Life Situation as Next of Kin to Persons in Need of Care
To my beloved children: Daniel, Adam, Anna, and my little grandchild Lucas.

För att man skall kunna flyga
måste skalet klyvas
och den ömtåliga kroppen blottas.
För att man skall kunna flyga
måste man gå högst upp på strået
fastän det böjer sig
och svindeln kommer.
För att man skall kunna flyga
måste modet vara aningen större
än rädslan och en gynnsam vind råda.

Ur diktsamlingen Skärmar; Instruktion för flygrädda, Margareta Ekström
Elisabeth Liedström

Life Situation as Next of Kin to Persons in Need of Care: Chronic Sorrow, Burden and Quality of Life
Abstract

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Nursing research has been performed during the last 20-30 years, about the next of kin’s vulnerability. Despite this, the health care system has had difficulties to integrate the next of kin in a way that gives support. The overall aim of the thesis was to describe and further explore the life situation of the next of kin to persons who are long-term ill, disabled, and/or older, and in need of care. Method: Multiple methods were used. Study I had a descriptive design, 44 next of kin of patients with multiple sclerosis were interviewed, latent content analysis was used for the analysis. Study II had a mixed method approach; the descriptive core study was analyzed with directed content analysis. The supplementary study with descriptive, correlative design was analyzed with descriptive and correlative statistics. Forty-four next of kin of patients with multiple sclerosis were interviewed; thereafter 37 of them answered a questionnaire about Quality of Life. Study III had a descriptive, explorative design. Twelve next of kin of older persons were interviewed with repeated informal conversational interviews, analyzed with latent content analysis. Study IV was cross-sectional with a descriptive, correlative design. Eighty-four next of kin of persons who were long-term ill, disabled, and/or older answered two questionnaires about Burden and Quality of Life that were analyzed with descriptive and correlative statistics. Results and Conclusions: Next of kin described a balance/imbalance in their relations to others and a high burden, but in general a good Quality of Life. Some next of kin also experienced chronic sorrow. Significant correlations were found between interpersonal relations and Quality of Life as a whole. Love and obligations were two anchor points on a continuum, describing the next of kin’s relationship to the ill/disabled person. The relationship with the health care personnel was described through cooperation and obligations. Good communication was seen as the key to balance the relationship with others. One possibility to achieve symmetrical communications is to adapt the Partnership Model, as a tool for creating good relationships. Honest and specific communication between the health care personnel, the next of kin, and the care receiver are necessary.

Keywords: life situation, next of kin, informal caregiving, chronic sorrow, burden, quality of life, Partnership model

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Original studies

This thesis is based on the following studies that will be referred to as Studies I, II, III, and IV.


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Abbreviations

CB Scale  Caregiver Burden Scale
COAT  Carers Outcome Agreement Tool
HRQoL  Health Related Quality of Life
MS  Multiple Sclerosis
NANDA  North American Nursing Diagnosis Association
NCRCS  Nursing Consortium for Research on Chronic Sorrow
QoL  Quality of Life
SQoL  Subjective Quality of Life
1. INTRODUCTION

In Sweden, as in the other Nordic countries, the society has the responsibility for people in need of care.\[1\] The communities are obliged by Swedish law to support next of kin if they are caring for a person who is long-term ill, disabled and/or older. The goal with supporting the next of kin is to show the society’s appreciation to the next of kin’s for their informal caregiving to another person. It is also of importance to contribute to and strengthen the next of kin’s quality of life (QoL) and to prevent burnout by reducing stress and strain in the next of kin. As the public system has increasing difficulties to meet the needs of the population, the informal care given by the next of kin today is very comprehensive.\[2\]

My interest in this field is based on working for many years as a nurse and midwife, which might have affected my interest and pre-understanding regarding the life situation of the next of kin. As a midwife at the maternity ward, I saw it as very important to involve the future father but also other next of kin’s in the care. The interest in the next of kin’s life situation has also emerged from personal and private experience from the community health care; it is needed in nursing research to follow the next of kin’s life situation in a rapidly changing society. This work started by reading a study about spouses who experienced chronic sorrow when their partner had multiple sclerosis (MS),\[3\] and an interest arose to study whether chronic sorrow also occurred in a larger population, which resulted in Study I. In Study II the research continued by studying how the QoL among the same next of kin’s was affected. Based on these results, questions arose whether next of kin’s experiences were diagnose specific, or as MS occurs at a relatively young age, if the age of the care receiver affected how the next of kin perceived their life situation. In Study III I therefore interviewed the next of kin’s to older persons in need of care to explore how they perceived their life situation. In Study IV, the concepts burden and QoL were studied, in the next of kin of persons who are long-term ill, disabled and/or older regardless of the care receiver’s age or diagnosis. The study was broad and nationwide.

Within nursing research several studies have been performed during the last 20-30 years, about next of kin’s life situation, showing their vulnerability and burden, and the focus has been at the specific disease of the person receiving care. However, an encounter between formal care, the next of kin, and the care receiver, is a meeting between humans, not a meeting on the basis of diagnosis. The health care system has also changed during this time span, and the society has had difficulties to integrate the
next of kin. Therefore, the purpose with this thesis was to increase the understanding of the next of kin’s life situation in the context of caring for a person who is long-term ill, disabled and/or older.
2. BACKGROUND

In the ethics code for nurses, it is determined that nurses have responsibilities to promote health and prevent illness, and they shall also promote an environment in which the individual and the next of kin are respected.[4] The health care personnel need knowledge about the next of kin’s life situation when being an informal caregiver. The literature shows that the next of kin can have experiences of chronic sorrow and/or burden, and their QoL can be affected. The health care personnel also need to be aware of the importance of communication and how to support the next of kin.

2.1. Life situation

In this thesis, life situation is seen as the person’s life as a whole that is influenced by several dimensions, with focus on experienced chronic sorrow, burden, and QoL. It is the everyday life in the surrounding environment with everyday activities in interaction with emotions, thoughts and their meanings as well as other individual experiences with a deeper content. A person’s life situation consists of emotional, intellectual, existential, biological, physical, and socio-cultural dimensions. The life situation can also be seen as a person’s quality of lodging, approach to their work, economic situation, relations and interactions with other persons, and the person’s activity, and view of one’s own person.[5] The next of kin’s life situation can be influenced by burden, chronic sorrow, and their QoL can be affected.[6-10] The life situation also means health, housing situation, diversity of leisure activities, social participation, ownership of consumer durables, mobility, and participation in sport and holidays.[11] The life situation can be seen as a context in which everyday life takes place.[12]

2.2. Informal caregiving

In this thesis the next of kin is seen as the person whom the long-term ill, disabled and/or older person appoints as his/her next of kin or self-identified next of kin to someone in need of care. The next of kin can also be seen as an informal caregiver. Denoting a next of kin or informal caregiver is that he/she does not belong to the formal health services in the county or municipal care,[2] and does not possess any training about care, and does not in general receive any economic reimbursement for this care.[13] The formal caregiving, on the other hand, is given by the public and local municipality and the county or private companies on construction.[14]

In Sweden 18% of the population (≥18 years of age), almost every fifth person, is providing informal care. The next of kin aged 30-44 primarily
provide care for a child, those aged 45-64 mostly provide care for a parent, and those aged ≥65 provide care for a spouse or partner in a very high degree. The most common care receivers are parents, and generally in all age groups, it is common for a woman to help her parents. From an age perspective, the need to help a husband, wife, or partner increases with age. Few of next of kin are aware that the municipalities must offer to provide support for them. Generally very little is done by the municipality and the county council to prevent illness and improve the informal carer’s health. The development of appropriate support has worked slowly. Most informal care delivered to long-term ill, disabled and/or older person is provided by the next of kin. The next of kin is often a blood relative such as a son/daughter, father/mother, brother/sister or a non-blood relative such as a spouse/cohabiting partner; but the next of kin can also be a friend, a neighbor, or a living apart partner. The next of kin may belong to the family, depending on how family is defined.

Changes in life expectancy, combined with changes in the patterns of diseases affecting populations, will lead to a large increase in the number of persons with long-term illnesses and/or disabilities in most parts of the world. And changes in fertility will change the number of adults who are economically active or available to fulfill informal caregiving. Socio-economically, the next of kin’s informal caregiving is of great importance for the formal care and represents huge financial savings to society. The next of kin often take on the task of support for the person in need of care, with just little or no information or knowledge about what it means, and they do not see themselves as informal caregivers. Formal care providers have in the recent years become aware that the next of kin’s are an important resource for both the care receiver and the formal carer.

Informal caregiving means that the next of kin’s do things for the persons in need of care that they cannot do for themselves, such as personal care tasks involving lifting, toileting, and washing. Their caregiving also means that the chores are performed with accuracy and consideration, and involves a feeling of being responsible for the care receiver. Further, informal caregiving also means performing practical chores for the care receiver, as for example, purchasing food, transporting, taking care of the house, and assisting in contacts with authorities and formal caregivers. It can also consist of helping to manage finances, mail, bills, and so on. The next of kin do not simply do things for the care receivers; they can also support them with encouragement, personal attention, and conversation that may support their sense of identity and worth. The risk of illness among the next of kin increases in relation to the extent of the care they provide. It has been shown, in a study of self-reported health status, that
being informal caregiver can have both positive and negative effects on the next of kin. The next of kin may experience anxiety and stress, joy and satisfaction, fatigue and depression, or they can maintain a good quality of life. Studies also show that they can experience chronic sorrow.

### 2.3. Chronic sorrow

In this thesis the definition of chronic sorrow is based on the Nursing Consortium for Research on Chronic Sorrow’s (NCRCS) theory about chronic sorrow, the middle range theory of chronic sorrow. The concept chronic sorrow is defined as the experience of significant loss of personal meaning, ongoing loss or several loss experiences, pervasive sadness or grief, permanent sadness or grief, periodic sadness or grief, potentially progressive sadness or grief, and periods that can be triggered by occurring events. The periodic nature of chronic sorrow means periods of satisfaction and happiness that are interspersed with episodes of re-grief or sadness. The person who is grieved for is not dead or gone, thus there is no finality. The loss cannot be removed and requires continuing re-adaptations. The intensity of such a sorrow can vary from time to time for the same person, from situation to situation, and from one person to another.

In connection with the experience of losses, the next of kin describes feelings as loneliness, sadness, emptiness, despair, helplessness, fear, shock, frustration, confusion, bitterness, disappointment, disbelief, nervousness, anger, and also guilt and self-blame. The person who was the first to describe chronic sorrow was Olshansky. He described chronic sorrow by parents who had mentally retarded children. Sorrow persists when impairments are permanent and the child continues to live. He explained that this reaction is an understandable and natural reaction to a tragic fact. The term gained use in professional literature, but the underlying phenomenon of chronic sorrow was not documented by research for two decades. Eakes, Hainsworth, Lindgren and Burke were a group of nurse researchers who established the NCRCS in 1989. They explored the relevance of the concept of chronic sorrow among individuals who experienced a variety of loss situations. The NCRCS also developed a theory about chronic sorrow, the middle range theory of chronic sorrow. This theory provides a framework for understanding the reactions of individuals to loss events. The theory has been recognized as a nursing diagnosis by the North American Nursing Diagnosis Association (NANDA) and is included in nursing diagnosis textbooks.

The concept chronic sorrow is not the same as depression, which is a pathological state with psychological and psychosomatic components.
Depression is a mood disturbance that can lead to decreased initiative, reduced concentration, a negative self-image, feelings of guilt and self-blame, changed sleep pattern, and/or reduced appetite with weight loss, or the converse.\textsuperscript{[36, 37]} Persons with chronic sorrow somehow continue to function in all important situations of their lives, and it is viewed as a normal response to loss.\textsuperscript{[31]} Chronic sorrow is a form of grief but it differs from acute grief, which is time-limited. In acute grief individuals pass through stages of avoidance, confrontation, and re-establishment in response to an external loss. Chronic sorrow is unresolved grief; it differs from pathological grief, which is a long-term reaction to a single event. By comparison, the person experiencing chronic sorrow is due to an ongoing loss or multiple losses over time.\textsuperscript{[29, 37, 38]}

Earlier research regarding chronic sorrow in the next of kin has been focusing on chronic sorrow in parents of long-term ill children,\textsuperscript{[38, 39]} mentally disabled children,\textsuperscript{[8, 40]} children with diabetes,\textsuperscript{[41]} children with epilepsy,\textsuperscript{[22]} children with neural tube defects,\textsuperscript{[23]} and children with lissencephaly.\textsuperscript{[24]} Chronic sorrow has also been studied in parents of adolescent and adult children with progressive neurodegenerative disease,\textsuperscript{[25]} mental illness,\textsuperscript{[26]} and cerebral palsy.\textsuperscript{[9]} Also patients and their next of kin have been studied in the case of Parkinson’s disease,\textsuperscript{[27]} and Alzheimer’s,\textsuperscript{[28]} and furthermore in the next of kin of individuals with MS,\textsuperscript{[3]} and in other severe chronic illnesses.\textsuperscript{[42]} From the research it is apparent that the presence of an unpredictable chronic illness or disability can affect the experience of burden and the QoL, not only of the care receiver but also of this person’s next of kin.\textsuperscript{[43]}

2.4. Burden

In this thesis, the caregiver burden is seen as the emotional reactions to the caregiving experience, as stress and strain, low emotional mood, depression, worries, anxiety, frustration, and anger.\textsuperscript{[6, 13]}

Many of the next of kin’s have experienced burden in connection with informal caregiving to the care receiver.\textsuperscript{[6, 13]} The concept of burden was first mentioned by Grad and Sainsbury,\textsuperscript{[44]} as they described burden experienced by the next of kin to persons with mental illness. The burden concept has been adopted by other authors in the research of informal care, and they assumed burden to be an overall term in order to describe the physical, emotional, and financial consequences of providing care.\textsuperscript{[45]} The majority of theoretical models which have been developed to explain the burden and the stress of next of kin’s have been based on the Transactional Stress Theory.\textsuperscript{[46]} Later on, burden as a research construct was developed by Zarit et al.,\textsuperscript{[47]} as they defined caregiver burden as the next of kin’s
perceived physical or emotional health, financial status, and social life to be negatively affected when caring for the care receiver. Caregiver burden can also be defined as a reaction resulting from an imbalance of care demands relative to the next of kin’s personal time, social roles, physical and emotional states, financial resources, and formal care resources. Montgomery et al. define burden in a more specific and detailed way. They estimate a distinction between subjective and objective burden. Subjective burden is defined as the next of kin’s attitudes and emotional reactions to the caregiving experience as, for example, a low emotional mood, worries, anxiety, frustration, and depression. Objective burden is defined as the different areas of the next of kin’s life, employment, social life, and leisure. The objective burden is observable and concrete.

The caregiver burden has previously been studied, such as the breaking point when home care no longer offers sufficient support and safety to persons with dementia. And in the next of kin of MS patients, Aronsson found that perceived burden was correlated with higher risks of depression and lower quality of life in the next of kin of patients with MS. Experiences by the next of kin of older persons with dementia showed a high emotional burden, as well as persons with mental illnesses. A relationship has been seen between the next of kin’s experiences of burden, depression, and QoL.

2.5. Quality of life

In this thesis the definition of the QoL is based on Naess’ theory and Kajandi’s application. The meaning of the QoL depends on the context in which it is used, and the theoretical perspective, which means different things to different people. A distinction between QoL and health-related quality of life (HRQoL) is made, where the latter is a concept that includes aspects which are influenced by disease. The QoL research is a part of social science and contributes to the knowledge of how humans live in societies. As other parts of social research, it collects data that may broaden the understanding of the thoughts, feelings, and actions of human beings. Many definitions have often paired components of happiness and satisfaction with life to the concept QoL.

Naess estimates that life research is located somewhere between philosophy and social science. Naess elucidates “quality of life” as equivalent to “happiness, satisfaction, or well-being,” a psychological and emotional term and associated with the experience of individuals living a good or poor life. The QoL denotes a type of welfare; it is seen as a psychological indicator in contrast to, for example, “level of living,” which is seen as a socioeconomic indicator of welfare. Naess defines that a person enjoys a
high QoL when the person is active, has good interpersonal relations, has self-esteem and has a basic mood of happiness. To be active means that the person has a zest for life, involves her/himself in things outside of her/himself that are experienced as meaningful: has energy, engagement, does not feel tired, has freedom of choice and feels her/himself in control of own actions, and has achieved self-realization, i.e., develops and uses one’s own talents and capabilities. Good interpersonal relations means to have a close, warm relationship to at least one other person; friendship, loyalty; feels identity with; and belongs to a group. Having self-esteem means that the person feels well, is sure of his/her own abilities and skillfulness, feels able to cope, is useful, feels self-acceptance, absence of feelings of guilt or shame, and lives up to one’s own expectations. Having a basic mood of happiness can be seen when a person has rich and esthetical experiences, a feeling of identity with nature, is open and receptive, feels security, harmony, and an absence of anxiety, emptiness, depression, discomfort, and pain. Several previous studies within nursing research are performed with Naess’s theoretical model as a basis, which concerned healthy groups, nursing students, people looking for work, and studies concerning psychiatric outpatients, chronic psychiatric patients, patients with lesions after bacterial meningitis, patients with MS and their next of kin, patients with muscular dystrophies and their next of kin, patients with low-grade glioma and their next of kin, and patients with head injury.

2.6. The Partnership Model

In health-related contexts, as in nursing research, system theories are often used to understand the health care personnel, the next of kin, and the care receiver. In the communication situation they are participants in a system where each individual’s actions affect the whole—where one does affects the other. System thinking is to understand the dynamics of the system, as a group of units in mutual interaction. A relational communication theory based on the assumption that interpersonal communication has the purpose to establish, maintain, and transform relationships, while the relationship for its part determines how communication occurs. One significant contribution to understand interpersonal processes is explained by Watzlawick et al. Their description of communication theory is that it is impossible not to communicate; it means that there is no such thing as no communication. All non-verbal communication carries a message. A relationship has varying degrees of symmetry. An asymmetric communication means that the communication is unilateral. It means that one part speaks actively when the other part is listening passively. Often the asymmetric communication is about that one
part, which has both power and is strong, and the other part is weak and insecure. In a symmetrical relationship, the conditions are equal between the persons.\footnote{70}

One possibility to achieve symmetrical communications is to adapt the Partnership Model, developed by Nolan et al.,\cite{71-73} which is of relevance for clinical practice. The model is a way of closer cooperation between the care receiver, his/her next of kin, and the health care personnel. The model consists of a framework that involves “six senses” that are seen as prerequisites for good communication and good relationships. The “senses” have been developed with the participation of older persons, informal caregivers, health care personnel, and student nurses.\cite{71-73} With this model good care can only be delivered where there is a triadic relationship. All persons have a key role to play and have unique knowledge to contribute. All three persons involved in the care (the health care personnel, the next of kin, and the care receiver) should experience a sense of security, a sense of continuity, a sense of belonging, a sense of purpose, a sense of achievement, and a sense of significance.\cite{71-73} To feel a sense of security as a next of kin means to feel safe and to be confident in the ability and knowledge to provide good care to the care receiver. It also includes having adequate support networks and help when needed and could even refrain from the informal care when necessary. Feeling a sense of continuity means perceiving links and connections, to maintaining shared interests with the care receiver. It also stands for having the ability to maintain good and individual care, whether delivered by others or by self. A sense of belonging means feeling a part of things, to have a feeling of that you are not in this alone, and that you are able to maintain and/or improve relationships. Having one or more goals to aspire to, maintain the integrity and dignity, well-being, and the care receiver’s personality are all parts of feeling a sense of purpose. A sense of achievement stands for making progress towards these goals, knowing that you have done your very best, and feeling that you have provided good care. You meet challenges well and develop new skills and abilities. A sense of significance means feeling that you matter as a person, that the caring efforts are appreciated and valued, and experienced as an enhanced sense of self.\cite{71-73}
3. Rationale for this thesis

From the previous nursing research, the conclusion has been drawn that there is a risk of emotional, psychological, financial, social, and physical distress in the next of kin due to the changes in their life situation and the most often unpredictable future, when becoming an informal caregiver.\[8\] There are also growing needs for long-term care in the society. These reflect two interrelated processes: one is the growth in factors that increase the prevalence of long-term disability in the population; and the second is the change in the capacity of the informal care. The aging of the population has an impact on both of these processes. As the population ages, the percentage with chronic diseases and related disabilities begins to increase significantly. Moreover, population aging is associated with a decline in family size and a rise in the number of older persons in relation to the younger population. This increases the pressure on children to take on the role as informal caregivers as they are a major source of support to the older persons.\[15\]

There is nursing research, performed during the last 20-30 years, about the next of kin’s vulnerability,\[13, 14, 18, 19\] despite this knowledge; the health care system has had difficulties to integrate the next of kin in a way that gives support to the next of kin. Therefore, further studies are needed to increase the knowledge regarding how the next of kin’s experience their life situation today. Without support from other persons, the next of kin can be at risk for stress, burden and a decreased QoL. This can be particularly severe if the next of kin are not healthy themselves.

The nurses shall in their profession promote health and prevent illness, but also promote an environment in which the individual and the next of kin can be respected.\[4\] They should also meet the next of kin in all kinds of health care and make it possible to plan interventions that support the next of kin. It is important for the health care personnel to find out how the next of kin experiences their life situation. An increased partnership in the care between the care receiver, the next of kin, and the health care personnel gives the possibility for the care receiver to live at home, even if the illness/disability becomes worse.
4. AIM

The overall aim of the thesis was to describe and further explore the life situation of the next of kin’s to persons who are long-term ill, disabled and/or older, and in need of care with the following specific aims for the included studies:

**Study I:** to explore the presence and meaning of chronic sorrow in the next of kin of patients with MS.

**Study II:** to describe the QoL of the next of kin of patients diagnosed as having MS.

**Study III:** to increase the understanding of the next of kin’s experience of their life situation in connection with their informal caregiving of older persons.

**Study IV:** to describe the next of kin’s experienced burden and QoL, and the relationship between the QoL, burden, and socioeconomic variables.
5. MATERIAL AND METHODS

5.1. Design
This thesis includes four studies that have the next of kin’s life situation in focus with descriptive, correlative, explorative and cross-sectional designs. Qualitative, quantitative and mixed method approaches are used to explore next of kin’s life situation. Participants, data collection and data analysis are presented in a comprehensible form for each study, in Table 1.

Table 1. Overview of the design, approaches, participants and methods

<table>
<thead>
<tr>
<th>Study</th>
<th>Design/Approach</th>
<th>Participants</th>
<th>Data collection</th>
<th>Data analysis</th>
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<tbody>
<tr>
<td>I</td>
<td>Descriptive</td>
<td>44 next of kin of patients with MS (of which 35 next of kin had chronic sorrow)</td>
<td>Interview</td>
<td>Latent content analysis.</td>
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<td></td>
<td>Qualitative</td>
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<tr>
<td>II</td>
<td>Descriptive</td>
<td>44 next of kin of patients with MS</td>
<td>Interview</td>
<td>Directed content analysis.</td>
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<td></td>
<td>Qualitative</td>
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<td>Mixed method</td>
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</tr>
<tr>
<td></td>
<td>Descriptive</td>
<td>37 next of kin of patients with MS</td>
<td>Self-assessment questionnaire</td>
<td>Descriptive, correlative statistics.</td>
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<td>Correlative</td>
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<td></td>
<td>Mixed method</td>
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</tr>
<tr>
<td>III</td>
<td>Descriptive</td>
<td>12 next of kin of older persons in need of care (21 interviews)</td>
<td>Informal conversational repeated interviews</td>
<td>Latent content analysis.</td>
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<td></td>
<td>Explorative</td>
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<td>Qualitative</td>
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</tr>
<tr>
<td>IV</td>
<td>Descriptive</td>
<td>84 next of kin of persons who were long-term ill, disabled and/or older</td>
<td>Self-assessed questionnaires</td>
<td>Descriptive and correlative statistics</td>
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<tr>
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<td>Quantitative</td>
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</table>

Multiple methods were applied in this thesis, which means that the design consists of two or more studies with different methods, but with the same focus. In multiple methods, each research study is self-contained, complete, and publishable as a stand-alone article. This is in contrast to a mixed method, which was used in Study II. A mixed method design consists of a core study, i.e., the qualitative part in Study II. The quantitative
part in the same study is supplementary and not comprehensible or publishable apart from the core study.\[74\]

5.2. Participants

5.2.1. Studies I and II

Studies I and Study II included the next of kin of patients with MS recruited from earlier research regarding MS patients.\[75\] The patients (n=61) in the earlier study were asked if they were willing to let the researcher contact their next of kin regarding participation in the present studies. Those who said yes provided the name and address of one next of kin. The inclusion criteria were the individual whom the patient had named as his/her next of kin. There were no restrictions on who could be the next of kin; consanguinity was not a requirement. A letter with information about the studies was thereafter sent to the 46 identified next of kin. After 5-7 days, the next of kin received further information over the telephone before they decided if they were willing to participate. Two declined participation and thus 44 persons were included in the studies; see Table 2 for demographic information.

Table 2. Demographic data among next of kin in Studies I and II (n=44)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total, n=44</th>
<th>Male n=20 (45.5%)</th>
<th>Female n=24 (54.5%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (MD) (Range)</td>
<td>46.3 (47.5) (19-70)</td>
<td>46.9 (43.5) (26-69)</td>
<td>47.8 (49.5) (19-70)</td>
</tr>
<tr>
<td>Civil status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>7</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Married, cohabiting</td>
<td>37</td>
<td>19</td>
<td>18</td>
</tr>
<tr>
<td>Relation to the patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouses/cohabiting</td>
<td>29</td>
<td>19</td>
<td>10</td>
</tr>
<tr>
<td>Parent, not cohabiting</td>
<td>10</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Sibling, not cohabiting</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Adult child, not cohabiting</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
5.2.2. Study III

Study III concerned the next of kin of persons who were older and needed care. The next of kin were recruited from earlier research, within the research group, whose overall aim was to explore what a meaningful everyday life is for older persons, ≥65 of age. The older persons’ receiving care were from home care (n=15) or from nursing home care (n=25). They were asked by the managers at their units whether they were willing to submit the name of their next of kin, for possible participation in the study. The inclusion criterion was the individual whom the older person had named as his/her next of kin. There were no restrictions on who could be the next of kin; consanguinity was not a requirement. Twelve older persons agreed to give the name of their next of kin: seven were from the home care and five from the nursing homes. The next of kin received written information from the manager of the nursing home or home care and then signed the informed consent form with the staff, which then sent it to the researcher. The next of kin were after a few days contacted by telephone by the researcher who gave more information about the study and asked regarding study participation. All twelve next of kin agreed to participate. See Table 3 for demographic data concerning the next of kin.

| Table 3. Demographic data among next of kin in Study III (n=12) |
|-----------------|-------|---|---|
|                | Total, n=12 | Male n=5 | Female n=7 |
| **Age, mean (MD)** | 59.3 (57.5) | 58.2 (56) | 60.1 (59) |
| **Range**       | 43-80     | 51-67   | 43-80   |
| **Civil status** |          |        |        |
| Living alone    | 3        | 1      | 2      |
| Married, cohabiting | 9      | 4      | 5      |
| **Relation to the older person** | | | |
| Spouses, cohabiting | 2 | 1 | 1 |
| Spouses, not cohabiting | 1 | 0 | 1 |
| Sibling, not cohabiting | 1 | 1 | 0 |
| Adult child, not cohabiting | 8 | 3 | 5 |
| **Working situation** | | | |
| Working, full-time | 8 | 3 | 5 |
| Working, part-time | 1 | 1 | 0 |
| Retired | 3 | 1 | 2 |
5.2.3. Study IV

Study IV is a part of a larger cross-sectional research project with the aim to increase the understanding of the next of kin’s life situation in the context of caregiving for persons who are long-term ill, disabled and/or older.

Four questionnaires were used in the larger project and, in this study, two of the four questionnaires were included. The recruitment of the next of kin was broad and nationwide. Three general and nationwide associations for next of kin and 29 associations directed to a specific diagnosis were contacted by mail or telephone to inquire if they were willing to give brief information to their members about the study, thus helping with the recruitment of respondents.

Nineteen of the associations were willing to publish study information on their website, in monthly journals, newsletters, Facebook page or Blog, and gave information in person at their meetings. The inclusion criterion was to be a self-identified next of kin to a long-term ill, disabled, and/or older person in need of care. There were no restrictions about the care receiver’s age, gender, diagnosis, intensity and duration of the next of kin’s caregiving, and consanguinity was not a requirement.

The 111 next of kin’s who were interested to participate in the study received more detailed written study information, an informed consent form, the questionnaires, and a pre-paid envelope for their return, all sent by post. Eighty-four next of kin completed the questionnaires, which gave a response rate of 76%. Data collection took place from June 2012 to December 2012. Demographic data for the next of kin, see Table 4, and for the care receiver, see Table 5.
Table 4. Demographic data for the next of kin

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total (n=84)</th>
<th>Male (n=17)</th>
<th>Female (n=67)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (MD)</td>
<td>57.1 (57.0)</td>
<td>59.2 (66.0)</td>
<td>56.5 (55.5)</td>
<td>0.47</td>
</tr>
<tr>
<td>Range</td>
<td>23-82</td>
<td>31-76</td>
<td>23-82</td>
<td></td>
</tr>
<tr>
<td>Civil status, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>0.33</td>
</tr>
<tr>
<td>Cohabiting</td>
<td>69 (82.1)</td>
<td>16 (94.1)</td>
<td>53 (79.1)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>11 (13.1)</td>
<td>1 (5.9)</td>
<td>10 (14.9)</td>
<td></td>
</tr>
<tr>
<td>Living apart</td>
<td>4 (4.8)</td>
<td>0</td>
<td>4 (6.0)</td>
<td></td>
</tr>
<tr>
<td>Relation to care receiver, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>0.00</td>
</tr>
<tr>
<td>Spouse</td>
<td>38 (45.2)</td>
<td>11 (64.7)</td>
<td>27 (40.3)</td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>23 (27.4)</td>
<td>1 (5.9)</td>
<td>22 (32.8)</td>
<td></td>
</tr>
<tr>
<td>Adult child</td>
<td>18 (21.4)</td>
<td>4 (23.5)</td>
<td>14 (20.9)</td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>1 (1.2)</td>
<td>0</td>
<td>1 (1.5)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>4 (4.8)</td>
<td>1 (5.9)</td>
<td>3 (4.5)</td>
<td></td>
</tr>
<tr>
<td>Cohabiting with care receiver, n (%)</td>
<td>49 (58.3)</td>
<td>8 (47.1)</td>
<td>41 (61.2)</td>
<td>0.29</td>
</tr>
<tr>
<td>Employment* (%)</td>
<td></td>
<td></td>
<td></td>
<td>0.15</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4 (4.8)</td>
<td>1 (5.9)</td>
<td>3 (4.6)</td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td>2 (2.4)</td>
<td>0</td>
<td>2 (3.0)</td>
<td></td>
</tr>
<tr>
<td>Worker</td>
<td>47 (56.6)</td>
<td>6 (35.3)</td>
<td>41 (62.1)</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>30 (36.2)</td>
<td>10 (58.8)</td>
<td>20 (30.3)</td>
<td></td>
</tr>
<tr>
<td>Have own illness* (%)</td>
<td>33 (39.8)</td>
<td>6 (35.3)</td>
<td>27 (40.9)</td>
<td>0.54</td>
</tr>
<tr>
<td>Somatic</td>
<td>27 (81.8)</td>
<td>6 (35.3)</td>
<td>21 (31.8)</td>
<td></td>
</tr>
<tr>
<td>Mental</td>
<td>6 (18.2)</td>
<td>0</td>
<td>6 (9.1)</td>
<td></td>
</tr>
<tr>
<td>Support to the next of kin* (%)</td>
<td>19 (22.9)</td>
<td>2 (11.8)</td>
<td>17 (25.8)</td>
<td>0.84</td>
</tr>
<tr>
<td>Call contacts</td>
<td>12 (63.2)</td>
<td>2 (11.8)</td>
<td>10 (15.2)</td>
<td></td>
</tr>
<tr>
<td>Respite care/assistant</td>
<td>5 (26.2)</td>
<td>0</td>
<td>5 (7.6)</td>
<td></td>
</tr>
<tr>
<td>Economic grant</td>
<td>1 (5.3)</td>
<td>0</td>
<td>1 (1.5)</td>
<td></td>
</tr>
<tr>
<td>Massage</td>
<td>1 (5.3)</td>
<td>0</td>
<td>1 (1.5)</td>
<td></td>
</tr>
</tbody>
</table>

*n=83
Table 5. Demographic data for the care receiver

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total n=92</th>
<th>Male n=54 (58.7%)</th>
<th>Female n=38 (41.3%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (MD) Range</td>
<td>56.7 (68.0)</td>
<td>66.0 (65.0)</td>
<td>54.6 (69.5)</td>
<td>0.21</td>
</tr>
</tbody>
</table>

Illness indicated by next of kin*

<table>
<thead>
<tr>
<th></th>
<th>n=88 (100.0)</th>
<th>52 (59.0)</th>
<th>36 (41.0)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somatic</td>
<td>62 (70.5)</td>
<td>34 (65.4)</td>
<td>28 (78)</td>
</tr>
<tr>
<td>Mental</td>
<td>26 (29.5)</td>
<td>18 (34.6)</td>
<td>8 (22.0)</td>
</tr>
</tbody>
</table>

*p=88, 4 next of kin did not report specific illness

5.3. Data collection

5.3.1. Studies I and II

The data collection was by way of an interview guide and a questionnaire. In Study I and in the core study of Study II, the next-of-kin version of the Chronic Sorrow Questionnaires/interview guide, developed by Burke et al.,[37] was applied. The interview guide consisted of 16 open-ended questions designed to capture the next of kin’s thoughts and feelings, which can be linked to chronic sorrow and quality of life. Apart from the interview guide, one general question was asked, Study II; “What is quality of life for you?” Follow-up questions were asked in order to evoke more in-depth accounts.

One of the co-authors (GA) produced a translation of the interview guide in consultation with Burke. The interview guide was then translated into Swedish (Appendix 1) by an authorized translator. A few of the interviews were conducted in the next of kin’s home; most were conducted at the interviewer’s place of work. Each next of kin (n=44) was interviewed once and the interviews lasted 50-90 minutes. The interviews were performed by a nurse from a research center. All interviews were audio-taped and then transcribed verbatim, with inclusion of all expressions of emotion.

In the supplementary part of Study II, Kajandi’s[5] questionnaire, Subjective estimation of Quality of life (SQoL), was applied. Kajandi developed the questionnaire from Naess’s[58] theoretical model. It is a questionnaire which is intended both for healthy as well as for patient groups. The questionnaire includes variables measuring external life conditions, interper-
sonal relations, and internal psychological states. Kajandi’s questionnaire has been used in several previous studies that concerned healthy groups: nursing students and people looking for work.

The SQoL contains of 18 items, covering three dimensions: External life conditions: housing quality, work/occupation quality, personal economy (3 items); Interpersonal relationships: relationship to partner, relationship to friends, relationship to mother, relationship to father, relationship to own children (5 items); Internal psychological states: engagement, energy, self-actualization, freedom, self-assuredness, self-acceptance, emotional experiences, security, general mood (9 items); and Quality of life as a whole (general estimation).

See Appendix 2. The respondent evaluates the degree of satisfaction in his/her current life situation for each of these 18 items. The questionnaire has a Likert-type scale with nine values (1, 1.5, 2, 2.5...), where 5 is the most positive rating. Four items involve alternative answers, mutually exclusive: Work/occupation quality (Have no work or meaningful occupation), Relationship to partner (Have no partner), Relationship to friends (Have no friends) and Relationship to own children (Have no children). Thus, a given score on one alternative excludes scoring on the other. The instrument was chosen on account of its reliability and validity, and its applicability to the next of kin. Cronbach’s Alpha was 0.84 in Study II.

The questionnaire was filled in after the interview, by the next of kin and sent back by post within seven days. One next of kin declined to answer the questionnaire and six did not answer, despite a reminder. In total 37 next of kin answered the questionnaire.

5.3.2. Study III

Informal, conversational interviews were conducted in Study III to increase the understanding of the next of kin’s experiences of their life situation in connection with informal caregiving of older persons.

The interviews were repeated: nine participants were interviewed twice, one said that one interview was enough due to lack of time, one canceled the second interview without given a reason, and one was not available after the first interview. Consequently, there were 21 interviews in total. The interval between the first and second interviews varied from four weeks to three and a half months.

The informal conversational interview questions emerge from the immediate context and there was no predetermination of question topics, except a general question over their life situation. The interviews started with a
general question: “How do you feel about your life situation?” Follow-up questions were, for instance, “What do you think about that?” and “How do you feel about that?” After the first interview, each participant was sent a transcription of his or her interview by post, to read before the second interview; this was done to give the participant a chance to reflect on what had been said and to make a richer conversation the next time. Before the second interview, the author read the transcripts and made notes. In the second interview, follow-up questions were asked, for example, “What have you been thinking about it all since the last time we met?” and “What did you mean by that?” In this way, the earlier interview was extended.

Each next of kin chose the location for the two interviews. Data collection took place during the period May 2011 to February 2012. The interviews lasted from 60 to 90 minutes. All interviews were recorded on an MP3 player and transcribed verbatim by EL, with inclusion of all expressions of emotion.

5.3.3. Study IV

In Study IV two questionnaires were applied: the SQuoL \cite{5} and Caregiver Burden Scale (CB scale). \cite{78} These were done to increase the understanding of the next of kin’s life situation, to describe their experienced burden and QoL, and also the relationship between the QoL, burden, and socioeconomic variables.

The data collection of the SQuoL is performed in the same way as in Study II, see paragraph 5.3.1. In Study IV the scores are summarized within each dimension and thereafter an average value is calculated for each dimension: External life conditions, scores from 3 to 15; Interpersonal relationships, scores from 5 to 25; Internal psychological states, scores from 9 to 45; and Quality of life as a whole scores from 1 to 5.

Elmståhl et al. \cite{78} developed an instrument to measure caregiver subjective burden, the CB Scale. The questionnaire covers: caregiver’s health, feelings of psychological well-being, relations, social network, physical workload, and environmental aspects that might be important (see Appendix 3). The instrument is used for assessment of the next of kin’s experience of burden, and it has shown good validity and reliability. \cite{78} The questionnaire consists of five dimensions: General strain (8 items), Isolation (3 items), Disappointment (5 items), Emotional involvement (3 items), and the Environment (3 items). The items have scores from 1 (Not At All), 2 (Seldom), 3 (Sometimes,) to 4 (Often). A higher score indicates a greater burden. The CB Scale is tested on families of patient groups. \cite{48, 78, 79}
The internal consistency in the present study was analyzed with Cronbach’s Alpha and was acceptable for the dimensions General strain (0.85), Disappointment (0.74) and Emotional involvement (0.74). However, Cronbach’s Alpha was lower for the dimensions Environment (0.63) and Isolation (0.60). Coefficients in the vicinity of 0.70 may be adequate, especially for subscales, and coefficients of 0.80 or greater are highly desirable.[80]

The scores are summarized within each dimension and thereafter a mean value is calculated for each dimension. The dimension General strain, scores from 8 to 32, Isolation, scores from 3 to 12, Disappointment, scores from 5 to 20, Emotional involvement, scores from 3 to 12, and Environment, scores from 3 to 12.

Demographic data was collected about the next of kin’s age, gender, civil status, relationship to the care receiver, and if they were living together with the care receiver. Additional questions concerned employment, length of time employed, and how many hours a week the next of kin had cared for the care receiver. Further questions were if the next of kin had one’s own illness, what kind of illness, if the next of kin had any support themselves, and what kind of support. The final questions focused on the care receiver’s age, gender, and what kind of diagnosis the care receiver had received (see Table 4).

5.4. Data analysis
5.4.1. Study I
In Study I the first phase was to examine whether the next of kin had chronic sorrow. The interviews were read once and listened to twice to ascertain whether chronic sorrow was present. As soon as the analysis begins, ongoing communication between the researcher and the text is present.[70, 81] The assessment was based on seven criteria from the literature: 1) the experience of significant loss of personal meaning, 2) ongoing loss or several loss experiences, 3) pervasive sadness or grief, 4) permanent sadness or grief, 5) periodic sadness or grief, 6) potentially progressive sadness or grief, and 7) periods that can be triggered by events.[30] Chronic sorrow was verified in this study when four of the seven criteria were fulfilled. Interviews with five of the next of kin were excluded because the criteria for chronic sorrow were unmet. There was doubt concerning nine additional subjects; therefore, an independent assessment was made by one of the co-authors (GA). This resulted in the exclusion of four of the nine interviews. Thus, 35 next of kin were included in the further analysis.
The interviews were subjected to latent content analysis.\[81\] In the next phase of the analysis, the transcribed interviews were repeatedly reviewed to gain a deeper understanding of their content, and meaning units were identified. The meaning units were sorted in content areas according to the seven criteria of chronic sorrow. Thereafter, they were condensed and abstracted by means of inductive analysis. The process of abstraction involved the creation of codes, sub-themes, and themes. The theme represents the underlying meaning on an interpretive level developed from the condensed units, codes and sub-themes. Themes are not necessarily mutually exclusive; the themes are an expression of the latent content of the text.\[81\] During the process of analysis, the main author together with the two co-authors scrutinized and repeatedly discussed the results to ensure trustworthiness.

5.4.2. Study II
In the qualitative part of the study, directed content analysis was applied to analyze the data from the interviews. This method is recommended when existing theory or prior research would benefit from deeper scrutiny; it is a deductive application.\[82\] The theoretical approach was based on Naess’ theory concerning quality of life and Kajandi’s application.\[5, 58\] The process of analysis started with listening to the tapes and reading all the interviews several times to gain a general sense of the whole. The interview text was divided into meaning units consisting of sentences with focus on the QoL. The meaning units were sorted in accordance with the dimensions in the SQoL: External life conditions, Interpersonal relationships, and Internal psychological states.\[5\] Thereafter, the meaning units were coded in accordance with whether their content matched items within these dimensions. Text that could not be categorized with the initial coding scheme was given a new code, and in this study the new code “relationship to siblings” emerged.\[82\] The different stages of the analysis were scrutinized and discussed within the research group.

In the quantitative part of the study, descriptive statistics were used to analyze the background data. The Spearman’s Rho correlation was applied to investigate the correlation between the “Quality of life as a whole” and other items in the SQoL.\[83\] In the statistical analyses, probability values of <0.05 were considered as statistically significant. To establish the internal reliability in the questionnaires and their dimensions/items, Cronbach’s Alpha coefficient was calculated.\[83\]
5.4.3. Study III
In Study III, the data were analyzed with latent content analysis.\textsuperscript{[81]} The first author read through the transcriptions several times in order to acquire a general sense of the whole. Meaning units related to the same central meaning and relevant to the aim of the study were identified. The meaning units were condensed into a description close to the text in order to grasp the manifest content. In the next step an interpretation over the underlying meaning in the condensed meaning units were done to reach the latent content. The condensed meaning units were then seen as a whole, reflected over, and abstracted into three sub-themes, threads of meaning running through the condensed text. The sub-themes constructed the theme: “A balance or imbalance in next of kin’s daily life.”\textsuperscript{[81]} Throughout the process of analysis, the authors scrutinized and repeatedly discussed the results in order to ensure the trustworthiness of the data analysis and the best form of presentation.

5.4.4. Study IV
Descriptive statistics were used to analyze the background data as well as the SQoL\textsuperscript{[5]} and the CB Scale\textsuperscript{[78]}. Spearman’s Rho correlations were tested between the dimensions in the CB Scale\textsuperscript{[78]} and the dimensions in the SQoL\textsuperscript{[5]}, “QoL as a whole,” and Quality of personal economy, gender, next of kin’s own illness and civil status. The Mann-Whitney U test was used to describe differences between male and female respondents regarding the CB Scale\textsuperscript{[78]} and the SQoL\textsuperscript{[5]}. To establish the internal reliability in the questionnaires and their dimensions/items, Cronbach’s Alpha coefficient was calculated.\textsuperscript{[80]} In all the statistical analyses, probability values of <0.05 were considered as statistically significant.\textsuperscript{[80]}
6. Ethical considerations

Studies I and II were approved by the Research Ethics Committee, Örebro University Hospital, Sweden, (§ 500:16 188/01). Studies III and IV were approved by the Regional Review Board in Uppsala, Sweden (dnr 2011/009).

The next of kin received both written and oral information about Studies I, II, and III. In Study IV all received written information and some of the respondents also telephoned the author to get the oral study information. Study participation was voluntary, with the right to withdraw at any time without giving a reason, and participation was based on informed consent. The potential participants were informed that confidentiality would be preserved. The next of kin were free to choose where they wanted the interview to take place. The interviews were audio-taped, respectively, and digitally recorded on an MP3 player, with the permission of the individual participants. There was no time limit for the interviews, allowing for pauses if the participant exhibited distress. A few participants displayed sorrow or anger during the interview, but they did not express any objection to continuing with the conversation–on the contrary, the conversation seemed to provide an opportunity to alleviate discomfort. Some participants expressed gratitude for being asked about their experiences. The participants had the possibility of contacting the interviewer by telephone or letter/mail (Studies I, II, III, and IV).[84]

Being allowed to hear another person’s story is a privilege but also involves special obligations. To be an outsider sharing another person’s life implies an obligation to communicate the results and thereby promote the development of good care. Parts of the results (Studies I and II) have been presented orally at meetings arranged for the participants with partners, friends, and health-care professionals.
7. Results

The results from each study will be presented separately.

7.1. Study I

Chronic sorrow was found to be present in 80% (35 out of 44) of the next of kin. The results are presented in terms of three themes: Loss of security, Loss of sense of community in family life, Loss of joy and recreation, and containing overall six sub-themes, in italic text.

7.1.1. Loss of security

The next of kin described deep dissatisfaction and a sense of powerlessness with regard to the future effects of the disease. They described fear, anxiety, and uncertainty, and they had a sense of “Loss of hope regarding the future.” The disease governed the whole family life. When the person with MS was living alone and the next of kin was a parent, there was anxiety regarding how this person would cope when the next of kin could no longer help. Spouses reflected anxiously on the kind of relationship that would exist between themselves and the person with MS in the future.

When the next of kin expressed a sense of “Loss of participation and sense of being respected,” it was derived from a lack of understanding on the part of nursing staff, relatives, friends, and acquaintances. The next of kin felt they no longer participated in their previous social networks, nor did they feel that they were participating in the care provided by the formal caregivers. They expressed that the formal caregivers treated them unprofessionally and disrespectfully and that they had to fight for their rights and perceived themselves as gatekeepers. They also experienced that the formal caregivers lacked continuity and a holistic perspective in care. When the next of kin were not treated with respect, they lost their trust in all health care personnel. They felt despair and a sense of powerlessness, and it was made worse by a sense of not being able to participate.

7.1.2. Loss of sense of community in family life

The next of kin ruminated about the obligations and rights they had as next of kin vis-a-vis the person with MS; it was expressed as they felt a “Loss of freedom and independence.” They felt there was an unspoken demand that they had the responsibility for all practical things around the care receiver. Some of them expressed that they wanted to escape the situation, but the thought of leaving the care receiver weighed heavily on their conscience. Not being able to participate in the ill person’s life, due to work or due to living somewhere else, was experienced as a “Loss of a shared everyday life.” The next of kin also experienced strain and a loss of
a shared everyday life when they had too much practical work to do taking care of their own home and children. Spouses sometimes felt alone in the relationship, missing daily life together, having no one with whom to share thoughts, feelings, and events. The situation was more intolerable if the person with MS could find no joy in life.

7.1.3. Loss of joy and recreation
The next of kin ignored their own feelings to cope with their life situation; this is described as “Loss of contact with one’s own feelings.” Chronic sorrow was also associated with “Loss of relaxation.” Social activities were reduced because the care receiver was too tired to participate or friends kept their distance. Next of kin had no desire to do things on their own; as a result, they gave up activities in which the care receiver could no longer participate. It was hard to relax their tension; they were always feeling tense and worried about what might happen.

7.2. Study II
First, the results of the core study are presented in the three dimensions: External life conditions, Interpersonal relationships, and Internal psychological states, with the 18 items in italic text. This is followed by the results from the supplementary study, which is presented in descriptive and correlative statistics.

7.2.1. External life conditions
In essence, the next of kin was satisfied with their housing quality. Those who lived in the countryside experienced a freedom in that, although it could be difficult to get through the winter. As one member in the family had MS, some families adapted their houses such as removal of carpets and thresholds, rebuilt kitchens and bathrooms; someone even bought a single story with floor heating. The next of kin was also pleased with their work/occupation quality, but sometimes the care receiver’s illness caused the next of kin difficulty with regard to work. It was a process to go through, to get a private life with leisure time, work, and caregiving to function. Many next of kin were anxious about their quality of personal economy because their future was uncertain. Some had planned their lives on the basis of two incomes, and wondered if they would be able to keep their house. When the person with MS lived on his/her own and the next of kin was a parent to the adult child, they worried if they should be able to help the child in the future.


7.2.2. Interpersonal relationships

*Relationship to the partner*, being a couple, and being able to trust and have confidence in each other, was important. Some next of kin said they came closer to each other through the difficulties they had shared and said that they had learned to appreciate each other more. It was important to give them time to talk thoroughly to each other about their feelings. The next of kin described that it was important to find joy in their life, to be able to forget their troubles, to be able to trust, and to have confidence in each other. On the other hand, there were also next of kin who described the relationship as stressful and said it could be difficult to achieve a satisfactory QoL. It did not feel like a normal family life or a satisfactory married/cohabiting life. Some relationships were described as stormy with constant conflicts. Worries were also expressed as to how the relationship would be affected if the ill person’s condition grew worse. It gave the next of kin a bad conscience to think about separation and what kind of life the person with MS would have if they did separate. The next of kin also expressed a feeling of not having the right to complain. *Relationship to friends* was important in order to have someone to meet and talk to, someone who could listen and understand the next of kin’s life situation, and someone who could help with practical matters. It was also important to have good relationships with their own spouses and the spouses’ mother, father, own children, and siblings. They could help with practical matters such as giving help with the children. Adult children with their own families gave help to their parents diagnosed with MS. Some had contact with each other every day, and some a few days a week. Certain next of kin mentioned that the relationship had deepened since the diagnosis. In some cases, in the initial stage of the disease, the next of kin had not fully understood the situation and therefore had not assisted enough. Thus, they got a bad conscience because from an experience of abandoning the person with MS.

7.2.3. Internal psychological states

The next of kin were involved and showed great energy in defending the ill person’s interests. They felt a sense of engagement and strength such as they had not felt before the diagnosis, but at the same time they wanted to be involved more. The next of kin expressed that the QoL was being healthy and having freedom and time for self-actualization, to do what they wanted to do. The next of kin’s freedom was limited because they no longer did what they used to do. When the person with MS acquired a wheelchair, the next of kin experienced more freedom. A limitation on freedom was when the ill person needed help immediately; the next of kin had to drop everything and go and help. When the next of kin and the ill person did not live together, the next of kin sometimes had to take care
both of their own and the ill person’s households, and on weekends they invited the ill person home to them. Next of kin that lived in or near the countryside or had a weekend cottage to go to expressed a sense of freedom; it was good for one’s QoL. If they went away without the ill person, it could be difficult to relax. Changing occupation to be able to help the ill person strengthened the self-assuredness. There was an inner security and a strong self-assuredness from being the one the person with MS relied on, the one who always was there, and defended the ill person’s interests. This increased both the self-assuredness and self-acceptance. There were negative emotional experiences when the next of kin felt that the whole family was unfairly treated, indeed insulted. This might be before the diagnosis had been established, or afterwards, when the person was not considered sufficiently ill to receive immunological treatment to reduce the deterioration. Not getting immunological treatment caused the next of kin and the care receiver to feel powerless. This caused seeking care elsewhere, in another county or even another country. The next of kin experienced that it was very difficult when the person with MS became deteriorated. And it was also trying when other people, such as friends, kept asking how the person with MS was and the next of kin was obliged to answer “Oh, fine” (which was not true). They found it a strain to talk about the disease. It was necessary to accept living for the moment.

There were next of kin’s that had the ability not to worry about the future and therefore felt less uncertain. Others thought long term and worried ahead; they felt a loss of security. There was anxiety about the future, about what would happen if the person with MS should not be able to take care of his or her children. Some next of kin had gone to a psychologist for a time after the ill person received the diagnosis. One person felt so much stress that she jumped in the air, if the telephone rang; she was constantly prepared for a disaster. The next of kin felt less secure if they were not cohabiting with the person with MS. If the next of kin, for instance, were going on holiday, they felt a heavy burden of responsibility for leaving the person with MS alone. The next of kin expressed feelings of anger, frustration, powerlessness, and depression, but there was a demand to be strong, capable, and able to cope with the situation without showing feelings. It was a question of adapting to the situation. If the ill person with MS became worse, the next of kin experienced sadness and despair, but if the person with MS felt well, the next of kin also felt well. On the whole, it was a pleasure being able to support the person with MS. But it also affected their general mood.
7.2.4. Descriptive statistics
The next of kin answered the SQoL questionnaire, covering the dimensions External life conditions, Interpersonal relationships, and Internal psychological states. The highest overall ratings were for the items Housing quality, Relationship to partner and Relationship to own children (all median 5.0), and the lowest rating was for Have no children (median 2.5). Since only one next of kin answered the item “Have no friends,” this item was excluded from the presentation of the results.

7.2.5. Correlation statistics
The results of the Spearman Rho correlation analyses concerning the “QoL as a whole” and other QoL items showed that seven of nine items within the dimension Internal psychological states were positively associated with the overall QoL in the SQoL. There was also a significant correlation between the overall QoL and the dimension Interpersonal relationships. See Table 6.
Table 6. Estimation of SQoL in Next of Kin (n=37) and correlations between separate items and the rating of QoL as a whole in the SQoL

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Item</th>
<th>n</th>
<th>Md</th>
<th>IQR</th>
<th>M</th>
<th>SD</th>
<th>Item’s Correlation with QoL as a whole***</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>External life conditions (total score)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Housing quality</td>
<td></td>
<td>37</td>
<td>5.0</td>
<td>4.0-5.0</td>
<td>4.4</td>
<td>1.1</td>
<td>ns</td>
</tr>
<tr>
<td>2. Work/occupation quality</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Have work/meaningful occupation</td>
<td></td>
<td>35</td>
<td>4.0</td>
<td>4.0-5.0</td>
<td>4.1</td>
<td>0.7</td>
<td>ns</td>
</tr>
<tr>
<td>b. Have no work/meaningful occupation</td>
<td></td>
<td>2</td>
<td>3.0</td>
<td>1.0-5.0</td>
<td>3.0</td>
<td>2.8</td>
<td>ns</td>
</tr>
<tr>
<td>3. Quality of personal economy</td>
<td></td>
<td>37</td>
<td>4.0</td>
<td>3.0-4.8</td>
<td>3.9</td>
<td>1.0</td>
<td>ns</td>
</tr>
<tr>
<td><strong>Interpersonal relationships (total score)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>4. Relationship to partner</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Have a partner</td>
<td></td>
<td>32</td>
<td>5.0</td>
<td>4.0-5.0</td>
<td>4.3</td>
<td>0.9</td>
<td>ns</td>
</tr>
<tr>
<td>b. Have no partner</td>
<td></td>
<td>5</td>
<td>3.0</td>
<td>1.5-3.3</td>
<td>2.5</td>
<td>1.0</td>
<td>ns</td>
</tr>
<tr>
<td>5. Relationship to friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Have friends</td>
<td></td>
<td>36</td>
<td>4.3</td>
<td>3.1-5.0</td>
<td>4.1</td>
<td>1.0</td>
<td>0.44**</td>
</tr>
<tr>
<td>b. Have no friends</td>
<td></td>
<td>1</td>
<td>1.0</td>
<td>1.0-1.0</td>
<td>1.0</td>
<td></td>
<td>ns</td>
</tr>
<tr>
<td>6. Relationship to mother</td>
<td></td>
<td>36</td>
<td>4.0</td>
<td>4.0-5.0</td>
<td>4.1</td>
<td>1.1</td>
<td>ns</td>
</tr>
<tr>
<td>7. Relationship to father</td>
<td></td>
<td>34</td>
<td>4.0</td>
<td>3.0-5.0</td>
<td>4.0</td>
<td>1.1</td>
<td>ns</td>
</tr>
<tr>
<td>8. Relationship to own children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Have own children</td>
<td></td>
<td>31</td>
<td>5.0</td>
<td>4.5-5.0</td>
<td>4.6</td>
<td>0.7</td>
<td>ns</td>
</tr>
<tr>
<td>b. Have no own children</td>
<td></td>
<td>6</td>
<td>2.5</td>
<td>1.0-4.6</td>
<td>2.8</td>
<td>2.8</td>
<td>ns</td>
</tr>
<tr>
<td><strong>Internal psychological states (total score)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Engagement</td>
<td></td>
<td>36</td>
<td>4.0</td>
<td>3.0-4.5</td>
<td>3.9</td>
<td>0.9</td>
<td>0.52**</td>
</tr>
<tr>
<td>10. Energy</td>
<td></td>
<td>36</td>
<td>3.3</td>
<td>3.0-4.0</td>
<td>3.4</td>
<td>0.9</td>
<td>0.37*</td>
</tr>
<tr>
<td>11. Self-actualization</td>
<td></td>
<td>37</td>
<td>4.0</td>
<td>3.0-4.0</td>
<td>3.7</td>
<td>0.9</td>
<td>0.63**</td>
</tr>
<tr>
<td>12. Freedom</td>
<td></td>
<td>37</td>
<td>4.0</td>
<td>3.0-4.5</td>
<td>3.6</td>
<td>1.0</td>
<td>ns</td>
</tr>
<tr>
<td>13. Self-assuredness</td>
<td></td>
<td>35</td>
<td>4.0</td>
<td>3.0-4.0</td>
<td>3.7</td>
<td>0.8</td>
<td>0.55**</td>
</tr>
<tr>
<td>14. Self-acceptance</td>
<td></td>
<td>36</td>
<td>4.0</td>
<td>3.0-4.0</td>
<td>3.8</td>
<td>0.9</td>
<td>0.49**</td>
</tr>
<tr>
<td>15. Emotional experiences</td>
<td></td>
<td>36</td>
<td>4.0</td>
<td>4.0-5.0</td>
<td>4.1</td>
<td>0.8</td>
<td>ns</td>
</tr>
<tr>
<td>16. Security</td>
<td></td>
<td>37</td>
<td>3.0</td>
<td>3.0-4.0</td>
<td>3.3</td>
<td>0.8</td>
<td>0.62**</td>
</tr>
<tr>
<td>17. General mood</td>
<td></td>
<td>37</td>
<td>4.0</td>
<td>3.0-4.0</td>
<td>3.6</td>
<td>0.8</td>
<td>0.56**</td>
</tr>
<tr>
<td>18. QoL as a whole</td>
<td></td>
<td>37</td>
<td>4.0</td>
<td>3.0-4.0</td>
<td>3.8</td>
<td>0.8</td>
<td>-</td>
</tr>
</tbody>
</table>

Note. A higher value indicates a more positive estimated QoL. SQoL = subjective quality of life. IQR = Interquartile range (25th - 75th percentile). * p > 0.05. ** p < 0.01. *** Spearman rank correlation (rho).

7.3. Study III

From the theme: A balance or imbalance in next of kin’s daily life three sub-themes were developed, here presented in bold text.

7.3.1. Balance and imbalance in the relationship with the older person, other family members, and friends

A balance or imbalance in the interaction with the older person, family members, and friends was seen in the next of kin’s experiences of daily
life. The care of the older person took so much time that there was little time left over for other family members and friends. Some next of kin described their relationship with the older person as undemanding, with good communication, and mutual respect. Other next of kin had had a tough time for several years. It was difficult to obtain positive feedback from the older person, who on occasion could be mean and behave insultingly, always helping the older person despite so little generosity and understanding in return. When an older person had moved to a nursing home, the next of kin had a certain sense of freedom, but at the same time a feeling of having abandoned the person. Some next of kin described a kind of loneliness deriving from never feeling loved by the older person. Another kind of loneliness resulted from difficulties with intimacy and sex. The next of kin also spoke of inner conflicts and bad consciences in respect of other family members and their friends, since spending so much time caring for the older person meant that they did not have time for others; their psychosocial life situation had deteriorated. In addition, they wanted to be involved in the care of the older person, but they often had too difficult a work situation. When the next of kin was the only child of the person they were caring for, there was mention of missing a brother or sister to talk to and share the responsibility. In contrast, the next of kin who did have siblings reported that they did not receive much help from them. They had feelings that they were left to shoulder the responsibility all on their own.

7.3.2. Balance and imbalance in the relationship with the staff from the municipal care

The next of kin felt that the relationship with the staff in the municipality care affected their life situation. The interaction could be in balance or imbalance, depending on whether the communication was good and a mutual respect existed between them. Some of the next of kin spoke of the hard struggle to find a place in a nursing home for the older person, as places are in short supply. The wait for the promised home care could also be long—it could be more than six months. During the period of waiting, there was relief from the burden when the older person was in respite care for a few weeks. Other next of kin experienced another kind of relief when the older person attended day care for a few hours a week. The next of kin described the difficulty of communicating with the municipal health care staff about this problem, because of the difficulty of getting in touch with the right person. The next of kin wondered what role the staff expected them to play in the care. They were conscious that they often took on too much, and at times it was trying. The next of kin believed that they could not say what they wanted to the staff, because they were dependent on them. The next of kin’s experience of their life situation was also af-
fected by high staff turnover, which gave them the perception of a lack of continuity in the home care. The person assigned responsibility for the care was often replaced and was difficult to get in touch with. There was mentioning of home care staff as being there but not present. Some next of kin described the period with home care as tough, without security. They felt powerless and could not trust the care, which meant stress and a sense of having too much responsibility. Furthermore, at times the personnel had said disrespectful and even insulting things to the older person, which upset the next of kin.

7.3.3. Balance and imbalance in the demands affected one’s own health

A balance or imbalance in the demands affected the next of kin’s health. It could be satisfying to be able to help, but they lived with a mental unrest that affected their own health. An imbalance was seen when the next of kin referred to their own health as a part of their life situation, where their own illness made it hard for them to find the strength to care for the older person. When the older person was living alone, the next of kin felt insecure, afraid that something might happen that required assistance. The next of kin spoke of sadness and guilt in relation to being unable to arrange a better life for the older person. The next of kin of older persons who were in nursing homes also mentioned guilt; they found it difficult to let go of the responsibility. In relation to their daily life, the next of kin believed it was required of them to be strong and help the older person, and thought they had no right to complain. They often accepted the situation and asked nothing for themselves. Some of the next of kin said that they were looking forward to better times, with more freedom. Another way for the next of kin to handle daily life was to limit their help. They put greater demands on the older person and gave more attention to their own concerns. They were also able to make use of day care or respite care. However, it was very difficult to set limits on the workload in the face of feelings of guilt.

7.4. Study IV

The results from the demographic data and the two questionnaires, the SQoL and the CB Scale, are presented in text and tables. The dimensions and items from the SQoL and the dimensions from CB Scale, are presented in italic.

7.4.1. Demographic data

Of the 84 respondents, twenty percent were male. The male participants mostly cared for a spouse or an adult child, while the females cared for a spouse, an adult child, or even parents to a greater extent than the males.
Forty-seven percent of the males were living together with the care receiver, while sixty-one percent of the women did. The women were more often working outside the home than the men; the men were more often retired than the women. Female participants reported having mental illnesses to a greater extent than the males. Few of the next of kin’s had their own support (see Table 4). The next of kin’s had been caring for the care receiver from two months to 39 years, and from one to 168 hours week. However, most of the next of kin reported non-specific intervals in terms of years or hours of giving care.

7.4.2. Descriptive and correlative statistics

The highest overall ratings were for the items Housing quality and Relationship to partner, and the lowest rating were for Have no partner and Have no friends. In general there were high estimations of the items in the SQoL. The results of the correlation analyses between the QoL as a whole and the 17 SQoL items showed that all items included in the dimension External life conditions and the dimension Internal psychological states were significantly correlated with the QoL as a whole, with the highest significance for security and general mood. From the dimension Interpersonal relationship correlations for Have no partner, Have no friends, Relationship to mother and Have no children were non-significant. See Table 7.
Correlations between all five dimensions in the CB Scale, all three dimensions in the SQoL, the QoL as a whole, and the item Quality of personal economy, gender, next of kin’s own illness, and civil status, are shown in Table 8.
Table 8. Correlations of CB Scale, SQoL, “QoL as a whole”, Quality of personal economy and demographic data for next of kin.

<table>
<thead>
<tr>
<th></th>
<th>Caregiver Burden Scale</th>
<th>SQoL</th>
<th>Item in SQoL</th>
<th>Demographic variables</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>General strain</td>
<td>Isolation</td>
<td>Disappoiment</td>
<td>Emotional involve-ment</td>
</tr>
<tr>
<td>General strain</td>
<td>1.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isolation</td>
<td>0.471**</td>
<td>1.000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disappointment</td>
<td>0.688**</td>
<td>0.593**</td>
<td>1.000</td>
<td></td>
</tr>
<tr>
<td>Emotional involvement</td>
<td>0.499**</td>
<td>0.247*</td>
<td>0.345**</td>
<td>1.000</td>
</tr>
<tr>
<td>Environment</td>
<td>0.535**</td>
<td>0.244*</td>
<td>0.487**</td>
<td>0.202</td>
</tr>
<tr>
<td>QoL as a whole</td>
<td>-0.435**</td>
<td>-0.402**</td>
<td>-0.385**</td>
<td>-0.197</td>
</tr>
<tr>
<td>External life conditions</td>
<td>-0.565**</td>
<td>-0.337**</td>
<td>-0.400**</td>
<td>-0.046</td>
</tr>
<tr>
<td>Interpersonal relationships</td>
<td>-0.350**</td>
<td>-0.254*</td>
<td>-0.318**</td>
<td>-0.319**</td>
</tr>
<tr>
<td>Internal psychological states</td>
<td>-0.483**</td>
<td>-0.359**</td>
<td>-0.362**</td>
<td>-0.287**</td>
</tr>
<tr>
<td>Quality of personal economy</td>
<td>-0.406**</td>
<td>-0.321**</td>
<td>-0.409**</td>
<td>-0.117</td>
</tr>
<tr>
<td>Gender</td>
<td>0.191</td>
<td>0.179</td>
<td>0.255*</td>
<td>0.302**</td>
</tr>
<tr>
<td>Next of kin’s own illness</td>
<td>-0.216</td>
<td>-0.257*</td>
<td>-0.217*</td>
<td>0.052</td>
</tr>
<tr>
<td>Civil status****</td>
<td>-0.083</td>
<td>0.066</td>
<td>0.010</td>
<td>-0.034</td>
</tr>
</tbody>
</table>

*Correlation is significant at the 0.05 level (2-tailed). ** Correlation is significant at the 0.01 level (2-tailed). ***Quality of life as a whole (Kajandi).
In general, high estimations were found in the dimensions within the CB Scale (Table 9), and high correlations were also found between the dimensions. Worth mentioning, however, is that civil status had no correlation with any of the included variables, and gender had only significant correlations with Disappointment \((p<0.05)\), Emotional involvement \((p<0.01)\), and Quality of personal economy \((p<0.01)\) (Table 8). These findings are also confirmed in the sub-analyses with the Mann-Whitney U test of all included variables, comparing male and female next of kin, where only the dimensions Disappointment and Emotional involvement from the CB Scale, and Quality of personal economy from the SQoL, showed significant differences between genders. Male next of kin’s scored significantly lower in both Disappointment \((p=0.02)\) and Emotional involvement \((p<0.01)\) than the females. The females, on the other hand, rated their Quality of personal economy significantly lower \((p=0.01)\) than the males. Mean values for the different dimensions from the SQoL are shown in Table 9.
Table 9. Descriptive statistics for the five dimensions in Elmståhl’s CB Scale, the dimensions in Kajandi’s SQoL, “QoL as a whole”, Quality of personal economy from the SQoL in terms of male/female participants.

<table>
<thead>
<tr>
<th>Instrument</th>
<th>All participants (n=84)</th>
<th>Male participants (n=17)</th>
<th>Female participants (n=67)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>Md</td>
<td>IQR</td>
</tr>
<tr>
<td>(Elmståhl) Dimensions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General strain</td>
<td>3.08</td>
<td>0.61</td>
<td>3.25</td>
<td>2.75-3.50</td>
</tr>
<tr>
<td>Isolation</td>
<td>2.81</td>
<td>0.68</td>
<td>3.00</td>
<td>2.33-3.33</td>
</tr>
<tr>
<td>Disappointment</td>
<td>2.82</td>
<td>0.69</td>
<td>3.00</td>
<td>2.45-3.40</td>
</tr>
<tr>
<td>Emotional involvement</td>
<td>2.36</td>
<td>0.77</td>
<td>2.33</td>
<td>1.67-3.00</td>
</tr>
<tr>
<td>Environment</td>
<td>2.34</td>
<td>0.79</td>
<td>2.33</td>
<td>1.67-2.91</td>
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<tr>
<td>(Kajandi) Dimensions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>External life conditions**</td>
<td>11.35</td>
<td>2.08</td>
<td>11.50</td>
<td>10.38-13.00</td>
</tr>
<tr>
<td>Interpersonal relationships***</td>
<td>18.45</td>
<td>3.56</td>
<td>19.00</td>
<td>16.00-21.00</td>
</tr>
<tr>
<td>Internal psychological states****</td>
<td>31.23</td>
<td>6.59</td>
<td>32.50</td>
<td>27.00-35.38</td>
</tr>
<tr>
<td>QoL as a whole</td>
<td>3.45</td>
<td>0.91</td>
<td>3.50</td>
<td>3.00-4.00</td>
</tr>
<tr>
<td>Quality of personal</td>
<td>3.54</td>
<td>1.14</td>
<td>4.00</td>
<td>3.00-4.50</td>
</tr>
<tr>
<td>economy****</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. IQR= Interquartile range (25th-75th percentile). *n=66, **n=82, ***n=79, ****n=80, *****n=83
8. Discussion

8.1. Methodological considerations
The focus in this thesis has been on the next of kin’s life situation, even though several earlier studies within nursing research have been performed focusing on the next of kin. Despite this knowledge and despite that the health care system has changed during this time span, the society has had difficulties to support the next of kin. Their inputs as informal caregivers are also expected to increase in the future. Multiple methods were applied in this thesis to obtain a more complete picture of the next of kin’s life situation.\[74\] The combination of different designs and analyses can be seen as strengths in this thesis.\[74\] All studies, I–IV, were scrutinized and discussed during the process within the research group to attain credibility/validity. Also, debriefing sessions were conducted with other researchers to discuss the studies in order to further strength the credibility/validity. It is possible for the readers of the studies to assess the transferability to other contexts, since a clear description of the approach of the studies are made.\[80\] The amount of data necessary to answer the research questions varies depending what is in focus and the data quality. The reader of this thesis can judge the credibility in how meaning units, condensations, abstractions, sub-themes, and themes are performed. Another way to judge the credibility and transferability is to show representative citations in the studies from the transcribed text,\[80\] which was done in Studies I, II and III.

8.1.1. Sample
The samples of the next of kin in the different studies were broad and chosen to study if there was something in their life situation that was common for the whole group. The participants in Studies I and II were recruited within earlier research of patients with MS, and in Study III within earlier research of older persons. There were a limited number of participants in the quantitative part in Study II, which restricts the external validity of the result. However, it is considered sufficient with 37 respondents answering a questionnaire, when this part is not comprehensible or publishable separated from the core study,\[74\] in this case the qualitative part of Study II. Twelve next of kin participated in Study III and can be seen as a low number. According to Sandelowski,\[85\] the sample size in qualitative research should be large enough to achieve a variation of experiences and also small enough to permit a deep analysis of the data.\[85\] The data from the interviews were rich in information, and the researchers therefore determined that the number of participants was adequate.\[85\] A strength was that 84 next of kin out of 111 completed the questionnaires
in Study IV, which gave a high response rate of 76%. It is common that questionnaires achieve a response rate less than 50%.[80]

8.1.2. Data collection

Studies I and II were based on only one interview with each next of kin; although the number of participants was large, this limitation should be borne in mind when interpreting the results. To attain dependability it was important that all persons interviewed received the same main questions.[86] A weakness to use a semi-structured interview guide may be that important and salient topics can have been omitted.[77] Another weakness can be that the interviews in Studies I and II were not performed by the same person that analyzed the data, in contrast to Study III, where the interviews were conducted and analyzed by the same person that, apart from the verbal communication, could also observe the body communication.[77] However, the interviews in Study I and II were performed by one person who strengthens the dependability. [77] The repeated informal interviews in Study III gave many opportunities to explore the meaning of being a next of kin.[77] Interviewing the participants twice was a way to ensure credibility; the next of kin could make changes if something had been misunderstood and the time available for reflection deepened the conversation.[77] One disadvantage in Study IV, with using the different association’s websites to reach potential participants, may be that only those who had computer skills and access to a computer could read the information regarding recruitment. It may have been difficult to reach the very oldest next of kin because they are not users of computers to the same extent as younger persons. However, the recruitment was also made through monthly journals and personal meetings with personnel at the associations. The age of the participants ranged up to 82 years of age, indicating that it was still possible to recruit older participants this way.

8.1.3. Data analysis

To attain credibility in Studies I, II, and III, the different stages of the qualitative analysis were scrutinized and discussed within the research group.[86] Latent content analysis, described by Graneheim et al.,[81] was selected in Studies I and III, due to their applicability to different text material, and also the application to communication theory as described by Watzlawick et al.[70, 81]

Directed content analysis was chosen in Study II due to the fact that an existing theory, in this case a theoretical approach on the QoL, would benefit from deeper scrutiny.[82] The semi-structured interview guide used in Studies I and II made it easier to handle the analyses. However, a short-
coming in the analysis process in Study I, in contrast to Study II, was the difficulty to sort the statements into content areas, because some of the criteria were insufficiently distinct. To assure credibility, the participants received the SQoL questionnaire\textsuperscript{[5]} after the interviews in order to avoid influence from the questionnaire during the interview. A strength in Study II is the use of mixed methods, which help to obtain a more complete picture of how next of kin describe the QoL. Other strengths of using structured questionnaires were the ability to collect unambiguous answers and to cover a large, geographically spread population relatively quickly and economically. A disadvantage in Study IV was that there were no statistical analyses made of the next of kin’s caring, in terms of hours a week or years, and this was due to the highly varying and unspecific reported data. Worth mentioning is also that no medical diagnosis for the care receiver was confirmed, as the illness or disability of the care receiver was reported only by the next of kin. However, in this study, the interest was in the next of kin’s experienced burden and their QoL, regardless of the care receiver’s diagnosis.

8.1.4. Preunderstanding

Preunderstanding is the beliefs, assumptions, and knowledge that are used to understand something that is in focus. It can be both a barrier such as prejudice and opportunities to create new knowledge. The preunderstanding is not just about things that we learned as personnel, but it is also about values and experiences that we have with us from life outside of the health care system.\textsuperscript{[87]} The reflections generated in these studies were derived from the different events that have been experienced from within the author’s clinical field as an registered nurse and registered midwife in the county council acute care, and from personal private experiences from the community health care sectors. It is necessary for the researcher to have both an ‘inside and outside’ perspective. It is impossible to avoid looking at the material subjectively, even if the intention of the researcher was to do so by scrutinizing and discussing the text within the research group. It is important to distance oneself in order to avoid influencing the data, but at the same time maintain closeness to the clinical field and the knowledge necessary to understand it \textsuperscript{[88]}. Limited knowledge of the field being studied can make it difficult to put the qualitative data in the right context. In this sense, personal experience is a strength.\textsuperscript{[85, 88]}
8.2. Discussion of the results

The results of this thesis showed that a broad group of next of kin described a balance or imbalance in their relations to others and a high burden. Some next of kin also experienced chronic sorrow, but in general they experienced a good QoL. Significant correlations were found in Studies II and IV between interpersonal relations and QoL as a whole. Love and obligations were two anchor points on a continuum describing how the next of kin presented their relationship to the ill/disabled person. The relation with the health care personnel was described through cooperation and obligations. The balance or imbalance in the different relations affected next of kin’s life situation in several ways. Good communication was seen as the key to balance, the relationship with others, and as a tool for creating good relationships. Nolan et al.\[71\] mean that if there is a good relational communication between the health care personnel, the care receiver, and the next of kin, the conditions will be good for the relationships. A relational communication has the purpose to establish, maintain, and transform relationships. Watzlawick et al.\[70\] estimate that when the conditions are equal between the persons participating in the communication, the communication is symmetrical. Communication involves both verbal- and non-verbal body language, and it is therefore impossible not to communicate, as all non-verbal communication carries a message. One way to achieve symmetrical communications in clinical practice is to adapt the Partnership Model\[71\].

In the following discussion, the results will be discussed in the light of the six senses of the Partnership model: senses of security, continuity, belonging, purpose, achievement, and significance.

8.2.1. Love and obligations in the relationship to the care receiver

In the next of kin’s descriptions of their feelings of responsibility for the care receiver, love was present. They had a strong energy and engagement in defending the care receiver’s interests. This is in line with other studies; the next of kin were protective,\[89-92\] and they acted as advocates.\[93, 94\] Some next of kin in this thesis described that they and the care receiver came closer to each other through the difficulties they shared. They also had a sense of meaning and satisfaction in providing care and a good communication with the care receiver. This can be interpreted as senses of security, continuity, belonging, purpose, and significance. It was a question of adapting to the new life situation as they had learned to see life in another way than earlier. In line with this, Sherman et al.\[95\] found that having a close person suffering from a disabling condition helped many next of kin to reprioritize their lives in a manner that enhanced their appreciation of things previously taken for granted. The life situation might
be evaluated based on many factors, not only the next of kin’s role as an informal care giver.

The next of kin have a superior knowledge of the care receiver; they know the care receiver better than anyone else. The relationship between the next of kin and the care receiver may be based on a long relation with good communication. The next of kin can meet the care receivers’ needs, thereby creating a sense of security, continuity, belonging and significance. In line with this, Lundh et al. explain that family members may feel that they are more competent and give better care than the health care personnel.\cite{72} Bell\cite{96} also describes that the next of kin know how the care receiver wants to be treated by others. This may be one reason for why the results in this thesis show that next of kin experienced good QoL, despite high burden and/or chronic sorrow.

The results from Study II show that when the care receiver and the informal caregiver were partners, there was a statement of feeling a strong fellowship, which could be important for the QoL. Growing together and being a couple were more important than ever when one person in the relationship was ill; the couple learned to appreciate each other more. The informal caregiver might have a sense of continuity, belonging, and significance. They described their relationship with the care receiver as undemanding, with good communication, and mutual respect between them; they had a sense of security. The relationship was described as a silent, mutual commitment which was meaningful for both themselves and the care receiver; they were content. Samuelsson et al.\cite{54} describe how the quality of the relationship before the onset of the care receiver’s illness/disability affected the informal caregiver’s experience of burden. If the relationship earlier had been poor, it was seen as the next of kin’s withdrawal and was ambivalent. Zegwaard et al.\cite{97} stated that the next of kin’s psychosocial well-being depends on if the next of kin has a feeling of “freedom of choice” when taking on the role of informal caregiving. It is of importance that the next of kin experiences caregiving to the care receiver as a voluntary, satisfying, and enriching act of compassion, and that the next of kin does not experience any feelings of burden. “Freedom of choice” was defined as a non-conscious psychological state. Coy et al.\cite{98} express that informal caregivers with strong family functioning tended to have a low feeling of burden, and it had a positive effect on the informal caregiver’s mental health. Etters et al.\cite{6} also found that caregiver burden is influenced by the relationship between themselves and the care receiver.

However, there were also disagreements and arguments in the next of kin’s relation to the care receiver, when the relationship was described as
trying and stormy, with constant conflicts between the next of kin and the care receiver. If there was a poor communication in the relationship, this might result in no sense of belonging.

The next of kin could have feelings of inner conflict, guilt, anxiety, chronic sorrow, fear, and loneliness. Some of them also had feelings of decline in freedom, and they felt powerless against the illness/disability. These were concerns because it made it difficult to communicate with the care receiver, which created in no security in the daily life and for the future. There are several studies that state that if there is an imbalance in the communication and the relationship, there is no basis for a good dependent care.\textsuperscript{[12, 99]}

The results in this thesis show that a decline in freedom was one of the most difficult parts in the next of kin’s life situation, and they felt that they had no right to complain. It was a process to go through, to get work, to have a private life as well as leisure time to function together. The next of kin felt isolated and lonely in their informal caregiving, feeling that they shouldered the responsibility all on their own. They needed to share the responsibility with the health care personnel to get a sense of purpose, achievement, and/or significance in the informal care. These next of kin had no opportunities left for a social life with leisure and recreation; they had no senses of belonging in the social life. The situation could be experienced as one of overwhelming demands. These next of kin felt that the demands were affecting their health. Pinquart et al.\textsuperscript{[100]} mean that negative effects on the informal caregivers’ physical health are most likely to be found when they are psychologically distressed. This is in line with Sand\textsuperscript{[1]} and Stackfleth et al.\textsuperscript{[101]} who estimated a relationship between care provision and self-estimated health status.

Informal caregiving can be seen as an unavoidable obligation; the next of kin wanted to be involved in the care, but they often felt burdened with too much responsibility. The next of kin had a sense of significance; they were important in the care receiver’s life and in the informal caregiving situation. It could be difficult for the next of kin to stop their caregiving, because it is tantamount to abandoning the care receiver, and this is associated with a poor conscience. Stoltz et al.\textsuperscript{[102]} describe that when the future was unknown, it was difficult to “just go on.” The next of kin tried to manage one day to day, struggling with denial, guilt, anger, anxiety, fear, and unhappiness. They tried to think positively, experiencing that hope was important and a way of positive thinking for most of the next of kin.
8.2.2. Cooperation and obligations in the relationship with the health care personnel

The next of kin mostly had a good communication with the health care personnel in the nursing homes; it was a balance in the relationship that can be interpreted as that they had a sense of security and belonging. They felt, due to the good communication, they had the same purpose, and achievement as the personnel and by that a sense of significance.

However, it was more often an imbalance in the relationships with the health care personnel in the hospital and home care. It was difficult to communicate, the next of kin even felt that they and the care receiver were treated nonchalantly, which led to that no sense of belonging could exist. They had a hard time knowing where they should turn when problems arose, as it was difficult to get in contact with the right person, which led to no security. Decisions were not followed up and with a poor communication, the next of kin got no sense of the “six senses”.

The next of kin in Study III experienced a lack of security when there was lack of communication and a high staff turnover in the home care, which created a lack of continuity. They wanted to communicate about how they best could help the care receiver and what help was available from the community, which can be interpreted as that they wanted to have the same continuity and purpose as the health care personnel. The next of kin did not want to search for information; they wanted to be informed. Another wish was to be involved in decisions taken by the health care personnel. The meaning of support is to have a sense of togetherness with others in the care situations. Salin et al. state a lack of cooperation between the next of kin and the health care personnel in respite care. No more than 38% of the next of kin had discussed aims and objectives of the respite care period, and only 9% learned to know one nurse well. They felt that the nurses were not interested in how they were managing. Contrary to this, Benzein et al. found that Swedish nurses have a supportive attitude to involve families in nursing care.

When the next of kin’s own illness made it hard for them to find the strength to care for the care receiver, an imbalance was seen in their life situation. The next of kin felt powerless, seeing the care receiver getting worse but receiving no help from the health care system. To live with the unpredictable course of the care receivers’ health also brought strain and stress on the next of kin’s health, did not create a sense of security. Many next of kin to young people with a deteriorative illness and/or illness with disabilities experienced multiple losses, i.e., chronic sorrow.
The next of kin felt an obligation from the society to provide support for the care receiver that can be interpreted as a hindrance to their possibilities to experience the six senses. Mostly, the next of kin wanted to care for the care receiver, but they often felt that the requirements exceeded the resources to handle the task, this is also in line with Twigg et al. There is a tendency to assume that the social care system only steps in when the informal support is unavailable. To be an informal caregiver says nothing about the quality of the informal care or the relationship between the next of kin and the care receiver. Even if the relationship is good between them, it is not certain that all next of kin would like to, can, and feel that it is appropriate to be informal caregivers. There are discrepancies between the health care personnel or decision makers in the community on the one hand, and the next of kin on the other hand, of how support is defined. It seems as the health care personnel’s view of support is in service provision; the next of kin may have another point of view of what support is for them. In this thesis the results show that many next of kin were lacking support from the society. The informal caregiving is an emotional relationship of responsibility, worry, anxiety, and stress, but the next of kin also have a need to be involved in the care. Therefore, they are in need of individual support. This is in line with Cheung et al. who describe informal caregiving as a complex emotional relationship of responsibility. The next of kin in this thesis felt that they were often marginalised in the health care system which is in line with the results from several other studies. These results strengthen the assumption that the health care system has had difficulties to integrate the next of kin in a way that gives support to the next of kin.
9. Conclusion

The results of this thesis show that there exists a need for honest and specific communication between the health care personnel, the next of kin, and the care receiver. Good care can only be delivered where there is a triadic relationship. In this thesis, however, the focus was on the next of kin’s perspective.

The next of kin in this thesis in general had a good QoL, despite their experiences of high burden and that some had chronic sorrow. This may depend on that the next of kin and the care receiver are very close to each other, there is love between them, and a mutual feeling of responsibility to help and take care of each other. If the relationship between the next of kin and the care receiver is not good, they may experience the informal care as more burdensome. They have nonetheless a strong feeling of responsibility. The next of kin do not abandon the care receiver, but they are in need of support from others to handle their life situation. Without support to the next of kin from others, the next of kin can be at risk of illness themselves.

It could be an imbalance in the relationships between, on the one hand the next of kin and the care receiver and, on the other hand, the health care personnel. The results show that it is important with good communications to promote good relationships and to create quality in the relationships with others. A symmetric communication creates good relationships, and it is also important to remember that there is no such thing as absence of communication. All non-verbal communication carries a message.

When discussing the result from the Partnership Model[71] all the “six senses” were applicable which signify a use of the Model to support next of kin. It is a way to achieve a symmetric communication, where all three parties in the care, the care receiver, the health care personnel, and the next of kin contribute with their unique knowledge. Good care can only be delivered where there is a triadic relationship. All parties should experience a feeling of the "six senses."

The results show the importance for the nurses and health care personnel to have a general knowledge and an ability to understand the next of kin’s life situation, regardless of the care receiver’s diagnosis, as they meet the next of kin to persons in need of care within all the health care system. The next of kin, the care receiver and the health care personnel are participants in the communication situation, where each individual’s actions affect the whole – what one does affect the other.
10. Clinical implications

The findings of this thesis highlight a continued strained life situation of the next of kin, although there is nursing research, which has been performed during the last 20-30 years, to find solutions to support the next of kin. There are several international intervention studies of informal caregivers, concerned informal care of people with cognitive disturbances, with different supervision programs, and support arrangements. They were systematically evaluated and summarized by the Swedish Council on Technology Assessment in Health Care (SBU).[112]

Without support to the next of kin from others, the next of kin can be at risk of illness themselves, especially because their burdens are expected to grow. The next of kin are not a homogeneous group; they are different persons, with different needs, and experiences of being a next of kin. It is therefore important to take the individual differences under consideration when designing nursing interventions, to meet the different needs, as well as the demands of male and female next of kin.

One way of promoting good communications with good relations and the sharing of responsibility among all parties engaged in the care would be to apply the Partnership Model developed by Nolan et al.[71] This would mean actively striving to give the next of kin the opportunity to become involved in all aspects of the care, with meaningful dialogue and support both for the care receiver and for the next of kin. To achieve support to the next of kin might also be to apply a planning instrument, Carers Outcome Agreement Tool (COAT).[114, 115] The tool is a scientifically formulated instrument for planning, monitoring, and evaluating support to the informal caregivers. The instruments consist of four questionnaires and are based on areas identified as important by the informal caregivers. A user’s guide for the informal caregiver as well as a manual aimed at the health and social care staff has been prepared. The tools consist of question areas where the next of kin have the opportunity to assess their individual needs, their situations, and discuss their support needs with the staff.[99, 100] Another way of supporting, or a complement to the COAT, may be to establish kin groups, bringing together the next of kin who are in similar situations.[101] Most kind of support seems to be lacking for the next of kin included in the present study.

Haberstroh et al. [113] claimed that there is generally a high consensus related to the effects of education and support for the informal caregiver’s, in order to enhance their quality of life. It is important to involve the infor-
mal caregivers in the treatment and to provide interventions that are both suitable and specifically tailored to meet their needs.
11. Populärvetenskaplig sammanfattning av avhandlingen

I Sverige liksom i övriga nordiska länder, har samhället ansvar för människor i behov av vård och är skyldiga enligt lag att stödja anhöriga som vårdar en person som är långsiktigt sjuk, funktionshindrad och/eller äldre. Det offentliga systemet har allt svårare att möta befolkningens behov av vård, därmed är den informella vård som i dag ges av anhöriga, mycket omfattande. Anhöriga riskerar känslomässiga, psykologiska, ekonomiska, sociala och fysiska påfrestningar på grund av sin livssituation som informella vårdare. Trots flera decenniers forskning kring anhörigas utsatthet har vården haft svårigheter att integrera anhöriga i vården på ett sätt som ger stöd till dem i deras situation.

Sjuksköterskor skall i sitt yrke, bland annat främja hälsa och förebygga sjukdom, men också främja en miljö där varje individ blir respekterad. Ett ökat samarbete i vården mellan personen i behov av hjälp, den anhöriga och vårdpersonal kan ge personen som är i behov av hjälp en möjlighet att bo kvar i hemmet, även om sjukdom/funktionshinder försämras.

Syfte
Det övergripande syftet med denna avhandling har varit att öka förståelsen för de anhörigas livssituation i samband med att vara informella vårdgivare till personer som är långsiktigt sjuka, funktionshindrade och/eller äldre.

I Studie I utforskades förekomsten och beskrevs innebörden av kronisk sorg, hos en grupp anhöriga till patienter med diagnosen MS. I Studie II fortsatte forskningen genom att studera hur anhöriga till MS-patienter upplevde sin livskvalitet. Baserat på dessa resultat uppkom frågan om anhörigas upplevelser var diagnosspecifika, och om upplevelsen av livssituationen hade att göra med åldern på den som behövde omvårdnad. Eftersom MS debuterar vid en relativt ung ålder intervjuades därför i Studie III, anhöriga till äldre personer som var i behov av vård, om upplevelser kring sin livssituation. I Studie IV, studerades livssituationen bland anhöriga till personer som är långvarigt sjuka, funktionshindrade och/eller äldre, detta oavsett vårdmottagarens ålder eller diagnos med fokus på bördan och livskvalitet.
**Metod**

Olika designer och både kvalitativa (I, II, III) och kvantitativa metoder (II, IV) har använts för att få en allsidig beskrivning och mer komplett bild av de anhörigas upplevelse av sin livssituation.

**Urval**

I forskningsprojektet har ett strategiskt urval/lämplighetsurval genomförts genom att i delstudie I och II inkludera 44 anhöriga till patienter med MS från ett större projekt. I delstudie III användes också ett strategiskt urval/lämplighetsurval genom att tillfråga 45 äldre personer som deltog i ett större projekt. Detta resulterade i att 12 anhöriga inkluderades i studien. I delstudie IV gjordes en rikstäckande rekrytering av anhöriga genom att kontakt togs med 3 allmänna föreningar för anhöriga och 29 föreningar riktade till specifika diagnosgrupper. Nitten föreningar publicerade information om studien på sina webbplatser, i månatliga tidskrifter, nyhetssbrev, Facebook-sidor eller bloggar, alternativt gavs informationen personligen vid deras respektive möten. Åttiofyra anhöriga deltog i studien. De anhöriga fick både skriftlig (I-IV) och muntlig information (I- III) om studierna, och deltagandet var baserat på informerat samtycke.

**Datainsamling och analys**


**Instrument och frågeguide**

Burke/NCRCS, frågeguide har använts i Studie I och II, vilken består av 16 öppna frågor riktad till anhöriga. Frågeguiden är utvecklad för att

Resultat
Delstudie I visade att 35 (80 %) av deltagarna ansågs ha kronisk sorg. De kände en förlust av trygghet, förlust känsla av gemenskap i familjelivet samt förlust av glädje och möjlighet till rekreation. Delstudie II visar att anhöriga känner en hög livskvalitet trots en oviss framtid. I intervjuerna uppgav de flesta anhöriga att de hade en förtroendefull och trygg relation med sin partner, men andra beskrev en ansträngd situation och det fanns oro för en försämrad relation i framtiden. Sju av nio frågor inom dimensionen inre psykologiskt tillstånd hade ett samband med den allmänna livskvaliteten i SQoL. Det fanns också signifikant samband mellan den allmänna livskvaliteten och dimensionen; relationer, det vill säga relationen med vänner.

Slutsats

12. Acknowledgements

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Appendix

Burke/N.C.R.C.S. Chronic Sorrow Questionnaire (Cargiver Version). In Swedish: Burke/N.C.R.C.S. Kronisk sorg – en frågeguide, (riktad till anhörig), appendix 1

Subjective Quality of Life. In Swedish: Självskattad livskvalitet, appendix 2

Caregiver Burden Scale. In Swedish: Vårdgivares belastnings skala, appendix 3
Burke/N.C.R.C.S. Kronisk sorg – en frågeguide
(Riktat till anhörig)

Jag skulle vilja ställa några frågor till dig om tankar och känslor som du har upplevt sedan ________________ (namn) diagnositerades med ________________________ (tillstånd).

Jag är intresserad av dina synpunkter så att sjukvårdare kan bli mer lyhörda och hjälpsamma mot människor i liknande situation.

1. Hur fick du först reda på att ________________ (namn) hade ____________ (tillstånd)?

2. Kan du komma ihåg hur du kände när du först fick reda på det? (Kan tillägga: Vad tänkte du då?)

3. Vad hjälpte dig bäst att acceptera nyheten om ________________ s tillstånd?

4. Var det något särskilt som hände som inte var till hjälp? (Om ja: Kan du ge mig ett exempel?)

5. När du tänker tillbaka på hur du först reagerade när du fick kändedom om ________________ s tillstånd, har det då funnits tillfällen när du återigen haft samma känsla av ________________________ (använd individens egna ord från svaret på fråga 2. Om svaret är ja, ställ frågorna 7 – 16; om nej, ställ fråga 6.)

6. Vad känner du just nu när du tänker på ________________ s tillstånd?

(Om de känslor som beskrivs överensstämmer med kronisk sorg, ställ fråga 7; om inte, fortsätt till fråga 14.)

7. Kan du berätta för mig om ett tillfälle (om fråga 6 har ställts, inflika "ett annat" här) när du har känt på det här sättet? (Kan tillägga: Vilka var omständigheterna? Kan du beskriva hur det kändes?)

8. En del anhöriga kan i vissa situationer uppleva att dessa känslor frambringas igen. Har du upplevt situationer där känslorna frambringats på detta sätt? (Om ja: Kan du berätta för mig om några av dessa tillfällen?)

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9. Hur skulle du vilja jämföra dessa senare upplevelser med dem du hade då du först fick kändedom om ____________ s tillstånd?
   a. De brukar vara mer intensiva
   b. De brukar vara lika intensiva
   c. De brukar vara mindre intensiva

10. Var andra människor medvetna om att du hade de här känslorna? (Om ja: hur visste de det?)

11. När du upplevde de här känslorna, fanns det några människor som var särskilt hjälpsamma? (Om ja: Vilka var de? Kan du komma ihåg vad de gjorde som hjälpte dig?)

12. Vilka var minst hjälpsamma? På vilket sätt?

13. När någon anhörig känner sig riktigt nere över ______________ s tillstånd, vad kan han eller hon då göra för att känna sig bättre?

14. Jag hoppas att det här arbetet skall hjälpa oss att ge praktiska råd till dem som är anhöriga till personer med ______________(tillstånd)

   Vad skulle du vilja berätta om vad de har att vänta sig? Vad behöver de veta?

15. Finns det något som du vill förmedla till sjukköterskor och andra vårdgivare om att hjälpa människor i din situation?

16. Får jag bara kolla en sak med dig innan vi går vidare till nästa del. Några har sagt att de kände sig väldigt ledsna när de fick kändedom om sin anhöriges ______________(tillstånd) och att det då och då kunde hända något som gjorde att de kände samma sorg om igen. För andra har det inte varit på det viset. Hur är det för dig?

   Jag skulle vilja be dig om lite allmän information om dig och din familj för att kunna färdigställa intervjun.

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Introduktion

Självskattad livskvalitet

I detta frågeformulär undersöks hur du upplever olika förhållanden i ditt liv som har med begreppet livskvalitet att göra. Frågorna försöker fänga hur du har haft det inom olika livsområden på den senaste tiden.


Yttre livsvillkor

1 Arbetssituationen/Sysselsättningssituationen

Denna fråga handlar om vad du tycker om din arbetssituation. Gör en helhetsbedömning av hur du trivs med ditt arbete; om tiden du arbetar är lagom lång, om det ställs lagom mycket krav på dig, hur kontakterna med arbetskamrater och chefer fungerar, hur arbetsmiljön är etc.


Slutligen om du inte har något arbete eller meningsfull sysselsättning kan du ange i den undre skalan vad du tycker om att sakna arbete eller en meningsfull uppgift/aktivitet.

Min arbetssituation/sysselsättningssituation är?:

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Jag har inget arbete/meningsfull sysselsättning och det tycker jag är?:

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©Madis Kajandi, 2006. Good Life Assessment Scale – subjective version. Detta formulär får endast användas efter överenskommelse med upphovsrättsinnehavaren. V.g. kontakta Madis Kajandi, madis.kajandi@akademiska.se eller tel. 018-6111054, för vidare information.
2 Boende

Denna fråga handlar om hur du bor för närvarande. Gör en helhetsbedömning av hur du trivs med boendet, dvs. hur standarden är, vad du tycker om grannkapet och grannarna, servicen i området och över huvudtaget hur det passar dig att bo så här.

**Mitt nuvarande boende är?:**

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3. Den ekonomiska situationen


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Mellanmänskliga relationer

4. Parrelation/Avsaknad av partner

Denna fråga handlar om hur du upplever förhållandet till din partner (make/maka, fästmö/fästman, pojk-/flickvän etc.).

Gör en helhetsbedömning av hur du tycker att ni trivs tillsammans, om ni kan prata personligt med varandra, om ni kan uttrycka känslor för varandra, hur ni har det sexuellt, om det finns balans och jämlikhet i ert förhållande, om ni kan lösa oenighet/konflikter bra osv.

Om du inte har någon partner för närvarande är det meningen att du skattar i den nedre skalan vad du tycker om att sakna en partner.

**Relationen till min partner är?:**

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**Jag har ingen partner för närvarande och det är?:**

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</table>
5. Vänskapsrelationer/Avsaknad av vänner

Denna fråga handlar om relationer till människor i ditt liv som kan kallas dina vänner. Gör en helhetsbedömning av hur ni har det tillsammans, om du kan prata personligt med dem, om ni har roligt, om du känner att det finns balans och jämlikhet mellan er, om du kan vara ärlig osv.

Om du saknar vänner är det meningen att du skattar i den nedre skalan vad du tycker om den situationen.

Relationen till mina vänner är?:

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Jag har inga vänner för närvarande och det är?:

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6. Relationer till föräldrarna

Denna fråga handlar om relationen till dina föräldrar. Gör en helhetsbedömning av hur du tycker att er kontakt har fungerat när du var yngre och hur du tycker att den fungerar nu.

Om någon eller båda föräldrarna är döda görs en bedömning utifrån hur det var när de levde och hur minnet av kontakten lever kvar inom dig.

Relationen till min mamma var/är?:

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Relationen till min pappa var/är?:

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7. Relationer till egna barn/avsaknad av egna barn

Denna fråga handlar om relationerna till dina barn. Gör en helhetsbedömning av hur du upplever att ni har det tillsammans du och dina barn och hur du känner dig som förälder. Om du har flera barn är det meningen att du gör ett ungefärligt genomsnitt av hur relationen fungerar till de olika barnen.

Om du inte har några barn kan du ange i den nedre skalan vad du tycker om den situationen.

**Relationen till mitt/mina barn är?:**

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**Jag har inget barn och det är?:**

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8. Engagemang

Denna fråga handlar om i vilken utsträckning du kan känna engagemang för det som händer i din omvärld och för saker som intresserar dig. Det handlar om att följa med i tidningar och radio/TV, och det handlar om att kunna fördjupa sig och vara aktiv inom ett eget intresse. Det kan vara en hobby, eller något inom ett föreningsliv, inom ditt arbete etc.

**I vilken utsträckning kan Du känna engagemang i Ditt liv?:**

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9. Energi

Denna fråga handlar om i vilken utsträckning du har krafter, ork och uthållighet att göra olika saker. Både saker man måste göra och saker man tycker om att göra ingår.

**I vilken utsträckning har Du energi att göra olika saker?:**

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</table>
10. Självförverkligande

Denna fråga handlar om i vilken utsträckning du har kunnat förverkliga dina talanger och dina drömmar om hur livet skulle bli. Om det finns bitterhet inom dig över att något inte blev som du önskade så ingår även det.

I vilken utsträckning har Du kunnat förverkliga Dig själv och saker i Ditt liv?:

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11. Frihet

Denna fråga handlar om i vilken utsträckning du kan känna frihet i ditt liv. Frihet handlar om att kunna välja vad man vill göra och hur man gör det. Hinder för friheten kan vara av yttre slag, som att inte ha pengar t.ex.; hinder kan också vara av inre slag, som att inte våga göra saker man skulle vilja. Gör en helhetsbedömning av balansen mellan frihet och hinder i ditt liv.

I vilken utsträckning kan Du känna frihet i Ditt liv?:

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12. Självsäkerhet

Denna fråga handlar om i vilken utsträckning du kan känna dig kompetent, duglig och effektiv i ditt liv.

I vilken utsträckning kan Du känna självsäkerhet i Ditt liv?:

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13. Självacceptans

Denna fråga handlar om i vilken utsträckning du kan acceptera dig själv sådan du är. Alla människor har brister, men vi kan skilja oss vad gäller hur vi kan uthärda att ha brister.

I vilken utsträckning kan Du acceptera Dig själv sådan Du är?

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</table>
14. Känsloupplevelser

Denna fråga handlar om i vilken utsträckning det finns känsloupplevelser i ditt liv. I frågan ingår om man kan känna alla slags känslor; glädje, lycka, ilska, ledsnad men även känslor i samband med naturupplevelser, musik, konst och andra yttringar av livet.

I vilken utsträckning förekommer det känsloupplevelser i Ditt liv?

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15. Trygghet

Denna fråga handlar om tryggheten i ditt liv just nu och om du kan känna tillförsikt inför framtiden. Ytterligare livsmöjligheter kan påverka tryggheten och ångest, oro och annan till synes ofobad rädsla kan vara tecken på en inre otrygghet.

I vilken utsträckning kan Du känna trygghet i Ditt liv?:

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16. Sinnesstämnings


Jag är för det mesta?

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<td>Nedstämd</td>
<td>och ser mörkt</td>
<td>på tillvaron</td>
<td>Medel</td>
<td>I mycket</td>
<td>Gladlynt och ser ljust på tillvaron</td>
</tr>
</tbody>
</table>

17. Total livskvalitet

Slutligen vill vi be dig göra en skattning av din livskvalitet i livet som helhet.

Min livskvalitet är?

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>½</td>
<td>2</td>
<td>½</td>
<td>3</td>
<td>½</td>
</tr>
<tr>
<td>Mycket dålig</td>
<td>Medel</td>
<td>I mycket</td>
<td>god</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Caregiver Burden Scale

Questions
Please, place a tick in the appropriate box.

No 1. Do you feel tired and worn out?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 2. Do you feel lonely and isolated because of your relative’s problem?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 3. Do you think you have to shoulder too much responsibility for your relative’s welfare?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 4. Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 5. Do you find yourself facing purely practical problems in the care of your relative that you think are difficult to solve?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 6. Do you ever feel offended and angry with your relative?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often
Caregiver Burden Scale

Questions
Please, place a tick in the appropriate box.

No 7. Do you think your own health has suffered because you have been taking care of your relative?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 8. Has your social life, eg with family and friends, been lessened?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 9. Does the physical environment make it troublesome for you taking care of your relative?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 10. Do you feel tied down by your relative’s problem?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 11. Do you feel embarrassed by your relative’s behaviour?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 12. Has your relative’s problem prevented you from doing what you had planned to do in this phase of your life?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often
Caregiver Burden Scale

Questions
Please, place a tick in the appropriate box.

No 13. Do you find it physically trying to take care of your relative?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 14. Do you think you spend so much time with your relative that the time for yourself is insufficient?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 15. Do you worry about not taken care of your relative in the proper way?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 16. Are you sometimes ashamed of your relative’s behaviour?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 17. Is there anything in the neighbourhood of your relative’s home making it troublesome for you to take care of your relative?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often

No 18. Have you experienced economic sacrifice because you have been taking care of your relative?
☐ Not at all
☐ Seldom
☐ Sometimes
☐ Often
Caregiver Burden Scale

Questions
Please, place a tick in the appropriate box.

No 19. Do you find it mentally trying to take care of your relative?
☐ Not at all¹
☐ Seldom²
☐ Sometimes³
☐ Often⁴

No 20. Have you a feeling that life has treated you unfairly?
☐ Not at all¹
☐ Seldom²
☐ Sometimes³
☐ Often⁴

No 21. Had you expected that life would be different than it is at your age?
☐ Not at all¹
☐ Seldom²
☐ Sometimes³
☐ Often⁴

No 22. Do you avoid inviting friends and acquaintances home because of your relative’s problem?
☐ Not at all¹
☐ Seldom²
☐ Sometimes³
☐ Often⁴

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Örebro Studies in Care Sciences*


* Seriens namn var tidigare (nr 1–24) ”Örebro Studies in Caring Sciences”. 


