. This implies understanding different experiences and encounters of healthcare practitioners; using a quantitative approach would mean that the answers would not be able to generate the experiences from the perspective of the parents themselves but what the researcher would assume would be the problem. Therefore, using a qualitative approach was both ontological and epistemological.

Qualitative research captures some social or psychological aspects of the world; it takes records of the messiness of real life, organises it within a framework and gives it an interpretation (Braun & Clarke, 2013). Qualitative research is also inductive due to its flexibility; it is a method which is geared towards understanding the meanings and experiences of the subject in context (Crowe et al., 2015). For this reason, a qualitative method was used in exploring and understanding the needs of parent caregivers and their experience with the healthcare system. Qualitative research proved to be flexible and allowed the researcher to understand the parents experience using in-depth semi-structured interview method.

A constructivist ontological stand was taken in this research, in trying to understand the needs of parent caregivers, their coping mechanisms and their experiences with the healthcare system (Ormston et al., 2014). Each participant had to give an account of what they felt they needed for themselves, how they have been able to cope and how they viewed their different experiences with the healthcare system. Parents may be from the same or different municipality, and they will have individual needs, coping mechanism and encounter with the healthcare system. Also, the researcher focused on the individuality of their reality and the way it had been socially constructed during the interpretation of their interview.

Epistemology focuses on ways to know and learn about the world and how reality is formed; it focuses on gathering knowledge (Ormston et al., 2014). Generating knowledge through the interpretation around the world of the participants by exploring and understating their needs, coping mechanisms and experience with the healthcare system; and interpretivism epistemological position was taken (Ormston et al., 2014)

4.2. Data collection, sampling and interview process

With the research question in mind, participants were chosen. Participants were selected through purposive sampling. The technique used in purposive sampling is also called "judgement sampling", this technique uses a deliberate method to recruit certain category of participants for the sole purpose of specific research (Robinson, 2014; Tongco, 2007).

The initial plan of recruiting participants for the interview was disrupted due to the COVID-19 pandemic (Coronavirus SARS-CoV-2) in the country and world at large. Few participants I had gotten from a voluntary organisation in Stavanger pulled out from the research, due to the new regulations by health officials and the government mandating all her citizens to stay at home on lockdown and avoid person-person contact which was done to control and prevent the spread of the virus. The new rules affected parents who had to work from home and also help their children attend their on-line schooling, making it difficult to have the interviews done through the internet. However, an alternative means of recruiting parents were sought. While I could not get the desired number of participants within Stavanger municipality, I had to use parents from various municipalities. Mails were sent to different disability organisations in

Norway, attaching a consent letter, stating the purpose of the research and informing the organisations of the age range of the children who parents cared for. My contact details were left with the organisations, and their assistance was implored in informing their members of my research and their voluntary participation in the interview. Parents who were interested contacted me via the information I left and dates, time and venue for interviews were fixed. All the participants were primary caregivers of children with disability. The children were below the age of 18 with one or various forms of disabilities, 5 (five) children have Attention Deficit Hyperactivity Disorder (ADHD), 2 (two) children have Phenylketonuria (PKU) and 1 (one) has both Attention Deficit Hyperactivity Disorder and Tourette syndrome. The total number of parents interviewed were 8 (eight): 3 (three) fathers and 5 (five) mothers. And the parents were within the age range of 30-55 years. One of the parents was in the medical professional but did not have prior knowledge on the disability of her child, while some of the parents were on social benefits and could not work due to ill health which had nothing to do with their child's disability. Most of the single parents had 50% jobs and were not able to work 100% due to their caregiving role; some were single with no partner or a partner who had shared custody while others were married and had help with their spouses (Table 1). Before proceeding to commence on the interview, consent forms were sent via mail and their rights were also explained to them, the forms were sent back to the researcher duly signed.

The process of conducting an interview is to generate, gather and gain information (Seidman, 2006). Using an interview to obtain the information on the research objectives proved to be very useful for the study, through semi-structured, in-depth interview. Semi-structured interview with a detailed interview guide which engages the participants in obtaining information and in-depth knowledge from their experience was adopted through the interview process. An interview guide with open-ended questions was used in generating answers which were in line with the research question. An open-ended, semi-structured interview guide was used due to the flexibility it brings in the interview process, it enables the researcher to gain the necessary answers and does not restrict the interview to just the questions jotted down, but along the line of the interview, more questions can be asked and gotten (McIntosh & Morse, 2015). Participants were able to explain and express themselves with the liberty of open-ended questions. They were from different municipalities in Norway; this helped the researcher in having a broad analysis of experiences from not just Stavanger municipality but various municipalities.

The interviews were meant to be conducted through the face-face method, but improvising was made for participants who could not meet due to distance. They were conducted through various means; one-on-one (in restaurants and cafes), Zoom video calls, Skype, Microsoft Team and Telephone calls; all were done within the convenience of the parents. The interview was done within an average of 50 minutes.

Due to the different interview methods used during the research, the researcher made sure to maintain the views and interpretation of its participants and not an imaginative or assumption of what the needs of the participants will be. The participants were interviewed within their nature and comfort zone; therefore, one can say that whatever was said during the interview process was without discomfort or under duress.

Table 1. The demographic background of the parents and their children

Participant	**Sex**	**Age**	**Employment**	**Marital status**	**Municipality**	**Child**				**Number of Children**
						Sex of child	**Number of children with disability**	**Age**	**Disability**	
P1	F	44	AAP - Long term sick leave	Widow	Karmøy	F	2	13 & 15	ADHD	2
P2	M	47	100% - Police officer	Married	Oslo	M	2	6 & 8	PKU	2
P3	F	44	50% - Kindergarten teacher	Married	Stavanger	F	1	12	ADHD	2
P4	F	55	Medical practitioner / Now studying for a teaching profession	Single	Stavanger	F	1	16	ADHD	2 (Twins)
P5	M	35	100% - Lecturer	Married	Stavanger	M	1	7	PKU	2
P6	F	33	Teacher	Partners	Stavanger	M & F	3	5,12 & 15	ADHD	5 (2 biological and 3 step)
P7	F	32	50% - SFO	Single	Karmøy	M	1	10	ADHD	1
P8	M	33	Student	Single	Vestfold	M & F	2	13	Son (Tourette & ADHD) / Daughter (Dyslexia)	2

4.3 Limitations to the study

During the research study, several limitations posed to hinder certain situations. Future research should put them into consideration before embarking on research in this field.

1) Recruiting participants was not as easy as I had anticipated. The initial plan for recruiting and conducting the interview was to gather participants from different institutions and organizations in Stavanger who have direct contact with parent caregivers of children with

disability. This plan was to enable the results of the data collected to be diverse and can be a representation of most parent caregivers from different institutions within a particular municipality. Due to the bureaucracy surrounding organisations in Norway, the researcher could not get participants from NAV (Norwegian Labour and Welfare Administration), HABU (Barne- og ungdomshabilitering) and the Health Institutions, for example, Helse og omsorg. To get participants through these institutions would, usually require a due and lengthy process of seeking approval before getting participants for the study. The researcher was strongly advised not to use any of the institutions mentioned above since the ethical application will not go through Norwegian Centre for Research Data (NSD) but through REC (Regional Committees for Medical and Health Research Ethics). This would require a lengthy application period since the time for the research will prove to be limited for the application period.

2) Language proved to be a barrier during the interview process; the participants would have given out more information if they could speak in their native language, which is Norwegian. Communicating for an extended period in English made the participants miss some vital information, but most of them had to send in more details of their experiences.

3) Parents interviewed were only a parent and not two parents (father and mother) within a family. The researcher would have loved to interview both parents together, to get their views, but most of them had to take care of the children while the other partner had the interview.

4) The dominant form of disability was Attention Deficit Hyperactivity Disorder (ADHD), while it was not an issue in the research. Research suggests that ADHD is a milder form of intellectual disability, and in most cases, maybe overlooked as a disability (Ahuja et al., 2013). However, in the course of my research, most caregivers in most need are parents of children with ADHD which is often dismissed as a mild disability and usually not given the needed attention as other disabilities,

5) The number of sample size was due to the limitations stated above, and the results from this sample should not be considered as a generalization of all parent caregivers neither is it a representation of all forms of disability in Norway. Therefore, this result is restricted to the information gotten from the participants the researcher was able to interview.

4.4. Data coding and analysis

The analysis of the study was based on the voices of the parents who are caregivers of children with disability. They shared their experience as parents, spouses, single parents, workers, daughters, sons and siblings to other external family members. The analysis was also about their experience with the healthcare system and how they have been able to cope with their experience. To understand the needs of the parents and their encounter with the healthcare system, getting their quotes and the way they expressed themselves, I employed the use of thematic analysis of Braun & Clarke (2006) to enable me to focus on the stories of these parents and interpret it just the way they had told and explained it to me. These authors listed six phase-guideline in analysing data, creating themes through the voices of the participants. The steps are listed below:

1. Familiarizing with the data through listening to the recordings and the transcribed notes.
2. Generating initial codes from the transcribed data and trying to find similarities amongst the words of the participants.
3. Searching for themes and fixing the ones most like each other or have the same meaning.
4. Reviewing themes- going through to make sure the themes are appropriate.
5. Defining and giving names to themes.
6. Writing the report and presenting the findings.

Crowe et al., (2015), explained that thematic analysis employed in capturing meanings with a data set, while it also helps in interpreting data, ways of organising and finding patterns of meaning within the given data (Braun & Clarke, 2006). It can also be used within multiple participants description of their understanding to have a broader understanding of account (Crowe et al., 2015). It is flexible to use and provided me with the ability to identify different and similar elements and patterns within the voices of the participants, which enable me to form the result section.

Nvivo 12 Pro software was used in the analysis and coding of the data. The recorded interviews were first transcribed verbatim into a word document, then read several times to have a sense of the whole data. While reading through the transcribed interviews, the audio recordings were also listened to again to avoid errors. On creating Nodes on the software, the participants were anonymised by being represented as P1, P2, P3, P4, P5, P6, P7, P8. The initial codes generated 16 themes, after going through numerous times, looking for similar patterns among the data and looking for difference(s), they were reduced to three themes with ten sub-themes. A tabular form of themes will be presented in table 2.

4.5. Ethical considerations

All ethical guidelines were duly followed during the research process. Participation was voluntarily and was assured of anonymity of their information. Before the interview commenced, each participant was briefed of their role in the interview and research, in as much as they had already been informed during the recruitment phase. The researcher was aware of the sensitivity of the topic to the participants and made sure they were in their comfort zone. A request form was given to them, which stated their rights and confidentiality of the information provided and was also signed to attest to the agreement of their participation. They were also aware that the results and analysis would be used for scholarly publications, research articles and other academic purposes. They could withdraw at any point in time, and they would not be judged for any action taken within the withdrawal.

The chapter has summarized that the study is a qualitative study with ontological constructivism and epistemological interpretivism as its philosophical underpinnings through a semi-structured in-depth interview. Eight participants were recruited through purposive sampling from different municipalities in Norway. They were primary caregivers who had one or more children living with varying forms of disability. Thematic analysis was used in analysing collected data. Limitations and ethical procedures were also discussed.

CHAPTER FIVE

RESULTS AND FINDINGS

Introduction

This chapter will talk about the result of the interview conducted with each parent, it will be divided into three themes and will also have sub-themes, which is based on the findings from the experience of the parents. I will begin with the theme "more is better", which will be followed by the theme "information"; lastly, the theme "emotional roller coaster" will be discussed (Table 2). Explanations of themes will be made, and direct quotes from parents will follow to provide clarity further.

Table 2: Summary of themes and sub-themes

Main theme	Sub-theme
More is better	Required rest
	Self-care
	Finance
	Assistance
Information	Just a little too late
	Knowledge is power
Emotional roller coaster	Stability
	We matter too
	Hope versus reality

5.1 More is better

Parents agreed, identified, and understood that parenting has changed their lives and were grateful to have such an experience of caring for another human being. They were affirmative that having a child will require certain things to change within the home but admitted that having a child with special care needs was different and they would have preferred things to be a little bit different for them in their lives and homes. This theme is sub-divided into 4 (four).

5.1.1 Required rest

Most mothers who had accepted the changes motherhood had done to them and described that the essential thing they needed for their day to go on efficiently was to have to be in bed for more hours. They explained that since they couldn't change their sleeping hours, they won't be able to complain about it because those were the challenges of parenthood; but, if they had the opportunity to make it better, then they would.

> *"5 hours is not enough, 8 hours is just ok for me" (P7)*

> *"I am not stressing about it, but it would be nice to have somewhat do you call it coherent sleep. To be fully awake, when I wake up I am tired during the day, yeah, but I don't stress about it because I think it has been like this forever almost forever, so am used to it but it would be nice to have some proper sleep" (P1)*

> *"I sleep less, but I have done that since I have become a mother" (P3)*

Like most mothers who had accepted the changes in parenthood, parents; both fathers and mothers who worked full-time and had 100% type of jobs talked about how it was for them at the early stages of the life of their children and how it had affected daily life.

> *"Oh yeah, I was tired from busywork, and when she didn't get to sleep until very late and could wake up 2 or 3 times through the night, I didn't sleep much at all, that made me…" (P4)*

> *"Yes, sometimes because we have had a problem especially with the oldest one he hasn't slept through the whole night for the last 2 years" (P2)*

The effect of insufficient sleep was on both parents who worked half-time, had 50% jobs or who could not work due to ill health. They all admitted that the hours of sleep they got at night was a significant determinant of how their day would turn out to be.

5.1.2 Self-care

Caring for a child with special needs has been a norm for most parents, and they have over-looked the aspect of caring for themselves to enable them to care for the family. Participants had forgotten what it meant to have time and care for themselves but reflected on the fact that if given the opportunity they would appreciate giving themselves little time-out from caregiving role

> *"Time, but I think that's something that goes for every parent, well time is one thing, sometimes it could have been nice to have some sort of..." (P2)*

> *"that is something I have denied myself of thinking about that, I always thought, the most important are the children, their wellbeing must go before me, and I never realised that I have to have some time of my own to feel something else that a mother or working person, to feel like a woman or a normal human being that also needs intellectual or other kinds of input from the world around me, it was quite recently that I actually accepted that it is natural and that it is allowed" (P4)*

For the parents to care for a child with disability requires that their lives would revolve around the children to make them comfortable. At the same time, the daily activities deprive them of creating their own time for things which will matter in their personal lives, which they had no control of how to make things balance. They viewed time as the most significant factor in their lives and the lack of their ability to control it.

> *"but time is probably the biggest, biggest factor and of course" (P3)*

> *"I think I would have liked more time" (P6)*

> *"Yeah, it's not so much I have for myself. I could have needed some relief (stress-wise). I am alone with him. I have very little free time, not to mention day(s) for myself" (P7)*

> *"Before I had more time, how do you say it? I could use the time when the kids were at school to do things that I needed to have done like house chore and errands yeah*

> *without thinking about how they are doing at home, they are constantly fighting, it was easier when they went to school and I could like prepare myself for the evening before they come back, to be more in place. I don't have that…"(P1)*

> *"the clock was the chauffeur master in our lives, I had to go to work and then they go to lessons after school, either music lessons, gymnastics or dancing or whatever and then bed time. It was 24hours, it was always the clock was always the master of what we did" (P4)*

> *"there has never been any routine, and that's maybe the core problem, the lack of routine because of the unpredictability, you can't predict the next hour, the next day, the next week, if it's going to be any…" (P8)*

While most parents tried to make the situation comfortable enough for everyone and also try to fit their schedule into that of their children, some were of the opinion that, it would have been easier for them if they had spoken out to people around them and asked for help so that they would take care of themselves.

> *"I should have opened up more with my friends earlier but I just I went down and went down, I should have been more open earlier on and maybe also asked friends for help to perhaps baby-sitting sometimes, to get some time off , I never did ask them that, I should have arranged it so that I had more time off for myself and friends " (P4)*

> *"Obviously yes. It would be nice to kind of have more time to spend with, you know, other friends. You have to organize everything with the kids and then at the weekends, you have to do something. And often, if you stay a day at home, it's more stressful than you do something " (P5)*

> *"this takes a lot of time so my spare time, my free time with friends and family got massively reduced. Couple of years ago I didn't have so much time alone because it was more stressful for me to go away to relax than just be home because its better to be there and fix things" (P8)*

5.1.3 Finance

The Norwegian welfare policy provides care packages for parents and families caring for a child with a disability, and most participants could not complain about it. Still, they felt that things would have been better for them if they had more financial resources to engage in activities which will enable them to care for their physical, emotional and psychological needs.

> *"maybe the financial aspect, if I could I would spend the night in a hotel every once in a while just to have…… but that's not something my financial situation allows me to do and I don't expect anyone to…… Sandnes can not pay me to go to sleep in a hotel, but sometimes I just wish I could have this place where I can go and relax even for an evening, even for few hours just peace and quiet, well sometimes they are outside of the house everyone, and there is just me then I turn up the music and just sing, sing and dance" (P3)*

> *"If I could work lesser hours than I do now, though economically I would need the money. It would have helped with the daily chores at home" (P6)*

5.1.4 Assistance

Participants would have preferred if someone shared the parenting role with them, to make the caregiving role less stressful or tiring. Some explained they could manage the situation well. But the mere fact of having someone to talk to and share either the physical or psychological burden of caring for a child with disability will help them have more time to do and plan other things in the home. At this point, they understand the saying "two heads are better one".

> *" Another person to share the responsibility with, I was alone, so there was no father involved. Its been quite hard. I have been a parent all the time, so I often miss someone to discuss with on the level of having the same responsibility for the child as I have, I could discuss it with the teachers, friends, and family, I also felt that was quite a heavy burden" (P4)*

> *"Yeah, I could do more, it's like I am just weighed down. It's not easy when to take care of my needs and theirs if you have someone to do things with like when you are 2 parents you do things I miss that because it's my husband, he was, even if I don't know it then, it was easier to get things done when we were 2" (P1)*

> *"my parents and my sisters they live up North in Norway so I miss them especially at the time when both my husband and daughter got diagnosed, and you could feel" (P3)*

> *"It's very difficult because I don't have any contact person. I think there should have been some meeting with someone from the health authorities at least once a month and had some help and guidance I've been doing the caregiving for about 8 years now and it's much easier now than in the beginning. So most of the help and assistance is really needed in the beginning than later (P6).*

For some, they could get things done and did not need day-to-day assistance, but one parent needed more moral and psychology push to start the day.

> *"I think for me I need someone, I think I miss the just get it done button,… (laughs) so it's like to get me started I know how to do things, and I know I should do them but I just don't get around to do it, I don't know that could be fixed. It will be odd to have someone constantly in the house telling me or just working/ walking. I just need someone to work with" (P1)*

Even though they couldn't find help and assistance from the system, parents were of the view that they would have preferred if they had someone come into their homes just for brief moments to help hem care for their children.

> *"that you could sort of just have someone to take care of them for a weekend so that you could have just time off, we are quite happy with using family for this because we have grandparents on both sides, so we manage to do this sometimes" (P2)*

> *"Yeah, we have been to Bulgaria sometimes, I think is 4 or 5 times something or like that but then I had my parents with me; my mother and her boyfriend, I don't think I could do that alone, I think I would go crazy not having any adult to talk to and to be completely alone, I think it is a recipe for a meltdown (laughs)" (P1)*

For some parents, the feeling of rejection when seeking assistance prevents them from asking for help from the municipality. They preferred not asking anyone for assistance than asking and getting "No" for an answer

> *“having my daughter with all her issues and having another child with disabilities I would have asked for help much earlier, and I also think that if I had gotten a no, I would have said why? Why not? You have to; I would never have done that before, I think I was also afraid of having no as an answer if I had asked for help what if they say no what would I do then, I would expose myself as a mother that can't bring her own children up in a proper way and when I do ask they say no” (P4)*

> *“Feeling (unwanted) when you feel that you are the only one that initiates contact” (P1)*

A parent talked about her experience with people around her telling her she was not fit to be a mother if she complained of the need to get some help and assistance and time to care for her own needs. She said that her silence cost her physical and emotional breakdown, and she had learnt from her past and has decided to speak out and demand for assistance and time to give care for herself.

> *“it is a learning process. I have to stand up for myself and say: tonight is about me, this is what I need, I need to go out and be with my friends, I need to get away from all of this, and I have been better the last few years, but still I think it's me later…I think for me it's mostly about me standing up for myself” (P3)*

Extended family members were found in helping most parents with daily activities, weekend sleepovers, travel companions and carer, which went a long way to ease the care burden for parents.

> *“my parents they helped a lot as long as they were healthy and I have got a sister, she knows my daughter very very well, she is like a 2nd mother, so I know she will, and a couple of friends that I have that will support both my children if I die or anything happens to me” (P4)*

> *“I have my in-laws, my husband’s parents they live here so a little bit of support from them, but they are getting older and even though when she was a toddler maybe until she was 5, 6 they could have her in weekends, for sleepovers” (P3)*

> *“ they can stay at their grandparents as well so they can stay when I usually have something to do, I can leave one of them with their grandparents or both so that they*

> *don't fight as much, it can be really tough, it can get physical as well so it's not something I do often to leave them completely alone" (P1)*

> *"But we do get a lot of help from our family…like my mother-in-law is visiting, I say, at least like 5 weeks per year. When she's here, she's doing a lot with the kids. And also my mother is coming some time not as often." (P5)*

Assistance was seen not to be sufficient for parents who had more than a child, especially if the child or other children did not have any form of disability. They were not able to have their me-time due to the other children they had to care for, look after and make up for the time they have not been able to provide.

> *"Not a lot and I think the reason is that I wasn't free I still had another child to care about, and she wanted to have her friends visiting so this weekend was filled up with children activity, either way, I had one less child but still children thing to do" (P4)*

Friends were not left out with the way parents tried to cope with the care burden, and most parents appreciated the existence of friends who understand or tried to understand what they were going through and volunteered to help them from time to time. Some parents also had friends who they were confident in leaving the care of their children in case they were not available.

> *"But I have some really good friends around who have really been there, I lean a lot on my friends, I do. They are the ones I complain to when I think when everything is boiling, and I just text my friend: am really struggling. I have one of my best childhood friends actually from North, not really in Stavanger, and we have daughters in the same age so we have been visiting and she stays over there, and she has been really great but not from any official system" (P3)*

> *"some of my friends have children of their own, and they are very supportive, when they go to cabins, they go on weekend trips, and sometimes some of them take maybe one of their kid and my oldest kid and just like ohhh we take him for a walk. I have been blessed with good friends who are tolerant and want to learn, for me its been a good experience" (P8)*

> *“a couple of friends that I have that will support both my children if I die or anything happens to me” (P4)*

Lack of trust in caring for their children has made parents not get involved in applying for assistance from outside the home. He believed that people would not understand how to care for the children the way it should be, and it may bring their children to harm’s way, therefore accepting to carry the burden alone.

> *“For us, it’s a bit difficult to do I think, because I saw this picture once posted on Facebook in a group for PKU parents and it says this is the list of the people I trust taking care of a diet for my kid and the list was (a torn small piece of paper) like this so I think its something like that its difficult. We cant call service for nannies or something like that we need someone we can trust” (P2)*

5.2 Information

5.2.1 Just a little too late

Getting a diagnosis for an intellectual disability was difficult for most parents. Healthcare system made the process of diagnosis very tedious for the parents, and most times, it would take more time before diagnosis will be made. Parents who had female children with ADHD spoke from their perspective of the difficulty with early diagnosis due to the structure of the psychological test used for ADHD patients and noted that it was mainly constructed for male children. In contrast, a parent with a male child talked about the ease of getting his child diagnosed.

> *“the youngest one I had to fight for several years for her to have the diagnosis, they didn’t want her in because they felt that she didn’t have enough symptoms to look at if it could be ADHD I got the report from the doctor who sent a message to the specialist healthcare, and then you get a reply, and they denied it, and I applied once again, and they denied it” (P1)*

> *“My child, my boy at 8 he was very stereotypical with ADHD, it was easy to get the diagnosis, he was physically active, he was mentally impulsive, was talkative, not loud but a little bit flimsy typical of ADHD (P8)*

When it came to the needs of parent caregivers and their experience with the healthcare system, parents expressed their lack of early diagnosis for their children, knowledge and information about the disability and ways in which the healthcare could have made it better. They talked about the effects of not having their children diagnosed earlier if acquired earlier would have helped both parents and children in understanding the phases they were going through, to have an understanding and a plan on how to set and achieve goals in their lives.

> *"One of them was diagnosed with ADHD when she was 12, quite late at the psychiatry out clinic for children- I think that's quite late in Norway, normally they should be diagnosed quite earlier" (P4)*

> *"My daughter got her diagnosis in 3rd grade, and my son got his in 5th grade. That's already late. I asked for help at the hospital several times. If the diagnosis were earlier they would have gotten help earlier" (P6)*

> *"It happened that things took much longer than necessary… It was quite tiresome for him and for me especially. It really took its psychological toll on both of us" (P7)*

> *"I think the waiting for parents who are worried about the child is maybe the biggest obstacles and of courses we know that kids develop so fast, there is a lot happening in 6 months so if you don't get the process started and you have a caseworker that cant follows the case you can easily end up with a wrong diagnosis or no diagnosis and then maybe it's too late. The caseworker told us there are so many girls aged 14-16 being sent from the psychologist with not wanting to go to school and they can look back and say but this girl has ADHD and they have never been diagnosed because girls behaving so differently from guys, so that's a big scare" (P3)*

The effect of having their children diagnosed at a late stage in their life affected most mothers psychologically. Due to the lack of early diagnosis, these mothers did not understand what their children had, and it made them feel it was their faults, and they were unfit to take up the role of motherhood, finding out about the diagnosis provided a little bit of relief for the parents.

> *“Yeah, it's frustrating for the parent and the child to have these issues and not knowing why they have it, what’s the problem, is the problem with the child, is the problem within yourself where should we start but with my child” (P4)*

> *“then I thought maybe it's just me, maybe am not doing a good job, maybe it's just at home she is like that, so for me her getting the diagnosis was also kind of a relief because I could finally start to think that it was not my fault, I couldn’t have done anything thing different,” (P3)*

> *“Ok when I found out? Hmmm, I think I was relieved because it was yeah because it was finally we got the answer to why things were as they were and there was a reason for it, yeah.” (P1)*

Not getting diagnosed early hindered the parents from applying for social assistance from the municipality, therefore, being unable to get assistance and have someone to share the care burden attributed to caring for a child with a disability.

> *“I think, one of the reasons is because my daughter was 9 when she got the diagnosis and things at home sort of work, days went by, and you wouldn’t think about it, and actually the counsellor at BUP said why don’t you apply for Avlastnings, and I said I think that now is too late because she is 12, she is 12 ½ actually because she is born in January,. But I think if she had gotten diagnosed earlier, I think maybe I would have asked for Avlastnings,” (P3)*

Furthermore, when asked for the reason of the late diagnosis on most of the females children with ADHD, the parents who were caregivers as well as patients with disability gave their own understanding of what they felt was the problem with the healthcare system and early diagnosis of the disability. While there needs to be cooperation amongst all sectors; kindergarten, health system, family, school etc, parents should not be made to wait long to the detriment of their child’s health alongside their health before the child can get the help they need

> *“its too rigid, like for ADHD you have to have symptoms in more than 1 area in life so if its just one area you don’t have the diagnosis, but still the symptoms that she had is coherent with the diagnosis. For me, I think they have a long way to go. It's like they know a lot about children and ADHD but coming to adults they don’t have enough knowledge I got denied as well first, and then it was the doctor who diagnosed my oldest*

> *daughter that sent to BUP so he was the one that sent a complaint for me and they took me in, and after 3 sessions I got the diagnosis" (P1)*

> *"But the fact is there is to much time going to waste waiting. There are long queues to get tested for a lot of diagnoses, especially with ADHD and different behavioural diagnosis. There is a very long waiting time to get into the system; you have to have, the kindergarten or the school or the parent have to have written really good application to get through the system, you have to be able to tell what your child's problem is before you can even consider them to listen to you" (P3)*

The bigger problem of the healthcare system, according to the parents is the difference in approach within different municipalities, parents advocate for uniformity within the system as a form of solution to the problems of late diagnosis.

> "*I think the biggest worry in Norway is the big difference between different areas in Norway; if you live in Sandnes you may have this, if you live in Stavanger you may have this, if you live in Bødo there is a different system, so there is no coordination, if you move, you won't meet the same system and I think that's not good, I think there should be a plan, I think even if you live in a commune that has bad economy, you should have the same support as you would do if you live in a place with good financial assistance" (P3)*

5.2.2 Knowledge is Power

Parents when asked about their experience with the healthcare system, they observed that most of the professionals who came to their homes for evaluation and assessment were not fully knowledgeable about the diagnosis. The little they knew about the diagnosis did not help the parents, therefore making it difficult for the parents to understand what they had to deal with, especially with the health of the child.

> *"With every issue, I have had is almost every time about knowledge in the healthcare professionals or the welfare service the lack of knowledge, not the lack of knowledge, the lack of updated knowledge the lack of updated knowledge" (P8)*

This made parents refer to the internet and other search platforms for help outside Norway.

> *"The knowledge I have, I have mostly found myself during an online course, during the literature, during searches on the internet most of the job because there was no one telling us this is a good page or you can get information from here, and that was a bit difficult" (P3)*

> *"I read books, and I googled, I felt like ok no one knows what it is, I have to know, and I started to teach myself, I sent emails to an American professor, dug deep and hard, I spent maybe the 1st years or 18 months in intensive search, trying to understand like the biology, psychology and neurology behind this" (P8)*

The parents who got any information on the diagnosis felt that it was inadequate and only helped them at the beginning of the diagnosis. Parents are advocating for more courses and programs which will provide more information on the diagnosis. This can be done by providing a possible solution(s) on how they can deal with the diagnosis and how there should be follow up programmes for them and not just leaving them alone with a young child, a parent that is yet to understand the situation and a future of uncertainty.

> *"but doing that giving my medications and so long you are on your own, they don't know anything about, no anything is wrong, they do know something, and you don't get too much help and support after you have had the diagnosis so that is something that really really should be improved, but I am working on that" (P1)*

> *"It's nice to have the right diagnosis and medications, but without anyone to turn to when the need arises, you then are left with the option of turning to google for solutions. It's not alright that after your child is diagnosed with ADHD, you are like 'almost on your own'. If you have got the right medicine, then that's good, but there is no one to turn to after that" (P7)*

> *"we got a 3-hour course telling us about the diagnosis, about different kinds of medications, about different kinds of challenges with the diagnosis but that's it nothing else" (P3)*

> *"Knowledge definitely makes everything easier. If you don't have the basic knowledge you don't know what to wonder about, you don't know what to talk; you don't know*

> *what you don't know, except with some basic knowledge you can ask the right questions maybe" (P8)*

The healthcare system has been found to do the best they can especially with the resources and knowledge they have, but most parents expect them to do more for them and their children because they are expected to know more than the parent and help the parent understand and manage the child.

> *"It would have been nice to have a course for the parents to help them tackle the challenges better. More information on how to tackle the ensuing challenges, better communication techniques; especially in dealing with the child's reaction to the situation; explaining things to the child in a better way. Often I have seen it that I have failed as a mother but not that is because of the ADHD, nothing to do with me being able to take care of my child see if it fits in this place" (P7)*

Getting information and being equipped with knowledge about the diagnosis of one's child can be of advantage to the parent and can also help healthcare professionals understand ways in which they can treat and attend to each child. Still, it also has its disadvantage for the parent.

> *"and the negative thing about this was at school and at the lower level of healthcare service, my local healthcare, I was the one with answers, I felt very alone because I didn't get anyone to share with and at my kids' school anything I said was becoming the law, on one level that's fine because I know my kids best but on another level I felt like why can't anyone help me, why can't anyone say oh, that's wrong, it's better to do this, I felt alone in that way and also this kind of..... they say you have full control, you know everything so we can't do anything for you, because you know it all" (P8)*

5.3 Emotional roller-coaster

5.3.1 Stability

The emotional drain of having to change doctors for a child within a short period of time and not informing the parents or making the child adjust or understand the reason for the change has affected parents in negative ways. They are of the view that there should be stability within the system and regulate the way plans are made for not just the children but the parents.

> *“Its been a roller coaster but now we know why there is this constant roller coaster ride” (P3)*

> *“she had so many different treaters; first she had one she was very nice, but then she got pregnant and then she went out, and then she got another one, and he also got sick, and he was gone, and they were another 2, so eventually she got another 4, and it takes times for a child especially a child who is an introvert to get in contact and involved with another person and trusting the other person so it all took a very long time before they could say yes she’s got ADHD” (P4)*

5.3.2. We matter too

Aside from taking up the new role of becoming parents, they start learning to be caregivers to children with disability by learning to comprehend the said children. Parents often became surprised when they realised the way healthcare workers treated them with information sharing by not carrying them along with new development and informing them of things to do. Most of these parents felt they were not appropriately consulted in the decision making or that their opinion were not sorted for, to know their thoughts if they were comfortable with the available arrangement of things. These became a reason for concern to these parents because they felt there should be a form of partnership, were everyone works together to make things work. While a father had his experience of healthcare workers assuming he was not capable of performing the job as a caregiver, but the mother of the children would be the appropriate individual to contact in case of the information. A parent also felt the healthcare system did not care about their own needs especially with getting help or assistance

> *“Obviously, the start was a shock. We got a call. All we had to do…I think it was on the 3rd day after we came home from the hospital and then we got a call: oh! You need to be in Oslo tomorrow. Tomorrow morning, you need to be in Oslo; so we got in the plane with a week old baby and flew to Oslo. That was a bit of, of course, a shock” (P5)*

> *“Also with the healthcare systems the mother of my children was always the go-to contact person in the beginning, but then after some time they like ohhhh… maybe we should talk to this guy because he is always here, he is the one taking the phones ooohhhh… let's start with the mother, and then they slide over to me after some time” (P8)*

The parent in the medical field was not spared from the exclusion and neglect of healthcare workers. A parent was left with no care and recognition for her needs due to the assumption that she should be more informed because of her professional qualification.

> *"you know what I mean, you can manage this yourself cant you?, you being a doctor and all and they leave it up to me to take the rest of the treatment yourself, mostly" (P4)*

A father spoke about their lack of recognition of his role as not just a father but also a parent and one who should also take up caregiving roles within the home front. He pointed out the societal view of gender in the caregiving role

> *"as a father, that kind of businesses was not used to having fathers that have responsibilities at home, that kind of responsibilities and at the same time, many of them like my old boss was like ahhh ADHD is nothing real, you know its made up. So for me, it was very difficult to match both responsibilities at work with responsibilities at home" (P8)*

The health system, organisations and workplaces may not recognise and appreciate the role parents play in the lives of their children. Yet, these parents take joy and pride in the role they play, especially when they see the smiles on their healthy and happy children.

> *"You know, I get a lot of...playing with the kids gives me a lot of energy. So, this is something that I enjoy. I really enjoyed taking the role of an active father. You know, caring because…it's nice, you know, you get a lot of affection from the child back which is nice, and it's also a societal thing that I get a lot…you still feel more…so, I see that both my mother and mother-in-law, if I do a lot with the kids, they think – Oh! He's so great, you know. You get a lot of appreciation that really (Laughs)…you know because you are breaking some traditional rule. It gives you some positive feedback"* (P5)

When asked what they had to say about the reaction and treatment they got from healthcare professionals, a parent gave suggestions on how they should be treated and viewed.

> *I think like other parents to ADHD and my feeling is that many of them are not satisfied with the health system and I think one reason is that I know there are limitations, the health system is not perfect, there are people working where they have their limitations, the system is huge, it can't be perfect (P4)*

> *"I would like to let them know that they are dealing with human beings and not papers" (P7)*

> *I think they need that someone sees them, that someone recognises that they do struggle sometimes, that they are tired, that your mind is so focused I think sometimes on the child with the disability that you forget yourself, you forget maybe other friends and family and you can kind of sort of maybe your mind is in a bubble, to be seen and to be asked how are you, what do you need, is there something we can do for you, what can we do to help you (P3)*

Admitting to the flaws of healthcare practitioners was a way a parent found a balance in his dealing with the professionals.

> *"So as soon as I started to see them as normal people the treatment and the cooperation between the parent and the hospital got better because maybe they also understand that ok this parent has meanings and options about this" (P8)*

Of all the parents interviewed, only one parent spoke of the health professional understanding and acknowledging that she should be tired from the work and role she played. The parent appreciated that she was also being recognised as a patient who is also in need of care.

> *"she didn't ask; she just stated "you have to be tired," she said to me and when she said that I could just feel everything falling apart and my tears and I started crying because someone just told me how I actually felt" (P3)*

5.3.3. Hope versus reality

The future of their children was of great concern to parents. How would they take care of themselves when they come of age, will they want to leave the house and become independent? While most were of the view that independence comes with responsibility which they were not sure their children would understand how to handle. At the same time, others also want their children to become independent to enable the parents to have time to shift the focus to themselves and take care of and their own needs. But most were certain their children were not going to be ready to leave the house when the time comes.

> *"I do also worry about the future, what will become of her? That a teenager gets help or assistance from a parent is normal, but when she 19, 20 and most other at the same age are getting independent from their home maybe they move to their own little apartment and have to manage on their own, I do worry when I think about" (P4)*

> “*That’s sort of a scary thought. It's scary when they grow bigger and become more independent because they want to try out things themselves, they want to be in their natural opposition against their parents and what are they going to object to? Are they going to object by not taking their formula, their exchange, will they object by eating something that they should not eat? That’s probably my biggest fear and also because this is in a period where it's so important that the brain gets the nutrition that it needs and doesn’t get out of balance so to say that’s my biggest fear when they get older I think it is going to be easier, but I think their teenage period is probably the worst” (P2)*

> *“Yeah, I would be lying if I said am not, at the same time I know most people with ADHD that get diagnosed and the medication and get the proper training they will do just fine on the other side I know they are in danger so because of their impulse and the constant search to relax their brain and then she has difficulty in learning to keep track of time, but yeah I do have some fears for her future, but at the same time I think she is going to be ok, she is a strong girl, a very strong girl” (P3)*

Furthermore, parents may desire for their children to move out and become independent, but they admit that the price of independence means loneliness for them and not having to be with their children as often as they would want to.

> *“Its like yeahhhhhhhhhh and NO, its …… I look really really forward to not having to fight with them constantly and just be with them when we have the fun times you know because I think it is going to be a different kind of relationship when they leave the house, I hope so, but at the same time it's like ohhhhh I don’t want them to leave, its both” (P1)*

> *“Most definitely, because I think I could have more time for myself in the evenings or weekend, if I want to go away for weekend I could just do that I can't do that now when they live at home, if they are living away and more independent I can live my own life, but I also think that I will probably miss them, you know when you have twins, and they both move out at the same time then you are suddenly alone, but I hope one, not at the same time so I can get used to living alone both looking forward to living my life on my own but also afraid of if it gets too lonely”. (P4)*

The solution on how parents can overcome the fear and worry of what will become of their children when they leave home was given by one of the interviewed parents. He was of the opinion that the healthcare system should educate not only parents but also the children when they come of age to understand what the diagnosis is all about and how to help maintain good health, in turn, will make parents worry less about their children.

> *"But I think maybe they should be a little bit more pushy from the hospital to get them to go to controls sending in blood samples and see how their levels are so they can sort of support them better" (P2)*

CHAPTER SIX

DISCUSSION OF FINDINGS

Introduction

The chapter will commence with identifying the needs of parent caregivers of children with disabilities, understand their experiences with the Healthcare system in Norway and identify ways in which these parents try to cope with their caregiving role. I will discuss the findings of the interview conducted with regards to the theoretical framework and other research findings. The implication of social work practice, healthcare system, policy makings and the educational sector will also be discussed. The first and second research questions will be addressed simultaneously with the theoretical framework.

6.1 Physiological Needs

In the interview conducted, there were two themes found under the physiological needs: sleep and the second finance. Most parents interviewed complained of inadequate sleep and rest which they could not avoid in their daily lives, Giallo et al. (2013) explained one of the various aspects which affect the health and well-being of a parent with a disabled child is exhaustion or fatigue. Parenting a child with a disability can be time-consuming. The child having irregular sleep routines due to the disability or unknown causes prevent the parents from also sleeping especially during the night when sleep was essential; the lack of sleep for the parents made them have rough days, and most couldn’t coordinate their activities due to the lack of adequate rest and their physical and psychological state being affected. The effects of the lack of physiological needs have also been supported (Brinker et al., 1994; Conger et al., 1995; Giallo et al., 2013; Rhodes, 2003). Parents caregivers who do not get the necessary rest of an average human being end up being stressed out, which affects not only their psychological state but also their interaction with the children and family members, and also deal with their children’s disability negatively and differently (Conger et al., 1995). Parents might have accepted their new way of life not having sufficient sleep, but most of them had to make the enormous sacrifice of reducing their jobs to 50% while those who could not navigate both the workforce and caregiving had to stop working and rely on welfare benefits. Most free periods of rest for parents are the time children spend at the school, where parents can also make plans for themselves and other family members. When parents are stressed from their caregiving role, it hinders the early and swift intervention for the development of the child (Brinker et al., 1994; Giallo et al., 2013). Lack of rest and tiredness has resulted in health deficits which usually results in parents lack of cognitive retention, memory loss and misguided decision-making, lack of clarity in thinking (Hockey et al., 2000; Van der Linden et al., 2003). Therefore, professionals who are charged with the care of children with disabilities should work towards making sure parents are stress-free, and most of the burden has been relieved from them before meetings and appointments for implementing and working with parents for a better quality of life for the child (Dervishaliaj, 2013; Giallo et al., 2013; Rhodes, 2003). Professionals have to work closely with parents to enable them to get to their own state of homeostasis, help them create a balance in their daily lives. Most parents do not have the time to create or find this balance due to different task carried out. Parents mostly find it difficult to plan and execute their daily activities in their favour; they are mostly occupied with taking care of others at the expenses of their own health. Although, professionals can help them find and work around a balance, through engaging in in-home assistance for parents; when children go on respite care, other children in the family who are not disabled should be taken care of by other professionals or family members and not the parent. Parents who do not have sufficient rest may end up not reaching their highest potential therefore not getting their self-fulfilment needs.

In the area of finance, research has proven that inadequate finance has a significant effect on families, especially families with children who have disability (Abelson, 1999; Blum & Sherman, 2010; Redmond & Richardson, 2003). These authors, as mentioned earlier, explained that parents try to avoid poverty by balancing the financial status of the family due to the extra expenses of a child with disabilities. In the case of parents in Norway, the welfare state model provides generous health and disability financial benefits for families who have people with disability. This welfare benefits have enabled families to fill in their financial needs and can lay-off from work during the early, formative years of their young children. However, caring for a child with a disability is hard, and it can lead to financial constraints on the economy of the family, hindering the family from undergoing extracurricular activities which will require money. Data collected during the research showed that parents still hoped to have more financial stability in their home to enable them to engage in activities that will help them with their physiological and psychological needs. Most parents are of the opinion of having more money to go on vacations or to hotels where they can get some rest and rejuvenate themselves from the stress of caring for a child with disability. Vacations, relaxation, fun and leisure activities have been found to help caregivers improve on their quality of life, value and worth. It also makes them happy and helps improve relationships with family members and spouse, and friendships can also be made on such trips (Mactavish et al., 2007). Parents find it hard to use the financial resources they have to engage in their belonging social needs which makes them lack these needs. They cannot go out and hang out with friends the way they used to before having children. However, parents also had a problem with reducing their work hour due to the financial lack it will cause, but if an opportunity presented itself, they would take some time off to enable them to have little leisure and rest for themselves.

Despite substantial financial, health and disability benefits provided for its population by the Norwegian government, her citizens still lack financially to take care of their essential needs. The social worker should work with policymakers to put into personal consideration needs of parent caregivers whose health and quality of life should be of priority due to the task they carry out in the family. There should be provision for assistance or more financial aid for parents to enable them to attend to not just the financial needs of the home but also the physiological and psychological needs of these parent caregivers. Single parents who have full-time employments should also be put into consideration in terms of the number of hours they work and the social assistance they get from the municipalities. While most parents will not want to complain to the municipality due to their personal feelings, they would also want to have a few hours away from their jobs where they can have time for rest but can also not be affected financially.

Norwegian families may not have financial needs like most families in Europe or other continents, but they still need more financial resources to take care of their personal needs. According to Maslow (1943), when a human being lacks security in terms of their finance, they can not achieve their other needs like social belonging, esteem and self-fulfilment.

6.2 Psychological Needs

According to Maslow (1943), psychological needs are under two categories: belongingness and esteem. In the data acquired, parents lacked and needed a sense of belonging, which was in the form of assistance. Parents need help from people, especially in handling their child’s behaviour and also in having the opportunity to create more time for themselves (Huus et al., 2017). With the data acquired, I noticed parents lacked time for self-care due to their lack of intimacy, friendship, and maintaining a steady social circle. During the interview, parents discussed their lack of social support from the system, family and friends due to distance of most of their relatives, they felt lonely and didn’t have people to talk to and help with the care. Parents explained the presence of friends and family members will help find free time to have some rest, elevate them from the stress and make time for themselves and other activities. These findings from the interviewed parents are in line with early results by researchers (Giallo et al., 2013; Hogan et al., 2002; Jones & Passey, 2004; Murphy et al., 2007). However, parents who had friends and relatives who still kept in touch, couldn't reciprocate the emotional gesture due to lack of support from the system. Most parents preferred staying at home and caring for their child since no one could care for them. When they left the house to mingle with friends, they got calls of emergency regarding the child with disability thereby not being able to maintain a social and intimate relationship with individuals. Friends and family members withdraw from most parent caregivers, this affects parents negatively and can cause stress, health relapse of the parent and can affect the family dynamics (Jones & Passey, 2004; Perry, 1989). Parenting a child with disability prevented most parents the freedom and independence to associate and socialize in the society and the lack of assistance from the municipality, system or commune in form of providing more respite care made it impossible to have an active social life.

Social support comes in ways of emotional support, has been found to improve the self-esteem of individuals (Hogan et al., 2002). Having friends, families and social workers who can help you share the load and also form an emotional bond with parents can eliminate the stage of self-care (Giallo et al., 2013). Healthcare workers should also be a source of strength and should provide parents with the emotional stability they need. They should also help create a fair and friendly atmosphere for parents to enable them to feel comfortable discussing their problems and hopes.

The second research question: understanding the experiences of parent caregivers with the healthcare system was answered under psychological needs. In Maslow's hierarchy of needs, there were three themes in relation to his esteem needs and regarding the response to the question: knowledge is power, stability, and we matter too. These themes indicate the experiences parent caregivers encountered with the healthcare system, where the healthcare system did not provide adequate medical and professional information about the diagnosis to the parents which left parents struggling with knowing and understanding the diagnosis. Most interviewed parents were not knowledgeable in the field of medicine or child psychology and placed their trust on the health system they felt knew more than the parents and should educate them about their child's diagnosis and not the other way round. The trust was not reciprocated back because these professionals only had limited information about the diagnosis and relied more on out-dated medical books and journals for help than facing the practicality at hand. This gap in knowledge prevented parents from fulfilling their parenting and caregiving role. Parents can go into the state of anxiety, confusion and mistrust for the system due to lack of information and knowledge about the diagnosis of their child (Balling & McCubbin, 2001). Similar to this, studies on experiences of parent caregivers of children with disabilities have found parents not to question the expertise of healthcare professionals but have come to the realisation that these professionals have less knowledge about the health implication of the new diagnosis, life expectance and solutions to their children's disabilities (Goddard et al., 2000). Also, dealing with the lack of information on their children's health is not the only challenge parent face; sometimes they get to notice the unannounced replacements in health professionals who were charged with the care of both the parent and the child. They often complain of the instability of the practitioners in their practice and administration of their children, which caused psychological and physiological stress on the parents and children. They would have preferred prior notice made to the parent and psychological briefing and preparation for the child and themselves. There were cases of healthcare professionals not conducting a follow-up on the children and their caregivers. Parents were left to care for the children immediately after the initial diagnosis without professional guidance or check-up; these made them feel alone in their journey and stressed them out more because they didn't know if they were doing the right thing. The feeling of being alone and not knowing what next to do after the diagnosis makes parents think the professionals do not care about them and how they feel and are not interested in caring for their children (Goddard et al., 2000). While parents feel sad when not carried along in the care, diagnosis and decision making of their child's health, it also makes them look incapable of the caregiving task and can affect their perception of how people view them and reduce their self-esteem in their parenting role (Lindblad et al., 2005). Professionals need to understand parents and their expertise in their caregiving role; treat them as their equals.

Social workers should educate the parents on their rights to know and ask questions about their child's health. They should also teach the parents of the right to demand explanations for information given and parents should also be aware that professionals do not know it all but instead, they, the parents, have a say in the lives of their child because they know the child more than the professionals. All parents need is to be included in the planning and decision makings on the health of their child; they want to learn and know to enable them to become the unskilled professional caregiver of their children. Furthermore, irrespective of gender, they want people to appreciate the caregiving job they do and that fathers also make good caregivers to their children as well as their mothers. Lindblad et al., (2005) further explained that parents want to be acknowledged for being a carer to a child with a disability. They also want healthcare professionals to recognise that they are human beings who also have worries, needs and care and should also be looked after the way they care for their children. Usually, when parents receive such attention from professionals who work with them, it gives a feeling of emotional security and confidence in the role they play in the life of their child. Professionals and parents can work together in achieving the goal, which is a healthy child and a stress-free parent. Also, parents have been viewed to be experts in the lives of their child. At the same time, all professionals involved in the case are experts in their field (e.g. child welfare, nutritionist, child psychology, radiologist, pedagogist etc.), coming together to work as a team by sharing information in different areas of expertise which aids in reducing the stress on both the parents and all parties involved (Lindblad et al., 2005).

6.3 Self-fulfilment needs

Furthermore, self-fulfilment needs answered the first and second research question. Self-actualizations needs were part of the parents’ personal needs: hope versus reality. Also, parents explained their experience with the healthcare system as one which left them with self-actualization needs which the study found to be: just a little too late. Based on the first research question, which is understanding the needs of parent caregivers. Parents want to grow old and enjoy their old age; they want the fulfilment and sense of accomplishment in their journey through parenthood; they want to see their children become independent and accountable in life. But most of these parents are worried that it will not happen for their children with disabilities, the children’s inability to grow and think of independence has caused psychological stress and worry for the parents. Research conducted on mothers of children with disability proves that the thought of the future of their children and the hope of liberating their children from emotional and financial dependence has resulted in more stress, depression (Little, 2002; Ogston et al., 2011). The hope and possibility of leaving the house when the time comes is met with the reality of if it will ever happen and the fear of how the children will cope, care for their physical and mental health, understand and learn to take their medications, especially at the right time. The feeling of hope for the future of the child has been found to be a mechanism parents use to protect themselves against psychological stress (Lindblad et al., 2005; Ogston et al., 2011). The parents need for freedom and pursuing long term goals is dependent on the child’s ability to become free and independent. The reality may be glaring for the parents but using the hope and working with the children towards a future that is uncertain has been found to help parents achieve their own personal happiness and satisfied with their parenting skills and styles (Ogston et al., 2011). Moreover, this study found that parents on second thoughts realised that once independence comes for their children, they become lonely and sad due to their lack of social belonging as a result of all the years spent in caring for a child who will have to leave home eventually. The adverse effects of worry and the reality of their child being unable to leave home someday affect not only the parents but also the parents' ability to focus on the present situation and other children in the family (Ogston et al., 2011). Social workers and healthcare professionals can help parents teach children how to prepare for adulthood by educating the children through pictograms and visuals thereby stimulating the mind on the advantages of independence. Also, children go to the hospital for regular check-ups, there should be classes to educate them on how to administer their medications on their own. Parents should also be taught ways to equip their children with the knowledge on what independence is and how the children can live on their own. These lessons will be favourable to both the children and also parents in obtaining their happiness of their children moving on in life and themselves being able to move on to old age without worry.

The second research question on their experiences with the healthcare system left parents with more physiological, psychological, and belonging needs than should have been expected of the system which has been designed to help their patients. Parents were in dismay especially at the early stages of childhood, their children were not behaving in ways of children within their age bracket, and when they sort assistance from the healthcare system, there was no positive response. Other studies also confirm the parents’ experience with the healthcare system in terms of early diagnosis and professionals lack of empathy, collaboration and research on the symptoms parents indicted to them (Dabrowska & Pisula, 2010; Gray, 1994; Jones & Passey, 2004). Parents were filled with self-blame, disappointments, sadness on being sent home without any solution to the problem instead were told all was well while they knew all was not well. Most of the children who were diagnosed late are children with non-verbal and invisible disabilities which professionals have to carry out a standardized test to determine the problem, but the professionals in charge of these duties were found wanting in this study. The literature review of Gray (1994), found that doctors were reluctant in diagnosing children who showed serious medical problems due to their young age and their parents were told to have been exaggerating the problems, and they should not worry because the children will outgrow the problem. A study of autistic children in Poland showed children also got diagnosed at a far end of their childhood and the few lucky ones may get diagnosed on or before the age of 3; the author also explained that the onset of diagnosis is not a prerequisite for treatment and support from the healthcare authorities (Dabrowska & Pisula, 2010). However, if parents are sent home with the same problem they came to the healthcare centre with, when the problem escalates, and diagnosis is given at a later time in the child’s life, one can say the diagnosis is a little too late for most parents. This is because they have been denied the opportunity to seek for help at the early stage thereby leaving them with the option of taking care of their child who had a problem neither the parent nor the child could understand and deal with. Parents during the interview admitted that it led to psychological stress and deprivation of the early knowledge of their child's health. Parents also talked about not just having a late diagnosis, but most times, a misdiagnosis was given, which sends the family members back to their initial stage of psychological stress. Study shows that their lack of early diagnosis and misdiagnosis will also affect the effectiveness of a successful treatment and therapy (Gray, 1994).

On the other hand, female children were usually at the receiving end of misdiagnosis, or late diagnosis due to the standardized tests used in evaluating and diagnosing most of these non-verbal and learning disabilities which were developed to have more masculine features than feminine. When a diagnosis can not be made due to the characteristics of the tests, it confirms to the health practitioners of their initial thought of parents exaggerating the problem and the children being fine (Marcus, 1977). Parents who believed and trusted their parenting style ignored the wrong diagnosis and demanded more test be conducted on their children till a satisfactory diagnosis was made; they were found to strive better in their caregiving role and find happiness in their parenting style (Huus et al., 2017). The educational system can help these parents by providing them with a recommendation letter to back up since most parents begin the observation when children start school. Teachers should also work with parents in understanding these learning disabilities. Social and caseworkers should also help parents demand their right to get adequate and proper health attention to their children. A parent during the interview explained the lower level of the healthcare system (local care) and the higher level of the healthcare system (bigger hospitals) for children and wondered if the bureaucracy in the healthcare system is to blame for the delay of diagnosis. A solution of reducing the diagnosis process to a minimum was also proposed; this is to enable parents to get the diagnosis on time and not wait for months for this diagnosis.

6.4. Devising coping mechanisms for caregiving role

The third research question was to understand coping mechanisms parents used in their caregiving roles. With no assistance from relevant authorities', parents had to develop their coping mechanisms in no hierarchical order or Maslow's needs (as seen in figure 1). Parents used their available personal needs as coping mechanisms through the caregiving journey. Taanila et al. (2002), explained that parents use the resource they have and put them into useful coping mechanisms. External support through family members and friends were used by parents as coping mechanisms. Relevant research has also shown the importance of these support for parents and its effect on their physical and psychological health (Dabrowska & Pisula, 2010; Gray, 1994, 2006; Murphy et al., 2007).

In trying to cope through their lack of physiological needs while caring for their children and family members, parents in this study sort and got support from their family members and friends who were able to help them look after the children while they had time to rest. Grandparents, friends and extended family members helped these parents by looking after the children, taking the children out on camping with other children while the parents had time to go out to socialise with friends or just themselves or also rest. They also went on vacations with these parents to help care for the children and parents on such trips. Parents have been shown to appreciate such support from external source due to the positive effects it has on reducing the stress they go through (Murphy et al., 2007). Co-operation among family members on ways to help and assist these parents in relieving them of few minutes of caregiving have been researched to improve parents ability to care for their children (Taanila et al., 2002). Parents also coped by voicing out their need for a break from all their activities and wanting to rest, demanding for their esteem, need of freedom to also not just be parent caregivers but human beings who deserve to take a little time off from home, to enable them to be more efficient in the home. Taanila et al. (2002), talks about the openness of their struggles and personal needs and taking responsibilities as coping mechanisms used by parents. Emotional appraisal helped parents cope with their caregiving role. Parents build on their emotional strength and the emotional support of people around in coping with their caregiving role and other needs they could not get. Gestures people gave while parents cared for their children and other family members made parents want to do more and were filled with the pride of a capable parent who other people saw the work they did. Seeing their children look at them with love and admiration added emotional strength to continue with the special role of caring for a child with disabilities. Parents have also seen their parenting experience as one which has shown them of their ability to take up any challenge in life especially being a caregiver to a child with special needs and care (Murphy et al., 2007). Building on their self-fulfilment needs also helped to cope with their situation were mechanisms parents established. Parents researched on ways to cope, building on their parenting skills and improving on their knowledge about the diagnosis instead of waiting for people to come help them, they explored their parenting and coping mechanism from the internet, reading online and being better at the life-long job they have found themselves. Most parents may not want to tell people of their difficulties in their daily lives but family members are encouraged to give a helping hand to parent caregivers of children with disabilities, few hours of relief can play in great role in making the parent continue doing more in their caregiving role. Parents find it difficult to trust children in the care of other individuals, social workers and other formal caregivers should educate and equip themselves with information on the disabilities of the cases they handle, this will in turn enable parents build their trust and know these professionals have the care of their children in mind and they want to assist.

This chapter answered the research question of the study. Discussing the nine sub findings, which are under three main themes in the result section: these findings are required rest; parents were found to be in need of adequate rest in their daily lives. Getting the required rest will make the rest of their day and activities better. Also, parents needed time for self-care; parents need to focus on themselves a bit more and at the same time, not neglecting their children and other family members can help their mental health positively. Moreover, having sustainable financial security can go a long way in allowing the parents' caregivers to sort out some of their personal needs.

Furthermore, parents caregivers need assistance from all authorities necessary to cope with the physiologically and psychologically needs in order to continue carrying out their caregiving role effectively. The other need for parent caregivers was the inability to have an early diagnosis for their children; there were delays from the healthcare system, which affected the lives of both the children and other family members. The late diagnosis was not the need parents wanted. The parents' caregivers also need to be informed about their children’s disabilities and possibly parenting style for children with special needs care. Parents wanted to be empowered with information about their children’s health, but they could not get it from healthcare professionals; they were left to care for their children with no knowledge on how to do so. Parents caregivers were noticeably concerned about the instability of healthcare practitioners in the lives of their children and the psychological effects it had on the children. They wanted practitioners to be able to attend to their children for a little more longer before a change in the practitioners without prior notice. The need to be included was another need for these parents caregivers. They felt the healthcare system neglected them in decision makings about their children; they felt the healthcare system overlooked their role in the lives of the children and wanted the healthcare system to know they also mattered. The last need of parent caregivers was the need for their children to be able to gain independence at the appropriate age, leave home, get a job and become financially independent. Although, most parents caregivers were uncertain because of their children’s lack positive attitude toward the prospect of leaving home one day or the fear of their children unable to care for themselves if they eventually leave home. Finally, the coping mechanisms parents developed for themselves were through external resources from family and friends. They were able to build up their emotional support to continue in their journey. These needs of parent caregivers were analysed using Abraham Maslow’s theory of needs. Possible recommendations in the field of social work, healthcare sector, educational and policy-making were also discussed under each finding and analysis.

CHAPTER SEVEN

CONCLUSION

This study was conducted on parent caregivers of children with disabilities with a focus on participants in Norway. The study was aimed at exploring parents' caregiving role and understanding their needs. Their experiences with the healthcare system were also studied, and the coping mechanisms they used in their caregiving role was studied. There have been studies on children with disabilities and the experiences of their parents and family members, but much has not investigated the needs of these parents in terms of their physical, psychological, and social needs. This study was aimed at bringing more knowledge on the field of caregiving and healthcare. The research had three questions to explore:

1. What are the needs of parent caregivers of children with disability in Norway?
2. From the perspective of parent caregivers, what were the experiences with the healthcare system?
3. What coping mechanisms do parent caregivers use in their caregiving role?

The result of the questions was obtained by adopting an inductive qualitative research design and using a semi-structured interview method. The results from the data transcribed showed that parent caregivers needs and their experiences with the healthcare system were categorised under Physiological needs, Psychological needs and Self-fulfilment needs. These categorisations were done using Abraham Maslow's theory of need. This study further showed that parents caregivers developed their coping mechanisms through experience and encouragement in the life journey. Also, the needs of parent caregivers, as well as recommendations of how to help parents meet their needs, were explored during this study. Further recommendations on the improvement of communication and relationship between parent caregiver's healthcare practitioners, social workers, and education sector, understanding and utilising of social policies were also introduced.

7.1 Further studies

Findings from this research identified various areas which further studies can work on. The interviewed parents caregivers talked about the effects their parenting role had on the other children who didn't have any form of disability and were worried about the future outcome.

Some of the children wanted to have the disability to get the attention their other siblings got. Researchers should venture into research on the experiences or perception of disability by siblings of disabled children. Healthcare workers and social workers should also work with parents in helping these siblings gain a sense of acceptance within the family and the education of what disability entails.

Furthermore, most parent caregivers coping mechanism have been their parents (grandparents of the children) and the uncles and aunties of these children and friends. Consequently, research can be done on the experience of part-time caregiving to a niece or nephew with a disability.

Research should also be conducted on couple’s experience or needs in their caregiving role. A quantitative study with a larger population of parents can help policymakers determine to a large extent what a higher percentage of Norwegian parent caregivers need and experience.

Parents during the conclusion of the interview section were asked if they had questions to ask the interviewer. Most parent caregivers of children with ADHD requested for more studies to be done on them and said they feel neglected in the field of disability.

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APPENDIX I

Consent Form

Participation in a Research

This is an invitation to take part in a research project titled **Needs of Parent Caregivers of Children with Disability and their experiences with the Healthcare System**. This research is part of my master's degree programme at the University of Stavanger where I am studying Nordic master's in social work and welfare.

The main aim of this study is explore the needs of parent caregivers especially when it comes to caring for a child with disability, being a parent, working full-time or part-time, going about social activities and also taking care of the home and other family members. The research has in mind the current situation in the country and how parents have been able to create a balance. Similarly, the study also aims to understand coping mechanisms parents use in their caregiving role. Additionally, the study will also want to explore the experiences parents have had with the healthcare system.

You are participating in this research because you are a parent caregiver to a child with disability.

Who is responsible for the research project?

I am the lead researcher for the project and my name is Ijeanuri Rosemary Okafornta, a student at the University of Stavanger, Norway, being guided under the supervision of Associate Professor Richard Piech also from the University of Stavanger.

What does participation imply?

This research is a qualitative research, the data for the research will be collected through a one-on-one interview (electronic means), the research will require between 6 to 9 parent caregivers. Parent caregivers of children with any form of disability. The interview will be conducted at the convenience of the parent and the duration will be approximately 30 to 60 minutes. An audio recording will be used to gather the information during the interview. Questions will be asked using a semi-structured interview guide. Parents can ask questions during the process. All questions will be geared towards understanding the needs of parents, how these needs can be addressed and their perspective about the role of healthcare system.

Participants

Voluntary participation of parents' caregivers will be needed for the study. All participants have the right to withdraw from the research at any point and there will be no negative consequences for withdrawing. All information will be treated with confidentiality and we will respect the anonymity of the parents. The participants interest will be respected all through the research process. The interview will be conducted within the month of March 2020. English language will be preferable for the interview.

Your Personal Information

Your personal data gotten during the research will be used only for this research and all data will be confidential and anonymised. The recordings will be kept in the University of Stavanger in the care of my supervisor Richard Piech and me the lead researcher. After the completion of the project, all audio-recordings will be destroyed and personal data and will be pseudonymised in case of further study and research. You have the right to inform me to destroy your personal data if you do not want it to be used for further research.

Your rights

As a participant, so long as you can be identified in the collected data, you have the right to:

- access the personal data that is being processed about you
- request that your personal data is deleted
- request that incorrect personal data about you is corrected/rectified
- receive a copy of your personal data (data portability), and
- send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data

In case of further questions or inquiry, you can contact the lead researcher or the supervisor with the contact stated below;

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Data Protection Officer (Personvernombud)

University of Stavanger

________________________ ________________________

Date Signature (Student researcher)

Consent for participation

I have read all the information and I am willing to participate in this project.

________________________ __________________________

Date Signature

APPENDIX II

Interview Guide

Needs of parents caregivers of children with disability and their experience with the healthcare system

Information about the study

This study is aimed at exploring the needs of parent caregivers and their experiences with the healthcare system. These needs will be in line with your role as a parent and a caregiver to a child with a disability. Your experience with the healthcare system will also be documented. This interview will be based on anonymity and your names will not be used nor will I require you to tell me your name. Any information shared with me will be confidential and will be used for only this research. You are free to ask me any question during this interview and you can stop the interview whenever you feel like doing so.

Do you have any question?

Background Information

Gender:

Age:

Relationship status:

Employment status:

Number of children:

Age of child(ren) with disability:

Type of Disability:

Municipality:

Interview Questions

1. Describe your experience and role as a parent?
    How many hours do you sleep?

    Is it adequate?
    How many hours do you work in a day at work?
    What are the things you lack as a parent or a caregiver?
    Do you have people who assist you in taking care of your daily activities? Do you have family members helping you?

2. Describe a typical weekend and holiday in your house? How are your vacations like? How do you socialise?
3. What do you feel about your role as a parent?
    - How about your other children/siblings of your child?
    - Can you describe the changes you have made since you became a parent and caregiver?
4. How well do you know and understand your role as a parent and caregiver?
    - Do you have good knowledge of your child’s health?
    - How have you been able to cope with your role as a parent and caregiver
    - Are there things you would have loved to do differently if given the opportunity?
    - How do you feel about your child growing up and moving away from home?

Role of Healthcare services

5. Do you visit the healthcare facilities? Describe your experience with healthcare professionals?
    - How often do you book an appointment?
    - Do they come over to the house? What do you do when they are around? Has their presence helped in any way?
    - Have you mentioned your concerns about your personal needs and health to a professional?
    - What has the health service done to help with your needs?
6. What ways can the healthcare system improve on when it comes to the needs of parent caregivers?
7. What do you think healthcare professionals can do to make caregiving less stressful

Our interview session is almost over, do you have anything to say or add in respect of all we have discussed?

Thank you very much for your time. Do have a nice day