

Department of Public Health and Community Medicine
Social Medicine
The Sahlgrenska Academy at Göteborg University
Göteborg Sweden

Dilemmas and consequences
of chronic disease -
lived experiences of coeliac
disease and neuropathic pain



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by
Annette Sverker
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Annette Sverker

The Sahlgrenska Academy, Göteborg University
Box 453
SE-405 30 Göteborg
Sweden

annette.sverker@socmed.gu.se

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In dedication to our lovely daughters,
Karin och Anna

DILEMMAS AND CONSEQUENCES OF CHRONIC DISEASE- LIVED EXPERIENCES OF COELIAC DISEASE AND NEUROPATHIC PAIN

Annette Sverker

Department of Public Health and Community Medicine/Social Medicine,
The Sahlgrenska Academy at Göteborg University, Box 453,
SE – 405 30 Göteborg, Sweden.

ABSTRACT

Background: A more patient-centred health care needs to be based on patients' and their close relatives' experiences of the daily life with a chronic disease. Coeliac Disease (CD) and Neuropathic pain (NP) are common chronic diseases where such knowledge is missing. Individuals with CD and associated gluten-free diet often experience a relief when they receive the diagnosis, but long-term follow-up have shown declined quality of life and self-perceived health especially in women. No treatment that gives patients with NP a complete pain relief is available. Patients need to learn to live with pain.

Aims: The overall aim of this thesis was to extend our knowledge of what it is like to live with a chronic disease, from the perspective of NP and CD. The specific aims were to explore the experienced dilemmas, consequences and strategies of patients with chronic NP, and of persons with CD and their close relatives.

Method: Qualitative methodology was used in all four studies, combined with a quantitative method in study IV. The critical incident technique (CIT) was chosen as the method for data collection, with a questionnaire on household activities for the fourth study. Interviews were carried out with 39 informants suffering from NP, with 43 informants suffering from CD, and with 23 close relatives to the CD informants. Questions were asked about occasions in their everyday life when they were hindered or reminded of the NP or CD. Interviews were transcribed verbatim and analysed qualitatively. Categories were identified and the analysis and results were continuously discussed in the research group and at seminars.

Results: A broad range of dilemmas, disturbances and consequences were experienced in the daily life with chronic disease. Emotional reactions, relationships and the management of daily life were the main categories of dilemmas experienced by the persons with CD. Failures, inabilities and restrictions were identified as disturbances in the everyday life with NP. Disease-related worries, management of daily life and disturbances in social life were identified in the interviews with close relatives. The overall pattern and types of consequences experienced in relation to dilemmas of CD were similar in women and men, irrespective of whether they were gluten-intolerant or close relatives, both women and men reported in the questionnaire that women had the main responsibility for household activities.

Conclusion: This thesis showed that persons suffering from CD or NP had several lived experiences in common regardless of the chronic disease. In spite of the differences in clinical presentation and treatments between the two diseases, there were several similarities in the variation and quality of lived experiences identified, and the influence of these in the men's and women's lives. A possible explanation to lower quality of life in women with CD compared to men might be the unequal distribution of household work. The informants pointed out that information and knowledge on the diseases and the necessary adjustments in everyday life were insufficient among personnel and in the society. This indicates that there is a need of knowledge improvements of chronic diseases in society.

Keywords: Burden of dietary restriction, chronic disease, coeliac disease, critical-incident technique, dietary dilemmas, neuropathic pain, next of kin experiences, quality of life.

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DILEMMAN OCH KONSEKVENSER AV KRONISK SJUKDOM - LEVDA ERFARENHETER AV CELIAKI OCH NEUROPATISK SMÄRTA

Annette Sverker

Socialmedicinska avdelningen, Sahlgrenska Akademien vid Göteborgs Universitet,
Box 453, 405 30 Göteborg

SAMMANFATTNING

Bakgrund: En mer patientcenterad hälso- och sjukvård bör baseras på patienters och nära anhörigas erfarenheter av det dagliga livet med kronisk sjukdom. Celiaki och neuropatisk smärta är två vanliga kroniska sjukdomar där sådan forskning saknas. Individer som får diagnosen celiaki och börjar äta glutenfri kost upplever ofta en lättnad, men uppföljningar har visat att livskvalitet och självskattad hälsa försämras efter en tid. Detta gäller i synnerhet kvinnor. Det finns ingen tillgänglig behandling som ger patienter med neuropatisk smärta en fullständig smärtlindring. Patienterna måste lära sig att leva med smärta.

Syfte: Det övergripande syftet med avhandlingen var att öka kunskapen om hur det är att leva med kronisk sjukdom med utgångspunkt i celiaki och neuropatisk smärta. Specifika syften var att utforska upplevda dilemman, konsekvenser av dessa och strategier för att hantera dilemman och konsekvenser bland patienter med neuropatisk smärta och bland personer med celiaki och deras anhöriga.

Metod: Kvalitativ metod användes i samtliga delstudier och i kombination med en kvantitativ del i en delstudie. "Critical incident"-tekniken valdes som metod för datainsamlingen. En enkät om hushållsaktiviteter utvecklades för den fjärde delstudien. Trettio patienter med neuropatisk smärta samt 43 personer med celiaki och 23 nära anhöriga till dessa intervjuades. I intervjun ställdes frågor om situationer i personens dagliga liv då man blivit påmind om eller hindrad av sin sjukdom. Intervjuszvaren skrevs ut ord för ord och analyserades kvalitativt. Analysen och de kategorier som identifierades och analyserades diskuterades kontinuerligt inom forskargruppen och vid seminarier.

Resultat: Informanterna hade erfarenhet av en rad olika dilemman, störningar och konsekvenser i sitt dagliga liv. Känslomässiga reaktioner, relationer och att hantera det dagliga livet var de huvudkategorier av dilemman som personer med celiaki hade upplevt. Misslyckanden, oförmåga och begränsningar var genomgående störningar i vardagslivet med neuropatisk smärta. Sjukdomsrelaterad oro, att hantera det dagliga livet och störningar i det sociala umgänget identifierades som dilemman bland nära anhöriga. Det övergripande mönstret och typen av konsekvenser var liknande hos kvinnor och män oavsett om de hade celiaki eller var en nära anhörig. Både kvinnor och män rapporterade i enkäten att kvinnor hade huvudansvaret för hushållsaktiviteter.

Konklusion: Den här avhandlingen visade att personer som har celiaki eller neuropatisk smärta hade flera levda erfarenheter gemensamma. Trots skillnaderna i symptom och behandling i de båda sjukdomarna var det stora likheter i variation och typ av levda erfarenheter och inflytandet över kvinnors och mäns vardagsliv. En möjlig förklaring till att kvinnor med celiaki upplever lägre livskvalitet kan vara den ojämna fördelningen av hushållsarbetet. Deltagarna i studierna påpekade att information och kunskap om sjukdomarna och de nödvändiga anpassningarna i det dagliga livet var otillräcklig både inom hälso- och sjukvården och i samhället i stort. Detta indikerar att det finns ett behov av förbättring.

Nyckelord: Diet restriktioner, celiaki, "Critical incident"-tekniken, dilemma, kronisk sjukdom, livskvalitet, neuropatisk smärta, nära anhörig.

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ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to by their roman numerals.

- I Hensing, G.K.E., Sverker, A.M. & Leijon, G.S. Experienced dilemmas of everyday life in chronic neuropathic pain patients – results from a critical incident study. *Scandinavian Journal of Caring Sciences*. 2007; 21: 147-154.
- II Sverker, A., Hensing, G. & Hallert, C. "Controlled by food" – lived experiences of coeliac disease. *Journal of Human Nutrition and Dietetics*. 2005; 18: 171-180.
- III Sverker, A., Östlund, G., Hallert, C. & Hensing, G. Sharing life with a gluten-intolerant person – the perspective of close relatives. *Journal of Human Nutrition and Dietetics*. 2007; 20: 1-11. In press.
- IV Sverker, A., Östlund, G., Hallert, C. & Hensing, G. "I lose all these hours..." Exploring gender and consequences of dilemmas experienced in everyday life with coeliac disease. Submitted.

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ABBREVIATIONS AND TERMINOLOGY

Abbreviations / terms	Definitions
CD	Coeliac disease
CIT	Critical incident technique
Close relative	Spouses, cohabitants and parents living at the same address as the informant
Dilemma	“A perplexing or awkward situation perceived by a patient to cause disturbances in the performance of his / her everyday life”[1, 2]
GFD	Gluten-free diet
NP	Neuropathic pain
Person with coeliac disease	The expressions “person with coeliac disease” and “gluten-intolerant person” have been used interchangeably in this thesis

INTRODUCTION

Living with a chronic disease has a significant impact on the daily life of the affected person and his / her family [3]. In spite of this, few studies have been carried out on the lived experiences of chronic diseases [4]. This is remarkable, since the care of people with chronic diseases also consumes a large proportion of health and social care resources. It is important to highlight the difficulties and dilemmas that arise during the course of living with different conditions and dealing with changing needs. With increased knowledge regarding problems in everyday life based on the experiences of those affected, health care personnel are better able to recognise the complexity of living and coping with chronic diseases. Disadvantages recognised can be used as a basis for the development of programmes for treatment, rehabilitation and support that are more relevant to the lives and concerns of patients and their families [3-5].

During the last decade the prevalence of chronic diseases has increased. This can be explained by an increased identification of persons with chronic diseases. Another explanation for the increase is that many fatal diseases can now be treated, resulting in increased and/or prolonged survival. This development during the last decade has been on both the political and medical agenda in Sweden, but also worldwide [6]. The World Health Organisation has identified chronic diseases and conditions as the leading cause of disability by 2020 [7]. Cardiovascular disease, cancers, chronic obstructive lung disease and diabetes have become a major and growing public health problem throughout the world [6].

During 1998-2000 approximately 40% of the adult population in Sweden replied in the affirmative when asked if they lived with a long-term chronic disease or condition [5]. The proportion of people who report long-term disease or illness rose during the 1990s. This is partly in connection with a rise in the number of minor conditions with increased medical treatment, but also an increase in serious conditions [5].

Thus, chronic diseases and conditions are common and can be seen as a public health problem, not only due to their importance in health care, but also since chronic diseases and conditions are an essential determinant of the general public's health. Research on the social consequences of chronic diseases and conditions is necessary to promote the prevention of negative consequences for the individual and his/her family. It is possible that such knowledge might contribute to lowered health costs, but more research is needed.

The study of chronic diseases and conditions, and the social consequences associated with them, has been one of the areas of research in social medicine, and this research tradition is the point of departure for this thesis [8]. Today most of this research in social medicine is carried out within health services research, where the consequences of illness and disease constitute a central factor [8]. An example of earlier research is the thesis by Gåfväls [9], who focused on adults with insulin-treated diabetes. The aim of her research was to acquire a deeper knowledge of how diabetes affected different areas of life and to find factors that can be applied generally and have the greatest impact. She found that living with diabetes is a different experience for different people, and that gender and the presence of chronic complications had an impact on the relationship to the disease. Bendtsen [10] studied rheumatoid arthritis: the patient's perception of the disease, care, quality of life, coping and well-being. In a recent thesis from 2006, Faresjö [11] estimated the occurrence of irritable bowel syndrome in the general population and the impact on the everyday life of those suffering from irritable bowel syndrome. These are three examples of theses within social medicine focusing on chronic diseases and conditions, and the contribution to knowledge that can be used in the health service to improve the treatment and care of patients and their families.

In social medicine the social network of individuals has been identified as an important factor for health, and therefore close relatives have been approached and included in this study [12-14]. The lives of the patients outside the clinical context have sometimes been neglected in health research, and in this thesis attempts have been made to include the social context, both by including close relatives as study subjects, but also by studying the dilemmas as they occur in the everyday life of the patients, irrespective of the arena where they occur and irrespective of their clinical importance.

The study of chronic diseases and conditions is an important part of social medicine and the associated health services research and can be carried out as epidemiologic studies, as evaluation of health services interventions in treatment and rehabilitation and as intervention studies on preventive measurements. However, it is also important to find out about people's own experiences of what it is like to live with a chronic disease, or be a close relative of someone with a chronic disease, and for this aim qualitative methods are best suited [4]. Knowledge on patients and close relatives experiences is required in order to meet the individuals' needs and wishes in connection with care and treatment, and thus get closer to the individuals' own experienced reality, which

can also be seen as part of the core of social medicine. Since the 1980s, research into subjective experiences of illness has grown, and we know that the course of a patient's chronic disease can become a dominant part of their daily life and their social life. Sometimes the person with the disease also takes on the role as a patient and being part of a social system [4]. It is thus of great importance to increase patient-based research on chronic diseases and conditions, but also to include the perspective of the close relatives in order to form a basis for health care that is also directed outwards, outside the clinic and inside the everyday life of the patient and his/her family.

The two different chronic diseases in this thesis

This thesis focuses on people's experiences of living with a chronic disease. The two diseases that we have chosen to study are neuropathic pain (NP) and coeliac disease (CD), and we have done this from the perspective of being an individual affected by the disease, or a close relative to someone affected. CD is a public health problem, since it is a chronic disease in the western world [15], affecting up to 1% of the general population [16-19]. Research indicates that CD is more prevalent than earlier surveys have indicated, both in the United States and in Europe [19, 20]. Several earlier studies have also shown that living with CD has negative effects on the lifestyles of individuals and their quality of life compared with the general population [21-26]. Earlier research has also found that women with CD scored lower than the general population on subjective health [27] and also expressed worse health-related quality of life than men with CD did [15].

NP is also a common, chronic condition, accounting for approximately 20% of patients visiting pain clinics, and the prevalence in the general population has been estimated to be at least 1% [28]. Approximately 50% of NP patients are found to receive acceptable alleviation of their pain with available methods [29] and thus have to deal with the pain in their daily lives. The emphasis on care and rehabilitation therefore seems more important, since there is no optimal treatment for the underlying disease process [3].

Obviously there is a need for more research and increased knowledge in order to gain a deeper understanding of the problems of living with CD and NP, which should be taken into account in the care and treatment of these patient groups. Health care personnel would be able to offer more professional and patient-focused care if more systematic knowledge of the problems and consequences of living with a chronic disease were available. The patient perspective also considers a combination of

experience, knowledge, cultural and social understanding of the patient's life situation, which is very important for health care personnel [30]. This is also in line with laws and directives on health care that were introduced in Sweden during the 1990s, to strengthen the patient's rights and give them greater influence over their care and treatment. According to the Health Services Act, the demands for patient influence and participation in health care include a number of different aspects, such as how patients are treated, how they are informed about the disease and its treatment, the patients' own knowledge about their disease, their experience of the health service, and also how satisfied they are with the care they receive [31].

BACKGROUND

Description of chronic disease

At the beginning of this century, chronic disease became a major public health problem of industrialised countries [6]. Chronic diseases carry both psychological and social consequences and the daily life experiences of living with a chronic disease necessitates adaptation in multiple life domains [32].

Definition of chronic disease

The definition of chronic disease is complex and in the literature there are several definitions. A general definition is that chronic diseases are those diseases that can only be controlled and not at present cured [3]. Another definition is that chronic diseases are “illness that are prolonged, do not resolve spontaneously and are rarely cured completely” [33]. The terms ‘chronic disease’, ‘chronic condition’, ‘lifelong disease/condition’, ‘long-term disease/condition’ are commonly used interchangeably in the literature. In everyday language, the terms ‘disease’ and ‘illness’ are also often considered to describe the same phenomena, but there are differences in the levels of meaning. Disease is a biological concept; it denotes a state of non-health, in which the body is suffering from a malfunction of one or more parts. Illness describes the consequences and symptoms of a disease [34, 35]; it is a more subjective personal experience connected with the person’s response to being unwell [36]. In the following text in this thesis, the terms ‘chronic disease’, ‘chronic illness’ and ‘long-term disease / condition’ will be used interchangeably.

Epidemiology of chronic disease

The epidemiology of chronic diseases is not easy to describe. Definitions of chronic disease vary; most studies of chronic disease have been based on clinical populations rather than the general population, and epidemiological measures are developed and adapted to acute diseases, such as for example infectious disease and heart disease, rather than to chronic and recurrent disease [37]. The main causes of severe or significant disability appear to be stroke, Parkinson’s disease, rheumatoid arthritis, multiple sclerosis and cardio-respiratory conditions [38]. When studying which are the most common diseases, there are different methods to measure chronic disease, which give different results depending on which measures are used and how they are defined. Studies of self-reports such as the Survey of Living Conditions have shown that almost 40% of the adult population in Sweden, aged 16-84 years, replied

in the affirmative when asked whether they suffered from a chronic disease, experienced difficulties as a result of injuries, had some handicap or other weakness, or if they took medicine because of some disease. Approximately 30% of the population, aged 16-84 years, who suffered from a chronic disease, regularly took medicine for the disease, or both took medicine and had regular contact with primary health care. About 16% of the population had difficulties or great difficulties as a result of their chronic disease. More women than men reported living with a chronic disease. The most commonly described self-reported chronic diseases in Sweden were those related to the musculoskeletal system, to the nervous system or sense organs, to the respiratory organs, to the endocrine system and in connection with various injuries [5]. A Swedish study by Hagström *et al.* [40] investigated the perception of chronic disease (for more than one year) among the working population in a Swedish municipality in 2000 compared with 1980; they found that 40% stated that they suffered from a chronic disease in 2000, which was twice as many compared with 1980. The authors' explanation for the findings was that nowadays there are more conditions to treat and control, since medical treatment options have increased and more conditions can be treated pharmaceutically [40].

Another method to measure chronic disease is the use of health care statistics, measuring the number of patients undergoing hospital treatment per 100,000 inhabitants, men and women, of all ages. The most commonly described chronic diseases in Sweden using this measure was cardiovascular diseases, injuries poisoning and fractures, diseases of the alimentary system, cancer and symptoms/signs and abnormal findings [41]. Health care statistics are naturally influenced by e.g. supply and demand, as to whether people choose to seek care or not, and also by the distance they have to travel for treatment. A further way of measuring chronic illness is to use the proportion of people on long-term sick leave. The most commonly described chronic diseases using this measure were musculoskeletal diseases, mental illness, injuries, diseases of the nervous system and sense organs, cardiovascular diseases, drug/alcohol abuse, and symptoms not applicable to a specific group of diseases [42].

Description of coeliac disease

Experiencing or risking adverse food reactions is a common health problem [43]. CD or gluten intolerance is a disease of food intolerance, and one of the two described chronic diseases in this thesis.

Definition of coeliac disease

CD is defined as a permanent intolerance to gluten, and the related proteins in wheat, rye and barley, causing characteristic damage to the small bowel mucosa. The mucosal lesions vary both in severity and extent. The general opinion is that CD is a complex inflammatory disorder with multifactorial causes. It is also clear that the disease is genetically determined [18, 44]. A necessary cause for a diagnosis of CD to be made is exposure to gluten peptides in the food [17, 45].

Epidemiology of coeliac disease

CD is one of the common chronic disorders in children and it was previously considered to be a childhood disease, with the majority of diagnoses occurring in children under the age of 2 years [17, 46]. In the middle of the 20th century, coeliac disease was a rare condition among adults. One reason could be that CD was not identified in the different ways in which it was expressed. Early epidemiological studies reported the prevalence in England and Wales to be 1/8000 and in Scotland 1/4000 [47]. An early epidemiological study in Sweden among adults found a prevalence of 1/3700 [48] and another study from Sweden showed an incidence of 1/982, indicating that CD was more common than previously thought [49]. Hallert *et al.* [50] found prevalence in Sweden around 1/1000 and there was an increased awareness that CD was under-diagnosed [50]. Nowadays there are better opportunities to identify the disease and CD is a chronic disease in the western world up to 1% of the general population [15]. The disease is twice as common in women as in men [16-19]. The prevalence of CD appears to have changed over the last 30-40 years, in connection with these improved opportunities to identify the disease [51]. The true prevalence of CD is more difficult to ascertain, because many people have atypical symptoms or none at all. Screening programmes indicate that the disease is still under-diagnosed. Recent population screening studies suggest that the prevalence of CD may increase as 1 in 100 [18, 19].

Clinical manifestations of coeliac disease

Very often symptoms and signs of malabsorption become obvious when gluten-rich weaning food is introduced. Diarrhoea, weight loss, vomiting, a distended abdomen and failure to thrive were common symptoms for the young infants. Adult presentation is of course increasingly common and CD can occur at any age. Similarly, symptoms including diarrhoea, weight loss and general weakness are the most common ones in adults [52]. Nowadays CD presenting with a malabsorption syndrome is not

the general rule [53, 54]. CD is a much more complex disorder with symptoms that are not confined to the gastrointestinal tract. When the disease presents later in life the symptoms tend to be vaguer [55]. It is now recognised that the persons do not always have gastrointestinal symptoms, but may present insidiously, for example with iron deficiency anaemia, osteoporosis, ataxia or peripheral neuropathy [56]. According to a study of Fasano and Catassi [46], only 20-50% of adult individuals with CD have subjective symptoms [46].

Treatment of coeliac disease

The key treatment of CD is lifelong adherence to a gluten-free diet, GDF. Wheat, rye and barley-based products must be avoided [17, 55]. Earlier recommendations also included cutting out oats from the diet, but clinical data available suggest that the great majority of persons having CD tolerate oats [57-59]. On a GDF the small bowel mucosal lesion heals and the symptoms disappear [17].

Complications of untreated coeliac disease

Probable complications, which were found in persons with CD before diagnosis or in relation to non-compliance with the gluten-free diet, were risk of anaemia, osteoporosis [59, 60], reduced infertility and unfavourable outcome of pregnancy [61, 62], psychological and neurological symptoms [63, 64]. Psychiatric symptoms are common in untreated adult coeliac disease, the most frequent findings being depression and anxiety [65-68].

Consequences for medical health care

As mentioned above, in the 1940-1950s, when CD was rare, only persons with gastroenterological symptoms in combination with signs of malabsorption were recognised. About twenty years ago, only those at the top of the CD iceberg were diagnosed [69]. Nowadays we know that CD can occur with many different symptoms, and this knowledge has implied that many more people have been diagnosed [70].

If more persons with silent and latent CD are diagnosed, an expected consequence is that health care personnel must be prepared for inquiries asking for information about the disease and the different consequences of living with the disease, for both the gluten-intolerant person and his/her family. By extension, information and increased knowledge in society is also needed. Thompson *et al.* [71] focused on food consumption patterns of adults with CD who adhere to a strict gluten-free diet, and they found that access to CD specialist dieticians is important. It is also well known that rigorous dietary nutritional advice for both

gluten-intolerant persons and their close relatives is important, since studies have shown that gluten-intolerant persons eat a diet containing too little roughage and too much fat [71, 72].

Collin [73] reported that evidence today does not support mass screening of CD, and there is no consensus suggesting mass screening. Serologic screening assays allowed mass screening for the disease, but there was no evidence to suggest that symptom-free persons with CD had an increased risk of complications from being undiagnosed. The strongest indicator for widespread screening was the prevention of osteoporosis. Collin [73] also discussed that screening of asymptomatic individuals for CD was even harmful. In many ways, a life-long gluten-free diet is not easy to maintain and the cost-effectiveness of population screening is dubious. However, Collin [73] suggested increased awareness when physicians in medical health care met patients who were at risk of developing CD. Infertility, neurological symptoms such as polyneuropathy, ataxia, epilepsy with posterior cerebral calcification, and osteoporosis are conditions in which CD should be kept in mind [73].

Description of neuropathic pain

NP is part of the neurological disease spectrum and is the other described chronic disease in this thesis. Since the incidence of different pain conditions has increased in both women and men in Sweden and also worldwide, alleviating chronic pain is a health care priority [74].

Definition of neuropathic pain

The International Association for the Study of Pain (IASP) defines NP as “Pain initiated or caused by a primary lesion or dysfunction in the nervous system” [75] (Merskey and Bogduk 1994 p.212). NP may be caused by an inappropriate response of the nervous system to innocuous or noxious stimulation, and may be initiated by a range of disorders [76]. Usually NP is divided into central NP (from brain) and peripheral NP (from spinal marrow). It can be compared with “normal pain” as follows: in normal (nociceptive) pain and pain due to tissue inflammation, the sensory experiences reflect the normal adaptive functioning of the pain system [77, 78]. Niv *et al.* [78] explained NP as “If the pain system is compared to an electronic burglar alarm, nociceptive and inflammatory pains are like the detection of a malevolent intruder. In contrast NP represents false alarms due to a malfunction in the circuitry” [78] (Niv *et al.* 2006 p.3).

Epidemiology of neuropathic pain

It is difficult to say what proportion of the overall burden of chronic pain is neuropathic, but Bowsher found more than 550,000 cases in the UK population of 56 million at any one time, i.e. a prevalence of about 1% [28]. The most common of the diagnoses classically accepted as NP are diabetic polyneuropathy and postherpetic neuralgia (PHN) [79]. NP has been reported to occur in about 35% of patients with chronic diabetic polyneuropathy [80]. About 60% of limb amputees suffer from NP [81]. It has been estimated that about 30% of spinal cord injury patients suffer from pain [82]. Central NP is reported by about 8% of stroke patients [83], by about 28% of patients with multiple sclerosis, and by about 75% of patients with syringomyelia [84].

Clinical manifestations of neuropathic pain

NP is part of the neurological disease spectrum and may be an expression of severe medical pathology. NP is also a symptom of a number of severe chronic diseases varying in their aetiology and presentation. Apart from traumatic nerve damage, a number of diseases may be accompanied by NP. Central NP is most common after stroke, multiple sclerosis or spinal cord injuries. There may be many causes of peripheral NP, including trauma (e.g. post-operative, post-traumatic neuralgia), nerve compression (entrapment, tumour), metabolic disorders (e.g. diabetic polyneuropathy) or inflammatory conditions (e.g. post-herpetic neuralgia). Evoked pain is defined as allodynia when caused by normally non-painful stimuli, usually a light, moving mechanical stimuli [75, 85, 86]: is usually perceived as a steady burning and / or “pins and needles” and / or “electric shock” sensations. The differences are due to the fact that “ordinary” pain stimulates only pain nerves, while NP often results in the firing of both pain and non-pain (touch, warm, cool) sensory nerves in the same area, producing signals that the spinal cord and brain do not normally expect to receive [78, 86, 87].

Treatment of neuropathic pain

Antidepressants and anticonvulsant drugs have statistically significant efficacy in the treatment of NP. For approximately 50% of the NP patients alleviation of the pain is acceptable with available methods [29]. Severe NP can in some cases be treated with long-term strong opioid therapy, dorsal column stimulation or even deep brain stimulation [29]. However, it is generally acknowledged that NP is difficult to treat successfully. Multimodal rehabilitation often reduces the pain, and studies have shown that people often return to paid work and periods of sick leave are shorter [74]. The use of cognitive-behavioural interventions has been used in many chronic painful conditions, and even if no studies

have examined homogeneous samples of patients with NP syndromes, cognitive-behavioural interventions would probably improve the quality of life even for these groups of patients [88]. Lundberg and Axelsson [74] also found that cognitive therapy, in comparison with other therapies, had an effect on sustained pain both socially and physically, and also on the patient's ability to master the pain [74].

Consequences for medical health care

NP accounts for only a small minority of patients with chronic pain, but the total human and financial costs associated with NP make up a much larger proportion of the overall burden of chronic pain [79]. NP is reported to account for 3% of patients in primary care centres, and for 6 – 7% of patients in hospital units overall [89, 90], and about half of all patients referred to specialty pain clinics [28, 91].

Daily life with a chronic disease

Living with a chronic disease means a variety of dilemmas and consequences in everyday life [92, 93]. An important but often neglected perspective in medical research is the patients' own experiences of what it is like to live with a chronic disease. Most studies have an epidemiological approach and qualitative studies based on patients' experiences are less common. However, since the 1980s this perspective has become more common, with a growing interest in studying the subjective experiences of illness and also the coping process, and it is recognised as an important source of knowledge also for public health research [3, 4, 94, 95].

Lived experiences of chronic disease from the patient perspective

Living with a chronic disease has an impact on a person's quality of life [96-99]. Several studies have also shown that when adhering to a GDF it has effects on the lifestyles of individuals with CD and their quality of life [15, 21, 22, 25, 100, 101]. A German study on adults with CD found that despite being on a gluten-free diet, the persons with CD suffered from more symptoms and had a worse quality of life than the general population [24]. Two Italian studies reported different emotional impact of living with CD [102, 103]. There are also studies showing that adults with CD had depressive symptoms as a features of the disease [65, 68, 104]. Lee & Newman [23] found that maintaining a gluten-free diet included difficulties for the gluten-intolerant persons when dining out, travelling and in family life [23]. Almost the same findings were found

in the Canadian coeliac health survey by Cranney *et al.* [105] where the informants reported difficulties when travelling, making purchases and having meals with other people outside the home [105].

A similar pattern of effects on quality of life has also been shown in NP patients. Meyer-Rosberg *et al.* [106] assessed health-related quality of life using the Short-Form 36 in a group of 126 adults with chronic NP. They found that scores on the SF-36 were significantly worse in all domains in the neuropathic population compared with the general population [106]. In a review study by Jensen *et al.* [107] 52 articles were identified that examined the association between NP and health-related quality of life. They found strong and constant evidence that the presence and severity of NP is associated with greater impairments across a broad spectrum of health-related quality of life domains, including physical, emotional, role and social functioning [107].

Lived experiences of chronic disease from the patient perspective – differences between women and men

In a Swedish 10-year follow-up, Hallert *et al.* [27] studied the quality of life in patients with CD using the SF-36. They found that adult persons having CD scored significantly lower and thus had worse quality of life than the general population, notably within the general health and vitality domains. However, this low scoring was confined to women only. The male CD population scored better than the background population [27]. An American study of the impact of gluten-free diet on quality of life showed the same pattern, with a dominance of negative impact on women [23]. In a study comparing persons with CD and type-2 diabetes, Hallert *et al.* [108] found that women with CD had a lower level of subjective health than men, were less satisfied with the outcome of treatment and expressed more concern about the impact of their disease on social life and having to abandon important things in life [108]. In yet another Swedish study, women with long-standing CD expressed worse health-related quality of life than men did [15]. In her thesis, Gullacksen [109] interviewed women with chronic pain and found that they had a feeling that their position in the family changed and was threatened during sick leave, because it was impossible to continue being responsible for the household work. Before the chronic pain occurred it was natural for the women to do both the paid and unpaid work. After the chronic pain started it was not a matter of course to ask their partner to do the housework besides the paid work [109].

Lived experiences of chronic disease from the close relatives' perspective

Close relatives are important and a key resource for the health and quality of life of persons with chronic diseases. There are several studies that indicate the importance of social support in the case of chronic disease [110-115]. In contrast, chronic disease also leads to disadvantages, not only for the diseased but also for those close to them [116, 117]. To the best of this author's knowledge, no studies have been carried out on relatives of persons with CD or NP. Gullacksen [109] described in her thesis that is not usual in scientific pain research to describe the experiences of partners living with a person with chronic pain [109]. However, there are studies focusing on the experiences of close relatives living with a partner suffering from fibromyalgia, stroke, muscular dystrophy, diabetes, and heart attack patients [111, 118-122]. An interesting finding was the study by Kuyper and Wester [123], who found that partners of patients with chronic disorders experienced contradictory feelings: guilt and fear if they prioritised themselves, and feelings of anger and resentment if they prioritised their relative's spinal marrow [123].

Management of chronic disease in daily life from the patient perspective

Daily life with a chronic disease implied learning to live with new vital necessity and new conditions in life. All this implied a continuous adaptation to the new way of life. There is increasing knowledge about the ways in which people adapt or cope with stressful life events and adapt to a new life situation. Many differences are found in adjustment among persons who have experienced chronic pain, but fewer investigations have been carried out on CD. Several studies have used models of stress and coping to help explain individual differences in the management of chronic and other diseases [124]. The concept of coping was originally developed in studies of stress and how persons managed stressors. In the theory developed by Lazarus and his co-workers [125], coping was regarded as a process, depending on its context [125]. From this perspective, coping changes over time and in accordance with the situational contexts in which it occurs. Two major types are described by Lazarus & Folkman [125] those that change the situation, such as seeking information about the condition, learning to control symptoms and also planning for the short and long term (problem-focused coping); and those that control emotional responses to an event (emotion-focused coping) [125]. In the literature of pain some researchers categorise coping

efforts into active and passive dimensions [126]. Active strategies are defined as responses requiring a person to initiate some instrumental action to manage pain. Passive strategies involved withdrawal or giving up control to an external force or agent [127]. Several studies have discussed the positive use of cognitive-behavioural interventions in many chronic painful conditions [88, 128, 129].

It is well known from earlier studies that women with CD describe more distress caused by restrictions in their daily life [27, 108]. Hallert *et al.* [15] reported from their qualitative study, where they interviewed 10 persons who had been on a GFD for ten years, that the level of acceptance was higher for men; they reported that CD was a natural part of life and as such nothing to focus on particularly. The women described behaviour in terms of checking every meal, and wanted gluten-free food without asking for it, in contrast to the men for whom just plain coffee was enough. The coeliac men took advantage of using a problem-oriented coping approach, while the women sought an emotionally oriented strategy and showed less satisfaction with the outcome [15].

AIMS OF THE THESIS

The general aim of this thesis was to extend our knowledge of what it is like to live with a chronic disease, from the perspective of NP and CD.

The specific aims and questions of each study were:

- to explore the qualities of dilemmas experienced by patients with chronic NP in their everyday life (I)
- What dilemmas were experienced, and what kinds of disturbances were associated with these dilemmas? What were the consequences of these dilemmas? How did patients manage dilemmas and their consequences? (I)

- to explore the dilemmas experienced by women and men in their everyday lives in relation to their CD, and to explore the qualities of these dilemmas in relation to specific situations and living conditions (II)

- to explore dilemmas experienced by close relatives in their everyday lives, when living with a person suffering from CD, and to describe the strategies that close relatives used to deal with these dilemmas (III)

- to explore consequences of experienced dilemmas in women and men in relation to the social context of their everyday lives as personally affected by CD, or as close relatives to someone affected by the disease (IV)

RESPONDENTS AND METHODS

Study design

The studies in this thesis were qualitative in design, and qualitative method was used in all of the studies I-IV. The critical incident technique (CIT) was chosen to be an appropriate method for data collection. In study IV a combination of qualitative (CIT) and quantitative methods was used.

The methodological approach in the thesis

Phenomenology

CIT can be described as part of a phenomenological approach, perceived as the effort to describe human experiences as they are lived. Phenomenology is concerned with understanding a phenomenon rather than explaining it, and phenomenology is not just a research method but also a philosophy and an approach [130].

The phenomenological method

The phenomenological method consists of describing the structure of lived experiences, or what that experience means to those who live it [130]. The phenomenological method is an inductive, descriptive research method. The goal of the method is to describe the total systematic structure of lived experience, including the meanings that these experiences have for individuals. In the phenomenological method the researcher approaches the subject and the experience with an open mind, accepting whatever data are given [131]. A necessary criterion is that the researcher must approach the phenomenon to be explored with no preconceived expectations or categories. The concern of the phenomenological researcher is to understand both the cognitive subjective perspective of the person who has the experience, and the effect that perspective has on lived experience or behaviour of the person [132]. In the phenomenological method, epoché or bracketing is a methodological attitude towards the studied phenomenon. As a researcher this includes setting aside personal or theoretical concepts, opinions and expectations about the phenomenon and striving to describe it as precisely as it is given [133].

Overview of the studies and study population

An overview of main topics, inclusion criteria, data collection method and study population on which the four studies in this thesis are based, is presented in table 1.

Table 1. Overview of main topics, inclusion criteria, data collection method and study population on which the four studies in this thesis are based

Study	Main topics	Inclusion criteria	Data collection method and study population
I Experienced dilemmas by women and men in everyday life in relation to neuropathic pain.	Exploring what kind of dilemmas were experienced. Exploring disturbances, consequences and managing associated with these dilemmas.	Neuropathic pain, central or peripheral pain. Attended a four-week rehabilitation programme for neuropathic pain patients.	Semi-structured interviews. Number of informants=39, of which 23 women and 16 men.
II Experienced dilemmas by women and men in everyday life in relation to coeliac disease.	Exploring what kind of dilemmas were experienced.	Definitive diagnosis of coeliac disease during 1991-1998. Born 1961-1981. Permanent address in Östergötland and near the city of Jönköping	Semi-structured interviews. Number of informants = 43, of which 32 women and 11 men.
III Experienced dilemmas by close relatives living with a person suffering from coeliac disease.	Exploring what kind of dilemmas were experienced. Exploring managing strategies associated with these dilemmas.	Being a close relative to an informant in study II. Cohabiting with the informant.	Semi-structured interviews. Number of informants =23, of which 6 women and 17 men
IV Gender and consequences of dilemmas experienced in everyday life with coeliac disease.	Exploring the consequences of experienced dilemmas by women and men in relation to the social context.	The total population from study II and study III.	Semi-structured interviews. Questionnaire. Number of informants = 66, of which 38 women and 28 men.

Study I

Patients included in study I had NP of central or peripheral origin. All had attended a course in a four-week rehabilitation programme for NP at the Pain Rehabilitation Centre at Linköping University Hospital and the Department of Rehabilitation in Linköping. The criteria for inclusion in the rehabilitation programme were:

(1) chronic NP (>6 months), (2) pain resistant to TENS, conventional analgesics, tricyclic antidepressants, anticonvulsants and conventional analgesic blocks, (3) pain intensity high enough to interfere with daily life, and (4) a calculated estimate (by evaluation and group consensus before entering the treatment programme) that the multidisciplinary treatment programme would benefit the patient. Criteria 3 and 4 were based on a global, clinical evaluation by physiotherapist, occupational therapist and rehabilitation physician, and team consensus before patients entered the treatment programme. Forty-two patients were invited to participate in this study (I) after they had been selected for the rehabilitation programme. Three patients (two men and one woman) declined to participate in the study (I). The final study population thus consisted of 39 patients: 23 women and 16 men.

Demographic characteristics of the patients in study I are shown in table 2.

Table 2. Characteristics of the population in study I

	Women (n=23)	Men (n=16)	Total (n=39)
Age (years)			
20-39	7	7	14
40-59	12	6	18
60-80	4	3	7
Marital status			
Married/cohabiting	12	12	24
Single/divorced/widowed	11	4	15
Occupational situation			
Full- or part-time work	13	6	19
Disability or old-age pension	8	8	16
Unemployed	2	0	2
Student	0	2	2
Pain intensity (Visual Analogue Scale)*			
1-4 (light/moderate)	1	2	3
5-6 (strong)	5	6	11
7-8 (severe)	9	3	12
9-10 (intolerable)	2	1	3
Pain duration in years			
0.5-5	10	7	17
6-10	6	6	12
11-20	7	3	10

*Information missing from 10 patients.

Study II

The informants were treated at four Swedish hospitals: Linköping, Norrköping, Motala (Östergötlands county council) and Jönköping rural district, situated in southern Sweden, covering a population of more than 500,000 individuals. Inclusion criteria were CD, born during the period 1961-1981, permanent addresses in the county of Östergötland and near Jönköping, and a definitive diagnosis of CD during the period 1991-1998. The informants were identified by the patient registers of dieticians at the Departments of Internal Medicine at Linköping, Norrköping and Motala hospitals. All informants who fulfilled the criteria were included: 43 informants in all. They were invited to participate in study II by letter. Of the twelve who declined to participate, there were six women and six men. Of the remaining 31 identified for participation in study II, 21 were women and 10 were men. At the fourth hospital,

in Jönköping, the informants were identified by a CD specialist at the Department of Internal Medicine, who identified 32 informants that fulfilled the inclusion criteria. All identified informants received a letter with information on the study (II) and an invitation to contact the researcher if they were interested in participating. This procedure was slightly different compared with the one used in Östergötland. The reason was that, due to ethical and legal reasons, the CD specialist did not want the researcher to contact the patients directly before they had shown interest in the study (II). Of the 32 identified as fulfilling inclusion criteria, 12 informants were interested in participating in study II: 11 women and 1 man. The dropout thus consisted of 20 individuals. The final study population was 43 informants: 32 women and 11 men. Our sample consisted of all those diagnosed with CD at the hospitals during 1991-1998 in the catchment areas of four different hospitals, covering a population of more than 500,000 individuals. Demographic characteristics of the informants are shown in table 3.

Table 3. Characteristics of the population in studies II-IV

	Gluten-intolerant persons n=43		Close relatives n=23	
	Women (n=32)	Men (n=11)	Women (n=6)	Men n=17)
Age (years)				
20-29	13	4	1	4
30-39	19	7	3	9
40-49	0	0	2	3
50-59	0	0	0	1
Education				
9-year compulsory school and vocational school	2	1	0	1
Upper secondary school (2 years)	4	1	0	4
Upper secondary school (3 years)	14	6	1	7
University	12	3	5	5
Employment status				
Full-time work	12	9	4	15
Part-time work	9	1	1	0
Student	4	1	1	2
Unemployed or sick-listed more than 3 months	3	0	0	0
Parental leave	4	0	0	0

Study III

All of the participants with CD in study II (n=43) who were cohabiting (n=36) were asked for permission to contact one close relative of their choice. All except one gave permission. Of the 35 close relatives, 12 declined to participate. The dropout among close relatives consisted of 11 men and 1 woman. Of the remaining 23 close relatives who participated in study III, 17 were men and six were women. Of these, 21 were partners and two were parents. Demographic characteristics of the informants are shown in table 3, page 29.

Study IV

This study (IV) was based on data collected from the 43 gluten-intolerant persons, identified in study II, and 23 close relatives to gluten-intolerant persons, identified in study III. Study IV included 38 women and 28 men. Demographic characteristics of the informants in this study (IV) are shown in table 3, page 29.

Data collection

In this thesis two different methods for data collection were used: CIT and a questionnaire. No existing questionnaire with the content that we wanted to elucidate was found, and thus a new questionnaire was developed, described in more detail below.

Critical incident technique

CIT is described as a highly flexible qualitative research method, by which observations of human behaviour in defined situations can be collected [134, 135]. It captures, in a structured way, the qualities of perceived dilemmas and experiences. The method was developed and first used to improve the selection of pilots and the pilot training programmes in the United States Air Forces Psychology Program[134]. A critical incident is the most central concept in CIT and represents an event of great importance to the person involved. Flanagan [134] defined a "critical incident" as "any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act. To be critical an incident must occur in a situation where the purpose or intent of the act seems fairly clear to the observer and where its consequences are sufficiently definite to leave little doubt concerning its effects" [134] (Flanagan 1954 p.327). In this thesis a critical incident was a dilemma defined as a "perplexing or awkward situation perceived by a patient to cause disturbances in the performance of his / her everyday life" [1, 2].

In a critical incident study the number of participants included is of less interest. The analytical basis is the number of critical incidents reported. There is no strict rule, but the general advice given is to collect incidents until redundancy appears [134, 136].

The interview

In this thesis, data was collected through semi-structured interviews to make it possible for the person with NP and CD and the close relatives to describe experiences in their own words. Based on a questionnaire used in earlier studies, an interview guide with similar content was developed [1, 2, 137, 138]. After a short introduction, the informants were asked the following question:

- Can you describe the last occasion in your everyday life when you were hindered by or reminded of your NP/ of your intolerance to gluten/ of being a close relative to someone with CD?

Follow-up questions allowed the subjects to describe:

- More about this situation or dilemma.
- The consequences of the dilemma.
- The measures taken to handle or manage the situation.
- Suggestions for measures that could have prevented the dilemma.

Each interviewee was asked to describe their three most recent dilemmas. In study I and II we also included a question on the most severe dilemma that the informants had experienced in relation to their NP / CD. In all of the studies the questions were also pre-tested to evaluate their functionality and to fine-tune the interview guide. Minor changes were made.

The questionnaire

As an attempt to put the results from the qualitative part into a social context regarding household activities, and thus give a deeper understanding of the reasons behind previously found differences in men and women living with CD, a questionnaire was developed for an identification of numbers and proportions of the women and men that had certain experiences. No existing questionnaire with the content that we wanted to elucidate was found, and thus a new questionnaire was developed. The questionnaire included demographic information, and information on food preparation, purchase of food, cooking habits

and meal behaviour. To evaluate its functionality the questionnaire was tested on 16 persons, who were dieticians, researchers, and academic personnel at Linköping and Göteborg University. The questionnaire was revised and pre-tested by two gluten-intolerant persons and two close relatives who did not participate in the studies (II, III) in order to evaluate its functionality in a population for which the questionnaire was intended. Some changes were made after the pre-test. Finally this version of the questionnaire was tested by two gluten-intolerant persons and minor changes were made. The questionnaire distributed to the gluten-intolerant persons included 30 questions, and for the close relatives 25 questions were included. The questionnaires distributed to the gluten-intolerant persons and the close relatives are available in Swedish and will be sent on request.

The questions analysed in this thesis were:

- Who makes preparations for and comes to a decision about purchasing foodstuffs?
- Who buys foodstuffs for the household?
- Do you usually read the table of contents on the foodstuffs when buying food?
- Who cooks the food?

Data collection procedure

Study I

Patients received information about the study (I) by letter, and two weeks later they were contacted by telephone. Participation was voluntary and based on informed consent. All interviews were conducted by the same interviewer (AS, second author) who was not involved in any other way in the rehabilitation programme. The length of the interviews ranged between 60 and 90 minutes. The interviews were conducted in a relaxed atmosphere in “non-hospital-like” rooms at the two hospitals. For practical reasons (e.g. travel) some patients were interviewed before (n=7), some during (n=22) and some after (n=8) the treatment programme.

Studies II-IV

The gluten-intolerant persons and the close relatives were invited to participate in the study (II, III) by letter. They received information

about the objectives of the study, explaining that their participation would be voluntary and that they could withdraw at any time. They were also informed about guaranteed confidentiality. Two weeks after they received the introductory letter the informants were contacted by telephone and asked about participation. A time and place for the interview was arranged. All participants were conducted by the same interviewer (AS, first author) at a confidential place chosen by the participant, either in their homes or at the hospital. Interviews lasted between 45 and 90 minutes; they were taped with the informant's permission and transcribed verbatim. The gluten-intolerant person and the close relatives who wanted to participate in the study (II, III) also received a questionnaire by post and they were asked to fill it out in advance and bring it with them to the interview.

Data analysis

For to facilitate the understanding a description of the various terms and concepts that has been used in this thesis is given in figure 1.

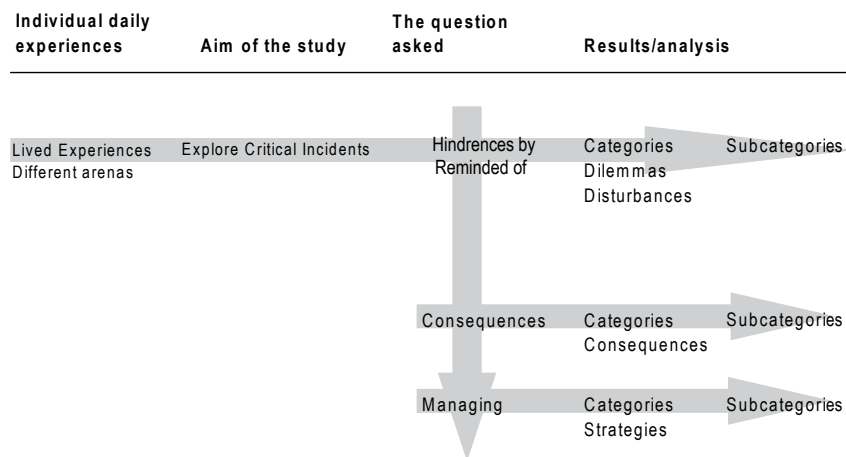


Figure 1. Description of theoretical and operationalised concepts and terms used in this thesis.

Lived experiences are what people continuously experience in their everyday lives at various arenas. In the interviews we asked the individuals to tell us about situations when they had experienced hindrances, or were reminded of the disease. Such situations are critical incidents and from the descriptions of critical incidents we identified dilemmas, consequences and how these incidents were managed. Through the qualitative analysis we identified categories and

subcategories of dilemmas, disturbances, consequences and strategies, which were the terms used in the articles. It is worthy of note that a lived experience of a dilemma and of a consequence can result in similar categories or subcategories. An example is that shame can be a dilemma, but also a consequence of a dilemma. It may also be the case that something which on one specific occasion might be experienced as a dilemma for one individual may be a consequence of an experienced dilemma for the same individual on another occasion. In study I we also identified disturbances, by analysing, grouping and naming comprehensive, common experiences of critical incidents. Thus, more refined experiences of critical incidents were identified in that study by identifying both the dilemma and disturbances.

The first step in the analysis of the interview data was to read each interview several times in order to become familiar with the data and to obtain a sense of the whole. The transcribed interviews were read both horizontally (the whole interview of an individual patient) and vertically (the answer to a specific question from all patients) [1]. The horizontal reading gave contextual and complementary information, while the vertical reading was done in order to capture common features in the answers. In the data reduction the researchers marked the dilemmas that were critical. The dilemmas presented varied with regard to degree of difficulty and intensity.

In the initial part of the analysis the dilemmas were first abstracted from the text, given a label, transferred onto cards and then organised into groups. The groups of dilemmas were then reformulated into different kinds of behaviour. Parallel to several re-readings and reflections upon analysis, the dilemmas were then more systematically sorted and classified into subcategories and categories. The next step in the analysis was to reduce the information presented in the categories to short definitions, and to find appropriate terminology or labels for each category.

The analysis of the questionnaire began by AS (the first author) registering the answers from the gluten-intolerant persons and their close relatives. The registered answers were checked once again by the same person (AS, the first author). Statistical analysis of frequency distribution was undertaken using the Statistic Package of Social Sciences (SPSS).

Ethical considerations

This thesis was performed in accordance with the World Medical Association Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects which safeguard that the participant's right of autonomy and self-determination are respected [139]. Scientific ethics have naturally been taken into consideration in that research has been carried out in areas where there has been an expressed need for research.

Permission for studies I- IV in this thesis was obtained from the Research Ethics Committee of the Faculty of Health Sciences at Linköping University, Sweden.

Participant ethics

All participants were informed about the aim of the study and what their participation involved both by letter and by verbal information before the study began. It was also made clear that participation was voluntary and that the participants could withdraw from the study at any time.

After the written information was sent home to the participants, they were contacted two weeks later, giving them time to consider whether or not they wanted to participate. Informed consent was obtained for the studies in the thesis. In doing personal interviews, there is always a risk of crossing what the participants consider to be their private sphere. In all of the studies, the interviewer (AS) always had extra time, if necessary, to deal with questions, emotions and psychological reactions from the participants in relation to the interviews. In working with the material, care was taken to safeguard the participants' personal integrity. In the quotations from the individual participants, details were deleted from the interviews so that individual respondents cannot be recognised.

The interview tapes, transcriptions of the tapes and questionnaire responses are kept in a locked filing cabinet at the Department of Social Medicine and Public Health, Linköping University (study I), and at the Department of Social Medicine at the Sahlgrenska Academy, Göteborg University (studies II-IV). The interview tapes, transcriptions of the tapes and questionnaire responses were only used for scientific research.

RESULTS

The results from the different studies are given below. Study I, focusing on everyday life with NP, is shown separately. In studies II-IV, all the studies focused on everyday life with CD and the results are therefore shown together. A description and explanation of the various terms and concepts that has been used, was given earlier, in figure 1, page 33.

Study I

Study I explored the qualities of dilemmas and disturbances, experienced by patients with chronic NP in their everyday life. Furthermore, consequences of their experienced dilemmas and strategies to manage the NP were analysed.

Dilemmas and disturbances

Nine categories of dilemmas were analysed when the patients were hindered by or reminded of their NP. The experienced dilemmas were housework, physical activity, sitting, personal hygiene, sleeping difficulties, hypersensitivity to external stimuli, social relationships, transportation and leisure time. Disturbances were failures, inabilities and restrictions. It is important to note that these disturbances were not associated with one specific dilemma but associated more or less with all kinds of dilemmas.

Consequences

The consequences of dilemmas experienced by patients with NP were: increased pain, psychological consequences, physical symptoms, social consequences and fatigue. The most common consequence was increased pain, i.e. that pain was more intense than usual. The psychological consequences were grouped into states of depression including sadness, feelings of worthlessness and incapability, and general psychological symptoms such as anger, fear, nervousness, irritability and lack of concentration.

Managing dilemmas

Furthermore we identified seven categories of how dilemmas were managed. The majority of the patients used active-oriented strategies to manage their pain, e.g. alternative way, cognitive strategies, continued activity and physical activity. 'Alternative way' meant using all possible ways of doing whatever activity the patient was doing in another way so as to avoid increased pain, for example a change of posture, use of a technical aid, or doing things more slowly. A common strategy for

managing dilemmas was using cognitive strategies. However, the patients did not use a specific cognitive technique. The patients in study I tried to influence and manage the pain through thoughts, imagery and mental training. Continued activity implies that the patient just actively ignores the pain and continues the activity disregarding the pain.

Studies II-IV

These studies explored experienced dilemmas and consequences of experienced dilemmas by women and men in their everyday lives in relation to their CD, and among close relatives in their everyday lives when living with a person suffering from CD (table 4).

Table 4. An overview of categories and subcategories of lived experiences of dilemmas, and consequences of experienced dilemmas in everyday life among persons (n=43) with coeliac disease, and among close relatives (n=23) of persons with coeliac disease.

Dilemmas Persons with coeliac disease (Study II)		Dilemmas Close relatives (Study III)		Consequences Persons with coeliac disease and close relatives(Study IV)	
Category	Subcategory	Category	Subcategory	Category	Subcategory
Emotions	Isolation Shame Fear of becoming contaminated by gluten Worries about being a bother	Disease related worries	Bad conscience Anxiety Witnessed vulnerability	Emotional consequences	Sadness Irritability Shame Being constantly anxious Feeling sorry for the other person Experiencing conflicts
Relationships	Unwanted visibility Neglect Being forgotten Disclosure avoidance Risk-taking	Disturbances in social life	Lack of information Lack of knowledge Lack of understanding	Being different	Being a social nuisance Forgoing pleasures
Management of daily life	Restricted product choice Double work Constantly being on call	Management of daily life	Double domestic work Restricted freedom of action Preferential right of interpretation	Daily concerns about gluten	Loss of time High prices Few options
				Sense of constant preparation	Pre-discussion Pre-explanation Pre-planning Keeping gluten in focus
				Body sensations due to coeliac disease	Forced unhealthy eating Feeling peckish Feeling queasy due to gluten

The findings from the interviews with 43 persons with CD showed that the disease had important implications for the individual person and his / her social life. Emotions, relationships and the management of daily life were the three categories of dilemmas identified, and the arenas where they were experienced were: food situations at work, while making purchases, when travelling, in relation to meals at home and meals outside the home.

The findings from the interviews with the 23 close relatives were along the same lines, and showed a variety of dilemmas that affected the situation of the whole family. Three main categories of dilemmas were identified and labelled: disease-related worries; management of daily life; and disturbances in social life. The dilemmas were experienced in the arenas within the family, in social relations with friends and relatives, and in interaction with service professionals in restaurants and shops.

We also analysed how the close relatives living with a person suffering from CD managed the dilemmas. The close relatives described four different handling strategies to manage daily life, each of them leading to a different outcome. The described strategies included: planning in advance for all meals; all members of the family following a GFD; avoiding visits to friends, relatives and restaurants, due to not knowing how they would be treated. Finally, the last strategy described was to become more knowledgeable by teaching one's social network about CD.

The main consequences of experienced dilemmas were daily concerns about gluten, sense of constant preparation, being different, experiencing emotional consequences and body sensations due to CD. The main finding was that types of consequences experienced in relation to dilemmas of CD were similar in women and men, irrespective of whether they were gluten-intolerant themselves or a close relative. In order to gain a deepened understanding of possible gendered consequences of CD, and to put the disease into context regarding household activities, a questionnaire was used to identify the numbers and proportions of the women's and men's experiences. The distribution of household work related to the food preparations, purchases and cooking habits of women and men living with CD, either as personally affected or as close relatives, is shown in table 5.

Table 5. Distribution of household work related to food preparations, purchases and cooking by women and men living with coeliac disease, either as affected or as close relatives

Type of household work	Preparations		Purchases		Cookery habits **	
	Women 38 (%)	Men 28 (%)	Women 38 (%)	Men 28 (%)	Women 34 (%)	Men 25 (%)
Person responsible and executing the task						
Solely myself	8 (21)	4 (14)	6 (16)	4 (14)	13 (38)	3 (12)
Solely my spouse	*	*	*	*	3 (9)	8 (32)
Both, but mostly myself	16 (42)	1 (4)	16 (42)	1 (4)	*	*
Both, but mostly my spouse	0	13 (46)	2 (5)	7 (25)	*	*
Both	13 (34)	9 (32)	13 (34)	15 (54)	16 (47)	13 (52)
Other/missing	1 (3)	1 (4)	1 (3)	1 (4)	2 (6)	1 (4)
Total	38 (100)	28 (100)	38 (100)	28 (100)	34 (100)	25 (100)

* This alternative was not used for this question in the questionnaire.

**This question was only answered by those living alone.

DISCUSSION

This thesis showed that living with a chronic disease from the perspective of persons with CD and NP has important implications for the individual person and an unexpected profound impact on self-perception and social relationships. Interviews with close relatives to persons with CD identified that sharing life with an adult gluten-intolerant person involve also the close relatives in emotional and social dilemmas. Thus, a chronic disease, even if its symptoms are possible to control in this case through a special diet, can in a negative way be associated with disadvantages not only for the person suffering from the disease but also for those close to them. An interesting finding was that most of the consequences of experienced dilemmas were related to the CD itself rather than to being a gluten-intolerant person or a close relative. An important finding was also that the unequal distribution of household work seemed to contribute to a “triple burden” for both women and men, but that the effects of this “triple burden” might influence women more since they had the main responsibility for the household work.

In the discussion section below there is first an account of methodological considerations, strengths and limitations. After this the main findings of the thesis will be discussed. Finally general conclusions, including clinical implications and suggestions for future research, are presented.

Methodological considerations, strengths and limitations

Description of pre-understanding

The studies in this thesis had a phenomenological approach and an important feature was to bracket earlier knowledge and preconceptions in order to identify the informants’ own experiences as closely as possible. As a researcher this included setting aside personal or theoretical concepts, opinions and expectations during the analytical phase [133]. My professional background is more than 20 years as a social worker at a university hospital, most of the time at a neurological clinic, and a short period at a pain and rehabilitation centre. As a medical social worker at a hospital I have had a counselling and therapeutic role in encounters with patients affected by different kinds of chronic diseases such as multiple sclerosis, Parkinson’s disease, stroke, epilepsy and chronic pain, and these encounters have led to a genuine interest and great respect for patients, their relatives and the difficulties they need to deal with. Throughout the

research I have tried to be highly aware of this, and as a research group we have tried to minimise the effect of my background experiences on the findings, through different procedures described in more detail below. Unlike my experience of NP, I had no earlier professional experience of CD. A personal experience is that a close relative has had the disease for more than ten years. However, it is also important to recognise that some background information might be of value, so bracketing earlier knowledge and preconceptions is a balancing act between well grounded background information that can contribute to deepen the interviews and analysis, and preconceptions that hinder identification of new perspectives and experiences provided by the informants.

The critical incident technique

The CIT is a well-established method for data collection, and several studies have been performed on different populations including patient groups [1, 2, 134-136, 140-143]. The choice of CIT for the studies included in this thesis was guided by earlier studies which had shown that CIT is efficient in capturing also minor dilemmas of importance for the daily life of the patient [1, 2]. We are satisfied with the choice of the method for data collection, since we really think that the method has been efficient in capturing both minor dilemmas and major recurrent dilemmas. This conclusion is based to a large extent on the diversity of the dilemmas identified. A disadvantage was that interviewees in a few cases had difficulty remembering dilemmas and it is also possible that there could be gaps in their memory. To avoid the interviewees only describing uncommon or the most dramatic dilemmas, instead of everyday events, the informants were asked to describe the three most recent dilemmas in their everyday lives.

A general limitation of CIT is that it is intended only to capture “critical incidents” rather than the whole range of lived experiences in an individual’s life. Patients with chronic diseases can report that in spite of the problems associated with their disease they have matured as persons or have found new perspectives of life that are actually positive rather than negative experiences. However, by using CIT we focused only on critical incidents, and naturally this implied that the picture given of the everyday life might be interpreted as more problematic than the participants actually thought that their life was. Another aspect related to the fact that this is a qualitative study is that we only focused on problematic situations, irrespective of the degree of difficulty or frequency of these situations.

The interview as a data collection method

Kvale [144] clarified and emphasised the difference between the aim of interviews as part of treatment or therapy [144]. In the latter case the aim is to start a process of change for the person, while the aim of the research interview is to collect new information through the interview. The professional background as social worker is complex and includes experiences of different types of interview and communication situations. Most of these experiences and competencies have been an advantage and strength throughout the research process. The social worker use therapeutic, counselling, motivating, supporting and investigating interviews, and in several cases the main goal of the interviews is to receive new and in-depth information, or to listen and understand. This background was an advantage in the interviews, but since the material discussed during the interviews was centred on dilemmas or problematic situations a special emphasis was made to avoid an opening of therapeutic alliances or start therapeutic processes. However, as far as possible I think that the framework of the research interview was obvious to all informants and that the borders to therapeutic interviews were kept.

Trustworthiness of qualitative studies

The four most common criteria to evaluate that qualitative research is trustworthy has been described by Dahlgren *et al.* [145] and they are listed in table 6, and discussed below in relation to the trustworthiness of this thesis [145].

Table 6. Criteria for assessing the trustworthiness of research findings according to qualitative research traditions (After Dahlgren *et al.*, 2004; p.47)

Question asked	Qualitative criteria	Trustworthiness in this thesis
Have we really measured what we set out to measure?	Credibility	Asked about most severe dilemma (studies I and II) Triangulation among researches (studies I-IV) Feedback on results from the informants (study II)
How applicable are our results to other subjects and other contexts?	Transferability	Saturation point. No new categories emerged. Thick descriptions
Would our findings be repeated if our research were replicated in the same context with the same subjects?	Dependability	Research process was written down Personal notes about research during the process Seminar discussion about categorisation (study II-IV)
To what extent are our findings affected by personal interests and biases?	Conformability	An additional author in studies III-IV Counselling bias Pre-understanding and previous knowledge(AS)

Credibility of qualitative studies

In qualitative research, truth value is assessed by credibility. One way of increasing the credibility in our studies was to ask about the most severe dilemma (studies I and II). We found a high correspondence in content between dilemmas and the most severe dilemma asked for at the end of the interview. Credibility was reinforced since similar dilemmas returned. Another technique for enhancing credibility was triangulation, which was used in all four studies. Researcher triangulation was used in the following way when the dilemmas were identified and categorised. In study I, close reading of complete interviews or significant parts of the interviews was carried out by all authors. In the categorisation an initial suggestion was presented by the second author (AS) and then discussed and revised by the two other authors (GH and GL).

In study II, two of the authors (AS and GH) identified and categorised the same data, GH with methodological knowledge related to CIT. In the final stage of the analysis the results were also scrutinised by the third author (CH), a CD specialist. In studies III-IV, two of the authors (AS and GÖ), both with long experience of interviewing persons in clinical care, as well as methodological knowledge related to CIT, identified and categorised the same data. In the final stage of the analysis the results were also scrutinised by the third author (GH), who was not involved in the categorisation. An additional way of increasing the credibility is by giving feedback on the results to the participants. In study II the participants got a copy of the published paper with a letter providing an opportunity to discuss and reflect with the first author (AS). However, I have not heard from any of the participants. There is an on-going process of giving feedback on the results to the participants in study I. The intention is also to give feedback on the results to the participants in studies III and IV when the studies are published.

Transferability of qualitative studies

An important question in research is how applicable the results are to other subjects and in other contexts, and applicability is assessed by transferability in qualitative research. Qualitative research never tries to obtain statistical generalisation; the aim is more a matter of qualitative descriptions and analytical generalisations. An important question concerns the sample selection since qualities of the population also should be captured in the research population [145, 146]. One way of showing that we captured relevant dilemmas, consequences and strategies could perhaps be that in all studies we reached a saturation point in

the results where we did not find any new categories in the material. In qualitative studies it is not possible, nor is it the aim, to completely generalise the findings from a qualitative study to other populations. The knowledge that is presented in this thesis in the form of lived experiences, dilemmas, consequences, and how to manage daily life, can in my opinion be transferred to a certain extent to similar study populations. This conclusion is drawn from the fact that some findings in this thesis appear in other studies with nearly the same study populations. A certain amount of knowledge about what it is like to live with a chronic disease can without doubt be transferred to other study populations and this has been shown, since we found that sometimes there were similar experiences when living with CD and NP; in other words, there are certain specific experiences connected with the very fact of living with any chronic disease, and not with a particular one [145]. These thoughts are in line with those of some other researchers. Dahlgren *et al.* [145] discussed that it is possible to generalise knowledge from qualitative studies. It is the knowledge and the theory that could be applicable to similar situations, questions and problems, regardless of the demographic characteristics [145]. Svensson [146] also discussed that the results from a qualitative study could be transferred to populations other than that in the present research [146]. Graneheim [147] discussed that it is up to the reader to judge if the results can be transferable to other contexts, depending on the researcher's ability to describe the research process so the reader is able to judge the transferability [147].

Dependability of qualitative studies

Consistency in qualitative research, i.e. dependability, refers to whether the measuring instrument is trustworthy; [145] if our findings would be replicated in the same context with the same subjects. To ensure dependability in this thesis, decisions about the research process were written down and there were also different types of personal notes about the research process. During the time I have worked with this thesis I have had scientific seminars at the Department of Social Medicine at the Sahlgrenska Academy, Göteborg University, with participants from different scientific and professional backgrounds, and in these seminars the categorising of the results in studies II-IV has been discussed to reinforce dependability.

Confirmability of qualitative studies

Finally, confirmability is to a large extent connected with credibility. Confirmability refers to the researcher's ability to be neutral and not colour data with pre-understandings. However, confirmability refers

more to the neutrality of the data rather than the neutrality of the researcher [145]. To avoid a possible research bias from study II on patients with coeliac disease, an additional examiner and author (GÖ) participated in study III.

Another possible bias is what we could call a “counselling bias”. As a social worker I have great experience of listening to people in the counselling and therapeutic role, and understanding what people say in such a perspective. This might have influenced the research interview and the interpretation of data. When scrutinising the results and when looking back at the research process, my impression is that there is a wide range of perspectives represented in the data. Social and emotional experiences have been mentioned, but also physical and financial experiences have for example been referenced. However, the distribution of experiences into details and the depth of descriptions are sometimes better carried out in social and emotional experiences than other fields. Examples of this are the subcategories ‘isolation’ and ‘shame’ in study II, and the subcategories ‘bad conscience’ and ‘anxiety’ in study III. Even if I have tried to be as open as possible, the expectations and attitudes from the patients are not easy to check, and it is possible that they would have told for example a researching physician or an occupational therapist about other critical incidents. We tried to minimise this and other selection processes in the patients by asking for the three most recent dilemmas, but still there might have been some selective remembering.

Throughout the process we have been very aware of a possible “counselling bias” and several times we have scrutinised the interviews to identify whether this bias has influenced our reading of the material, for example by interpreting experiences in more emotional terms than presented by the interviewees. However, we have not found any such misclassification, and thus if “counselling bias” has occurred it has probably been during the interviews.

Thus, it is possible that the interviewees’ stories to some extent were influenced and censored by knowing my background as a social worker at the hospital. However, I have never had any counselling or therapeutic contact with any of the participants in any of the studies.

Main findings

In focus of this thesis were lived experiences of persons with two different chronic diseases, NP and CD, and close relatives to persons with CD. One of the differences between CD and NP is the possibility of treatment. CD is a chronic disease that has a satisfactory treatment in the gluten-free diet. NP on the other hand is a chronic disease that with the best of the drugs only gives approximately half of the NP patients a reduction in pain intensity [29]. In spite of this difference an overall and common impression of what it is like to live with a chronic diseases is “to struggle one’s way” in managing with a variety of dilemmas, disturbances and consequences.

Similarities in lived experiences between coeliac disease and neuropathic pain

In spite of the differences in clinical presentation and treatments between the two diseases, we found several similarities in how NP and CD affected different aspects of people’s lives. Perhaps the most obvious was how the diseases influenced the individuals’ social lives and social relationships. NP patients experienced how their pain affected their social lives in several ways. For example, they chose not to participate in leisure or other activities or left earlier from parties. The persons with CD, also reported that the disease had social consequences and influenced their social life in different ways. They experienced that living with CD could give rise to a feeling of being deviant or an outsider in a social context. Other studies have reported that living with a chronic disease meant that there were various consequences in social relationships, so our findings were in line with those studies [9, 111]. Another similar finding was that NP patients experienced psychological consequences, for example sadness, feelings of worthlessness, anger and irritability, and persons with CD experienced sadness, shame, irritability, and being a social nuisance.

Lived experiences of disclosing or not disclosing the disease

Both CD and NP are invisible conditions and people who live with an invisible disease have a choice about whether to disclose the disease or not. If they choose to disclose it, this might reveal information that can discredit them; and hiding a disease involves the risk of being found out, which also has its risks, for example difficulty in dealing with the responses from people around [148, 149]. The informants in this thesis experienced that whatever way they chose implied consequences for daily life. The GFD often involved the social embarrassment of being

marked out as different from other people. We found that those with CD experienced strong emotions in their daily life, such as isolation, shame, fear, and worries about being a bother. Johnson *et al.* [150] described that feelings of being different could easily result in lowered self-esteem and a form of distrust and avoidance of social relations [150]. According to the informants in this thesis they described that they avoided disclosing the disease for to steer clear of these feelings of being different and feeling accused. However, disclosure avoidance was associated with lies, and the gluten-intolerant persons described that it also affected the quality of their social life in a negative way, for example in connection with lunch-time at a restaurant with their workmates. Instead of disclosing, they ate glutenous food and took risks in their daily life by eating food without checking if this specific type contained gluten. There are studies found that the main thing is to be normal and not feel different or as if you are accused of something [151, 152]. Gåfväls [9] found in her thesis that one effect of diabetes and social life was that people with diabetes more often lived alone and had a less widespread social network than controls, and she discussed that it could be due to their sense of being different from others and therefore suffering from lower self-esteem [9]. Several other studies have shown that persons with chronic diseases avoided talking about their disease to people around, in order to avoid feelings of blame and the consequence of increased stigmatisation [153-156]. Obviously, disclosure avoidance used in order to maintain solidarity and a sense of belonging to the group, might increase the feeling of being an outsider and different.

Lived experiences from the perspective of close relatives

Also close relatives experienced a changed and lost social network; they described for example that food and eating situations were suddenly transformed from pleasant situations bringing people together, into complicated situations, because of the social network's lack of information, knowledge and understanding. It is interesting that a number of studies have shown that these lived experiences of close relatives in terms of changed and lost social networks were quite similar to those of close relatives in connection with very different chronic diseases [111, 118, 119, 122, 157-159]. It is possible that the chronic disease in general caused dilemmas in social lives and social relationships for the person with the disease and the close relative, but in different ways independent of the onset of the chronic disease and the personalities of those involved. If so, it seems necessary to recognise the complexity of the social disadvantage in order to provide care and treatment support

that is more relevant to the life situation and concerns of the persons with chronic disease and their close relatives [3].

The findings in study III, showed that close relatives experienced a variety of dilemmas that affected the situation for the whole family in a negative way. This is a well-known finding, but not earlier described for CD, in that other studies – as described earlier in this thesis – have reported that daily life with a chronic disease also affected the close relatives in different ways. However, the findings in this thesis also showed that the close relatives described giving care and were committed in different ways around the person with CD. The close relatives described this commitment for example in vulnerable situations at parties or at a dinner when no gluten-free alternative had been prepared for the person with CD. The close relatives also described their extra care caution in the kitchen and also when shopping for food, so as not to harm the gluten-intolerant person as a result of mistakenly buying food containing gluten. This is an interesting finding, in the perspective that most of the interviewed of the close relatives were men and earlier studies found that it was usually female partners took the overall responsibility for household activities either as patient or the caregiver [160, 161]. However, Andersson [120] studied the quality of life of stroke patients and their carers and found changes in domestic roles [120]. This increased sensitivity found among male close relatives in relation to CD is unknown in previous research and could be followed up in more studies on chronic disease.

Need for information, communication and education

In papers II-IV those suffering from the chronic disease and their close relatives expressed problems connected with information sharing. Several studies, including the findings of this thesis, have shown that patients and their relatives lack both basic knowledge and information, but also in some cases has the wrong information. However, there are also studies describing how people with chronic disease experienced that they had more knowledge about their disease than the health care professionals. This created some problems since the health care personnel had difficulty in making use of the knowledge these people had, and thereby neglected their wishes about care and treatment [162-164].

Gluten-intolerant persons in this thesis explained that sometimes the disease and their diet restrictions had absorbed their whole life situation, and these experiences point to the need for more knowledge about CD [23, 68]. There are other studies that have focused on the need to also provide close relatives with information [109, 165]. In her thesis,

Gullacksen interviewed women with chronic pain, and all of them expressed that their families lacked knowledge about chronic pain, and that there was a need for education and information in the families [109]. One way for medical health care staff to deal with this might be by giving family-oriented information. There are also other aspects of the importance of family-oriented information. Since findings in this thesis showed that close relatives to persons suffering from CD showed great respect and care for the person suffering from the disease, it is important for health care personnel to consider that also the close relatives need support, knowledge and encouragement. The results from study IV provide new insights into gendered consequences that could be useful to consider with regard to family-oriented information. Women and men with CD experienced a “triple burden” in managing also their disease and the GFD on top of paid and unpaid work. However since women according to results from the questionnaire study had the main responsibility for household work, this “triple burden” might affect women in a more negative way compared to men. It is not possible to draw any firm conclusions based on study IV, and future research is needed but still this “and its possible effect specifically on women might be something that is important for health care personnel to address in their guides of people with CD but also other diet related diseases in order to reduce the gendered consequences of living with diseases that imply diet changes or other household work demanding diseases.

In summary, and according to the informants and earlier research it seems to be vital for the medical health care service to take the matter of information, communication and education seriously [71, 72]. However, it is important that the knowledge approach is firmly established in individuals, since we know from earlier studies that “knowledge itself” is not enough for changing behaviour [9]. It is interesting to note that problem-based learning in health education programmes according to studies by Ringsberg *et al.* [166, 167] helped persons with asthma-like symptoms to reflect upon themselves, and their disorder, and to find new coping strategies [166, 167].

Family consequences of living with a chronic disease

Living with a chronic disease had consequences and disadvantages not only for the person with the chronic disease but also for those close to them [3] and it seems relevant to talk about family consequences of chronic illness. In study I the NP patients reported several social consequences that directly or indirectly affected the family, for example unhappy children or increased dependency on a family member. An

interesting finding in study IV was that the overall pattern and types of consequences experienced in relation to dilemmas of CD were similar in both gluten-intolerant persons and their close relatives. Muños-Furlong [168] described family members with a child who was allergic to certain foods, who in their daily life continuously adapted recipes, read labels and selected restaurants as consequences of the allergic child [168].

Gender differences in living conditions, or in consequences?

Several studies showed that women in general describe a lower quality of life than men [169-171]. Several studies indicate that women with CD scored significantly lower than men with CD on subjective health [15, 23, 27, 108]. In study IV, women with gluten intolerance, but not men, described as consequences of experienced dilemmas, pre-discussion, pre-explanation and pre-planning, keeping gluten in focus and forgoing pleasures. These experiences, as well as loss of time and the specific effects suggested in relation to the described above, might be contributing reasons for women's with CD lower health-related quality of life. It is interesting that this "triple burden" was discussed, if not in these exact words, by Emery *et al.* [160], who found that it did not matter if the woman was the patient or the caregiver; she both focused on others and maintained the domestic roles [160]. Studies that examined the effect of gender on early recovery from cardiac surgery, found that after a heart attack men tended to reduce their work and increased the support they had from their partners, while women took on household responsibilities more quickly after coming home from hospital [32, 172].

In a Swedish report [173], it was found that the health care personnel made very few connections between the treatment given and gender. From earlier knowledge about women as caregivers and that women more often have the responsibility for the household work it seems important that the health-care personnel develop a gender specific attitude in care and treatment [174].

Chronic disease management from the neuropathic pain and coeliac disease perspective

Living with a chronic disease affects most aspects of life [3]. In this study of NP patients they expressed several different ways of managing their dilemmas, including alternative ways, cognitive strategies, continued activity, rest, treatment, physical activity and refraining from or discontinuing activity. These strategies were both emotion and

problem focused. An interesting finding was that NP patients often used cognitive strategies to manage pain through thoughts, imagery and mental training. Most of the NP sufferers in this study did not use a specific cognitive technique, but several such techniques exist and if health care personnel more systematically offered learning possibilities in cognitive techniques this would probably lead to an improvement in pain management also for patients with NP [74, 88, 124] .

When analysing how close relatives living with a person suffering from CD managed the dilemmas they described four different handling strategies to manage daily life, each of them leading to different outcomes. They described a number of strategies and all were more problem-oriented coping approaches: planning in advance for all meals; all members in the family eating gluten-free food; avoiding visiting friends, relatives, and restaurants due to not knowing how they would be treated. Finally, the last strategy described was to become more knowledgeable by teaching one's social network about CD. Maybe the experiences of strategies to manage daily life from close relatives to persons having CD could be discussed and taking part of in care and treatment of CD, in for example a problem-based learning health education programme or in the patient societies [166, 167].

In this thesis we did not analyse how those with CD felt about strategies for managing their daily life with the disease. An earlier study found that women more often described more distress caused by the restrictions in daily life, closely related to their checking on what the food contained. The men with CD used a more problem-oriented coping approach, while the women sought an emotionally oriented strategy and showed less satisfaction with the outcome [15].

Is there a package of lived experiences associated with chronic diseases?

A starting point of the research performed within this thesis was the lack of knowledge on what it is like to live with chronic diseases. Studies based on experiences of those affected or their close relatives are still rather scarce within medical research, and specifically this is true for studies of close relatives. Based on separate studies of CD and NP, who are two quite different chronic diseases, I wanted to gain more knowledge not only on the lived experiences associated with these disease, but also on the daily life with chronic disease in general. Given the limitations when it comes to transferability of findings from qualitative research I will discuss some ideas or hypotheses on general experiences associated

with the very fact of living with any chronic disease, and not with a particular one. It seems as if chronic diseases are followed by a package of experiences and that this package fills up or empty out during the years living with the disease. These experiences can be very specific and associated to a certain disease but also more general associated to the life with a chronic disease.

A tentative description of the general chronic disease package of lived experience contains a broad range and a large amount of lived experiences with variation in when and where they occur what different aspects they imply and in which life domains they occur. An illustration of the chronic disease package is presented in figure 2.

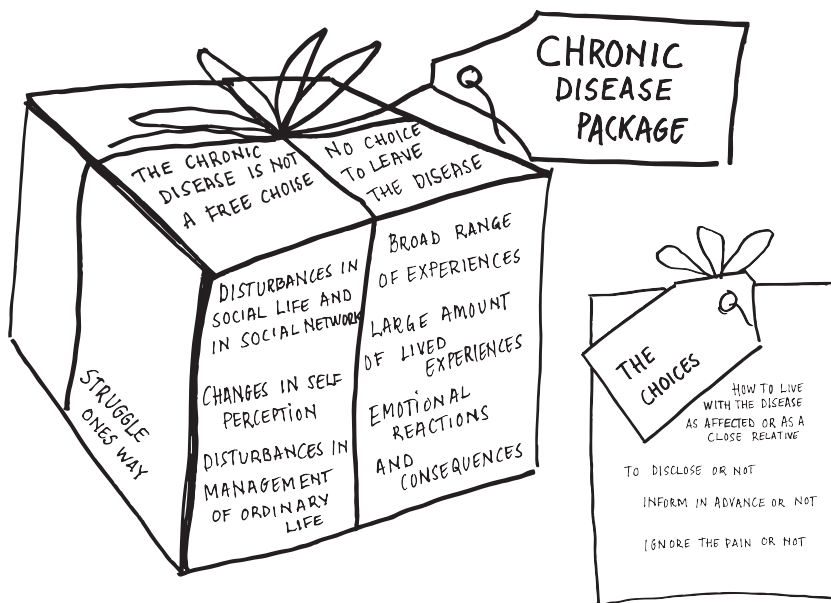


Figure 2 A tentative description of the general chronic disease package.

The lived experiences consisted of hindrances and difficulties in the daily life such as emotional reactions and consequences, disturbances in social life and in social network, changed self perception, and disturbances in managing the daily life. Since the choice to leave the disease does not exist it is just to struggle ones way in managing with a variety of dilemmas, disturbances and consequences of these. The management of the diseases was often described as an integrated part of the everyday life. And it is important to note that even if there is no choice of leaving the disease, the persons affected by a chronic disease lived their possibility to

choose how to live with their disease as affected or as close relative. They disclosed or they did not. They informed in advance or they did not. They chose to ignore the pain or they did not.

However much more research needs to be done to more closely explore and describe the life of chronic disease. Given the importance for the public health and for the health care this seems to be a high priority.

IMPLICATIONS FOR FUTURE RESEARCH

According to the findings in this thesis even invisible diseases have a great impact on the daily life of the person with the disease, as well as the close relatives. More research is needed to further explore the difficulties of these impacts. Future studies should also address other chronic diseases to identify specific and general experiences of living with chronic diseases.

Most of today's rehabilitation programmes for NP patients have a patient centred design and the findings of study I underline the value of such an approach. However, future research is needed to follow patients over time to see whether a team-based rehabilitation programme provides the patients with long-lasting and effective strategies other than those developed by the patients themselves. The effects of closer co-operation between patients and health care professionals in the development of rehabilitation and other programmes would be of interest to study, as programmes that involve experienced patients in the information to newly diagnosed individuals.

CD is another story since the adherence to GFD implies a rapid improvement of health. However, this thesis shows that there is an information need and future research should explore further how patients with CD cope with their emotions and disturbed relationships. How does the life with a diet related disease in the long run influence the identity of a person and of specific interest would be the association between the disease, the diet and the development of masculinity, since we found that in specific men reported disclosure avoidance.

Future studies should also address the unequal distribution of household work and its effects as regards coping with chronic disease. The reason for women's reported lower quality of life might be that the disease not only adds an extra burden, which is the same in both women and men, but adds this extra burden in other living conditions where women in most cases have the main responsibility for household work. There is also a need for more research about connections between the treatment given by health care personnel and gender.

Finally, close relatives to persons affected by disease have been an almost forgotten group in health research and much more research is needed to further explore how the close relatives cope with their changed daily life, their emotions and their relationships. This is needed since living with a person affected by a chronic disease might add extra worries and work that might lead to decreased health also in the close relative. However,

another aspect is that close relatives can be important collaborators for the health care personnel. Future studies also need to address whether there are any general differences between women's and men's roles as close relatives.

GENERAL CONCLUSIONS

This thesis showed that persons suffering from CD or NP had several lived experiences in common regardless of the chronic disease. In spite of the differences in clinical presentation and treatments between the two diseases, there were several similarities in the influence of the person's lives. Emotional reactions and consequences like sadness, anxiety and irritability were common issues in the interviews. In addition, relationships to others, the family, friends, relatives and the workplace were affected due to restrictions and lack of knowledge and understanding from the social environment.

Close relatives to persons suffering from CD experienced a variety of dilemmas that affected the situation for the whole family. Disease related worries, like bad conscience and anxiety, disturbances in social life, and management in daily life, for example the preferential right of interpretation of the person with CD was identified in the interviews.

Most of the consequences of dilemma experienced were related to the CD itself rather than to being affected or close relative. A possible explanation to lower quality of life in women with CD compared to men might be the unequal distribution of household work.

The informants in this thesis pointed out that information and knowledge on the diseases and the necessary adjustments in everyday life were insufficient among professionals and in the society. This indicates that there is a need of knowledge improvements of chronic diseases in society.

The ambition of this thesis was to explore lived experiences among diseased and close relatives from the perspective of two chronic diseases, in order to acquire knowledge on what it is like to live with chronic diseases in general and also to compare the effects of two different chronic diseases.

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My hope is that this thesis will provide one piece of the larger knowledge base on living with a chronic disease.

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