

Experiences of continuity when living with chronic heart failure

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“The movement from initial interruption to complete immersion usually occurs with both bumps and jolts and long smooth stretches”

Cited with kind permission of Professor Kathy Charmaz

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ABSTRACT

The overall aim of this licentiate thesis was to explore how persons living with chronic heart failure (CHF) experience continuity and discontinuity in their daily life and in their healthcare contacts. The specific aims were: To illuminate whether persons with CHF experience discontinuity in their life and, if so, what helped them to preserve and strengthen continuity in their daily lives (Paper I). The aim was also to describe how the interaction in healthcare encounters contributes to either continuity or discontinuity in the daily life for persons with CHF (Paper II). The Grounded Theory Method (GTM) was used in the collection and analysis of data. Interviews were conducted with 18 participants, including 13 individual interviews and one group interview with five participants. The average age of participants was 76 years. The participants had been diagnosed with CHF from six months to more than five years with a varying severity of the disease. The results showed that life with CHF resulted in disruptions, losses and setbacks in relation to corporeality, temporality and identity. This caused experiences of discontinuity in daily life. To bridge these experiences, the participants constructed recapturing approaches that helped to reconcile them with their lives (Paper I). Moreover, the results showed that a ‘patient-centred agenda’ or a ‘person-centred agenda’ in the healthcare encounter, created from the normative discourse and professional actions, resulted in a sense of either continuity or discontinuity (Paper II). In conclusion, living with CHF could be troublesome in many ways but, despite this, the participants continuously managed upcoming limitations to overcome the obstacles in order to preserve continuity in their lives. Therefore, support from healthcare professionals is needed to preserve continuity in daily life, together with a healthcare organisation that supports one’s ability to manage and overcome discontinuity in daily life.

Keywords: Chronic heart failure, continuity, continuity in daily life, continuity of care, grounded theory method, illness

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SAMMANFATTNING PÅ SVENSKA

Behovet av att erbjuda kroniskt sjuka en sammanhållen och kontinuerlig kontakt med vården är belyst i ett flertal studier. Vårdkontinuiteten hotas när en person har flera vårdkontakter och i samband med överflyttning, informationsöverföring och bristande kommunikation mellan dessa vårdgivare. Det saknas kunskap om hur personer med kronisk sjukdom upplever vardagen och vårdkontaktarna ur ett kontinuitetsperspektiv. Licentiatavhandlingens övergripande syfte var att utforska kontinuitetens betydelse för personer som lever med kronisk hjärtsvikt (CHF). Specifika syften var; Att belysa om personer med kronisk hjärtsvikt erfar diskontinuitet i livet och om så är fallet, vad som hjälper dem att bevara och stärka kontinuiteten i deras dagliga liv (Paper I). Att beskriva hur möten med hälso- och sjukvård bidrar till antingen kontinuitet eller diskontinuitet i det dagliga livet för personer med kronisk hjärtsvikt (Paper II). Grounded theory metod (GTM) användes vid insamling och analys av data. Intervjuer genomfördes med 18 deltagare. Åtta män och fem kvinnor intervjuades enskilt och fem kvinnor intervjuades i grupp. Medelåldern var 76 år. Deltagarna hade en diagnostiserad kronisk hjärtsvikt från 6 månader till mer än fem år med olika svårighetsgrad av sjukdomen (NYHA I-IV).

Resultatet av studien visade att livet med CHF resulterade i avbrott, förluster och motgångar i deltagarnas vardag. Sjukdomen påverkade också deltagarnas identitet, kropps-, och tidsuppfattning. Även det dagliga livet påverkades och upplevelsen av diskontinuitet ökade allt eftersom sjukdomen progredierade. För att överbrygga diskontinuitet konstruerades strategier som bidrog till att deltagarna försonades med sin livssituation och att kontinuiteten i livet stärktes (Paper I). Resultatet visar att hälso- och sjukvården bör stödja förmågan hos personer med kronisk hjärtsvikt att skapa kontinuitet i livet. Resultatet visade också att hälso- och sjukvårdspersonalens förhållningssätt bidrog till att skapa en känsla av antingen diskontinuitet eller kontinuitet i kontakten och att en ”Personcentrerad agenda” ökade förutsättningarna för att skapa kontinuitet i vardagen för personer med CHF (Paper II).

Nyckelord: Grundad teori, kontinuitet, kronisk hjärtsvikt, kronisk sjukdom, livskontinuitet, vårdkontinuitet

LIST OF PAPERS

This Licentiate thesis is based on the following papers, referred to in the text by their Roman numerals.

- I. Östman M, Jakobsson Ung E, Falk K. Continuity means “preserving a consistent whole” – A grounded theory study. *Int J Qualitative Stud Health Well-being*. 2015, **10**:29872. <http://dx.doi.org/10.3402/qhw.v10.29872>
- II. Östman M, Jakobsson Ung E, Falk K. Health-care encounters creates both discontinuity and continuity in daily life when living with chronic heart failure – A grounded theory study. *Int J Qualitative Stud Health Well-being*. 2015, **10**: 27775. <http://dx.doi.org/10.3402/qhw-v10.27775>

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ABBREVIATIONS

CHF	Chronic Heart Failure
GTM	Grounded Theory Method
HLA	Heart and Lung Association
NYHA	New York Heart Association
WHO	World Health Organisation
WMA	World Medical Association

1 INTRODUCTION

This licentiate thesis, based on two studies, explores the phenomenon of continuity in daily life and in connection with healthcare contacts from the perspectives of persons living with chronic heart failure (CHF).

Living with disease and illness ‘that last a year or more and require ongoing medical attention and/or limit activities of daily living’ is described as a chronic condition (Hwang, Weller, Ireys, & Anderson, 2001; Warshaw, 2006). This could affect a person’s life with disruptions in daily living (Ambrosio et al., 2015; Charmaz, 1991, 2002) as well as likely contributing to complex healthcare needs (Barnett et al., 2012; Coleman, 2003). Similar experiences are described in the context of living with the chronic condition of CHF according to two review studies (Jeon, Kraus, Jowsey, & Glasgow, 2010; Yu, Lee, Kwong, Thompson, & Woo, 2008). It is well known that CHF increases with age (Barasa et al., 2014; McMurray et al., 2012; Yancy et al., 2013; Zarrinkoub et al., 2013), although a slight decrease has been noticed in recent years, according to Swedish data (Zarrinkoub et al., 2013). Despite this, the number of persons with CHF is increasing due to the absolute numbers of elderly persons in society (WHO, 2015; Barasa et al., 2014). This means that the healthcare system should pay attention to the potential problem that a chronic condition such as CHF could cause disruptions both in a person’s daily life and in relation to healthcare.

1.1 Chronic heart failure

CHF is defined as a syndrome which affects the heart’s ability to supply the body with blood because of functional or structural damage in the heart resulting in fluid retention, breathlessness, fatigue and limited exercise capacity (McMurray et al., 2012; Yancy et al., 2013). It is a common disease, and affects about two percent of the adult population in Sweden and other Western countries (McMurray et al., 2012; Yancy et al., 2013; Zarrinkoub et al., 2013). The diagnosis CHF is based on the experiences of symptoms and objective signs of cardiac dysfunction (McMurray et al., 2012). Symptoms are the person's subjective experience of illness (Ekman et al., 2005a) and self-reported symptoms are often the first diagnostic clue due to its slow and insidious onset according to K. Falk, Swedberg, Gaston-Johansson, and Ekman (2007). However, the symptoms are not always specific, which sometimes makes it difficult to distinguish it from other diseases (McMurray et al., 2012). CHF is progressive, and the disease trajectory may differ

between persons, though it is usually a pattern of gradual deterioration, from a relatively stable phase that is interrupted by episodes of acute deterioration, some recovery and finally death (Goodlin, 2009; Murray, Kendall, Boyd, & Sheikh, 2005).

Even though persons with CHF are treated according to current guidelines and multidisciplinary programmes, they often experience bothersome symptoms such as shortness of breath, lack of energy and fatigue (K. Falk, Swedberg, et al., 2007; McMurray et al., 2012; Yancy et al., 2013; Zambroski, Moser, Bhat, & Ziegler, 2005). These symptoms may contribute to a reduced quality of life (Ekman, Fagerberg, & Lundman, 2002; K. Falk, Granger, Swedberg, & Ekman, 2007; Nordgren, Asp, & Fagerberg, 2007) and as CHF progresses from mild to severe, the symptom burden increases (Whellan et al., 2014; Zambroski et al., 2005). The classification of mild to severe CHF is made with help from the NYHA classification assessment in order to predict outcome (Bennett, Riegel, Bittner, & Nichols, 2002). This may sometimes be difficult to classify, because symptoms are subjective and influenced by a number of factors, and the assessment often differs between the patient's experiences and the healthcare professional's opinion (Ekman et al., 2005a). However, based on the randomized control trial study COMET, self-assessed symptoms seems to be a good way to predict outcomes as hospitalization and mortality, according to Ekman, Cleland, Andersson and Swedberg (2005b).

Persons living with CHF might be restricted in their daily life (Ryan & Farrelly, 2009; Thornhill, Lyons, Nouwen, & Lip, 2008), due to distressing symptoms, impaired physical ability, powerlessness and hopelessness (K. Falk, Patel, Swedberg & Ekman, 2009; Jeon et al., 2010; Ryan & Farrelly, 2009; Yu et al., 2008). Age seems to matter when it comes to living with CHF, and older persons experience severe and frequent disorders resulting in poor health-related quality of life, according to a review by H. Falk, Ekman, Anderson, Fu, and Granger (2013). However, according to another Swedish study by Nordgren et al. (2007), living with moderate to severe CHF as a middle aged person does not seem to be less troublesome, although the experience may vary. Living with severe CHF and palliative care is felt to be living a 'roller coaster life' and 'knocking on death's door', according to a study by Brannstrom, Ekman, Norberg, Boman and Strandberg (2006). Also, family members described the experience of being a passenger in a 'roller coaster life' as being in constant worry and having a feeling of always being on duty (Brannstrom, Ekman, Boman, & Strandberg, 2007). Thus, living with CHF requires adjustments of identity and lifestyle and finding strategies to

safeguard independence (Jeon et al., 2010; Stull, Starling, Haas, & Young, 1999; Yu et al., 2008).

CHF, as a progressive syndrome with periods of ups and downs, may often result in frequent and long-lasting healthcare contacts or/and acute hospitalizations (Liao et al., 2007; Mejhert et al., 2013; Swedberg et al., 2005). It seems that living with moderate to severe CHF could contribute to experiences of fragmented care due to a lack of coordination and poor communication. Difficulties in navigating and accessing care can also contribute to the experience of discontinuity in relation to healthcare contacts (Browne, Macdonald, May, Macleod, & Mair, 2014; Nordgren et al., 2007; Ryan & Farrelly, 2009).

1.2 Continuity

Two theoretical perspectives are used in this thesis to interpret the importance of continuity for persons living with CHF: Atchley's (1989) theory of continuity in relation to the normal aging process and the model of Haggerty et al. (2003) in relation to dimensions of continuity of care. The choice of Atchley's (1989) theory of continuity is based on the fact that aging is still there even if someone is living with one or more chronic conditions. This theory is broadly used in relation to continuity in the normal aging process. The multidimensional model by Haggerty et al. (2003) was used in order to describe dimensions of continuity of care in relation to healthcare practice and the fact that their definition of continuity of care can be viewed from both a person perspective and a healthcare perspective. These two models, together with Charmaz (2006), constructivist grounded theory, are the epistemological foundation for this licentiate thesis.

1.2.1 Concepts of continuity of life

The concept of continuity has several dimensions. One way is to describe continuity from a philosophical point of view, which recurs in several contexts through history beginning with Aristotle, who believed it to be an essential feature of space and time (Keele, 2008). As a prerequisite for human life, continuity is central to achieving our personality, and, according to Smith (2010), it is created in relation to social structures based on preserving social relationships and daily routines over time. This is similar to Harré (1998), who explains continuity as maintaining one's position in the world, time and space in relation to the concept of personality.

Another way is to describe continuity through the life course, which can be explained as the subjective perception that changes are linked to, and, according to Cohler (1982), fits in with individual personal history. In relation to normal aging, continuity is regarded as an elusive concept that in one way means remaining the same, being uniform or unchanging. This static view of continuity seems to be difficult to fit into a person's changing world. Continuity should rather be seen as a dynamic process to promote both individual preference and social approval. Experiences of both continuity and discontinuity are accommodated in a person's life process due to changes in life. Changes can be linked to continuity as an antonym, and can be regarded as both negative and positive where changes are a part of life, and the fact that adaptive strategies based on past experience are used to deal with changes and creating a balance in life (Atchley, 1989).

1.2.2 Concepts of continuity of care

From the healthcare perspective, the concept of continuity of care is widely used without a clear definition and is entangled with other concepts of care, according to a review by Uijen, Schers, Schellevis, and van den Bosch (2012). The concept of continuity of care has changed over the past decades due to contextual factors such as specialization of medical care, consumer movement, changes in primary care structure and the development of medical treatments and technology. However, from the 2000s, according to Freeman, Shepperd, Robinson, Ehrich, and Richards (2001) models have been developed so as to focus on the patient's perspective on coordinated and smooth progression of care. Saultz (2003) has defined a hierarchical model of three levels so as to show relationships between informational, longitudinal and interpersonal continuity. Furthermore, other multidimensional models have been developed which distinguish between three dimensions of continuity in relation to healthcare: informational, management and relational (Haggerty et al., 2003; Reid, Haggerty, & McKendry, 2002). This model is frequently used today (Gulliford, Cowie, & Morgan, 2011; Haggerty, Roberge, Freeman, & Beaulieu, 2013; Uijen, Schers, et al., 2012; Waibel, Henao, Aller, Vargas, & Vázquez, 2012).

A commonly used definition by Haggerty et al. (2003) states that experiences of the continuity of care depend on healthcare events that the patient has experienced as continuous, associated and consistent with their medical and personal context. Patients appear to experience continuity of care when they are given information, feel confident and secure about the care pathway, and have a relationship with a trusted clinician (Haggerty et al., 2013; Tarrant, Windridge, Baker, Freeman, & Boulton, 2015). However, the opposite

experience, namely lack of continuity in different care contexts, can be described as discontinuity. Discontinuity implies experiences of change that create disruption in the ongoing processes. According to some studies (Andreasen, Lund, Aadahl, & Sørensen, 2015; Axelsson & Bihari Axelsson, 2006; Browne et al., 2014; Schoen et al., 2011), this could occur in connection with fragmented and poorly coordinated care, i.e. transfers between different healthcare providers and settings, delays and interruptions in care and treatment, and problems in understanding (Naithani, Gulliford, & Morgan, 2006; Tarrant et al., 2015). High-frequency alteration of staff in home healthcare has also been described, inducing experiences of discontinuity (Gjevjon, Eika, Romøren, & Landmark, 2014).

According to a study among patients with diabetes, continuity of care is regarded a prerequisite for being given good quality of care (Naithani et al., 2006). This is in line with a study by Björkelund et al. (2013) about how continuity of care is a contributory component to the quality of primary care. According to Guthrie, Saultz, Freeman, and Haggerty (2008), continuity of care matters in the sense of having a relationship with a doctor in addition to access and coordinated healthcare. It also reduces inpatient hospitalisations and emergency department visits, and results in fewer complications (McAlister et al., 2013; Hussey et al., 2014). This in turn lowers healthcare costs, according to Hussey et al. (2014). Personal continuity of care also seemed to contribute to significantly better medication adherence, according to Uijen, Bosch, et al. (2012). Moreover, in a position statement from the council of cardiovascular nursing and allied professionals Jaarsma et al. (2014) states that continuity of care has a pivotal impact on patient safety. However, Bodenheimer (2008) suggests that new models of healthcare collaboration with patient and family have to be developed in order to enhance continuity of care with a focus on individual preferences.

1.3 Rationale

Living with CHF may initially be quite free from trouble but, as the disease progresses, the burden of symptoms increases, which can result in experiences of disruptions, even though the persons try to manage their daily life. Experiences of disruptions in daily life may contribute to increased contacts with healthcare in the form of more frequent visits or hospitalizations which, in turn, require sustained and planned lifelong contacts with a large number of healthcare professionals and caregivers. Prior research has shown that persons living with chronic conditions have an increased need for continuity in their healthcare contacts compared with

those who rarely seek healthcare (Nutting, Goodwin, Flocke, Zyzanski, & Stange, 2003; Pandhi & Saultz, 2006; Saultz & Albedaiwi, 2004). However, the current development of specialized medical care may contribute to disruptions due to fragmented care; this, then, can result in experiences of discontinuity. Thus, the need for continuity of healthcare contacts as well as in daily life might be a future requirement in the care of the chronically ill.

Continuity is an essential phenomenon of life. However, up to now experiences of continuity most often have been studied in relation to the concept continuity of care, with the purpose of evaluating patients' experiences of healthcare models and of continuity with a single care provider (Bentler, Morgan, Virnig, & Wolinsky, 2014; Haggerty et al., 2013; Uijen, Schers, et al., 2012; Waibel et al., 2012). It has been based on a deductive design and described from an organisational perspective, where structure, planning, collaboration and follow up in relation to healthcare appeared to be important. Nevertheless, few studies have been found describing how continuity shapes one's daily life in association with a chronic condition. Thus, continuity needs to be further examined from various perspectives, and a good reason for carrying out this study was to deepen our knowledge of what contributes to continuity or discontinuity in daily life and in healthcare contacts when living with CHF.

2 AIM

The overall aim of this thesis was to explore how persons living with chronic heart failure, experience continuity and discontinuity in their daily life and in their healthcare contacts.

The specific aims were:

- To illuminate whether persons with CHF experience discontinuity in their life and, if so, what helped them to preserve and strengthen continuity in their daily lives (Paper I).
- To describe how the interaction in healthcare encounters contributes to either continuity or discontinuity in the daily life for persons with CHF (Paper II).

3 PARTICIPANTS AND METHOD

3.1 Design

The design is inductive. The epistemological starting point was to seek knowledge in empirical data; thus, Grounded Theory Method (GTM) was regarded as the most appropriate method to use in order to identify psychosocial processes and actions (Charmaz, 2009). To explore how persons living with CHF experience continuity in their daily life and in healthcare contacts, the constructivist grounded theory by Charmaz (2006, 2009) was chosen. Using this method, it was possible to gain various perspectives, patterns and connections from the participants' lived experiences, and to find an abstract understanding with depth, power and relevance of how these persons construct and act from their own reality. The theoretical perspective of social constructionism underlies this method, and symbolic interactionism represents a constructionist perspective, assuming that person constructs their social reality through individual and collective actions due to the fact that people are active, creative and reflective (Blumer, 1969; Bryant & Charmaz, 2007; Mead & Morris, 1934). Constructivist grounded theory focuses on how and why people create meanings and actions in certain situations and in connection with others, location and time (Bryant & Charmaz, 2007; Charmaz, 2006). With this design, a systematic approach was used to collect and analyse data, constructing concept, resulting in a formative theory grounded from the data (Bryant & Charmaz, 2007; Charmaz, 2006; Glaser & Strauss, 1967).

3.2 Participants and settings

The participants were recruited from different settings: primary healthcare centres, a specialist clinic at a county hospital and a local heart and lung association (HLA). The selection was purposively and comprised eight men and five women from the primary healthcare and the specialist clinic together with five women from the HLA. Age ranged between 62 and 88 years (mean age: 76 years), and they had lived with CHF from between six months and more than five years. The severity of their condition ranged from being almost free of symptoms to living with a significant symptom burden, which was classified using a self-reported assessment of the symptoms of breathlessness and fatigue (Ekman et al., 2005a) based on the functional classification by the New York Heart Association (NYHA) by Bennett et al. (2002). Participants diagnosed with CHF, aged ≥ 20 years who understood

and spoke Swedish and lived in standard housing were included. The diagnosis of CHF was confirmed from the participants' medical records, in accordance with the criteria from ESC guidelines (McMurray et al., 2012).

3.3 Data collection

Data was collected from audiotaped interviews from February 2011 to September 2012. In paper II, data collection was extended to include four individual follow-up interviews in June 2014 in order to clarify and develop the previous information. The participants received an information letter and, after one week, they were contacted by telephone regarding the request for participation, aim of the study and an appointment for the interview. The individual interviews were the basis for data collection. These interviews were conducted in the participants' homes or at a primary care setting, according to the participants' wishes, and lasted for 25 to 75 minutes. All interviews were carried out by the first author (MÖ) except for one, which was conducted by the second author (EJU). As a complement, a group interview was used to enrich our understanding in that the participants collectively interpreted their experiences (Morgan, 1997). The group interview was conducted by the first author (MÖ) with assistance from a moderator who had extensive experience of group interviews. The group interview took place in the HLA meeting room and lasted for one hour and 40 minutes.

An interview guide was used in both the individual and group interviews to support the data collection and structure the interviews on continuity and discontinuity in life and in healthcare. In order to cover the most important areas of interests, the interviews began with broad-based, open questions with follow up probes. Questions such as, "Please tell me what it is like to live with CHF", "Please tell me how you make your life cohesive, despite illness" and "Please tell me how healthcare makes your life cohesive, despite your illness" was used. The participants were encouraged to talk freely, and there was a flexible use of the interview guide due to the participant's narratives, because some spoke freely and some were more reticent.

3.4 Data analysis

The data were transcribed verbatim, and the analysis began after each interview. Throughout the whole process, data collection and coding were carried out simultaneously in order to explore, deepen and refine questions which led to new questions. By using a constant comparative method to

systematise and analyse data, we compared meanings and identified similarities and differences (Charmaz, 2006, 2009; Glaser & Strauss, 1967). The construction of codes, categories and concepts was carried out continuously so as to be more specific until no further insight was forthcoming (Charmaz, 2006; Morse, 2000). To gain a broad understanding of the whole, the texts were read carefully and then an open coding was started. The texts were read line by line and labelled with codes based on phrases or names as close to the data as possible. Then the codes were compared with each other on the basis of similarities and differences. When all the codes had been identified and started to stand out, the next step, focused coding, was begun, and data were organised and grouped temporarily as categories. Step by step in line with the constant comparative method, the analyses were brought to a more abstract level that generated concepts, confirmed by their properties. During the whole process, memos were used, which means that reflections, questions and ideas were recorded. This supported us in building new ideas, identifying gaps in data collection but also in clarifying the relationships between the codes and categories.

3.5 Ethical considerations

The study underlying paper I and II was approved by the regional Ethical Review Board in Gothenburg (Dnr.543-10). The project was planned and conducted in accordance with the principles outlined in the Declaration of Helsinki (WMA, 2013). The participants were given both verbal and written information regarding the aim, procedures and contact details. For those who wished to participate in the study, written informed consent was obtained before the interview began. The participants received information about their right to withdraw at any time, that the interviews would be recorded and transcribed, and that identifying details would be removed so as to ensure confidentiality. They also received information that their responses would be presented as anonymous excerpts or quotes in scientific publications, so no one would recognize them as individuals even if they could recognize their own expressions. Respect was paid during the interviews to the participants' condition and, if unpleasant experiences occurred at or after the interview, they were offered telephone contact with a counsellor for further follow-up.

The participants were allowed to choose the location for the interview and the intention was that the situation should feel as comfortable as possible, even though some issues could be perceived as being uncomfortable. In the group interview, the participants were not able to choose the location but the meeting room was chosen to make them feel as comfortable as possible in the

situation. It was not possible to ensure confidentiality between the group participants. However, this was discussed with the participants before the interview started, so that everyone was aware of this. In the interview situations, data collection, analysis and presentation of material was carried out with openness, sensitivity and responsiveness to the participants. This also required that the researcher reflected upon their own thoughts and attitudes, and was aware of their position of power in relation to the participants.

4 RESULTS

4.1 Experiences of continuity in daily life – Paper I

This thesis explored the experience of continuity to persons suffering from CHF. The results revealed that persons with CHF experienced constant disruptions in their daily lives caused by the condition, but especially how they used their most salient features in maintaining continuity in daily life. This ongoing process helped the participants to experience “a consistent whole”, by inventing actions to restore, preserve and strengthen continuity. Moreover, this process was facilitated by re-adjustment to the situation and the fact that the persons reconciled themselves to their fate and a completely changed life situation.

The concepts in the figure below; *Experiences of discontinuity*, *Recapturing approaches* and *Reconciliation* are to be understood in relation to coreality, temporality and identity (Figure 1).

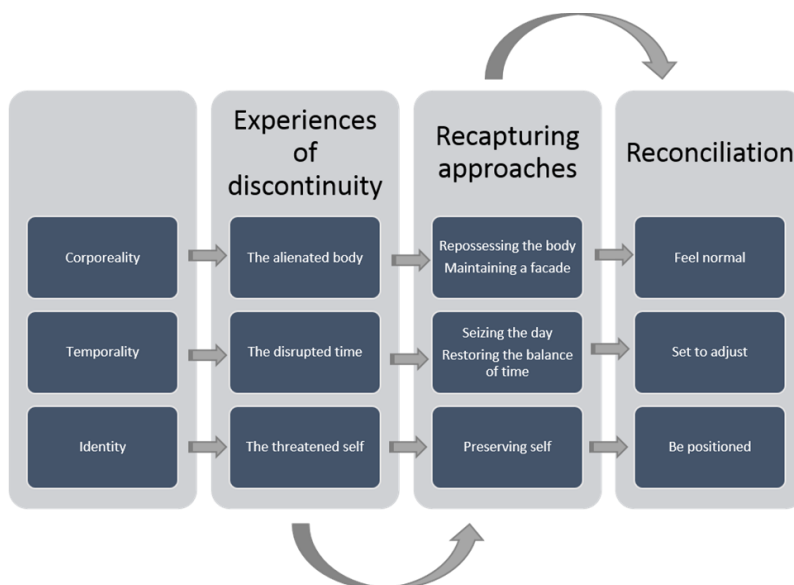


Figure 1. Experiences of discontinuity and creative actions to preserve continuity in daily life. Östman, Jakobsson Ung & Falk. Published in *Int J Qualitative Stud Health Well-being*. 2015, 10:29872

Experience of discontinuity emerged from a common sense idea that body, time and identity was changed, when the disease literally took over one's daily life. The participants felt that they lived with a failing body, which in turn led to uncertainty and lack of confidence in their own ability. The illness made demands, consumed time, disrupted daily living and raised awareness of a limited future and imminent death. Becoming "someone who is ill" and dependent on others, endangered the participants' self-image. However, the participants used continuity-preserving activities in order to create a daily life similar to the one they had previously lived. Recapturing approaches meant balancing physical abilities, finding a rationale for the failing body and focusing on what functions well. The participants tried to restore the balance in time and space by lowering requirements, dividing actions and creating short-term goals. They also invented actions so as to maintain social contacts in order to preserve the self. Reconciliation was achieved when they successfully adjusted to the new life situation. Participants could reconcile to their situation when they could integrate the illness in their life and experience a sense of "still being me" despite the CHF.

4.2 Experiences of continuity in healthcare contacts – Paper II

The results showed that healthcare encounters contributed to both continuity and discontinuity in daily life on the part of those living with CHF. Good and bad encounters were, according to the participants, not solely based on emotions, but were illustrated by rational actions and healthcare environments characterised by unspoken norms and procedures in the contacts. In the model below (Figure 2), the results are summarised in two perspectives; *Patient-centred agenda* and *Person-centred agenda*. Both perspective illuminating the characteristics of the care encounters, the attitudes of healthcare professionals and the normative discourse.

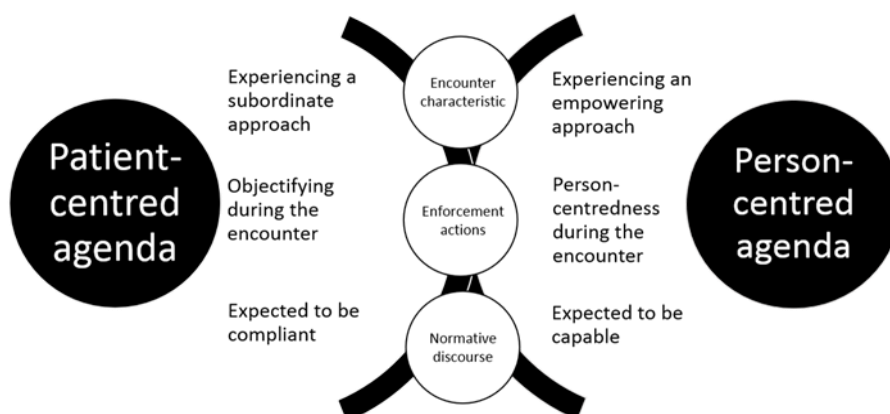


Figure 2. The connection between the healthcare encounters experienced as enhancing discontinuity or continuity in daily life. Östman, Jakobsson Ung & Falk. Published in *Int J Qualitative Stud Health Well-being*, 2015, 10: 27775

When the participants experienced a Patient-centred agenda, the feeling of disruption was transferred from the healthcare situation to the participants' daily life. When healthcare professionals adopted the role of being an expert, with no interest in the individual's life situation, the participants regarded the encounter as insufficient. These encounters were characterised by a lack of understanding and ignorance. The participants were seen as a sick body, a

diagnosis and the persons were reduced to patients who were expected to be compliant. These experiences caused frustration, powerlessness, helplessness, a lack of confidence and dependency as regards healthcare which reduced the persons' ability to live and manage their daily life as they wanted. On the other hand, a Person-centred agenda contributed to the experience of continuity in daily life. The participants were strengthened by understanding the disease CHF. They developed self-confidence and the power to act, which induced a sense of security in living and managing everyday life as expected. The participants experienced continuity-promoting encounters when there was a genuine interaction between them and the professionals. Thus, continuity was created when healthcare professionals were genuinely interested in and courageous enough to regard the patient as a unique person with social and emotional needs and capable of making their own decisions.

4.3 Summary of the results

The overall results showed that persons living with CHF constructed various actions so as to reduce disruptions and preserve continuity in daily life. These actions were focused on solutions in relation to the situation they were in, which also meant that actions could be evasive. They were constantly active and created various actions by using their own abilities and resources, although they could need support from healthcare in order to manage their everyday lives. This support was experienced in connection with a person-centred agenda, which in turn enhanced the experience of continuity in daily life.

5 DISCUSSION

5.1 Discussion of the results

The general aim of this thesis was to deepen our knowledge of what contributes in creating continuity and discontinuity in life and in healthcare contacts from the perspective of persons living with CHF. Our findings shed new light on, how persons with CHF use recapturing approaches so as to mitigate disruptions and reconcile themselves with their changed life situation in order to preserve continuity in life, a process that is not entirely straightforward. The results also illustrate continuity as an important part of the person-centred agenda in the healthcare encounter. The person-centred agenda contributed not merely to their continuity of care, but also to creating opportunities for sustained and enhanced continuity in life, which in turn affected the participants' ability to live their life in the best way possible.

The concept of continuity has several dimensions. In the context we have used the explanations of the concept by both Atchley (1989) and Haggerty et al. (2003) as they to some extent reflect some aspects of continuity in our results. Atchley's (1989) theory of continuity in normal aging was used to explain continuity of life from a personal level, and the multidimensional model of Haggerty et al. (2003) was used to elucidate continuity from an organisational level, with a personal perspective. In the context of continuity of care, both models reflect relationships with other persons and the influence of the social environment. However, our results correspond to some content to the multidimensional concept of continuity of care according to informational and relational continuity (Haggerty et al., 2003). Nevertheless, surprisingly little was mentioned in the interviews about management continuity, such as transferring information or co-operation between healthcare professionals. This could naturally be due to the fact that the participants assume that this works, and they do not reflect on the healthcare structures and co-operation between healthcare professionals, which is in line with the results by Haggerty et al. (2013).

Living with CHF entails living in an unpredictable life situation, from moments of well-being to the experience of a life-threatening symptom evoking feelings of that life is like a roller coaster (Brannstrom et al., 2006). According to our findings, experiences of discontinuity were described due to losses and limitations in relation to the alienated body, disrupted time and threatened self, experiences that in turn induced various limitations and disruptions in daily life as well as existential disruptions in life. The

consequences of ‘being someone who is ill’ created a loss of self in relation to identity as a healthy person leading to changes in the position of the social context and within the family, especially when friends and acquaintances pull away. Loss of identity revealed a seemingly hopeless situation of fear and insecurity in daily life, which is partly consistent with previous research about the impact of CHF on everyday life (Burstrom, Brannstrom, Boman, & Strandberg, 2012; Davidson, Dracup, Phillips, Padilla, & Daly, 2007; Jeon et al., 2010; Yu et al., 2008).

According to the participants’ narratives, our findings show that the impact of CHF has negative consequences for the continuity of life. This evokes various recapturing approaches for repossessing the body, maintaining a façade, seizing the day, restoring the balance of time, and preserving the self. The psychosocial processes could be both evasive and confrontational, but the intention was to promote continuity in daily life. These findings are in line with Ambrosio et al. (2015), who state that living with chronic illness involves various processes from disavowal to acceptance with the intention of managing daily life, and are also reinforced by other studies (Larsson & Grassman, 2012; Najafi Ghezeljeh, Yadavar Nikraves, & Emami, 2014; Welstand, Carson, & Rutherford, 2009). Thus, according to Larsson and Grassman (2012), a chronic condition might be integrated into everyday living without shattering or disrupting the individual’s life. This kind of integration has also been found as markers of continuity among persons living with stroke, chronic kidney disease or lung cancer, where the persons themselves enhance their continuity in life by creating explanations, lowering expectations and identifying markers of continuity (Becker, 1993; M. Hinojosa, R. Hinojosa, Boylstein, Rittman, & Faircloth, 2008; Leveälähti, Tishelman, & Öhlén, 2007; Llewellyn et al., 2014).

Our findings showed how persons with CHF constantly tried to maintain their daily routines in order to preserve continuity in life. One strategy aimed at maintaining belonging to the family, to well-known social contexts and familiarity with the close environment. The social networks gave a sense of security and predictability both to the participants themselves, but also to relatives and friends, which in turn helped them take control and put their illness into the background. Atchley (1989) regards the physical and organisational environment as an important issue for adaptation and daily routines in normal aging. We assume that aging as a process is the same whether a person is healthy or living with a chronic condition such as CHF, even though it seems to be more difficult to maintain continuity when living with a chronic condition.

Another strategy described was the participants' intention to constantly find solutions to handle discontinuity. By reinforcing their self-image, keeping on fighting and never giving up, this helped them to maintain the perception of the ideal-self. Adjusting and never giving up is regarded as a crucial attitude to maintain life as it used to be and to manage the illness situation; this has also been found by others (Brink, 2009; Denz-Penhey & Murdoch, 2008; S. Falk, Wahn, & Lidell, 2007). Moreover, we have found that the participants used this strategy to deny illness and avoid difficult decisions about the remaining part of their life just because of fear of being defeated by the disease. This attitude is also described in research by Charmaz (1991) into living with chronic illness, where these persons are trying to control the disease rather than be controlled by it, in order to achieve balance in life.

Whatever strategy the participants used, they strove to go on living their life as it was before they became ill. They wanted to feel normal, set to adjust, and be positioned in order to minimize discontinuity and preserve continuity in daily life. Atchley's (1989) descriptions of continuity in normal aging are also useful to understand experiences of disruption when living with a chronic condition. Strategies that are used to achieve continuity in this context depend on the severity of the disruption in daily life rather than on the diagnosis or the illness itself.

Living with CHF makes persons dependent on long-term contact with healthcare and these contacts seemed to affect the participants' daily life depending on the nature of the encounters. According to our findings, it seemed important for the participants to meet the same healthcare professionals at each encounter, regardless of profession. They stressed the problem of always having to meet different healthcare professionals, of not being recognized, of being pushed aside and always having to repeating their medical history. To be left alone to face your fate without anyone in healthcare to care for you contributes to mistrust and experiences of discontinuity in your contacts with healthcare. In line with other studies, continuity of care seems to be more valued by persons with complex healthcare needs than by persons who are relatively healthy and who rarely seek care (Browne et al., 2014; Nutting et al., 2003; Pandhi & Saultz, 2006; Schers et al., 2002; Tarrant et al., 2015; Waibel et al., 2012). Based on these findings, we can assume that healthcare encounters need to be conducted differently to support continuity in healthcare contacts for persons with long-term illness.

The participants described how a patient-centred agenda elicited a sense of being regarded as a diagnosis and not as an individual with a chronic illness.

Our findings show that a patient-centred agenda was perceived as hindering the process of readjustment in relation to the illness when the participants experienced themselves as subordinate to the professionals, when being objectified during the encounter and when they were expected to be compliant. As earlier described, this paternalistic model does not support the individual's understanding of and desire for taking responsibility for their situation (Cribb & Entwistle, 2011; McCormack, Mitchell, Cook, Reed, & Childs, 2008). This has previously been described with regard to living with chronic illness, but not specific to CHF (Kjerholt, Wagner, Delmar, Clemensen, & Lindhardt, 2014; Naylor, 2012). Our findings show that these experiences contributed to disruptions and a sense of discontinuity in daily life, not only in relation to healthcare contacts. It also has consequences in daily life as a result of reduced ability to manage various disruptions. However, our findings suggest that disruptions and discontinuity could be minimized or avoided when a person-centred agenda is provided to persons with CHF.

The intention was not to evaluate whether either of these agendas was right or wrong, and rather to stress that both forms are needed, but on different occasions, to promote continuity of care. However, a person-centred agenda contributed to the experience of continuity when the participants experienced support and person-centredness and were regarded as knowledgeable during the encounter. When the professionals behaved in a person-centred way, the participants were able to understand the complexity of CHF, which in turn increased their self-confidence and capability to act and, last but not least, gave them a sense of security in managing disruptions due to their experience of illness in daily life. Ekman et al. (2011) stress the importance of person-centred care for individuals with long-term disease, and the model has been shown to contribute to an increased quality of life, a reduced symptom burden, an increased confidence and improved ability in self-care for those living with CHF. This is also described in other studies (Dudas et al., 2013; Ulin, Malm, & Nygårdh, 2015; Ulin, Olsson, Wolf, & Ekman, 2016). Our results support these findings, but add that person-centred care promotes continuity in life for those with CHF.

Our findings showed that the healthcare model in the encounter affected continuity in life. A person-centred approach with the possibility of personal involvement where healthcare professionals have the skills to relinquish control and support the person's own needs and actions promotes continuity in life, even though the encounters represent a small part of the person's life. These findings add a new perspective of continuity, which might be seen as a further development of descriptions of continuity in healthcare contacts by

Haggerty et al., (2003). According to our findings we add how different encounter characteristics, actions and the normative discourse in healthcare affect the experience of continuity in care as well as in daily life. It does not help that healthcare professionals know and take care of the patients over time, if they do not care about them as unique persons with expertise of living with CHF.

5.2 Methodological aspects

The results are based on the qualitative inductive method GTM in order to deepen understanding, define important areas and explore strategies, actions and psychosocial processes (Bryant & Charmaz, 2007; Charmaz, 2006, 2009; O'Connor, Netting, & Thomas, 2008). As the purpose of this method is to give a description of context and its dimensions, a structure was given to understand the phenomenon of continuity in its context (Charmaz, 1990, 2006; O'Connor et al., 2008). One advantage of GTM is that there is an openness and flexibility in the process of constructing theories and concepts within a specific area. The disadvantage, however, is that it contributes to a certain chaos that requires time and patience during the process (Charmaz, 2006). Although, according to Charmaz (2006), GTM permits the collection of detailed and contextual data from participants' unique perspectives, and having continuity as a sensitizing concept enabled us to get answers to our research questions. The concepts of continuity were constructed from qualitative interviews based on participants' explanations of how they dealt with different situations based on their reality, dreams and fantasies. The intention was to give voice to the participants' experiences; it was not our mission to analyse what was true or false in their narratives. However, we are aware that some of the actions mentioned by the participants are hardly feasible due to imbalances in resource supply and demand.

Data were analysed with a constant comparative method according to GTM, which means comparisons of data at each level and between interviews according to similarities and differences. The comparisons between data strive for an inductive way to generate more abstract concepts (Bryant & Charmaz, 2007). This is a systematic but at the same time flexible and creative analysis where collection of data, analysis and theory generation was conducted simultaneously until no further insights were found. The number of interviews was not predetermined, which resulted in 13 individual interviews and one group interview. The number of interviews could be seen as a limitation, but on the other hand, the number of interviews is not

important in GTM (Charmaz, 2006). The most important thing is to continue collect data until no further insight is achieved, which was done.

The choice of individual interviews with participants from different healthcare contexts was made in order to obtain a broad picture of the area studied. To complement data collection, a group interview was used with members from a local heart and lung association. The choice of adding a group interview was made in order to gain further insights due to the dynamic process that occurs when all participants contribute to enriching the discussion (Kitzinger, 1995; McLafferty, 2004), and a moderator with extensive methodological knowledge and experience of group interviews was used to guide and ensure the results (Morgan, 1996). Another point of adding a group interview from HLA is that, according to Giddens (1991), being in an association represents reflective persons in a modern society, who reflect on their situation and its consequences, which helped to enrich our collection of data.

5.2.1 Trustworthiness

According to Charmaz (2006), the essential criteria for assessing quality in GTM are to achieve credibility, originality, resonance and usefulness. By carefully following the steps of GTM, describing the method and analysing in detail as well as presenting the results based on the concepts and with quotes from the interviews, we have attempted to achieve trustworthiness (Charmaz, 2006, 2009; Lincoln & Guba, 1985; Patton, 2002). Credibility involves both confidence in the data as well as the interpretations that are made. To achieve credibility, data was collected through gathering rich data from a heterogenic group of persons with varied experiences, staying close to the participants' own words, continually comparing codes and categories, writing the draft in the authors' mother tongue, performing repeated critical reviews of the analysis, and cross-checking between the authors. Furthermore, there was an awareness of the impact of the participants' interactions in addition to the researcher's reflexivity (Bryant & Charmaz, 2007). In this case, all the interviews except one were conducted by the first author (MÖ), whose theoretical education is based on the healthcare science perspective and the practical experience of being a district nurse working within the specialty of heart diseases. The other two authors (EJU, KF) have extensive knowledge in the field of healthcare sciences, GTM and are linked to Person-Centred Care at the University of Gothenburg in Sweden. This may have influenced the understanding of living with CHF and interpretation of participants' experiences of continuity in the data collection, analysis and results.

According to Charmaz (2006), in order to reach the criterion of originality, the findings must provide new insights into the area studied. Our data shed new light on the experiences of continuity in daily life and in healthcare contacts according to those who are living with CHF, which assisted us in achieving originality. The terms of resonance were confirmed by obtaining a broad picture of the area studied, which was achieved by purposeful sampling of participants, both women and men in different age's ranges. However, despite our intention, the youngest participant was 62 years old. This can be seen as a limitation due to the high mean age of the participants (76 years) and the co-morbidity. On the other hand, the mean age is representative of the population that lives with CHF. Although this disease affects elderly persons more widely than younger ones, and elderly persons often live with more than one chronic condition according to other studies (Alecxih, Shen, Chan, Taylor, & Drabek, 2010; Barnett et al., 2012; Jhund et al., 2009; McMurray et al., 2012; Yancy et al., 2013). The fact that only women took part in the group interview can be seen as another limitation. However, several attempts were made to recruit men to a group interview, but without success.

The usefulness is obtained by means of increased knowledge and new relevant information on the context of continuity in daily life and in relation to healthcare contacts when living with CHF. The implication of our findings reinforces the need for a rapid implementation of person-centred care for those with all kinds of chronic condition. Thus, the results can be transferred into other populations with chronic conditions, although transferability should be done with caution, according to Lincoln and Guba (1985).

6 CONCLUSION

Continuity of life seems to be of the utmost importance for persons living with CHF. These individuals have striven to preserve their self-image by integrating the illness in their life using continuity-preserving strategies and interacting in a well-known environment in relationship with significant others. Persons living with CHF were capable of managing their daily life with professional support from the healthcare profession in using their capability to promote, preserve and strengthen continuity. It was also important with access to healthcare when needed and coordinated healthcare. To support continuity of life for person's living with CHF, implementation of a person-centred agenda is suggested regardless of caregiver or healthcare organisation.

7 FUTURE PERSPECTIVES

Continuity-preserving incentives should be provided for those living with chronic illness. Tomorrow's healthcare ought to implement a person-centred approach and reveal discontinuity problems in order to be able to support chronically ill individuals in their quest for continuity in life. Moreover, caregivers can promote continuity in healthcare by implementing a more transparent healthcare system with flexibility, fewer barriers, increased access to desired contacts and better care collaboration. The importance of continuity-promoting aspects that emerge in this study can be used when introducing and implementing person-centred care. To deepen the knowledge of continuity in life for those living with CHF, the experiences of continuity should be investigated further by using validated instruments. Moreover, the effects of a person-centred approach of the experiences of continuity in life should be explored and evaluated.

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