

# **The Silent and Invisible Care-givers**

**The essential structure of being a young caregiver of  
chronically ill parents, diagnosed with MS**

**A PHENOMENOLOGICAL STUDY**

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**Submitted in part fulfilment of the degree of Master of Science in Nursing,**

**The Royal College of Nursing, London**

**February 2005**

## **Statement of authorship**

This dissertation is submitted to the RCN Institute in part fulfilment of the MSc in Nursing and has been conducted and presented solely by myself. I have not made use of other people's work (published or otherwise) and presented it here without acknowledging the source of all such work.

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February 2005

**Total word count: 20.000**

## **Abstract**

During the last decade, there has been a growing interest in drawing attention to the many young children and adolescents, who often must provide demanding and intimate care for their chronically ill parents, diagnosed with MS. Although caring may be the one way young children and adolescents can address or alleviate some of the concerns they may have for their chronically ill parents, their care-giving experiences and responsibilities can seriously affect their well being as well as their transition to adulthood (Dearden and Becker, 2000).

Due to their sometimes young age and their reluctance to draw attention to their care-giving responsibilities, young children and adolescents have sometimes been overlooked by professional caregivers as they are often not easily located or classified and in relation to public and professional judgements. Although children and adolescents have often revealed their competence and maturity through the provision and management of care, they have nevertheless been regarded as subordinates to adults, having few rights and limited authority (Aldridge and Becker, 1993).

There is little knowledge available regarding the lived experiences of young caregivers in Iceland who until now have remained unrecognised and somewhat hidden from many professional caregivers and the Icelandic welfare systems. The research question of this study was ‘ what is the essential structure of being a young caregiver of chronically ill parent diagnosed with MS ?’. The Vancouver School of doing phenomenology was the phenomenological school chosen for this study. The sampling was purposeful and the eleven participants (co-researchers) in the study, participated in twenty dialogues (unstructured interviews).

The findings of this study indicate that being a young caregiver of a chronically ill parent, diagnosed with MS, can be a difficult and burdensome experience. The young caregivers in this study had to face many new realities when their parents became chronically ill and their family lives often dramatically changed. Most of the young caregivers were involved with managing all domestic duties, for years assuming responsibilities for themselves and sometimes their siblings, without professional help or assistance. Those who had access to help and support from relatives, expressed having had considerable opportunities to enjoy their lives but those with little or no access to such support, experienced much more hardship and repeating episodes of anxiety and depression. Most of the young caregivers had few recollection of formal support from either social or health care professionals and most had no recollection of any support from their teachers. Their childhood and adolescence memories were shaped with bitterness and little comprehension of how or why they had been left to manage so much responsibilities, so completely on their own. Most of the young caregivers became periodically isolated from their friends and most had little desire to discuss their problematic lives with their peers. Most of them learned to follow 'sensible rules', that later developed into the ability of creating personal stability, an ability which helped them fight off episodic depression while meeting the many demands of every day living. Many of them were able to find supportive partners, who became their shelter in life and supported them in giving up their posts as primary caregivers for their, often, disabled parents. Although all of the young caregivers were profoundly fond of their parents, most of them believed their care-giving efforts had become somewhat damaging for them and believed they should have been replaced by a more qualified carer.

## Acknowledgements

I would like to express my deepest gratitude to the participants (co-researchers) in this study, for spending their precious time with me and for their devotion and courage to share their stories with me. Their contribution will without any doubt inspire other young caregivers to reveal their stories. I have also to thank my colleagues at the MS society, who helped me find the participants in this study.

I would also like to express my deepest gratitude to my mentor and supervisor, Dr. Sigríður Halldórsdóttir, professor at the University of Akureyri, for her encouragement and support throughout my entire studies. Her vision for enhancing the quality of nursing has inspired us all.

I would also like to thank my dearest friend, Katrín Blöndal, for sharing this journey with me and supporting me during the last but sometimes lonely months of my studies. Another friend, Hildur Magnúsdóttir, I also thank, for her efforts to inspire me with her critical way of thinking and her encouragement throughout my studies.

Last but not least, I especially thank my two daughters, for their love and understanding throughout my MSc studies and I also thank their father, Hákon Gunnarsson and my sister Kristín, who took great interest in my studies and gave me valuable support.

This study was funded by grants from the Icelandic Nurses' Association and for their support, I am most grateful.

# Table of content

1. Introduction	
1.1. Research question .....	1
1.2. Purpose of the study .....	1
1.3. Introduction of the study .....	2
1.4. Rationale for the study .....	4
1.5. Ethical background of the study .....	6
1.6. Summary .....	9
2. Literature review	
2.1. Care-giving as a burden .....	11
2.2. Care-giving resulting in social exclusion .....	13
2.3. Care-giving without professional support .....	13
2.4. Care-giving and being cared for .....	14
2.5. Summary .....	15
3. Research design: methodology and methods .....	16
3.1. Introduction of the philosophical underpinnings of the study .....	16
3.2. Philosophical underpinnings of the study .....	17
3.3. Methodology and philosophical perspectives .....	19
3.3.1. Phenomenology .....	19
3.3.2. The Vancouver school of doing phenomenology .....	20
3.4. Methods used for data collection .....	21
3.4.1. Data collection .....	21
3.4.2. Sampling .....	22
3.5. Summary .....	23
4. Data collection and analysis .....	24
4.1. Data collection and data analysis .....	24
4.2. Trustworthiness – the rigour of the study .....	29

4.3.	Ethics .....	30
4.3.1.	Permission to conduct this study .....	30
4.3.2.	Characteristics of the participants .....	31
4.3.3.	Access to respondents .....	31
4.4.	Summary .....	33
5.	Findings .....	34
5.1.	Phenomenological description .....	35
5.2.	Key themes .....	38
5.3.	Recognising and adapting to new realities in life .....	40
5.3.1.	Being overwhelmed by the invasion of a foreign illness .....	40
5.3.2.	Living without a true childhood.....	44
5.3.3.	Caring for a parent in need .....	46
5.4.	Identifying further restrictions in life .....	48
5.4.1.	Caring without being cared for .....	49
5.4.2.	Taught but not supported in school .....	51
5.4.3.	Secret and isolated lives .....	52
5.5.	Employing personal resources while embracing support in life .....	54
5.5.1.	Creating personal stability .....	54
5.5.2.	Releasing tension, anger and sorrow .....	56
5.5.3.	Having a partner in life .....	57
5.6.	Moving towards independence while making plans for the future ....	59
5.6.1.	Leaving home .....	59
5.6.2.	Having learned valuable lessons in life .....	62
5.6.3.	Creating a vision in life .....	64
5.7.	Summary .....	65
6.	Discussions .....	66
6.1.	Being a young caregiver .....	66
6.2.	Caring without professional support .....	70

6.3. Being cared for while creating personal stability .....	72
6.4. Moving on towards independence in life .....	74
6.5. Conclusions .....	75
6.6. Limitations .....	76
6.7. Recommendations .....	76
References .....	78
Bibliography .....	84
Appendix I .....	87
Appendix 2 .....	89
Appendix 3 .....	93
Appendix 4 .....	95
Appendix 5 .....	97
Appendix 6 .....	101
Appendix 7 .....	103



# **1. Introduction**

In this dissertation I will present a phenomenological study of the lived experience of being a young caregiver of a chronically ill parent, diagnosed with Multiple Sclerosis (MS). The aim of this study is to contribute to a deeper understanding of the phenomenon of being a young caregiver, by exploring how eleven young Icelandic adults constructed meaning and understanding of their lived experiences, while they as children and adolescents provided care for their chronically ill parents diagnosed with MS.

## **1.1. Research question**

The research question of this study is ‘what is the essential structure of being a young caregiver of chronically ill parent diagnosed with MS’.

## **1.2. Purpose of the study**

The purpose of this study is to explore the lived experience of the young caregivers and to explore how they managed to lead their lives, while growing up and providing care for their chronically ill parents. The purpose of this study is in addition, to provide social and health care professionals as well as policy makers in Iceland with important knowledge regarding the living conditions of young caregivers, who perform caring tasks within the context of the family unit but have until now remained unrecognised and somewhat hidden from many

professional caregivers and the Icelandic welfare systems. Constructing knowledge and understanding of their lived experiences can serve to contribute to the enhancement of welfare systems and services that address and meet the human rights, needs and wishes of young caregivers in our country, especially those who have a parent diagnosed with MS.

### **1.3. Introduction of the study**

In an effort to explore the lived experience of being a young caregiver (Table 1., p.3), eleven young adults, were invited to participate in this study. They had all cared for their chronically ill parents diagnosed with MS during their childhood and adolescence and most of them had been their primary caregivers. In order to gain understanding of their lived experiences, the young caregivers were asked to reflect on how they adapted to and managed the, sometimes, dramatic life changes when their parents were diagnosed with MS and became chronically ill. The young caregivers were asked to reflect on how the illness affected their lives, and identify the possible restrictions they had to face, while also reflecting on what resources they could employ in managing their every day living while caring for their parents. As most of the young adults had left their posts as primary caregivers, they were also invited to reflect on their present situations, the lessons they had possibly learned, while reflecting on possible dreams or visions regarding personal and professional growth in future situations.

**Young caregivers** can be defined as children and young people, aged 5-20, who provide care to another family member, usually a parent, who has a physical illness or disability, mental ill-health, a sensory disability, is misusing drugs or alcohol, or who is frail. Many of these young caregivers will experience restrictions on their childhood development or in their transition to adulthood (Becker et al., 1998).

**Table 1. Definition of a young caregiver**

The eleven young adults in this study were 18-25 years old, but were 6-16 years old when they began caring for their chronically ill parents. Most of them were 9-12 years old when they began caring for their parents, two young caregivers were 6 years old and two were 16 years old. Most of them have cared for their parents for 8-10 years, three cared for 5 years and two for 14 years, average years of care-giving was 9 years.

There is limited knowledge available in Iceland regarding the living conditions of young children and adolescents who care for their chronically ill parents and this study is presumably the first to address the lived experience of being a young caregiver of a chronically ill parent, diagnosed with MS. Although this study will only reveal how these eleven young caregivers constructed meaning and understanding of their lived experiences, it is, however, my believe that such knowledge and understanding can serve to further guide social and health care professionals as well as policy makers in supporting and enhancing the well being of young caregivers in our country.

#### **1.4. Rationale for the study**

The provision of care by family members to another family member is not a new phenomenon and families have for centuries provided care for chronically ill and dependent family members. More people are, however, surviving chronic illnesses today than before and due to rapid advances in support systems and technology the number of patients, suffering from serious physical and mental disabilities has steadfastly risen (Flickinger and Amato, 1994). For the last decades, family ties and family structures have also been changing, families have become smaller and the numbers of families of single parents have been steadfastly rising. Small families are, however, vulnerable for sudden and permanent disruptions (Twigg and Atkin, 1994) and when single parents become chronically ill and dependent, the physical and psychological life changes that can result from their illnesses and disabilities can cause disruptions of established family patterns and family interactions (Jewett, 1982; Flickinger and Amato, 1994).

The population of children living with a parent who has been diagnosed with MS is constantly increasing, as most MS patients choose to live at their homes with their families, despite their, often, severe disabilities and dependencies. Due to the unpredictable nature and the multiple symptoms of the MS illness (Table 2., p.5), many children of MS patients experience many difficulties adjusting to and coping with their parents' fluctuating but often deteriorating conditions (Blackford, 1992).

**Multiple Sclerosis (MS)** is an unpredictable chronic illness of the central nervous system and despite many scientific advances in understanding the mechanism and management of the illness, no cure has yet been discovered to prevent the apparent normal myelin in becoming damaged at multiple sites (Guberman, 1994).

**Table 2. Definition of Multiple Sclerosis**

Many MS patients become dependent and disabled in the ‘prime’ of their lives and many have to rely on their spouses and their children to provide personal care for them. When adult family members become unavailable, or when families are inadequately supported by social and health care professionals, many children and adolescents seem to take on caring responsibilities, while also managing the many and diverse household chores which previously have remained with the parent (Aldridge and Becker, 1993; Frank, 1995). Becoming a caregiver of a chronically ill patient, diagnosed with MS, and providing them with intimate care while managing the, sometimes, complex domestic duties may perhaps be a demanding task for everyone. Young children and adolescents may, however, be especially vulnerable for taking on responsibilities of such nature as the mere consequences of their caring involvements may seriously affect their well being and their transition to adulthood (Dearden and Becker, 2000).

The lived experiences of being a young caregiver, may involve multiple realities and it may be impossible to achieve a single explanation for this complex phenomenon (Appleton and King, 1997), as different things take on different meaning, to different people in different circumstances (Koch, 1999; Clarifying Theory for Practice, Study Guide, p.82). Since no scientific knowledge has yet

been constructed regarding young and perhaps highly responsible caregivers in Iceland, I believe it is time to begin such quest of inquiry, by exploring the lived experiences of eleven young caregivers, who until now have never revealed their stories of their silent existence.

### **1.5. Ethical background of the study**

For more than a decade, social and health care professionals as well as academics have studied and explored the effects and consequences of young children and adolescents caring for their chronically ill parents (e.g. Aldridge and Becker, 1993, Frank, 1995; Flickinger and Amato, 1994; Watson, 1999; Cree, 2003; Aldridge and Becker, 2003). In that process there has been a growing interest in drawing attention to the many children, who often provide demanding and intimate care for their chronically ill parents and must often assume overwhelming responsibilities in managing all domestic duties within their homes. Despite their considerable responsibilities as young caregivers, their experiences are not easily located or classified and in relation to public and professional judgements and pronouncements, they have often been overlooked and regarded as powerless subordinates to adults (Aldridge and Becker, 1993; Tatum and Tucker, 1998). Although young caregivers have often revealed their competence and maturity through the provision and management of care, they are still regarded as children, who have few rights and limited authority (Aldridge and Becker, 1993). Children as well as their chronically ill parents have, however, human needs and wishes and I share the believes of Aldridge and Becker (1996), who claim that many social and health care professionals have limited knowledge and understanding of the amount of care, children and

adolescents perform within their homes. Aldridge and Becker (1996) also claim that too many professionals have little understanding of the ‘young caregiver’s paradigm’, which embraces the children’s rights philosophy and the human rights of children who care, without undermining the multiple human needs and wishes of the ill or disabled care recipients.

There are, however, those who have challenged these statements (e.g. Keith and Morris, 1995; Olsen, 1996), believing the identification of ‘children as carers’ undermines and silences the voices of those who are being cared for, believing that the ‘disability right paradigm’ should continue to have priority over that of their carers. Keith and Morris (1995) maintain that the concept of ‘care-giving’ is all too often used for minimal care or practical assistance, which is essential for many disabled people to maintain their independence, equality and control in life. Keith and Morris (1995) also claim that young caregivers are increasingly creating pressure groups of ‘civil rights agitators’ in which members refuse to act as unpaid helpers for their disabled family members, resulting in further increasing the gap between family members, while decreasing the abilities of the disabled to perform necessary domestic or parenting tasks. The advocates for the disability rights perspective (e.g. Olsen, 1996; Morris, 1997) have in addition maintained that young caregivers, who must take on much caring responsibilities, should not be undermined by giving them a ‘welfare role’ since increasing number of disabled parents have begun demanding statutory right for practical assistance, while also demanding that they should not have to rely on their children for help.

But young caregivers in Iceland have never been given a ‘welfare role’ and their silent existence has for long been hidden from social and health care professionals and no statistical knowledge is yet available regarding their

number, nor is there any knowledge available regarding the lived experiences of these young but often responsible caregivers.

The ombudsman of children in Iceland has also announced publicly, that serious shortage of studies regarding living conditions of Icelandic children and adolescents has served to delay the progression and construction of policies and guidelines for professionals responsible for the well being of children, to support and protect children who might be living under constricting and burdening circumstances.

For years I worked as a community care nurse and had little knowledge regarding the nature and consequences of the care children and adolescents provided for their chronically ill patients. Like many colleagues of mine, I believed they were fully capable of ‘assisting’ their parents, while undertaking some ‘trivial’ domestic tasks within their homes. Sadly, I must confess, I participated in believing that the ‘disability right paradigm’ had priority over that of their carers and for a while, in spite of my professional awareness, I failed to recognise the enormous responsibilities many children take on in their homes. Today I work at a neurological unit in Reykjavík and although I have somewhat grown into more professional maturity, both my colleagues and myself realise that much work has yet to be done to ensure quality health care for all our MS patients and their family members.

Constructing knowledge and understanding of the lived experience of children and adolescents of chronically ill patients, diagnosed with MS, is in my opinion of vital importance. Such knowledge and understanding can enhance the development of nursing interventions, aimed at meeting the needs of the newly diagnosed MS patients, those with more advanced illness and their family members. Such interventions can help all parties to adjust to living with this serious illness. Although the attention of many health care professionals has often



been solely directed towards the patients and the often overwhelming experience of being diagnosed and becoming chronically ill (Kralik et al., 2001), health care providers need to create a caring environment, which embraces the needs and wishes of our MS patients, while protecting, at all times, the well being of their children. The needs of the patients' immediate family members at my unit have, sadly, sometimes been left unattended and perhaps only been addressed when the possibility of emotional or psychosocial distress has been raised. I nevertheless believe nurses can create and sustain an environment where being available for all family members is possible (Johns, 2000), while promoting positive parent-child interaction and positive family communication, which can serve to minimize both patients' and children fears and anxieties.

This study can, in my opinion, also serve to promote communication of nurses in both acute and community care settings as understanding the lived experiences of young caregivers can serve to enhance our information delivery and teamwork of nurses caring for the chronically ill patients and their families. As knowing what is desirable, gives meaning and purpose to our practice (Johns, 2000), I also believe nurses can be challenged and empowered to take on the leading role in helping and empowering the children and adolescents who must face dramatic disruptions in their families and adapt to living with a parent diagnosed with Multiple Sclerosis, this unpredictable and often very disabling chronic illness.

## **1.6. Summary**

In this section, I clarified the compelling need for constructing knowledge and understanding of the lived experience of being a young caregiver of chronically ill parent diagnosed with MS, in Iceland. In the following section, I will present a

literature review of the most significant studies and academic literature, regarding the many aspects of being a young caregiver, especially of people with MS.

## **2. Literature review**

In this section, I will present some of the literature regarding the many aspects of being a young caregiver. Many studies demonstrate that young caregivers must face many diverse realities and experience many difficulties, while caring for their parents.

Many researchers and academics have studied and identified how the lives of children and adolescents can be altered and affected by becoming young caregivers. The following themes were identified when reviewing the literature: Care-giving as a burden, care-giving resulting in social exclusion, care-giving without professional support and care-giving and being cared for.

### **2.1. Care-giving as a burden**

One of the pioneers in studying the effects of care-giving on the children of MS patients was Arnaud (1959), who tested the emotional stability of 60 children and demonstrated that children and adolescents who care may experience many psychological difficulties, including heightened levels of dysphoria and hostility, severe body concerns, limited interpersonal relationships, dependency longings and experience false maturity reactions (Arnaud, 1959, cited in Kikuchi, 1987). The idea of parental illness directly affecting the wellbeing of their children has been supported by other studies (e.g. Olgas, 1974) who with a Draw-a-person test, demonstrated that children of MS patients often display severe body-image distortion and Kikuchi (1987), who with semi-structured interviews, demonstrated that children and adolescents of parents diagnosed with MS experienced their parents' illness as a threat to achieving happiness, describing

sentiments of painful nature such as fear, anger and sadness as the main threats, which hampered them from being able to make informed choices and influenced the extent to which they achieved happiness.

Tatum and Tucker (1998), interviewed 24 young caregivers and concluded that young people sometimes choose or are sometimes forced to take on caring duties and domestic responsibilities, viewed as the legitimate domain of the adult world, but too many caring responsibilities can seriously challenge self image and the well being of young caregivers. England (1997), in a descriptive survey including 168 care-givers, also demonstrated that some young caregivers have higher scores for emotional arousal, lower scores for self-coherence and lower ratings of perceived health, than children and adolescents with no caring and crisis experiences. Frank (1995), interviewed 16 young caregivers and claimed too many children deliver physically and highly emotionally demanding tasks, shaped by the uncertainty of the illness and the duty many young caregivers have towards the person cared for.

Cree (2003) explored worries and problems of 61 young caregivers, by using questionnaires and concluded they all needed profound, professional support as their lives are at all times stressful and being a young caregiver only puts additional pressures on one's life. The caregivers in Cree's (2003) study experienced severe eating and sleeping problems, some of them also experienced serious psychological difficulties, including deliberate self-harm and some attempted suicide. According to Cree (2003) the number and extent of worries and problems was greatly influenced by the length of time caring for a family member, as all problems increased according to the length of time spent caring.

## **2.2. Care-giving resulting in social exclusion**

The acts of care-giving, carried out by many young caregivers can be vital to the maintenance of the family unit, but such acts can, according to Tatum and Tucker (1998) have the power to exacerbate the social exclusion of many young people. Aldridge and Becker (1993), who interviewed 11 young caregivers and Dearden and Becker (2000), who interviewed 60 young caregivers, concluded that too many caring responsibilities can seriously affect young caregivers opportunities and mere enjoyment for socializing with peers, which can lead to social exclusion, both during childhood and also later in life. According to Frank (1995) many young caregivers are also more likely to miss time from school and educational opportunities, which can easily enhance the resentment, anger, and emotional exhaustion, already experienced by many young caregivers. Additionally, such restrictions can hamper their possibilities to grow educationally and later in life (Tatum and Tucker, 1998).

## **2.3. Care-giving without professional support**

Aldridge and Becker (1996) and Jenkins and Wingate (1994) have, in their papers, contemplated why so many young caregivers go on unrecognised by professional caregivers and why so many have not been attended to by social welfare agencies.

Despite the important part health care professionals can play in providing holistic care for both patients and their families, some studies (e.g. Kristjanson, 1996; Yates, 1999; Grbich et al., 2001; Aldridge and Becker, 2003) indicate that many young caregivers have experienced complete lack of professional support

throughout their entire care-giving periods, claiming that health care professionals tend to identify caregivers as people experiencing ‘normal’ response in the context of the illness, not people needing professional interventions.

Many young caregivers have been reluctant in identifying themselves and revealing, how much care they perform, experiencing both embarrassment regarding their caring responsibilities, as well as fearing professional interference or family split up (Frank, 1995). Many social and health care professionals seem to have ignored or minimised the caring contribution made by young caregivers to family life, resulting in adding to the resentment and anger many young caregivers have towards professional caregivers (Frank, 1995; Tatum and Tucker, 1998).

Aldridge and Becker (2003) interviewed 40 young caregivers and maintain that many professional caregivers fail to understand the caring experiences and consequences of many young caregivers, which has served to further delay the professional caregivers in identifying and meeting the needs of the still younger caregivers in society.

## **2.4. Care-giving and being cared for**

Care-giving can create a level of expectations and commitment for the parent that will necessitate the ongoing expenditure of energy, time and effort (Tatum and Tucker, 1998) and as care-giving can be a difficult and burdensome experience (Frank, 1995, Aldridge and Becker, 2003), in the UK, more attention is today being directed towards studying and subsequently enhancing the levels of

resources and services being offered to both young caregivers and the person cared for (Tatum and Tucker, 1998).

Aldridge and Becker (2003) have sought to study the lived experiences of young caregivers, while also studying the lived experiences of their chronically ill parents. Although they believe the two perspectives are not antipathetic and should not be conflicted, they are, nevertheless, consciously fighting off the sometimes, loud voices of those who believe the rights and needs of chronically ill people, should always take priority over their child carers (e.g. Keith and Morris, 1995; Olsen, 1996). Aldridge and Becker (2003) wholeheartedly believe that by studying the complex needs of all family members, social and health care professionals will be offered a more complete knowledge and understanding of why and how children care, while recognising what eventually goes on within homes and families of the chronically ill patients. Since the young caregiver's perspective is completely missing in Iceland, that is the one I chose to study.

## **2.5. Summary**

In this section, I presented some of the literature regarding the many aspects of being a young caregiver. In the following section, I will present the philosophical perspective guiding this study. I will also discuss phenomenology and the Vancouver School of doing phenomenology in particular, the chosen methodology for this study. I will also discuss the methods used for sampling and data collection.

### **3. Research design: methodology and methods**

In this section I will, firstly, present the interpretivist-constructivist paradigm, the chosen philosophical perspective for studying the lived experience of being a young caregiver. In that process, I will explain how reality is perceived (ontology) and how knowledge of reality is obtained (epistemology) within this chosen paradigm. Secondly, I will discuss phenomenology and the Vancouver School of doing phenomenology in particular, the phenomenological school chosen for this study and, finally, introduce the methods used for sampling and data collection.

#### **3.1. Introduction of the philosophical underpinnings of the study**

The aim of this study is to construct knowledge and understanding of the phenomenon of being a young caregiver of a chronically ill parent, diagnosed with MS. The research question is ‘what is the essential structure of being a young caregiver of chronically ill parent diagnosed with MS’. I believe interpretivist-constructivist paradigm is the optimal philosophical perspective to approach the subjective knowledge and understanding of how young caregivers construct meaning and understanding of the multiple realities of their lived experiences. I believe that I can only through dialogues reach understanding of their world of meaning and interpret it, as the data cannot speak for itself (Halldórsdóttir, 2000). I also believe that the Vancouver School of doing phenomenology is the optimal methodology to approach the delicate experience of having cared for chronically ill parents. Within the Vancouver school there is a reverence for the co-researcher and his or her lived experience and the aim of



inquiry is foremost to understand co-researchers' experiences, in an evolving dialogue of the parts and the whole in the hermeneutic circle, while gathering and analysing data, together with research participants (the co-researchers), who are empowered to participate in verifying the case constructions and participating in constructing the essential structure of the phenomenon (Halldórsdóttir, 2000).

### **3.2. Philosophical underpinnings of the study**

This phenomenological study of the lived experience of being a young caregiver was conducted within the interpretivist-constructivist paradigm. According to Schwandt (1998) the interpretivist-constructivist paradigm is concerned with the philosophy of knowing and being and it involves the basic believe that in order to understand the world of meaning one must interpret it from the point of view of those who have experienced it.

Within the interpretivist-constructivist paradigm there is an emphasis on understanding, interpreting the human being as an inseparable part of the social world we live in, while the emphasis is on reconstructing the constructions human beings initially hold and to reach consensus of the constructions made (Guba and Lincoln, 1998). Human beings develop and construct meaning from the experience of being born into a cultural world and with their historical background, and within their linguistic context they can understand and interpret their own hermeneutic meaning of existence as well as the shared meanings of others (Koch, 1995; Annells, 1996).

Ontologically the interpretivist-constructivist paradigm views the world of experiences as it is lived and undergone by social actors and objects the positivist worldview, where the world is seen as a pre-existing reality driven by natural

laws and where the goal of inquiry is to provide identifiable and verifiable account of these immutable laws (Guba and Lincoln, 1998). The interpretivist-constructivist paradigm visions a reality, which is apprehendable in the form of multiple intangible mental constructions, socially and locally specific in nature, where knowledge and truth are constructed, not discovered by mind (Guba and Lincoln, 1998). This means that reality is viewed as pluralistic and there will always be many different constructions of the phenomenon being a young caregiver. The ontological position is thus that of relativism, believing that all human beings have their own 'real' understanding of reality, as all humans give different meaning to reality, events and phenomena through sustained and 'complex processes of social interactions' (Schwandt, 1998).

Epistemologically, in the interpretivist-constructivist paradigm the emphasis is on interpreting and understanding the human being as an inseparable part of the social world we live in. This paradigm denies the positivist epistemology, where the investigator and the investigated human being (object) are seen as two independent entities and the investigator is able to gain knowledge of an object without influencing it or be influenced by it, influences in either direction seen as threats to the validity and the truthfulness of the knowledge to be found (Walters, 1995; Guba and Lincoln, 1998). Epistemologically, the interpretivist-constructivist paradigm asserts that the subjective investigator and the object of investigation (subjective co-researcher) are seen as two interactively linked entities, and findings are constructed as the investigation proceeds (Guba and Lincoln, 1998). The interpretivist-constructivist paradigm also believes in entering each investigation (dialogue) in a subjectivist and transactional approach, with emphasis on believing that what is real is a construction of the mind (Schwandt, 1998). Through an interaction with the world, we invent concepts and ideas to make sense of our experiences, e.g. of being a young

caregiver, and continually test these constructions of meaning. The human is thus always prepared for new interpretations and new constructions of meaning (Schwandt, 1998).

Although positivism provides the world of science with important knowledge of the MS illness, I believe positivism cannot reach the lived experience of being a young caregiver of chronically ill MS patient.

### **3.3. Methodology and philosophical perspectives**

In the following section I will discuss phenomenology and the Vancouver School of doing phenomenology in particular, the phenomenological school chosen for this study.

#### **3.3.1. Phenomenology**

The philosophy of phenomenology has deep roots within the history of human inquiry and studies the life-world and asks what it means to be human (van Manen, 1990). Phenomenology is also considered to be a methodology that seeks to gain understanding and meaning of human experiences and behaviour (Spiegelberg, 1982; Cohen and Omery, 1994). Various schools of phenomenology have been developed with different epistemological, ontological and methodological approaches. They are however all concerned with understanding the meaning of human phenomena (Cohen and Omery, 1994; Guba and Lincoln, 1998).

### **3.3.2. The Vancouver School of doing phenomenology**

The Vancouver School of doing phenomenology, the phenomenological school chosen for this proposed study is a human science methodology for studying lived experiences of human beings and has been inspired by the work of Professor Joan Anderson at the University of British Columbia, Vancouver, Canada. Professor Sigríður Halldórsdóttir further developed and published this school. It has also been influenced by Spiegelberg's analysis of phenomenology, Ricoeur's hermeneutic interpretative phenomenology and Schwandt's constructivism (Halldórsdóttir, 2000).

Within the Vancouver School, it is believed that in order to understand the world one must interpret it (Schwandt, 1998). The Vancouver School believes with the interpretivist paradigm and espouses moderate realist ontology, a transactional epistemology and methodologically the Vancouver School adopts the hermeneutic and dialectic approach, which involves the art and the skill of understanding the essential meaning and constructions of human actions. The philosophical construct of hermeneutics is the hermeneutic circle and language and history supply the shared sphere in the hermeneutic circle (Appleton and King, 1997).

Although the Vancouver School does not stand for the fundamental epistemological position of the Husserlian phenomenology with its 'phenomenological reduction', of separating the objective natural world from the subjective conscious mind, the Vancouver School, nevertheless, challenges the researcher to reflect on his or her presuppositions about the world and write down, in a reflective journal, his or her thoughts about the enfolding study, although complete elimination of one's presuppositions is, in my opinion, never possible.

The Vancouver School has also been influenced by Paul Ricoeur, who believed with Husserl that phenomenology should seek to return ‘to the things themselves’, beyond that of static description of human experience, but should seek to incorporate a description of subjective human experience, beyond the range of consciousness (Spiegelberg, 1982). He believed it necessary for phenomenology to incorporate a hermeneutical presupposition, which is not confined to the objective structural analysis of texts, or the authors of texts (Halldórsdóttir, 2000). The phenomena of consciousness should be expressed in the symbols and the texts in which they are expressed (Spiegelberg, 1982; Halldórsdóttir, 2000).

### **3.4. Methods used for data collection**

#### **3.4.1. Data collection**

In this phenomenological study dialogues (unstructured interviews), were used as the data collection method, as recommended by the Vancouver School (Halldórsdóttir, 2000), where my task was to be open and accepting in empowering the participants (co-researchers) to voice their genuine views, opinions and feelings without constraints. Although dialogues may have ‘pitfalls’, where researchers fail to construct trust or lose their professional distance and ‘go native’, dialogues can provide a greater breadth of data than other qualitative interviews (Fontana and Frey, 2000). Within the Vancouver School there is a reverence for the participant (co-researcher) as a truth-telling individual and fellow researcher of the lived experience under study and the dialogue becomes a bridge the researcher uses to visit the world of the co-

researcher in order to understand (Halldórsdóttir, 2000). In this study, all interactions with co-researchers were seen as negotiated accomplishments of both researcher (myself) and co-researchers that were shaped by the contexts and situations in which they took place (Fontana and Frey, 2000). As recommended by the Vancouver School, data gathering and data analysis concurrently proceeded in an evolving dialogue, in a hermeneutic circle of the parts and the whole, where I sought truth and intention to understand the essence of co-researchers' lived experiences (Halldórsdóttir, 2000).

### **3.4.2. Sampling**

The sample in this study was purposive sampling, as suggested within the Vancouver School and included eleven young adults, who all had parents diagnosed with MS. A purposive sample has been defined as sampling procedure that is governed by emerging insights about what is relevant to the study and purposively seeks both the typical and the divergent data these insights suggest (Erlandson et al., 1993 cited in Appleton and King, 1997). As little scientific knowledge is available regarding young caregivers in Iceland, I needed to select at least 10 participants (co-researchers) as my aim was to 'define a group' (Sandelowski, 1996) of young caregivers, who until now have remained hidden from public and professional authorities. I also believed that 20 dialogues could provide me with clear picture of the phenomenon and provide me with the 'richness of data' as recommended by the Vancouver School (Halldórsdóttir, 2000).

Although, I knew nothing of their caring responsibilities beforehand, all participants had cared for their parents for longer or shorter period of time and

had thus the lived experience under investigation and they were the source of knowledge for the understanding of the phenomenon. Within the Vancouver School, the participants are seen as the experts of the lived experience and become co-researchers, who make sense of the data in a meaningful way together with the researcher (Halldórsdóttir, 2000). The sample size was not predetermined, as it is essential to discover the variety of constructions that can exist and will help to articulate and illuminate the phenomenon under study (Appleton and King, 1997), which is also cultivated within the Vancouver School (Halldórsdóttir, 2000). The data gathered with the eleven participants served, in my opinion, to ensure informational adequacy and completeness of the phenomenon and saturation was eventually achieved (Morse, 1991).

### **3.5. Summary**

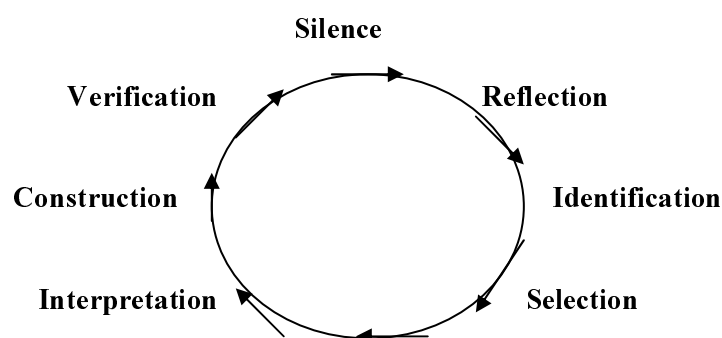
In this section I presented the philosophical perspective chosen for this study. I also discussed phenomenology and presented the Vancouver School of doing phenomenology, the phenomenological school chosen for this study. In addition, I presented the methods used for sampling and data collection. As data collection and data analysis run concurrently in an evolving dialogue, these two research elements will be discussed in more unity, in the next section, in which, I will also reflect on trustworthiness and ethical aspects of the study.

## 4. Data collection and analysis

In this section, I will discuss in details the data collection and the data analysis. In that process I will demonstrate how I sought to construct a trustworthy study. I will also discuss ethical issues, especially regarding the sensitive needs and rights of the eleven young caregivers, who revealed their experiences of being a young caregiver of chronically ill parent, diagnosed with MS.

### 4.1. Data collection and data analysis

In the Vancouver School of doing phenomenology the process of data collection, data analysis, interpretation and the construction of the phenomenon is indeed a process, but not a linear process. It is a cyclic process, which involves seven basic steps to be entered and re-entered throughout the research process. These stages are: silence, reflection, identification, selection, interpretation, construction and verification (Halldórsdóttir, 2000) (Figure 1., p.24).



**Figure 1.** The seven basic steps of the Vancouver School of doing phenomenology, from Halldórsdóttir, (2000, p.56)



The research process of the Vancouver School can also be described in a process of twelve basic steps (Appendix 7).

In the Vancouver School it is maintained that the first step in the process of doing a phenomenological study is silence (Spiegelberg, 1982; Halldórsdóttir, 2000). In that process I consciously made effort to silence my mind, and disconnect myself from my prejudgements and professional knowledge of the phenomenon 'young caregiver', in order to embrace new knowledge of the phenomenon and enhance my ability to listen and understand (Koch, 1995). The stage of silence was re-entered throughout the study, as it gave me the mental space and peace needed to proceed in the hermeneutic circle. I, however, do not believe I was able to eliminate (bracket) all my preconceptions, since I am like others, shaped by my experience and culture but I was able to acknowledge and discipline them. A reflective journal was kept throughout the research process, which served to record my thoughts, silences and decisions during the research process and serves to contribute to the study's trustworthiness (Koch, 1996; Halldórsdóttir, 2000).

Data was collected in April-September 2004 and during the dialogues (each approximately 1 hour) the participants were asked to reflect on how their lives had changed when their parents were diagnosed with MS and became chronically ill. They were also asked to reflect on all possible restrictions and resources they employed during their care-giving years. My task was to be open and accepting in helping the participants to voice their genuine views, opinions and feelings without constraints (step 3). Each participant participated in two dialogues, although I felt the richness of data and a clear picture of the phenomenon had been formed in my mind, long before the 22<sup>nd</sup> dialogue was completed. Participating in two dialogues was, however, essential for both parties, as it takes time to 'create an interview' and to get to know the participant and their lived experiences, beneath their rational façade (Fontana and Frey). As the goal of

dialogue is an intersection of my horizon of the horizon of the participants (Koch, 1998), it also took, in my opinion, some time and effort to 'fuse our horizons' in the hermeneutic circle, where understanding was made possible (Koch, 1996). During the first dialogues, I made all efforts to maintain a tone of 'friendliness', while remaining close to the topic of inquiry (Fontana and Frey, 2000). I began by 'breaking the ice' with general questions, gradually moving to more specific ones, while moving and reflecting back and forth in time, somewhat 'checking' the reliability of the respondent's statements. The participants had little difficulties describing their caring responsibilities. Some of them had, on the other hand, difficulties discussing their emotions and the embarrassment some of them had towards their parent's disabilities. In order to help them, I often felt compelled to 'come forth' to them, without 'dressing down' and help them come to terms with and accept their feelings (Fontana and Frey, 2000). I often had to empower them during the first dialogue, without 'going native' but as the dialogues proceeded, their stories tended to flow effortlessly, although their stories were often filled with feelings of anger and grief (Fontana and Frey, 2000). Later, when the study was almost completed, most of the participants revealed to me that opening up and sharing their stories with me had served to help them 'loose some pounds' while recognising the immense value of their caring efforts. This study thus served, in my opinion, as an empowering experience for most of the participants.

The dialogues were audiotaped and transcribed verbatim (step 4) and each co-researcher was given a copy of the transcript, as I wanted them to keep the stories, they had never revealed before (Sandelowski, 1993).

In order to get a sense of the whole, the transcripts were read very thoroughly in silence and reflection. In an effort to gain understanding of the essence of the co-researcher's expressions, my attention was directed towards the key statements

(themes) in each transcript, while identifying the similarities in the various key statements that had special bearing on the phenomenon under study. The themes of these key statements were then coded (selected) in the transcript as I worked on gaining sense (interpretation) of the whole story and catch the essence of what the co-researchers were really saying (step 5) (Table 3., p.27).

<p><u>The theme:</u></p> <p>Being overwhelmed by the invasion of a foreign illness</p> <p><u>Key statements:</u></p> <p>‘I felt devastated when my mother became chronically ill’.</p> <p>‘I made effort not to think or talk about the illness, that helped for a while’.</p> <p>‘For a while, I feared the very worst’.</p> <p>‘Not knowing anything about the illness or what to expect still haunts me’.</p> <p>‘We never received any professional support or information when father was diagnosed’.</p>
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**Table 3. An example of some key statements and a theme selected.**

When I had dialectically interpreted the transcripts, I had to identify the different themes that had been constructed for each case and constructed the essential structure of the phenomenon for each co-researcher (step 6). The structure of the co-researchers’ stories had very similar essences, most of them had for years, cared for their parents in silence without professional help or support, while developing their personal maturity and security. The co-researchers were asked to verify each case construction, who then participated in construction of the phenomenon (step 7), which involved a conscious effort to ascertain validation of the interpretations and the meaning that has been constructed (Halldórsdóttir,

2000). This step is perhaps the most important step in the Vancouver School, as it was a conscious effort to minimize the methodological danger of selecting my own preconceptions of the phenomenon (Halldórsdóttir, 2000). This process involves a validation of the interpretations and the meaning that has been constructed, while allowing the co-researchers 'to have access to what has been made of their experience' (Sandelowski, 1993, p.28; Halldórsdóttir, 2000). This validation is extremely important and I believe with Denzin (2000), that a text and an author's authority can always be challenged and trustworthy materials should be subjected to the constant comparative method in order to increase credibility of findings. Some co-researchers made some minimal changes but agreed that the case constructions were according to their lived experiences. When the case construction of each transcript had been verified, all the case constructions were then compared in order to find common threads and differences, which resulted in a construction of the essential structure of the phenomenon (step 8). Having completed that delicate task, I sought to verify if the essential structure fitted with the data by comparing it with the transcripts of all the dialogues in the ever-repeated hermeneutic circle (step 9). The final analytic structure of the phenomenon involved a construction of meaning. It involved identifying the over-riding theme, which described the essence of the phenomenon, what the phenomenon; being a young caregiver means to the participants (step 10). This involves the art and the skill of interpreting and involves again a sincere hermeneutic dialogue between the part and the whole. As cultivated within the Vancouver School, I introduced the final analytic framework to four of the co-researchers for verification (step 11), to see if they recognised the analytic description as their own experiences (Halldórsdóttir, 2000). Writing up the findings involved constructing a multivocal text, where everyone was given a space to voice their stories. The co-researchers inevitably

looked for themselves in the findings and were able to recognise their pseudonyms and the stories they had revealed. Here, as before, the ‘member check’ was aimed at enhancing the credibility of the findings, by faithfully presenting the co-researchers multiple realities, while also confirming the validation of my own constructions of their assumed realities (Sandelowski, 1993; Cutcliffe and McKenna, 1999).

#### **4.2. Trustworthiness – the rigour of the study**

In this study, I made all efforts to create and demonstrate a trustworthy and rigorous research. I believe with Koch (1996), that if researchers succeed in clarifying philosophical and methodological perspectives and provide precise descriptions of the whole research process and the data collection process in particular, trustworthiness may be established.

The sample size of eleven participants and the data collection with 20 dialogues in all over four months period, lessen the danger of ‘holistic fallacy’ when the researcher has an incomplete mental picture of the phenomenon due to inadequate sample size or data collection, as well as decreasing the danger of ‘premature closure’ when data analysis is completed too soon (Halldórsdóttir, 2000). As recommended by the Vancouver School the co-researchers in this study participated in two dialogues each, which is another strategy to prevent ‘premature closure’. Although most had typical experience of the phenomenon, there were those who had atypical experience (Halldórsdóttir, 2000). I hope my commitment to methods and procedures increased the text’s credibility, transferability, dependability and confirmability (Denzin, 1994; Koch, 1996).

Although it is impossible to provide readers with detailed description of the ‘story of the dialogues’, I made every effort of not ‘going native’ or losing my professional distance (Fontana and Frey, 2000), although I sometimes had to provide the co-researchers with my subjective compassion when they had difficulties admitting to their feelings of shame and grief. I believe the sample was not ‘homogenous’, or ‘elite’, which can threaten credibility and fittingness (Sandelowski, 1986), when the co-researchers, have too similar profiles (Halldórsdóttir, 2000), although some of the co-researchers showed remarkable mature profiles.

As recommended by the Vancouver school, I kept a reflective journal throughout the research process, which served to record my thoughts, silences and decisions during the research process and served to contribute to the study’s trustworthiness (Koch, 1996, Halldórsdóttir, 2000). Although I was not able to eliminate all my preconceptions, I hope I was able to establish and demonstrate trustworthy findings, by checking and questioning, both privately and with the co-researchers, the case constructions, as well as the final analytic framework and thus the essential structure of the phenomenon (Halldórsdóttir, 2000).

I realise that the findings have limited generalizability, as the realities constructed within this study are culturally and socially located and one study will not provide the whole picture of any phenomenon (Halldórsdóttir and Hamrin, 1996).

### **4.3. Ethics**

#### **4.3.1. Permission to conduct this study**

Permission to conduct this study was obtained from the National Bioethics Committee of Iceland and reported to the Committee of Personal Protection in

Iceland, in accordance with rules and regulations in Iceland. Since ‘young caregivers’ is an unknown entity in Iceland, the National Bioethics Committee believed the participants should, in the introduction letter, be offered professional support beforehand, if they suffered emotional distress revealing their stories. This request was of course honoured and an MS nurse offered to assist the participants, if needed. Having given my promises not to enter any emotionally disturbing subjects, unless the participants themselves chose to discuss them, permission, from the National Bioethics Committee of Iceland, to conduct this study was granted the 30<sup>th</sup> of March 2004 (Appendix 1).

#### **4.3.2. Characteristics of the participants**

The young caregivers in this study were young adults from the ages 18-25 years old, but were 6-16 years old when they began caring for their chronically ill parent. Most of them were 9-12 years old when they began caring for their parent, two young caregivers were 6 years old and two were 16 years old. Most of them had cared for their parent for 8-10 years; two had cared for 4 years and two for 14 years. Most of them had already left their posts as primary caregivers, although most still participated in caring for their chronically ill parent.

#### **4.3.3. Access to respondents**

Young caregivers have, until now, been somewhat ‘unidentified’ caregivers in Iceland and no support groups or societies have yet been established for young caregivers in Iceland. In order to gain access to children of chronically ill parents, two employees at the MS society in Reykjavík were asked to seek permission

from 20 MS patients in the society, to give me their permission to ask their grown up children to participate in this study. All MS patients gave their permission and I received a list of 20 young caregivers, of whom I had no former attachment to. I had no knowledge of their caring responsibilities, nor had I any knowledge of the MS patients, who all were most eager to offer their beloved young caregivers opportunities to reveal their stories and let their voices be heard. I sent letters to ten of the twenty young adults, who all agreed to participate and one participant asked whether a sibling could also participate, which I welcomed.

Ethical principles were one of the highest priorities in this study, which involved protecting the human rights and needs of all participants during the entire research process. In that process I sought to protect their confidentiality and anonymity in the best possible way, giving them pseudonyms in the transcripts, their identities only known by the two employees at the MS society and to some of their parents. All participants received an introductory letter, which informed them about the purpose of the study, the methodology, the methods used in collecting data and how data would be recorded and destroyed, when the study was completed (Appendix 5). They were also informed about the research question, my desire to construct understanding of their caring efforts and the importance of letting their voices be heard among Icelandic social and health care professionals. They were all informed that they had the power to withdraw from the study, whenever they wanted and at no time would they be asked to discuss delicate personal matters, unless they themselves wanted to. The participants were also informed about their involvement in constructing the essential structure of the phenomenon and that nothing would be printed without their consent. The participants gave their signed consent, no one withdrew from the study, no one



accepted the counselling service offered and most of them expressed they had benefited from revealing their stories.

#### **4.4. Summary**

In this section I discussed the Vancouver School of doing phenomenology, the methodology chosen for this study. I also discussed trustworthiness and ethical considerations, the essential elements of all studies. In the next section, I will present the findings of this study.

## 5. Findings

In this section, the main findings and the essential structure of the phenomenon, being a young caregiver, will be presented. The aim of this study is to further contribute to understanding the phenomenon; being a young caregiver by exploring how eleven young Icelandic adults constructed meaning and understanding of their lived experiences, while they were children and adolescents and provided care for their chronically ill parents, diagnosed with MS.

The research question of this study is ‘what is the essential structure of being a young caregiver of chronically ill parent diagnosed with MS’.

The young caregivers were invited to reflect on how they adapted to and managed the, sometimes, dramatic life changes when their parents were diagnosed with MS and became chronically ill. The young caregivers were asked to reflect on how the illness affected their lives, and identify the possible restrictions they had to face, while also reflecting on what resources they could employ in managing their every day living while caring for their parents. As most of the young adults had left their posts as primary caregivers, they were also invited to reflect on their present situations, the lessons they had possibly learned while reflecting on possible dreams or visions regarding personal and professional growth.

This section, will firstly, present a short phenomenological description, which contains a summary of the main findings of this study, involving a description of the essential structure of the phenomenon under study, encompassing the conclusions of the reflections and co-constructions of the lived experience of being a young caregiver of a chronically ill parent, diagnosed with MS.

Following the phenomenological description, the findings will be presented in details, where the four key themes that emerged from the dialogues will be fully disclosed, involving a detailed presentation of the essential structure constructed. In that process every co-researcher's voice and opinion will be given the space to fully enclose their, often, complex experience of having cared for a chronically ill parent during their years as children and adolescents.

### **5.1. Phenomenological description**

The aim of this phenomenological study was to construct understanding and ultimately meaning of the lived experience of being a young caregiver in Iceland. Most of the young caregivers in this study began caring for their parent shortly after they became chronically ill. The parents of two young caregivers were, however, diagnosed before they were born and they began caring for them as soon as they were able to, when they were 5-6 years old.

The findings of this study indicate that being a young caregiver can be a difficult and burdensome experience. The young caregivers in this study had to face many new realities when their parents became chronically ill, and their family lives often dramatically changed. The new realities had many faces and many young caregivers experienced much sorrow and anxieties, as they watched and witnessed their parents becoming more disabled and dependent, the lives of all family members often disrupted by this unwelcome intruder. The new realities also demanded that most young caregivers became highly involved with the tasks of providing their parents with intimate personal care and emotional support. Caring for their parents in that manner, was for many young caregivers an embarrassing, difficult and restricting task and for some very unrewarding as some of the parents did not always recognise, accept or value their caring efforts.

While recognising the many faces of their realities, the young caregivers became more and more involved with managing domestic duties and most of them eventually assuming responsibilities for themselves, sometimes for their siblings and often everything within their households.

While reflecting on the restrictions in life and the support they were provided with during the caregiving years, the young caregivers who had access to help and support from close relatives, expressed having had considerable opportunities to enjoy their childhood and years of adolescence. Their relatives were able to recognise and value their responsibilities and thus make all possible efforts to participate in caring and supporting both the young caregivers and their chronically ill parents. Those who had little or no access to such support experienced much more hardship and repeating episodes of anxiety and depression and not being able to fully enjoy and participate in life.

While reflecting further on restrictions in life, most of the young caregivers in this study had, during the early years as caregivers, few recollections of any formal support from either social or health care professionals. Perhaps their often young age and immaturity restricted them in recognising what professional alternatives were available for them in their every day care-giving efforts or even completely replacing them in their care-giving efforts. Their childhood and adolescence memories of most young caregivers were thus shaped with bitterness and little comprehension of how or why they had been left to manage so much responsibility, so completely on their own.

Most of the young caregivers in this study had no recollections of having received any formal emotional support from their school teachers, but most of them believed they missed not having had opportunities to dialogue about their problems at home with their teachers, the sometimes only adult in their outside world.

Most of the young caregivers in this study recalled having become periodically isolated from their friends and peers, when their caring involvements had become both too demanding and time consuming. Many expressed having had little desire to discuss family problems that were too foreign or not comprehensible for those living within the safety and warmth of 'ordinary' homes.

Many of them were lucky to find good and supportive partners, who soon became their shelter in life, somewhat taking on the role of supporting and caring for the young caregiver and sometimes also participating in caring for the chronically ill parent-in-law to be. Their partner also serving to support the young caregivers in giving up their posts as primary caregivers for their often disabled parents.

Many young caregivers in this study believed they had, as children, learned the value of following 'sensible' rules as children, which later developed into the ability of creating personal stability. This personal stability helped them in becoming responsible for themselves and everything within their homes, a stability which helped them fight off episodic depression while meeting the demands of every day living. Many of them also believed their personal stability had helped them in making plans for the future, as well as making plans in enhancing their abilities in seeking further professional and educational opportunities.

Some young caregivers had left home and their posts as primary caregivers, having realised their care-giving efforts had become somewhat damaging for them and perhaps also for some parents. Some of them were, however, still highly involved with caring and supporting their chronically ill parents but needed this care to be shared with a more qualified carer. Most young caregivers were learning to enjoy their newfound freedom and happiness despite their parents' deteriorating condition and their shadowed childhood and adolescence

memories. Although most of the young caregivers would certainly have preferred a different way of growing up, they nevertheless believed their many responsibilities and difficulties had served to help them grow to more maturity. They also believed they had learned valuable lessons in life, in becoming responsible for themselves while managing household and finances, skills that many of their peers were still struggling with.

Most of them believed they were able to recognise good health as a valuable gift in life and made effort to be thankful for every opportunity they now had in sharing life with friends and families. Although the young caregivers were not always successful in fighting off the, sometimes, troubled memories, most of them were nevertheless blessed with enormous enthusiasm, believing positive and optimistic attitudes in life to be highly valuable, knowing their fates and fortunes ultimately remained in their own hands. Some of the young caregivers had for long reflected on the obvious lack of official support for young caregivers and many had visions on how to amend the condition of burdened children in our country.

All of the young caregivers were profoundly fond of their parents and believed their parents deserved all the help they needed, most of them nevertheless agreed with one caregiver's statement, who described the core of her care-giving experience as; *'Knowing deep down that everything that doesn't kill you, eventually strengthens you'*.

## **5.2. Key themes**

In an effort to gain understanding of the essence of the young caregivers expressions, my attention was directed towards the key statements (themes) that

in my opinion had special bearing on the phenomenon under study. Having selected the key statements from the transcripts and in an ever-repeated hermeneutic dialogue, the essential structure of the lived experience of being a young caregiver was eventually identified and co-constructed, resulting in identifying four important and interwoven elements of their care-giving experiences.

- |   |
|---|
| <ul style="list-style-type: none"> <li>• Recognising and adapting to new realities in life.</li> <li>• Identifying restrictions in life.</li> <li>• Employing personal resources while embracing help and support in life.</li> <li>• Moving towards independence while making plans for the future.</li> </ul> |
|---|

**Table 4. The four co-constructed themes that emerged from the dialogues**

The four themes identified, had in both my and my co-researchers opinion a special bearing and truthful meaning of the phenomenon of being a young caregiver of a parent diagnosed with MS. In the following section the four themes will be presented in more details, where every co-researchers' voice will be heard and given the space needed in order to fully understand the essential structure of how the eleven young caregivers constructed meaning of their lived experiences.

### **5.3. Recognising and adapting to new realities in life**

This key theme involves the experience of realising that a parent has become chronically ill, which involves learning to accept this illness and adapting to a new situation in life.

#### **5.3.1. Being overwhelmed by the invasion of a foreign illness**

Most of the young caregivers in this study, expressed having experienced many difficulties when their parents became chronically ill. Most of them experienced fear and anxiety of not knowing, if or how, this foreign and intrusive illness would influence or disrupt their lives and those of their beloved parents. Kate was 12 years old when her mother was diagnosed with MS and described her experience in the following words; *'This illness came like a predator into my life...had difficulties coping with how rapidly mother was changing'*.

Elsa was 8 years old when her mother was diagnosed and could remember her mother becoming chronically ill; *'My mother had been ill for many months and I cried myself to sleep many times...not knowing what was wrong'*.

Some of them consciously sought, at first, to deny the presence of the illness, like Adam, who was 12 years old when his father became ill and he pointed out; *'I had enormous difficulties watching my father becoming ill...I tried to put every thought of this mysterious illness aside'*. The young caregivers often avoided talking about it with their parents, hoping their parents would soon become well again, the illness would *'simply go away'*. Most of the young caregivers believed their parents had also been offered very limited information regarding the MS illness, thus having little understanding of how this unpredictable illness would



affect them and eventually their families. Most of the young caregivers believed their parents sparse knowledge directly influenced the limited flow of information and discussions within their homes, which for some young caregivers increased their feeling of denial and of not actually wanting to face this slow but persistent invasion.

Some of them also feared that the MS illness would be fatal for their parents, as experienced by Jane, who was 9 years old when her mother became chronically ill; *'My mother became partially paralysed...I just broke down and cried, fearing she would probably die'*. Some of the young caregivers believed that due to their sometimes, young age and immaturity, they perhaps lacked the abilities to understand and rationally evaluate the nature of this unpredictable chronic illness. Paul, who was too young to remember when his mother became ill, pointed out; *'When my mother became ill, I was quite young and became quite annoyed and sad...this once cheerful woman just went away'*.

Some of the young caregivers had memories of having watched television programs about the MS illness, showing very disabled and dying patients, fearing the fates of their parents would be very similar. Most of them expressed having received little or no information about their parents' illness from health care professionals, regarding the nature of this chronic and unpredictable illness. For many, not knowing much about this illness, added to their anxieties regarding their already uncertain realities. Doris was 11 years old when her mother became ill and she pointed out; *'Father told me this illness would probably make her feel more tired...but I would have wanted to know the truth'*. Many of them also believed that having never been offered an opportunity to openly discuss this illness with professionals, created a 'state of silence' within their homes, no one ever openly speaking about the illness and how it affected everyone within their

homes. Kate claimed she and her sister never talked about the illness in all the 8 years of her caring for their mother.

A few of the young caregivers believed they benefited from not knowing how aggressively this illness eventually affected their parents. However most of them believed they suffered because they completely lacked all knowledge and understanding regarding the cognitive impairments, some of their parents suffered from. Most of them believed such knowledge could perhaps have decreased the emotional trauma, many of them had to battle with and perhaps such knowledge could have served to better prepare them for delivering their caring efforts. Doris described her experience as follows; *'I knew nothing about caring for people with mental disabilities....still don't'*. Most of them believed that an offer of valuable information from a trustworthy health care professional, when coming to terms with an illness of this magnitude would probably not have been fully understood but could have helped them make valuable connection with important professionals within the health care system. Most of them also believed an offer of valuable information could have constituted an emotional support or a 'kind gesture' for better understanding the meanings and consequences, which an illness of this magnitude held for their present and for their future situation, a support most of them certainly needed. Most of the young caregivers believed they were somewhat treated as immature and insignificant objects while their parents' became chronically ill and received their MS diagnosis. Jane had a vivid reflection of this experience; *'The doctor never spoke directly to me...I had to find everything out for myself...how this illness affects people'*. Elsa could also recall how; *'The memory of me not knowing anything still stays with me...someone really kind should have told us the truth'*.

Harold was too young to remember when his mother was diagnosed, he had only heard stories of the times she had been diagnosed but he was also the only young

caregiver who believed this chronic illness had never challenged or altered his childhood and adolescence wellbeing in any way.

Roger, another young caregiver had no recollection of his mother being well and healthy, his mother having been diagnosed with this chronic illness long before he was born. According to him, he gradually learned that his mother was chronically ill, never having to experience the changes in life when a healthy parent becomes chronically ill.

*I was very young when I realised my mother was in no way like other mothers...she lived in her own world of which I had for years no understanding...no one told me much about this illness and no one realised how sick my home life was.*

The young caregivers who already had become adolescents when their parents were diagnosed believed they had never gone through a period of denial but could recall feelings of deep sadness and helplessness while watching their parents and their sometimes very best friend, become more and more dependent and disabled. Carol was 16 years old when her mother became ill and she pointed out; *'We knew something was terribly wrong...no one ever told us anything about the illness...I felt emotionally neglected'*.

Daniel was 16 years old when his father was diagnosed with MS and he pointed out; *'My father had difficulties walking ... I was not surprised to learn he had MS...I had to search for the medical information myself... just couldn't continue dragging useless information from this poor doctor of ours'*.

### 5.3.2. Living without a true childhood

Most of the young caregivers in this study had to adapt to new roles within their homes as their parents became chronically ill, including the tasks of cleaning and cooking and, gradually, most of them became responsible for managing all domestic duties and sometimes their family financial problems. Kate was able to clarify her domestic duties and pointed out: *'I became responsible for everything at home... felt it was my duty doing so...my sister was too young to manage on her own...I had to grow up very fast...that was before I began worrying about money'*.

Alison was also able to recall the nature of her domestic duties; *'I have in fact been responsible for everything within my home since I was 10 years old...there was no one to teach me...not when she was feeling very low...always tried my best'*.

Adam claimed his domestic responsibilities were not always easily managed but pointed out; *'I have been the master of the house since I was 12 years old'*. Elsa was also able to recall her experiences of learning to manage her domestic duties, despite her young age; *'I helped my sister by washing the dishes...gradually I learned the necessary things...mother always being so tired and weak'*.

Paul could recall how his domestic involvement began and recounted:

*My mother tried to help me manage cleaning and cooking, but gradually I had to take over... I was probably not older than 9 years when I got a life of my own...I have no idea why I didn't end up in a mental institute (laughs).*

As most of the young caregivers were living with sole, but chronically ill parents, none of them could rely on other adults within their homes to assist them in managing their households. Most of them also believed they had as young caregivers to 'grow up very fast', in learning new skills in managing their homes

alongside their scholarly and personal schedules. Jane claimed she got little assistance from her sisters and pointed out; *'Gradually, I became the head chef...but it seems like everything else has also become my responsibility'*.

Many of the young caregivers experienced the domestic duties as both tiresome and time consuming, most of them also believing that, for years, they completely lacked the necessary knowledge on how to manage these tasks properly. Although their chronically ill parents soon lost their physical or mental strength to assist them, having to cope with their growing weaknesses or disabilities, many parents also had to abandon their parenting roles and duties to fully provide their young children with the care and support they nevertheless needed. None of the young caregivers believed they ever 'parented their parents', although they claimed they sometimes 'felt like parents', as they often had younger siblings to care for.

Roger who expressed he never had been properly cared for, claimed he completely lacked the knowledge needed to manage his household and stated;

*My mother has never been able to cook and clean properly...but I didn't know how to...my home was a depressing place...but her being so mentally damaged, left me in total solitude and misery for years...in fact I never had a mother...*

Doris, had vivid memory of how distressed she often felt while learning to manage her domestic duties;

*Father was never at home...I had to take care of mother and my little sister...and each and every night I just collapsed into bed...everything was done out of duty not joy...I had to raise myself...never had a true childhood.*

Most of the young caregivers had some difficulties reflecting on how troubled and abandoned they felt, while struggling with creating stability and finding the

‘sensible’ path in growing up. Some of the young caregivers had early memories of having developed self-discipline while watching and learning the same ‘sensible rules’, their friends had to learn to follow. The sensible rules were many and helped some of the young caregivers learn how much money to spend, how and when to study for school, how much time to spend watching television and when to return home in the evening. Most of them also claimed that following these sensible rules served to help and guide them in constructing more personal stability in the many but demanding years to follow. Many young caregivers not only had to assume the responsibilities of their own upbringing but sometimes also that of their still younger or older siblings, caring and assisting them in managing and coping with their own troubled realities. Doris had to care for her younger sister for many years; *‘She was too young...I had to help her do her homework...wash her at nights and our clothes’*.

### **5.3.3. Caring for a parent in need**

Most of the young caregivers had memories of having begun caring for their parents soon after their diagnosis, the young caregivers still recognising and adapting to how the illness was causing their progressive and irreversible dependency. All young caregivers but one believed that providing intimate physical and emotional care and support for their parents were demanding, embarrassing and difficult tasks and many caregivers believed that growing into the caring role, not necessarily meant growing into more intimacy with their parents. Kate described her caring experience in the following way; *‘I had difficulties watching my mother change into this...childlike, obsessive person. I tried to stay away from home as much as I could’*.

As the young caregivers had for years little practical knowledge on how to perform these tasks and little comprehension of how to efficiently support their parents, most of them also experienced much anxiety and depression in trying to help their parents manage their own sorrow and greave in having become chronically ill and dependent people. Jane experienced difficulties supporting her mother and pointed out; *'I always tried to support my mother in her anguish and greave...trying to spend as much time with her as I could...but she continued to be depressed...no one sleeps while your mother weeps in the dark'*.

Many young caregivers had parents with serious physical disabilities, who had to rely on their young children's' care for bathing and toileting, as described by Kate;

*Helping her to the toilet, every night...many times was the most difficult task of all...no child should help cleaning their parents that way...I would never want my sister to replace me and help her in that way...would be horrible for her.*

Most of the young caregivers considered these tasks both unpleasant and often quite difficult but also degrading for the parents themselves. Roger described his caring efforts as follows; *'I have had to help my mother to the toilet since ever...waking up many times every night is difficult for everybody'*. There were, however, a few young caregivers who believed these caring tasks served to strengthen the parent-child relationship, believing their chronically ill parents deserved the best possible care and support available. Most of them, however, believed the cognitive impairments, which many of their parents suffered from, served to enlarge the growing gap between the chronically ill but dependent parents and their often anxious and depressed caregivers. Their cognitively impaired parents, often being angry and violent, but also childlike and 'out of character', while their young caregivers experienced much difficulties trying to

help and soothe them; the most difficult and unrewarding caring tasks most of them had to manage. Doris described this experience in the following words; *'No one prepared me for these mental changes...I lost my mother years ago...and now we have to care for her like a child...who sometimes has violent tantrums'*.

Some of the young caregivers even experienced their parents being both aggressive and verbally abusive towards them, making critical remarks, not always recognising, accepting or valuing their caring efforts. Alison expressed that her caring efforts were of little value; *'I suppose I was this single mother of three...my task being that of taking care of everyone...mother never gives me any credit and has often told me how useless I am'*.

Carol recalled how her mother didn't accept her caring efforts; *'Mother has been depressed and often cruel to me...everything I do for her is wrong or absurd'*.

Two of the young caregivers in this study not only had parents diagnosed with MS, but parents who had considerable alcohol and drug problems to deal with, resulting in their young children and adolescents, having to face even more difficulties in helping and supporting them. These two caregivers had for years little comprehension and few resources with which to cope or manage, when their already disabled parents became heavily intoxicated or drugged.

Paul described this experience in the following words; *'Mother tried to drink her depression away...that was so marvellous...but when I tried to stop her from taking pills...I became the worst bastard of all...I soon learned how to dial 911'*.

#### **5.4. Identifying further restrictions in life**

This key theme involves the experience of receiving limited help and support from friends, family and professional caregivers, while giving care to a chronically ill parent.



#### 5.4.1. Caring without being cared for

The young caregivers who had little or no access to help and support from close relatives expressed having experienced much hardship and repeating episodes of anxiety and depression, and Kate expressed; *'My grandmother kept her distance...scolded me if I dared leaving mother alone'*.

Most of the young caregivers had few recollections of any formal support from either social or health care professionals during their early years as young caregivers, despite their parents' growing need for complex and well-structured care, and as Kate pointed out: *'I had for years, no idea that we had the right to receive help from our community'*. Adam also expressed; *'My father somehow got lost in the system...for years we were never offered help from the community...they don't even have services during evenings and weekends'*.

Some parents were offered limited nursing care, which mostly involved nurses helping them managing their MS medical treatments, tasks which some of the young caregivers also frequently managed. When their MS medical treatments ceased, the nurses also ceased coming, perhaps believing the young children or adolescents were quite capable of 'assisting' them to manage their physical needs. Although the young caregivers occasionally encountered the nurses at their homes, they never dared asking them to help or assist them in their caring efforts, perhaps subconsciously fearing that the professional health care providers were able to make announcements to higher authorities in perhaps attempting to disrupt or separate their somewhat dysfunctional families. Kate was able to clarify that experience and pointed out; *'Perhaps I was slightly afraid of them'*. Many young caregivers also believed their, sometimes, young age and immaturity, served to restrict them in recognising and making claims for resourceful but professional alternatives that could help or even serve to replace

them in their caring efforts. The childhood and adolescence memories of many, shaped with bitterness and little comprehension of how or why they had been left to manage so much responsibility, so completely on their own. Roger expressed his views on this matter; *'My mother was unable to mother me...always scolding me...no guidance...what I needed was some woman to help both of us'*. Some of the young caregivers could recall memories of their parents repeatedly rejecting professional help from either district nurses, or social workers, claiming they could well manage bathing or toileting on their own. Kate was one of those who for years received no professional support in her caring efforts, and expressed; *'Mother made sure no one knew how bad things were...nobody asked me...but then I had to shout out and call everybody in order to get their full attention'*. Elsa was also able to recall her mother dismissing community nurses; *'Mother playacts this happy person...always refused outside help...though she can't manage anything at home'*.

The young caregivers had difficulties understanding why the professionals involved, had never sought to confirm these statements with the patients' young but heavily responsible children. Some of the young caregivers could recall having, as adolescents, made some effortless attempts to expose their distress to the few healthcare and social professionals they encountered, but claimed the professionals always misinterpreted their complaints, or had never taken them seriously. Paul had little difficulties reflecting on such incidences;

*Mother was this genius in pretending she could manage...even when she had fallen and hurt herself...no one at the hospital bothered to doubt her statements...or even believe my plea...she scolded me for having called the ambulance...If she had been offered professional care, I would have left home that same minute...as I eventually did.*

The professionals assumingly not fully comprehending the nature of their caring efforts and their professional involvement, not becoming fully active until the young caregivers themselves had gained enough strength and maturity to officially voice their opinions and, sometimes, deep resentment towards the social and health care systems. The young caregivers having, at last, become empowered or strong enough to express opinions, which had dwelt within them for many years. Alison expressed her resentment towards the social and health care system and said; *'I don't understand how people can fool professionals...mother describing us as difficult and unhelpful children...when I protested and told them about her alcohol problems...they told me mother should be allowed to have a life'*.

#### **5.4.2. Taught but not supported in school**

Most of the young caregivers in this study had no recollection of receiving any formal support from their teachers in managing their care-giving roles. Although most of their teachers knew about their parents' illnesses, they apparently never sought to discuss with their pupils the possible problems they were experiencing at their homes. Kate never recalled being offered support and said; *'They never asked...they knew for sure...I didn't want anyone at school to see how mentally impaired she had become'*. One young caregiver recalled having had little desire to expose her distress to her teachers as she imagined her excellent performance in school would overshadow or conquer her sometimes-depressed state of mind. Her hours at school rather helped her forget than remember. She, however, claimed that her silence only served to increase her miseries, that she somewhat pushed people and teachers away, adding further to her isolation in life. Most of

the young caregivers had good and pleasant memories from their years at school but some of them believed they missed not having had opportunities to dialogue about their often troubled realities with their teachers, the sometimes most important adult in their outside world. Jane believed her teachers could have supported her more and expressed; *'None of them asked me how things were going at home...all of them knew how ill she was'*. Roger believed he missed educational support and claimed; *'I was just treated as a problem in school...although I wanted help and support'*. All the young caregivers in this study had to rely on their own abilities and resources to manage their homework for school and those who had good learning abilities had little difficulties doing so. Some of the young caregivers, who had learning difficulties expressed having dropped out of school much sooner than they wanted and anticipated, not having had enough educational support, not having been able to manage school alongside their demanding duties at home. Elsa believed her caring responsibilities served to slow down her performance in school and pointed out: *'I needed all the help I could get doing my assignments...but not even that was offered'*.

#### **5.4.3. Secret and isolated lives**

Most of the young caregivers in this study recalled having become periodically isolated from their friends and peers, when their caring involvements had become both too demanding and time consuming. Jane wanted to support her mother and expressed;

*I became isolated from my friends for some time...spending more time with mother...imagining that would help her...I didn't have the time I needed to play with my friends...I envied them...knowing they led this perfect life.*

Some of them had little desire to share their experiences with their friends and to expose to them how demanding and difficult their lives sometimes were, but as Kate and many other caregivers expressed; *'There was little help in talking about problems, your friends and peers do not share or understand'*. Jane also expressed; *'I didn't want anyone to see how sad and miserable my life was...they didn't understand my problems then...and still don't'*. Carol kept her mother's illness hidden for years and said; *'I have never had the nerve to tell my friends how cruel and horrible my mother sometimes was...although it was always on the tip of my tongue'*.

Some of the young caregivers expressed having, as young adolescents, been somewhat embarrassed or ashamed of their parents' disabilities, not wanting 'others' to witness how 'pitiable' their lives had become. Roger claimed he never wanted his friends to play at his home and said; *'My friends had their own problems to deal with...we played outside for hours and hours to forget'*. One caregiver also believed that discussing the problems at home with her peers could have placed more strain on her social networks, as many of her peers knew nothing of her mother's illness. The young caregivers, who had friends who also had chronically ill parents and shared similar experiences, were able to dialogue with those friends about their lived experiences, which for them was extremely rewarding and supportive. Two young caregivers claimed they never had any desire to share their problems with their friends, although their care-giving efforts were perhaps more demanding than for any of the other young caregivers. Both found more comfort in working out or taking long walks in rainy, stormy weathers. Both had some difficulties reflecting on their lived experiences,

opening up and sharing their stories with me. Both, however, managed to open their fists and later revealed that opening up had somewhat helped them *'loose a few pounds'*.

## **5.5. Employing personal resources while embracing support in life**

This key theme involves the experience of receiving help from relatives and friends, and the experience of mobilizing resources to create their own personal stability.

### **5.5.1. Creating personal stability**

Many young caregivers in this study believed they had early in adolescence, consciously sought to create personal stability, in an effort to manage or control the more difficult or depressing episodes in their lives, when they were having troubles combining their personal needs and wishes with their still demanding caring responsibilities. Creating personal stability was perhaps difficult for some of the young caregivers, especially for those who had received little guidance and support in life. Those who had begun raising themselves as children, and had consciously sought to follow the same 'sensible rules' their friends had to follow were, as adolescents, somewhat successful in learning the different but still 'sensible rules' to live and develop by. Creating personal stability was for many an effort to construct and maintain a sense of independence, a vehicle that kept most of them going for as long as they possibly could. Many young caregivers believed they only achieved creating this personal stability as they became adolescents and gradually grew into more maturity. This stability often served as

an effective remedy for depression and fatigue and involved the young caregivers becoming consciously responsible for their lives and their well being, having the ability to organise their tight schedule efficiently, knowing how much time and effort was needed to manage all domestic, social and scholarly duties properly but simultaneously.

Kate believed she had successfully managed to create such stability and pointed out;

*I had to raise myself... usually did what my girlfriends had to do...go home at ten...not watch too much television...always determined to continue studying...having a goal in life keeps you going.*

Alison was also content with her personal stability and claimed; *'I have always been responsible for my own life...always had to organise my life...to know how much time I should spend cooking or doing homework'.*

One young caregiver had difficulties creating personal stability as he perhaps had little guidance and very few resources throughout his childhood. He got caught in 'bad company' resulting in him using drugs and stealing for money. This young man, however, was able to free himself from this bad habit, deciding both he and his mother deserved something better in life. In that process he somewhat isolated himself from his 'friends' and was lucky enough to find a path to a better way of living. Another young caregiver found for some years some consolation in drinking heavily with his friends, a habit he somewhat lost control of. He had, however, little difficulties changing this habit, perhaps knowing that alcoholism ran in his family and that knowledge served to help him ultimately change his lifestyle. For many young caregivers, creating personal stability also involved enhancing their learning abilities and opportunities and eventually seeking further and higher education, as Daniel said; *'Spending much time on your own...helps you evaluate your possibilities in life...I had to continue relying on*

*my learning abilities and myself*'. Those who had good learning abilities believed they were perhaps better equipped to meet the demanding task of keeping their caring tasks and scholar schedules in harmony. Those who had learning difficulties found it more difficulties to find a 'solid ground' in life, while making choices regarding their future and careers possibilities.

Some of the young caregivers believed they consciously sought to enhance their personal strength by trying not to reflect on how difficult life was, but concentrating instead on hoping and perhaps knowing that help and support would soon find its way to them, being determined not to let their depressing responsibilities break them down. In that process most of them were thankful for being in good health and sought comfort in having opportunities to go out with peers, working outside the home and keeping jobs alongside their school and subsequently gaining new friends and opportunities in life. Paul believed it had supported him much to have; *'A good job all through school and good mates...it kept me going'*, and Jane said: *'I needed a life of my own...got a job at a pizzeria...needed the company, not the money'*.

### **5.5.2. Releasing tension, anger and sorrow**

Many young caregivers had access to help and support from close family members and believed their assistance helped them managing their caring duties and helped them releasing their tension, their anger and sorrow, as for Jane who stated; *'We were always able to call dad...when everything was falling apart...he always had time for us...supported us tremendously'*. The family members were able to recognise and value the young caregivers' responsibilities and often participating in caring and supporting both the young caregivers and their



chronically ill parents. Alison, who was supported by her grandmother said; *'She has been as my shelter in life...I went visiting her when I needed care and needed to restock my energy tanks'*.

Doris, who received help from her aunt stated; *'She comes every day... helps mom when she breaks down and refuses to go on...and helps me tremendously'*.

Paul, who received, as a young boy, much emotional support from his father said; *'I used to call him and talk... sometimes for hours...he did everything he could to support me...kept me going. He of course was angry that I couldn't move to him...but I couldn't leave mom alone'*.

Some of their family members were also able to provide the young caregivers with financial support. Having access to financial support was of vital importance for most young caregivers as none of them received any financial support from their communities when their parents were no longer able to provide for their families. Most of the young caregivers received financial support from their fathers, living elsewhere, who nevertheless experienced great difficulties in watching and witnessing their children having to manage so much responsibility with so few resources. The young caregivers, receiving this substantial support, strongly believed that having access to funds and family truly mattered and enhanced their abilities to enjoy their childhood and years of adolescence as Jane pointed out; *'Father gives us the money we need...he always has time for us'*.

### **5.5.3. Having a partner in life**

Many young caregivers in this study believed their lives had changed exceedingly, when they met their partners in life, and most of them were lucky enough to find good and supportive partners, who soon became their support and

shelter in life, somewhat taking on the role of caring for the young caregiver and sometimes also participating in caring for the chronically ill parent-in-law to be. Roger asserted his girlfriend had caring skills he himself never had developed and said; *'She helps me take care of mother...she understands and cares deeply for both of us'*. The young caregivers also claimed that having a partner, included having gained new families and enjoying family gatherings, which for them was very fulfilling. Paul believed he now had found happiness in life and said; *'I was lucky to meet my girlfriend...now life is full of adventures...and now I enjoy Christmas for the first time in years'*. Daniel also believed his life had become full of joy when he met his girlfriend and pointed out; *'Her family is my family and has replaced the one I lost...without her I wouldn't have managed...what counts is having a good relationship and a goal in life'*.

Spending time with their new families helped some of them unwind and temporarily forget their often sad and troublesome realities. Many young caregivers believed their partners helped them realise their responsibilities had for long been more than overwhelming and they supported them in voicing their distress among social and health care professionals. Kate believed her boyfriend helped her give up her primary care-giving role and stated; *'He supported me making the decision to call the community nurses...and everyone...finally I had the nerve to cry out loud that I wouldn't do this any more'*.

Their partners thus directly liberated their loved ones as well as helping them release their feeling of guilt for leaving their posts as primary caregivers, while supporting them in going on with their lives. Doris believed her boyfriend had opened her eyes to how little her father has helped her care for her mother and expressed; *'My boyfriend lives with us...but he is really angry with my father...helped me realise how utterly stuck I still am'*. One young caregiver claimed that his girlfriend helped him realise that his drinking habits were not

helping him much on the road to achieving a better and more prosperous life. This resulted in him finding more peace and more energy within himself without the company of alcohol. Most of the young caregivers, who had partners, had already moved with them to other residences, claiming they were now truly enjoying life, often for the first time in their lives. The young caregivers also claimed they were now very active in life although they truly enjoyed their quiet and stable family life, now able to share their domestic responsibilities with their significant other, which sometimes involved *'just making dinner when they felt like doing so'*.

## **5.6. Moving towards independence while making plans for the future**

This key theme involves the experience of moving towards independence and giving up the primary care-giving role. This key theme also involves reflecting on the lessons learned and on how to construct more wellbeing for young caregivers.

### **5.6.1. Leaving home**

Most of the young caregivers in this study had moved to new premises and had already left their posts as primary caregivers for their chronically ill parents. Those who already had left expressed having at last found freedom in life, now being able to spend as much time as they desired, with friends and sometimes, new families. Alison had already begun packing and said;

*I love my mother deeply...but now I need to concentrate on doing well at school without having a home to look after...I just reached this point in my life where my wishes need to be valued...for once.*

They believed they now felt happy for the first time in many years, although their happiness certainly was shadowed by some of their dark memories and their parents' deteriorating condition. Some of them expressed they had for long realised that their caring efforts had become somewhat damaging for both their parents and themselves, the young caregivers sometimes spending time and energy arguing with their parents, not having anymore the patience or the devotion they perhaps once had. Kate believed that leaving her care-giving post had become necessary and pointed out; *'Today I am happy...we needed a break mother and me...I had become too controlling...but I am very fond of mother...although she sort of left me years ago...I cannot stay away from home for long'*. The young caregivers believed their parents needed professional care and support, not the sometimes, irritable attitude of their grown up children. Most of them expressed they had in fact chosen and wanted to care for their chronically ill parents, but not in this magnitude and they needed this care to be shared with someone more qualified and competent carer. Daniel had a good relationship with his father and pointed out; *'We have this unbreakable link...he is not always rational but I try to respect his wishes...he is being well looked after and I try to visit him every day...as his safety is my security'*.

Most of them believed they had for years been searching for a way out, but being somewhat unfamiliar with how to enforce the interventions of social and health care professionals. Roger, who had sought assistance from the community when his mother had fallen and hurt herself pointed out; *'She has become too ill to live on her own... I won't be content until she has been moved to a nursing home...but living with her had become too much for me'*.

Most of the young caregivers, who had left their homes, also claimed they had little difficulties leaving their parents as they were very content with the professional help their parents were receiving, their parents now enjoying the company of women who often shared similar interests and experiences. Paul expressed gratitude towards the nurses who now are attending to his mother and claimed; *'I left home when mother was finally provided with the nursing care she needed...I couldn't have left earlier...no matter what...I visit her sometimes...but only for a short time'*.

The young caregivers also believed the parents themselves were more content as they were now receiving more continuity of care than before, which gave them a sense of security. Earlier, their parent often had to spend too much time on their own, while their young caregiver was occupied working or attending school. The young caregivers also believed that their parents enjoyed becoming the masters of their homes, now receiving nursing and social care at their homes, instead of having to move to nursing homes. They, nevertheless, had never fully abandoned their parents and went frequently visiting and some were still involved with caring for their parents, believing their parents still needed their emotional support. Most of the young caregivers who had left their homes, believed their relationship with their parents had changed for the better, most of them having left their resentment and anger somewhere behind, when they moved, only to be replaced with deep love and affection for the parents they had most certainly devoted their lives to for many, many years. Jane expressed having felt guilty when she left home but claimed; *'It was important to move and now I take her out as often as I can...which is somewhat demanding...the wheelchair and everything...but we are very connected mother and me'*.

The two young caregivers, who were heavily burdened and had not left their posts as primary caregivers still had little knowledge of what freedom meant as

they had not yet found safe and well structured caring plans for their parents. Both had fathers who had long ago abandoned their care-giving posts. Their voices have not yet been heard among social and health care providers and not within their closest families. Elsa had decided to give up her caring role completely and stated; *'Now I am finishing school and then I am off...so I can have my freedom... my father will have to manage...he has told me so many times, not to put my life on hold'*. Elsa having realised her caring efforts had for long restricted her in going on with her life.

### **5.6.2. Having learned valuable lessons in life**

Most of the young caregivers believed their roles and responsibilities as young caregivers had shadowed their childhood and adolescence and most expressed they would certainly have preferred a different way of growing up as described by Kate; *'I wish my life had been less difficult...but I have learned to be responsible for my self...and I believe I can do anything I want to do...my lesson in life is knowing deep down that everything that doesn't kill you, eventually strengthens you'*.

Paul had a similar story to tell:

*No one should go through what I had to go through...I don't believe my past experiences will ever help me...except in the kitchen... I am still learning to let go of the pain...I feel as if I am an old grey-haired bold man (stroking his very black, thick hair).*

Alison had no difficulties expressing her sentiments towards her caring experience and pointed out; *'I wish I had never been put in this position...but*

*today I feel I can handle everything...and I believe I deserve all the best life can offer for having been so devoted'.*

Most of them, however, believed they had learned some valuable lessons in life and all their many responsibilities had helped them grow to more maturity. Most of them also believed they had developed important skills and competence in managing households and finances, skills which many of their peers were still struggling with. Doris believed some of these tasks were of little importance but said: *'I have certainly learned much in life...but does it matter to know how to cook and clean...everyone eventually learns that...but I have friends in need and they turn to me'.*

Although none of the young caregivers led luxurious lives, most of them had nevertheless learned to be responsible for themselves and save and spend their money sensibly. Some even expressed having helped and supported friends in trouble and believed they had certainly acquired some knowledge on how to provide people with emotional support. Many young caregivers believed one of the most valuable lesson learned was that of breaking the silence and learning to speak openly about their parents' conditions and their caring responsibilities. The caregivers having at last learned that their silence had trapped them for years and not protected.

Most of them believed they were able to recognise good health as a valuable gift in life and were thankful for every opportunity they had in sharing life with friends and family. Although they were not always successful in fighting off the sometimes troubled memories, most of the young caregivers knew that being positive and optimistic served them best, knowing quite well that their fates and fortunes ultimately lay in their own hands. Daniel was able to express the core of his caring experience as follows; *'I have grown much throughout my care-giving*

*years...sort of opened up...I see life differently today...nothing should be taken for granted...at least not your health'.*

### **5.6.3. Creating a vision in life**

Most of the young caregivers believe the lack of effective resources for young caregivers is a serious problem in Iceland. They have for long realised that their lived experience is both obscure and unknown among officials and is probably also a very well protected secret within many families. Alison has little understanding of why children in Iceland are neglected and left unattended;

*If we had lived in a welfare state, this would never have happened...we would have received much more care and support...nobody cares about the well being of children in this country...the authorities don't even know that we provide this care for our parents...or just choose to ignore it...*

Some of them have obviously spent time and effort reflecting on and creating a vision of how to construct more wellbeing for young children, who today are caring for their chronically ill parents and perhaps all domestic duties as they once did. Jane believes she can offer a hand in helping other young caregivers;

*I would like to participate in supporting children experiencing difficulties...they need access to someone they can trust...perhaps someone anonymous...I never dared talk about my mother's depression to anyone...fearing she would find out and become even more depressed...*

Most of them believe they could, if asked to, participate in developing support groups or even participate in constructing a welfare system to serve the many but silent young caregivers in Iceland. One young caregiver believes emphasis should be put on helping teachers and school authorities in finding and helping



young but heavily burdened caregivers. She has good memories from school and believes teachers, as highly qualified professionals, are in the optimal position in recognising all possible symptoms of an unhappy and burdened pupil. Doris expressed having difficulties understanding why there are no support groups for children of chronically ill MS patients as there are support groups for children of alcoholics. She believes such groups could well have served to help her and perhaps many others; *'I believe we, the older caregivers, should support the younger caregivers...learning to know young children and sharing our experiences with them could serve to prevent them from becoming too isolated and too burdened'*.

Although most of them are prepared to participate in developing systems, which can serve to prevent children from being too burdened by care-taking responsibilities, for too many years, Daniel believes his mind more often dwells with the mere ideology of spending official money and effort on human resources instead of dead, empty things; *'How can people spend millions in constructing bridges no one ever uses...why are people's lives so worthless'*.

## **5.7. Summary**

In this section the findings of this study were presented, involving the essential structure of the phenomenon 'being a young caregiver of a chronically ill parent, diagnosed with MS'. In the next section, I will discuss the findings, in light of the literature. I will also discuss the limitations of the study and make some recommendations for implementing the study.

## **6. Discussions**

In this section I will discuss the findings of this phenomenological study. In that process I will disclose my interpretations and the co-constructions of the lived experience of being a young caregiver of a chronically ill parent, diagnosed with Multiple Sclerosis. I will also discuss how the findings of this study correlate and how they differ from previous studies and the academic literature regarding young caregivers. In this section, I will also discuss the limitations of this study and make recommendations for implementing the study.

### **6.1. Being a young caregiver**

The findings of this study demonstrate that becoming a young caregiver of a chronically ill parent, diagnosed with MS, involves recognising and adjusting to many new realities in life, which for many can be a difficult task. Although few studies have addressed children and adolescents' lived experiences of having their parents diagnosed and becoming chronically ill, I conclude with Jewett (1982) who claims that the most critical events of a child's life are those that disrupt established patterns of family interaction. I also believe the findings of some studies (Lindgren, 1992; White et al., 1993; Grbich, 2001) rightly indicate that family members of the chronically ill patient, experience much emotional distress when a diagnosis is delivered, the lives of all filled with a feeling of disruption and distress, and many family members have difficulties adjusting to the new diagnosis. In an effort to further understand the effects of one family member becoming chronically ill, I also believe with Altschuler (1997), that problems affecting one person in a family inevitably affect other family members

and when faced with an illness, the whole family has to adapt to considerable changes in roles, structures and patterns of relating (p.40).

Most of the young caregivers in this study felt abandoned and frightened when their parents gradually became chronically ill, but in an effort to find meaning and understanding in their new realities, I believe many young caregivers in this study experienced an emotional reaction which was perhaps more disabling than the illness itself, similar to what Kralik et al. (2001) have described.

Soon after their parents' diagnosis, most of the young caregivers in this study became fully involved with caring for their parents, which is in accordance with some studies (Aldridge and Becker, 1993; Twigg and Atkin, 1994; Frank, 1995; Walker, 1996; Frank et al., 1999), which have found that young caregivers of chronically ill parents do not necessarily choose to become carers but have rather been constrained by circumstances and their caring efforts are only activated as a natural progression of maintaining the balance and union within their families.

Care-giving can, however, be a lonely and isolating experience (Twigg and Atkin, 1994) and in unison with this study, Frank (1995), Walker (1996) and Frank et al. (1999) conclude that far too many children and adolescents become primary caregivers for their dependent and chronically ill parents while often assuming responsibilities for themselves, their siblings and everything within their households. I believe this may have been due to their young age and immaturity to recognise and see alternatives to escape what had to be employed, similar to what Frank et al. (1999) describe but as their very status as children and adolescents reinforces certain powerlessness, I believe they were too often overlooked by professional carers, their experiences and needs too often shrouded in a veil of mystery and silence, something also brought up by Aldridge and Becker (1993).

According to Aldridge and Becker (2003) too many caring responsibilities are likely to seriously challenge the self-image and the well being of young caregivers. Some young caregivers in this study had memories of having become depressed and emotionally drained when their domestic duties became overwhelming and their parents became heavily dependent and even failed to recognise, accept or value their caring efforts. The young caregivers had, as in Aldridge and Becker's (2003) study, little comprehension and few resources of how to cope and manage with such complex and difficult situations.

Although Aldridge and Becker (1993) demonstrate that care-giving by youngsters does not promote feelings of security, I, nevertheless, believe Aldridge and Becker (2003) rightly demonstrate that many children become remarkably capable of fulfilling parent-like roles, when others are unavailable to lend assistance in that respect. In this study there was, however, not 'role reversals' within the young caregivers' homes, as the young caregivers never saw themselves 'parenting their parents', as described by Thomas et al. (2003), although the young caregivers, who provided care for their siblings, sometimes 'felt like parents'.

Burdened young caregivers who miss parental nurturing and support may sometimes miss normal developmental phases of childhood, according to Flickinger and Amato (1994) and can develop both physical and mental health problems (Aldridge and Becker, 2003; Vitaliano et al., 2004), including sleeping and eating disorders, alcohol and drug problems (Cree, 2003). None of the young caregivers in this study, however, experienced any physical health problems and none experienced eating or sleeping disorders. Although many periodically suffered from depression and few had periodically alcohol and drug problems, all of them had made remarkable recovery, all of them had consciously made efforts not to let the sometimes shadowed memories continue to affect and burden them

in present and future situations. However as this is not a qualitative study this might be the effect of an elite bias.

The burden of care-giving can, according to some studies (e.g. Aldridge and Becker, 1993; Frank, 1995; Walker, 1996 and Frank et al., 1999) have multiple effects, as too much care-giving can result in social exclusion, both during childhood and later in life. Social exclusion in childhood can also cause 'late maturity' among many young caregivers as they can experience difficulties mixing with other children and developing social lives of their own (Dearden and Becker, 2000; Frank et al., 1999). This is, however, in my opinion, only partially in accordance with the findings of this study. Although many caregivers in this study were heavily burdened, most of them believed they only became periodically isolated from their friends, which was rather the consequence of not wanting to spoil their already well developed social networks with tales of difficult households but also due to not having enough spare time to spend playing and enjoying life. Although most of the young caregivers missed not having been able to share their problematic lives with their friends, which is also reported by other studies (e.g. Frank, 1995; Frank et al., 1999; Aldridge and Becker, 2003), I believe most of them accepted that and moved on. Most of the young caregivers in this study made both conscious and unconscious efforts to create stability and follow 'sensible rules' in growing up and developing self-discipline, which made them more capable of coping with and managing their lives and ultimately helped them grow to more maturity. I have not seen this factor in other studies.

## **6.2. Caring without professional support**

The young caregivers in this study had, in my opinion, to face far too many restrictions during their childhood and years of adolescence, as I share their expressed views of not understanding why they were left to manage so many responsibilities so completely on their own. According to some studies (e.g. Frank, 1995; Aldridge and Becker, 1996; Becker et al., 1998, Aldridge and Becker, 2003) support systems for young caregivers are often either inadequate or ineffective, their families often, for many reasons, not receiving effective family support services and their problems often not seen by professionals in any holistic context.

The obvious lack of information, intervention and professional support, the young caregivers in this study experienced, can perhaps be somewhat explained by how reluctant young carers often are in identifying themselves and calling attention to themselves and their caring duties (Jenkins and Wingate, 1994), but may also be partly due to the fear both parents and some children have regarding family separations (Becker et al., 1998). Another reason for the lack of professional intervention, may also be explained by the fact that social and health care professionals have also for years, mainly focused on the ‘disability rights paradigm’, which involves valuing the rights and needs of disabled people over their child carers (Aldridge and Becker, 1996), our good social and health care professionals somewhat believing that if disabled people’s rights and needs were fully acknowledged and served, then children would not be called on to caregiving at all (Keith and Morris, 1995). The Icelandic social and health care professionals may also have difficulties distinguishing between situations where children develop ‘task oriented competences which can be a strength in their lives’, and those where children have ‘too many responsibilities because they are

forced early to take care of their sick parent and miss out on their social development' (Göpfert et al., 1996, p.282, cited in Aldridge and Becker, 2003).

The obvious inattention of Icelandic social and health care professionals can also be accounted for by the complete lack of research, debate and policy in Iceland regarding young caregivers as no formal legislative policies or procedures have yet been constructed, which accommodate and address the well being and needs of young caregivers. Although some authors (e.g. Olsen, 1996) believe the rights and needs of disabled people should take priority over that of their carers, I believe with Aldridge and Becker (1996) who claim that the 'young carers paradigm' has not been sufficiently addressed or studied and all research on behalf of young caregivers could serve to elevate the long lasting suppression and denial of the rights of a large and disadvantaged social group.

The lack of emotional and sometimes educational support, which many young caregivers in this study experienced in their schools, may also be explained by the lack of well structured policies for teachers and school nurses to address and support children and adolescents who care for their parents at home. I believe with Frank et al. (1999) that the school system plays an important part in shaping self-perception and personal confidence, but as school systems often fail to recognise children and adolescents, burdened with caring responsibilities, they have also failed to make all necessary efforts to meet the educational and emotional needs of those children (Aldridge and Becker, 1993; Frank et al., 1999). Although some young caregivers in this study demonstrated excellent performance in school, I also believe with Aldridge and Becker (2003) that heavy caring responsibilities of children are often reflected in poor educational performance, social exclusion, which may continue to alter their educational and professional opportunities later in life.

### **6.3. Being cared for while creating personal stability**

Most of the young caregivers in this study had close relatives who became their shelters in life, while helping them caring for their parents. As families will attempt to protect themselves from what they see to be unnecessary or unwelcome external interventions (Frank et al., 1999), families and relatives of some young caregivers became closer and more dynamic, perhaps also unconsciously keeping the caring responsibilities hidden from ‘outside’ professional caregivers. Although I believe with Aldridge and Becker (2003) that such support is of utmost importance as children who are able to form important attachments with relatives and family carers can augment their own feelings of security and wellbeing, I nevertheless believe with Frank (1995) that many relatives only become partly involved, leaving the primary care to the young children and adolescents. As poverty is often the reality of many families coping with chronic illnesses (Twigg and Atkin, 1994), family members were often more concerned with providing the young caregivers with important financial support, rather than accelerating the involvement of qualified professionals to replace, the often, burdened young caregivers.

I believe that the young caregivers who had found their partners in life, were those who truly received the family support they needed, their partners serving as their shelter in life, helping them voice their distress among social and health care professional. The partners thus also served in my opinion, as the first carers, helping them make choices about care-giving, while helping them make social contacts in seeking professional caring interventions (Aldridge and Becker, 2003).

Most of the young caregivers in this study were able to learn to cope with their realities as they ‘created personal stability’ in order to better tolerate their



difficulties and minimize the effects of care-giving, similar to what Richardson and Poole (2001) describe. By creating personal stability they consciously made efforts to ignore things that couldn't be mastered, while undertaking activities to create order, discipline and control in their lives, as also seen in Kralik et al. (2004). This important personal quality was, however, not found among the young caregivers in some of the previously mentioned studies (Aldridge and Becker, 1993; Frank, 1995; Walker, 1996, Frank et al., 1999; Dearden and Becker, 2000; Aldridge and Becker, 2003), where young caregivers seem to demonstrate symptoms of 'false maturity' as they only appeared to be responsible and mature beyond their years, while expressing adult attitude towards their lived experiences.

This personal stability can in my opinion be translated as an element of self-management. Self-management of chronic illness has been described as a process of doing, being and becoming (Kralik et al., 2004) and has been demonstrated as the most important factor of incorporating an illness into life. Although none of the young caregivers were chronically ill, their behavioural patterns were similar to those who have to find meaning and understanding of self-management instead of merely learning to live with the symptoms of an illness (Kralik et al., 2004). In that process chronically ill patients identify self-management as a process initiated to bring about order in their lives. Creating order or self-management involves the four following themes: recognising and monitoring the boundaries (of the illness), mobilizing the resources (in life), managing the shift in self-identity (deteriorating symptoms) and balancing, pacing, planning and prioritising (to move on with life). Self-management is thus not learned through structured education but rather as a result of trial and error through daily life experiences, a process in which people learn to reconstruct their self-identity by exploring their personal limitations or boundaries (Kralik et al., 2004). This self-

management was, in my opinion, highly comparable with the lived experience of learning to become and be a young caregiver of chronically ill parent diagnosed with MS.

#### **6.4. Moving on towards independence in life**

Most of the young caregivers in this study had already left their posts as primary caregiver and moved to other residences. Most of them believed they had learned to take responsibility and learned valuable lessons during the years as primary caregivers, identified as the positive aspects of caring (Thomas et al., 2003). Despite these expressed views, I believe with Aldridge and Becker (1993) that the positive aspects of caring tend to be overshadowed by painful and distressing conditions and memories of young caregivers' lives. Giving up their primary care-giving role was for most of them extremely important and was only achieved when they finally become empowered and had created knowledge and an environment in which they were able to behave as responsible adults and make decisions on how to care for their chronically ill parents (Porter-O'Grady, 1999, cited in Williams, 2002). As empowerment can also be described as having the knowledge, skills, attitudes and self-awareness necessary to influence behaviour in order to improve the quality of life (Anderson et al., 1995) many young caregivers had also created a vision of how to construct supportive and caring resources for children and adolescents, facing similar difficulties they once had to face. Although they had not been given opportunities to further develop their visions, many were prepared to inspire and motivate policy makers to further develop the current but static well fare system for young caregivers in Iceland. In that process, most of them believed their participation and expert

knowledge was pivotal if social and health care professionals were ever to accomplish to protect and promote the basic human needs, values and emotions of young caregivers in Iceland.

## **6.5. Conclusion**

Care-giving may be the only way young children and adolescents can address or alleviate some of the concerns they may have about their chronically ill parents but such care-giving should be acknowledged and shared by qualified social and health care professionals in our country.

Most of the young caregivers in this study were for years never asked or consulted about the nature and the consequences of their care-giving activities and presumably professional help and support was withdrawn or withheld because the children were considered capable of participating in caring for their chronically ill parents. The lived experiences of many young caregivers were shadowed with troubled memories, of having been left to manage far too many responsibilities completely on their own. Although many became emotionally drained and often depressed, most of them were, nevertheless, equipped with enormous enthusiasm, determined not to give up and of not breaking down. Many had successfully created personal stability as an element of self-management, which served to bring about order in their lives and served to enhance their abilities and possibilities in seeking personal and professional contentment in present and future situation. The young caregivers had all served and cared well for their parents as well as other family members, e.g. younger siblings, but for years they were only seen but never heard.

## 6.6. Limitations

The following limitations were identified as having significant value with this study, although they didn't alter or affect the quality or the findings of this study (Table 5., p.76).

- The study cannot reflect the lived experiences of all young caregivers in Iceland and other young caregivers may possibly have different stories to tell regarding their caring experiences.
- The study has no generalisability, although the lived experiences of most co-researchers in this study were remarkably similar and almost all had suffered silently for years without support. The sample was not too homogeneous and 'elite bias' was avoided, although participants (co-researchers) were both articulate and accessible. They were not 'high-status' members of their group, which can threaten both credibility and fittingness in qualitative studies (Sandelowski, 1986).
- In this study, long-term effects of burdened and difficult childhood experiences are not examined, but they need to be studied in due time and only time will tell how well the young caregivers eventually will cope and manage in their adult lives.

**Table 5. The limitations of the study**

## 6.8. Recommendations

In order to implement this study, the following recommendations will be put into action by myself and my colleagues within the MS society (Table 6., p 77).

- To formally offer Icelandic policy makers and others responsible for the well being of children and adolescents, access to the findings of this study, in order to encourage authorities to gather more information regarding the number of young caregivers and the nature of their care-giving efforts, while caring for chronically ill parents, diagnosed with MS. Such information can facilitate the construction of effective strategies and guidelines for school authorities, social and health care professionals, to support Icelandic young caregivers, caring for chronically ill parents.
- To offer the Ombudsman of children in Iceland, access to the findings of this study. The Ombudsman has already expressed her interest in this study, awaits the publication of the study and has already expressed her enthusiasm to influence higher officials to commence constructing guidelines for social, health care and school authorities to meet the needs of young caregivers, caring for chronically ill parents, diagnosed with MS.
- To continue constructing knowledge and further research regarding the lived experience of being a young caregiver of chronically ill parent in Iceland.
- To make formal request for permission from the MS society to form and launch in April 2005, two support groups for young caregivers who have cared for their chronically ill parents, diagnosed with MS. The first meetings of these support groups will be organised by myself and two nurses employed at the MS centre in Reykjavík. These support groups will meet once a week and members will be offered opportunity to openly discuss their caring experiences. Members of these support groups will also be offered opportunity to influence and further develop the philosophy of this support group, but the two nurses and I have already discussed offering members courses in household and financial management.

**Table 6. Recommendations for implementing this study**

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## Appendix 1

Háskólinn á Akureyri,  
heilbrigðisdeild  
Sigríður Halldórsdóttir, prófessor  
Sólborg v/Norðurlóð  
600 Akureyri

  
VÍSINDASÍÐANEFND  
National Bioethics Committee  
Vegmúli 3, 108 Reykjavík,  
Tel: 551 7100, Fax: 551 1444  
e-mail: visindasidanefnd@vsn.stjr.is

Reykjavík, January 27, 2005  
Ref: VSNa2004010001//BH/-

**Regarding: 04-002-S1 The lived experience of young adults, caring for single parents diagnosed with Multiple Sclerosis.**

The National Bioethics Committee received your response, dated March 10<sup>th</sup> 2004, to the committee's requests and comments sent in a letter dated February 2<sup>nd</sup> 2004, concerning the above-mentioned research project.

In your reply you responded to the Committee's comments in accordance with the Committee's letter.

Enclosed with the letter was a copy of a application to the Data Protection Agency as well as new copies of the information sheet and consent form for the research participants.

It is hereby confirmed that the National Bioethics Committee of Iceland granted your research proposal its full approval in a letter dated March 30<sup>th</sup> 2004.

The National Bioethics Committee kindly requests that researchers include the given referral no. given to their project by the committee in published research papers. The National Bioethics Committee would also like to receive copies of research papers portraying research approved by the committee.

Respectfully yours,  
on behalf of the National Bioethics Committee,

  
Olaf Yr. Atladóttir, Managing Director

Copy to: Katrín Björgvinsdóttir, Gullsmára 5, 201 Kópavogi.

Háskólinn á Akureyri  
heilbrigðisdeild  
Sigríður Halldórsdóttir, prófessor  
Sólborg v/Norðurslóð  
600 Akureyri



VÍSINDASIÐANEFND

Laugavegur 103, 105 Reykjavík,  
Sími: 551 7100, Breðsimi: 551 1444  
netfang: visindasidaneft@vsn.stjr.is

Reykjavík 30. mars 2004

Tilvísun: VSNa2004010001/03-7/BH/-

**Varðar: 04-002-S1 The lived experience of young adults, caring for single parents diagnosed with Multiple Sclerosis.**

Vísindasíðanefnd þakkar svarbréf þitt, dags. 10.03.2004 vegna áðursendra athugasemda við ofangreinda rannsóknaráætlun sbr. bréf nefndarinnar dags. 02.02.2004.

Í bréfinu koma fram svör og skýringar í fimm liðum til samræmis við athugasemdir Vísindasíðanefndar.

Með bréfinu fylgdi nýtt og endurbætt upplýsingabréf til þátttakenda rannsóknarinnar á íslensku og ensku ásamt afriti af umsókn til Persónuverndar.

Fjallað var um svarbréf þitt og önnur innsend gögn á fundi Vísindasíðanefndar 30.03.2004 og voru þau talin fullnægjandi.

Rannsóknaráætlunin er endanlega samþykkt af Vísindasíðanefnd.

Vísindasíðanefnd bendir rannsakendum vinsamlegast á að birta VSN tilvísunarnúmer rannsóknarinnar þar sem vitnað er í leyfi nefndarinnar í birtum greinum um rannsóknina. Jafnframt fer Vísindasíðanefnd fram á að fá send afrit af birtum greinum um rannsóknina. Rannsakendur eru minntir á að tilkynna rannsóknarlok til nefndarinnar.

Með kveðju  
f.h. Vísindasíðanefndar,

*Bryndís Valsdóttir*

Bryndís Valsdóttir, starfandi framkvæmdastjóri



## Appendix 2

Katrín Björgvinsdóttir  
Gullsmári 5  
201 KÓPAVOGUR



Persónuvernd  
Data Protection Authority

Rauðlaugavegur 10 105 Reykjavík Iceland  
tel: 354 510 9600 fax: 354 510 9606  
e-mail: postur@personuvernd.is  
web page: personuvernd.is

Reykjavík, 3 February 2005  
Tilvísun: 2004030169 PS/-

*The following is a translation from Icelandic to English of a letter from The Data Protection Authority to Professor Sigríður Halldórsdóttir, dat. 18 March 2004, signed by Dórður Sveinsson, legal counsel:*

### **“Regards: Research project on lived experience of care of parents with MS disease**

The Data Protection Authority refers to the application of Sigríður Halldórsdóttir and Katrín Björgvinsdóttir, dat. 10 March 2004, for a permission for the processing of personal data because of a research project on “the lived experience of young adults, caring for single parents diagnosed with Multiple Sclerosis (MS).” It is stated that the project is the final stage in Katrín’s M.Sc. education in nursing.

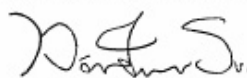
According to the application, the project is a prospective one in which data on participants will be gathered through interviews. No data will, on the other hand, be obtained from documents. In information letters for participants, it is stated that Margrét Sigurðardóttir, sociologist at the MS Society, and Sigbrúður Ólafsdóttir, nurse at the same society, shall find participants for the project; they are both well acquainted to MS patients and their families. The number of participants will be between 10–15.

The Data Protection Authority considers it clear that the project does not fall under any provisions in legal acts or regulations that state that a permission from The Data Protection Authority must be obtained. A permission is, therefore, not needed in this case. Also, The Data Protection Authority does not find it to be obligatory to notify the processing of personal data in the project according to Art. 31 and 32 of the Act on the Protection of Privacy as Regards the Processing of Personal Data, No. 77/2000, cf. Rules on When to Notify and Seek a Permission for the Processing of Personal Data, No. 90/2001, i.e., if documents that bear with themselves data on diseases will not be used to find participants. If that will be done, the processing in question will be of sensitive, personal data, cf. Art. 2, Point 8:c, of Act No. 77/2000; such processing must always be notified, cf. Art. 6 of Rules 90/2001, cf. Art. 31 of Act No. 77/2000.

If there will only be used data on names and addresses, without them bearing with themselves data on diseases, the processing will fall under the exemption from the obligation of notification that the processing of general personal data that have been made accessible to the public (in this case general public register data on names and addresses) does not have to be notified, cf. Art. 5, Sec. 1, Point 4, of Rules No. 90/2001, cf. Art. 31, Sec. 3, of Act No. 77/2000. If there will not be used documents to find participants, no processing of personal data, on the other hand, finds place with regard to the search of participants, and then, also, there is no need of notifying.

Finally, it shall be stated that all other work because of the project, as it is described in the application, does not constitute processing of personal data, since no personal identifiers will be registered according to what is said there."

Respectfully  
On behalf of the director of The Data Protection Authority

  
Þórður Sveinsson  
Legal counsel

Sigríður Halldórsdóttir prófessor  
Steinahlíð 8a  
603 AKUREYRI



Persónuvernd

Baráttastíg 10 105 Reykjavík  
sími: 510 9600 hréfasími: 510 9606  
netfang: [postur@personuvernd.is](mailto:postur@personuvernd.is)  
veffang: [personuvernd.is](http://personuvernd.is)

Reykjavík, 18. mars 2004  
Tilvísun: 2004030169 ÞS/-

#### Efni: rannsókn á upplifun af ummönun foreldra með MS-sjúkdóminn

Persónuvernd vísar til umsóknar Sigríðar Halldórsdóttur og Katrínar Björgvinsdóttur, dags. 10. mars 2004, um heimild til vinnslu persónuupplýsinga vegna rannsóknar á „upplifun ungra einstaklinga af ummönun á einstæðum foreldrum sínum sem greinst hafa með mænisigg (MS).“ Kemur fram að rannsóknin sé lokaáfangi Katrínar í M.Sc. námi hennar í hjúkrunarfræði.

Af umsókninni verður ráðið að um framsýna rannsókn er að ræða þar sem upplýsinga um þátttakendur verður aflað með viðtölum við þá. Ekki verður hins vegar aflað neinna upplýsinga úr skriflegum gögnum. Í kynningarbréfi til þátttakenda kemur fram að Margrét Sigurðardóttir, félagsfræðingur hjá MS-félaginu, og Sigbrúður Ólafsdóttir, hjúkrunarfræðingur hjá sama félagi, finna þátttakendur í rannsóknina, en þær þekki báðar vel til MS-sjúklinga og fjölskyldna þeirra. Þátttakendur verði á bilinu 10–15.

Persónuvernd telur ljóst að rannsóknin falli ekki undir nein þau ákvæði í lögum og reglum sem áskilja að aflað sé leyfis Persónuverndar fyrir vinnslu persónuupplýsinga. Þarf því ekki leyfi í þessu tilviki. Þá telur Persónuvernd ekki að skylt sé að tilkynna vinnslu persónuupplýsinga vegna rannsóknarinnar í samræmi við 31. og 32. gr. laga nr. 77/2000 um persónuvernd og meðferð persónuupplýsinga, sbr. reglur nr. 90/2001 um tilkynningarskylda og leyfisskylda vinnslu persónuupplýsinga, þ.e. ef ekki verður notast við skráð gögn, sem bera með sér sjúkdómaupplýsingar, til að finna þátttakendur. Verði það gert er um að ræða vinnslu viðkvæmra persónuupplýsinga, sbr. c-lið 8. tölul. 2. gr. laga nr. 77/2000, en hún er ávallt tilkynningarskyld, sbr. 6. gr. reglna nr. 90/2001, sbr. 31. gr. laga nr. 77/2000.

Verði eingöngu stuðst við gögn um nöfn og heimilisföng, án þess að þau beri með sér sjúkdómaupplýsingar, fellur sú vinnsla undir þá undanþágu frá tilkynningarskyldunni að ekki þarf að tilkynna vinnslu almennra persónuupplýsinga sem hafa verið gerðar almenningi aðgengilegar (í þessu tilviki almennar lýðskrárupplýsingar um nöfn og heimilisföng), sbr. 4. tölul. 1. mgr. 5. gr. reglna nr. 90/2001, sbr. 3. mgr. 31. gr. laga nr. 77/2000. Verði ekki notuð skráð gögn til að finna

Þátttakendur er hins vegar ekki um neina vinnslu persónuupplýsinga að ræða í tengslum við leit að þátttakendum og er þá ekki heldur þörf á tilkynningu.

Að lokum skal tekið fram að öll önnur vinna vegna fyrirhugaðrar rannsóknar, eins og henni er lýst í umsókninni, er ekki vinnsla persónuupplýsinga, enda verða hvergi skráð nein persónuauðkenni eftir því sem þar segir.

Virðingarfyllt  
f.h. forstjóra Persónuverndar



Þórður Sveinsson  
lögfræðingur

## Appendix 3

### To Whom It May Concern;

Reykjavík, the 2<sup>nd</sup> of March 2004.

We, Margrét Sigurðardóttir, social worker at the MS Society in Iceland and Sigþrúður Ólafsdóttir, registered nurse at the MS society, hereby confirm, that we will assist Katrín Björgvinsdóttir in finding research participants for her study. As this study involves exploring the lived experience of being a young caregiver of chronically ill parent, diagnosed with MS, we will ask 10-20 MS patients, members of our Ms society, to give Katrín access to their grown up children, to whom Katrín will introduce the study and offer them to participate in her study. We promise full confidentiality and we will not reveal any information regarding the possible identity of the participants or the nature of the study. Although our part in this study, is only that of finding participants for the study, we have accepted the condition of the National Bioethical Committee of Iceland to become informal participants of the study

Yours truly,

-----  
Margrét Sigurðardóttir, social worker at the MS society in Iceland.

-----  
Sigþrúður Ólafsdóttir, registered nurse at the MS society in Iceland.

**Til þeirra er þetta mál varðar;**

Reykjavík, 2.mars 2004.

Við undirraðar Margrét Sigurðardóttir, félagsráðgjafi hjá MS félaginu og Sigprúður Ólafsdóttir, hjúkrunarfræðingur hjá MS félaginu, samþykkjum að veita Katrínu Björgvinsdóttur aðstoð okkar við MSc rannsókn hennar sem lýtur að því að rannsaka reynslu uppkominnna barna MS sjúklinga af því að annast langveika foreldra sína. Við höfum ákveðið að biðja 10-20 MS sjúklinga að veita henni aðgang að uppkomnum börnum þeirra og kynna þeim rannsóknarverkefni sitt og bjóða þeim þátttöku í rannsókninni. Við heitum fyllsta trúnaði og munum ekki veita nokkrum upplýsingar um rannsóknina og hvaða einstaklingar munu hugsanlega veljast í rannsóknina. Þáttur okkar í þessari rannsókn verður ekki annar en höfum við samþykkt að verða við bón Vísindasiðanefndar og verðum því óformlegir samstarfsaðilar í rannsókninni.

Virðingarfyllst,

-----  
Margrét Sigurðardóttir, félagsráðgjafi MS félagsins á Íslandi

og

-----  
Sigprúður Ólafsdóttir, hjúkrunarfræðingur MS félagsins á Íslandi

## Appendix 4

### To Whom It May Concern

Reykjavík, the 1<sup>st</sup> of April, 2004,

I, Theodóra Frímann, registered MS nurse, hereby confirm that I will assist Katrín Björgvinsdóttir, in her study, by offering the participants in her study consultation and emotional support, if need for such assistance will be needed. Since the research question is concerned with exploring the lived experience of being a young caregivers of a chronically ill parent, diagnosed with MS, some emotionally disturbing subjects may possible arise during reflecting and dialoguing on their lived experiences. If the participants suffer any emotional distress while revealing their stories, I will offer each participant my professional help and assistance, which will fit the needs and desires of the participants involved.

Yours truly,

-----

Theodora Frímann, registered MS nurse  
Neurological Unit B-2,  
Univeristy Hospital in Iceland.

## Til þeirra er þetta mál varðar

Reykjavík, 1.apríl 2005.

Ég, Theodóra Frímann, veiti hér með samþykki mitt að veita þátttakendum, í rannsókn Katrínar Björgvinsdóttur, minn faglegan stuðning og aðstoð við að vinna úr hugsanlegum erfiðleikum sem þeir upplifa við að segja sögu sína af umönnun af langveikum foreldrum sínum, greindum með MS. Þar sem rannsóknarspurningin lýtur að því að rannsaka upplifun ungra einstaklinga af því að hafa annast langveika foreldra sína, geta slík rannsókn vakið upp óþægilegar minningar og sársauka og mun ég því leitast af öllum mætti við að hjálpa þátttakendum við að vinna úr þeim tilfinningum. Mun sú faglega aðstoð þá miðast við þarfir og óskir þessa einstaklinga.

Virðingarfyllst

-----  
Theodóra Frímann  
Hjúkrunarfræðingur,  
Taugalækningadeild B-2,  
Landspítalinn Háskólasjúkrahús.



## Appendix 5

### An introductory letter

My name is Katrín Björgvinsdóttir and I am a nurse at the University Hospital in Fossvogur. I am also a student in a master's program in nursing that is a collaboration between The Royal College of Nursing Institute of Higher Education in London and The University of Akureyri in Iceland.

One part of my studies is to conduct a research and since my interests lie in caring for people diagnosed with multiple sclerosis (MS) and their families, I approach you. I have for long been interested in further exploring and constructing understanding of how children of patients, diagnosed with MS adapt to and manage the sometimes, dramatic life changes as their parents are diagnosed with this chronic illness. I am also interested in exploring how or if their parents' illness has affected their childhood and years of adolescence, and what resources they have employed in managing their every day living as well as the responsibility of perhaps being highly involved in providing intensive health care and support for their chronically ill parents. The findings from the study can not only serve to provide some of the young adult caregivers a voice to express themselves and letting their believes be known and understood. The finding from the study can also enable other health care providers to recognise your needs and wishes, possibly serving to provide responsive and appropriate health care for you and others with similar experience.

As I believe that the young caregivers are the true experts of the lived experience of caring for the chronically ill parent, I am interested in hearing your story, how your parent's illness has influenced your life and how you have adapted to and managed the responsibility of care-giving. The methodology for this study is called phenomenology and has its roots in philosophy. By using phenomenology, the researcher seeks to gain a deeper understanding of human experiences and behaviour and in this context the phenomenon is the experience of being a young caregiver. The methods to be used in this study are called dialogues and during those dialogues the researcher asks the participant to voice his or her genuine views of this experience and the researcher

listens to his or her story. These dialogues last about one hour, are audiotaped and then transcribed by the researcher (me). The dialogues could be more than one as two dialogues can provide more depth and more understanding of your experience. There will be few participants in this study, approximately seven people will be asked to participate.

To ensure anonymity, each participant will be given a pseudonym in the transcripts and each transcript will be identified with codes, not names. Some of these codes will be used in the research report but not be traceable. The anonymity of the participants is very important and every effort will be made to secure confidentiality.

Each participant, will be asked to read his or her case construction in order to verify that their own story is correctly understood. Later in the study, some of the participants will also be asked to verify the essential structure of the phenomenon. Only I will see the written and coded transcripts and when the study is complete, all tapes will be destroyed.

I would be very honoured if you could participate but if you do not wish to, it is of no inconvenience for me. I respect your decision, but if you decide to participate you can withdraw at any moment during the study. You can also choose not to discuss any delicate, personal matters during the dialogues.

If you are interested in participating, and giving me an opportunity to hear your story, please contact me at the number below. If any questions arise while reading this letter, please do not hesitate to contact me.

Yours truly,

Katrín Björgvinsdóttir, Gullsmári 5

201 Kópavogur, Telephone 554-3675, 691-3675.

## Kynningarbéf

Nafn mitt er Katrín Björgvinsdóttir og ég er hjúkrunarfræðingur á Taugalækningadeild, B-2 á Landspítala Háskólasjúkrahúsi. Ég er einnig nemandi í meistaranámi í hjúkrunarfræði við RCN Háskólann í hjúkrunarfræði í London sem er í samstarfi við Háskólann á Akureyri.

Hluti af námi mínu felst í rannsóknarvinnu og þar sem ég hef lengi haft áhuga hjúkrun MS sjúklinga og fjölskyldum þeirra, þá leita ég til þín. Ég hef lengi haft mikinn áhuga á að rannsaka uppkomin börn MS sjúklinga, hvernig þeim sem ungum börnum og unglingum gekk að aðlaga líf sitt að veikindum foreldra sinna, hvaða áhrif veikindin hafa almennt á æsku og unglingsárin þeirra og hvort og þá hvernig stuðning þessir aðilar fengu. Það er trú mín að það sér löngu tímabært að afla þekkingar á því hvers konar umönnun börn og unglingar MS sjúklingar veita foreldrum sínum, hversu mikla ábyrgð þau axla og þá hvernig lækna og hjúkrunarfræðingar geti stutt við bak þeirra og stuðlað að betri og lífsgæðum þeim til handa.

Margrét Sigurðardóttir, félagsfræðingur hjá Ms félaginu og Sigbrúður Ólafsdóttir, hjúkrunarfræðingur hjá MS félaginu sem þekkja vel til MS sjúklinga og fjölskyldna þeirra, aðstoðuðu mig við að finna þig og fleiri uppkomin börn MS sjúklinga og hafa þær væntanlega haft samband og útskýrt rannsóknina fyrir þér.

Rannsókn af þessu tagi gæti nýst heilbrigðisstarfsfólki afar vel og einnig öðrum fagstéttum sem sinna málefnum barna og unglinga þar sem mjög lítil þekking er til á Íslandi um börn og unglinga sem annast langveika foreldra. Rannsóknin gæti einnig nýst þátttakendum sjálfum vel, svo og öðrum sem búa við svipaðar aðstæður.

Að mínu áliti eru börn sjúklinga sérfróðir um þá upplifun að annast langveikt foreldri og langar mig þess vegna að heyra sögu þína og hvaða áhrif veikindin hafa haft á æsku-og unglingsárin þín. Þess vegna langar mig að biðja þig að taka þátt í samræðum við mig og deila lífsreynslu þinni, með mér. Samræður þessar er rannsóknaraðferð sem tilheyrir aðferðafræði sem nefnist “Fyrirbærafræði” eða phenomenology (á ensku) sem á rætur í heimspeki og lítur að því að rannsaka mannlegt eðli og mannlega reynslu, hvað felst í því að vera manneskja. Í þessari fyrirbærafræðilegu rannsókn er tilgangurinn helgaður þeirri viðleitni að fá dýpri þekkingu og aukinn skilning á því að

vera umönnunaraðili foreldris með MS. Samræður þessar munu taka um það bil 1 klukkustund og munu verða teknar upp á segulband og síðan vélritaðar af mér. Hugsanlegt er að þér verði boðið að taka þátt í tveim samræðum, þá fengist betri og dýpri skilningur á lífsreynslu þinni. Einnig verður þér boðið að lesa yfir samræðurnar til staðfestingar að allt sem er skráð sé rétt skilið og rétt með farið. Hugsanlega verður þér einnig boðið að lesa yfir hluta af rannsóknarniðurstöðum.

Til að tryggja nafnleynd mun enginn annar en ég mun hafa aðgang að segulbandsupptökunum og hinum vélrituðu gögnum. Þegar rannsókninni er lokið verður öllum gögnum eytt. Þar sem hugsanlegt er að hlutar úr samræðum verði notaðir í rannsóknarskýrslunni, munu þátttakendur fá dulnefni en raunveruleg nöfn ekki notuð.

Þar sem viðræður af þessu tagi geta vakið upp viðkvæmar, persónulegar tilfinningar þátttakenda, verður öllum þátttakendum boðið upp á stuðningsviðtöl hjá Theodóru Frímann, MS-hjúkrunarfræðingi ef óskað er. Hún hefur veitt MS sjúklingum og fjölskyldum þeirra slík viðtöl lengi við góðar undirtektir.

Það myndi gleðja mig mikið ef þú sær þér fært að taka þátt í þessari rannsókn sem vonandi gæti gagnast þér persónulega, þar sem samræður sem þessar losa oft um tilfinningar sem eru mörgum þungar byrðar. Ef þú hins vegar ekki kærir þig um að taka þátt, þá skil ég og virði ákvörðun þína. Ef þú ákveður að taka þátt, þá máttu hætta þátttöku hvernær sem er í ferlinu og þú þarft alls ekki að ræða viðkvæm, persónuleg mál, kjósir þú það ekki.

Ef þú hefur áhuga á þátttöku og vilt deila lífsreynslu þinni með mér, vinsamlegast hringdu þá í símanúmerin hér fyrir neðan. Ef einhverjar spurningar vakna, hikaðu þá ekki við að hringja í mig og ég mun svara öllum fyrirspurnum.

Með fyrirfram þökk

Katrín Björgvinsdóttir, hjúkrunarfræðingur Taugalækningadeild, B-2

Gullsmára 5, 201 Kópavogur, heimasími: 554-3675, gsm: 691-3675.

## Appendix 6

### A letter of informed consent

The name of the study: The lived experience of being a young caregiver of a chronically ill parent, diagnosed with Multiple Sclerosis.

The purpose of the study is to explore and construct understanding of the phenomenon of children and adolescents caring for a chronically ill parent, by asking young adults to reflect on their caregiving experiences. Constructing such knowledge could serve to make their somewhat obscure existence more perceptible which can enable health care providers to recognise the needs and wishes of others with similar experiences.

I have decided to participate in this study. The dialogues will take place at the time and the place I decide and will last approximately one hour. If asked to, I will participate in another dialogue. I am aware that the dialogue will be audiotaped and then transcribed by Katrín herself. I am also aware that I can always refuse to discuss delicate, personal matters during the dialogues and withdraw from the study at any moment during the study.

I am aware of the confidentiality that has been promised and that no one but Katrín will have access to the tapes and the transcripts that will not have my name on them. The transcripts and case constructions will be shown to me for verification. I will also give Katrín my permission to contact me later during the study, to discuss with me the findings of the study. It is my understanding that quotes from the transcripts that may be used in the research report but will not be traceable to me.

I feel that I have enough information about the study, but should questions arise I can always contact Katrín at telephones: 554-3675 or 691-3675.

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Date and place

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Name of participant

## Upplýst samþykki

Heiti rannsóknar: Upplifun ungra einstaklinga af þeirri reynslu að annast langveika foreldra sína sem greinst hafa með Mænusigg (Multiple Sclerosis).

Tilgangur rannsóknarinnar er einkum sá að byggja upp og afla vísindalegrar þekkingar á fyrirbærinu: að annast langveikt foreldri sem greint hefur verið með MS, með því að biðja unga einstaklinga að hugleiða ýtarlega og segja frá reynslu sinni af því að annast, í lengri eða skemmri tíma, langveikt foreldri, greint með Mænusigg (MS). Slík þekking gerur nýst mörgum og einkum þeim sem hafa þessa reynslu en þar sem fáum er kunnugt um lífsskilirði og ábyrgð þeirra, gæti slík þekking nýst heilbrigðisstarfsmönnum, við að átta sig á óskum og þörfum þessa hóps fyrir frekari hjálp og stuðning.

Ég hef ákveðið að taka þátt í þessari rannsókn. Samtölin munu fara fram á þeim stað og á þeirri stundu sem ég ákveð og munu þau taka um það bil eina klukkustund. Ef umbeðin, þá mun ég taka þátt í öðru viðtali. Ég geri mér grein fyrir því að samtölin verða tekin upp á segulband og síðan vélrituð af Katrínu sjálfri og enginn annar fái aðgang að þeim. Ég geri mér einnig grein fyrir því að ég get ávalt neitað að ræða viðkvæm málefni og auk þess get ég hætt þátttöku í rannsókninni hvenær sem ég vil. Ég geri mér grein fyrir því að fyllsta trúnaðar hefur verið lofað og nafn mitt komi hvorki fram á hinum vélrituðu samtölum né heldur í handriti rannsóknar. Mér hefur verið boðið að lesa yfir samtölin til staðfestingar. Ég veiti Katrínu auk þess leyfi til að hafa samband við mig seinna í rannsóknarferlinu ef hún þarf að ræða niðurstöðurnar rannsóknarinnar við mig. Ef Katrín óskar má hún nota tilvitnanir mínar í handrit rannsóknarinnar, enda kemur nafn mitt hvergi fram, getur enginn rakið þessar tilvitnanir til mín.

Mér finnst ég hafi fengið góðar upplýsingar um rannsóknina en ef einhverjar spurningar vakna má ég hafa samband við Katrínu í síma 554-3675(heima) og í símar 691-36759.

Nafn þátttakanda:

Staður/dagsetning:

## **Appendix 7**

### **The twelve steps of the Vancouver School of doing phenomenology**

1. Selecting dialogue partners (the sample).
2. First there is silence (before entering a dialogue).
3. Participating in a dialogue (data collection).
4. Sharpened awareness of words (data analysis).
5. Beginning consideration of essences (coding).
6. Construction the essential structure of the phenomenon for each case  
(individual case constructions).
7. Verifying the single case construction with the co-researcher.
8. Construction the essential structure of the phenomenon from all the cases  
(metasynthesis of all the different case constructions).
9. Comparing the essential structure with the data.
10. Identifying the over-riding theme, which describes the phenomenon  
(interpreting the meaning of the phenomenon).
11. Verifying the essential structure (the findings) with some research  
participants.
12. Writing up the findings.