

Understanding mental illness and promoting mental health

Experiences of Exhaustion Disorder and Effects of a Person-Centred eHealth Intervention

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*To my informants in this thesis called
participants*

ABSTRACT

Health is subjective, involving the whole person, and cannot be determined by others. It is a resource in life, not merely the absence of disease and illness. Common mental disorders (CMDs), including stress-related conditions, are a growing public health problem in Sweden and account for an increasing proportion of sick leave due to psychiatric diagnoses.

The overall aim of this thesis was to build an understanding of the meaning of being affected by exhaustion disorder (ED), and to explore experiences of support and evaluate the effects of a person-centred eHealth intervention in patients on sick leave due to CMDs.

A multi-method qualitative and quantitative approach was used to gather and analyse data. Studies I and II involved interviews with twelve people affected by ED; the aim was to describe and interpret their experiences of being affected by ED and of support in the process of promoting health. Studies III and IV report from a randomized controlled trial (RCT) evaluating the effects of a person-centred eHealth intervention (consisting of phone support and a digital platform) in primary care patients (n=209) on sick leave due to CMDs.

The findings show that people with ED experience existential challenges and need allies in their struggle for acknowledgement as persons. Person-centred eHealth support improves self-efficacy and partly decreases symptoms of burnout. Still, it does not seem to affect sick leave for patients with CMDs.

This thesis concludes that the illness perspective and health-promoting care initiatives need a broader recognition in health care and other institutional organizations that encounter people with CMDs. This approach begins with interpersonal relationships where professionals need to meet the patient as a person rather than the disease alone, which is emphasized in person-centred care (PCC).

Key words: health, common mental disorders, exhaustion disorder, interview, experiences, phenomenological hermeneutics, person-centred care, eHealth, randomized controlled trial.

SAMMANFATTNING PÅ SVENSKA

Psykisk ohälsa är ett växande problem i vårt samhälle. Sjukskrivningstalen ökar och den främsta orsaken till de är stress. Utmattningsyndrom är en av de allvarligaste konsekvenserna av långvarig stress och uppkommer vid frånvaro av återhämtning. Det finns ett behov av att öka förståelsen för utmattningsyndrom och hitta nya tillvägagångssätt för att stödja personer med psykisk ohälsa. Därför tar denna avhandling ett utforskande perspektiv gällande personers upplevelser av att drabbas av utmattningsyndrom och deras upplevelse av stödjande insatser för att främja sin hälsa och hantera sin vardag. Vidare undersöktes även effekter av ett personcentrerat stöd på distans för personer sjukskrivna för vanliga psykiska tillstånd inom primärvården.

Resultaten grundar sig på intervjuer med 12 personer sjukskrivna för utmattningsyndrom samt enkätsvar från 209 personer sjukskrivna för vanliga psykiska sjukdomar i primärvården (107 patienter erhöll vanlig vård och jämfördes med 102 patienter som erhöll vanlig vård och ett personcentrerat telefon- och digitalt stöd på distans). Resultaten från intervjuerna visade att utmattningsyndrom innebär en kamp för att hitta stöd i en situation där deltagarna har tappat fotfästet och hamnat i en existentiell kris, likt en återvändsgränd, i livet. I denna situation var de i behov av ett stödjande nätverk som hade förståelse och kämpade vid deras sida som allierade i en kamp om att behålla sin värdighet och främja hälsa. Även om utmattningsyndrom är en medicinsk diagnos beskrevs tillståndet som en existentiell och personlig kris där deltagarna relaterade dessa till relationella, familjerelaterade och arbetsrelaterade utmaningar. Då det finns begränsat med medicinska instrument för att mäta psykisk ohälsa blir hälso- och sjukvårdspersonal själva verktyget i bedömning och stöd för personer med psykisk ohälsa. De professionellas förmåga att se och förstå ”personens” upplevelse är således en förutsättning för att kunna ge stöd. Detta resultat belyser de professionellas utmaning och samtidigt de hjälpsökandes utsatthet i relation till psykisk ohälsa. Frånvaro av denna förmåga hos professionella ledde till att deltagarna inte upplevde sig sedda vilket ledde till en förlust av deras värdighet. En gemensam förståelse däremot innebar att deltagarna upplevde sig bekräftade vilket var en förutsättning för återhämtningsprocessen. Det personcentrerade stödet på distans ökade deltagarnas nivåer av självtillit och minskade till viss del symtom

på utmattning för vissa deltagare. Detta stöd påverkade dock inte sjukskrivningsnivåerna.

En övergripande förståelse av resultaten visade att den medicinska och professionella kunskapen är central men att dess användbarhet förutsätter hälso- och sjukvårdspersonalens förmåga att också kunna skapa relationer. Personcentrerad vård och hälsopromotion är idag kärninsatser i vården. Personcentrerad vård belyser vikten av att se patienten som en person med resurser, förmågor samt behov och hälsofrämjande insatser syftar till att förbättra personers och grupperns välbefinnande vilket effektivt förebygger sjukdomar. Dessa kärninsatser i vården är till fördel för såväl patienter, personal och samhällets folkhälsa. Resultatet från denna avhandling visar att personcentrerad vård och hälsofrämjande insatser behöver ett utökat utrymme och mandat i sjukvården för att främja psykisk hälsa. Resultaten visar även att ett e-hälsoalternativ baserat på personcentrerad vård kan främja och förbättra hälsan för patienter med psykisk ohälsa, vilket kan ses som en del av lösningen på de utmaningar som individer, vårdinrättningar och samhället står inför på grund av den ökande psykiska ohälsan i vårt samhälle idag.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals:

- I. Alsén S, Ali L, Ekman I, Fors A. Facing a blind alley – experiences of stress-related exhaustion: a qualitative study. *BMJ Open*. 2020;10(9). <http://dx.doi.org/10.1136/bmjopen-2020-038230>
- II. Alsén S, Ali L, Ekman I, Fors A. Having allies – experiences of support in people with stress-related exhaustion: a qualitative study. *Submitted*.
- III. Cederberg M, Alsén S, Ali L, Ekman I, Glise K, Jonsdottir IH, Gyllensten H, Swedberg K, Fors A. Effects of a Person-Centered eHealth Intervention for Patients on Sick Leave Due to Common Mental Disorders (PROMISE Study): open randomized controlled trial. *JMIR Ment Health*. 2022 Mar 15;9(3):e30966. <https://doi.org/10.2196/30966>
- IV. Alsén S, Hadzibajramovic E, Jonsdottir IH, Ali L, Fors A. Effectiveness of a person-centred eHealth intervention in relation to symptoms of burnout in patients on sick leave due to common mental disorders - Secondary outcome analysis of a randomised controlled trial. *In manuscript*.

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ABBREVIATIONS

CI	confidence interval
CMD	common mental disorder
ED	exhaustion disorder
GPCC	Gothenburg Centre for Person-Centred Care
GSE	general self-efficacy
GSES	General Self-Efficacy Scale
HCP	health care professional
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10 th revision
ITT	intention-to-treat (analysis)
OR	odds ratio
PCC	person-centred care
PP	per-protocol (analysis)
RCT	randomized controlled trial
RN	registered nurse
SD	standard deviation
SMBQ	Shirom-Melamed Burnout Questionnaire
WHO	World Health Organization

INTRODUCTION

Mental illness is a significant concern and one of the foremost reasons for sick leave in a number of Western countries (Henderson, Harvey, Øverland, Mykletun, & Hotopf, 2011). There has been a dramatic rise in sick leave and disability benefit claims during the past decade. In Sweden, the sick leave numbers related to mental illnesses, especially those related to stress-related disorders, have increased during the last decade and is now the most common reason for sick leave in Sweden (Försäkringskassan, 2019). Besides having a negative impact on the patients and their families, its costs to society in terms of health care, sick leave and productivity loss for employers is high (OECD, 2013). The burden of mental illness is a challenge for health care systems, not least in primary care settings, where most of the patients receive care (OECD, 2013; Sundquist, Ohlsson, Sundquist, & Kendler, 2017). To address these issues, care processes that modify current ways of work in health care and improve the relationship between health care professionals, patients and their families need to be explored (Gask & Coventry, 2012).

A person-centred approach is a form of care in the health and care sciences that aims to facilitate health for people in different situations. In health and care science, as well as in person-centred care (PCC), the understanding of patients and their significant others is based primarily on their experiences (Dahlberg, 2010; Svensk Sjuksköterskeförening, 2010). Besides needing to focus more on including patients' experiences of their situation, the health care system requires additional opportunities for future social services in health and medical care. PCC emphasizes the co-creation of care in partnership between the patient (often with relatives) and health care professionals (HCPs) and facilitates a more collaborative view on health care in which patients are engaged as active partners in the planning of their care (Ekman et al., 2011).

There is a growing interest in how eHealth services can be used in health care. One crucial aspect is the need for educational information systems that will facilitate both the work of HCPs and the situation for patients. Digitalization can contribute to increased transparency and a change in the traditional structures; however, it also poses ethical challenges, concerning informed consent, online professional practice, and privacy and equity issues

(Eysenbach, 2001; Svensk Sjuksköterskeförening, 2020). E-Health services based on the person-centred approach may be one feasible way to identify patients' resources, meet their needs, and co-create care between patients, family, and health care professionals (Siira, 2020; Svensk Sjuksköterskeförening, 2020).

Health and care research focuses on people's experiences and the understanding of disease, illness and suffering. It looks at recovery and the preservation and promotion of health, dealing with both biological and sociocultural structures. Health care organizations are central to health care research and optimizing care so that health care resources are focused where they are most needed (Dahlberg, 2010; HSL, 2017). This thesis includes interview studies aiming to describe and interpret patients' experiences of being affected by exhaustion disorder (ED) and to improve the understanding of support in promoting health and facilitating recovery. The thesis also includes a randomized controlled trial (RCT) evaluating the effects of a person-centred eHealth intervention (consisting of phone support and an interactive digital platform) for patients on sick leave due to Common mental disorders (CMDs).

BACKGROUND

The Background will introduce the main concepts related to this thesis. This chapter will present the concepts of health, CMDs, PCC and eHealth.

HEALTH

Health has been a central concept in care science since the 19th century (Simmons, 1989). Several different definitions of health have been proposed, and different ways of understanding health can be divided into different health models. By understanding and combining these different models, we can improve health outcomes and quality of care (Larson, 1999). Several medical models describe health as the absence of disease. Other models, which are based on wellbeing, emphasize health promotion, and higher function and integration of the body, soul and spirit; while environmental models relate health to adaptation to the physical and social environment.

The most widespread definition of health, which has greatly influenced health work in the world during the latter part of the 20th century and up to today, is the World Health Organization (WHO) definition from 1947. The WHO defined health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" (WHO, 1947). This definition has been criticized for being too broad and for describing a state that is hard to achieve. However, this holistic formulation was ground-breaking in its ambition and went beyond the idea that health is only about the absence of disease and, moreover, that it also comprises mental, physical and social domains (Huber et al., 2011; Hwu, Coates, & Boore, 2001). The definition also considers the individual's experiences of their situation as it contains the word "wellbeing" in the description of health and takes a step from a one-sided biomedical perspective towards a health-related, individual person's perspective (WHO, 1947).

Boorse's health theory (1977) assumes an absolute distinction between health and disease and has significantly influenced the Western world.

According to this view, health is defined as the statistical normality of biological function with the complete absence of pathological conditions, and whether a person is healthy or not is decided by others (1977). This perspective has been criticized (Huber et al., 2016; Jadad & O’Grady, 2008) for being too absolute because the individual is judged to be either healthy or ill, depending on whether their condition corresponds to the definition a condition has been given. This objectifying approach of the human being focuses on the function of individual body parts and excludes the individual’s experience of their situation in assessing the state of health (Huber et al., 2016; Jadad & O’Grady, 2008).

The elements of the model defined by Boorse still constitute health care to a large extent (Boorse, 1977). This model of health is based on a dualistic separation of the body and mind characterized by a mechanistic understanding of the body, in which measurable, physical health is assumed to be completely separate from psychological and social processes. Symptoms must be associated with signs to be evaluated, and the diagnostic process excludes factors considered irrelevant (Sigurdson, 2011).

According to the biopsychosocial model, health must be understood as a combination of psychological, biological and social factors, somewhat more than only biological relations influencing disease and illness. Biological factors include genetics, sex, disability and comorbidities. Social factors include family background, social support, cultural traditions and socioeconomic status, while psychological factors include personality, past trauma, coping skills, and attitudes. The biopsychosocial model has been used to explain many diseases, especially when purely biomedical explanations are lacking (Engel, 1977). Even though the model accepts that both the mind and the body affect health, it has been criticized for being dualistic, assuming a clear mind–body division. As all factors are considered relatively stable without much change over time, the model is also viewed as deterministic (Borrell-Carrió, Suchman, & Epstein, 2004).

In contrast to the biomedical perspective, the holistic perspective considers “the human being as a whole”, that is, it considers the person (and not just

their physical body) to be healthy or not healthy (Nordenfelt, 1995). This standard view of health shared by, among others, Nordenfeldt (1986) and the WHO (2006) is that health is self-assessed and cannot be determined by others. Health should be considered a resource for daily living rather than a life goal in itself (2006). Nordenfeldt (1986) defines health as the ability to realize meaningful goals, which is also part of Dahlberg (2010) suggesting that health can be understood in terms of wellbeing and the ability to complete large and small life projects. As such, it implies a relationship with freedom and vulnerability, entailing an existential element (Dahlberg, 2010). This ability-based model is also argued by Nussbaum (2009), who proposes that health and happiness are not only a solitary set of beliefs but also a set of capabilities, involving abilities and opportunities to do things that are essential for the person's wellbeing (Svenaeus, 2021). According to Svenaeus, the ability-based holistic model contributes to understanding health accounts and the differences in people's way of evaluating situations and setting goals for themselves in life. To reach a further understanding of health according to the holistic perspective, Svenaeus suggests adding a phenomenological understanding so that these person-based variances also concern the way individuals experience their bodies and the environment they live in (Svenaeus, 2021).

One factor often described in relation to health is stress. The definition of stress is commonly based on Selye (1956), who described stress as the body's response to any request made of it. Selye explained that negative stress occurs when the doses of stress exceed the threshold of adaption. Lazarus & Folkman (1984) described stress as a result of the interaction between the environment and the person. How a person interprets, and relates to, stress and challenges depends on their personal resources for stress management. When the demands on the individual exceed the individual's resources to manage them, the wellbeing of the individual is jeopardized (Lazarus & Folkman, 1984). The *stress vulnerability model* described by Zubin & Spring (1977) proposed that vulnerability factors combined with perceived stress could lead to a person developing mental illness. This model opened the discussion on mental illness by moving from seeing affected persons as unfamiliar to viewing them as people with extraordinary experience (Brennan, 2005).

DETERMINANTS OF HEALTH

The year 2021 marked the 30th anniversary of the “Dahlgren–Whitehead model” of the main determinants of health, also known as the Rainbow Model (Dahlgren & Whitehead, 1991). The model was developed to describe and understand the main determinants of health, described as a series of layers. The centre of the model represents individual factors such as genetics, sex and age. The first level, or layer, contains factors of an individual’s lifestyle including exercise, diet and sleeping habits. The second level consists of social and community factors such as support and the social network. The third level constitutes conditions related to living and working, for example health care services, the work environment, water and sanitation, food production, agriculture and education. Socioeconomic, cultural and environmental conditions are presented in the fourth level, and all these four layers of influence can be transformed into four layers of political actions (Dahlgren & Whitehead, 2006). The model has increased co-operation between people in diverse sectors to co-operate on a shared goal and give each sector responsibility in developing and implementing strategies for promoting health. The model’s holistic view of the determinants of health is health-promoting, while other models often focus entirely on risk factors (2006).

MENTAL HEALTH

“Mental health” is a concept that is often used in general conversation but is given different meanings in different contexts. Sometimes it refers to its positive dimension in the form of mental wellbeing. However, “mental health” is often used to refer to mental illness, from mild anxiety to severe psychiatric conditions (SKR, 2020). In most European countries, mental health implies a traditional understanding of health as an absence of symptoms. It is rarely understood as the continued ability to live a sustainable life regardless of symptoms (Keogh et al., 2017). Mental health is often described in negative terms as the absence of objective signs of mental illness or in relation to society’s idea of what is considered normal. However, positive mental health can be considered to exist in itself (Hedelin & Strandmark, 2001). This pathogenic approach considers that a person is healthy until something

happens that leads to the development of disease. Mental health/illness should be understood as a broader phenomenon (Brennan, 2005).

“Disease” is used as term for bodily dysfunctions and as a complement to the bodily perspective, where “illness” conveys an experience-based meaning of disease and “sickness” conveys a sociocultural-based meaning of being unwell (Svenaesus, 2016). The term “disease” is based on a biomedical perspective and can be defined as any derivation or interruption of a part of the body’s typical structure or function, as manifested by characteristic symptoms and signs (Fortune, 2003, p. 547). Even if a person exhibits symptoms that correspond to diagnosis criteria, it does not necessarily mean that the person experiences disease or disorder. The personal experience of ill health defines illness, which can be experienced even when no disease can be found (Boyd, 2000). This humanistic perspective implies a change in condition or social function experienced by the individual and is understood in terms of meaningfulness for the individual (Brenner & Wrubel, 1989). All dimensions of disease need to be considered to reach a complete understanding of the sick person, and the starting point for “illness” is the phenomenology of the disease, which looks at how it feels to be sick in contrast to being healthy (Svenaesus, 2016).

When it comes to understanding and measuring health and illness in mental care, we face interpretation challenges within the diagnostic biomedical framework due to lacking physical measuring instruments. Clinical diagnoses are based on signs, symptoms and disability – events in life that are not considered “normal”. The distinction between “normal” and “pathological” reactions is difficult. The notion of mental illness or mental health is closely linked to our personal and cultural ideas of a valuable, meaningful, and good life (Bolton, 2013). In addition to the medical perspective, it is therefore necessary to acknowledge descriptions of symptoms and consider lived experiences in the interpretation process to understand illness in mental health care (Svenaesus, 2016; Toombs, 2013). This perspective is also crucial in medical and somatic care, where the disease is a biological issue and an experienced and cultural phenomenon. However, in mental health care, the different dimensions are essential because, firstly, the brain’s functions are more challenging to understand and measure than those of the rest of the body. Secondly, the functional complexity connects to experiences and values about

what is good for our survival and meaningful in a broader context (Svenaeus, 2016).

DETERMINANTS OF MENTAL HEALTH

A person's mental health level is determined not only by disease, genetics and lifestyle, but also by multiple social, psychological, and biological factors (including hormones, violence, persistent socioeconomic pressures, and sexual violence). Social changes, gender discrimination, an unhealthy lifestyle, social exclusion, human rights violations and stressful work conditions also affect mental health. Specific psychological and personality factors and biological risks, including genetic factors, make people vulnerable to mental health problems (WHO, 2018). At a population level, mental health can be seen to be the result of interaction between the individual and society and is primarily affected by how society is shaped. Political decisions in areas other than health care are essential, and in order to achieve good mental health and eliminate the differences in health, all people must be given similar conditions. The overall public health goal is to create societal conditions for fair and equal health in the entire population and close significant health gaps within a generation. The health development of the population is central, not only for individuals' wellbeing but also for sustainable societal development (Folkhälsomyndigheten, 2020).

In Sweden, the proportion of reported stress increased during 2006–2020, especially among women under 45 and in the groups with upper secondary and post-secondary education. In 2020, 14% of 16–84-year-olds stated that they felt stressed, and the proportion was higher among women than among men (Folkhälsomyndigheten, 2020). The sharp increase in mental illness among children and young people places great demands on the health services to treat an increasing number of people who need help. Even though the “first line”, primary psychiatric care, has been given increased resources to help patients with milder symptoms, the treatment of and support for these patients have obvious limitations (Socialstyrelsen, 2019). Moreover, mental illness has increased due to the COVID 19 pandemic, stressing the urgency to strengthen mental health systems. We need to find ways to promote mental wellbeing and

target determinants of poor mental health, and we need interventions to treat those with a mental disorder (Santomauro et al., 2021).

COMMON MENTAL DISORDERS

Depression and anxiety is the most prevalent mental disorders worldwide and is often described as CMDs (WHO, 2017). Even though this definition is not entirely clarified, it is widely used internationally when referring to the most prevalent but not the most severe cases of mental illnesses (Henderson, Glozier, & Elliott, 2005; Knudsen, Harvey, Mykletun, & Øverland, 2013). Even for those with milder symptoms, the conditions can significantly negatively affect the quality of life and cause difficulties in handling working and personal life (R. Johansson, Carlbring, Heedman, Paxling, & Andersson, 2013; Socialstyrelsen, 2021). These conditions are a significant issue for many countries and healthcare systems, causing frequent, long mean duration, sick leave spells, which a risk of recurrence (Henderson et al., 2005; Koopmans et al., 2011; Lidwall, 2015; OECD, 2012; Shiels, Gabbay, & Hillage, 2016). In 2019, depression and anxiety disorders were the two most disabling conditions among mental disorders and categorized among the 25 top leading causes of the worldwide health burden (Vos et al., 2020).

In Sweden, the risk of having depression some time during life has been estimated to be 36% for women and 23% for men, and approximately 25% of the total population suffer from anxiety syndromes some time during their lifetime (Socialstyrelsen, 2021). The most substantial risk factors for CMDs are female gender and low family income (Baumeister & Härter, 2007; Kessler et al., 2005; Steel et al., 2014; Sundquist et al., 2017). In 2020, the COVID 19 pandemic induced a global increase in depression and anxiety disorders. In Sweden, the expected number of depression and anxiety disorders exceeded 23–24% and showed the highest increasing percentage of all Nordic countries (Santomauro et al., 2021).

CMDs are generally treated in primary care (Sundquist et al., 2017), and most treatments target different symptoms, aiming to minimize the restrictions the illness has on life (Millward, Lutte, & Purvis, 2005). The Swedish national guidelines for treatment of depression and anxiety disorders recommend that treatment comprise medication or cognitive behaviour therapy, or both. The

guidelines also stress the need for health care resources in the form of staff and organizational structures, facilitating continuity of treatment for these conditions. Furthermore, guidelines highlight the importance of facilitating patient participation in treatment and care. With a salutogenic approach, the patient's resources, perceived self-efficacy, and control should support the patient in dealing with symptoms of meaninglessness and developing strategies to handle their illness in their everyday lives. Communication skills and a holistic approach to the patient's circumstances and care needs are essential (Socialstyrelsen, 2021). However, treatments that positively affect symptom relief do not necessarily impact the duration of sick leave (Ejebj et al., 2014; Soegaard, 2012). Regardless of the condition, the timing and process of return to work are essential. Besides the general characteristics of the illness and the severity of symptoms, the sick leave process also depends on individual factors such as perceptions, beliefs, and other psychosocial influences (Henderson et al., 2011).

Stress-related disorders including, for example, adjustment disorder, reaction to acute stress, and ED can also be present, in addition to CMDs (WHO, 2017). In Sweden, the number of cases of sick leave related to mental illnesses, especially those related to stress-related disorders, has increased during the last decade (Socialstyrelsen, 2017), and today stress-related disorders account for an increasing proportion of sick leaves in psychiatric diagnoses (Försäkringskassan, 2019). There are no specific treatment guidelines for stress-related disorders (Salomonsson et al., 2020), but as factors at work are the most common types of stressors (Hasselberg, Jonsdottir, Ellbin, & Skagert, 2014), the work situation often needs to be adjusted. Previous research has shown that collaborating with the workplace facilitates return to work (Etuknwa, Daniels, & Eib, 2019; Mikkelsen & Rosholm, 2018; Nieuwenhuijsen et al., 2014).

STRESS

The term "stress" has its origins in the 1930s in the work of the American physiologist Walter Cannon (1987) in which he describes how external threats to survival disrupt the biophysical equilibrium. The stress theory was further

developed, based on the importance of psychological factors, by Tache and Selye (1985). Lazarus and Folkman's (1987) transactional view of stress arises from the relationship between a challenge that the individual faces and the individual's experience of having or not having access to resources to handle the situation. Stress arises when the individual feels that the problem is more significant than their resources and threatens their wellbeing.

Research over many years has shown that determining the cause of stress is complicated since stress reactions and stressful situations are multidimensional, involving complex cognitive processes causing different experiences and coping by each individual and situation (Ursin & Eriksen, 2004). Besides the psychological response to stress, several other systems are involved, such as cognitive, emotional, and behavioral stress responses. In addition to different psychological reactions, stress involves several biological systems contributing to several health impairments (Jonsdottir & Dahlman, 2019). Exposure to stress increases the risk for physical (Chandola, Brunner, & Marmot, 2006; S. Melamed, Shirom, Toker, Berliner, & Shapira, 2006) and mental (Clark et al., 2012; Cole, Ibrahim, Shannon, Scott, & Eyles, 2002) symptoms; also, cognitive impairments are frequently reported (Jonsdottir et al., 2013). Psychological stress is also associated with increased risk for dementia (Johansson et al., 2010). Besides having a negative impact on the patient's wellbeing, it also bears a risk of stigmatization (Verhaeghe & Bracke, 2012).

EXHAUSTION DISORDER

“Burnout” is an internationally used term to describe the consequences of severe and long-term stress mainly associated with work-related psychosocial factors (Melamed et al., 2006). “Burnout” is not a validated clinical diagnosis and was not meant to be used in clinical practice (Maslach, Schaufeli, & Leiter, 2001; Shirom & Melamed, 2006). A distinction between burnout and ED has been made, where “burnout” describes a crisis-related reaction to work while “ED” is associated with malfunction and clinical symptoms (Åsberg, 2003). In 2003, an expert group at the Swedish National Board of Health and Welfare (Åsberg, 2003) established the diagnostic criterion of “exhaustion disorder (ED)”, and in 2005 a separate diagnostic code, International Statistical

Classification of Diseases and Related Health Problems, 10th revision (ICD-10), code F43.8A, for the condition was established. The diagnosis improved descriptions of patients with stress-related exhaustion. The diagnostic criteria state that at least one identified stressor, work- or non-work-related, should have been present for at least 6 months and that a lack of psychological energy dominates the clinical picture. Four of the following symptoms should have been present almost every day for at least 2 weeks: concentration or memory impairment, emotional instability, reduced ability to cope with demands and/or time pressure, disturbed sleep, apparent physical weakness and physical symptoms such as muscular pain (Grossi, Perski, Osika, & Savic, 2015).

Underlying factors of ED are primarily related to work demands; nevertheless, the condition is also related to factors in private life and/or a lack of balance between private life and work (Andersen, Nielsen, & Brinkmann, 2012; Hasselberg et al., 2014; Sandmark & Renstig, 2010; Theorell et al., 2015). Whether the stress is work-related or the result of stress in private life, or both, clinical burnout is primarily related to the absence of recovery (van Dam, 2021). The period preceding burnout is usually characterized by symptoms of fatigue, muscular pain, headache and difficulties in living up to the emotional demands of family and friends. Affected individuals need to limit their social actions, which causes them feelings of guilt (Ekstedt & Fagerberg, 2005), and they often experience a situation in which their ideal self is not harmonized with their everyday life (Gustafsson, Norberg, & Strandberg, 2008).

In Sweden, most consultations with and treatments of patients with CMDs including ED take place in primary care (OECD, 2013; Sundquist et al., 2017). Experiencing a high level of stress is often accompanied by symptoms of anxiety and/or depression (Wiegner, Hange, Björkelund, & Ahlborg, 2015). CMDs are the most common reason for sick leave lasting longer than 14 days in people under the age of 50. A large proportion of sick leave due to CMDs is related to “adjustment disorders and other reactions to severe stress” (40%) and “depressive episodes” (30%), both of which can, in some cases, be linked to ED (Försäkringskassan, 2013). In a report by the government social insurance agency, ED is presented as a separate reason for sick leave, with a recovery period which, even with specialized rehabilitation and a gradual return to work, is expected to “not infrequently last more than 6 months and in

some cases up to a year or more” (Socialstyrelsen., 2017). Some studies have shown that 25–50% of patients with clinical burnout are not fully recovered after 2–4 years (Dalgaard, Hviid Andersen, Pedersen, Andersen, & Eskildsen, 2021; Eskildsen, Andersen, Pedersen, & Andersen, 2016; van Dam, Keijsers, Eling, & Becker, 2012). One Swedish study reports that one-third of patients with ED still have symptoms of exhaustion 7 years after initially seeking care (Glise, Wiegner, & Jonsdottir, 2020). Cognitive impairments and daily functioning have been reported 7–12 years after seeking care (Ellbin, Jonsdottir, Eckerström, & Eckerström, 2021). After returning to work, there is a 50% risk of relapse within 30 months (Karlson, Jönsson, & Österberg, 2014).

It is challenging to treat ED successfully, and the effect of return-to-work programmes is limited. However, interventions that aim to strengthen patients’ level of self-efficacy and include a workplace component during rehabilitation are more successful in improving return to work (Andersén et al., 2018; Black, Keegel, Sim, Collie, & Smith, 2018; Blonk, Brenninkmeijer, Lagerveld, & Houtman, 2006; Etuknwa et al., 2019; Lagerveld, Brenninkmeijer, Blonk, Twisk, & Schaufeli, 2017; Mikkelsen & Rosholm, 2018; Nigatu et al., 2017; Volker, Zijlstra-Vlasveld, Brouwers, van Lomwel, & van der Feltz-Cornelis, 2015). The absence of a structured workplace-oriented intervention, when supporting patients with ED, has been shown to increase the number of relapses during the rehabilitation period (Karlson et al., 2014). Concrete support has been described by Hörberg and colleagues (2020), suggesting that health professionals need to understand the patient and be flexible. Professionals need to understand the importance of the opportunity for the patients to “just be” in the recovery process. Furthermore, patients need support to find helpful tools that can contribute to achieving a balance in everyday life (Hörberg, Wagman, & Gunnarsson, 2020).

MENTAL HEALTH SERVICE

Mental health services usually have a provider-centred focus and the ambition to increase patients’ knowledge about their condition and treatment. Mental health research is normally done from a biological perspective, while psychosocial research and service user-centred research are limited (Jormfeldt et al., 2018). Consequently, the holistic view of health is often disregarded and

instead of focusing on facilitating health from an individual perspective, disease and deficits are in focus (Jormfeldt, 2011). Health-promoting support of the individual, on the other hand, is motivated by a positive regard for the subjectively experienced quality of life, and self-esteem in connection with psychiatric symptoms (Jormfeldt, Arvidsson, Svensson, & Hansson, 2008). Keyes and co-authors (2010), have demonstrated the connection between impaired mental health and increased mental illness, which confirms a need for health-promoting support in mental illness (2010). Mental health promotion aims to focus on achieving and maintaining health from an individualized and holistic perspective. The process of reaching individual goals is essential for achieving health, which also includes individual physical and mental wellbeing (Jormfeldt, 2011). A holistic view of health and recovery can facilitate health in people with various health care needs in various health care contexts (Gabrielsson, Tuveson, Wiklund Gustin, & Jormfeldt, 2020). The most important task for HCPs is to take responsibility in creating respectful encounters during which the individual's being and dignity are safeguarded (Hedelin & Strandmark, 2001).

eHEALTH

Swedish health care has undergone significant structural changes during recent decades. The considerable reduction in hospital beds and the shift towards more home care have influenced patients, significant others and HCPs (Svensk Sjuksköterskeförening, 2020). A clearly specified political aim is for patients to undertake more responsibility for their own health (SKR, 2016; Svensk Sjuksköterskeförening, 2020). eHealth aims to offer opportunities for digital services to facilitate for people to be involved in their own health and social care, as well as to support contact between individuals and service providers, and offer more efficient support systems for staff at service providers (SKR, 2016; Svensk Sjuksköterskeförening, 2020). The concept of eHealth is based on the WHO definition of health. The “e” indicates that digital technology can be employed to improve the chances of achieving good, equitable and accessible health for everyone (WHO, 2016). However, registered nurses (RNs) and other HCPs face new demands and needs in their efforts to provide the best and safest care possible. Patients' conditions and preferences regarding their preferred mode of communication should be considered. The power

balance between patients and HCPs shifts when patients have online access to information about health and illness. When patients and relatives access misleading or inaccurate information this places increased demands on RNs to advise and guide the patients in their efforts to achieve and maintain health (Svensk Sjuksköterskeförening, 2020). eHealth may lead to advantages for patients, including increased flexibility and the opportunity to take part in and influence their health, but it may also imply an increased threat to patient integrity (Eysenbach, 2001; Svensk Sjuksköterskeförening, 2020). The introduction of digital technology should be accompanied by careful consideration of ethical aspects. When using eHealth as support, professionals are responsible for ensuring that their approach to encountering and caring for patients is based on core nursing values (ICN, 2014).

Regardless of the patient's health condition, it is essential that the individual's resources are being considered and that this person is invited to participate as a partner in the health promotion process (Skärsäter & Wiklund Gustin, 2019; Svedberg, Jormfeldt, & Arvidsson, 2003). Therefore, such a person-centred approach is central in nursing and is one of the RN's core competencies along with teamwork and collaboration; evidence-based practice; quality improvement; safety; and informatics (Janeth & Margret, 2013).

PERSON-CENTRED CARE

PCC has a long tradition and history in nursing and health care, and the origin of the concept can be traced back to Florence Nightingale, who distinguished nursing from medicine when focusing on the patient's preferences and self-care management rather than the disease (Lauver et al., 2002; Nightingale, 1860). In the mid-20th century, person-centredness was mentioned in health care by psychologist Carl Rogers (1902–1987) who focused on people's perspectives and their experiences of their situation. This view is known as “client-centred psychotherapy”; later on, Rogers used the term “person-centred” to describe interpersonal relations. His theory was to consider the persons in need of help as experts on themselves; the therapist's role was to promote the patient's self-awareness (Rogers, 1951, 1961).

The psychologist Tom Kitwood (1896–1970) also used the term to distinguish a specific type of care approach from a more medical–behavioral approach to

care for patients with dementia. Instead of treating people with dementia as objects and as having only physical needs, he developed his framework to provide staff with critical thinking according to values that guided care and strengthened and supported personhood and wellbeing throughout the disease. Kitwood's approach encourages staff to focus less on *what* is done and more on *how* it is done and suggests that staff's focus should be on the person behind the disease (Fazio, Pace, Flinner, & Kallmyer, 2018; Mitchell & Agnelli, 2015).

Michael Balint (1896–1970) highlighted the concept of patient-centred medicine as another approach to medical thinking. In patient-centred medicine, in addition to trying to discover and localize illness, the physician also needs to examine the whole person to form an “overall diagnosis”. Balint suggested psychotherapeutic tools to distinguish diagnoses and to include everything known and understood about the patient as a unique human being. This approach helped general practitioners to be less disease-oriented and more patient-centred (Balint, 1969).

THE CONCEPT OF PERSON CENTRED CARE

Today, there are many similarities as well as differences in definitions of person-centredness across the human services literature. In the disability, ageing and mental health literature, the core themes emphasize engaging persons in partnerships, shared decision making, and meaningful participation in the care provision (Waters & Buchanan, 2017). Among reviews outlining these and similar components caring encounter (Håkansson Eklund et al., 2019; Morgan & Yoder, 2012; Sharma, Bamford, & Dodman, 2015; Slater, 2006). Mental health reviews focusing on shared decision making and self-directed care, two practices that have significant implications for mental health, include a paper by (Smith & Williams, 2016).

A review study by Håkansson Eklund (2019) and colleagues found that the term “person-centred is often used interchangeably with terms such as “patient-centred” or “client-centred”, which may lead to confusion . The concepts of person-centred and patient-centred care seem to have several overlapping similarities but differ in important respects. The goal of patient-

centred care is to achieve a “*functional life for the patient*”, while the purpose of PCC is “*a meaningful life for the person*”. Patient-centred communication involves exchanging information, while person-centred communication is an integral part of the entire caring encounter (Håkansson Eklund et al., 2019). Moreover, in patient-centred care, the holistic perspective is additive to the biological dimension, while the holistic view in PCC emphasizes the interdependence between dimensions rather than them being additive (2019). A patient-centred view focuses on *what* a person is, while a person-centred view focuses on *whom* the person is. The understanding of whom the person is has its starting point in the narrative (Kristensson Ugglå, 2020).

PCC advocates caring principles based on the importance of knowing the patient as a person, understanding the illness from the patient’s perspective, and treating the patient as a person with autonomy and capabilities (Ekman et al., 2011; Entwistle & Watt, 2013; Leplege et al., 2007; McCormack & McCance, 2006). Leplege et al. (2007) propose that PCC means addressing the person’s specific and holistic properties, addressing the person’s difficulties in everyday life, seeing the person as an expert, and respecting the person behind the disease (2007). Entwistle and Watt (2013) likewise highlight the importance of “treating patients as persons”. They suggest identifying, and focusing on, a subset of capabilities mainly associated with the concepts of person and being treated as persons. This subset could include, for example, capabilities to reason, initiate action, to be self-aware and self-directing, and to participate socially in a group or community of individuals who recognize each other as having significant ethical privileges (2013).

PCC care has become more critical in the context of care because of the increasing objective and disease-oriented view that gives insufficient regard to the subjective illness experiences and does not consider the particular interests and autonomy of the people who use the health services (Entwistle & Watt, 2013). A person-centred approach has an ethical point of departure and adds an enhanced view of the patient as a person and partner in health care. A prerequisite for PCC is to know the patient as a person, a capable human being with will, wishes, needs and feelings, and to engage the person as an active partner in the care and treatment process. The relational focus on the person, rather than the disease alone, facilitates the person’s life situation and health at the centre of care (Ekman et al., 2011; Kristensson Ugglå, 2020).

Implementing PCC in mental care is complex and require multifaceted solutions. It involves not only thinking of person-centeredness in the face-to-face encounter, but also achieving PCC in organisations and communities to facilitate people-centeredness (Gask & Coventry, 2012). It is essential to consider how the population's views are taken into account not only in health care but also in health and social care policy and the wider society (WHO, 2007).

Brendan McCormack and Tanya McCance (2006) have developed a framework for person-centred nursing. Their framework comprises four constructs: *prerequisite* (this is a focus on the RN's attributes), the *care environment* (this is a focus on the context in which care is delivered), the *person-centred process* (focusing on delivering care through various activities) and *expected outcomes* (i.e., the results of effective person-centred nursing). To achieve person-centred outcomes, the required prerequisites and care environment should be considered to provide adequate care (McCormack & McCance, 2006).

THE FRAMEWORK OF THE UNIVERSITY OF GOTHENBURG CENTRE FOR PERSON CENTRED CARE

In this thesis, I use the framework of PCC formulated by the University of Gothenburg Centre for Person-Centred Care (GPCC) based on the philosophy and ethics of Paul Ricoeur (Ekman, 2022; Ekman et al., 2011). This person-centred approach in health care emphasizes the importance of seeing the patient first as a person and as a capable human being with will, wishes, feelings and needs. The approach can be applied via three routes focusing on the partnership between the health professionals and the patient (often with their relatives) – the patient narrative; a mutual agreement; and joint documentation – which aim at initiating, integrating and safeguarding PCC. Forming the partnership, in other words, means thoroughly listening to the patient's narratives; a co-created and mutually agreed health plan incorporates the partnership; and the partnership is safeguarded by documenting the plan. Person-centred care aims to shift from the traditional focus on the patient as a passive recipient of medical treatment to a more collaborative view on health

care where patients are engaged as active partners in the health planning and decision-making process about their care and treatment (Ekman, 2022; Ekman et al., 2011).

Paul Ricoeur (1913–2005) described his understanding of humans as “homo capax” – capable humans – and distinguished between two fundamental aspects of the self, or identity, which he called *ipse* (selfhood) and *idem* (sameness). *Ipse* is the inexpressible inner core that marks the essence of who we are. *Idem*, conversely, is a more external way of identifying the self. *Ipse* determines “*who*” the self is, and *idem* is “*what*” the self is comprised of (Ricoeur, 1994). Application of PCC in practice involves valuing the patient’s personal experiences of their condition in the care context, which, according to Ricoeur, could be described as incorporating *ipse* (“self”) into a care context that tends to focus on *idem* (“identity”) (Kristensson Uggla, 2020). A person cannot only be understood as something that exists without being in relation to their own self, other people, and the institutional context. Ricoeur’s ethical intention is formulated as “*aiming for the 'good life' with and for others, in just institutions*” (Ricoeur, 1994, p. 172). In the endeavour for attaining the “good life”, Ricoeur believes that all actions should aim towards the “good life”. The “good life” in the Aristotelian tradition is what is good for a human. Ricoeur argues that *ethics* (understood in Aristotle’s terms as an endeavour to achieve the good life) should take precedence over *morality* (understood in Kant’s sense as universally valid, binding norms) (Ricoeur, 1994). PCC aims to eliminate or minimize a patient’s triple inferiority (which is due to institutional, existential and cognitive disadvantages), which the patient encounters in contact with the care context and facilitate more just institutions. PCC presupposes conscious ethics as a basis for care actions and seeks to operationalize this ethical standpoint in practice (Kristensson Uggla, 2020) .

RATIONALE

This thesis takes its departure in health and care science, in which the concept of health and the subjective patient experiences play an essential role in the care and the research field (Dahlberg, 2010; Morrow, 2020). The nursing and care sciences have for long claimed that their discipline is based on the patient's perspective. They acknowledge the patient as, firstly, a subject but also her/his object body and therefore congruent with PCC (Ekman et al., 2011). Previous research has shown that focus on health promotion and disease prevention in the health care system effectively improves health, and according to the national public health goals (Prop. 2002/03: 35), health promotion is supposed to be the main focus of health care (Folkhälsomyndigheten, 2021). Despite this, health care today is characterized by a biomedical approach and its underpinning philosophy to determine and treat illness and disease (Alonso, 2004; Kristensson Uggla, 2019, p. 275).

As well as the biomedical view, health and care science takes a holistic view of the human. In terms of this, health not only is related to the absence of disease but also includes mental and social aspects (Huber et al., 2011; Hwu et al., 2001). The challenges of interpretation, in the biomedical approach, of mental health further indicate the importance of a holistic perspective and of considering the patient's lived experiences in care and research (Bolton, 2013). Ricoeur's phenomenological hermeneutics approach assumes that the meaning of lived experience is possible to grasp through the mediation of the interpretation of texts although the objective meaning of a text is different from the subjective intentions of its author, i.e. the narrator (Ricoeur, 1976).

As mentioned above, mental illness is highly prevalent and negatively affects the individual and their family, and its costs to society are high. The burden of mental illness is a challenge for health care, especially primary care, which is where most patients with CMDs receive care. Little is known about patients' life situations concerning stress-related mental illness. The concept of health and mental illness is complex, and both previous and present life situations affect the notion of illness and, therefore, health. Health can be promoted by understanding the subjective illness signs, including symptoms, which is an

ambition in health and care science as well as PCC. PCC emphasizes the importance of knowing the patient as a person and engaging the patient as a partner in care. It is crucial to increase the understanding of ED and find new approaches to support patients in health care based on their resources and needs. An eHealth option based on PCC to promote and enhance health and the general caretaking of patients with CMDs could be part of the solution for how to handle the challenges that face individuals, health care facilities and society because of CMDs.

AIM

The overall aim of this thesis was to build an understanding of the meaning of being affected by ED, to explore experiences of support and to evaluate the effects of a person-centred eHealth intervention in patients on sick leave due to CMDs.

SPECIFIC AIMS

- I. To explore patients' experiences of stress-related exhaustion.
- II. To explore experiences of support in people with stress-related exhaustion.
- III. To evaluate the effects of a person-centred eHealth intervention for patients on sick leave due to CMDs.
- IV. To compare levels of self-reported symptoms of burnout between a control group receiving usual care, and an intervention group receiving usual care with the addition of a person-centred eHealth intervention, in patients on sick leave due to CMDs.

METHODS

METHODOLOGICAL VIEWPOINTS

To reach a comprehensive understanding of how CMDs affect health and life requires a process of interpretation. In this thesis, this was facilitated through an overall hermeneutic approach. Acquiring knowledge through research can never be entirely neutral, as humans are influenced by previous experiences, social context, and how society is shaped. Therefore, a person's view of the world impacts their interpretation. The author of this thesis has a preunderstanding in relation to experiences as a RN, specialized in psychiatric care, working in both in-patient and outpatient clinics with children, youths, and adults. However, it is essential to minimize the influence of this preunderstanding when interpreting and receiving knowledge. (De Witt & Ploeg, 2006; Lincoln & Guba, 1985; Lindseth & Norberg, 2004; Polit & Beck, 2021). Studies I and II contains interview data on the meaning of health concerning ED. Phenomenological hermeneutics research rest on the ground of subjective knowledge. As a philosophy of knowledge applied in the phenomenological hermeneutics approach the epistemology is grounded on the belief that it is knowledge-making is possible through subjective experience and perceptions. The phenomenological hermeneutic approach in Study I and II relate to Ricoeur's epistemology, where both subject and object are affirmed, and the interpretation theory is the theoretical basis for interpretation (Ricoeur, 1976). Studies III and IV relate to the positivist philosophy of creating knowledge based on directly or indirectly measurable variables, such as rating scales of perceptions or attitudes, and thus prioritize the general over the unique and individual (Polit & Beck, 2021).

OVERALL STUDYDESIGN

A multi-method design was used to examine different aspects of CMDs. This design aims to provide a comprehensive picture of the study area, by incorporating qualitative and quantitative data, and using interviews and questionnaires (Morse, 2003). Both inductive and deductive approaches were used, and interpretive and descriptive studies were performed to provide an inclusive understanding of CMDs. According to Polit and Beck (2021), different analysis methods can complement one another and generate a deeper knowledge. Studies I and II were qualitative, and Studies III and IV quantitative. An overview of the study design is shown in Table 1.

Table 1. Overview of the study design

	Design	Data collection	Participants/material	Data analysis
I	Qualitative interview study	Semi- structured face-to-face interviews	Twelve participants, seven women and five men, diagnosed with exhaustion disorder	Phenomenological hermeneutical analysis
II	Qualitative interview study	Semi- structured face-to-face interviews	Twelve participants, seven women and five men, diagnosed with exhaustion disorder	Phenomenological hermeneutical analysis
III	Quantitative randomized controlled study	Self-reported data on sick leave and general self-efficacy	209 participants	Descriptive statistics and logistic regression
IV	Quantitative randomized controlled study	Questionnaire data measuring self-assessed burnout using the Shirom-Melamed Burnout Questionnaire (SMBQ)	209 participants	Descriptive statistics and linear mixed models

PARTICIPANTS AND SETTINGS

Studies I and II

In Studies **I** and **II**, twelve patients registered at different primary health care centres in a large city in Western Sweden were interviewed. Designated HCPs screened the medical records for patients on sick leave due to ED (ICD-10 code F43.8A). A strategic sample was recruited to ensure a range of men and women of different ages. Participants were invited to participate in the study based on the following inclusion criteria: (a) diagnosed with ED by a physician; (b) ongoing sick leave no longer than six months due to ED; and (c) having the mental and physical ability to participate in an interview. The time and place for the interview were chosen by the participants according to their preference. The interviews were conducted until the authors considered the interview questions fully answered. In total, twelve patients participated, seven women and five men, aged 25–46 years (Table 2). Six of the participants were married and/or living with partner, and six were single. Eight had an academic education, and four had a primary school education. All participants were on full- or part-time sick leave at the time of the interviews, except for one who returned to full-time work 2 days before the interview.

Table 2. Demographics of the participants

Participants	<i>n</i> =12
Female	7
Male	5
Age	
25–34	5
35–44	6
45–54	1
Civil status	
Living with a partner	6
Living alone	6
Employee	
Blue collar	4
White collar	8

Studies III and IV

In Studies **III** and **IV**, participants were recruited from nine primary health care centres between February 2018 to June 2020. Participants on sick leave for no longer than 30 days due to CMDs and diagnosed by a primary care physician were considered eligible for inclusion. Patients’ medical records were screened by designated HCPs (for inclusion and exclusion criteria, see Table 3). In the first phase, a letter was sent to eligible participants giving brief information about the study. The addressees were also informed who they could contact for more information or further details about the study within the upcoming week. Patients willing to participate were mailed additional information about the study and a consent form to sign and return. When the

written consent had been obtained, the patients were randomized based on a computer-generated random list created by a third party. They were stratified by age (<50 or ≥50 years) and diagnostic group (depression, anxiety, or stress reactions and disorders). The participants were randomized to either a control or an intervention group and were informed about their allocation.

Table 3. Inclusion and exclusion criteria, Studies III and IV

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> - Is aged 18–65 years - Understands written and spoken Swedish - Has a registered address - Is currently employed or has been studying at least part-time during the last 9 months - Is currently on sick leave, which has not exceeded 30 days, due to any of the following physician-made ICD-10 diagnoses: mild to moderate depression (ICD-10 code F32 and F33), mild to moderate anxiety disorder (F41), reaction to severe stress and adjustment disorder (F43, except post-traumatic stress disorder, but including exhaustion disorder (F43.8A) 	<ul style="list-style-type: none"> - Has been on sick leave >14 days during the last 3 months due to any of the diagnoses listed under “Inclusion criteria” - Has severe impairments hampering the use of the telephone and eHealth intervention - Has ongoing alcohol and/or drug abuse - Has any severe disease with an expected survival of <12 months or a disease that might interfere with follow-up; or might experience the intervention as a burden - Is participating in a conflicting study

Table 4. Baseline characteristics, Studies III and IV

	Control group n=107	Intervention group n=102
Age, mean (SD)	42.2 (11.7)	42.3 (11.2)
Gender, n (%)		
Female	93 (87.7)	82 (80.4)
General self-efficacy (GSE) score, mean (SD)	25.9 (6.1)	25.8 (6.4)
Shirom-Melamed Burnout Questionnaire (SMBQ) score, mean (SD)	86.0 (8.1)	87.7 (9.9)
Civil status, n (%)		
Living alone	30 (28.0)	40 (39.2)
Married/living with a partner	77 (72.0)	62 (60.8)
Country of birth, n (%)		
Sweden	91 (85.0)	89 (87.3)
Other	16 (15.0)	13 (12.7)
Educational level, n (%)		
Compulsory schooling	7 (6.6)	6 (5.9)
Secondary school	16 (15.1)	21 (20.8)
Vocational college	20 (18.9)	15 (14.9)
University	63 (59.4)	59 (58.4)
Current sick leave, n (%)		
0%	4 (3.7)	2 (2.0)
25%	3 (2.8)	5 (4.9)
50%	21 (19.6)	30 (29.4)
75%	3 (2.8)	5 (4.9)
100%	76 (71.0)	60 (58.8)
Diagnosis, ICD-10 codes, n (%)		
Stress (F43)	69 (64.5)	65 (63.7)
Depression (F32 and F33)	23 (21.5)	21 (20.6)
Anxiety (F41)	15 (14.0)	16 (15.7)
Illness history, n (%)		
Previous stress	29 (27.4)	34 (33.3)
Previous depression	28 (26.4)	30 (29.4)
Previous anxiety	33 (31.1)	29 (28.4)
Previous sleep disorder	15 (14.0)	17 (16.7)
Current medication, n (%)		
Antidepressant	54 (50.5)	43 (42.2)
Sedative	49 (46.2)	37 (36.3)
Sleep medication	26 (24.5)	25 (24.5)

ICD-10 = International Statistical Classification of Diseases and Related Health Problems, 10th revision; SD = standard deviation.

DATA COLLECTION AND PROCEDURE

Studies I and II

The interviews were conducted between June 2018 and February 2019. All participants selected where they wanted to be interviewed; the interviews took place in the participants' home, at the author's office or in a café. The interviews were performed 2–4 months after the start of the sick leave and lasted between 28 and 79 minutes (median 45 minutes). The aim of the interview was explained to the participants, who were then asked to narrate their experiences. The interviews were tape-recorded and transcribed verbatim.

In Study I, the opening question was “How do you experience being affected by stress-related exhaustion?” To obtain more in-depth narratives of the experiences, the interviewer asked follow-up questions such as, “What does that mean to you?” and “How do you feel about that?”

Study II is based on the same twelve interviews as described above in Study I. However, the research question and analysed data were different. The opening question in Study II was “How do you experience support in everyday life?” To obtain more in-depth narratives of the participants' experiences, the interviewer asked the same follow-up questions as above.

Studies III and IV

Studies III and IV are based on the “Person-centred eHealth for treatment and rehabilitation of common mental disorders (PROMISE)”, an open RCT in which the control group received usual care while the intervention group received usual care with the addition of a person-centred eHealth intervention. The intervention is built on PCC principles and consists of phone support and an interactive digital platform.

Control group

Patients enrolled to the control group received usual care. Patients on sick leave for CMDs are usually offered an appointment with a physician, who helps the patients reach treatment decisions and follows up on their sick leave. The

recommended treatment for CMDs consists of medication or psychological therapies such as cognitive behaviour therapy, or both (Socialstyrelsen, 2021).

Intervention group

In addition to usual care, the patients in the intervention group received PCC through telephone support and a digital platform (MyHealth). After allocation, they were contacted by an HCPs, received access to the MyHealth platform, and scheduled an initial PCC conversation by telephone.

Telephone support

In the PCC conversation, the HCP listened to the patient's narrative with the intention to capture their experiences of their current situation and health status, as well as their expressions of resources, needs, goals and abilities. Patients' expressions of themselves were the focus of the conversation, and their narratives during the conversation served as guidance for the co-creation of the health plan. Depending on the patients' wishes, the health plan was documented by either the patient or the HCP. During the 6-month intervention, the health plan was modified and reformulated in line with the patients' health process.

Digital platform

The health plan was uploaded to the MyHealth platform. Conditional on the patients' consent, the health plan and other functions on the platform could be made available to those in the patients' social network and others, such as workplace representatives. Subsequent telephone conversations were arranged in agreement between the HCPs and patients.

The MyHealth platform was considered a tool for the patients to facilitate taking an active part in their recovery and rehabilitation. The patients could use it to rate and follow their wellbeing, health process and symptoms, and this symptom information was visualized as graphs that showed trends and developments over time. The patients could also use the platform to write a health diary and communicate with HCPs by messaging. In addition, the platform provided relevant links to different web pages on CMDs. Participants

could choose to use and communicate solely via the eHealth platform, or only by telephone, or both (a further description of the intervention is found in Studies III and IV, and in the study protocol in (Cederberg et al., 2020).

MEASURES AND OUTCOMES

Study III

Questionnaire data measuring self-reported self-efficacy and sick leave were collected by letter at baseline and after 3 and 6 months. Data on baseline characteristics were gathered from medical records or self-reported in the questionnaires. Self-efficacy was assessed using the General Self-Efficacy Scale (GSES) (Schwarzer & Jerusalem, 1995), which has a validated Swedish version (Love, Moore, & Hensing, 2012). The primary outcome measure is a composite score (Packer, 2001), reflecting changes in general self-efficacy (GSE) and degree of sick leave (25%, 50% or 75% of full-time). The GSES consists of ten items, where responses are scored on a 4-point scale (1 = not at all true; 2 = hardly true; 3 = moderately true; and 4 = exactly true). The total score ranges from 10 to 40, and higher scores indicate a heightened sense of GSE. Previous research has suggested 5 points to be a threshold for minimal important change (Fors et. al., 2018; Fors et.al., 2015).

Data on sick leave were self-reported by the participants in questionnaires. Patients were classified as unchanged, deteriorated or improved. Patients who had reduced their sickness absence and increased their GSE by ≥ 5 units at 6 months' follow-up were classified as improved. They were classified as deteriorated if they had increased their sickness absence or had reduced their GSE by ≥ 5 units at 6 months. Those who had neither deteriorated nor improved were considered unchanged.

Study IV

Self-reported questionnaire data measuring the level of burnout were collected by letter at baseline, and at 3 and 6 months from the inclusion date. The Shirom-Melamed Burnout Questionnaire (SMBQ) (Melamed, Kushnir, & Shirom, 1992) was used and correlated with the clinical

diagnosis of ED (Glise, Ahlborg & Jonsdottir, 2012). The SMBQ initially contains 22 items with the subscales: physical fatigue, cognitive weariness, tension and listlessness. However, the Swedish revised 18-item version was used, where the subscale tension is excluded. The statements are answered on a seven-point scale changing from one ('almost never') to seven ('almost always'). The score ranges from 18 to 126, with higher values indicating high burnout. A value of 79 is considered a cut-off for clinical burnout (Lundgren Nilsson, Jonsdottir, Pallant, & Ahlborg, 2012).

DATA ANALYSIS

Phenomenological hermeneutic analysis

Studies I and II

The phenomenological hermeneutic approach allows a structured and comprehensive analysis of a text (Lindseth & Norberg, 2004; Ricoeur, 1976). The analysis consists of three intertwined steps: naïve reading, structural analysis, and interpretation of the whole. In the naïve reading step, the text is read repeatedly to grasp its meaning as a whole. In the structural analysis, the text is divided into meaning units abstracted and formed into subthemes. The structural analysis involves a dialectic movement shifting focus between the meaning units and the overall impression of the text. Several structural analyses and interpretations of the text were performed. In the final part of the analysis, interpretation of the whole, the entire text was re-read and interpreted in relation to the authors' pre-understandings, the naïve reading, and the structural analyses to formulate a comprehensive understanding of the combined narratives. Using Ricoeur's phenomenological hermeneutics and interpretation theory in Studies I and II helped us understand the lived phenomenon of stress-related exhaustion.

Statistical analysis

Study III

Descriptive and analytical statistics were used to compare the study groups. Differences in characteristics between groups at baseline were analysed using Pearson's chi-square test for categorical variables, Student's *t*-test (independent) for continuous variables and Fisher's exact test for dichotomous variables. The difference between groups in the dichotomous version of the composite score and regarding improvement of ≥ 5 units on the GSES was calculated using binary logistic regression, and odds ratios (ORs) with 95% confidence intervals (CIs). The changes in between-group differences in GSE scores were analysed using the Mann-Whitney U test, and missing outcome data for GSE in the composite score were imputed. For the ordered (three levels) categorical version of the composite score and self-reported sick leave, the Mantel-Haenszel chi-square test was applied. To ensure robustness, a sensitivity analysis was performed by excluding patients who reported causes of sick leave other than CMDs ($n=3$) and patients who reported 0% sick leave at baseline ($n=6$) (their sick leave periods had expired once they were randomized). A per-protocol (PP) analysis was performed, including the intervention for participants who had at least one phone conversation with the HCPs and used the MyHealth platform at least once during the intervention period. The significance level was set at $P<0.05$ (two-sided).

Study IV

Longitudinal associations between the intervention and the control group in SMBQ score were analysed using linear mixed models with random intercept in SPSS version 25 (IBM SPSS, Armonk, NY, USA). Time at 0, 3 and 6 months was included as a continuous variable from the inclusion in the study. The interaction between group and time was tested to evaluate whether the development over time was different between the two groups. Descriptive statistics are given in percentages and counts for categorical variables and means and standard deviations (SDs) for continuous variables. Parameter estimates along with the 95% CIs are presented as a measure of association. Several post hoc analyses were done to understand the nature of the interaction effect. To evaluate the magnitude of change, expressed as the raw score

difference between baseline and 3 and 6 months, as well as the change between 3 and 6 months, independent sample *t*-test was performed to assess between-group differences.

ETHICAL APPROVAL AND TRIAL REGISTRATION

Research involving people is regulated by law (SFS 2003:460) to protect the individual and respect human values. The studies have been carried out according to research ethics guidelines and the Declaration of Helsinki (World Medical Association, 2004). Approval for the interview studies was obtained from the Ethical Review Board at the University of Gothenburg (Dnr: 497-17, T 526-18). The participants received oral and written information about the study and were assured that they could withdraw from the study at any time without giving reasons. All interview data were treated confidentially. Sharing lived experiences about life can be difficult and may raise sensitive issues. Where necessary, patients were offered to consult with a counsellor. Written consent was obtained from each participant.

The RCT was registered in ClinicalTrial.gov (Identifier NCT03404583). Approval was obtained from the Ethical Review Board at the University of Gothenburg (Dnr: 497-17, T023-18, T526-18). All participants obtained written and oral information about the study, and all participants agreed to participate by giving signed written consent. All data were stored in a data record (with authorized access only). Before processing the data, we had the participants' social security numbers and names replaced with an identifier code. This ensured that no individual participant could be identified when analysing and presenting the data. Only research staff involved with the study had access to the key code.

In all four studies the participants answered questions and questionnaires that could be experienced as personal and that could awaken sensitive thoughts and feelings. Any participant who posted alarming comments or shared self-destructive comments in the questionnaires or on the MyHealth platform was contacted by an HCP who followed a strict procedure to ensure that participants received adequate help and were referred to their contact in primary care.

FINDINGS

SUMMARY OF THE INDIVIDUAL STUDIES

In study I (Alsén, Ali, Ekman, & Fors, 2020), the interviews aimed to investigate the experiences of being affected by ED. In the analysis, we interpreted experiences of being affected by ED as *a loss of access to oneself and one's context and feelings of being trapped and lost in life*. The main theme, themes and subthemes of Study I are:

Facing a blind alley

Loss of access to oneself

Constraints determine conditions

Loss of self-recognition

Deprivation of dignity

Endless struggle

Managing everyday life

Searching for explanation and understanding

Process of negotiation

Lost in the middle of nowhere

Life on hold

Excluded from life

Rethinking life

The patients experienced a variety of symptoms. The most common were paralysing fatigue in combination with cognitive impairments. These symptoms contributed to difficulties in partaking and fulfilling essential needs in life and one's everyday context. Being disabled raised feelings of powerlessness, and the patients expressed feelings of losing their foothold on life. Feelings of meaninglessness and being lost and trapped in life occurred, and no matter how much they struggled, the participants felt limited in their ability to change. Life was perceived as indefinitely paused.

The narrative texts disclosed that patients affected by ED had the experience of facing a blind alley. This implies that the participants were in a limit situation (more information on the limit situation concept is given in the Discussion) where they were forced to stop, rethink their decisions and find a new direction and a more sustainable way to live their life. This situation implied loss of self-recognition because health problems took over their abilities to do what they wanted to do in life. Reduced abilities caused loss of dignity, and this experience was especially evident in contact with HCPs who failed to see them as a unique person. Being affected by ED was experienced as an endless struggle to try to keep up with life, find explanations and reasons for the health problems, and accept their loss of previous abilities in life.

Another finding was that the participants felt lost in the middle of nowhere, as they experienced life as on hold. Other people's lives seemed to be moving ahead while their own lives were going around in circles, and they had little ability to influence the situation. They felt excluded from life, as they could not participate in a context such as work and family gatherings as they used to do. Activities that had previously giving their life meaning were no longer possible. They started rethinking life, reflecting on previous and present life situations, and facing the consequences of their previous way of living. In summary, ED is a complex and severe condition that presents the personal identity with existential challenges. The situation meant a crisis and openings for new insights, and many of the participants felt that they urgently needed a caring dialogue to deal with feelings of shame, guilt and meaninglessness.

In **Study II**, the interviews aimed to investigate the experiences of support in people with ED. In the analysis, we interpreted support experiences as *having allies to maintain one's dignity*. The main theme, themes and subthemes of Study II are:

Having allies to maintain one's dignity

Being acknowledged

- Being taken seriously
- Personal commitment
- Time for recovery

Proper guidance

- Qualified and trustworthy professionals
- Tailored interventions
- Being trusted to establish new routines

The participants struggled to be acknowledged and maintain their dignity, and they felt supported when others became their allies in this struggle. Professionals, and family and friends needed to show understanding of their situation and guide them in their rehabilitation process. They were acknowledged as a person instead of a patient, by being taken seriously, with others acting in a personal way and showing them commitment. Understanding from professionals, family and friends was shown through giving the participants time and space, which facilitated their recovery.

Professionals needed to be aware of the complexity of the condition to act in a professional and trustworthy manner; otherwise, the patients felt unsupported. A professional encounter had to contain elements of a personal relationship based on knowledge and empathy. Knowledge, clear directives and rehabilitation plans were needed to reduce the participants' stress. Combining personal relationships with personal guidance meant that the patients received tailored interventions, which was crucial for them. A sense of security in "being taken care of" facilitated a focus on the internal process of helping oneself and setting one's own crucial needs before the needs of others.

Studies III (Cederberg et al., 2022) and **IV** report on an interventional RCT evaluating a person-centred eHealth support for patients with CMDs. Altogether 1,317 patients in primary care were screened between February 2018 and June 2121. Of these, 588 declined to participate, 199 were non-responders, and 315 did not meet the inclusion criteria. The remaining 215 were included in the trial. After randomization, six participants withdrew from the study, which left 102 participants in the intervention group and 107 in the control group (Studies III and IV). A PP analysis was conducted on 85 participants (Study III). No significant differences in any baseline characteristics were observed in Studies III and IV (Table 4).

Composite score (Study III)

The primary outcome measure was a composite score of changes at 6 months comprising GSE and reduction in the level of sick leave. At 3 months' follow-up, the composite score showed a greater improvement in the intervention group than in the usual care group (19.6%, n=20, vs. 9.3%, n=10; OR 2.37; 95% CI 1.05, 5.34; $P=0.038$). At the 6-month follow-up, the significant difference did not persist (31%, n=31, vs. 23.4%, n=25; OR 1.47; 95% CI 0.80, 2.73; $P=0.218$). A significant difference between the control and intervention group was observed on the ordered (three-level) composite score ($P=0.04$) at the 3-month follow-up, but this difference was no longer significant at the 6-month follow-up ($P=0.15$) (Table 6).

The PP analysis included 85 participants who had at least one phone conversation with an HCP and who had used the MyHealth platform at least once during the intervention period. At the 3-month follow-up, the composite score showed a greater improvement in the intervention group compared with the usual care group (21.2%, n=18, vs. 9.3%, n=10; OR 2.6; 95% CI 1.13, 6.00; $P=0.024$). At 6 months' follow-up, no significant difference was detected between the groups (35.7%, n=30, vs. 23.4%, n=25; OR 1.8; 95% CI 0.97, 3.43; $P=0.063$). There was a significant difference between the control and intervention groups on the ordered (three-level) composite score ($P=0.009$ and $P=0.028$, respectively) at the 3- and 6-month follow-up. At the 3-month follow-up, a significant effect was found in GSE alone between the control and intervention group ($P=0.034$) in the intention-to-treat (ITT) analysis and

similarly for the PP analysis ($P=0.012$). There was no significant difference between groups in the ITT analysis of GSE ($P=0.068$) at 6 months, but the difference remained in the PP analysis ($P=0.040$) (Table 5). Sick leave alone did not differ between the groups, regardless of whether an ITT or PP analysis was performed (Table 7). In the follow-up at 3 months, 49.4% ($n=41$) of the control group ($n=83$), 53.6% ($n=45$) of the intervention group ($n=84$) and 54.7% ($n=41$) of the intervention group in the PP analysis ($n=75$) reported 0% sick leave. At the follow-up at 6 months the corresponding numbers were 69.8% ($n=67$) for the control group ($n=96$), 69.9% ($n=58$) for the full intervention group ($n=83$) and 72.4% ($n=55$) for the intervention group in the PP analysis ($n=76$).

Table 5. Composite scores at the 3- and 6-month follow-ups

	Control n=107, n (%)	Intervention n=102, n (%)	95% CI	OR	P- value	PP analysis n=85, n (%)	95% CI	OR	P-value
3 months									
Composite score			1.048–5.340	2.37	.04		1.133–5.996	2.61	.02
Improved, n (%)	10 (9.3)	20 (19.6)				18 (21.2)			
Deteriorated/ unchanged, n (%)	97 (90.7)	82 (80.4)				67 (78.8)			
Composite score ^a					.04				.009
Improved, n (%)	10 (10)	20 (20.8)				18 (22.0)			
Unchanged, n (%)	76 (76)	67 (79.8)				59 (72.0)			
Deteriorated, n (%)	14 (14)	9 (9.4)				5 (6.1)			
6 months									
Composite score ^b			0.795–2.730	1.47	.22		0.968–3.429	1.82	.06
Improved n (%)	25 (23.4)	31 (31)				30 (35.7)			
Deteriorated/unchanged n (%)	82 (76.6)	69 (69)				54 (64.3)			
Composite score ^c					.15				.03
Improved n (%)	25 (24)	31 (33)				30 (37.0)			
Unchanged n (%)	64 (61.5)	53 (56.4)				45 (55.6)			
Deteriorated n (%)	15 (14.4)	10 (10.6)				6 (7.4)			

^aThere were seven missing values in the control group, six missing values in the intervention group in the intention-to-treat (ITT) analysis, and three missing values in the intervention group in the per-protocol (PP) analysis.

^bThere were two missing values in the intervention group in the ITT analysis, and there was one missing value in the intervention group in the PP analysis.

^cThere were three missing values in the control group, eight missing values in the intervention group in the ITT analysis, and four missing values in the intervention group in the PP analysis.

CI = confidence interval; OR = odds ratio.

Table 6. Change in general self-efficacy (GSE) from baseline to the 3- and 6-month follow-ups

	Control n=107	Intervention n=102	95% CI	OR	P-value	PP analysis n=85	95% CI	O	R	P-value
3 months										
Mean change, GSE score (SD)	-.038 (5.2) ^a	2.069 (5.9) ^b			.034	2.557 (5.4) ^c				.012
Increase ≥ 5 points, n (%)	11 (10.3)	23 (22.5)	1.167–5.530	2.54	.019	21 (24.7)	1.293–6.342	2.86		.010
6 months										
Mean change GSE score (SD)	1.380 (5.9) ^a	3.204 (6.6) ^b			.068	3.463 (6.6) ^c				.040
Increase ≥ 5 points, n (%)	28 (26.2)	36 (35.3)	.851–2.782	1.54	.154	34 (40.0)	1.020–3.468	1.88		.043

^an=84 at the 3-month follow-up and n=94 at the 6-month follow-up.^bn=84 at the 3-month follow-up and n=82 at the 6-month follow-up.^cn=75 at the 3- and 6-month follow-ups.

CI = confidence interval; OR = odds ratio; SD = standard deviation.

Table 7. Overview of self-reported sick leave at the 3- and 6-month follow-ups

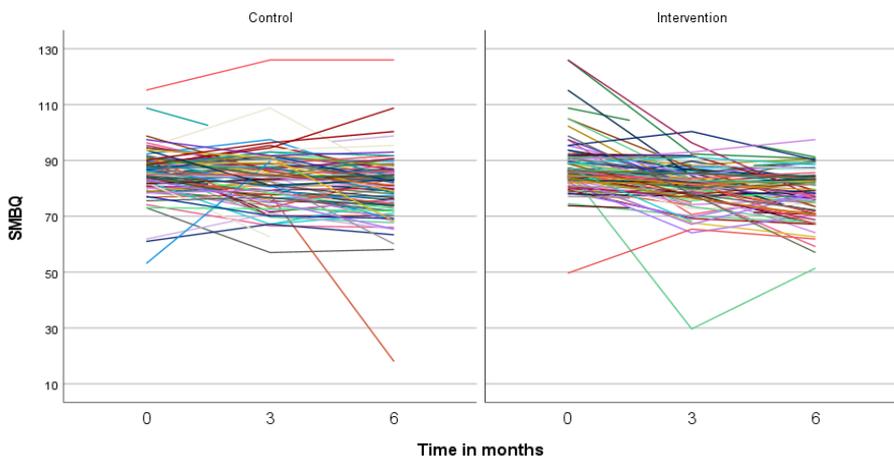
	3-months		P-value	6-months		P-value	Per-protocol analysis (n=85) ^c , n (%)
	Control (n=107) ^a , n (%)	Intervention (n=102) ^b , n (%)		Control (n=107) ^a , n (%)	Intervention (n=102) ^b , n (%)		
Level of sick leave							
Decreased (%)	62 (74.7)	65 (77)	.85	82 (85)	70 (85)	.96	64 (84)
Unchanged (%)	19 (22.9)	16 (19)		11 (12)	11 (13)		11 (15)
Increased (%)	2 (2.4)	3 (4)		3 (3.1)	2 (2)		1 (1)

^an=83 at the 3-month follow-up, n=96 at the 6-month follow-up.^bn=84 at the 3-month follow-up, n=83 at the 6-month follow-up.^cn=75 at the 3-month follow-up, n=76 at the 6-month follow-up.

CI = confidence interval; OR = odds ratio.

In Study IV, a secondary outcome measure of the RCT study was used to compare levels of SMBQ scores between the control group receiving usual care and the intervention group receiving usual care with the addition of person-centred eHealth support. Our findings showed that the individual variation in SMBQ score for each patient was large (Figure 1), but the overall trend for both groups seems to have been a decrease in SMBQ score over time (Figure 2).

Figure 1. Shirom-Melamed Burnout Questionnaire (SMBQ) at each time point for each patient in the intervention and control group



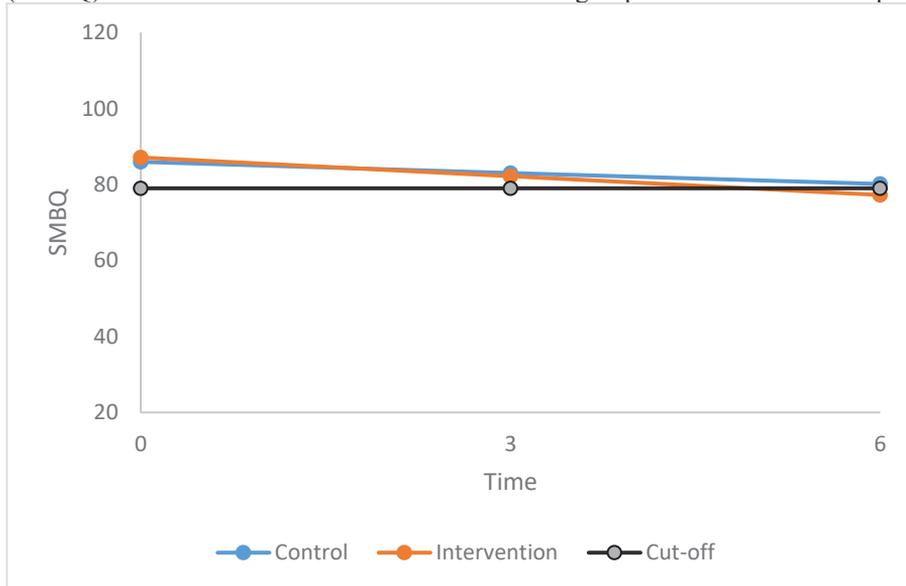
This was also seen in our analysis, where time was significantly associated with SMBQ score and the average decrease over time was -1.64, with 95% CIs ranging from -1.29 to -2.00 points on the SMBQ scale. The difference between the groups was not significant, but the interaction between time and groups was significant, which means that the change over time between the groups was different. The intervention group started at a higher average level compared with the control group (estimated mean 87.1 vs. 86.0) and shifted at 3 months (82.2 vs. 83.9). At 6 months, the estimated mean SMBQ score was below the clinical cut-off for burnout in the PCC (intervention) group (77.2), while the control group remained just above the threshold (80.1).

Table 8. Average change in Shirom-Melamed Burnout Questionnaire (SMBQ) scores within each group, and differences in change between groups and time points.

	Group	Mean change in score (SD) within each group	Mean differences between the groups, score (95% CI)	<i>P</i> -value
Baseline–3 months	Control (n=77)	-2.4 (8.53)	5.3 (2.27, 8.39)	0.001
	Intervention (n=76)	- 7.7 (10.54)		
3–6 months	Control (n=74)	-3.3 (9.63)	-0.74 (-3.59, 2.11)	0.608
	Intervention (n=70)	-2.5 (7.44)		
Baseline–6 months	Control (n=88)	-5.8 (10.17)	3.98 (0.63, 7.33)	0.020
	Intervention (n=76)	-9.8 (11.55)		

CI = confidence interval; SD = standard deviation; SMBQ = Shirom Melamed Burnout Questionnaire.

Figure 2. Estimated mean score on the Shirom-Melamed Burnout Questionnaire (SMBQ) for the intervention and control groups at each time point



Post hoc analyses showed that both groups had decreased SMBQ scores over time. Between baseline and the 3- and 6-month follow-up, the PCC group's score had decreased significantly compared with the control group's ($\Delta=-7.7$, SD 10.5, vs. $\Delta=-2.4$, SD 8.5; $P=0.001$, and $\Delta=-9.8$, SD 11.6, vs. $\Delta=-5.8$, SD 10.2; $P=0.020$, respectively). No differences between the groups were seen between the 3- and 6-month follow-up (Table 8).

DISCUSSION

Comprehensive understanding of the findings

The findings from the studies yield an understanding of CMDs as challenging conditions that require a holistic approach including personal, tailor-made caring and support. A common challenge for patients and HCPs is understanding and supporting mental illness in the context of primary care, where the biomedical approach is dominant. Even though ED is a medical diagnosis, the condition is described as an existential and personal challenge, which is also dependent on relational, family-related and work-related systems. As there are limited no medical instruments (e.g., x-ray or blood samples) available to assess mental health and illness, HCPs are reliant on themselves and the interpersonal relationships with persons seeking care to make that assessment. Therefore, successful support for persons affected by CMDs depends on the ability of individuals (family, friends and professionals) to understand their situation, which highlights the challenge for professionals and the vulnerability of the help-seeking person.

In the studies, the participants with ED had struggled to find this support in a situation where they had lost their foothold and felt lost in life. They needed people who could understand them and stand by their side as allies to help them maintain their dignity and promote their health. Unsupportive encounters could lead to experiences of lost dignity for the participants, while a successful encounter was a starting point for recovery. HCPs, workplace representatives and the members of their social networks who listened to the patients' experiences and tried to understand illness from the patients' perspective were better able to understand the complexity of the illness, which facilitated support. Meeting professionals who understood the power of getting to know the person behind the disease and valued the interpersonal relationship was perceived as supportive, which again demonstrates the importance of being seen as a person and being offered individualized care.

The person-centred eHealth support increased the levels of self-efficacy and slightly reduced the symptoms of burnout in some participants. The participants' narrated experiences (Studies I and II) and self-rated experiences

(Studies III and IV) did not, however, correspond to the level of sick leave, which remained unaffected despite the support. The discrepancy between the participants' subjective illness experiences and the standardized termination of sick leave increased the participants' level of stress and obstructed the recovery as the participants felt unacknowledged and unsupported. This situation highlights yet another challenge for professionals and it also highlights the vulnerability of the help-seeking person. Overall, the findings showed that the illness perspective needs wider recognition in health care and other institutional organizations that encounter people with CMDs.

CMDs are multifaceted and underline the need for a more comprehensive view of health, including but not limited to the biomedical perspective. The findings, consequences, and guidance for health will be discussed under the following headings: "Existential consequences and the role of society", "Confirmation of personhood and the role of allies" and "Supporting mental health through a person-centred eHealth support".

Existential consequences and the role of society

In our findings, ED, one of the most severe and disabling diseases related to stress, affected the participants' identity and raised questions about life and its meaning. The disorder meant that life was on hold: the participants felt excluded from life because relevance and meaning were missing (Alsén et al., 2020). An existential angle of being affected by ED is also shown in previous research describing experiences of struggling with a threatening nothingness (Rehnsfeldt & Arman, 2008), being disconnected from oneself, the body and world (Engebretsen & Bjorbækmo, 2019; Jingrot & Rosberg, 2008), and living in darkness, struggling with the creation of meaning (Arman, Hammarqvist, & Rehnsfeldt, 2011). We interpreted this existential challenge as *facing a blind alley*, a metaphor for how ED affects a person's existence and raises existential challenges. By applying the philosopher Karl Jaspers concept of limit situation (Jaspers, 1994), we concluded that being affected by ED is a defining existential experience. According to Jaspers, limit situations include death, struggles, and existential anxiety that remains unchanged by suffering, and people do not perceive the limit situation until they confront it concretely and

personally. These confrontations are unavoidable, and they open up an opportunity to discover something about oneself and one's existence (Jaspers, 1994). This assumption aligns with our findings showing that being affected by ED made the participants realize their limitations and gave them insight into what was crucial for them. When affected by ED, the participants saw this as an expression that they had not lived sustainably. They had now reached their own limit as well as the limit of their own life sustainability.

Jonna Bornemark (2006) has further developed Jaspers' concept of limit situation to mean that we can begin to understand our situation as a limit – which is more than merely understanding our own limitations. Hence, “limit situation” should be understood as a concept that marks the limitation of a human being but also as a way of exploring the human situation as a limit (Bornemark, 2006). The participants experienced it as challenging and disappointing to have to face inevitable pressure from the family and society, as well as work-related difficulties, and they described all these factors in combination as the reason for their stress. It has been stated that, although stress is felt in response to many interacting factors, for many people it is largely due to lack of opportunities (or the inability) to cope with contemporary demands (Lazarus & Folkman, 1984). The question is whether we have now, with all the present-day challenges, reached the limit of what humanity can handle? Today's increasing stress-related mental illness may indicate that society has reached its limit.

Lips (2020), argues that the structural environment is one crucial reason for mental illness. When explaining mental disorders, we commonly look at psychological (individual) factors. When psychological factors are emphasized over societal factors, the responsibility for the illness is placed on the individual rather than on the structural environment and society (Lips, 2020). This probably increases stigmatization, negatively affecting the affected person in contact with HCPs, workplace representatives, and members of their social network. This highlights the importance of increased knowledge about mental illness and a public health responsibility to reduce stigmatization and thus facilitate health for the public.

Paul Ricœur's “just institutions” is a major concept in his definition of the ethical intention, which suggests that all humans have an inherent strive, which

is “*aiming at the ‘good life’ with and for others in just institutions*” (Ricoeur, 1994). “Just institutions” refers to equality and encompasses the idea of living well beyond interpersonal relationships (Kristensson Uggla, 2011; Ricoeur, 1994). Society, the health care system, and professionals as representatives for the just institution would entail that all people are treated well and equally, and if the institutions are not just, the pursuit of health is hindered (Ricoeur, 1994). In her work on social justice (Nussbaum, 2013) elaborates on Ricoeur’s “just institutions” concept by highlighting the system’s important task of enabling the people who live in it. Society must offer fundamental social justice in terms of improving the quality of life for all people. Nussbaum uses the term “capability” to highlight that quality of life is defined based on the abilities that people have. Capabilities are the results of abilities, and it is society’s moral obligation to give people opportunities and support their needs to develop their capabilities – and to give people opportunities to choose and act.

According to public health goals and the health care system, all people should have the same possibilities in life and should be treated the same (Folkhälsomyndigheten, 2020; ICN, 2014). According to the professional and ethical oath for RNs (ICN, 2014), HCPs generally have the intention to do good. Moreover, health care aims to organize care so that health care resources are focused where they are most needed (HSL, 2017). However, in today’s already strained context, this overall approach can be a challenge for HCPs as they need to adapt to an inflexible system where “one size fits all”. Ricoeur’s ethical intention to do good can be complicated and may be lost in the work process (Kristensson Uggla, 2020) and broader institutional contexts (e.g. society, public health, and cultural and political communities). Therefore, HCPs and people seeking care face several challenges in today’s health care system and society. PCC aims to eliminate or minimize the triple inferiority (which is due to institutional, existential and cognitive disadvantages) that a patient encounters in contact with the care context, and to facilitate more just institutions. PCC presupposes conscious ethics as a basis for care actions and seeks to operationalize this ethical standpoint in practice (Kristensson Uggla, 2020).

Confirmation of personhood and the role of allies

Experiences of support, in patients affected by ED, were interpreted as the patient struggled to maintain their dignity, a situation in which they required allies (Study II). Participants experienced exhaustion due to essential and inevitable tasks in life, regardless of challenges from work or family, or both. The participants described seeking support for unfamiliar and appalling symptoms, which contrasted to previous vitality, and they expressed the need to be seen as a unique person. Ricœur (1994) distinguishes between two aspects of the self or identity, referring to one as *ipse* (selfhood) and the other as *idem* (sameness). As previously mentioned, *ipse* describes the indescribable inner core that marks the essence of who we are, while *idem* is an external way of identifying the self (i.e., *ipse* identifies “who” the self is, and *idem* is the “what” the self consists of). Studies I and II showed that professionals can fail to meet the person behind the disease, which means they focused more on *idem* (sameness) and disregarded the *ipse* (selfhood). This raises worries, especially as ED presents existential challenges that significantly impact a person’s identity. Based on this, we can understand the finding that the participants struggled against the feeling of being reduced to their disease and strived to maintain the notion of themselves as persons. Therefore, the participants were vulnerable when not being acknowledged and respected, which is in line with previous studies showing the importance of being respected and listened to (Nordh, Grahn, & Währborg, 2009) and the increase in distress and exhaustion (Daalen, Willemsen, Sanders, & Veldhoven, 2009; Engebretsen & Bjorbækmo, 2019) when encountering the opposite. Not being acknowledged as a person can contribute to detachment from one’s body (Jingrot & Rosberg, 2008) and existential anxiety (Alsén et al., 2020). Patients have described experiences of being changed into a person unknown to themselves when facing distrust in clinical encounters (Engebretsen & Bjorbækmo, 2019).

Not treating patients as persons is described by Sveneaus (2000) as unethical, and not seeing the patient as a person increases the risk of missing valuable information about the subjective experience of the disease. This assumption aligns with the psychologist Carl Rogers (1902–1987), who states that the therapists need to see the world through the patient’s eyes (Rogers, 1956). Our findings showed that confirmation of personhood (through acknowledgement) and the role of allies (reaching a common understanding) was facilitated

through the construction of the interpersonal relationship. Relationships with both a professional and a personal element were a prerequisite for the participants to experience support. These findings were conceptualized in relation to therapeutic alliance as described by Rogers (Overholser, 2007; Rogers, 1956). The core components of the therapeutic alliance are empathy, congruence (genuineness) and an unconditional positive regard (acceptance) (Overholser, 2007). The interpersonal relationship is crucial for care and support and, according to Rogers, the interpersonal relationship in psychology is founded on trust between the client and the therapist. Trust empowers the client to have the confidence to freely express their feelings, which enables the client and the therapist to work together for the client's benefit.

Our findings showed that having allies facilitated the participants' ability to self-support, which corresponds to Roger's assumption that the therapeutic alliance strives to create an equal partnership where therapists support empowerment and help patients find their way to change (Rogers, 1951, 1956). Hence, HCPs need to support patients with ED as persons first. Understanding *who* the person is has its starting point in the narrative. Therefore, professionals also need to support patients by initiating a caring dialogue that focuses beyond a patient-centred approach, incorporating *ipse* (self) into a care context that tends to focus on *idem* (identity, sameness) (Kristensson Uggla, 2020).

Supporting mental health through a person-centred eHealth support

The RCT conducted in this thesis aimed to operationalize the GPCC approach, with its emphasis on knowing the patient also as a person, and apply its core components: partnership, including the patient's narrative, and the co-creation and safeguarding of the care and health plan (Britten et al., 2020; Ekman, 2022; Ekman et al., 2011). The person-centred eHealth support aimed to give PCC at a distance for patients on sick leave due to CMDs.

Self-efficacy is a central concept entrenched in the GPCC approach. Self-efficacy relates to PCC at a theoretical level since both concepts address people's beliefs in their own ability to target and perform actions to achieve desirable goals. As the person-centred eHealth support builds on each patient's

resources and preferences, GSE was considered a suitable patient-reported outcome in the RCT study. General self-efficacy is well established as outcome measure (Luszczynska, Scholz, & Schwarzer, 2005) and was used as the primary endpoint in Study III to evaluate the effects of the RCT on the challenges arising from CMDs. The GSES has previously been validated in Sweden (Love et al., 2012). Our findings showed that usual care with addition of the person-centred eHealth intervention, compared with usual care only, for patients on sick leave due to CMDs, improved self-efficacy (Cederberg et al., 2022). Improved self-efficacy may have important implications for these patients. Previous studies have shown that improved self-efficacy is a crucial factor to enable self-management and is also a predictor for future health status (Lorig & Holman, 2003).

In Study IV a secondary outcome measure of the RCT was level of burnout, assessed using the SMBQ (Grossi et al., 2005; Jonsdottir, Hägg, Glise, & Ekman, 2009; Lundgren Nilsson et al., 2012) in the intervention group compared with the control group. The results showed that the intervention had a slight effect on symptoms of burnout during the first 3 months of the intervention. The intervention's limited effect on symptoms of burnout corresponds to previous studies showing that treatment and interventions for CMDs have limited effects on symptom relief (Arends et al., 2012; Perski, Grossi, Perski, & Niemi, 2017; Salomonsson, Hedman-Lagerlöf, & Öst, 2018; Wallensten, Åsberg, Wiklander, & Nager, 2019).

The findings in Study III and Study IV were self-reported and reflect the patients' experiences of disease. However, their illness experiences did not correspond to their level of sick leave. Although self-reported sick leave data may be congruent with employers' registers (Fredriksson, Toomingas, Torgén, Thorbjörnsson, & Kilbom, 1998), not having access to complete register data obstructed gaining more detailed information on the participants' sick leave process. Sick leave is a complex process as many factors at different structural levels are involved, e.g. medical experts, workplace representatives and social insurance agencies (Corbière et al., 2020). Although the patient's health status should be the point of departure for decisions regarding the rehabilitation process there are still standardizations and recommendations that professionals need to consider. This may also obstruct patients' ability to influence the process. Altogether, the results from the present RCT study raise questions

regarding the effect from a long-term perspective and further research is needed to assess the clinical value of these findings.

Methodological considerations

Qualitative and quantitative methods complement each other by using words and meanings, and numbers and statistics, important for gaining different kinds of knowledge. The method should always be guided by the overall aim of the research. Multi-method design is used to provide a comprehensive picture of the study area (Morse, 2003; Polit & Beck, 2021). A qualitative research method primarily aims to understand and describe the meanings of a phenomenon, such as experiences of ED and support (Studies I–II), but not generalizable facts about this topic. In qualitative analysis there are no fixed rules for sample size. For example, interviews can generate a large amount of data for the analysis and enough data to formulate meaning units and themes of the studied area (Polit & Beck, 2021). However, to assurance the trustworthiness of qualitative studies, several issues need consideration.

According to Lincoln and Guba (1985), trustworthiness in qualitative research refers to four criteria: credibility, dependability, confirmability, and transferability, in relation to each other. *Credibility* refers to the evidential value of the study, which must be conducted in a way that shows credibility; therefore, steps should be taken to demonstrate credibility. To ensure understanding of the phenomena in Studies I and II we aimed to reach rich narratives by enrolling participants of different age and sex and using follow-up questions tailored explicitly to each narrative to clarify the findings. *Dependability* refers to whether the findings are consistent and could be repeated. In Studies I–II, the participants had the same condition, were diagnosed by a primary care physician, and were at the start of their sick leave. The same person conducted the interviews, asking the same opening question and similar follow-up questions. Moreover, the interpretation of the texts was undertaken by several researchers to ensure the dependability of the findings. This can be seen as the creation of *Confirmability*, refining the objectivity or neutrality of the results (1985). Ricoeur (1976) states that there are several ways of understanding a text, and the interpretation of the study data characterizes one of several understandings. According to the

phenomenological hermeneutic approach, a pre-understanding can never be totally avoided and always has some influence on the analysis. However, there should be awareness of the pre-understanding and it should continuously be reflected upon to minimize its impact on the interpretation (Lindseth & Norberg, 2004). *Transferability* refers to the possibility of the findings applying to other groups and settings. This was promoted by a thoroughly described context, sample process and analysis, and the present results are likely to apply to different settings where people with CMDs are treated (Lincoln & Guba, 1985).

Quantitative studies are often discussed concerning validity and reliability. *Validity* refers to whether an instrument measures what it is intended to measure and *reliability* discusses the consistency of what is measured (Polit & Beck, 2021). All the questionnaires used in this thesis (Studies III and IV) are well established and the Swedish version has been validated. The GSES, used in Study IV, is widely used and has been tested nationally (Love et al., 2012) and internationally (Luszczynska et al., 2005). The SMBQ is well suited to measure the severity of illness and treatment outcomes in the working population and in patients in a clinical setting (Grossi et al., 2005). The validated revised 18-item Swedish version was used in Study IV, excluding tension (Lundgren Nilsson et al., 2012).

An RCT design was utilized to evaluate the effects of the person-centred eHealth intervention. This design is considered the gold standard as it protects against selection bias. Randomization is the only means of controlling for known and measured factors (e.g., sex and age) and for unmeasured and unknown factors (e.g., interventions in primary care) of CMDs that cannot be explained only by known factors such as age. Since only a part of the outcome can be explained by known factors, randomization is necessary to balance these unknown factors (Odgaard-Jensen et al., 2011). In Study III and IV we used a predefined stratification step to enhance internal validity and randomized a heterogeneous group, which reduced the risk of bias caused by factors that could contribute to the measured effects. A relatively large number of participants randomized from nine public primary health care centres in one city in Sweden satisfied the external validity. The sample was sufficiently large to increase reliability, and the significance level was set at 0.05, preventing type 1 and type 2 errors. Finally, a consistent follow-up period exceeding 6

months strengthened the *generalizability* of the study to other settings and samples (Polit & Beck, 2021). One issue was that the participants in studies III and IV were required to manage the Swedish language. If necessary, it would have been possible to include interpreters in connection with the telephone support, but the MyHealth platform is currently only available in a Swedish version. Another issue is that participants who were willing to participate in the RCT may also have been more attracted towards eHealth interventions, and thus possibly not representative of the larger population. The ethical approval did not include analysing reasons for declining to participate.

CONCLUSION

The findings of this thesis are that CMDs negatively affect health, and in our findings the described conditions did not fully harmonize with the biomedical perspective (Alsén et al., 2020; Bolton, 2013). These findings confirm that health is more than the absence of disease or infirmity (WHO, 1947). The participants' life situation cannot be defined as healthy as the participants neither were in "*a state of complete physical, mental and social wellbeing*" (WHO, 1947) nor had the "*ability to realize meaningful goals*" (1986) or "*large or small life projects*" (Dahlberg, 2010).

The findings further show that ED is an existential challenge, for the facing of which the person needs allies in their fight to promote health and dignity. In the study population this was facilitated through acknowledgement from the participants' supportive network (HCPs, workplace representatives, and social networks). The interpersonal relationship between patients and HCPs, characterized by a caring dialogue and being treated as a person, was a starting point for a partnership and co-creation of care. The person-centred eHealth support improved self-efficacy and resulted in a slight decrease in symptoms of burnout, which could impact these patients in managing their life situation. The findings show that PCC is a feasible approach that integrates people's health and aspects that affect it, such as illness, the life situation and social structures. However, our findings also indicate that some aspects of understanding and caring for persons with CMDs need further consideration in the clinical setting as professionals are acting within a medical paradigm where they are at risk of focusing on clinical signs instead of illness experiences. Personal symptom experiences are important, as described in the patients' narratives following PCC.

Furthermore, as mental illness is closely connected to personal values and personality, professionals need skills in building interpersonal relationships. A PCC partnership facilitates the understanding of the patient as a person and the tailoring of interventions and support according to the patient's needs. Finally, the aspect of societal structures and their impact on health also needs to be considered in the health care context when understanding and caring for these patients.

FURTHER PERSPECTIVES

This thesis shows the importance of HCPs including a more comprehensive perspective than the biomedical perspective when encountering patients with CMDs. The HCP's ethical responsibility is to restore health and wellbeing. For professionals to facilitate health, they need to consider the patients' entire life situation. To do this, they need to include patient's experiences of symptoms. This approach begins with interpersonal relationships where professionals need a more open and personal approach when meeting persons in need of help. Medical and professional knowledge is crucial; however, the prerequisites to this approach lie in the hands of the professionals and depend on their ability to also be able to create relations.

As medicine focuses on disease from a biological perspective, medicine and caring science are complementary in health care as both perspectives are needed to improve health. PCC emphasizes a more collaborative view on health care where patients are engaged as active partners in the health planning and decision-making process of their care (Britten et al., 2020; Ekman, 2022; Ekman et al., 2011). PCC is congruent with the essence of health promotion, of aiming to increase people's control over their health, which is essential for people and the wider society. The health promotion approach aims to improve and support health for people, communities, and organizations (WHO, 1986).

PCC and health promotion are coactive and essential parts of today's modern and ethical health care (Lloyd et al., 2020; Swedberg et al., 2021). These core approaches yield growing evidence of improved health outcomes (Hansson et al., 2016). Health promotion actions can work synchronously with PCC if they are developed in partnership with the person and consider that person's life context and socioeconomic conditions (Engel, 1977; Swinburn et al., 2011).

HCPs, workplace representatives and the patient's social networks are all important facilitators to increase the patient's wellbeing and health. Therefore, it is essential to increase our knowledge of CMDs, not only in health care but also in health and social care policy and in the wider society.

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