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The art of bouncing back

Patient perspective on cancer rehabilitation

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- Patient perspective on living with cancer

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INNOVATION ENGINEERING | LTH | LUND UNIVERSITY

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Momentary contentment theory is a grounded theory explaining how to find safety and balance in life despite an awareness of life´s unpredictability. The theory is based on communion with others, proactivity, and acceptance. It explains cognitive and emotional ways of finding a sense of safety and enjoyment despite illness and accidents. Three concepts are central to *Momentary contentment theory*: doing safety, destiny readiness, and middle consciousness.

In this thesis, I look at the lives of cancer patients through an explanatory model from *Momentary contentment theory*. I also examine whether *Momentary contentment theory* can help people find a way to feel safe in a cancer context. Narrative unstructured interviews were conducted with 19 cancer patients and 17 relatives. Methodologically I have used design thinking and classic grounded theory in an abductive process. I have used my own experiences as a relative and as a patient, and used the intuition and empathy that have been built up through those experiences as inspiration.

Patients struggle to be believed before a diagnosis. Then they have to deal with physical symptoms and fear of death during treatment. For those who survive, a life remains that is filled with the late effects of cancer and its treatments as well as the worry of relapse. Relatives struggle to keep their everyday lives going, where in several cases they take on different roles in their attempts to create a safety net to protect the patient against both the various effects of the disease and the mistakes of healthcare.

Through companionship, activity and an acceptance of life's unpredictability, one can create increased security and contentment in the moment. The "moment" is seen as clusters of moments, defined as longer or shorter periods of time. By referring to the moment as a subjective experience that does not follow a set timetable and that distinguishes between different situations for different people, life and one's own demands can be better adapted to illness. *Momentary contentment theory* can serve as an alternative approach to cancer rehabilitation; it explains and illustrates how activity, participation, and acceptance can be means to learning to adapt to new living conditions. A way to bounce back during the fluctuations of a life with cancer.

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MADE IN SWEDEN

Dedication
With love to Roland, Veronica, Hans and Åsa,
family and friends who all died during my doctoral studies

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Preface – I am sorry

I am sorry.

Three words, I am sorry. Put together they can mean the world to someone, or they are just something we say whenever we mistakenly hurt someone. A person. Or an animal. If I mistakenly stumble over my cat I say, "I am sorry", I suspect you do too. I have been waiting for those three words for a few months now.

At the age of 30 I chose to not have children of my own. The reason is I was told I had a low malignant brain tumor that eventually would come back after resection and likely kill me. Yearly MRI scans for the rest of my life. I did not want to bring a child into the world knowing it would have to live with that fear.

I chose to live as if I would die within five years. I have had a great life anyway, or maybe due to that fact. Who knows what would have been? All I know is that the diagnosis changed my life forever.

At the age of 46 I asked for a new pathological report, and I also asked the neuroradiologists to compare my MR images with older images to better detect changes. One radiologist suddenly spotted a growth that they had missed for three years, but he said it did not look like a brain tumor. I went to France for a second opinion and an hour after the professor in Montpellier told me I probably had a tumor recurrence I got a message from Swedish healthcare: "Congratulations Ulrika, your old tumor was benign, recurrence is no longer expected."

So, I stand here with an inoperable new brain lesion, being congratulated on the great prognosis on my old tumor. Neither lesion would have been correctly diagnosed if I hadn't asked for an investigation in accordance with international standards.

My friends are getting their first grandkids now, and I watch their love. I wonder, after 25 years of misdiagnosis, perhaps an "I am sorry" would be suitable? But we don't say "sorry" when kicking an object. When we kick the wall we say "oh shit".

I am a woman, a human being, struggling with not falling into bitterness, longing for three words I will probably never hear.

Ulrika Sandén

Preface II

This is a thesis on cancer rehabilitation, from a patient user innovation research perspective. When starting my PhD studies I had been in remission from a brain tumor for 12 years. However, just a few months into my studies I suffered a stroke and a possible tumor recurrence, so I ended up living a life that reflected my research. The illness sent me back to hospital for investigation and treatment and I was immediately stuck in a waiting mode. Nevertheless, I tried to be an active patient living an enjoyable life.

My research became more intense and of more personal importance. I was inspired by everyday experiences. Every time something difficult happened I challenged myself to find new solutions. Researcher bias and reflection became everyday topics and I had deep reflective discussions with all my supervisors. The first preface is a way to let my bias show clearly. The banana ruler (by Joel Elinder) introduces each chapter as a way to remind everyone that patients are people with individual minds, see appendix 1 The banana ruler.

A huge thank you to all my participants, in Sweden, as well as in Norway.

I would like to thank my supervisors for support, impressive endurance, and for allowing me to be creative all through my doctoral studies: Fredrik Nilsson, Lars Harrysson, and Hans Thulesius. Thank you also Bodil Jönsson and Annika Lindholm for valuable discussions and perspectives.

I would also like to thank all of those healthcare providers who have tried to treat me as an equal and as a human being. A special thanks to Per Odin; without your help, availability and acceptance of me as person, I would neither have been able to start nor finish this thesis.

Sammanfattning

Nuets förnöjsamhet är en grundad teori som förklarar hur man kan finna balans och glädje i livet trots en medvetenhet om livets förgänglighet. Teorin bygger på gemenskap, proaktivitet och acceptans. Den förklarar såväl kognitiva som emotionella vägar att finna trygghet och livsglädje trots sjukdom och olyckor. Tre begrepp är centrala för *Nuets förnöjsamhet*: att göra trygghet, ödesberedskap och mellanmedvetande.

I denna avhandling ser jag på cancerdrabbades liv genom att använda *Nuets förnöjsamhet* som förklaringsmodell. Jag undersöker också om *Nuets förnöjsamhet* kan hjälpa till att finna en väg till trygghet vid cancersjukdom.

Narrativa ostrukturerade intervjuer är gjorda med 19 cancerpatienter och 17 närstående. Metodologiskt har jag använt mig av "design thinking" och klassisk grundad teori i en abduktiv process. Jag har låtit mig inspireras av mina egna erfarenheter som närstående och patient, framförallt genom att använda mig av den intuition och empati som byggts upp genom de erfarenheterna.

Patienter kämpar med att bli trodda inför en diagnos. Sedan har de att hantera kroppsliga symtom och dödsrädsla under behandling och för dem som överlever återstår ett liv med cancerns seneffekter och oro för återfall. Närstående kämpar med att räcka till där de i flera fall tar på sig flera olika roller i sina försök att skapa ett säkerhetsnät för att skydda patienterna mot såväl sjukdomens olika effekter som sjukvårdens misstag.

Genom aktivitet, gemenskap och en acceptans för livets oberäknelighet kan man skapa ökad trygghet och ett *Nuets förnöjsamhet*. "Nuet" ses som olika långa kluster av ögonblick, definierade som längre eller kortare tidsrymder. Genom att hänvisa till nuet som en subjektiv upplevelse, som inte följer en tidtabell och som skiljer sig mellan olika situationer för olika människor, kan livet och egna krav bättre anpassas till sjukdom. *Nuets förnöjsamhet* kan fungera som ett alternativ vid cancerrehabilitering. Teorin förklarar och illustrerar hur aktivitet, deltagande och acceptans kan vara medel för att lära sig att anpassa sig till nya levnadsförhållanden. Ett sätt att bli motståndskraftig i cancerlivets svängningar.

Abstract

Momentary contentment theory is a grounded theory explaining how to find safety and balance in life despite an awareness of life´s unpredictability. The theory is based on communion with others, proactivity, and acceptance. It explains cognitive and emotional ways of finding a sense of safety and enjoyment despite illness and accidents. Three concepts are central to *Momentary contentment theory*: doing safety, destiny readiness, and middle consciousness.

In this thesis, I look at the lives of cancer patients through an explanatory model from *Momentary contentment theory*. I also examine whether *Momentary contentment theory* can help people find a way to feel safe in a cancer context. Narrative unstructured interviews were conducted with 19 cancer patients and 17 relatives. Methodologically I have used design thinking and classic grounded theory in an abductive process. I have used my own experiences as a relative and as a patient, and used the intuition and empathy that have been built up through those experiences as inspiration.

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Papers included:

I.   Sandén, U., Thulesius, H., & Harrysson, L. (2015). Nuets förnöjsamhet: en grundad teori om livsval och överlevnadsstrategier. *Sociologisk forskning*, 235-256.
I was the main author and did all the data collection. All authors participated in the analytical process,

II. Sandén, U., Harrysson, L., & Thulesius, H. (2015). Momentary contentment, a modern version of an old survival culture. *Grounded Theory Review*, *14*(2), 74-85.
I was the main author and did all the data collection. All authors participated in the analytical process.

III. Sandén, U. (2019). "Co-creation of lifelong rehabilitation design." *Brain, Body, Cognition* **8**(4): 381-393.
This paper is based on a conference paper at "Movementis", Harvard medical school.

IV. Sandén, U., Harrysson, L., Thulesius, H., & Nilsson F. (2017). Exploring health navigating design: momentary contentment in a cancer context. *International journal of qualitative studies on health and well-being*, **12** (sup2), 1374809.
I was the main author and did all the data collection. All authors participated in the analytical process.

V.   Sandén, U., Nilsson, F., Thulesius, H., Hägglund, M., & Harrysson, L. (2019). Cancer, a relational disease exploring the needs of relatives to cancer patients. *International journal of qualitative studies on health and well-being*, **14**(1), 1622354.
I was the main author and did all the data collection. All authors participated in the analytical process.

VI. Sandén, U., Harrysson, L., Thulesius, H., & Nilsson F. (2021). "Breaking the patientification process - through co-creation of care, using old arctic survival knowledge." *International Journal of Qualitative Studies on Health and Well-being* **16**(1): 1926052.
I was the main author and did all the data collection. All authors participated in the analytical process.

VII. Thulesius, Sandén, Petek, Hoffman, Koskela, Oliva-Fanlo, Neves, Hajdarevic, Harrysson, Toftegaard, Vedsted, Harris Pluralistic task shifting

for a more timely cancer diagnosis. A grounded theory study from a primary care perspective. Accepted for publication in Scandinavian Journal of Primary Health Care, September 9, 2021

First author was main responsible for the analytical process. All authors participated with different perspectives from different nationalities in this paper. I did substantive coding, memoing, and did analysis from a patient perspective as well as a social work perspective.

Paper not included

1. Persson, Clifford, Wallergård, Sandén. Exploring the use of virtual reality for managing emotions in cancer rehabilitation. Accepted for publication in JMIR Rehabilitation and Assistive Technologies

Reports not included

1. Sandén, U. (2016). På okänt cancervatten, Lund : Institutionen för designvetenskaper, Lunds tekniska högskola, Lunds Universitet, 2016.

2. Sandén, U. (2017). På okänt cancervatten - närståendes perspektiv, Lund University.

Books not included:

1. Sandén, U. (2006). ... och jag vill leva, Stockholm : Prisma, 2006 (Smedjebacken : Scandbook). Same book in english (Sandén 2016) and I want to live.

2. Sandén, U. (2019). Nuets förnöjsamhet. Copenhagen, Denmark, Saga Egmont.

University has three roles in society; To educate, to research, and to make that research available to people outside academia. In order to make *Momentary contentment theory* available to more people than those who read research articles, books and reports, I wrote a novel. A novel gives the reader a chance to feel what momentary contentment might mean for them. The novel is not included in this thesis other than as a reference (Sandén 2019). Prior to this novel I wrote a book (Sandén 2006) (Sandén 2016) about the relationship between me and my mom, previously diseased due to hematologic cancer, and my brain tumor survival trajectory.

Introduction and research questions

The incidence of cancer is increasing worldwide, based on GLOBOCANs calculations approximately 18.1 million new cancer cases and 9.1 million deaths occurred worldwide in 2018 (Bray, Ferlay et al. 2018). The total cost of cancer in the EU was estimated at €199 billion in 2018 (Hofmarcher, Lindgren et al. 2020). At the same time more and more people survive cancer (Torre, Bray et al. 2015, Bray, Ferlay et al. 2018) and the need for rehabilitation is thus increasing.

Many cancer patients experience anxiety problems that have to do with their lack of perceived control over whether, as well as when, their cancer will return or grow (Buhr and Dugas 2009) (Paukert, Pettit et al. 2010) (Tavoli, Tavoli et al. 2019). Depression is a common comorbidity in patients with cancer and an American study shows 113% higher annual healthcare costs for patients with depression comorbidity than for those without (Mausbach, Bos et al. 2018). Spouse caregivers have presented morbidity connected to high levels of stress, anxiety, potential burnout, depressive symptoms, marital distress, poor health, and unmet needs (Braun, Mikulincer et al. 2007, Sjövall 2011, Li and Loke 2013, Goren, Gilloteau et al. 2014, Lehto, Aromaa et al. 2018, Sandén, Nilsson et al. 2019, O'Rourke 2020). Increased levels of anxiety, depression, and worries continued in spouse caregivers after treatment due to fear of recurrence (O'Rourke 2020).

Studies have highlighted problems with offering rehabilitation in both Europe and USA. In Denmark 16% of cancer patients were referred for rehabilitation, and the higher the education level the higher the referral rate (Moustsen, Larsen et al. 2015). Silver et al report under-referral of cancer patients and relate it to a focus on the disease as well as lack of awareness of benefits of rehabilitation services for oncology patients (Silver, Stout et al. 2018). In Sweden it is statutory in law that all cancer patients should be offered cancer rehabilitation during the whole treatment process (8 kap. 7§). However, the national plan for cancer rehabilitation (RCC 2019) has yet to be implemented in all regions and according to Cancerrehabfonden's report from 2019 (Cancerrehabfonden 2019) only 19% of patients were offered cancer rehabilitation. The need for new approaches in cancer rehabilitation is urgent and the European

Commission had cancer as a prioritized area in its strategic recommendations on mission-oriented research and innovation (Mazzucato 2018).

Christensen (Christensen 2010) argued that healthcare requires a task-sharing with a move towards more outpatient services, where tasks are shifted from physicians to other workgroups. Thus, a move toward lower-cost venues and lower-cost caregivers. While other areas in society have included consumers and have been able to lower costs through disruptive innovations, healthcare has been immune to those kind of changes: "In most industries, disruption comes from startups. Yet almost all healthcare innovation funded since 2000 has been for sustaining the industry's business model rather than disrupting it" (p 3) (Christensen, Waldeck et al. 2017). Von Hippel developed open and user innovation and in this introduced the concept of lead users as innovators in 1986 (Hippel 1988). The quantified self-movement and personal science are patient movements within this area. Personal science includes self-tracking but goes further and includes analysis and reflections. A problem with self-knowledge research is the tendency for the results to stay with the researcher; consequently they rarely cause any resonance in science (Heyen 2020). Another issue may be the role of being a patient. Both Ware and Gunnarsson talk about contextualization and about becoming a patient (Ware 1992, Gunnarson 2016), but at the same time a health condition does not change the nature of a patient and their need to be an active part of society (Illanes 2019). Is there a process of patientification where cancer patients become patiently waiting patients, delegitimized and/or accepting a subordinate role? If so, how is that process created and maintained?

In this thesis I present an alternative to the patiently waiting patient. It is based on a collective way of dealing with cancer where helpfulness is at the core. Could this alternative also be beneficial to innovation processes? Looking at Schiavone's (Schiavone 2020) typology individual processes have individual users, whereas collective processes tend to reach larger communities of users.

Table 1: Schiavone et al. (2020) divide user innovation into a typology with four different kind of user innovators. (Schiavone 2020)

	End user	Intermediate user
Individual process	Single end user	Single user firm
Collective process	Community of end users	Network of user firms

Schiavone mentions two attributes among user innovators; a specific knowledge enabling them to spot unmet needs in advance and a lack of solutions to their needs (Schiavone 2020).

Innovations ideally provide value to a specific customer, patient or user (Christensen, Grossman et al. 2009). In the appended papers I present *Momentary contentment theory*, a novel middle range health theory, which through new empirical studies and in alignment with existing theory is tested toward a new substantive area. I look at its usability within cancer rehabilitation and explore a cancer trajectory process with the aim of finding new, proactive, and improved strategies to live a fulfilling life with and/or after cancer.

Research questions

How can Momentary contentment theory contribute to cancer rehabilitation?

How can Momentary contentment theory add knowledge about cancer trajectories?

How does Momentary contentment theory need to be modified to fit cancer patients' rehabilitation needs?

How is a process of patientification created and maintained?

How does Momentary contentment theory relate to other health theories?

Research focus and demarcations

In this thesis I present a grounded theory of momentary contentment and through modifications try to change its defined substantive area. *Momentary contentment theory* is in its original form a cultural coded middle range theory, see appended paper 2. Culture, as used in this dissertation, deals with how we think about the world differently, operating under different norms, attitudes, and cognitive processes (Vandello, Hettinger et al. 2014). Culture may be explained as rooted in its written language (Han 2020), or through the interrelationship between how psyches and culture interact (Cohen 2014). In this thesis I use culture as a dynamic phenomenon created and recreated through interactions. Through socialization we learn to adapt to rules, norms, and values as a way to maintain stability.

I do not, at this point, try to formalize the *Momentary contentment theory* and I have not tested it empirically. To try the theory empirically you would have to either a) manipulate people into using all parts of the theory, which would be ethically very questionable, or b) look at different parts as coping mechanisms which would be of low

scientific value if, as I do, you see the *Momentary contentment theory* as an approach to life rather than a collection of coping strategies.

In this thesis I have used the term cancer rehabilitation. Cancer rehabilitation in Sweden is supposed to be offered during the cancer care process, where the timeline is defined as the time cancer healthcare is involved (RCC 2019). The World Health Organization describes rehabilitation with words of participation, optimizing functions, and reducing experience of disability (WHO 2021). Gadamer (Gadamer 1996) distinguishes between the restoration of a sick person, and the recovery through which a person regains and returns to his knowledge and life, to also reproduce his unity with himself. My definition of cancer rehabilitation is not bound by the time a patient is involved with healthcare. Cancer rehabilitation refers to the process of learning to deal with life during and after cancer, much as Gadamer argues.

In the papers included I show a fit in context and theory between *Momentary contentment theory* and cancer patient needs. I define a *patient* as a person with a disease who is getting help from health professionals or thinking about getting help. You therefor become a patient when your mind is in tune with your relationship with the healthcare system. I have not included a healthcare professional perspective in this thesis. By *health professional* I mean a person working within healthcare and getting paid for it. The work can be done in different settings, such as primary care, in hospital or homecare facilities.

The choice of combining a design thinking approach with the use of classic grounded theory to analyze my data came naturally since I wanted to start at the very bottom in exploring the lives of cancer affected people, and if possible, make a change for the better.

Method

Research approach

In both innovation and design sciences there is an aim for change and improvement (Simon 1969, Brown and Katz 2009). A basic view in design thinking is that those affected by a design should also be part of the design process (Brown 2008, Erling, Pelle et al. 2012), which is an iterative process including many different steps. Problems are viewed from different and sometimes contradictive perspectives, and through integrative thinking and experimenting with questions and constraints, novel solutions and sometimes totally new directions are produced. Empathy and observations of the world help the researcher understand needs of different people. To be able to include various aspects, interdisciplinary collaborations is an important factor of the design process (Brown 2008). Friedrichs and Kratochwil argue pragmatism and abduction as methods to make useful science, where results are tested and modified to create efficient and efficacious knowledge (Friedrichs and Kratochwil 2009). These methods correlate to both classic grounded theory, which is judged by its relevance and its modifiability (Glaser 1998) , and to design research and innovation in their pragmatic view of change (Simon 1969, Brown and Katz 2009).

My research has its foundation in the inspiration I got from combining my own experiences as a brain tumor patient with the cultural expressions in Polarfjorden (see appended paper 3). I moved on to explore patient needs and theorize on how *Momentary contentment theory* may respond to those needs (see appended paper 5). Finally, through a multidisciplinary collaborative work with different disciplines, such as medicine, interaction design, health informatics, molecular medicine, biology, and nursing, I explore how to implement the ideas of *Momentary contentment theory* and how to create more value through convergence of disciplinary ideas. The basics of this thesis lie in the empirical data, the novel theory of momentary contentment and in its multidisciplinary work. Figure 1 shows the iterative process of including different empirical sources, such as virtual reality, patient perspective courses and from being part of different cancer communities, in the main study of modifying *Momentary contentment theory* to fit a cancer context.

The iterative design process may be divided into three spaces, inspiration, ideation, and implementation, where the designer repeatedly moves between the different spaces (Brown 2008).

1. Inspiration

In the inspiration space a designer looks for needs that are not met in society (Brown 2008). In the method's iterative process, needs may change during the prototype evolution which may give rise to new inspiration. I came back to inspiration several times, getting new ideas through experiences and observations. A main inspiration for this thesis came when I realized the importance of time in *Momentary contentment theory*. I observed how different culturally embedded traditions made people return to the moment, and in that moment do something to make life a bit better. Another major inspiration came from a meeting with the oldest man in the studied Arctic village, Rolf. He talked about life in Polarfjorden before WWII and showed me pictures of diseased children and families. I saw my own brain cancer community in front of me, all my friends who had died. Rolf talked about living close to mortality and morbidity with genuine calm and I thought "*what if this is bigger than me, what if urban cancer affected people can learn to live life, benefiting from generations of experiences in Polarfjorden*"?

Could a middle range theory be moved to another substantive area and provide health to cancer affected people? This is why I became a PhD student in innovation engineering at the department of Design sciences.

2. Ideation

Through narrative unstructured interviews with both cancer patients and relatives, I explored what they found important in their lives. A grounded theory inspired conceptualization of those interviews resulted in two reports (Sandén 2016, Sandén 2017). Looking at the interview data through the perspective of *Momentary contentment theory*, I found evidence of shared experiences, strategies, and needs within the groups of patients and relatives. However, the relatives lacked a common language and had a hard time mirroring themselves in each other. Patients had not only a common language but also an intersubjectivity of understanding each other. Contextually I was inspired by Tilly's (Tilly 1998) argument concerning how shared local knowledge creates space for deep improvisations in relationships (see appended paper 1). I found this to be true with cancer patients but not with relatives.

There was a fit in context and needs between Polarfjorden and cancer patients, but how would the theory need to be modified and used to fit with cancer affected people's needs (see appended papers 4 and 5)? Concepts, categories, and their properties were then compared between the different studies, and in the process the theory became

fragmented into its different coping strategies. I believe I got lost in the systematic, much as Davis (Davis 1971) describes "*I discovered – to my dismay – that the more systematic I tried to make it, the less interesting it became*" (Ibid p 340).

During my doctoral work a design student, Joel Elinder, showed me his project, the banana ruler (see appendix 1). It was a eureka moment. He told me that we need to think about what we measure, who for, and with what tools. The banana ruler (by Joel Elinder) worked as a mediating object (Marin, Reimann et al. 2014) between my different research contexts. I used design thinking with design tools and its iterative process to capture the meaning in my empirical data. Brown and Katz (Brown and Katz, 2009) write about the move between the abstract and the concrete through prototypes, and in this phase I tried fractions of ideas, prototyping, and thereby keeping the larger idea of a coherent theory alive through my struggles.

One tool being the diamond of participatory decision-making (Kaner 2014). It helped me move from fragmented needs to recognizing a commonality in life. The tool needed some modifications to fit the data. The result, seen in appended paper 6, came from an iterative process within the larger process (Sandén, Harrysson et al. 2021).

In the result section I connect and compare categories and their properties when moving the *Momentary contentment theory* to the context of cancer affected people. It is a first outline of a theory aiming at explaining how life can be lived with momentary contentment, a theory that needs to be further modified as we learn more.

3. Implementation

The implementation space can be described as several phases where prototypes are tested and evaluated. Through other related projects, such as the courses "Patient perspective and own ability" at Lund University and "Patient perspective and self-efficacy" at Helsinki University, I obtained information about living with cancer, what is important to patients and loved ones, and also what healthcare staff have to deal with in trying to do the best job possible. I have not included the course participants' statements and work as data, but it has given me new reflections and worked as new inspiration. Through virtual reality projects, set up in cancer rehabilitation facilities, I have been able to implement individual solutions to some needs, such as the smash room and the fire room (in cooperation with student Douglas Clifford who designed and created the rooms), see appendix 3. We have outlined a multidisciplinary digitalization project "Together for life" including both the private and public health sector as well as patients and relatives to cancer patients. The project consists of a cross disciplinary team mixing medicine, social work, sociology, innovation, health informatics, biomedicine, and engineering. Together, the project team members work

within and outside of traditional boundaries to address health in a cancer context. Our convergent work may be seen in that *Momentary contentment theory* has been referred to in different scientific areas such as: Theoretical biology in a book about future cancer research in the postgenomic era "*Rethinking cancer*" , chapter written by Emmy Verschuren (Verschuren 2021). Rehabilitation engineering, through physicists Bodil Jönsson's (Jönsson 2016) book about time and working, and in Anna Kåver, a psychotherapist's (Kåver 2020) book about meaning, courage and possibilities. Appended paper 7 includes 12 authors; all of us have been participating in online discussions from our different professions, countries, and experiences. A study on design research and eHealth shows how design research tends to involve several disciplinary areas and types of stakeholders, all of which interact and integrate through design research activities (Pannunzio, Kleinsmann et al. 2019).

All these implementations are part of an iterative process where products are evaluated, modified, and then reimplemented. The iterative process has thus not ended in implementation.
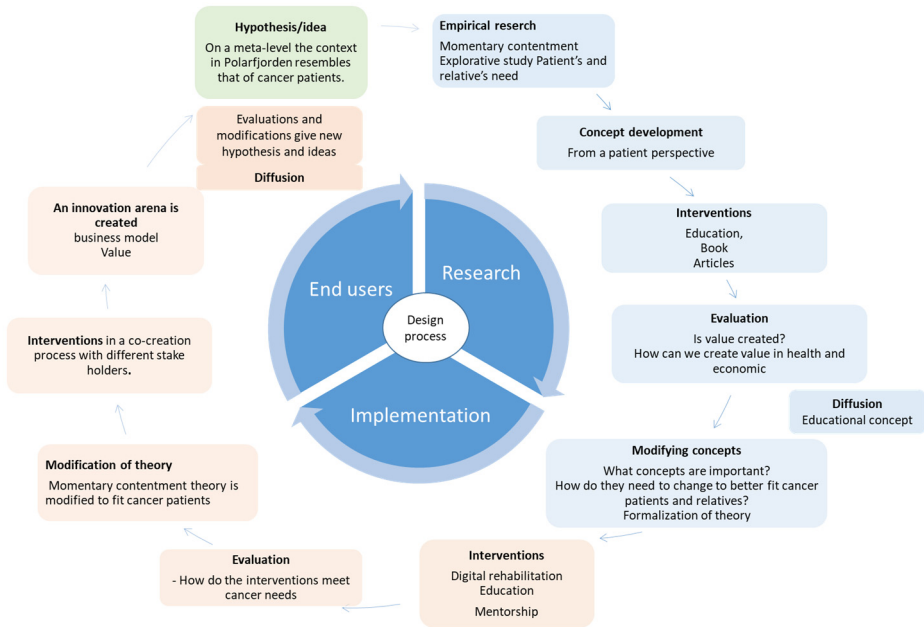
Figure 1: The iterative process toward implementation may be described as an overarching process with prototypes attached to it.

Data collection and analysis method

Data collection

I started with narrative interviews as a way to let participants decide what was important to share. The reason was my extended previous understanding of the disease as both a patient and as a relative of terminally ill parents. I was concerned about researcher bias and I wanted my participants' stories to evolve without any leading questions from me. Narrative interviews were a way to gather data based on what participants said, how they said it, and what they chose to talk and not talk about. Narrative interviews are useful when focus is on experiences revealed only when informants tell a story their own way (Gillham 2008). Detailed field notes were collected, coded, sorted, and categorized from a total of 19 patients in six focus group interviews, two individual interviews, and a follow up individual interview with one cancer patient. All the patients were considered cured or in remission. 17 relatives of cancer patients were interviewed in five focus groups, and six were interviewed individually. For 15 interview participants their cancer sick loved one was still alive. The participants were between 20 and 70 years old, both women and men. The cancer illnesses represented among patients were acute myeloid leukemia, head and neck cancer, esophagus cancer, prostate cancer, and bladder cancer; and among relatives cancer of the pancreas, breasts, kidney, lung, central nervous system (CNS) as well as lymphoma, myeloma, and sarcoma.

The interviews were unstructured and lasted between two and three hours. The question was: "Please tell me about your lives". Then the participants discussed various related topics while I as interviewer listened. In some interviews clarifying questions were used to avoid misunderstandings and to help the participants forward. Example questions were "What did you mean when you said you did not believe them?" or "How did you react to that?". The aim of these interviews was to explore seriously ill people's needs and concerns in everyday life and how they try to resolve them. The regional ethics committee at Lund University approved the studies (Reg nr 2015:53) and (2016:219).

Semi structured interviews with a specialized cancer care nurse and a cancer care physician were also conducted. I joined three therapists on four working days with patient counselling sessions at Region Skåne's cancer rehabilitation centers in Lund and Malmö. During my doctoral studies I also included experiences from the "Patient perspective and own ability" course (2017-2021) and from virtual reality prototyping.

Researcher bias

There are different views on researcher bias, "Bias is a natural outcome of our thinking patterns" (Welsh 2018), untested assumptions may cloud the objectivity of the researcher (Duignan 2016), and researcher bias is to be viewed and used as data (Glaser 1998). All of the above are important issues in this thesis. I was biased in my thinking patterns from the beginning. Having lived with a brain tumor disease for more than a decade, even though it had been in remission, and I had made many friends with cancer, some still living and many I had followed to their deaths. Most of my inspiration comes from thinking patterns, curiosity, discussions, and experiences in living with cancer. In design thinking as well as in user innovation experiences and reflections upon those are important parts of the research process. In grounded theory the researcher includes previous knowledge as data. During interviews and observations I have written memos and in doing so I have influenced the material. I have dealt with this through doing several interviews and observations, working towards saturation.

Visser (Visser 2017) brings yet another issue, how the research affects the researcher and Duignan (Duignan 2016) discusses how research subjects may be biased through a so called observer-expectancy effect. Researcher bias has affected both my research and me as a researcher. When I fell ill again in 2016 there was nothing more important in my life than finding a way to live a fulfilling life with the uncertainty of maybe having a growing brain tumor. The research became personal science. I have tried different solutions on my own life and through my research I have found new ways to deal with uncertainty, my own mortality, and I have created my own spaces of dignity. Wolf and De Groot have conceptualized personal science and suggest five phases in the research process: questioning, designing, observing, reasoning, and discovering. Doing personal science is a self-reflexive and iterative process (Wolf and De Groot 2020). During the process I have taken notes and shared those with my supervisors. I used my own experiences methodologically in a similar way to using other material. According to Glaser (Glaser 1998), in grounded theory bias should not be seen as a problem but should instead be treated as yet more data to add to the analysis. My experiences have mostly provided another depth in understanding the obstacles in living with cancer; these experiences thus served as inspiration for further studies.

Aguinis and Solarino (Aguinis and Solarino 2019) pinpoint the importance of transparency and the possibility of replicating a study. I believe my studies are very hard to replicate from the information I have given officially. Due to ethical reasons, I may not share in detail what cancer affected people have shared with me. I have instead used transparency toward my supervisors. I have dealt with the observer-expectancy effect as well as my own assumptions (Duignan 2016) in doing narrative interviews and trying to keep my own cancer trajectory hidden during interviews.

The process of including my experiences may be described as follows:

1. Writing down memos and diary notes.

2. Sending all notes to my supervisors.

3. Coding that material as well as further memo writing from the incidents found in the material. Discussions with supervisors.

4. Comparing the material with my interview studies. Looking for similarities and discrepancies.

5. Discussion with supervisors on what I have found and how to evaluate it.

6. New notes are then gone through using the same process and compared with old analysis.

I have dealt with researcher bias in two ways:

1. Transparency, where I have kept the notes from my own experiences and shown them as well as my coding and interpretations of those notes to my supervisors. The notes have been saved and (have been) compared to other data.

2. Only empirical data from participants other than myself is included in the appended papers; my own experiences have served as inspiration.

Grounded Theory Analysis and Design Thinking

Design thinking and classic grounded theory meet in both the iterative process and in the grounded approach where end users are involved (Glaser 1998, Brown and Katz 2009). I had previously used classic grounded theory when doing the *Momentary contentment theory* and chose to continue with the same analytical process even though I had no goal of working toward a new emerging theory. Classic grounded theory distances itself from traditional research and its use of verification of existing theses. Instead, a classic grounded theory's goal is an explanatory conceptualization focusing on the main concern in a substantive area (Glaser 1978, Glaser 1998). A classic grounded theory is based on data without preconceived ideas. It explains the behaviour of people within its substantive area through a middle range theory based on the relationship of categories (Glaser 1998, Hartman 2001). Glaser claims that classic grounded theory is epistemologically and ontologically neutral toward grand theories (Glaser 1998).

In grounded theory the researcher collects data through a *theoretical sampling* procedure where substantive and theoretical codes *emerge* and are compared to data. From the emerging theoretical notions, decisions on new data collection are drawn. The grounded theory process is thus an abductive procedure similar to that of a design process with prototyping, testing, and modification. I have continuously written and included theoretical notes, *memos*, in the *comparative work*. The course in 'Patient perspective and own ability' as well as virtual reality prototypes have served as prototypes for the diffusion of the ideas in *Momentary contentment theory* and as such evaluated through memo-writing and surveys, with focus on group level patterns. Each evaluation has created modifications in the course and virtual reality tools.

In my interviews I have listened to the informant's narratives as well as looked for contradictions. I have dealt with contradictions, sometimes seen as counteract descriptions, by writing memos of what I have noticed and my interpretation of it, and then looked for patterns at an abstract level. The contradictions have been both in body language versus verbal language and as only verbal contradictions. During the analyzing work I have also used other relationships with cancer affected people, like those in the academic course in 'Patient perspective and own ability', to see if the interpretations seem also to fit outside of my interview context. As my brain tumor grew back I also used myself as a research subject. In classic grounded theory (Glaser 1998) all kinds of data are included, but the focus is on incidents and memos rather than people. Data is thus collected gradually in combination with comparative analysis.

In the first *coding process* substantive codes are generated in a line-by-line comparison of field notes. The substantive codes are compared and conceptualized into categories. The categories are modified with new data in a constant comparison method. When new data no longer provides new information and a core category is found, all data is coded from the main category in selective coding toward that core category. New data may still be collected but all material goes through the selective coding process (Glaser 1998).

When a grounded theory is finalized comparisons to literature and previous research become increasingly important. The results in a grounded theory study are not reports of facts but rather probability statements about the relationship between concepts or an integrated set of conceptual hypotheses developed from empirical data (Glaser 1998). Even though I did not move forward to a new theory, concepts with properties still emerged; these were then compared to the *Momentary contentment theory*'s conceptual frame.

In theoretical coding, relationships between categories and concepts are found using theoretical codes. *Theoretical coding* is done all through the analytical process, even

though the work with comparing through theoretical codes intensifies after the *selective coding* process. In the process categories are compared and intertwined (Glaser 1998). "Each new empirical incident is analyzed to see if the data support—and continue to support—emerging concepts" (Holton 2015, p586). It is a constant comparing of incidents, also called indicators, which continues until the process yields the interchangeability of indicators. Where no new properties or dimensions are emerging from continued coding and comparison (Holton 2010).

I have moved the *Momentary contentment theory* from one substantive area to another and in that move the substantive data has changed. The constant comparison of categories and its properties has been an abductive research endeavor, where I have moved between induction and deduction. Nubiola describes abduction as the "process whereby hypotheses are generated in order to explain surprising facts" (p 118) (Nubiola 2005). According to Grinell there are three ways of understanding abduction: (i) a new hypothesis; (ii) a new hypothesis worth pursuing; and (iii) a likely explanation for what had happened (Grinnell 2019). Patient interviews were done in an inductive explorative way. I then looked at my interviews through the eyes of *Momentary contentment theory* and the work became abductive, testing hypotheses of both intended and unintended character. Pierce (Peirce 1960) argues "surprise" as a factor in abductive logical thinking, and many of my hypotheses came as a surprise, which is in line with the property of doing grounded theory. The abductive process is further elaborated in the discussion section.

Theoretical codes are what bind the categories together in order to integrate them in an emerging theory. As is the case with substantive codes, theoretical codes also emerge from the data (Glaser 1978). Even though I did not move forward to a new theory, concepts with properties still emerged; these concepts and properties were then compared to the *Momentary contentment theory*'s conceptual frame. Adding cancer affected people into the Momentary contentment study, new data and new codes emerged. The former theoretical cultural coding of Momentary contentment now changed. I have not been able to detect one code in front of the others but rather two main theoretical codes have emerged, a relational aspect and a temporal aspect, including several theoretical codes at a lower conceptual level. When a grounded theory is finalized comparisons to literature and previous research become increasingly important. The results in a grounded theory study are not reports of facts but rather probability statements about the relationship between concepts or an integrated set of conceptual hypotheses developed from empirical data (Glaser 1998).

Grounded theory is judged by fit, relevance, workability, and modifiability (Glaser 1998):

* Fit means that the categories will represent the data they conceptualize. This is achieved through continuous comparative analysis work. Such comparative work has continued through my doctoral studies since new empirical data has continuously emerged through the different research activities. The combination of classic grounded theory and design science, where activity is based on problem solving, aiming at changing something for the better (Simon 1969), was valuable in helping me find where preliminary results fitted as well as in highlighting modifications needed.

* Workability. The core category must be recognizable and explains how the main concern of the studied area is solved. This is achieved through focusing on the data. The main concern of *Momentary contentment theory* was more apparent with patients than relatives, at least in part due to the differences in contexts, se further explanation in the discussion section "Relatives through momentary contentment".

* Relevance. Research must be important and clearly tangible. This is achieved by allowing main categories and processes to emerge and by focusing on subject areas that are relevant to the society we live in. *Momentary contentment theory* in this thesis deals with the main issues of living with cancer.

* Modifiability. This means that the emerging theory is useful in other situations and in new research. This is what I am trying to show in this thesis, the applicability of *Momentary contentment theory* in a cancer context. The *Momentary contentment theory* has been modified to fit its new context of life close to one's awareness of life´s unpredictability. There are no predefined steps in design thinking, rather spaces of related activities that together form the continuum of innovation (Brown 2008). This process demands constant modifications and the theory presented in this thesis is not a final theory of momentary contentment.

Formalization

I have moved *Momentary contentment theory* from one substantive area to another and in that process the substantive area changed from Polarfjorden to that of "living in awareness of life´s unpredictability". I have used the same method as I would do if I was aiming to produce a formal grounded theory. According to Glaser (Glaser 1998), a formal grounded theory is a conceptual extension of a substantive theory's core category. It is based on conceptual generality and is an abstract of time, place, and people, yet can be applied outside of the substantive area. It is achieved by using the same generating procedures as in a substantive grounded theory, in particular, theoretical sampling and conceptualizing using constant comparisons (Glaser 2010). I chose to reconceptualize the *Momentary contentment theory* with the new data. At this point all data was included in the analytic procedures. Besides the *Momentary*

contentment study, the patient interviews and the interviews with relatives, I also wrote memos from my own experiences of living with cancer, and used experiences from the university course in 'Patient perspective and own ability'. All material was sorted, conceptualized, and compared. The concepts were given properties and by excluding both substantive areas I started to connect concepts and their properties to each other. "Formal grounded theory does not expand general implications by doing descriptive generalization, with its qualitative data analysis need for accuracy, context, unit condition, harping on indicators, or describing a general law. The core category is expanded by abstract conceptual generalizations based on grounded research. The researcher uses constant comparison to generate concepts, not to discover descriptive differences and similarities" (p 105) (Glaser 2010). Even though I have worked in this manner the theory is not formalized.

Reflections on the emergence of knowledge

The evolution of *Momentary contentment theory* may be viewed as annual tree rings. Where there have been several abductive processes, each contributed with both empirical and theoretical advancements of *Momentary contentment theory*. Through the development of the theory, I have been able to further understand my data and, in that course, knowledge has been built bit by bit into an iterative process.

Example	Surprising factor	Extended knowledge from Momentary contentment theory	How Momentary contentment theory has been modified due to the examples
Patient narratives	The way patients always added a positive remark after having criticized healthcare. The similarities in how my interview groups internally organized themselves.	Patientification process. The importance of time: - Adaptation - Clustering - Dividing - Freedom - Relativism The importance of shared understanding.	Momentary contentment theory is not for everyone. The substantive area changed.
Relative's narratives	They did not seem to mirror themselves in each other.	The importance of a common language to create an intersubjective companionship.	The substantive area changed. The importance of intersubjective shared knowledge.
Myself	I used middle consciousness only to deal with negative issues	I have learned to live a fulfilling life with my brain tumor. How a difficult situation as a loved one can be divided into clusters of moments	How middle consciousness is about hiding negative aspects of life. The concept has evolved to become a space of relief, such as a room of dignity.

Table 2: The table illustrates some examples of surprising factors that have been abductively reasoned.

Grinnell argues the importance of surprise in abductive research and refers to Bernard (1957) when discussing preconceived ideas. There is a risk of making research only a confirmation of your owns theory (Grinnell 2019). When I started my PhD studies my brain tumor trajectory was mostly a memory. However, within the first year I suffered a relapse and getting a new lesion changed my perspectives. I was surprised several times by how I reacted in different situations. I realized I needed something different than what healthcare was able to offer. I "*furthered my aim*", as Grinnell (Grinnell 2019) expresses it, because I want to live a fulfilling life. Personal involvement is a bias which needs to be handled, and it is also an enormous driving force to aim for yet another step in understanding the studied area. One example of an inspiration from my own life is the need to modify middle consciousness from the initial theory. Instead of putting things in a temporal standby, middle consciousness evolved to a room in both space and time. See appendix 2 Limericks as well as preface 1 for examples of how a room of dignity was created through humor and writing about my bitterness. I took

my own experiences and reviewed my data and saw a match. The results would not have been the same if I had not have had a relapse of my tumor; the inspiration I found from living my research and experiencing it first hand was unexchangeable. Riggare (Riggare, Hägglund et al. 2021) discusses personal science from an ethical point of view. She criticises when research findings are interpreted at a group level without any consideration of possible benefits of, or harm to, the participating individuals. I was thinking about doing traditional empirical studies, trying fragmented tools of *Momentary contentment theory* using life quality scales, but chose not to. The theory is a way of thinking and, much like Riggare, I find it unethical to make people use specific guidelines they may not personally benefit from.

Results
Momentary contentment theory in cancer care

The most important result in this thesis is the alternative approach to living with cancer that I present. *Momentary contentment theory* is a middle range grounded theory which seeks to explain how life can be balanced in awareness of life´s unpredictability. Its three main concepts of doing safety, destiny readiness, and middle consciousness offer an alternative to adaptation to the subordinate role of a patiently waiting cancer patient. So far those patients who wish to be more active and co-create their care have not had an alternative concept to hold on to and to identify with. They have mostly experienced frustration as their existence has been dependent on healthcare professionals' diagnosis, treatments, and changing prognosis. To those, *Momentary contentment theory* may be a strong and constructive way to move forward in life with a disease.

The partial results are:

- The very approach of momentary contentment and the development of this concept in cancer rehabilitation during the research projects.

- That momentary contentment has proven to be an alternative explanatory model for the needs of people with cancer and their life situations.

- This model can make other needs visible than those that can be discovered through the patientification glasses.

Main concepts

The *Momentary contentment theory* (Sandén 2014) emerged from studying the life of a small fishing village in northern Norway, Polarfjorden, see appended papers 1 and 2. The main concepts of *Momentary contentment theory* explain how a social life, despite an awareness of life´s unpredictability, can be lived in a safety- and contentment-enhancing way. It is in the combination of the main categories that ways of living may be found.

Doing Safety: In *Momentary contentment theory* doing safety is a process where people develop their own safety through activities of different kinds, often in companionship with others. In interviews patients developed a companionship with each other through confirmative comments and by showing an intersubjective understanding of each other. This companionship was also seen in the academic courses offered in patient perspective and own ability. Relatives showed no such sense of safety; rather the opposite. Many of them expressed a need to actually be the safety net; *"I was too afraid to get sick, who would then handle everything?".* Safety was expressed in interviews with both cancer patients and those related to cancer patients (see appended papers 4 and 5) as an important factor. Main activities connected to doing safety are altruism, preparations, and inclusion.

Destiny readiness: *Destiny readiness* explains an acceptance that life is what it is, a preparedness for uncontrollable events. A natural view of accidents, where there is no expectation that life will be easy, facilitates an inner destiny readiness of life's unpredictability.

Middle consciousness: In *Momentary contentment theory* middle consciousness is a way of putting situations that are difficult to do something about at the time into a standby mode, where it is withdrawn from everyday conscious level without being repressed. Middle consciousness is a relational category connected to issues regarding dignity and respect and a lack thereof. Translated into cancer situations, patients expressed waiting, patientification, and fear of morbidity and death as such situations. Many of the situations were connected to their relationship with healthcare. Through a middle consciousness people find the means to deal with a situation through isolation of negative feelings in time and/or space.

It is in the combination of the concepts that explanatory models appear. An acceptance of life's unpredictability together with activity help people move from anxious thoughts about what can happen in the future into a momentary experience, and in that moment, there is always something to do to make life a little bit better.

Tilly (Tilly 1998) argues a shared local knowledge as a basis for deep improvisations in relationships, which is needed in *Momentary contentment theory*. Patients shared concepts and an intersubjective understanding that explained their situation, while relatives seemed to lack a common language to describe their situation. Even if relatives of cancer patients also need balancing acts between safety feelings and danger, there is no immediate fit and the emerging theory is thus based on cancer patients' trajectories. The *Momentary contentment theory* includes social interactions as well as cognitive strategies, aiming at creating a cognitive and emotional balance to life's hardship. The theory explains a natural way of living in Polarfjorden, whereas cancer patients have to explore their new life situation and try to find their own everyday balance.

Momentary contentment theory, a conceptual representation

With the aim of moving the *Momentary contentment theory* from one substantive area to another I have made a conceptual representation of the theory.
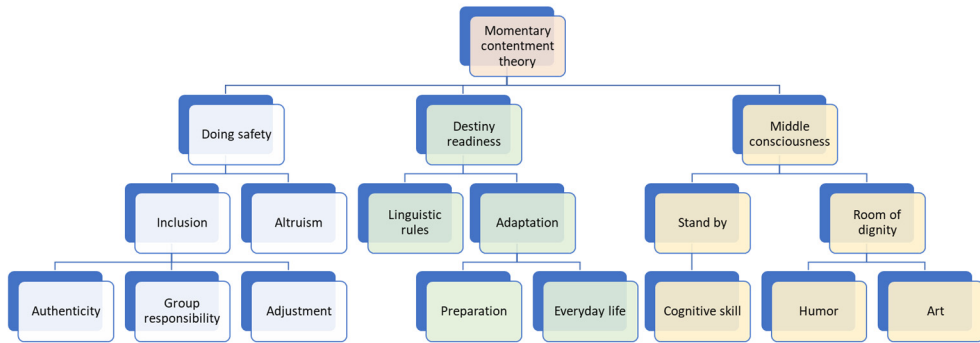
Figure 3 illustrates a conceptual representation of Momentary contentment theory.

Figure 4 shows the main components of three main concepts that in combination form the explanatory foundation of the theory. *Momentary contentment theory* is understood in its temporal and relational aspects, where the latter is further elaborated into personal and collective focuses, all including activity, emotions and cognition.

| Doing safety | Destiny readiness | Middle consciousness |

The combination of the main categories help explain the theory

Momentary contentment theory

The theory includes both temporal and relational aspects

| Temporal aspect | Relational aspect |

Activity, emotions and cognition work together within temporal and relational aspects

| Activity | Cognition | Emotions |
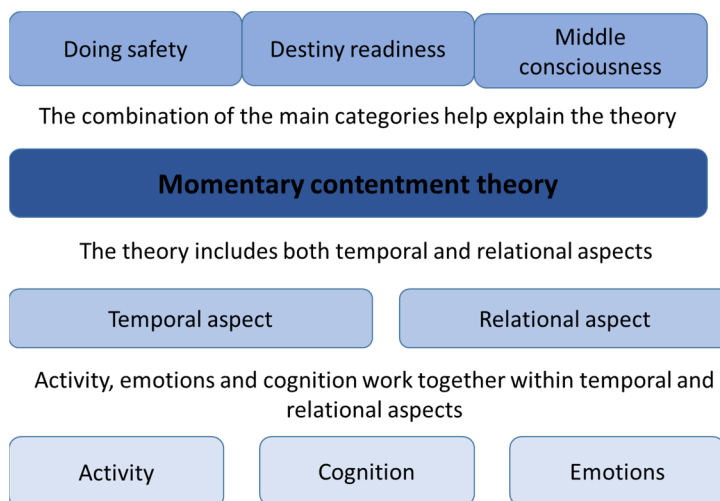
Figure 4 shows the relationships between the main concepts of Momentary contentment theory.

Temporal aspect

The *Momentary contentment theory* aims to illustrate how we can return to the present moment and in that moment do something to affect our situation. Time is viewed as a subjective experience where life situations are allowed to affect and change scheduled plans. Several human periodizations are based on various natural phenomena that are not socially determined. Two examples are the year and the day, which, unlike the socially and religiously constructed week and hour, have their basis in the earth's relation to the sun (Heidegren 2014). In the same way, we can choose to let a cancer disease create new periodizations, which become more adapted to our life as it really is. In other words, time can be divided in different ways, adapted to aspects of nature such as seasons, to personal life when illness and morbidity become a part of life, or as social constructions such as working time and leisure. In other words, new living conditions require new evaluation of our temporal constructs. In connection with cancer, time can be divided into treatment cycles. Or, through acceptance, we can learn to let go and slip into an ever-changing existence. Let settled plans be changed by both illness and other events. One thing leads to another and becomes a long chain of improvisations. When based on improvisations, actions become difficult to predict or causally trace back in content, but they may be predictable as expected behaviour depending on the situation.

Our life situation creates the pace in every moment, and every moment is a cluster of moments surrounding a context. Every cluster of moments is a new chance to affect

our momentary experience as well as the future. By relating to the present as a subjective experience which does not follow a common standardized timetable, a patient's life and demands can be better adapted to illness. We learn to let go and slip into an ever-changing existence with the goal of achieving safety through having fun. In summary:

- Time is framed by perceptions of the past and a future.

- Experiencing time is subjective and continuous.

- Time is experienced as moments.

- Moments of time may be merged into clusters.

- When the mind is in the present moment we can affect that moment.

- Moments can be filled in a contentment-enhancing way.

- Artistic activities can be combined with counteracts and make time pass.

- Waiting is a subjective experience.

- Waiting for something makes our mind move into the future.

- Waiting is a source of mourning and dwelling on future worries.

Relational aspect

According to Sinding-Larsen (Sinding-Larsen 2006) societies have two safety systems; externalized safety and relational safety. Individual members and communities need an intact integration to perceive a context as safe. Relational safety is connected to a feeling of belonging (Eriksen 2006), which correlates to group inclusion where authenticity is postulated (Shore, Randel et al. 2011). The relational aspect thus includes both a collective and a personal facet.

Collective

As described in appended papers 1-2, *Momentary contentment theory* is based on a collective common denominator of living in awareness of life´s unpredictability. This awareness is intersubjective and a part of the shared experience creating a structural dimension where "I know you know that I know". Within this structure safety is created through altruistic behaviours in communion with others. By not being left alone in helping someone, but rather combine the helping activity with the inclusion of more participants, where there is a helping in the helping part, feelings of overload (when the needs are extensive), may be exchanged for satisfactory feelings of belongingness. Linguistic aids may be used to include odd behaviour as something

ordinary as well as to facilitate talking about difficult things without anxiety. Through activity we may return to the present moment and there find momentary contentment by doing enjoyable things in companionship with others, or we can use that moment to prepare for hardship to come. Through companionship a helpfulness in altruism leads to inclusion, which in turn involves authenticity, inclusion, and a sense of belonging.

Activity

- Companionship in activities creates safety.

- Altruism is fetched by activity.

- Altruism is part of inclusive processes.

- The group is responsible for the inclusion of the individual.

- Authenticity is a necessity for inclusion.

- Inclusiveness inhibits loneliness.

- Helping in the helping process inhibits feelings of being overwhelmed.

Cognition

- Cultural and linguistic traditions can work in favour of inclusion or inhibit it.

- Momentary contentment needs room for improvisations in relationships.

- Companionship increases safety.

Emotions

- Safety is relational.

- Authenticity inhibits degradation.

- Authenticity in relationships enhances safety.

b) Personal

Hardship is met by a destiny-readiness attitude where linguistic aids are made up to support the middle consciousness, where we may find refuge from hardships. In *Momentary contentment theory* preparation is used against getting stuck in dwelling over what may happen. *Destiny readiness* explains an acceptance for life's hardships and opens up for a healthy view of life's different twists and turns. Instead of hoping for life to be easy, an opportunity for inner hope emerges. Hopefulness grows through confidence that we *can* and *will* cope with life. To find inner hope we need to move

from a 'hoping for' things to happen state of mind into a 'hopeful' state of mind where we are confident in that life is manageable. Through a *middle consciousness* we may put situations that cannot be controlled into a standby mode, where they can be disconnected from our consciousness without being completely repressed. Middle consciousness may be used to keep one's authenticity in an undignified situation. Different techniques may be used such as humor, fun activities and artistic work.

It is through a combination of the main concepts that momentary contentment may be achieved. *Momentary contentment theory* puts less focus on the meaningfulness in situations, but rather focuses on activity where the favoured priority is to do enjoyable things. Through an attitude of destiny readiness, where you do not expect life to be easy, you can create your own safety by proactivity and actual preparation. *Momentary contentment theory* explains how humor and linguistic aids help in reaching a positive attitude to life in all its colors. Laugh at the bad parts, enjoy the good days, prepare for the worst outcome, and be happy and thankful when life is not that bad.

Activity
- Safety is created in activities.
- Altruistic activity is safety enhancing.
- Planning and preparation can be hope enhancing.

Cognition
- Knowledge creates safety.
- Inner hope is enhanced through an acceptance that bad things as well as good things will happen.
- Through destiny readiness life becomes less catastrophic.
- Acceptance and adaptation to a realization that 'shit happens' in life, help keep our self when a life situation changes.
- Middle consciousness is both a process and a noun.
- Middle consciousness is a way to cognitively isolate fears in time and space; a standby mode.
- Counteracts are used as a way of placing degrading experiences in middle consciousness.
- Dignity may appear when degrading experiences are put in a standby.
- Safety is formulated in linguistic strategies.

-   Linguistic aids help normalize life.

Emotions

-   Feeling safe is emotional.

-   Emotions are existential.

-   Hope is an emotion.

-   Hope is dependent on authenticity.

-   Our self is dependent on authenticity.

-   Feelings of belongingness are necessary for inclusion.

Momentary contentment concepts in a cancer context

Altruism

People who are committed to helping others describe their self-esteem as better than do those who are not committed (Post 2005, Haller and Hadler 2006, Schnall, Roper et al. 2010). Altruistic activities create a sense of security that no one needs to stand alone when an accident occurs. Every time a group succeeds in resisting an external threat, the sense of companionship is strengthened and everyone's propensity to help is also strengthened for the next time (Post 2005, Schnall, Roper et al. 2010). In *Momentary contentment theory* altruistic behaviour is connected to companionship, as described in appended paper 1, which means you are usually not alone in a helping situation. You help each other also in the altruistic activities and it thus becomes a social activity to help others. To allow altruism to be a part of healthcare requires the view of the patient as a passive recipient to change.

The patients in my interviews expressed a wish to help others as a way to create meaning in their own struggles. This correlates to studies on altruism which demonstrate that altruistic actions increase both physical and psychological well-being as long as a person does not become overwhelmed (Batson, O'Quin et al. 1983). In a community where helpfulness is based on companionship in acts of altruistic behaviour, every situation, every moment of helpfulness can contribute to increased satisfaction for the helper and increased safety for the recipient.

In my interviews relatives did a lot of unpaid work which could be interpreted as altruistic. Quotes such as "*I have to be strong*" and "*I cannot get sick, who will then take*

care of everything" show a duty-driven motivation rather than altruistic actions. The relatives also expressed being overwhelmed by the demands they experienced were put on them. This shows the complexity and fragility of altruism.

Inclusion

In appended paper 4, I combine *Momentary contentment theory* with patient inclusion and innovation. Looking at inclusion through the definition by Shore (Shore, Randel et al. 2011) three parts are required for a person to feel included:

1. *The individual feels a sense of belonging.*

Healthcare from a patient perspective has at least two divided groups of people; the providers and the recipients of care. As recipients of care, my participants had different expectations of involvement but those that wanted to take on a bigger part in their care had a hard time being allowed into forums where decisions were made. One of my participants expressed it as "*you and I don't belong to the same kind of people*".

2. *You are allowed to keep your authentic self.*

Among patients, there are discussions about how to be a good patient. Expressions such as "*no one wants to be labelled a difficult patient*" make people not dare to be authentic to their own needs. There is a fear of not getting the same treatment if you become labelled as difficult. Patients also bear witness to changing their symptoms or not telling healthcare staff about all symptoms due to fear of being delegitimized. The fragmentation and objectification of patients also work against authenticity.

3. *The group takes responsibility for inclusion, not the individual.*

Some patients told stories about nurses taking the initiative to call them and ask how they were doing. Everyone telling a story like that expressed it as a positive experience.

Literature on patient participation and decision-making in choices of treatment highlights that while most patients want information and options, interest in making treatment decisions is considerably more variable (Sinding, Hudak et al. 2010). Most communications are viewed differently between patients and healthcare providers (Daley 1993). During my interviews many participants wanted more help in turning information into knowledge, but they differed in wanting to take part in making care decisions. This shows that we may invite patients to participate in their care but not expect the same approach for all. In the inclusion concept lies a need for authenticity. In *Momentary contentment theory* there are cultural procedures for keeping one's authenticity within the group.

Authenticity and patientification

In appended paper 6, the patientification process where patients learn to be submissive, is discussed. It is connected to a delegitimization process (Ware 1992) where people are denied their authentic experience. In many cases, a psychiatric disorder is imposed on the patient when the doctor directly or indirectly refers to perceived symptoms as mental or fictional (ibid 1992). The delegitimization seem to be partly unconscious, both by physicians and by patients. A study analyzing video data shows how hospital physicians denied existential questions without realizing that they did so (Agledahl, Gulbrandsen et al. 2011). In my interviews many patients described loss of authenticity when being fragmented, as one respondent put it "*I became a stick figure*". The patients expressed the importance of not having to chase their healthcare providers as well as the need to be believed and listened to. Both patients and relatives have used the term "magic number" when they came to palliative care and they were given a phone number where somebody answered the phone.

Waiting

Waiting is a time frame that many cancer patients struggle with. Several participants described how they encapsulated their fear of recurrence and progression to the period of waiting for an answer on a possible. They describe their waiting for scan results as a time frame filled with fear, so called scanxiety.
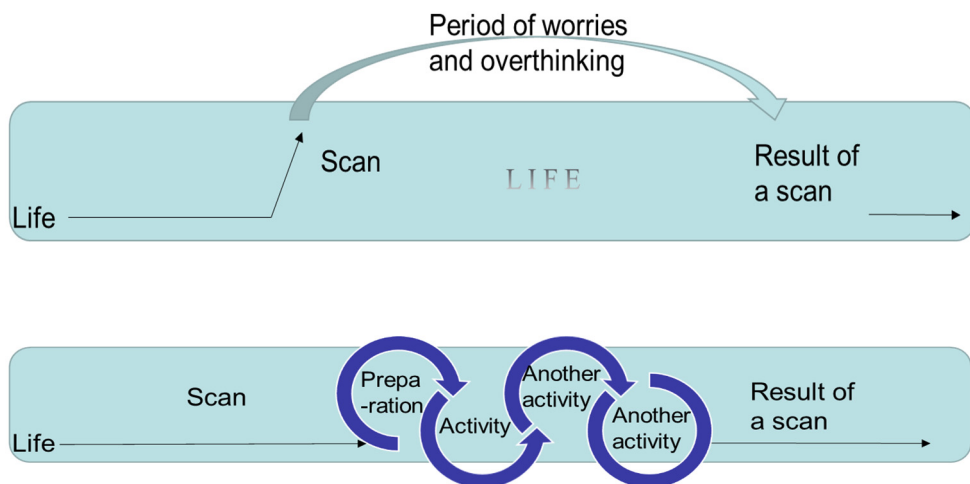

Figure 5: Illustration from appended paper 6. First image show how many participants dealt with scanxiety, the second image illustrates an alternative to scanxiety. Adding a *Momentary contentment theory* perspective with doing safety, destiny readiness, and middle consciousness the waiting period may look like the second image.

In *Momentary contentment theory* we can combine activity with thought processes as well as prepare for different results while waiting for answers. Through rigor in preparations, the question "what will happen" gets answered. It is then very hard to dwell on future worries when plans are made. It is natural to be afraid in that situation, but we may get rid of much of the scanxiety by limiting dwelling on what may happen.

Inner hope

Many patients expressed their positive experience when the physician offered an opportunity for the disease trajectory to go well but mentioned a negative experience when the physician was interpreted as being overly positive. When presented as an offer the positive attitude was hope inducing whereas the overly positive was seen as dishonesty or ignorance. Leaving an opening for the disease trajectory to go well meant that the patient could choose to incorporate the offered hope without any demands for positive thinking.

"I wanted someone to say this is going well"

"It was so nice when NN said that 'our goal is for you to get well'"

"I knew it wasn't true, statistics said different"

When waiting, many patients are told "*don't worry, let us hope for good results*". This asks for a passive 'hoping for' something to happen in the future. There is a big difference between living with hope (an inner hope) and hoping for something (Benzein 1999, Benzein, Norberg et al. 2001). Through every opportunity you manage to maneuver or counteract harmful effects, confidence that the disease can be managed increases. An inner hope manifests itself.

Linguistic aids

Studies of communicative evolutions have shown that it is impossible to distinguish the understanding of languages from their cultural context. Language creates feelings and experiences as much as the senses create language (Wilce 2014). This means that in anthropological studies it is important to investigate the different ways in which language is used, interacting with thoughts, feelings, and being (Ochs 2012). *Momentary contentment theory* includes several linguistic guides or aids, see appended papers 1, 2, 4, 5 and 6.

Many of the linguistic aids found in *Momentary contentment theory* have similarities with strategies found among the interviewed patients. One example is how hardships

are discussed in relation to their solutions. This way of discussing hardships limits dwelling on future concerns and provides an opportunity to discuss something difficult and at the same time cognitively uphold oneself through the solutions. Patients similarly seem to be able to discuss negative experiences through their counteract. Talking about the opposite of something negative can in communion with others make it possible to discuss something negative in a positive manner. In some interviews patients talk about physicians who treat people with decency and dignity in an overly positive way: almost ironic, even though I sensed no irony. It could be physicians who greet them nicely, take time to explain their disease, give them a cup of coffee etc. This behaviour would be seen as pleasant but also normal in most societal settings. By giving overly positive comments to ordinary pleasant behaviour, patients can talk about the opposite, about not being treated pleasant without mentioning it, and without bringing the feelings of hurt to a conscious level. This way of talking through a counteract need a form of intersubjectivity where I know that you know that I know.

Another linguistic technique is to use dualisms: that is complaining over something and simultaneously expressing an understanding of life. This does not diminish the complaint but rather adds another component which balances the negative. This linguistic aid illustrates a view of life, free from bitterness and with a lack of expectations that it should be easy. This is closely related to humor, see below.

Momentary contentment theory is free from positive thinking but includes positive expressions, like "it is important to take the opportunity to have fun while you can", illustrating a kind of perceived control over life.

Humor

Two major strategies in *Momentary contentment theory* are humor and laughter. Humor and happiness are closely related. Both emerged from ancient Greeks such as Plato and Aristoteles where happiness was linked to pleasure, to quality of life, and to meaning (Bykvist, Brulde et al. 2010), and in humor focus was on laughter (Fedakar 2020). Recent research extends over many sciences such as philosophy, sociology, social sciences, biology, neuroscience, and more. There are many studies linking humor to coping with cancer (Demjén 2016, Loyd 2017, Samant, Balchin et al. 2020). Loyd (Loyd 2017) argues that we should institutionalize the use of humor in cancer care centers.

One way to take control of one's situation is through humor. As a patient, you are the one who controls the humor. The humor in *Momentary contentment theory* is used as a counter-image to the unpredictability of life. Black, straight, affirmative, intersubjective

and healing humor. Besides creating laughter, humor may be used as a way to create understanding, to keep a distance and as a way to invite people into a world they do not really understand. Humor is a ritual of contentment that contains both laughter and confirmation. A study on rituals among palliative cancer patients illustrates how cancer patients use rituals to gain a sense of control (Butters 2021). In *Momentary contentment theory*, the bigger the incident, the darker the humor. The confirmation on a person's suffering is created through laughter and contributes to a satisfaction and an intersubjective confirmation "I know you know I know" without having to talk about what has happened. Humor is also a way to stay in reality without getting depressed (see appendix 2 Limericks). By going very far in using black humor, on the other hand, you can show that "I am in a place that you have no knowledge of", and in that place a safe room may be created, for example a room of dignity. In situations where illness and accidents risk harming the inclusion of a person, a great deal of humor is used to confirm that a person in their current situation is still part of the community.

Ten guidelines from *Momentary contentment theory* for increased safety and joy in life

1. Acceptance. Accept that life is unpredictable. Shit will happen, but so will positive things.
2. Activity. Fill time with activity, do at least one enjoyable thing a day.
3. Trust. Trust yourself and understand that you can handle what is coming. Let inner hope grow with your confidence.
4. Linguistic aids. Find ways to communicate difficult things.
5. Dignity. Find forms of expression to help see things from a different perspective, where you find your dignity.
6. Laughter. Find things, people and experiences that make you laugh.
7. Companionship. Realize you have a lot to give to other living beings.
8. Inclusion. Let loved ones in by explaining where and who you are.
9. Look back. On everything you have managed.
10. Above all, do enjoyable things.

Concluding remarks

I see *Momentary contentment theory* as an incremental service innovation and as such it must be incorporated into activities through those it concerns. It is thus not a management theory that is placed on top of something, but something that works its way into people's actions, if and when, they see it as important.

Discussion

The relation between health theories and momentary contentment

One central strength in *Momentary contentment theory* lay in the foundation from where the theory emerged. The culture studied in Polarfjorden is a living culture which has survived through hardships, economic transitions, and migration towards urban areas. What has remained in the culture is an approach to nature and climate's unpredictability. Where nature still contribute to both death and accidents, through for example avalanches, storms and the cold rough ocean. The culture is thus not based on something that has happened previously, but the theory emerged from life as it was lived at the time the study was done. As stated in appended paper 6, *Momentary contentment theory* resembles many other health theories, such as the Salutogenic theory (Antonovsky 1987) and self-efficacy (Bandura 1997) in its focus on empowerment. The strategies in momentary contentment have many similarities to coping strategies but they have different origins. Coping refers to something difficult we have to learn to deal with, while *Momentary contentment theory* has an adaptive base to life where contentment enhancing cultural traditions are used in good and bad times. For further information, see appended paper 1.

The Salutogenic theory by Antonovsky (Antonovsky 1987) is highly relevant to *Momentary contentment theory*. Antonovsky's studies on health-promoting factors state a sense of coherence as the single most important ability to mentally survive hardships. The Salutogenic theory consists of three different parts: a) comprehensibility, b) to find a situation manageable and c) to find meaning in what is happening. Antonovsky has sought the origins of health and in it he states that his theories are related to coping strategies, empowerment and other health promotion and survival theories. What distinguishes the Salutogenic theory is mainly the combination of the three factors

mentioned, that they provide a combination of cognition, behaviour. and motivation. The theory is also distinguished by the fact that it is not bound to its cultural context. Each culture can design the three factors according to its culture (Antonovsky 1987, Antonovsky 1996). *Momentary contentment theory* started in a similar way to Antonovsky's studies by studying survivors of hardship, but it differs in that Antonovsky studied previous hardship whereas in the emergence of *Momentary contentment theory* hardship was still present (Antonovsky 1987, Sandén 2014). The Salutogenic theory examines the healthy-sick as opposites on a scale and what makes a person move towards health. There are different ways to interpret and measure health in relation to illness; in a study on rheumatic arthritis patients, health was connected to the absence of disease symptoms and well-being experienced (Fagerlind, Ring et al. 2010). This differs from both *Momentary contentment theory* and the Salutogenic theory where contentment/health comes from an approach to life more than from an approach to disease. *Momentary contentment theory* focuses on contentment, safety, and the ability to cognitively and emotionally return to the present moment, and in that moment do something to affect the experience of it. Both theories are connected to empowerment and health promotion, they differ in both the temporal aspect and the need for reflection and meaning. They also differ in the view on strategies. Where Antonovsky talks about coping strategies, something to help when life is difficult, *Momentary contentment theory* discusses contentment strategies. Even if there are several similarities in these strategies they come from different origins, to cope or to enjoy life (Antonovsky 1987, Sandén 2014).

Strang (Strang 2007) refers to cancer and palliative care, how relatives are often able to move on and find meaning in what has happened. At the same time, he states that sudden and violent death should be more difficult to deal with, and that it becomes less understandable and thus more difficult to move on from. He exemplifies with major disasters such as Estonia and natural disasters. He addresses the unpredictability and the difficulty of life no longer becoming self-evident and refers to Antonovsky's research on the importance of context; that in natural disasters it is difficult to find a meaning or a larger context (Ibid 2007). In *Momentary contentment theory* reflection on meaning is not part of finding contentment in the moment. Instead of finding comprehensibility and meaning with experienced hardships, momentary contentment includes a) activity to affect difficult situations, b) accept life as unpredictable, c) an ability to place difficulties in an intermediate consciousness and d) to help and to ask for help. These guidelines contribute to a concrete approach to difficulties, where the activity becomes more important than reflections on goals and meaning. As a result, the theories both differ and align in the coherence part; the Salutogenic theory promotes coherence in what happens, whereas *Momentary contentment theory* promotes coherence in

relationships with both other people and in relation to what is actually going on. Living with cancer is unpredictable and in *Momentary contentment theory* you must accept fact as a fact. Symbolic statements like "shit happens" helps you to move on without meaning. Through returning to the present moment you may always be able to affect your situation in some way, which connects to the control aspect that Antonovsky also defines as important (Antonovsky 1987, Antonovsky 1996, Sandén 2014, Sandén, Harrysson et al. 2015, Sandén, Harrysson et al. 2017, Sandén 2019).

What about *Momentary contentment theory* and Mindfulness-to-Meaning Theory? Mindfulness may lead to a sense of meaning through stimulation of positive psychological states. Where you decenter from stress appraisals into a metacognitive state of awareness that promotes positive emotions. This motivates value-driven behaviour and leads to a positive circle (Garland, Farb et al. 2015). Both *Momentary contentment theory* and Mindfulness-to-Meaning Theory focus on the present moment, but mindfulness increases awareness and meaning, *Momentary contentment theory* uses the moment to feel more safe through activity, and by putting less impact on meaning.

There are many theories and methods including or referring to coping strategies. Stallman has tried to conceptualize those to a health theory of coping, where she conceptualizes coping strategies as either healthy or unhealthy depending on their likelihood of adverse consequences (Stallman 2020). Coping strategies are mostly connected to stress-related situations within health theories and they are conceptualized as actions to reduce unpleasant emotions and distress (Skinner, Edge et al. 2003, Stallman 2020). The purpose of contentment activities in *Momentary contentment theory* is to increase safety and enjoyment in life and is therefore not generally associated with reduction of stress. Through a destiny readiness attitude, where you do not expect life to be easy, you can create your own safety through proactivity and preparation. Humor and linguistic aids help in attaining a positive attitude to life in all its colors. *Momentary contentment theory* differs from many other health theories in its view of time. Time is viewed as a subjective experience and is secondary to life situations. A life situation creates the pace in every moment, and every moment is a gathering of moments surrounding a context. Every cluster of moments is a new chance to affect your future. This is explained and described in different ways in the appended papers 1-6.

Resilience and Momentary contentment theory

Resilience is a concept in many disciplines, all relating to the ability to bounce back from disturbance. In ecological resilience it may be a forest bouncing back and surviving through a bad storm. Holling defined it in 1973 as "Resilience determines the persistence of relationships within a system and is a measure of the ability of these systems to absorb changes of state variables, driving variables, and parameters, and still persist." (Holling 1973)(p 17). This definition works over the disciplines. *Momentary contentment theory* is bound by a temporal perspective and focuses on acceptance and activity through life. It is thus more a resilience theory of everyday life than one connected to coping strategies. However, middle consciousness can be singled out as a type of coping strategy in its ability to help bouncing back when nothing else seem to work. *Momentary contentment theory* may help people deal with changes in life, more than to cope with them. Then there are situations too difficult to incorporate in a fulfilling life and then you can use middle consciousness as a coping strategy to put issues in a standby mode. *Momentary contentment theory* may be seen as a resilience theory, but with some reservations.

Healthcare organizations from a patient perspective

Resilience as a relationship between a patient and their environment also includes healthcare. Many of my participants described a complicated relationship to healthcare professionals. Feelings of thankfulness and of being impressed by their work were combined with feelings of being fragmented and dehumanized. A resilience theory of cancer rehabilitation also needs to address these issues.

Healthcare is built in a hierarchical structure with sub-units at different levels. Each sub-unit take care of its own assignment. Tyrstrup describes the spaces in between units as organizational gaps (Tyrstrup 2014). Within this hierarchical structure patients are only receivers of care, also seen in health innovation (Bhatti, del Castillo et al. 2018, Glaser 2019). Patient or person-centered care present an alternative to the bio-medically oriented and paternalistic view of healthcare (Håkansson Eklund, Holmström et al. 2019). In this hierarchical organization politicians in many western countries have decided on patient/person-centered care (Westling 2018, RCC 2019). Standardizations and programs have been developed in order to promote the implementation of protocols and guidelines within healthcare (Tietschert, Angeli et al. 2019). However, many patients move between levels and sub-units in an individual way and the organization needs to include these movements when implementing

personalized care. It would need new tools for decision-making and cooperation between sub-units and levels in order for patient care not to just be subordinate to standardizations, if you do not just mean person-centered care *within the structure of healthcare*. Nilsson (Nilsson 2013) suggests patient process oriented care, where care follows the patient. That would need a change in both decision-making and hierarchical structures. Daley identifies communication as the essential ingredient to participation and is thus not restricted to facts and treatment plans, but to more existential issues (Daley 1993).

The Swedish Patient's Act portal section states: "This Act aims to strengthen and clarify the patient's position in healthcare activities and to promote the patient's integrity, self-determination and participation." In my interviews patients describe themselves as both fragmented in their bodies and viewed as a "patient" instead of as a person. Both patients and relatives expressed not being a part of their healthcare planning, see appended papers 4-6. A similar outcome was seen in a Picker Institute investigation in USA during the 1990's in where patients lacked information about aftercare and found healthcare professionals hard to reach (Gerteis 1993). Making political decisions in complex organizations, without an implementation plan brings a quote from Wittgenstein to mind: "Don't *for heaven´s sake*, be afraid of talking nonsense! But you must pay attention to your nonsense." (p 56e) (Wittgenstein and Wright 1984).

The patients interviewed describe what they perceive as well-meaning physicians who still neglect their needs. Cancer care lack incorporation of patient values and objective evidence into decision-making (Hirsch and Abernethy 2013). I see a built-in conflict, where patients hope for and sometimes expect inclusion and person-centered care. The healthcare staff tries to accommodate its patients as best they can in an organization built on sub-units. In this context patients need to deal with contradictory feelings. As shown in appended paper 6, patients are thankful for the help they are given and the effort they see healthcare staff put in. At the same time they experience fragmentation and being sent around to different units. Those mixed feelings need to be dealt with. In *Momentary contentment theory* middle consciousness is one way to bounce back from mixed emotions. In a state of sadness or feeling belittled as a human being by the people who have also been very helpful it may be guilt-inducing for patients to talk openly about these experiences. Through middle consciousness we can use different ways, such as artistic work or irony, to express mixed emotions. A way to allow the experiences to be there without blaming a specific person. In a painting one may express anger without the guilt of being angry at the person trying to help.

Relatives through momentary contentment

Due to differences in context, where relatives do not share the relational intersubjective awareness of one's own mortality and morbidity, I have excluded them from *Momentary contentment theory.* There are studies done on relatives of cancer patients showing morbidity of different kinds (Braun, Mikulincer et al. 2007, Sandgren, Thulesius et al. 2010, Sjövall, Attner et al. 2010, Sjövall 2011, Goren, Gilloteau et al. 2014, Möllerberg, Sandgren et al. 2016, Lehto, Aromaa et al. 2018). I have analysed my data through the eyes of *Momentary contentment theory.* My interviews with relatives show a lack of concepts to describe their situation; relatives had no common language. They describe being forced into different roles where the normal relationship is overridden by demands. They try to give words to their situation by comparing their situation with different concepts; explaining how they are both parents, lovers, carers, doctors, drivers, therapists and so on while trying to navigate their everyday life. The lack of language makes both companionship and linguistic strategies, two important aspects in *Momentary contentment theory,* difficult.

According to Wittgenstein, concepts and actions are interrelated. It is within language that existence is structured (Winch 2008). Wittgenstein's reasoning could explain the difficulties relatives had describing their feelings in both my interviews and in our university course "Patient perspective and own ability". Wittgenstein's argument that existence can be found in language would mean that the relative's experiences are not real. I would not go that far, but it was almost as if the relatives did not see themselves. This correlates to other studies showing that stress-related sick leave as well as non-individualized care for patients and relatives are expensive for society (Sjövall, Attner et al. 2010). Among the interviewed relatives, their feelings of inadequacy towards the disease, the shortcomings of healthcare and life in general were at the forefront. In the background I found a sense of loneliness in that they gradually and silently lose their normal relationship with the sick. The suffering of relatives is real, and we urgently need a language for their situation.

The study on relatives of cancer patients highlighted the importance of intersubjective shared knowledge for companionship to flourish, and it helped set the subjective area of *Momentary contentment theory.*

Final comment and Research contribution

The scientific value in *Momentary contentment theory* lie in the eye of the beholder. Depression and distress are major problems for both cancer patients and relatives, increasing the cost of cancer in the world, and new rehabilitation methods are needed. I argue that momentary contentment can work as an alternative approach, not for everyone but for some people at different points in their lives. *Momentary contentment theory* is a way to integrate the disease with life and in a resilient way patients may try to adapt to whatever happens.

My research contribution lie in moving a novel middle range theory, momentary contentment, to a cancer context with the aim of improving health. This thesis examines how patients may adapt to a life with cancer in an active and productive way. Through *Momentary contentment theory* the patient perspective, where patients are an active part in their own health and care, is given a concept and a theoretical base.

I have empirically explored cancer patients' life situation from a patient perspective. I have chosen to do narrative interviews in order to obtain a bottom-up perspective. My contribution lie in the conceptual explanation of a patientification process as well as in a description of patient needs, see appended papers 4-6 (Sandén, Harrysson et al. 2017, Sandén 2019, Sandén, Nilsson et al. 2019, Sandén, Harrysson et al. 2021). I have also studied relatives of cancer ill persons. Their situation is conceptualized as living in a terror-like situation, lacking both adequate support and a language to explain their experiences. See appended paper 5 (Sandén 2017, Sandén, Nilsson et al. 2019).

My research contribution to the field of User innovation lie in the results of a patient user innovation project as well as reflections from that process. I would not have been able to get this far without my own experiences of illness. By openly using my patient experiences in generating a middle range social theory I also contribute to the current movement of personal science.

Conclusions

There are both cognitive and emotional ways to deal with a cancer trajectory that may be introduced to cancer patients, letting them choose what suits their lives. Through *Momentary contentment theory's* main concepts of doing safety, destiny readiness and middle consciousness I introduce an everyday approach to increase quality of life for cancer patients. Activity and acceptance, time management and an inner hope are central parts of this approach, adding up to the main issue of enjoying life.

I propose a task-shifting rethinking of cancer rehabilitation which is based on inclusion, authenticity, and a person's individual preferences. Through an adaptive view on time management and an acceptance of life's unpredictability patients can in companionship with others create their own spaces of safety and contentment. *Momentary contentment theory* is presented as an alternative to approaches accepting the passive and submissive patient role. Healthcare may help by inviting patients to be a partner in a co-creation process of care; a partnership that sometimes has the patient as a project leader, and sometimes in a self-chosen passive stance.

In short:

- *Momentary contentment theory* may contribute to health for cancer ill people.

- *Momentary contentment theory* has many similarities to resilience in its adaptive bouncing back approach.

- *Momentary contentment theory* may serve as an alternative approach in cancer rehabilitation explaining and illustrating how activity, participation and acceptance are means to learn to adapt to new living conditions.

- Patientification is a process where patients learn to be submissive.

Future research

Formalization of Momentary contentment theory

I have tried to move the middle range *Momentary contentment theory* from one substantive area to another. Next step would be to try and formalize the theory. I see interesting research topics within this area:

Altruism and hope

A way to increase health, if done properly, is through altruism (Batson, O'Quin et al. 1983, Post 2005, Schnall, Roper et al. 2010, Sandén, Harrysson et al. 2015). The 'helping each other' part is already going on among patients but without education or external guidance. In interviews patients expressed a longing for more help as well as a way to share their experiences and help others. Through a mentor program the effects of altruism in cancer rehabilitation could be further studied. Patients carry experiences that if reflected upon could be of use for health professionals. Within the Together for Life project (see below), Karolinska Institute have plans on making patients mentors in medical school. Different outlets for altruistic work would be created and studied together with related questions of hope and safety feelings.

Relatives to cancer ill persons

We need to extend the studies about relative's morbidity into finding new solutions in how they may endure health. I see altruism as one potential way forward. If we find a way for relatives of cancer ill persons to go from duty-driven to altruistic-driven work, in combination with support and venting possibilities I believe we may decrease morbidity among relatives.

Relatives, in my interviews as well as in the university course "Patient perspective and own ability", expressed difficulties in seeing themselves as a person with their own needs, apart from the patient. Common expressions in connection with contacts with "Cancer friends" (Cancerkompisar, Swedish organization for relatives to cancer ill

people) were: *"I realized that I get to know everything I feel"* and *"there I understood that I was not crazy"*. In other words, close relatives described a life without venting possibilities.

Both patients and relatives go through different phases, all of which include waiting. For close relatives, it is a matter of waiting for normality. In most cases, this means either waiting for death or for the patient to regain health. Wishing death out of compassion upon a person you love may create mixed feelings. Perhaps moving toward relatives would open up new knowledge within the frame of *Momentary contentment theory*. I suggest a few research topics:

- Finding a language/concepts that describe and explain living as a relative to a cancer ill person.

- I propose a focus on the relationship between a loved one and a cancer ill person. How does the awareness of the illness affect their relationship? Is it possible to have different awarenesses?

- Why do many cancer patients experience loss of friends and loved one's when getting sick?

Healthcare research from a patient perspective

There are many entrances to patient perspective-based research of healthcare. Nevertheless, in health innovation the patient is often viewed as a recipient and not a participant or innovator (Bhatti, del Castillo et al. 2018, Glaser 2019). I chose to bring a few issues into the academic discussion about future research:

- How can we integrate standardization and person-centered care?
The definitions of patient- or person-centered care vary but a core view is to see the patient in a holistic way without fragmentation of the human body. That care is individualized around the person regardless of the healthcare setting (Morgan and Yoder 2012). Alongside patient-centered care, standardizations and programs have been developed in order to promote the implementation of protocols and guidelines within healthcare (Tietschert, Angeli et al. 2019). The official society talks about person-centered care and standardizations at the same time. These are often incompatible, if we do not just mean person-centered care *within the structure of healthcare*. That would mean that patients are viewed as a group more than as individuals, however, inclusion is very difficult to implement without accepting individual authenticity (Shore, Randel et al. 2011). Patient or person-centered care also

requires a change in mindset among health providers, as stated by family medicine physician Weston "If physicians are truly to connect with patients as partners in care, they must change their mindset and develop skills to involve patients in meaningful ways"(p 438) (Weston 2001). As long as standardization goes before person the care cannot be called person-centered and the discussion about how to implement person-centered care becomes a mere deflection from the main issues of organizational gaps and guideline-based care versus individual based care.

- How can we reach a true co-creation of care

Healthcare from a patient perspective has at least two divided groups of people, the providers and the recipients of care. Looking at inclusion through the definition by Shore (Shore, Randel et al. 2011), three different parts are needed for a person to feel included: belonging, authenticity, and group responsibility. As a recipients of care you are not allowed to participate in many events regarding your own care. One of my informants expressed it as "*you and I don't belong to the same kind of people*". In healthcare, among patients, there are discussions about how to be a good patient. Expressions such as "*no one wants to be labelled a difficult patient*" make people not dare to be authentic. There is a fear of not receiving the same treatment as you would being a 'good' patient, if you become labelled as difficult. Patients also describe changing their symptoms or not telling the healthcare provider about all symptoms due to fear of being delegitimized. The fragmentation and objectification of patients also work against authenticity. The patients interviewed describe what they perceive as well-intended physicians who still neglect patients' needs. Agledahl (Agledahl, Førde et al. 2010) studied hospital physicians consultations with patients through videorecordings and argued that the ongoing issues with patients complaining about lack of empathy and understanding from their physicians might indicate a systematic problem. Nevertheless, her analysis resulted in the concept Clinical Essentialising which explains the lack of emphatic response of the physicians who perceived it essential to stay strictly focused on biomedical doctoring.

Traditionally patients are often seen as a passive recipient of someone else's actions (Gunnarson 2016, Sandén 2017) and cancer care lack incorporation of patient values and objective evidence into decision-making (Hirsch and Abernethy 2013). In my interviews many patients raised occasions of being treated as a fellow human being as something special and they generally asked for continuity in relationships with health professionals. My interviewees seem to say the same thing in Sweden in 2015-2017 as literature illustrates from decades ago (Gerteis 1993). There seems to be a need to open communications, to individualize care, to manage organizational gaps and to view the patient as a unique human being. Alvesson's stupidity paradox may help explain the

deflection from patient needs to concept discussions such as person-centered care "However, in many instances being reflexive, requiring justifications, and engaging in substantive reasoning are not accepted as normal parts of organizational life." (p 1201) (Alvesson and Spicer 2012).

- Contradictory requirements

Schein (Schein 2010) talks about organizational rules, unspoken norms that create behaviour. There is a politically driven moral requirement to involve patients and to view them as individuals with individual needs at the same time as health professionals are required to follow rules and guidelines. There are several examples of healthcare professionals being forced into following instrumental requirements. From USA a decade ago "However, those who express concern for patient safety are routinely affected by reprisals from employers" (DagensMedicin 2011) to a recent report from The Swedish Junior Doctors' Association "More than 1,000 physicians have responded to the survey on the culture of silence in their workplaces. 31% of the junior physicians in the survey believed that there was a culture of silence in their workplace, and 21% stated that they themselves had not dared to shed light on work environment or patient safety problems due to fear of reprisals" (Sylf 2021). The discrepancy in actions between the discussions on implementation of person-centered care and the witnesses statements of the opposite from patients and relatives seem rather natural from the perspective of those contradictory requirements.

- How can we introduce accountability to healthcare

In my interviews a gate keeping function appeared, where a nurse dismissed people from seeing a physician on very loose grounds. People who were later given a cancer diagnosis from the symptoms, had their diagnosis being delayed due to a simplified cause and effect explanation. Ethnomethodology (Garfinkel 1967) has a concept of "accountability" which means that a person has a reporting obligation on his behaviour. The concept demands a mutual recognition of each other's accountability in a linguistic framework. How about the accountability in healthcare? How come we allow a gatekeeping function, knowing it delays diagnosis as well as delegitimizes people? Using Goffman's (Goffman 1990) metaphors of social life as a theatre, here is clearly a back stage and a front stage with an unnamed person watching the stages, a context we can change if we want to. One example showing the possibility to change this is the Borgholm primary care model (Ström 2018) where nurses are no longer gatekeepers for physician consultations. Patients call their physician when they have a problem as opposed to most Swedish primary care which is based on telephone triaging by nurses. In the Borgholm model nurses take care of nursing, physicians take care of diagnosing and treatment decisions, and the patients make the decision on who to contact. This

correlates to appended paper 7, and a further exploration of task shifting could be beneficial for future innovations.

Personal science

The Swedish Agency for Health and Care Services Analysis emphasizes the need for clear strategies and systematic work to better utilize patients' and relatives' experiences, knowledge and resources (Westling 2018). Biomedical researchers have also advocated a participatory approach, and integration of '*allostasis'*, referring to behavioural and psychological adaptations that affect health, as a proactive approach in chronic disease management (Sagner, McNeil et al. 2017). In personal science patients use digital tools to conduct N=1 trials and scientifically grounded research on themselves (Wicks 2018). The quantified self-movement started with patients using technology for self-tracking early this century and is now spread all over the world. In Sweden Sara Riggare has been a front figure (Wicks 2018, Riggare 2020, Riggare, Stamford et al. 2021). Wolf and De Groot expand the definition of Personal science as research where the questions asked are directly relevant to the individual asking the questions. Those questions concerns their private life, experiences, and emotions (Wolf and De Groot 2020). When I started to use *Momentary contentment theory* for my own well-being I was only looking for personal contentment. I have used the emerging theory for my own health and during that experience I have taken notes, written memos, and used those as research data. I have thus used myself in the research process and my own life has been my domain. As such we may argue my research is personal science, but it differs from most of the articles about personal science written so far in that I have not used digital tools nor have I measured my wellbeing in any quantitative way. My experiences have rather been used as inspiration for further studies and researcher bias has been an ongoing discussion during my doctoral studies. Here I propose

- a methodological study looking into the benefits and faults of including experienced based knowledge and into how to further develop personal science.
- a research preparatory course in using personal science.

Together for life

Companies, researchers from different fields and universities are in the process of trying to secure funds to create a user (driven) open innovation project with digital technologies as means to creating a rehabilitation structure; Together for life. The project has the same basic idea of cooperation and co-creation as the university course in "Patient perspective and own ability", with a patient needs base and an interpretative innovation approach. Through education and digitalization, we allow researchers, patients, manufacturers, relatives, and healthcare professionals to meet and share knowledge; making everyone learn from each other. Steinfeld and Tauke writes about Universal design and its verb Universal designing, about barrier free or accessible design; "Universal Design, however, is concerned with more than just removal of barriers. It seeks to eliminate discrimination by design and support full social participation for all members of society." (p165) (Christophersen 2002). The project aim at democratizing knowledge, and through optimal use of information and communication technology we may reach out on different levels, making it possible for everyone interested to learn something. The rehabilitation structure is also a means to promote the diffusion of *Momentary contentment theory* and its guidelines for contentment in the moment.

Building knowledge

In healthcare a dominant view on innovation is that it is gained from external and formal research programs that are transferred to practice as a final step (Herzlinger, 2006). In other words, the technocratic and medicalized model of healthcare is rarely optimal for patients but rather is internally focused, i.e. does not include the patient in the innovation process. Many informants expressed how they were subjected to delegitimization. One person described her experiences in healthcare as becoming a stick figure. How can we cooperate with a stick figure? Indeed, how can we believe to obtain authentic patient participation when delegitimization is allowed to continue? It is crucial for the evolvement of user innovation in health to start viewing patients as active resourceful human beings. Doing so would increase integrity in both research and care.

Biomedical researchers have advocated for a participatory approach, and integration of '*allostasis*', referring to behavioural and psychological adaptations that affect health, as a proactive approach in chronic disease management (Sagner, McNeil et al. 2017). At

the same time quality-of-life data is not routinely reported in clinical trials (Schnipper, Davidson et al. 2015).

Researchers from Lund University, University of Helsinki, Uppsala University, and Nord University have been discussing questions regarding co-creation of care and research. The discussions have included partial solutions like building research teams, to build a knowledge exchange community centered on the health of cancer patients, through co-creating courses, workshops, and events in which cancer patients and their relatives, healthcare professionals, and researchers meet to learn from one another. We need to comprehensively understand and evaluate care practices that may truly benefit cancer patients, including rehabilitation, intervention and preventative actions. The university courses in "Patient perspective and own ability" (Lund) and "Patient perspective and self-efficacy" (Helsinki) are ways to increase knowledge about different perspectives and about cooperation. These need to be both evaluated and developed further.

References

Hälso- och sjukvårdslag (2017:30). 2017:30. S. Riksdag. Stockholm.

Patientlag (2014:821). SFS 2019:964. S. Parliament.

Agledahl, K. M., R. Førde and A. Wifstad (2010). "Clinical essentialising: a qualitative study of doctors' medical and moral practice." Medicine, Health Care & Philosophy 13(2): 107-113.

Agledahl, K. M., P. Gulbrandsen, R. Førde and Å. Wifstad (2011). "Courteous but not curious: how doctors' politeness masks their existential neglect. A qualitative study of video-recorded patient consultations." Journal of Medical Ethics 37(11): 650-654.

Aguinis, H. and A. M. Solarino (2019). "Transparency and replicability in qualitative research: The case of interviews with elite informants." Strategic Management Journal 40(8): 1291-1315.

Alvesson, M. and A. Spicer (2012). "A Stupidity-Based Theory of Organizations." Journal of Management Studies 49(7): 1194-1220.

Antonovsky, A. (1987). Unraveling the mystery of health: How people manage stress and stay well. San Francisco, CA, US, Jossey-Bass.

Antonovsky, A. (1996). "The salutogenic model as a theory to guide health promotion." Health Promotion International 11(1): 11-18.

Bandura, A. (1997). "Self-efficacy." Harvard Mental Health Letter 13(9): 4-6.

Batson, C. D., K. O'Quin, J. Fultz, M. Vanderplas and A. M. Isen (1983). "Influence of self-reported distress and empathy on egoistic versus altruistic motivation to help." Journal of Personality and Social Psychology 45(3): 706-718.

Benzein, E. (1999). Traces of hope, Umeå : Univ., 1999 ; (Umeå : Larsson & co:s tr.).

Benzein, E., A. Norberg and B. Saveman (2001). "The meaning of the lived experience of hope in patients with cancer in palliative home care." Palliative Medicine 15(2): 117-126.

Bhatti, Y., J. del Castillo, K. Olson and A. Darzi (2018). "Putting Humans at the Center of Health Care Innovation." Harvard Business Review Digital Articles: 2-7.

Braun, M., M. Mikulincer, A. Rydall, A. Walsh and G. Rodin (2007). "Hidden morbidity in cancer: Spouse caregivers." Journal of Clinical Oncology 25(30): 4829-4834.

Bray, F., J. Ferlay, I. Soerjomataram, R. L. Siegel, L. A. Torre and A. Jemal (2018). "Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries." CA Cancer Journal for Clinicians **68**(6): 394-424.

Brown, T. (2008). "Design thinking." Harvard business review **86**(6): 84.

Brown, T. and B. Katz (2009). Change by design : how design thinking transforms organizations and inspires innovation, [New York] : Harper Business, cop. 2009 1. ed.

Buhr, K. and M. J. Dugas (2009). "The role of fear of anxiety and intolerance of uncertainty in worry: An experimental manipulation." Behaviour Research and Therapy **47**(3): 215-223.

Butters, M. (2021). Death and Dying Mediated by Medicine, Rituals, and Aesthetics : An Ethnographic Study on the Experiences of Palliative Patients in Finland. PhD Thesis, Helsinki.

Bykvist, K., B. Brulde and B. Brülde (2010). "Happiness, ethics, and politics: Introduction, history and conceptual framework." Journal of Happiness Studies **11**(5): 541-551.

Cancerrehabfonden (2019). CancerRehabRapporten 2019. Stockholm: 59.

Christensen, C. (2010). "Health Care: The Simple Solution." BusinessWeek(4170): 72-72.

Christensen, C. M., J. H. Grossman and J. Hwang (2009). The innovator's prescription : a disruptive solution for health care, McGraw-Hill.

Christensen, C. M., A. Waldeck and R. Fogg (2017). "The Innovation Health Care Really Needs: Help People Manage Their Own Health." Harvard Business Review Digital Articles: 1-5.

Christophersen, J. E. (2002). Universal design : 17 ways of thinking and teaching, Husbanken.

Clifford, D. (2020). Dynamisk upplevelse i Virtual Reality och dess effekt på cancerpatienter. Master Thesis, Lund University.

Cohen, A. B. (2014). Culture reexamined. broadening our understanding of social and evolutionary influences, American Psychological Association.

DagensMedicin (2011) "Visselblåsare utsatta i vården."

Daley, J. (1993). Overcoming the barriers of words. Through the patient's eyes. M. Gerteis. San Fransisco, Jossey-Bass.

Davis, M. (1971). "That's Interesting!" Philosophy of the Social Sciences **1**(2): 309-344.

Demjén, Z. (2016). "Laughing at cancer: Humour, empowerment, solidarity and coping online." Journal of Pragmatics **101**: 18-30.

Duignan, J. (2016). Dictionary of Business Research Methods, Oxford University Press.

Eriksen, T. H. r. (2006). Trygghet. Oslo, Universitetsforlaget.

Erling, B., E. Pelle and H. Per-Anders (2012). "Design Things and Design Thinking: Contemporary Participatory Design Challenges." Design Issues **28**(3): 101.

Fagerlind, H., L. Ring, B. Brülde, N. Feltelius and A. K. Lindblad (2010). "Patients' understanding of the concepts of health and quality of life." Patient Education & Counseling **78**(1): 104-110.

Fedakar, S. (2020). "An evaluation on classification of humor theories " Mizah Teorilerinin Sınıflandırılması Üzerine Bir Değerlendirme. **32**(126): 52-62.

Friedrichs, J. and F. Kratochwil (2009). "On Acting and Knowing: How Pragmatism Can Advance International Relations Research and Methodology." International Organization **63**(4): 701-731.

Gadamer, H.-G. (1996). The enigma of health : the art of healing in a scientific age, Cambridge : Polity Press, 1996.

Garfinkel, H. (1967). Studies in ethnomethodology, Prentice-Hall.

Garland, E. L., N. A. Farb, P. R. Goldin and B. L. Fredrickson (2015). "Mindfulness Broadens Awareness and Builds Eudaimonic Meaning: A Process Model of Mindful Positive Emotion Regulation." Psychological Inquiry **26**(4): 293-314.

Gerteis, M. r. (1993). Through the patient's eyes: understanding and promoting patient-centered care San Francisco, Jossey-Bass.

Gillham, B. (2008). Forskningsintervjun : tekniker och genomförande, Studentlitteratur.

Glaser, B. G. (1978). Theoretical sensitivity : advances in the methodology of grounded theory, Sociology Press.

Glaser, B. G. (1998). Doing grounded theory : issues and discussions, Mill Valley, Calif. : Sociology Press, cop. 1998.

Glaser, B. G. (2010). The SAGE handbook of grounded theory, SAGE Publications.

Glaser, J. (2019). "How to Ensure Your Health Care Innovation Doesn't Flop." Harvard Business Review Digital Articles: 2-5.

Goffman, E. (1990). Stigma : notes on the management of spoiled identity, Penguin Books.

Goren, A., I. Gilloteau, M. Lees and M. Dacosta Dibonaventura (2014). "Quantifying the burden of informal caregiving for patients with cancer in Europe." Supportive Care in Cancer **22**(6): 1637-1646.

Grinnell, F. (2019). "Abduction in the Everyday Practice of Science: The Logic of Unintended Experiments." Transactions of the Charles S. Peirce Society **55**(3): 215-227.

Gunnarson, M. (2016). Please be patient: a cultural phenomenological study of haemodialysis and kidney transplantation care. PhD Thesis, Lund : Lund Studies in Art and Cultural Sciences, 2016.

Haller, M. and M. Hadler (2006). "How Social Relations and Structures can Produce Happiness and Unhappiness: An International Comparative Analysis." Social Indicators Research **75**(2): 169-216.

Han, J. (2020). Theorising Culture: A Chinese Perspective, Springer International Publishing.

Hartman, J. (2001). Grundad teori : teorigenerering på empirisk grund, Studentlitteratur.

Hartman, J. (2004). Vetenskapligt tänkande : från kunskapsteori till metodteori, Studentlitteratur.

Heidegren, C.-G. (2014). Tid : sociologiska perspektiv, Stockholm : Liber, 2014 (Kina).

Heyen, N. B. (2020). "From self-tracking to self-expertise: The production of self-related knowledge by doing personal science." Public Understanding of Science 29(2): 124-138.

Hippel, E. v. (1988). The sources of innovation. , Oxford U.P.

Hirsch, B. R. and A. P. Abernethy (2013). "Structured Decision-Making: Using Personalized Medicine to Improve the Value of Cancer Care." Journal of Personalized Medicine 3(1): 1-13.

Hofmarcher, T., P. Lindgren, N. Wilking and B. Jönsson (2020). "The cost of cancer in Europe 2018." European Journal of Cancer 129: 41-49.

Holling, C. S. (1973). "Resilience and Stability of Ecological Systems." Annual Review of Ecology and Systematics 4(1): 1-23.

Holton, J. A. (2010). "The Coding Process and Its Challenges." Grounded Theory Review 9(1): 21-40.

Håkansson Eklund, J., I. K. Holmström, T. Kumlin, E. Kaminsky, K. Skoglund, J. Höglander, A. J. Sundler, E. Condén and M. Summer Meranius (2019). ""Same same or different?" A review of reviews of person-centered and patient-centered care." Patient Education and Counseling 102(1): 3-11.

Illanes, M. H. (2019). "Inclusiveness in Healthcare: Knowledge Ecosystems Innovation in Oncology and Chronic Disease." Proceedings of the European Conference on Knowledge Management 2(2): 1182-1192.

Jönsson, B. (2016). Tio tankar om arbete, Bromberg.

Kaner, S. (2014). Facilitator's Guide to Participatory Decision-Making, 3rd Edition. San Francisco, Jossey-Bass.

Kåver, A. (2020). Dansa mjukt med tillvaron : om mening, mod och möjligheter. Stockholm, Natur och Kultur.

Lehto, U. S., A. Aromaa and T. L. Tammela (2018). "Experiences and psychological distress of spouses of prostate cancer patients at time of diagnosis and primary treatment." European Journal of Cancer Care 27(1).

Li, Q. and A. Y. Loke (2013). "A spectrum of hidden morbidities among spousal caregivers for patients with cancer, and differences between the genders: A review of the literature." European Journal of Oncology Nursing 17: 578-587.

Loyd, S. P. (2017). "An ethnography of humor, ritual and defiance in a cancer care setting." Journal of Organizational Ethnography 6(3): 159-176.

Marin, A., M. Reimann and R. Castaño (2014). "Metaphors and creativity: Direct, moderating, and mediating effects." Journal of Consumer Psychology 24(2): 290-297.

Mausbach, B. T., T. Bos and S. A. Irwin (2018). "Mental health treatment dose and annual healthcare costs in patients with cancer and major depressive disorder." Health psychology : official journal of the Division of Health Psychology **37**(11): 1035-1040.

Mazzucato, M. (2018). Mission-Oriented Research & Innovation in the European Union. Brussel, European commission.

Morgan, S. and L. H. Yoder (2012). "A concept analysis of person-centered care." Journal of holistic nursing **30**(1): 6-15.

Moustsen, I. R., S. B. Larsen, J. Vibe-Petersen, K. Trier, P. E. Bidstrup, K. K. Andersen, C. Johansen and S. O. Dalton (2015). "Social position and referral to rehabilitation among cancer patients." Acta oncologica **54**(5): 720-726.

Möllerberg, M.-L., A. Sandgren, T. Lithman, D. Noreen, H. Olsson and K. Sjövall (2016). "The effects of a cancer diagnosis on the health of a patient's partner: a population-based registry study of cancer in Sweden." European Journal of Cancer Care **25**(5): 744-752.

Nilsson, F. (2013). Patientprocessorienterad vård : din vägledning till mer välmående och nöjdare patienter, Region Skåne, Utvecklingscentrum.

Nubiola, J. (2005). "Abduction or the Logic of Surprise." Semiotica **2005**(153): 117-130.

O'Rourke, L. (2020). Fear of cancer recurrence, anxiety and depression in partners of cancer survivors, University of Liverpool.

Ochs, E. (2012). "Experiencing language." Anthropological Theory **12**(2): 142-160.

Pannunzio, V., M. Kleinsmann and D. Snelders (2019). "Design research, eHealth, and the convergence revolution." arXiv e-prints.

Paukert, A., J. Pettit, M. Kunik, N. Wilson, D. Novy, H. Rhoades, A. Greisinger, O. Wehmanen and M. Stanley (2010). "The Roles of Social Support and Self-Efficacy in Physical Health's Impact on Depressive and Anxiety Symptoms in Older Adults." Journal of Clinical Psychology in Medical Settings **17**(4): 387-400.

Peirce, C. S. (1960). Collected papers of Charles Sanders Peirce, Belknap Press of Harvard Univ. Press.

Post, S. G. (2005). "Altruism, happiness, and health: it's good to be good." International Journal of Behavioral Medicine **12**(2): 66-77.

RCC (2019). Nationellt vårdprogram för cancerrehabilitering.

Riggare, S. (2020). "E-patients hold key to the future of healthcare." British Journal of Sports Medicine **54**(17): 1065-1066.

Riggare, S., M. Hägglund, A. L. Bredenoord, M. de Groot and B. R. Bloem (2021). "Ethical Aspects of Personal Science for Persons with Parkinson's Disease: What Happens When Self-Tracking Goes from Selfcare to Publication?" Journal of Parkinson's Disease **Preprint**: 1-7.

Riggare, S., J. Stamford and M. Hägglund (2021). "A Long Way to Go: Patient Perspectives on Digital Health for Parkinson's Disease." Journal of Parkinson's disease **11**: 5-10.

Sagner, M., A. McNeil, P. Puska, C. Auffray, N. D. Price, L. Hood, C. J. Lavie, Z.-G. Han, Z. Chen, S. K. Brahmachari, B. S. McEwen, M. B. Soares, R. Balling, E. Epel and R. Arena (2017). "The P4 Health Spectrum - A Predictive, Preventive, Personalized and Participatory Continuum for Promoting Healthspan." Progress in Cardiovascular Diseases **59**(5): 506-521.

Samant, R., K. Balchin, E. Cisa-Paré, J. Renaud, L. Bunch, A. McNeil, S. Murray and J. Meng (2020). "The importance of humour in oncology: a survey of patients undergoing radiotherapy." Current Oncology **27**(4): e350-e353.

Sandén, U. (2006). ... och jag vill leva, Stockholm : Prisma, 2006 (Smedjebacken : Scandbook).

Sandén, U. (2014). Nuets förnöjsamhet - en grundad teori med utgångspunkt i Nordnorskt vardagsliv. Master thesis, Lund University.

Sandén, U. (2016). -and I want to live, Vulkan.

Sandén, U. (2016). På okänt cancervatten, Lund : Institutionen för designvetenskaper, Lunds tekniska högskola, Lunds Universitet, 2016.

Sandén, U. (2017). Momentary contentment : exploring needs and innovation possibilities in a psychosocial cancer context, Lund : Department of Design Sciences, Lund University, 2017.

Sandén, U. (2017). På okänt cancervatten - närståendes perspektiv, Lund University.

Sandén, U. (2019). "Co-creation of lifelong rehabilitation design." Brain, Body, Cognition **8**(4): 381-393.

Sandén, U. (2019). Nuets förnöjsamhet. Copenhagen, Denmark, Saga Egmont.

Sandén, U., L. Harrysson and H. Thulesius (2015). "Momentary Contentment A Modern Version of an Old Survival Culture." Grounded Theory Review: An International Journal **14**(2): 74-85.

Sandén, U., L. Harrysson, H. Thulesius and F. Nilsson (2017). "Exploring health navigating design: momentary contentment in a cancer context." International Journal of Qualitative Studies on Health & Well-Being **12**(1).

Sandén, U., L. Harrysson, H. Thulesius and F. Nilsson (2021). "Breaking the patientification process - through co-creation of care, using old arctic survival knowledge." International Journal of Qualitative Studies on Health and Well-being **16**(1): 1926052.

Sandén, U., F. Nilsson, H. Thulesius, M. Hägglund and L. Harrysson (2019). "Cancer, a relational disease: exploring the needs of relatives to cancer patients." International Journal of Qualitative Studies on Health and Well-being(1).

Sandgren, A., H. Thulesius, K. Petersson and B. Fridlund (2010). "Living on Hold in Palliative Cancer Care." Grounded Theory Review **9**(1): 79-100.

Schein, E. H. (2010). Organizational culture and leadership., Jossey-Bass.

Schiavone, F. (2020). User Innovation in Healthcare: How Patients and Caregivers React Creatively to Illness, Springer International Publishing.

Schnall, S., J. Roper and D. Fessler, M. T. (2010). "Elevation Leads to Altruistic Behavior." Psychological Science **21**(3): 315.

Shore, L. M., A. E. Randel, B. G. Chung, M. A. Dean, K. H. Ehrhart and G. Singh (2011). "Inclusion and Diversity in Work Groups: A Review and Model for Future Research." Journal of Management Studies **37**: 1262-1289.

Silver, J., K, N. Stout, L. , J. Fu, M. Pratt-Chapman, P. Hajlock, J and R. Sharma (2018). "The state of cancer rehabilitation in the United States " Journal of Cancer Rehabilitation **1**(1): 1-8.

Simon, H. A. (1969). The sciences of the artificial. Cambridge, MIT Press.

Sinding-Larsen, H. (2006). Eksternaliserte og relasjonelle trygghetsregimer. Trygghet. T. H. Eriksen. Oslo, Universitetsforlaget**:** 205-234.

Sinding, C., P. Hudak, J. Wiernikowski, J. Aronson, P. Miller, J. Gould and D. Fitzpatrick-Lewis (2010). ""I like to be an informed person but…" negotiating responsibility for treatment decisions in cancer care." Social Science & Medicine **71**(6): 1094-1101.

Sjövall, K. (2011). Living with cancer : impact on cancer patient and partner. PhD Theses

Non-fiction, Lund : Lund University.

Sjövall, K., B. Attner, T. Lithman, D. Noreen, B. Gunnars, B. Thom, L. Lidgren, H. Olsson and M. Englund (2010). "Sick leave of spouses to cancer patients before and after diagnosis." Acta Oncologica **49**(4): 467-473.

Strang, P. (2007). Livsglädjen och det djupa allvaret : om existentiell kris och välbefinnande, Natur & kultur.

Ström, M. (2018) "Kan Borgholm-modellen bli lösningen för framtidens sjukvård?" Läkartidningen.

Sylf (2021). När underläkarna tystnar. https://slf.se/sylf/app/uploads/2021/02/tyst-lakarkar-en-rapport-om-tystnadskultur-bland-underlakarna.pdf, SYLF.

Tavoli, A., Z. Tavoli and A. Montazeri (2019). "The Relationship Between Emotional Functioning of the EORTC QLQ-C30 and A Measure of Anxiety and Depression (HADS) in Cancer Patients." International Journal of Cancer Management **12**(7): 1-5.

Tietschert, M. V., F. Angeli, A. J. A. van Raak, J. Clark, D. Ruwaard and S. J. Singer (2019). "Can organisational culture of teams be a lever for integrating care? An exploratory study." International Journal of Integrated Care **19**(4).

Tilly, C. (1998). Durable inequality, Berkeley, Calif. : Univ. of California Press, cop. 1998.

Torre, L. A., F. Bray, R. L. Siegel, J. Ferlay, J. Lortet-Tieulent and A. Jemal (2015). "Global cancer statistics, 2012." CA: a cancer journal for clinicians **65**(2): 87-108.

Tyrstrup, M. (2014). I välfärdsproduktionens gränsland – organisatoriska mellanrum i vård, skola och omsorg, Delrapport nr 5 i Uppdrag: Välfärd!

Vandello, J. A., V. E. Hettinger and K. Michniewicz (2014). Regional culture. Culture reexamined: Broadening our understanding of social and evolutionary influences. A. B. Cohen. Washington, DC, American Psychological Association**:** 77-91.

Ware, N. C. (1992). "Suffering and the Social Construction of Illness: The Delegitimation of Illness Experience in Chronic Fatigue Syndrome." Medical Anthropology Quarterly 6(4): 347-361.

Welsh, M. B. (2018). Bias in science and communication : a field guide, IOP Publishing.

Verschuren, E. (2021). Niche re-construction to revert or transcend the cancer state MIT Press.

Westling, K. (2018). Från mottagare till medskapare. Vårdanalys. Stockholm, Vårdanalys.

Weston, W. W. (2001). "Informed and shared decision-making: the crux of patient-centred care." CMAJ: Canadian Medical Association Journal 165(4): 438-439.

WHO (2021). Rehabilitation pamphlet. https://www.who.int/health-topics/rehabilitation#tab=tab_1, WHO.

Wicks, P. (2018). "Patient, study thyself." BMC Medicine 16(1): 1-3.

Wilce, J. M. (2014). "Current Emotion Research in Linguistic Anthropology." Emotion Review 6(1): 77.

Winch, P. (2008). The idea of a social science and its relation to philosophy, Routledge.

Visser, R. C. (2017). ""Doing death": Reflecting on the researcher's subjectivity and emotions." Death Studies 41(1): 6-13.

Wittgenstein, L. and G. H. v. Wright (1984). Culture and value, The University of Chicago Press.

Wolf, G. I. and M. De Groot (2020). "A Conceptual Framework for Personal Science." Frontiers in Computer Science 2(21).

Appendix

Appendix 1, the banana ruler

The banana ruler (design and idea: Joel Elinder) may function as an epistemological bridge between medical research, which is heavily influenced by positivism, and the medical work patients meet in clinical healthcare settings. Positivism refers to theory with terms that are measurable (Hartman 2004). In positivistic medical research, complexity is often reduced, both by excluding the unmeasurable and often also people with multiple diseases. Clinically however, humans enter in all their complexity, and as such there are seldom clear and certain absolute answers to symptoms and mixed diseases. The banana ruler works as a metaphor and a reminder of complexity when dealing with human research. In research you may choose your barriers and exclude uncommon cases from inclusion. In life you are stuck with what is.

"I extend my hand to the young man standing next to my friend and colleague. A little cautiously he says:

- Hi, I am Joel Elinder.

- Show her, Joel.

The student's hands reaches down into a bag and after a bit of rotting, he picks up a yellow banana in wood.

- I've made a banana ruler. It shows how we can learn new things by challenging old truths. Does a line have to be straight? Or can a ruler have the shape of a banana?

- If we had navigated the Titanic with this ruler, we would have missed the iceberg by just over 14,000 nautical miles, his teacher adds.

- Wow!

Suddenly I see it. The problems with our healthcare and our ways of dealing with life. Healthcare sees one disease at a time, even though very many patients suffer consequential injuries and illnesses and thus do not follow the template that healthcare expects from its research.

- We are not straight rulers, we are all unique banana rulers but receive treatment as if we were straight.

I speak loudly to myself and continue to think about how I as a patient see waiting as a straight line to be lived through, instead of taking each day in its uniqueness. When I in Norway tried to categorize, divide people, see patterns, they replied "no, Mette is who Mette is because she is Mette". If we are allowed to be unique, crooked, yes, like a banana ruler, what would life be like then? If healthcare workers saw each person as unique, if they tried to understand each individual and adapt healthcare accordingly, how would we change as human beings? If healthcare workers were allowed to use their unique abilities in the meeting with us patients, would more people want to work in healthcare then? Or would it turn into chaos?"

excerpt from my latest book "*Nuets förnöjsamhet*" (Sandén 2019).

Appendix 2 Limericks

The limericks are examples of combining humor and writing in creating a space of dignity, where bitterness does not rule. The writing combines doing safety in its activity of writing, destiny readiness in its linguistic way of turning bitterness to humor, and middle consciousness in that the issue of delegitimization is allowed to be there but in a different way.

Limerick 1

There was a woman from pseudoland
Who tried so very hard to understand
What they meant
When they present
Their previous hidden poker hand

Neurosurgeon said there is no tumor indication
Oncologist said we don't have enough information
Radiologist spoke
I say stroke
No recurrence, pathologist added, it's just imagination

Guessing wildly doesn't give a good impression
I which you had more pride in your profession
Your guess
Is my stress
Soon I have a hospital induced pseudodepression

You say you work with evidence and great discretion
I am trying to grasp, so let me ask you one more question
What is glowing

On camera growing
In chorus they answered, MR induced pseudoprogression

Aha! my tumor has been absorbed from photoconductivity
It is a camera fabrication causing a pseudoreactivity
symptoms, I can feel it
No chance to conceal it
But perhaps I also have imagination induced pseudoepileptic activity?

That's right, and now you should start a family
The neurosurgeon said looking very happily
You go girl
Unfurl
Try to get pregnant and do it very rapidly

It seems as your knowledge is quite shallow and hollow
From hysterectomy, pregnancy doesn't usually follow
Perhaps mister regnant
I can be pseudopregnant
But now you give me more craziness than I can swallow

One day I am well, the other you want to cut me open
Its like your knife is used like a slot machine's token
Don't want to believe
You try to deceive
And if I am lucky my trust for you is only pseudobroken

Limerick 2

There was a conference in patient perspective
We want to do good, that's our only objective
We're ahead
Doctors said
Working together and we will be more effective

The health professionals tried to patientification explore
When a young woman knocked on the meeting door
She smiled
This is wild
I love it, may I join you, so we can all learn some more

Oy, this will happen quite often, I do anticipate
That patients ask and demand to participate
Irresponsible
impossible
We cannot let them in, this is our place to dissipate

My dear, you will not understand our conversation
We don't want to increase your fear and imagination
All is best
If you rest
While we discuss the importance of participation

Nodding heads from both the old and the residency
Made her leave the room rather hesitantly
Banana people
Meet hospital sheeple

And their words sounded quite resonantly

And so it was that a good and important idea
Arisen from nothing but fear and word diarrhea
A great selection
Of a mere deflection
It's like a hospital version of Greek Medea

Appendix 3 Virtual Reality

Image from inside the Smash room, where you get to break everything in the rooms (Clifford 2020)

Image from the Fire room, where patients get to burn tumors and other symbolic things (Clifford 2020)

Paper I

ULRIKA SANDÉN, HANS THULESIUS OCH LARS HARRYSSON

Nuets förnöjsamhet

En grundad teori om livsval och överlevnadsstrategier

Contentment in the moment

"Contentment in the moment" is a classic grounded theory exploring safety and contentment within a small community in northern Norway. The purpose of the study was to explore the village's everyday life from a participant's perspective and to develop an understanding of their living conditions. We found different survival strategies, which have their roots in the village's history of poverty, isolation and harsh climate. Today these strategies have changed from a matter of life and death to a modern psychosocial foundation of contentment.

The study is based on four and a half years of observations, in-depth interviews and informal but focused conversations with people living in Polarfjorden. The data was analysed using the constant comparative method of classic grounded theory.

In this article we further relate our work to more general sociological theory, more specifically to Charles Tilly's work on reason and routines.

Keywords: contentment, happiness, risk, reason, grounded theory

DENNA ARTIKEL ÄR baserad på en studie av vardagslivet kring en norsk fjord strax ovanför polcirkeln, här kallad Polarfjorden. Bygden är placerad på en ö, cirka 15 kilometer från regionens handelscentrum som har drygt 5000 invånare. Den ligger 45 minuters bilresa från närmsta flygplats och sjukhus samt 7 timmars resväg med färja och bil från regionhuvudstaden. Före andra världskriget var Polarfjorden en isolerad plats med båt som enda möjlighet till kontakt med omvärlden. Försörjningen var fiske och gårdsbruk. De flesta männen var borta 3–6 månader på vinterfiske. Under den tiden ansvarade kvinnorna för hem, gård och barn. Över hela regionen kallades männen i dessa hushåll för "fiskarbonde". Många förlorade livet på havet, precis som fattigdom, oväder och sjukdomar skördade liv på land (Bottolfsen 1995, Lauritzen 2005). Under intervjuer med den äldre generationen, konfirmerat i bygdeböcker (Lauritzen 2005, Borgos 2007) och narrativ lokal litteratur (Rørtveit 2008), framkom tydliga överlevnadsstrategier som relationella mönster, utformade att passa den arktiska miljön.

Initialt mötte vi en slags tillfredsställelse hos invånarna och vår nyfikenhet väcktes kring deras livsval och bygdens förmåga att undgå såväl utflyttning som nedläggning av offentliga funktioner. Vår nyfikenhet skapade en grund för denna studie av vardagslivet i Polarfjorden, och som sedermera ledde oss fram till teorin om Nuets förnöjsamhet.

I en historisk jämförande studie mellan vestlänningen och nordlänningen av den norske historikern Jan Vea beskrivs den nordländska mentaliteten som en

avsaknad av innovativt beteende, omställningsvilja och tillväxtanda. I beskrivningen av nordlänningen hänvisar Vea till en subsidenskultur som innebär att den nordländske fiskaren historiskt arbetade hårt i hårda tider, men vid gott fiske avstannade produktionen. När årets fångstbehov var uppnått valde nordlänningen att njuta livet i stället för att, som vestlänningen, fortsätta fiska och öka produktionen (Vea 2009). Om man ser på detta ur ett tidsperspektiv uppvisar nordlänningen en uppdelning i "ledig tid" och "arbetstid" som inte i första hand är knutet till en social konstruktion som exempelvis fastställda arbetstimmar och bokade semesterdagar. Än idag arbetar flera fiskare i Polarfjorden utifrån fiskens vandring, vilket gör vinterfiske till en hektisk tid medan många tar fritt större delen av sommaren. Detta stämmer med antropologen Alfred Gells syn på att flera mänskliga periodiseringar har sin grund i olika naturfenomen som inte är helt socialt bestämda. Två exempel är året och dygnet som, till skillnad från den socialt konstruerade veckan och timmen, har sin grund i jordens relation till solen. (Heidegren 2014:25) Vea (2009) hänvisar till subsidenskulturen som något negativt för samhällsutvecklingen, men kan den nordnorska livsstilen ha andra fördelar? Finns det andra behov än ekonomisk tillväxt som Polarfjordingens följsamhet i tid tillfredsställer?

Syftet med studien är att utforska Polarfjordens vardagsliv utifrån dess invånares perspektiv. Men vilken betydelse har vår studie utanför den studerade regionen, i vidare sociologisk mening? Med hjälp av Charles Tillys reflektioner kring människors behov av skäl och förklaring till händelser och skeenden (2006), samt hur rutinmässigt handlande kan förstås relationellt (2000) anlägger vi i denna artikel ett sociologiskt perspektiv på studien om Nuets förnöjsamhet.

Att grunda teori i data

Studien bygger på anteckningar från knappt 4,5 års observationer av vardagslivet i Polarfjorden samt 14 djupintervjuer, i grupp såväl som individuellt. Dessutom har ett femtiotal delvis strukturerade samtal genomförts med både kvinnor och män från Polarfjorden och angränsande bygder. Sex fokusgruppsintervjuer genomfördes med män respektive kvinnor över 70 år gamla, män i yrkesverksam ålder, kvinnor i yrkesverksam ålder, föreningsaktiva och kvinnor mellan 80–100 år gamla från angränsande stad. Dessutom genomfördes åtta individuella ostrukturerade respektive semistrukturerade intervjuer med kvinnor och män mellan 30 och 98 år gamla från olika grupperingar i bygden. Vi skiljer på djupintervjuer, riktade samtal och observationer på så sätt att djupintervjuerna var uppbyggda runt frågan "berätta om ditt/era liv" och varade 2–6 timmar. Mot slutet av datainsamlingen avslutades intervjuerna med frågor för att bekräfta eller avfärda gjorda analyser. De riktade samtalen var en form av spontan kortintervju (10–30 minuter) om ett visst tema där informanten blivit tillfrågad om medverkan i direkt anslutning till intervjun. Observationerna består av 43 månaders deltagande observation och boende i bygden, varav två månader i form av boende i samman-

lagt 4 familjer. Under 10 månader, utspridda över två tillfällen, skedde observationerna från Sverige. Den delen gav information kring bygdens hantering av inträde/utträde ur gemenskapen.

Denna studie använder sig av klassisk grundad teori vilket innebär att den är baserad på en teorigenererande vetenskaplig metodik (Glaser 2010). Det finns olika varianter av grundad teori där klassisk grundad teori skiljer sig i kodningsprocessen samt i metodologiska antaganden om vad som bringar förklaring (Glaser & Strauss 1967, Glaser 1978, Walker & Myrick 2006). För att få ett "bottom-up" perspektiv använde vi oss i hög grad av narrativa ostrukturerade intervjuer. Ur bygdens och bygdeinvånarnas berättelser letade vi sedan mönster, processer och mekanismer. Noggranna anteckningar från såväl intervjuer som observationer har förts. Dessa har sorterats, kodats och kategoriserats. Efter varje intervju eller periodiserad observation har nya anteckningar kodats, analyserats och sedan jämförts med tidigare resultat. Begreppen har successivt arbetats fram för att i grunden förklara Polarfjordens och Polarfjordingens livshållning. Efter knappt fyra års studier kom vi fram till vår kärnkategori: *Nuets förnöjsamhet*. Vi valde sedan att koda och analysera allt material samt utföra ny datainsamling utifrån ett förnöjsamhetsperspektiv. Såväl intervjuer som observationer har genomförts till dess att mättnad har nåtts, det vill säga till dess att ingen ny information har framkommit i analys av nyinsamlad data (Glaser 2010).

Trots att denna studies huvudförfattare vuxit upp i Nordens största metropol har jämförelseperspektivet stad/land inte passat in i den teoretiska kodningen av data från den glesbefolkade Polarfjorden. Detta hindrar förstås inte den kreative läsaren från att spekulera över en sådan tolkningsansats. Orsaken till att stad/land inte visat sig tillräckligt teoretiskt relevant handlar om att grundad teori kräver att forskaren avstår från förutfattade spekulationer och istället låter tolkningen av data framträda under den faktiska kodningen och i skrivandet av teoretiska minnesanteckningar.

Teoretiskt urval
I enlighet med klassisk grundad teori togs nya beslut om insamling av data efter var intervju. Efter tre och ett halvt års observationer inleddes intervjudelen med två fokusgruppintervjuer. En med tre män 70–97 år gamla och en med tre kvinnor 70–89 år gamla. Syftet var att få en historisk beskrivning av bygdens vardagsliv. Båda grupperna blev ombedda att diskutera sina liv från det att de var små fram till nutid utifrån den enda frågan "Berätta om era liv". Det var ett sätt att låta dem bestämma vad som var viktigt att prata om, ett sätt att samla in data både utifrån vad de sa, hur de sa det, och vad de valde att tala om, utan att leda dem med frågor. I dessa intervjuer upptäcktes språkliga mönster, likheter i förhållningssätt och det gav oss en målande historisk bild. Såväl språk som förhållningssätt kändes igen från tidigare observationer och för att tydliggöra dessa mönster samt upptäcka variationer mellan generationerna intervjuades män respektive kvinnor i arbetsför ålder. Individuellt såväl som i fokusgrupper. Återigen med frågan "berätta om era liv". När mönster och variationer dök upp i analysen av data valde vi att samla in nya

uppgifter i enlighet med nya frågor som uppstod. Exempelvis uppstod i observationer mönster kring förhållningssätt gentemot sjuka individer och vi valde då att i en djupintervju med en sjuk invånare fråga hur hen ansåg sig bemött. Vi valde också att föra riktade samtal både med långvarigt sjuka och med människor som uppger sig aldrig ha varit svårt sjuka. Ett annat exempel är när vi såg en skillnad i hur olika former av hot mot bygden hanterades i observationer jämfört med hur invånarna i generella ordalag sade sig hantera liknande situationer. Vi valde då att lägga till vinjetter i intervjusituationer vilket tydliggjorde mellanmedvetandets funktion. På liknande sätt hanterade vi de olika mönster och variationer som uppstod utifrån rådande situation.

Vi valde att kontinuerligt intervjua byns äldsta individ, 97–98 år gammal, och vi har därifrån samlat anteckningar från mer än 10 timmars intervju. Hans berättelser var i slutet av studien testade mot lokal historisk och narrativ litteratur (Bottolfsen 1995, Lauritzen 2005, Borges 2007, Rørtveit 2008). Eftersom fiskekulturen visade sig vara en historisk bas för det moderna samhällets förnöjsamhet, valde vi att avsluta med en semistrukturerad intervju med en fiskare som kommer från en familj med generationer av fiskare. Detta gjordes för att se om hans livshistoria och minnen från sina föräldrar och far/morföräldrar skiljer sig åt eller ger nya data till analysen, vilket de inte gjorde. I stället bekräftades analysen.

Grundad teori har som mål att förklara vad som händer inom det område man har valt att studera, i detta fall Polarfjordens vardagsliv. Enligt klassisk grundad teori ska man utgå från de studerade forskningsobjektens huvudangelägenheter och undersöka vad som görs för att lösa dessa (Glaser 2010). Vi har låtit materialet styra det teoretiska urvalet och i intervjuer har anteckningar inom alla områden förts. Genom att informanterna lyfte fram det positiva i bygden som en balans till de yttre hoten som kommer med klimat, natur och isolering, utkristalliserades teorin om Nuets förnöjsamhet, förklarad utifrån de tre begreppen "Göra trygghet", "Ödesberedskap" och "Mellanmedvetande".
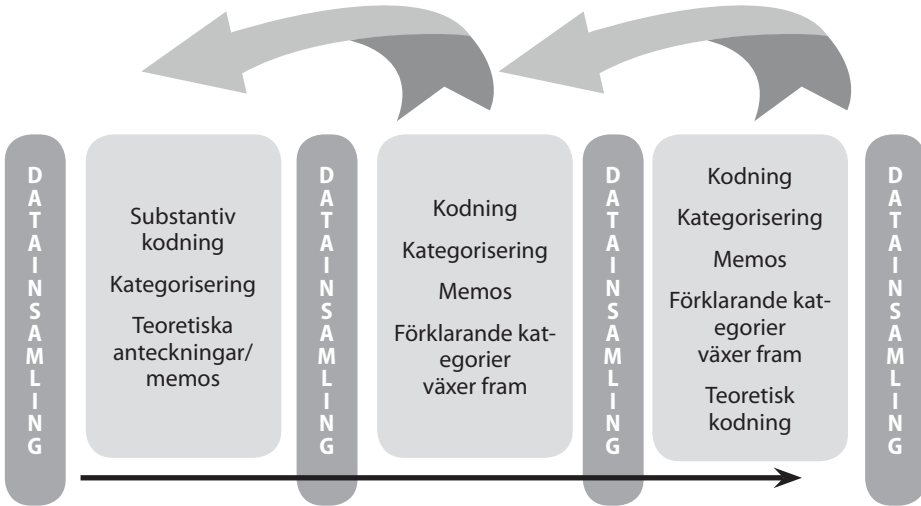
Det här är en pågående process av insamlande av ny data, jämförande arbete, analys och kategorisering.
Steget till selektiv kodning tas först när mättnad är nådd.
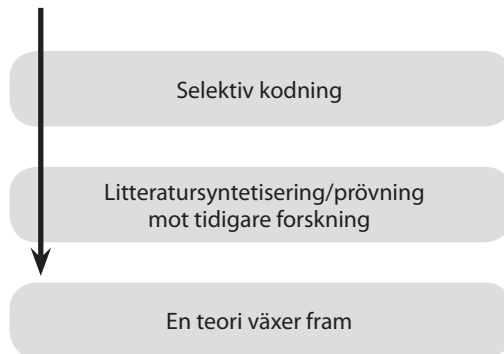
Anmärkning: För att få en överblick visar bilden endast några få tillfällen av datainsamling och analys. Det är dock en chimär. Processen är ständigt pågående med löpande jämförelser och kodning/analys av nytt insamlat material.

Figur 1: Forskningsprocessen

Utan skäl att söka skäl

Polarfjorden har en stark social struktur med offentliga inrättningar såsom skola, förskola och butik. De utgör en bas och genererar gemenskap och trygghet. Där finns ett tiotal föreningar som tillsammans med en inkluderande anda fördjupar denna trygghet och gör att ingen som inte vill behöver vara ensam. Genom att dela på många av samhällets ansvarsområden skapas stabilitet över tid. I såväl gjorda observationer som i intervjuer av dagens arbetsföra generation framstår tydliga strategier och verktyg med ursprung i den arktiska förkrigsmiljön för såväl individers som för bygdens överlevnad, modifierade för att passa dagens samhälle.

I sin bok *Why?* argumenterar Charles Tilly (2006), i kontrast till denna studies resultat, för att skäl och förklaringar är en viktig del i relationer, där en effektiv förklaring matchar den roll vi spelar vid den aktuella tidpunkten för förklaringen. Han delar in de skäl vi anger för olika ageranden i två dimensioner:

1. I vilken utsträckning de är beroende av logik respektive orsak-verkan
2. I vilken utsträckning de är beroende av allmän språklig förmåga eller specialiserade diskurser.

Om man knyter samman dessa två grupperingar av skäl så ger det fyra olika typer av orsaksförklaringar:

1. Konventioner, dvs ett allmänt tillgängligt språk och en logisk lämplighet.
2. Berättelser, dvs allmänt tillgängliga och förenklade beskrivningar av orsak-verkan.
3. Regler, dvs logisk lämplighet och specialiserad diskurs.
4. Tekniska förklaringar, dvs resonemang kring orsak-verkan och specialiserad diskurs.

Inom ramen för dessa förklaringstyper kan de verka reflekterande, upprättande, reparerande och/eller kompromisskapande för en relation (Tilly 2006).

I studien av Polarfjorden har en bild av en naturlig oreflekterad självklarhet i människors förhållningssätt vuxit fram ur det insamlade materialet. Har då Tilly trots allt en poäng även för livet i Polarfjorden och teorin om Nuets förnöjsamhet i sitt fokus på frågan *Varför*?

Det är bara sån det är

Aaron Antonovsky har tagit fram den salutogena teorin som bygger på en helhetssyn av vad som gör människor friska. Känslan av sammanhang är central och består av tre delar: begriplighet, hanterbarhet och meningsfullhet. Hans studier bygger på överlevande kvinnor från koncentrationslägren och vad som gjorde att somliga klarade att behålla god hälsa trots sina umbäranden (Antonovsky 1996). Vår studie inleddes i likhet med Antonovskys studier med en observation av välmående, men resultaten

har visat sig olika. Polarfjordingarna går vidare från olyckor, sjukdomar och livskriser utan reflektion över syfte och mening. Ingen av de äldre har gett uttryck för någon begriplighet eller mening med sina umbäranden. Snarare tvärtom. De har uppvisat en genuin förmåga att placera opåverkbara svårigheter i ett mellanmedvetande, i ett slags kognitivt "standby-läge", och att språkligen omformulera problem till lösningar.

> Exempel memo: Fokus ligger på lösning och problemet verkar vara en sekundär variabel som jag hittar mellan raderna. T.ex. mindes de äldre männen skrattande hur de värmde fötterna i kobajs och kokiss när de jagade korna 2 ggr/dag som barn. Det visar på ett problem med kyla men ingen pratade om kylan som ett problem. När jag frågade om det var kallt när de saknade skor framför allt under krigsåren så funderade de lite och svarade sen alla 3 "nej". Förutom kossorna hade de ju speciella sockor till hjälp. Så kallt var det inte.

När inget mer kan eller behöver göras har de funnit symboliska vägar vidare i uttryck som "*färdig med det*" och "*det är nu sån det är*". I en intervju med en nordnorsk räddningsofficer bekräftades det att människor på den Nordnorska landsbygden generellt har en god förmåga att fullt ut anamma språkligt stödjande uttryck, medan människor i de mellersta och södra delarna av Norge använder samma uttryck, men utan att få någon uppenbar hjälp av dem. De stödjande uttrycken har även observerats tillsammans med en självklar hjälpsamhet hos dagens arbetsföra generation.

> Exempel memo: En vinterdag kommer min närmaste granne förbi. Hon är höggravid och undrar om jag kan hjälpa henne om hon börjar föda under den annalkande snöstormen. "Blir vi insnöade får du bli jordmor". Hon säger det utan någon märkbar nervositet. Jag blir rädd varpå hon förklarar för mig "det är bara så livet är". Jag har också upplevt såväl snöstormar som översvämningar och sett hur bygdens invånare samlas för att hjälpas åt utan vare sig katastrofuttryck eller synlig oro. De beter sig som om det är en del av vardagen. När inget mer finns att göra lämnar de platsen utan någon reflektion över vad som hände, "färdig med det".

Med Tillys (2006) förklaringstyper kan relationen till livet och döden beskrivas som en del av en teknisk förklaring om livets oförutsägbarhet som verkar kompromisskapande. Språket fungerar både som en konvention och en inramning för hur historier berättas. Dess specifika uttryck innehåller tekniska lösningar samtidigt som uttrycken skapar, stärker och upprätthåller regler. Språket fungerar således upprättande, reparerande och/eller kompromisskapande i förhållande till Polarfjordingens behov. Om vi ser på Polarfjordingens sätt att omvandla svårigheter till lösningar så är det en form av konvention. Uttrycket "färdig med det" är en form av regel som bottnar i att inte älta saker. Accepterandet av "det är nu sån det är" fungerar som en teknisk förklaring. Men denna uppdelning i enlighet med Tillys olika förklaringstyper är i sig en tekniskt ganska ytligt beskrivande konstruktion som inte leder oss vidare i den djupa-

re förståelsen av Polarfjordingarna. Den ger mer uttryck för förståelse av förklaringstyperna som sådana. Användandet av Tillys förklaringstyper innebär att vi tillskriver Polarfjordingarna en förhandlingsvilja som vi inte fått ta del av (Tilly 2006:15). Vi prövar alltså en icke existerande företeelse, det vill säga nämnda förhandlingsvilja, men genom detta, och med hjälp av Tillys reflektioner, har vi tydligare åskådliggjort hur en föreskriven förhandlarmentalitet inte förekommer i denna sociala miljö.

Inkluderingsprocess

I våra intervjuer och observationer i Polarfjorden framkommer ett sammansvetsande socialt liv, synliggjort genom såväl inkludering som social kontroll och gemenskap. Lynn Shore m.fl. har tittat närmare på begreppet inkludering och funnit att det är många olika discipliner som använder det och därför finns många definitioner av begreppet. Författarna har försökt att finna en gemensam nämnare utifrån ett fokus på arbetslivet, men de diskuterar samtidigt grupper i mer generella ordalag. De har kommit fram till följande:

> We define inclusion as the degree to which an employee perceives that he or she is an esteemed member of the work group through experiencing treatment that satisfies his or her needs for belongingness and uniqueness (Shore m.fl. 2011:1265).

Definitionen är formulerad med individen som en passiv mottagare av erfarenheter och upplevelser. Det innebär att ansvaret att inkludera individen faller på gruppen, snarare än på individen som ansluter till gruppen. Inkludering sker således när individer får en känsla av tillhörighet till gruppen och, på samma gång, upplever sig vara en tydlig och unik individ (Jansen m.fl. 2014).

Den inkluderande kulturen i Polarfjorden framstår tydligt i såväl observationer som intervjuer. På gruppnivå skojas det om olikheter, samtidigt som man skapar utrymme för individualitet. Uttrycket "*hen NN, det er nu bara sån hen är*" används som förklaring när någon bryter mot gällande norm. I stället för att försöka förändra personen eller exkludera hen från gemenskapen, skapar man undantag för udda beteenden. I lägen då sjukdom och olyckor riskerar skada inkluderingen av en person används i hög grad humor till bekräftelse på att personen i sin nuvarande situation fortfarande är en del av gemenskapen. Humorns bekräftelse gör att ingen ytterligare förklaring krävs.

> Exempel memo: När NN tände på ett bål exploderade det med brännskador till följd. Så fort han var färdigbehandlad ställde han till med fest och temat för kvällen blev "bål-skämt" med grillkorv. På samma sätt spelade de och sjöng högt med i den norska låten "jag är inte sjuk, jag är bara svensk" när jag var svårt sjuk. På ett galet sätt stannade jag i nuet där jag kände såväl värme som bekräftelse utan att behöva vara ledsen över min situation. När vi skrattandes sjöng med i refrängen tillsammans så kändes det som om de bar mig.

Enligt Tillys modell om olika förklaringstyper berättas en historia för oss i syfte att förklara det udda beteendet. Som ett sätt för gruppen att ta ansvar för att den aktuelle individen får behålla både tillhörighet och autenticitet. Vi försökte att i vissa lägen skapa en teknisk förklaring på udda beteende genom uttryck som "det kanske beror på att NN har varit med om något jobbigt"? Responsen som gavs var då "nä, det är bara sån NN är". Etnometodologin har ett begrepp "accountability" som innebär att en person innehar en redovisningsplikt på sitt beteende (Garfinkel 1967). Om man sätter Polarfjordingarnas inkluderingsprocess i relation till etnometodologins accountability så ser man stora likheter men där Polarfjordingarna har funnit ett sätt runt redovisningsplikten. Genom att säga "Det är bara sån NN är" redovisas ett skäl där skälet är individen i sig. Det skapar utrymme för unika beteenden utan att ytterligare klarlägganden krävs. Resultatet av att inte ge någon förklaring till beteendet blir att NN inkluderas som hen är, där det unika inte ses som något unikt utan som naturligt för gruppen. När Tilly (2006) hävdar det mänskliga behovet av att ge förklaringar till beteenden, att dessa förklaringar är en central del av sociala relationer, så visar Polarfjordingarna att det går bra att leva i förnöjsamhet utan detta krav. Genom att inte fråga sig "varför", slipper hen att fundera på det.

Relationellt regelsystem

Charles Tilly argumenterar för att vi som samhällsvetare måste gå vidare från att beskriva den sociala konstruktionen av bland annat relationer och enheter till att förklara hur denna konstruktion faktiskt fungerar och har verkningar samt att vi genom att tydliggöra strukturer i våra vardagliga sociala interaktioner kan förstå våra skäl för att ange skäl (Tilly 2006).

Historiskt fanns i Polarfjorden en stor osäkerhet i mellanmänskliga relationer. När männen månadsvis var på havet behövdes sätt att hantera kvinnornas oro för om männen skulle klara livet, såväl som männens oro kring hur det gick hemma. Bottolfsen beskriver olika former av strategier som fiskarna hade på 1700-talet och inledningen av 1800-talet för att hålla tankarna fokuserade på det som skedde i båten. Det fanns många ödestrosuppfattningar om hur fisket exempelvis skulle försämras om en kvinna kom till båten eller om någon i manskapet nämnde namnet på ett husdjur hemma. Detta fyllde en tydlig pedagogisk funktion för att hålla fokus på här och nu (Bottolfsen 1995). Den äldre generationen beskriver i intervjuer hur de inte tänkte på den del av livet som de ej befann sig i. Kvinnorna placerade männen i ett slags mellanmedvetande under de månader de var på havet, detsamma gjorde männen med livet på land när de var på havet. Detta fenomen är synligt även i dagens generation.

> Exempel memo: Jag bodde ett halvår i Sthlm under våren 2013. All kontakt byggde då på mitt initiativ. När jag sen kom tillbaka till Polarfjorden var allt som vanligt. Var gång jag har återkommit har jag varit orolig över hur jag ska bli mottagen, men väl där har jag återigen blivit en del av bygden. När jag är där så är jag där, när jag är borta så är jag borta. Denna upplevelse har även framkommit i intervjuer och observationer. Som en kvinna sa "*det är som om de inte har märkt*

att jag har varit borta". Och en man sa "*vad är det för mening med att ha kontakt med folk på land när jag är på sjön, det skulle bara leda till en massa oro*".

Genom att varken exkludera eller inkludera dem som är borta från bygden, genom att placera dem i ett slags mellanmedvetande, så ökar möjligheterna att leva i nuet. Temporala tankar som saknad och längtan minskar, men utan att personer exkluderas.

Så långt överensstämmer Tillys resonemang med vår analys. Däremot ser vi inte hur orsakssamband, "skäl till att ange skäl", ger ytterligare förklaring på företeelserna i Polarfjorden, utan mer på hur de hjälpt oss att se just detta. Bland sociologiska förklaringsmodeller att pröva Nuets förnöjsamhet mot har vi Erving Goffmans begrepp bakre och främre regioner, där det i de bakre regionerna finns utrymme för ageranden som är dolda i de främre synliga regionerna. Goffman ger exempel på hur grannar i stora bostadsområden vet mer än vad som direkt uttrycks om varandra (Goffman 2009). Mellanmedvetandet kan inte jämställas med någon av Goffmans regioner men tudelningen hjälper oss att synliggöra och positionera denna mekanism för ökad trygghet och förnöjsamhet. I Polarfjorden är kunskapen om varandra stor och det finns saker som de flesta vet om, men som ingen pratar om. Det gäller till exempel företeelser som misshandel, alkoholism och vissa former av övergrepp. Denna information skulle i en liten bygd kunna bringa problem och osämja, men tack vare en förmåga att placera informationen i ett mellanmedvetande lyfts den inte in i det dagliga livet och de vardagliga interaktionerna. Den kan bortses från utan att helt försvinna. När behov finns av att samtala om skeenden som placerats i vad man kan kalla en slags bakre region, använder sig befolkningen i bygden av något som kallas xx-samtal. xx skiftar beroende på plats, men innebär ett förtroligt samtal, ofta mellan två personer, där det som sägs stannar på/i xx. Om man lämnar diskussionen på/i xx kan man låtsas som om det man fått veta inte finns och det är denna rörelse mellan medvetandenivåer som vi har valt att kalla mellanmedvetande. I nedan memo låter vi två olika motorcykelträffar illustrera Goffmans bakre region.

> Exempel memo: NN gick öppet hand i hand tillsammans med YY trots att NNs frus vänner var på samma tillställning. På fråga om han var orolig över att frun skulle få vetskap om affären skakade han på huvudet och sa "det som sker på träff stannar på träff". I ett annat tillfälle var jag med om en annan otrohetsaffär där en nära väninna var utsatt. Jag försökte prata med en gemensam vän om händelsen men hon avfärdade mig att "det hände ju på träff". Inte en enda gång har jag varit med om att något av mina xx-samtal eller "det som sker på xx stannar på xx" har spridits, trots att skvaller i övrigt är vanligt förekommande. Det är som om informationen läggs undan på en plats i hjärnan dit tillgång endast ges vid konkret behov.

Man gör saker som skulle skada varandra om inte denna bakre region fanns, en bakre region som när man befinner sig i den främre regionen placeras i ett slags mellanmedvetande. "*Det man inte vet, lider man inte av, om man tror sig veta och är trygg i att*

man hade fått veta om det var något att veta”. I vårt sökande efter förståelse kring detta mellanmedvetande eftersträvade vi så kallad ”accountability” i linje med etnometodologin (Garfinkel 1967). Vi lade till vinjetter med exempel från verkligheten i gruppintervjusituationer i syfte att höra hur och varför vissa beteenden och tankar existerar kring frågor som uppvisat diskrepans mellan narrativ intervju och observation, exempelvis otrohet och xx-samtal. Vårt syfte var att höra gruppens diskussion och ur den finna svar på även outtalade redovisningsskyldigheter. Vi lyckades inte få svar utan i stället försökte de intervjuade att omformulera frågan, ändra situationen, svara på icke ställda frågor. Efter 60 minuter gav vi av etiska skäl upp, för att inte skada den ordning som råder, och gick vidare i intervjun. Ett synliggörande av den bakre regionen eller en öppen medvetenhet om att saker göms undan i ett mellanmedvetande skulle riskera att minska den rådande trygghetskänslan. Polarfjordingens bakre region speglar en inre kognitiv plats att temporärt placera människor, företeelser och upplevelser som i öppenhet skulle minska förnöjsamhet och trygghet i nuet.

Funktionen med xx-samtal tar bort behovet av att ange skäl. Det behövs ingen orsak till att hålla tyst om vissa saker och att skvallra om andra. Det sker med en oreflekterad självklarhet. Tilly argumenterar i sin bok *Why?* för att vi ska fundera på hur och varför vi argumenterar och delar skäl med varandra (Tilly 2006: förord & 31). I studiet av Polarfjorden är det ett rimligt argument, men för polarfjordingen tycks det onödigt. Deras pendling mellan bakre och främre regioner gör livet enklare där den etnometodologiska redovisningsplikten göms undan i en bakre region och vid behov hanteras med ”hen NN, det är bara sån hen är”. Det innehåller ett visst mått av självbedrägeri, endast möjlig i sin oreflekterade självklarhet, vilken mer eller mindre omöjliggör ett introspektivt frågande kring ”varför”.

Hjälpsamhetskultur och altruism

Det finns en utvecklad hjälpsamhetskultur i Polarfjorden som historiskt var en nödvändighet för bygdens överlevnad.

> När man blev sjuk och behövde komma till sjukhus krävdes det att någon med båt tog den sjuke dit. Och var det dåligt väder fick man vänta, min bror dog i gulsot på vägen till sjukhuset. Det är nu sån det var ... Vid stormar och oväder så hjälptes vi såklart åt, eller hur menar du? Vad skulle vi annars göra?
>
> *En äldre man om hjälpsamheten tiden före andra världskriget*

Hjälpsamhetskulturen lever kvar, men idag handlar det sällan om liv och död. I sin självklarhet fungerar den i stället förnöjsamhetshöjande, både för den som hjälper och för den som blir hjälpt. Stephen Post pekar på att det finns en stark koppling mellan altruism och välbefinnande, glädje (happiness), hälsa och livslängd. Människor som engagerar sig i att hjälpa andra beskriver också sin självkänsla som bättre (Post 2005). Posts forskningsöversikt stämmer väl överens med intervjuer och observationer gjorda i Polarfjorden. I sin självklarhet blir hjälpsamheten altruistisk och leder till förnöjsamhet, både för den som hjälper och för den som blir hjälpt. Men vad händer om polar-

fjordingarna börjar fundera på varför, hur och när de hjälper varandra? Många studier kring lycka tar upp den hedoniska paradoxen, där den lyckobringande känslan och välbehaget av att hjälpa försvinner i det läget då det altruistiska inslaget undermineras. Att hjälpa för att bli förnöjd, tar bort förnöjsamheten (Bauman 2008, Norman 1998, Egonsson 2011). I och med att Polarfjordingarna inte ställer sig frågan "varför", inte söker skäl, så har de också svårt att ge förklaringar. Här framstår exemplet Polarfjordens hjälpsamhetskultur, med dess svårfångade självklarhet, som en mycket viktig komponent i förnöjsamhetsbegreppet. Daniel Batsons studie visar hur skört altruistiskt beteende är. Så länge en person känner empati med en hjälpbehövande så hjälper denne gärna till. Med minskad empatisk känsla eller när det krävs mer av den som ska hjälpa, så avstår allt fler (Batson m.fl. 1983). Våra observationer från Polarfjorden synliggör stor hjälpsamhet även när den egna insatsen är betydande och det vore enkelt att ta sig ur. Observationer visar också hur folk hjälps åt i hjälpsamheten. Det är sällan en person som står i valet att hjälpa eller inte, utan ofta delas bördan av flera.

> Exempel Memo: Jag körde i diket i snöyra. Bil efter bil stannade och för var bil som stannade försökte vi lyfta upp min bil. Det tog ca 30 min innan vi var tillräckligt många för att lyckas. Inte en enda bil körde förbi, alla stannade. Troligen hade någon eller några ärenden som de skulle komma att bli försenade till men ingen sa något om det, ingen verkade stressad. Detta har jag upplevt vid flera tillfällen när såväl jag som andra har fastnat i snödrivor eller hämtat in kor som rymt. Vi gör vad som behövs och sen lämnar alla platsen utan någon synbar reflektion.

Posts (2005) koppling mellan altruism och välbefinnande, lycka, hälsa och livslängd ger styrka åt argumenten att Polarfjordens hjälpsamhetskultur är direkt förknippad med förnöjsamhet. Den hedoniska paradoxen hjälper oss att förstå att det inte självklart alltid är bra att ange skäl för sina överväganden.

Kairos flöde av ögonblick
Heidegren (2014) diskuterar cyklisk respektive linjär tidsuppfattning och hänvisar till Jünger (1980): "Tid har man när man inte tänker på den; annars har tiden oss" (Heidegren 2014:132). Polarfjordingen har en förmåga att släppa taget och glida med i en ständigt föränderlig tillvaro. Uppgjorda planer tillåts ändras av såväl väder som av hjälpsamhetskulturen. En sak leder till en annan och blir en lång kedja av improvisationer. De är mycket svåra att förutse eller kausalt spåra bakåt innehållsmässigt. Det vill säga de är inte, som t.ex. systemteori skulle framhålla, förutsebara i innehåll, men däremot som förväntat beteende.

> Exempel memo: Att bo i bygden kan liknas vid att köra bil, man parerar hela tiden saker som händer, folk som ringer om hjälp, väninnan man skulle dricka vin med måste iväg och fixa något, vädret som ändras. Det händer oupphörligen saker som jag i stadsmiljön knappt la märke till men här tillåts var sak ta sin tid.

> Folk verkar inte reflektera över alla avbrott men det jag har märkt är att det är nästintill omöjligt att i tanken befinna sig någon annanstans än här och nu, där det händer saker. Det vill säga, man rycks med i nuet. Enda gången jag blir riktigt frustrerad är när jag försöker planera in saker i klockslag.

Om vi ser på tid ur ett temporalt orienteringsperspektiv så kan det förenklat delas upp i dåtid, nutid och framtid. Inom dessa tre tidsregioner finns olika dimensioner av tid. Terell Lasane och Deborah O'Donnell nämner sex olika: förlängning, densitet, valens, tillgänglighet, innehåll, strukturell organisation (Lasane & O'Donnell 2005). Daniel Stern talar vidare utifrån ett psykoterapeutiskt perspektiv om tid då han beskriver olika sätt att möta och mäta nuet. Det kan ses som en momentan, knappt observerbar bricka i ett kronologiskt tidsperspektiv eller som en fenomenologisk momentan situation, fri från omgivning i både tid och rum (Stern 2005). Trygghet har visat sig vara beroende av begreppet tid. I västvärlden har vi människor ett stort behov av att grunda och relatera oss själva i ett tidsperspektiv. Studier på t.ex. fångar som vistats i mörka rum har visat på psykologiska problem och hur de ofta finner ett sätt att för sig själva bedöma tid. Behovet handlar om att finna ett konsekvent ramverk, regelmässighet och förutsägbarhet för den enskilde individen (Lasane & O'Donnell 2005).

Våra observationer har vid sidan av yttre tvingande tidskrav visat en naturlig, flexibel och följsam syn på tid. Att tillåta sig bli trött av mörkret, att med glädje möta solen, att med fest välkomna värmen och så vidare. I sin jämförande studie mellan den nordländska och den vestländska norska mentaliteten beskriver Vea den nordnorska relativa tidsuppfattningen som något negativt. Hur den bidrar till negativ ekonomisk utveckling och är enligt Vea därmed negativ för såväl kulturen som den enskilde nordlänningen (Vea 2009). Veas jämförelse av dessa två samhällsbyggen påminner om Jüngers beskrivning av så kallade motbilder. Där fest, dans och lek utgör motbilder till den hektiska och jäktade tidsstyrda vardag som är vanlig i västvärldens stadsliv (Heidegren 2014). Detta är "motbilder" som är vanligt förekommande uttryck för förnöjsamhet och gemenskap i Polarfjorden, där de i intervjuer beskriver sig själva som just "bra på att ha kul".

> Exempel memo: Under två veckors tid har kommunordföranden inte kunnat nås med anledning av en musiktävling där kommunen deltar. Andra åtaganden har lagts åt sidan. Hon deltar i diverse inspelningar, bl.a. hoppandes i havet (2–3 grader), utklädd, påmålad skäggväxt m.m. Staden stängde av en gata och alla elever fick ledigt och bussades dit för inspelning av en musikvideo. I vår badklubb gick vi barfota i badrockar i kyla för att spela in vårt bidrag. Här prioriteras att ha roligt. Som en väninna från Sverige som var på besök sa inför ett annat jippo "det är inte enskilda personer som blir galna, det är hela bygden som helhet". En invånare sa på fråga om den Polarfjordska identiteten "vi vet hur man har roligt och vi prioriterar att ha det".

Att nordnorsken prioriterar att ha roligt i nuet framför planering för framtiden framkom i både observationer, och intervjuer samt finns även beskrivet i litteratur (Vea 2009, Mykle 1965). Psykologen Robert Levine argumenterar för en relativ tidsuppfattning där tempot som en person upplever sig ha i livet symboliseras både av föreställning om begränsningar och val samt om förändringar i livscykeln. På gruppnivå är den sociala tidsuppfattningen central för ett samhälles kultur. Skillnader i tidsuppfattning är det som mest särskiljer en kultur från en annan. Synen på tid inom ett samfund är ofta dold, omedveten och svår för utomstående att uppfatta (Levine 1996).

Vi har valt att förhålla oss till nuet som en subjektiv upplevelse, likt ett flöde som den grekiska mytologins kairos. Ett nu som inte följer klocktid utan är olika långt i olika situationer för olika människor. Stern diskuterar begreppet som ett ögonblick där händelser samlas och mötet med dessa medvetandegörs. Varje nu är en "kritisk tidpunkt" och varje kritiskt ögonblick är ett ögonblick av kairos. Varje ögonblick skapar det sammanhang i vilket nästa ögonblick kommer att äga rum. Här följer ett gyllene tillfälle att agera på olika sätt för att påverka och förändra sitt öde; för en minut framåt eller kanske för resten av livet (Stern 2004). I ett samhälle där hjälpsamheten bygger på altruism kan varje situation, varje ögonblick av hjälpsamhet, bidra till ökad förnöjsamhet för den som hjälper och ökad trygghet för den som blir hjälpt.

En självklar förnöjsamhet

Tilly presenterar ett systematiskt sätt att kartlägga hur och varför människor erbjuder förklaringar, ursäkter, motiveringar. Han argumenterar för angivandet av skäl som ett sätt att skapa, upprätthålla, transformera eller avsluta mellanmänskliga relationer (Tilly 2006:15). Polarfjorden och polarfjordingarna visar på ett aktivt skapande av sin egen trygghet. De lever med naturen och anpassar sig efter såväl årscykel som dagliga behov. Max Haller och Markus Hadler har genomfört en studie i lycka (happiness) och nöjdhet (satisfaction), två begrepp som är nära besläktade med förnöjsamhet. Studien jämför 41 länder och visar hur både mikrosociala och makrosociala förhållanden påverkar upplevelsen av såväl lycka som nöjdhet. Lycka påverkas mestadels av mikrosociala förhållanden såsom att individer är socialt integrerade. Nöjdhet däremot är mer ett uttryck för ekonomisk jämlikhet, välfärd och demokrati. För båda begreppen är förmågan att hantera livssituationen betydelsefull. Varje persons subjektiva upplevelse av sin livssituation visar sig i studien vara viktigare än den faktiska livssituationen. Viktiga faktorer är upplevd hälsa och privatekonomi, nära sociala relationer och känsla av att kunna påverka sin ekonomiska situation (Haller & Hadler 2006).

Om vi sätter detta i relation till Polarfjorden så liknar bygdens vardagsliv Haller och Hadlers beskrivning av vad som skapar lycka och nöjdhet, språkligt såväl som kognitivt och beteendemässigt. De har en förmåga att *skapa* sin egen trygghet med aktivitet, att kognitivt *förbereda* sig för det värsta samt att språkligt *förflytta* negativa upplevelser till något positivt och hoppfullt. Ur ett makroperspektiv skapar välfärdsstaten Norge en yttre trygghet. Vår studie visar att lycka/lycklig i Polarfjorden är nå-

got man vare sig gör, är eller pratar om. Det framträder som en osynlig biprodukt, observerbar i mekanismer och processer som exempelvis den aktiva trygghetsskapande miljön, beredskapen för att allt kan ske, förmågan att ha kul samt förmågan att separera det som kan påverkas från det opåverkbara.

Med Tillys (2006) begreppsapparat fungerar de relationella mönstren i Polarfjorden både upprättande, reparerande och kompromisskapande. Det finns således möjliga svar till varför när vi söker efter skäl till ageranden, men har de betydelse för Polarfjordingarna och deras förnöjsamhet? I sökandet efter förståelse såg vi inga tecken på att Polarfjordingarna vare sig ställde sig frågan "varför" eller hade ett behov av det. De har den relation de har till såväl naturen som till varandra. Man agerar erfarenhetsmässigt. Polarfjorden är ett samhälle med tydliga stereotypa relationella skript, där var och en vet vad som förväntas av hen och där hjälpsamheten är självklar. Vi har låtit bygdebornas egna historier stå i centrum och medvetet valt att inte rama in deras berättelser i färdiga modeller som exempelvis Tillys (2006) fyra förklaringstyper. Genom att inte nöja oss med att finna svar på *Varför* eller på vad som är sant eller falskt, så har vår förutsättningslöshet till slut bidragit till att kärnan i förnöjsamhet synliggjorts. Tack vare detta har en teori om Nuets förnöjsamhet vuxit fram.

Det stereotypa ger handlingsutrymme

Grundläggande för Polarfjorden är den gemensamhet som definierar livet. I intervjuer framkommer snarlika skildringar av klimat, årstider, föreningsliv, offentliga inrättningar och identifikationsmönster, på grupp- såväl som individnivå. Delarna skapar, både konkret och symboliskt, en helhet som delas av bygdens invånare, formulerat i uttrycket: "Det är nu bara sån vi är". De gemensamma skildringarna ger en trygghet vid sidan av det oförutsägbara. Den tydligast gemensamhetsskapande faktorn är naturen, i intervjuer beskrivet som en källa till kraft och återhämtning.

> Naturen betyder Allt! Polarfjorden har allt. Fjäll, fjord, öppenhet. Naturen fyller en med energi. Bara utsikten räcker, även om det är fantastiskt att gå på turer. Ren luft, glädje, lyx... Detta är lycka!
>
> *Invånare i Polarfjorden*

> Tre timmars promenad i Polarfjorden betyder att jag är högt på en bergstopp. Tre timmars promenad i platt mark är bara tre timmars promenad.
>
> *En psykiskt sjuk boende i Polarfjorden*

Charles Tilly (2000), som vi nu låter påverka vår analys på annat sätt än att ge skäl, reflekterar över hur beständig ojämlikhet i sociala relationer kan förstås. Han lyfter *improvisation* respektive *ritual* som olika sätt att interagera, där *intensitet* och *djup* står i relation till graden av *skript* och *delad lokal kunskap*. Få och svaga skript tillsammans med stor delad lokal kunskap leder till djup improvisation i relationer (Tilly 2000). I Polarfjorden finns stor delad lokal kunskap, men graden av skript och regler skiftar

beroende på situation. Figur 2 visar hur bygden ramas in av tydliga trygghetsskapande skript som skapar utrymme för en djup improvisation.

Skript

Djup improvisation
• Inkluderingsprocesser
• Frivilligarbete
• Relativ tidsuppfattning
• Hjälpsamhet
• Relation till naturen

• Skola, butik, förskola
• Föreningsliv
• Hjälpsamhetskultur
• Språkliga uttryck
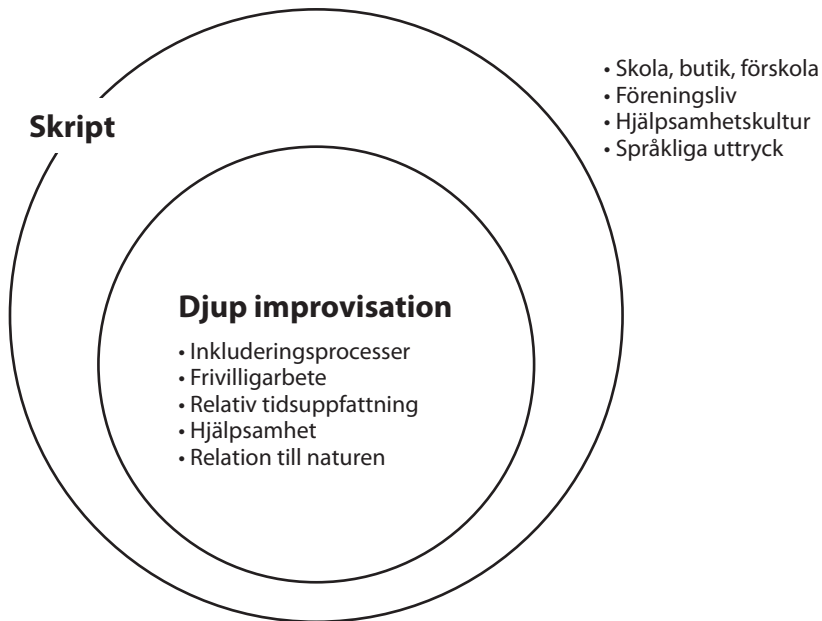
Figur 2: Stor delad lokal kunskap

Nuets förnöjsamhet

Historiskt var Polarfjorden ett utsatt samhälle med hög dödlighet. Idag är fattigdomen bekämpad och yrkesfisket kräver endast enstaka liv, men det ter sig som om människor fortfarande påverkas av det hårda klimatet och de långa avstånden. I såväl observationer som intervjuer fann vi psykosociala strategier för överlevnad, trygghet och förnöjsamhet. De förklaras genom de tre begreppen: "*Göra trygghet*", "*Ödesberedskap*" och "*Mellanmedvetande*" vilka bygger på mekanismer som i sin relation till varandra synliggörs i invånarnas *skapande* av trygghet genom aktivitet, i deras *beredskap* för och acceptans av livets skiftningar samt i deras förmåga att *separera* skeenden och tillstånd. De olika mekanismerna har förändrats från att historiskt ha varit en fråga om liv och död till att idag lägga en grund för förnöjsamhet i nuet.

Genom en transparent bystruktur med tydliga skript skapas en bas för trygghet. Skola, butik, sommarpub, klubbar och gemensamma årliga fester är några exempel på denna bas, men som är satt under hot. Flera grannöar har problem med utflyttning och under våra dryga fyra år av observationer har såväl förskola som skola hotats av nedläggning. I fallet med förskolan saknade kommunen pengar till nödvändig

upprustning varpå flera i bygden gick samman och renoverade byggnaden med frivilligkrafter. Skolan räddades genom protester. Ett annat hot kommer från det arktiska klimatet med stormar, ras och översvämningar. Även där finns en beredskap för och en förväntan om att olyckor sker. Hjälpsamhetskulturen skapar en trygghet så att ingen behöver stå ensam när olyckan kommer och var gång invånarna lyckas stå emot ett yttre hot stärks gemenskapen. Genom att invånarna i så hög grad hjälps åt förstärker de varandras benägenhet att hjälpa till även nästa gång. Det kan kopplas till flera studier om altruism som visar att altruism resulterar i positiv social integration (Post 2005) och att se någon utföra altruistiska handlingar ökar benägenheten att själv ställa upp (Schnall m.fl. 2010). I ett samhälle där hjälpsamheten bygger på altruism kan varje situation bidra till ökad förnöjsamhet för den som hjälper och ökad trygghet för såväl den som blir hjälpt som den som ser att hjälp ges. På så sätt interagerar Polarfjordingarnas *beredskap* med deras *hjälpsamhet* och förmåga att *separera* bort det som inte är aktuellt i nuet. En process där hjälpsamheten är självklar och bidrar till ett skapande av trygghet som vid behov därefter placeras i ett mellanmedvetande. Där mellanmedvetandet innebär att det finns en viss beredskap för att hjälpsamheten kommer att behövas igen, utan att fokus läggs på det som kan komma att ske i framtiden. Detta visade sig bl.a. i invånarnas oförmåga att se sin egen hjälpsamhet. I såväl intervjuer som observationer talades det om andras hjälpsamhet "han NN, det är den snällaste jag vet, han ställer alltid upp". På direkt fråga i abstrakt form uttryckte alla en tveksamhet gällande sin egen hjälpsamhet, men i vinjetter och observationer framkommer hjälpsamheten som generell och självklar. Växelverkan mellan beredskapen, hjälpsamheten och mellanmedvetandet skapar såväl trygghet som förnöjsamhet och genom den positiva bekräftelsen förstärks det självklara med att hjälpa vid varje ny händelse. Acceptans för att livet bringar svårigheter kan ses som ett skript som bottnar i hantering av otrygghet.

Genom grupprocesser skapas en bas för gemenskap. Tack vare att många i Polarfjorden är uppvuxna där med flera generationer bakom sig, kan en och samma person agera olika utifrån social kontext. Inkluderingsprocesser är exempel på hur improvisationer gror ur den delade lokala kunskapen. Eftersom de känner varandra så väl kan invånarna vid behov bryta mot eller modifiera bygdens sociala regler, dess skript. Exemplet från tidigare där bygden inkluderar beteenden som bryter mot gängse uppfattning om hur man beter sig visar hur bygden skapar stödskript. Genom att alla vet att "det er nu sån hen NN är" blir NNs beteende en accepterad del av en djupare improvisation. Man separerar sak från person. Vi har även sett hur man separerar det som går att påverka från det som inte går att göra något åt såsom mötet med sjukt och friskt i en och samma person. Det sjuka finns när hjälp kan ges, men annars läggs fokus på aktivitet och på det friska. Genom att *separera* det sjuka från det friska uttrycks *skapande* av trygghet genom hjälpsamhet. Samtidigt *skapas* förnöjsamhet genom aktivitet, vilket t.ex. kan betyda en fjälltur eller att delta på en fest. Polarfjordingarnas förmåga till att separera olika delar i samma person kan ses som en överenskommelse mellan invånarna som har sitt ursprung i det historiskt nödvändiga fokuserandet på nuet och på behovet av att betona det

friska hos varje individ (Bottolfsen 1995, Lauritzen 2005, Rørtveit 2008). Med Tillys (2000) begrepp kan gemenskapen beskrivas som en uppsättning skript som upprättar och reparerar relationer. Den delade lokala kunskapen finns i grunden och skripten pendlar.

Sandström m.fl. beskriver hur symboler av olika slag inte bara bidrar till en kollektiv anda och gemenskap utan även hjälper till att skapa mening och organiserar vardagen. Människans relation till sin omgivning är komplex. Vi överför det vi ser, hör och känner till synliga och osynliga symboler. Detta är något vi lär från barnsben som en del i vårt språk, kultur och sociala sammanhang (Sandström m.fl. 2006). Symbolers betydelse skiftar mellan miljöer och kulturer. När innebörderna av symbolerna är införlivade i vår sociala miljö hjälper de oss att identifiera oss med den (Trost & Levin 2010).

Den relativa tiden som vi diskuterar ovan symboliserar en identitet och ett livsmönster. Två andra tydliga symboler som rör identifiering är beröring och språkbruk. Beröring är en symbolisk interaktion som handlar om i vilken utsträckning man tar på varandra. En interaktion som är omgärdat av tabun (Miller 2007) och antropologer menar att tabubegrepp hjälper till att definiera gruppnormer och roller (Schoemaker & Tetlock 2012). I Polarfjorden är maskulinitet viktig, men det anses inte omanligt att en man klappar eller kramar om en annan man. Som en fiskare uttryckte det "det är inte farligt att röra varandra". Regler för beröring har i västvärlden blivit tydligare för att inte riskera sexuella associationer, men tabubeläggning av ömhet leder människan bort från altruism och socialisering (Miller 2007) – det vill säga bort från två viktiga beståndsdelar i skapandet av förnöjsamhet. Andra ritualer för att skapa trygghet och förnöjsamhet återfinns i språket. Varje samhälle har sin språkliga ideologi som innehåller mer än själva språket och synliggörs genom interaktioner och delade erfarenheter. Språket skapar känslor och erfarenheter lika mycket som sinnena skapar språket (Wilce 2014). För att må bra i samhällen med höga insatser kan språket fungera som skydd mot ångest genom att fokusera på det som är bra. Ochs (2012) och Wilces (2014) teorier om hur känslor interagerar med språket, hur de bildas med hjälp av språket samt hur de formar språket, skildras på olika sätt i Polarfjorden.

> *Vi visste aldrig vad som skulle ske, vi var förberedda på allt.*
> Äldre invånare om förkrigstidens svårigheter

> *Det är nu sån det är.*
> Ett vanligt förekommande uttryck efter en negativ händelse

> *Färdig med det.*
> Ett annat vanligt förekommande uttryck som betyder att det inte finns mer att
> vare sig säga, göra eller tänka om en viss händelse, det är ett uttryck som används
> som en avslutning på en situation, ett sätt att ta sig själv tillbaka till nuet.
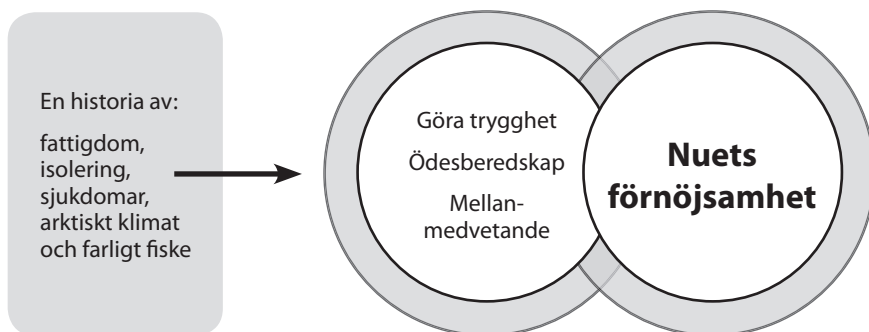
Figur 3: Polarfjordens historia av hög dödlighet och många faror ligger till grund för de tre balanserande begreppen som i sin interaktion grundar teorin om Nuets förnöjsamhet

Dessa språkliga mekanismer och symboler samspelar med *skapandet* av trygghet. "Färdig med det" följs ofta av en *aktivitet*. Vid olyckor och sjukdom är uttryck som "då måste vi passa på att ..." vanliga och *separerar* framtiden från nuet, där nuet inkluderar ett aktivt skapande av trygghet. I det att du gör något aktivt så förflyttas fokus till denna aktivitet, till nuet. Uttryck som "vi vet var vi bor" symboliserar en *beredskap* för det arktiska klimatet och dess utmaningar. Uttrycket används ofta tillsammans med "heldig" (har tur), vilket skapar en *separation* av nuet, där jag i nuet är "heldig", från den fara som kan komma i framtiden eller som har varit i det förflutna. Vi har tidigare visat hur hjälpsamhetskulturen är beroende av en relativ syn på tid och här framkommer hur även språket relaterar till temporala aspekter och drar individen mot nuet.

Humorn är ytterligare en ritual för förnöjsamhet som innehåller både skratt och bekräftelse. Ju större olycka, desto mörkare humor. Genom humorn dras man som drabbad mot nuet, där ältande av dåtiden såväl som framtidsuttryck "det blir nog bättre" eller "tiden läker alla sår" får liten plats. Bekräftelsen skapas därmed via skrattet och bidrar till en förnöjsamhet och en intersubjektiv bekräftelse "jag vet att du vet att jag vet" utan att man behöver prata om det som har skett.

Skripten finns där men är föränderliga och interaktionerna bygger på en hög nivå av improvisation. Som Tilly skriver: "sociala strukturer håller mer eller mindre ihop just för att improvisationen aldrig upphör" (Tilly 2000:65). Tillys reflektioner kring beständig ojämlikhet i sociala relationer hjälper oss förstå processen mot ett nuets förnöjsamhet. Skript skapar en trygghet och utrymme för den djupa improvisation som krävs för ett liv i ett arktiskt klimat med långa avstånd. Kombinationen av *beredskapen* för det okända, *skapandet* av trygghet och förmågan att *separera* känslor och tankar har visat sig leda till en process mot trygghet och förnöjsamhet i nuet.

Avslutning

Studien av Polarfjorden har visat på ett gemensamhetsskapande sätt att bygga upp vardagslivet. Med trygga stereotypa mönster i form av bygdestruktur, gemensamma beskrivningar och relationella skript, med en öppenhet och *beredskap* för att olyckan när som helst kan slå till och med en förmåga att *separera* delar i händelser och människor från varandra, *skapar* samhället en trygghet för både det gemensamma och det enskilda. De förnöjsamhetshöjande mekanismer som döljer sig i Polarfjorden bidrar i hög grad till invånarnas förmåga att leva i nuet, att ta dagen som den kommer, att fokusera på det som är möjligt att påverka och att samtidigt släppa taget om det som inte går att påverka. I grunden handlar det om ett förhållningssätt till livet. Att livet skulle vara självklart eller att i var olycka finna en mening är något som man i Polarfjorden inte uttrycker. Med symboliska uttalanden som "*ferdig med det*" och "*det er nu sån det er*" så går man vidare utan sammanhang och mening.

Vår studie har metodologiskt följt klassisk grundad teori och därför gjordes datainsamling och analys före en litteraturgenomgång med syntetisering av tidigare forskning. Vi fann ett kulturellt system med låg grad av abstraktion, självreflektion och temporala tankar och visar hur teorin om Nuets förnöjsamhet svarar på andra frågor än vad t.ex. Tillys idéer kring skäl skulle lett oss till. Den visar också på andra aspekter av hälsa än Antonovskys salutogena teori. Genom att studien har tillåtits stå fri från styrning av tidigare forskning har det jämförande arbetet med insamlat material fått leda den vidare. Till den grundade teorin: Nuets förnöjsamhet.

Referenser

Antonovsky, A. (1996) "The salutogenic model as a theory to guide health promotion", *Health promotion international*, 11 (1).
Batson, D.C, K. O'Quin, J. Fultz, M. Vanderplas & A.M. Isen (1983) "Influence of self-reported distress and empathy on egoistic versus altruistic motivation to help", *Journal of personality and social psychology* 45 (3): 706–718.
Bauman, Zygmunt (2008) *The art of life*. Cambridge: Polity
Borgos, J. (2007) *Sortland bygdebok: Gård og slekt. Del 3*. Sortland: Sortland kommune.
Bottolfsen, Ø. (1995) *Lofoten og Vesterålens historie 1700–1837: Fiskerbondesamfunnet*. Stokmarknes: kommunene.
Egonsson, D. (2011) "Zygmunt Baumans levnadskonst", *Filosofisk tidskrift* 32(4):3–16.
Garfinkel, H. (1967) *Studies in ethnomethodology*. Englewood Cliffs: Prentice Hall.
Glaser, B. (2010) *Att göra grundad teori: Problem, frågor och diskussion*. Mill Valley, California: Sociology Press.
Glaser, B. (1998) *Doing grounded theory: Issues and discussions*. Mill Valley, California: Sociology Press.
Glaser, B. & A. Strauss, (1967) *The discovery of grounded theory: Strategies for qualitative research*. Mill Valley, California: Sociology Press.

Glaser, B. (1978) *Theoretical sensitivity*. Mill Valley, California: Sociology Press.

Goffman, Erving (2009) *Jaget och maskerna: En studie i vardagslivets dramatik*. Lund: Studentlitteratur.

Haller, M & M. Hadler (2006), "How social relations and structures can produce happiness and unhappiness: An international comparative analysis", *Social indicators research* 75(2):169–216.

Heidegren, C-G (2014) *Tid: Sociologiska perspektiv*. Stockholm: Liber.

Jansen, W.S., S. Otten, K.I. van der Zee & L. Jans (2014) "Inclusion: Conceptualization and measurement", *European journal of social psychology* 44 (4):370–385.

Jünger, F.G. (1980 [1958]) *Spiegel der Jahre: Erinnerungen*. Stuttgart: Klett-Cotta.

Lasane, T.P. & D.A. O'Donnell (2005) "Time orientation measurement: A conceptual approach", i A. Strathman, & J. Joireman (red.) *Understanding behavior in the context of time: Theory research and application*. Mahwah: Lawrence Erlbaum Associates.

Lauritzen, H.N. (2005) *Mitt liv som nothun. Om silda og Eidsfjorden i eldre og nyere tid*. Sortland: Sortland kommune, SpareBank 1, Norges sildesalgslag, Norges råfisklag, Norges Fiskarlag.

Levine, R.V. (1996) "Cultural differences in the pace of life" i H. Helfrich (red.) *Time and Mind*. Seattle: Hogrefe & Huber Publishers.

Miller, G. (2007) "A wall of ideas: The "Taboo on Tenderness" in theory and culture", *New literary history* 38 (4):667–681.

Mykle, A. (1965) *Rubicon*. Oslo: Gyldendal.

Norman, R. (1998) *The moral philosophers: An introduction to ethics*. Oxford: Oxford University Press.

Ochs, E. (2012) "Experiencing language", *Anthropological theory* 12(2):142–160.

Post, S.G. (2005) "Altruism, happiness, and health: It's good to be good", *International journal of behavioral medicine* 39 (4):66–77.

Rørtveit, J.G. (2008) *Folket på Vinje: En fortelling om fiskar/kvinne/bonde Anna Serine Kristine Olsdatters liv 1827–1917*. Oslo: Kolofon.

Sandén, U. (2014) *Nuets förnöjsamhet: En grundad teori med utgångspunkt i Nordnorskt vardagsliv*. Masteruppsats. Lund: Lunds Universitet.

Sandstrom, K.L., D.D. Martin & G.A. Fine (2006) *Symbols, selves, and social reality: A symbolic Interactionist approach to social psychology and sociology*. Los Angeles: Roxbury Publishing Company.

Schnall, S., J. Roper & D.M.T. Fessler (2010) "Elevation leads to altruistic behavior", *Psychological science* 21 (3):315–320.

Schoemaker, P.J.H. & P.E. Tetlock (2012) "Taboo scenarios: How to think about the unthinkable", *California management review* 54 (2):5–24.

Shore, L.M., A.E. Randel, B.G. Chung, M.A. Dean, K. Holcombe Ehrhart, & G. Singh (2011) "Inclusion and diversity in work groups: A review and model for future research", *Journal of management* 37(4): 1262–1289.

Stern, D.N. (2004) "The present moment as a critical moment", *Negotiation journal*, 20 (2):365–372.

Stern, D.N. (2005) *Ögonblickets psykologi*: *om tid och förändring i psykoterapi och vardagsliv*. Stockholm: Natur och kultur.

Tilly, C. (2000) *Beständig ojämlikhet*. Lund: Arkiv.

Tilly, C. (2006) *Why? What happens when people give reasons… and why*. Princeton and Oxford: Princeton University press.

Trost, J. & I. Levin (2010) *Att förstå vardagen med ett symbolisk interaktionistiskt perspektiv*. Lund: Studentlitteratur.

Vea, J. (2009) *To kulturer: En sammenlignende undersøkelse av det vestnorske og det nordnorske kystsamfunnet: Med hovedvekt på det 19. og 20. århundret*. Kristiansand: Höyskoleforlaget.

Walker, D. & F. Myrick (2006) "Grounded Theory: An exploration of process and procedure", *Qualitative health research* 16 (4):547–559.

Wilce, J.M. (2014) "Current emotion research in linguistic anthropology", *Emotion review* 6 (1):77–85.

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Författarpresentation

Ulrika Sandén är socionom och Master i socialt arbete. Hon arbetar för närvarande vid Institutionen för Designvetenskaper vid Lunds Tekniska Högskola som forskningsassistent. I boken "… och jag vill leva" utgiven 2006 på Norstedts förlag kan läsas om upprinnelsen till hennes intresse för Nordnorge och viss förståelse ges för hennes väg mot forskning och grundad teori.

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Paper II

Momentary Contentment
A Modern Version of an Old Survival Culture

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Abstract

This is a classic grounded theory based in longitudinal data from everyday life in an environment in Northern Norway characterized by long distances, a harsh climate and people living close to nature and each other. The place has a history of poverty and isolation. Yet, old survival strategies prevail despite modernisation. The theory reveals a culture of momentary contentment with three dimensions: Doing safety, destiny readiness and middle consciousness. This momentary contentment culture explains how the participants resolve their main concern of enjoying life. Doing safety means that common and individual acts create stability. Destiny readiness illuminates a discourse of acceptance, a way of thinking that, with the aid of linguistic strategies, prepares for life changing events. Middle consciousness shows a way of handling difficulties by dividing and separating different phenomena.

Keywords: contentment, grounded theory, time, safety, happiness, altruism, hope.

Introduction

How is everyday life organized in an environment characterized by long distances, harsh climate and people being close to nature and each other? The first author had moved far away to such a place in Northern Norway and was struck by the special life approach of people living there. Before the Second World War this was an isolated place and the sea route was the only way to connect with other villages. Everyday life then included fishing boats perishing in the ocean storms as well as tuberculosis and other diseases on shore. This harsh environment called for different strategies for both physical and psychosocial survival. Isolation created a need for mutual help as well as functional relationships with both internal worries and external dangers. Eventually the fishing boats got safer, tuberculosis controlled and after the war a country road was built to connect with other villages (Bottolfsen, 1995; Rortveit, 2008). Accidents and deaths decreased significantly. Even so, our data suggests that to this day, much because of nature's capriciousness, life's natural course is seen as unpredictable. To find out what was going on in everyday life the authors chose to do a grounded theory based on years of observations—first unstructured and later more formalized. This article is based on a master thesis done by the first author.

Method and material

The data consists of interviews, conversations and notes from observations of everyday life

from 2010 to 2014. Before the study began, in December 2012, the notes were written in the form of diary entries and journalistic notes. The first author conducted a total of six focus groups and eight individual unstructured and semi-structured interviews that lasted between 2-6 hours each. In order to capture views of their everyday lives the informants were asked to freely talk about their experiences. In some of the later interviews, questions pertaining to the emerging theory were asked. The first author also gathered field notes from 15 conversations targeted towards the thesis and 50 informal, semi-structured conversations. In alignment with the classic grounded theory maxim "all is data" (Glaser, 2010) all research notes, diary entries and journalistic notes were discussed between the authors and included in the circular analytic process.

Theoretical Sampling

New decisions regarding data collection were made after each interview (Glaser, 1978). The first author started with interviewing elderly in groups of three with the only question "please tell me about your lives". This was a way to collect data from what they said, how they said it, and what they chose not to talk about. She then went on to interview people in working ages to collect a diversity of data and chose to collect new data in accordance with new questions arising based on the emerging theory. The first author did several interviews with the oldest individual, 97 years old, yielding more than 10 hours of historical data. Since the fishing culture turned out to be a historical base for modern society's contentment, at the very end we decided to make a semi-structured interview with a fisherman who comes from a family with generations of fishermen. This was to see if his life story and remembrances from his parents and grandparents attitudes differed or gave new data to the analysis, which it did not. Rather the analysis was confirmed.

Classic Grounded Theory Analysis

Notes from interviews and observations were written and theoretical memos were written and drawn in different shapes and forms in the comparative process. These memos have been sorted, coded, categorized, and compared to find relationships between categories and concepts using theoretical codes. After each interview or accrual observation the new material was coded, analysed, and compared with previous results. Data was thus collected and analyzed in stages until new data did not provide any new information, i.e., saturation was reached. At saturation the formulated theory was eventually slightly modified in light of existing literature (Glaser, 2010). All authors participated in the analysis. The concepts gradually emerged to explain the participant's attitude towards life. The core category emerged in May 2014. Thereafter, memos and field notes were written without discrimination, but interpretation and analysis was done selectively using the core category as a template. Eventually a grounded theory was generated, with the core category theoretically coded as a cultural manifestation—momentary contentment, explained through doing safety, destiny readiness, and middle consciousness. Grounded theory differs from many qualitative research methods in its focus on incidents and memos rather than persons

(Glaser & Strauss, 1967), and in this study the number of incidents coded and compared amounted to several hundred.

Strengths and Limitations

The strength of this study is the length of time during which the data collection was running, the large number of interviews and the extensive field notes taken. To our knowledge no prior classic grounded theory using ethnographic data of this longitudinal character has been conducted, thus we went into an unexplored methodological area. This can of course be a strength and a weakness. A limitation from a traditional qualitative data analysis perspective is researcher-induced bias. We dealt with this issue by credibility checks from discussing all data in between us as well as by collecting data until saturation was reached.

Results

We found a potential well-being promoting cultural and behavioural strategy with a temporal aspect—momentary contentment. It explains how to deal with the main concern of enjoying life. It also explains how recycling processes of old survival strategies may induce well-being through contentment in modern society. The observed area has a pre-World-War-II history of poverty, dangerous occupations and isolation, confirmed in local historical tales and novels as well as in historical literature (Bottolfsen, 1995; Lauritzen, 2005; Rortveit, 2008). To survive this environment different balancing compensation strategies evolved that are explained by doing safety, destiny readiness, and middle consciousness.

Doing safety

Doing safety illuminates ways to act in order to create stability. Through stereotypes and a well-developed collective support system the participants shape their own safety. The ongoing actions of helpfulness and inclusion create stability and a sense of belonging. It includes practical structures such as a local store, day-care, school, several clubs and annual activities, as well as psychosocial patterns of shared norms, common identity traits and linguistic tools. By using well-known and accepted stereotypes an ongoing confirmatory communion is created.

Destiny readiness

Destiny readiness is a way of thinking. It is characterized by an acceptance of life and an ability to deal with what is at hand by the use of spoken and symbolic language. Both interviews and observations show a down to earth way of handling crisis.

> One winter day my nearest neighbor came by. She was heavily pregnant and wondered if I would be willing to help her if she started to give birth during the approaching snowstorm. 'If we get snowed in, you will be the midwife'. She said it without any noticeable nervousness and ended up with explaining/calming me down 'that's just the way life is,' she said. (From memo)

In this context the theory "homeostasis of hope" fits to explain how people create instinctive

compensatory strategies to increase existential hope, including the denial of life-shortening clearance or by increasing the momentary enjoyment of life (Thulesius, 2003). Hope is often connected to some sort of worry and can evolve into demands, thus cognitively draw one from the present into thinking about the future (Sandén, 2006). However, hope is not commonly spoken of by the participants. Instead expressions like "what happens happens" and "one can't worry about the future, life is here, now let's live" are expressed. This means capturing the moment and dealing with what is at hand. These tools for acceptance and preparedness, in combination with a culture of helpfulness, open up for feelings of contentment in the moment.

<div align="center">Middle consciousness</div>

Middle consciousness explains the link between opposite thought processes as a way of handling difficulties and of facilitating a presence in the moment. There are, as an example, ways of dealing with entry and exit from the communion. In short, when someone is absent he or she is moved into a stand-by mode and only sporadic contacts may occur. Local and historical literature describes the importance for women and men to let go of each other while the men were out fishing for months at a time. The present moment needed full attention, as it was crucial for survival. By letting the thoughts of the two lives, when the man was out fishing and when he was at home, be intermittently related, they can exist in one's mind taking minimal energy from the present moment (Bottolfsen, 1995; Lauritzen, 2005).

Today this is not a necessity, but by putting thoughts of people that are not present in a standby mode, in a middle consciousness, feelings of missing and longing are decreased, feelings that otherwise contribute to thoughts that brings a person away from the moment. In a similar way, participants show an ability to separate sick from healthy, to see disability when help is needed, and to not see it when help is not needed or possible to give. Observations and interviews demonstrate how people at one point show great helpfulness and then, in another setting, treat the same person as fully fit. As a disabled person expressed it:

> The same people that I talk to about my disabilities and who help me cope can three days later ask me to join in a tough physical activity. It's like they haven't heard, I don't even think they are aware of doing this.

Observations show how participants separate illness from health, present from future to past, and what is possible to influence from what is not. By such separation, where parts are intermittently related, a connection through the middle consciousness is kept. This allows each part to be dealt with in its moment. In that moment there is always something to do, either attending the negative through helpfulness, humor, tenderness or the positive by doing safety through for example an activity.

Various combinations of doing safety, destiny readiness and middle consciousness show a structure and organisation of life that seems to retain social peace and stability. They are characterized by collective strategies for joy, safety feelings, inclusion and helpfulness; strategies working towards contentment in the moment.
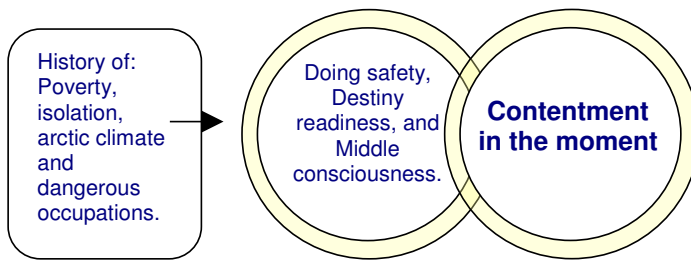
Figure 1. Outline of the development of Momentary contentment theory. The history of hardship and early deaths work as a foundation for the three balancing categories of contentment; doing safety, destiny readiness, middle consciousness; which in their interaction explains momentary contentment.

Momentary Contentment Theory

History shows an unfortunate and weather-beaten society that despite its vulnerability, historically as well as to date, found a way of life that creates contentment. Yesterday's proximity to death has due to climate, distances and nature-related accidents to some extent remained. Interviews and observations show that the balancing mechanisms that existed as a necessity before the Second World War still in large are present in modern life. As a consequence the degree of hardship has been reduced, but the power of balancing the hardship through doing safety, destiny readiness, and middle consciousness has not been reduced to the same extent.

The psychosocial survival culture shows an analogy with literature regarding what creates happiness, joy and satisfaction, linguistically as well as cognitively and behaviorally. People's subjective life experiences may be more important than the actual life situation itself (Haller & Hadler, 2006). Today the culture of helpfulness is not necessary for survival, but it still exists, nourished by accidents and rough weather. Altruism is central in interviews and observations, in the past as well as today. In groups altruism creates a common pride based on partially unconscious internal processes where it is hard to see one's own role. On the societal level, altruism works through well-developed voluntary work and a preparedness to fight for survival.

By including newcomers a base for confirmative communion is created. Contentment is achieved by doing safety in a collective support system that includes momentary helpful and altruistic inclusive attitudes. Simultaneously the language is characterized by adaptability and euphemistic expressions.

The spirit of accepting everyone as a participant in parties and clubs requires a certain form of preparedness that lessens worries of being alone and thus creates a feeling of safety. Together with linguistic strategies and communicative symbols thought processes are transmitted to enhance contentment in the moment. Expressions like "we know where

we live" symbolize a destiny readiness for the harsh climate and its challenges. But in order to protect the preparedness from worries, expressions like "heldig" (lucky) are often heard at the same time. Such expressions create an opportunity to separate a moment of "heldig" from a danger that might come or that used to be in the past, leaving a contentment in the moment.

The separation of those who are present from those who are absent creates a focus on the moment. In combination with inclusion processes no one has to be afraid of not being allowed back in the community when returning from being away. A woman who had been gone for a few months said it was like they hadn't even noticed that she had been gone. This separation phenomenon, a part of the middle consciousness, shows how different aspects are intermittently related by reciprocating in consciousness, thus not leaving issues neither repressed nor fully conscious.

By not expecting life to be easy in combination with a culture of always helping, an accident or hardship is not met alone. When no more help is needed or possible to give the ability to temporarily disconnect from the suffering of a friend or family member creates an opportunity to focus on the positive which includes health. Dark humor helps carrying the person in need through laughter and an activity together with linguistic tools keep bringing people back to the present. And, in the moment there is always something to do to make life a little bit better. If not for oneself, for a friend or a neighbor, thus in its altruistic manner creating contentment.

Four Manifestations of Momentary Contentment

Momentary contentment is specifically manifested in inclusion processes, nature's capriciousness, communication strategies, and in a culture of helpfulness.

Inclusion processes yielding contentment

The inclusion process is characterized by a combination of activity, openness, and individuality. In combination with a culture of helpfulness and altruism, safety and contentment are created. In order for individuality to spire in a culture where everyone is welcome the separation phenomena of the middle consciousness is used to disregard negative individual traits.

Shore et al. (2011) present the following definition of inclusion: "the degree to which an employee perceives that he or she is an esteemed member of the work group through experiencing treatment that satisfies his or her needs for belongingness and uniqueness" (p. 1265). Inclusion is thus established when individuals have a sense of belonging to the group and, at the same time, perceive themselves to be a distinct and unique member, combined with the group responsibility to include the individual, rather than the individual connecting to the group (Jansen et al., 2014). Through a combination of linguistic and separation phenomena inclusion is enhanced:

> The expression 'him NN, that's just how he is' is common when someone breaks the norm. Instead of

> trying to change the person or exclude him/her from the fellowship an exception for the behaviour is created, in other words a way to keep both belonging and authenticity. (From memo)

Shore et al. (2011) and Jansen et al.'s (2014) view on inclusion, with the combination of individual authenticity and group solidarity, is apparent in the term "the Swede".

> First I believed it was a way to distance me from the others but I soon found out it was just the opposite, 'the Swede' allowed me to break the norms and still be part of the communion. Every time I did something they thought was weird I just said 'I'm from Sweden' and it was accepted. If someone asked one of my friends 'what's she doing' he/she would say "never mind, she's a Swede". Now that they know me, after three years, they don't use 'the Swede' anymore, now they say 'that's just how she US is'. (From memo)

It doesn't logically work to say "she NN, that's just how she is" of a newcomer. Instead the new expression "the Swede" was created. It worked as an explanatory model in "she's from Sweden" and the odd behavior could thereby be separated from the norms without the need to change neither the norms nor the person challenging them. Space was created to allow norms to be broken without a person losing uniqueness, behaviour that otherwise would have put inclusion at risk.

Nature's capriciousness and contentment

Nature and the scenery have a central position as it draws people towards the present. Nature is characterized by unpredictability, beauty and the support it gives to the people. Some see it as a source of joy, some as a necessity for mental survival, while others relate to it as something to rest your eyes on. All refer to nature as something that generates energy and internal strength, thus creates a sense of belonging and pride, contributing to the stereotype description of the area. As a mentally ill participant expressed it: "Three hours walk here means I'm way up on a mountain top. Three hours walk in flat land is only three hours walk."

Alas, nature in combination with the rough climate is also a source of accidents and deaths. But in that hazardous environment the old culture of helpfulness and readiness is preserved which yet furthers contentment. The unpredictability is described as something natural and dealt with through a destiny readiness in where people put the danger in a stand by mode, in a middle consciousness. Through the middle consciousness they create a momentary space where they neither have to think about the danger nor repressing it. Thus they are allowing contentment through the scenery and are still ready to help as soon as help is needed which is yet another source of contentment.

Communicative manifestations – contentment talk

Many expressions and other communicative tools help the separation of positive from negative, thus supporting the middle consciousness maintenance. The tools also support a destiny readiness without reducing contentment in the moment. Symbols of tenderness, humor, and listening bring people back to the moment, away from straying minds of future and history. One characteristic of contentment talk is that hardships often are described by their solutions. This allows problems to exist on one level, leaving a preparedness that negative things can happen, but without giving unnecessary negative thoughts space in the

present moment.

> The elderly discussed how warm the cow pee and poop was, no-one during the discussion mentioned the coldness in chasing cows bare feet in the fall even though that was the issue at hand. Focus is on the solution and the problem seems to be a secondary variable which I find in between the lines. (From memo)

Another characteristic of contentment talk is contentment and safety enhancing expressions. The term "heldig" (in English that one can count oneself lucky) is frequently used in relation to being heldig (lucky) to live there; who has the best friends; who got to see the sun today. It thereby contributes to the general notion of contentment. It also functions as a way to describe and confirm the preparedness that hides behind being lucky. "Lucky me to have good friends" implies knowledge of possibilities of life to be otherwise. Another expression, "done with it," is used as a temporal linguistic tool to move on from negative thinking. It is a way to leave the past and return to the present moment. Observations and interviews have confirmed this phenomenon to linguistically put things aside and describe negative incidents with positive expressions.

A third characteristic of contentment talk is to give confirmation through humor: the worse the accident, the darker the humor. This opens up possibilities to create confirmation and joy in a bad situation. The confirmation appears as laughter and contributes to intersubjectivity and contentment in hard times.

Humor is often seen together with a fourth communicative characteristic, active listening. When nothing is possible in a situation, such as a serious disease, one can listen and laugh. Active listening provides no feedback on anxiety nor is the person interrupted. When an anxious person finishes talking, not seldomly with a "done with it" expression, the situation turns into an activity or plan for an activity. Confirmation is given through a combination of active listening, humor, and activity.

Every society has its linguistic ideology, which emerges in interactions and shared experiences. Studies of communicative evolution show that it is impossible to distinguish the understanding of language from its cultural context. Language creates feelings and experiences as much as senses create language (Wilce, 2014). Through the combination of different communicative tools, activities and stereotypes Doing safety, Destiny readiness and Middle consciousness are reinforced in a confirmatory communicative momentum.

<u>Culture of helpfulness and contentment</u>

Our data reveal a norm of helping when help is needed as if it is the most natural thing to do. The contentment inducing helpfulness culture has different levels of helping characterized by interactions between getting help, helping and altruism. The widespread culture of helpfulness creates a certainty of help being there independent of friendships and other relationships. It promotes feelings of safety and a readiness for what life has to bring. Participants talk about helping others, but not in an abstract way, only very concrete situational and as something obvious; like brushing one's teeth.

The obvious and non-reflected help brings an altruistic dimension to helpfulness.

Within happiness research there is something called the hedonic paradox where a pursuit for happiness decreases wellbeing otherwise connected to helping others (Bauman, 2008; Egonsson, 2011; Norman, 1998). Post (2005) finds a strong link between altruism and wellbeing, happiness, health and longevity—as long as a person is not overwhelmed from helping others. He describes how altruism results in positive social inclusion, in distraction from personal problems and self-centred anxiety, in increased wellbeing combined with experiencing meaning and purpose and in a more active lifestyle. Observations show engagement into each other's helpfulness. By assisting each other in giving aid one is not left alone in a commitment to help. By sharing the burden an extra level of safety feeling is created. In a culture where helpfulness is norm, there is no need to diminish the helpfulness, like "I owe you a favor" or paying back for given help, which would put the altruistic motion at stake.

Discussion and Further Research

Momentary contentment theory explains how people in a rough environment enjoy life by doing safety, destiny readiness, and middle consciousness. Momentary contentment might be found also in structural organizations, collective support systems, inclusion processes, and in individual thinking and communication. Momentary contentment is characterized by feelings of safety, inclusion and helpfulness where the present moment is emphasized due to nature's capriciousness and isolation.

When comparing with previous research Antonovsky's studies on health-promoting factors among concentration camp survivors emerged as relevant to study. Antonovsky (1996) generated the salutogenic theory, which connects cognition, behavior and motivation and indicates a sense of coherence (SOC) as the single most important aspect to mentally cope with hardship. SOC consists of three parts: comprehensibility, manageability and meaningfulness. It is not bound by cultural context, but may be designed to fit various cultural settings (Antonovsky 1996). Both SOC and the momentary contentment theory have evolved from empirical studies of different forms of hardship.

Antonovsky examined healthy-sick as opposing forces in a scale of what makes a person move towards health. But our field studies led us to focus on contentment, feelings of safety and the ability to live in the present. We have neither in interviews nor observations recognized what the salutogenic theory was promoting; none of the elderly expressed any meaning or sense of coherence in their hardships. Quite the opposite. They demonstrated a genuine ability to place uncontrollable difficulties in a middle consciousness, reformulating problems into solutions and use of laughter as therapeutic confirmations. In other words, they expressed adequate ways of not having to reflect on purpose and meaning.

The sense of coherence we found was focused on interactions with nature and others, but not in what happens. With symbolic statements like "done with it" and "this is just the way it is" participants move on without context and meaning. This differentiation in results can, at least partly, be explained by the different contexts in which the theories

evolved. Antonovsky's studies of survivors indicate a history of hardship that still influences one's mind and health. Our study involves ongoing hardship, thus the need to find solutions in the moment are of greater importance than finding meaningfulness in what has happened.

The grounded theory of momentary contentment presented in this article reveals a psychosocial capacity where accidents and deaths are apparent in every moment. In future research we wish to explore the possibilities to implement this psychosocial survival knowledge, tools and strategies into modern healthcare. We suggest that strategies and techniques yielding contentment presented in this article are modified and re-designed to help people living close to death and worries. The importance of patient participation and self-action in both diagnostic and treatment processes has been shown in patient testimonies and research (deBronkart, 2011; McDonald et al., 2013). The different ways of finding intersubjectivity, contentment and a momentary view on life by altruism, activities, hope, inclusion strategies, symbolic tools for differentiating between sick and healthy, active listening, and humor could eventually be tried in different contexts.

Conclusion

Momentary contentment theory is explained through its three categories: doing safety, destiny readiness, and middle consciousness, all strengthened by linguistic tools. Through old survival cultural manifestations, today's society found a culture that embraces people's capacity to live in the moment, taking each day as it comes, to act on the things that are possible to influence and to let go of that which cannot be simultaneously influenced. In the combination of doing, thinking and separating momentary contentment theory explains a hidden but present flow of less worrying, strengthened feelings of safety and enhanced satisfaction. By recycling and modifying identified tools and strategies for contentment in everyday life, we believe there is an opportunity to design a new way to approach psychosocial hardship. Interesting to address for future research would be to connect new studies on the safety and contentment of the patient-related care with Antonovsky's (1996) research on health and SOC to see how and if these two approaches can complement each other.

References

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health promotion international, 11*(1), 11-18. doi:10.1093/heapro/11.1.11

Bauman, Z. (2008). *The art of life*. Cambridge, UK: Polity.

Bottolfsen, O. (1995). *Lofoten og Vesteralens historie 1700 - 1837: Fiskerbondesamfunnet*. Stokmarknes: kommunene.

deBronkart, D. (2011). Let Patients Help. TED Talk. http://epatientdave.com/videos/ (accessed 22 Feb 2015)

Egonsson, D. (2011). Zygmunt Baumans levnadskonst. *Filosofisk tidskrift, 32*(4), 3-16.

Glaser, B. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.

Glaser, B. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.

Glaser, B. (2001). *The grounded theory perspective: Conceptualization contrasted with description*. Mill Valley, CA: Sociology Press.

Glaser, B. (2010) *Att gora Grundad teori: problem, fragor och diskussion*. Mill Valley, CA: Sociology Press

Glaser, B. & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Mill Valley, CA: Sociology Press.

Haller, M. & Hadler, M. (2006). How social relations and structures can produce happiness and unhappiness: An international comparative analysis. *Social Indicators Research, 75*(2), 169-216.

Jansen, W. S., Otten, S., van der Zee, K. I. & Jans, L. (2014). Inclusion: Conceptualization and measurement. *European Journal of Social Psychology, 44*(4), 370–385.

Lauritzen, H. N. (2005). *Mitt liv som nothun. Om silda og Eidsfjorden i eldre og nyere tid*. Sortland: Sortland kommune, SpareBank 1, Norges sildesalgslag, Norges råfisklag, Norges Fiskarlag

McDonald, K. M., Bryce, C. L., Graber, M. L. (2013). The patient is in: Patient involvement strategies for diagnostic error mitigation. *BMJ Quality & Safety,* 22 (supp 2), 33-39.

Norman, Richard (1998). *The moral philosophers: An introduction to ethics*. Oxford, UK: Oxford University Press.

Post, S. G. (2005). Altruism, happiness, and health: It's good to be good. *International Journal of Behavioral Medicine, 39*(4), 66–77.

Rortveit, J. G. (2008). *Folket pa Vinje - En fortelling om Anna på Vinje*. Norge: Kolofon

Sandén, Ulrika (2006). *... och jag vill leva*. Stockholm, Sweden: Prisma/Norstedts förlag.

Sandén, Ulrika (2014) *Nuets fornojsamhet - en grundad teori med utgångspunkt i Nordnorskt vardagsliv*. (Masters thesis, Lund University). Retrieved from http://www.lunduniversity.lu.se/lup/publication/4812621

Shore, L. M., Randel, A. E., Chung, B. G., Dean, M. A., Holcombe E., Gangaram K., Gangaram, S. (2011) Inclusion and diversity in work groups: A review and model for future research. *Journal of Management, 37*(4), 1262-1289.

Thulesius, H., Hakansson, A., Petersson, K. (2003). Balancing: A basic process in end-of-life

cancer care. *Qualitative Health Research, 13*(10), 1353-1377.

Wilce, J.M. (2014). Current emotion research in linguistic anthropology. *Emotion Review*, 6(1), 77-85.

Paper III

Co-creation of lifelong rehabilitation design.
Based on an autobiography

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Abstract

This paper presents a case study of a successful rehabilitation process combining design thinking, user innovation, sociology and neurology. The objective was to give a patient perspective on brain injury and a neurological rehabilitation model.

Momentary contentment theory and the Diamond of Participation creates an emotional, pedagogical and cognitive frame of safety in which patients and health care staff together can move forward in a co-creative process. Through participatory action research I show how plasticity, exercise, medication and cognition can be used to overcome brain surgery, neurological deficits and finally a mild stroke. Becoming cognitively brain damaged is similar to living in a cage of glass with invisible walls illustrating new and unknown limits. Through acceptance that life will never be the same one can find openings in the glass cage and thus reach the world outside. It is a frightening experience and the model may be used to illustrate the rehabilitation process thus making it less fearsome and giving more people with acquired brain injuries or neurological diseases a chance to increase their quality of life.

Keywords: rehabilitation, brain injury, patient perspective, co-creation, user innovation, design thinking, neurology

Introduction

Traumatic brain injury (TBI) is a critical public health and socioeconomic problem throughout the world (1, 2). The World Health Organization (3) has defined rehabilitation as "Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination." A literature review over multidisciplinary team care in rehabilitation of different

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health aspects show that MTC has great effects compared to control group or standard rehabilitative care (4). This was also shown in a Cochrane review with focus on acquired brain injuries among working age people (5). The same Cochrane review emphasize the varied nature of acquired brain injury and the need for different services to suit the needs of different populations. They conclude with concrete implications for practice (5). There are thus implications within healthcare rehabilitation. Another study looks at neurological rehabilitation methods from a cost-effectiveness point where the study ends with the patient being discharged (6). However, from a patient perspective rehabilitation does not end when discharged, rehabilitation is a natural part of life. Many patients struggle with understanding their new living conditions. Rehabilitation is so much more than what is done in hospital care, living with acquired brain injury means designing a partly new life. The varied nature of brain injuries, of population and the fragmented healthcare make the creation of an explanatory frame a wicked problem as defined by Rittel and Weber (7), where a solution would be complex. There is, as Davila, Epstein and Shelton (8) write in their introduction "*no silver bullet for innovation, no formula or structure for innovation that will work for every organization*." But design thinking means that good policy should include the views of the users (9). From a patient perspective, the hospital provides a small and very important portion of the total rehabilitation which is a lifelong iterative learning and modifying process. Habicht et al. (10) writes about patients as user innovators and how they use their personal professional expertise to solve a problem. Oliviera et al. (11) show how patients afflicted by rare diseases offer a tremendous source of information on how to improve patient medical care. Their contributions may complement the efforts by policy makers, research entities, and producers, to help improve the difficult situation of rare disease patients, whose needs for innovations are often underserved. In this article I will combine my experiences of different brain injuries with design research and momentary contentment theory to build a prototype for the rehabilitative iterative process, thus making it easier for both patients, relatives and health care staff to understand the process.

Method

This study is based on an autobiography starting with brain tumor surgery in 2004. I have been active in the rehabilitation process using participative action research. It is an interactive process in which problem solving activities are implemented and studied in a reflective understanding way (11). Zhang et al. (13) argue action research as a mean to enhance relevance in research, combining scientific knowledge with actions based on that knowledge. Almost daily notes have been made from 2004 and forward. From the perspectives of being a patient and a researcher I use design thinking combined with a pedagogic tool (14) in order to make an explanatory model with basis in my experiences.

Thakur et al. (15) writes about innovation in healthcare and the importance of understanding the challenges faced by healthcare organizations, such as multiple medical records of patients, incorrect doses and wrong medication. Patient perspective seems to be included as an addition, rather than being the center for a certain innovation. On a structural level, there are several studies showing the need for more patient centered processes. Bates and Robert (16) set the patient in focus of why healthcare at all exists and they believe that the patient is a forgotten resource in the development and production of new working methods, processes, surveys, and more. Patients could play a role in everything from observing, picking up ideas and thoughts, try first, listen, challenge, until the final design of service, environment, processes, flows and finally evaluate the effect of a finished product/service. This aligns well with design thinking and my daily notes have been analysed through Brown's (17) iterative process model with inspiration, ideation and implementation. Inspiration come from everyday problems, and includes analyzing the issues. Ideation is where one find keys, build prototypes and try different solutions. Implementation is where one use what works. When designing rehabilitation, time is a factor in which life happens and bring new factors into the iterative process. Large changes like for example a new brain injury might turn old solutions into problems. I have experienced three major changes, which have given me both a chance and a need to explore the nature of the rehabilitative process.

1. Brain tumor surgery 2004 followed by MCI diagnosis and rehabilitation program 2005. My first design process.
2. Parkinsonism in 2012 followed by a need to find new solutions to new problems. A new design process started with new brain issues.
3. Stroke in 2016. Followed by a recycling period of strategies from before. The third design process in which I am still functioning.

Frame of reference

The momentary contentment theory (18, 19, 20, 21) differs from many other health theories in its acceptance of life as unpredictable and hard to control. Safety is instead reached through activity, cognition and a collective helpfulness. It has its origin in a weather-beaten society that despite its vulnerability, historically as well as to date, has found a way of life that creates contentment. The theory is based on three safety balancing mechanisms. In combination they support stability and safety in an unstable life situation.

- In *Doing safety,* people create their own safety through activity and predictability. In a brain injury setting, group activities and predictabilities in care would be essential.
- *Destiny readiness* is a concept that explains an acceptance that life is what it is - an evolved preparedness for uncontrollable events.

This is a given when getting a brain injury, the whole world has changed. Dark humor helps putting words onto the non-understandable. However, it can be hard for relatives and healthcare staff to embrace both humor and this acceptance of little control.

- *Middle consciousness* is an ability to create order. By placing those situations that cannot be controlled into a standby mode, they can be disengaged from consciousness without being completely repressed. Here time is a major tool. By dividing time into framing activities acceptance becomes easier.

Dark humor, laughter and activity together with linguistic tools keep bringing people back to the present. And, in the moment there is always something to do to make life a little bit better (18, 21).

MCT involves life with little control, but in order to be useful in a rehabilitative process a pedagogical tool is added. In design activity experience labs are spaces for bringing different people into a co-creative process. These labs may look different but a central aim is to support and move participants thinking beyond their imagination (22). Looking at the pedagogical tool "Diamond of Participatory Decision-Making" (14, p 20) it shows phases that groups go through when facilitating sustainable agreements.

In the divergent zone everyone have their frame of reference. In the groan zone different frames of reference meet and collide, it is a zone of changing. In the convergent zone a new shared framework is reached.
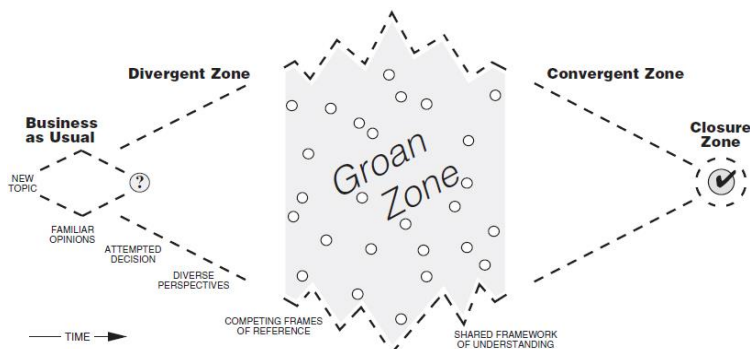

Figure 1.

Results – Lifelong learning

Rehabilitation provides disabled people with the tools they need to attain independence and self-determination" (3). In acquired brain injuries the cognitive functions changes and rehabilitation often include both body and mind. Patients have to change the way they imagined life to be, they facilitate new visions on life. Adaption becomes crucial but it is a frightening process when you don't know what the future might include. Momentary contentment theory (MCT) explains a way to reach safety feelings during uncontrollable events. Looking at MCT a key factor to safety feelings is a collective helpfulness. Knowing one is not alone within a hardship makes it easier to stay in the hardship (18). Co-creation is a key factor. The process can be described in different steps.
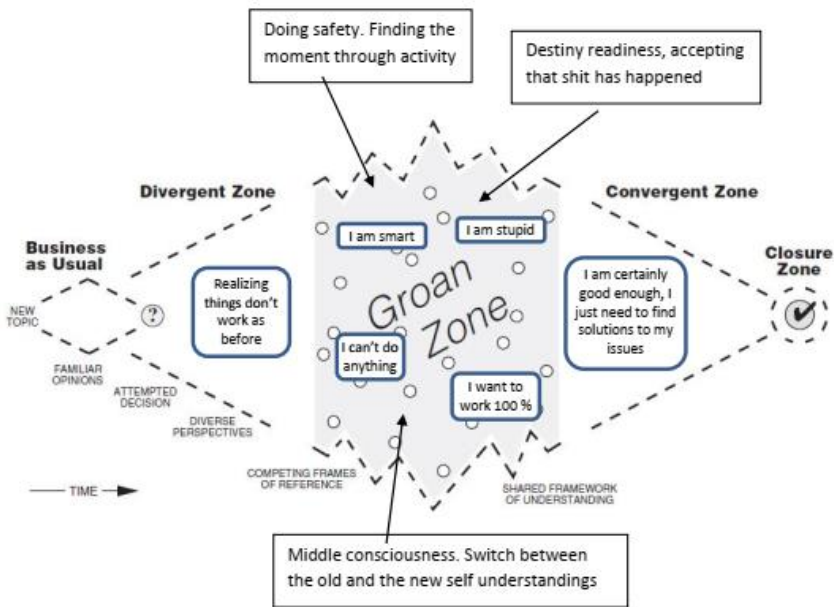
Figure 2.

Co-creators in the diamond of participation

Realizing there are damages - Helping me see the walls of glass

In 2004 I had a gross total resection of an astro-cytoma grade 2. It was placed in my right temporal lobe, damaging several cognitive functions. After the surgery I thought and believed that everything was fine. Both headache and epilepsy was gone. I was tired but in my mind not sick. Realizing ones brain is damaged is one of the bravest loops one can take and I hid my symptoms from both myself and the people around me. Besides memory losses I couldn't find my way around and everyday things got impossible to do, like cooking and reading. I also got a fatigue that made it all worse. As a first thing to do after surgery I was recommended to take a small course at the university. To test my cognitive functions. Studying was like walking into an invisible wall. I had a hard time reading the material and it was even harder to understand the text. After neurocognitive and ADL testing I was diagnosed with mild cognitive impairment (MCI) and sent to a specialized rehabil-itation program at the university hospital for

working age people with cognitive and emotional difficulties following an acquired brain injury. The rehabilitation program (23) was based on group activity for patients who are diagnosed to have the need for prolonged contact with the medical outpatient rehabilitation based on emotional and cognitive symptoms of his/her brain injury. Participant's TBI had different causes and prognosis, although we were all in working age. Individual rehabilitation plans were carried out. Severe brain fatigue, lack of human multitasking and also our different cognitive impairments created the need for change and adaptation to a quieter life. The rehabilitation program was divided into 6 weeks of rehabilitation, summer break and then six more weeks (23). I did my best to individualize the program to fit me and my issues but all of us shared the same main issues. Ohlsson & Alkhed (24) describe the program, how we by using knowledge, technology support and strategies such as planning and rest facilitated life. Fatigue and confusion lessened if every day was planned. Rehabilitation is based on individual plans and continuous monitoring of these counteract the risk of a situation where the professional assessment prevails over the individual´s and where the steps are general rather than individually designed. Group rehabilitation works through individual empowerment. Where participants, despite their disabilities, learn strategies to cope with and to regain power over their own lives and life choices (23, 24).

In brain damage rehabilitation you suddenly get thrown into the groan zone. The groan zone is where competing frameworks meet and you are forced to change your thinking into a new understanding. As Sevetson (25) puts it "The groan zone, which I often think of as the area of pain, is where you have to try to understand the wide range." It is a process where you, as well as the people around you, have different versions of yourself. Healthcare professionals and next of kins are involved but the main dispute is where the old you meet the new you. The vision of the self becomes slurred. Acceptance is often talked about in regards to chronic diseases and some argue its necessity to move on whereas others see it as a way to give up. I argue both are right. Acceptance of a chronic disease or a brain injury is in fact a shared framework of understanding the person you have become. You give up by giving up the old you and you move forward by exploring the new you.
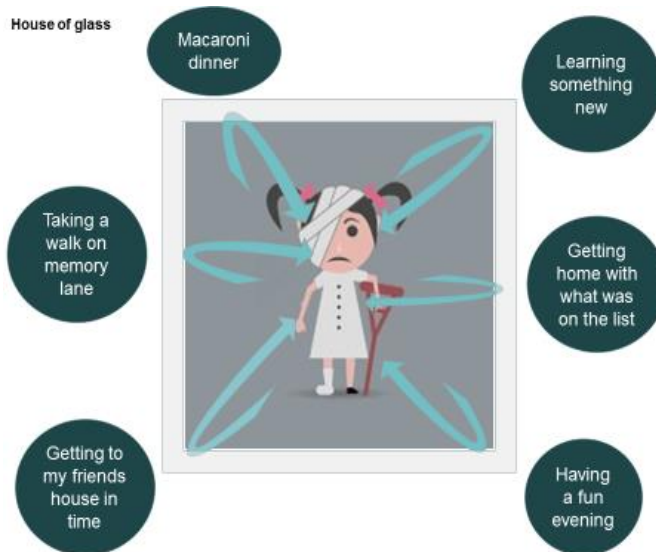

Figure 3.

It was like living in a room of glass where I saw myself succeed beforehand but never managed to follow through. I got an assignment of boiling macaroni and heat up some premade sauce. I saw the dinner in my mind and when I messed up the pans it was like running straight into an invisible wall. The same when they asked me to read an article. In my mind I saw myself finish in a few minutes, instead I tried to read line by line without understanding. When I finally got done with one section and trying to start the next I had forgotten the first. It was impossible to make sense of the article.

Confusion – moving towards accepting

Design is a relatively new research discipline and Herbert Simon (26) defined design activity as the creation of actions, aiming at changing existing situations to more desirably ones. Something that is crucial when you find yourself not being able to function in society. A new life with new abilities and boarders has to be learned and continuously relearned. During the rehabilitation program I was a research person in a study (23). The authors describe how the participants before the start of rehabilitation in many ways lacked control and thus power over their own lives. During the program, participants learned to plan activities, limit oneself to one or a few activities depending on individual capacity and do one thing at a time. The aim was to make life less fragmented and stressful. This was also correct for me. I didn't recognize myself and bit by bit I learned what didn't work without being able to see what worked. Here the future is scary and the past was in my case mostly forgotten. To cope with my fear I turned to anger. I yelled at the staff and even chased them with a wooden spoon once.

My first rehabilitative job was to make coffee at a public library. As I was really scared to fail, the question came to me "who am I if I can't make coffee"? In order to dare to try and thereby risk failure safety is needed. In MCT one can reach moments of safety feelings even in a stressful situation by combining the activity of doing safety with the cognitive process of accepting life as uncontrollable and allowing the mind to switch between poles of understanding (19). By cognitively accepting that life would never be what it once was I could release myself from my old expectations of the future. I then

combined that thought with doing things to create a new future, and thereby create some safety for myself. In order to create some space in time (19) one can use the MCT's middle consciousness where one move between poles and thereby create clusters of moments. In my case my body still worked and I signed up to New York marathon. Every time I ran I gave myself a break from being brain damaged, I felt normal, even better than normal.

Figure 4.

Acceptance – searching together

When I started to accept that there were damages to my brain the search for solutions could start. I felt the rehabilitation hospital was a war torture camp and the staff my personal torturers. I felt trapped in a cage of glass where I could only watch life but not participate. I had no idea whether or not I were ever to get out. Much similar to being in the groan zone in Kaners (14) pedagogic tool. My professional career was exchanged to an everyday research career. My research question was: how can I get out of my cage of glass? Change means life in the groan zone where the mindset need to be open for change. But that is hard.
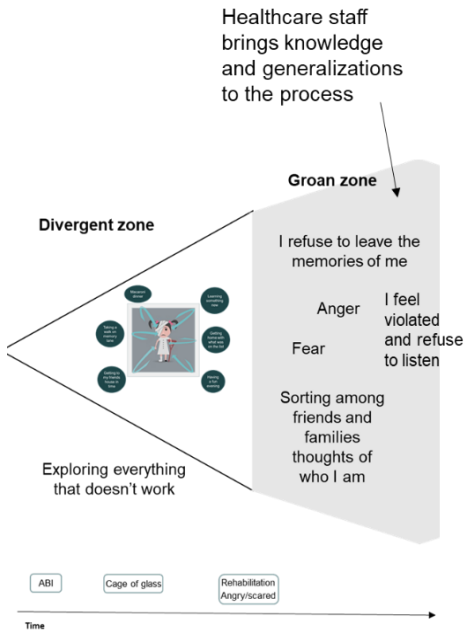
Figure 5.

Before getting a grip on the new life and my new brain I am angry and feel violated. In this state I am not ready to listen to an outsider. I need the staff to join me in the confusion. To let me know they don't have all answers but they are ready to discuss anything with me. This is not easy for health care professionals. In the groan zone they don't fix me, they stand next to me. One example, doctors told me it would probably be 5-10 years before my astrocytoma would return. In accordance with MCT and destiny readiness I accepted "shit happens" and gave myself 5 years to live. I then didn't need to think about what would happen thereafter. First the staff tried from the outside to lessen my worries with words like "it can take 7 or 8 years, don't think the worst." But by doing so they cognitively moved me from a safe zone where I had created a space of safety into a zone of worries. After a while they accepted my cognitive choice and in a way they then moved a step closer towards joining me in my groan zone. I became less alone. Together we could try different solutions. Another factor in MCT is activity, to create a safety space in time. Through activity one can manage time and limit the horizon of thoughts (19). First steps of rehabilitation is one way to use activity to conquer the moment.
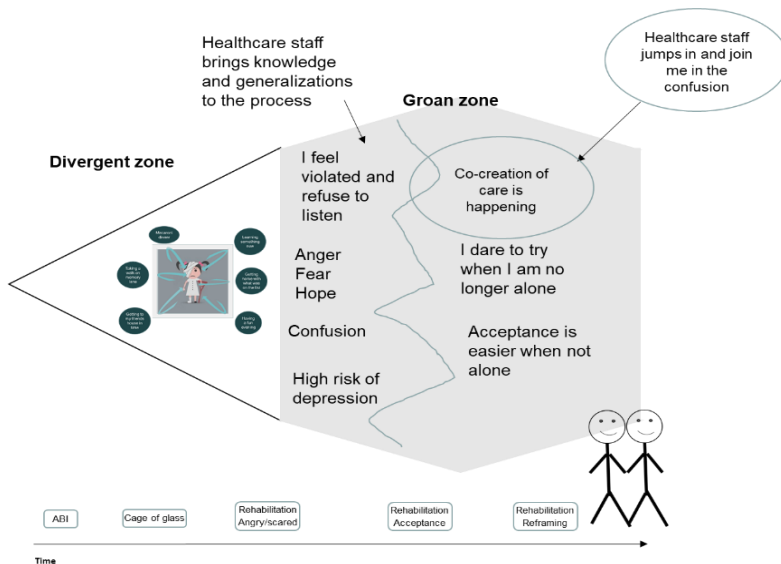
Figure 6.

It is important to not promise things that are not believable, instead telling the truth in a hopeful way may ease the process towards acceptance. When saying something that is not believable the person show he or she is not ready and moves away from my groan zone. Those relatives that are not willing to join the patient in the confusion need to step back in their predictions and judgements. Otherwise they risk slow the process down. In a healthy world significant others help each other to maintain the subjective reality. But in this process the subjective reality as well as the objective reality has changed. Often people want to say "everything will be fine" in different ways. But when fighting a brain injury, what is fine? In order to fully accept life as it has become the patient need to let go of old conceptions of life.

The longing for a functional life became an inspiration to innovative thinking and to designing solutions. I called myself a researcher of everyday life which enhanced my self-esteem some. Better self-esteem created more creative solutions. Barlach, Engberg and Pallesen (27) refer to a potential for increased patient influence by ensuring interaction and patient participation in the information exchanges. This provides patients with the opportunity to take responsibility for their own health development.

A must in order for rehabilitation to work life-long. Through a functional sensitivity in the suggestions the rehabilitation staff helped me find, create and modify personal tools for recovery. That sensitivity I have since copied and used in the ongoing rehabilitation process. Alongside with cognitive training I also exercised my body. I noticed how my cognitive functions became more alert when running regularly. The running served several purposes. It relieved me of some frustration, it gave me self-esteem and it also made me recognize myself, my brain was changed but my body still worked the same way as before. Better self-esteem made me dare to meet my fear which in my case was the world of everyday life.

Functional tools – Watching me fly

When I came back to rehabilitation after my trainee with making coffee I dared to try more. I listen to the staff and I also took their advice and personalized it to fit me. *I dared to fail, because I had succeeded*, I knew I could always make coffee. One by one I learned to find and open windows and doors in my cage of glass. I still jumped into an invisible wall sometimes but the more success I experienced the more I dared to see the crashes as a challenge to further understand and handle the new me.
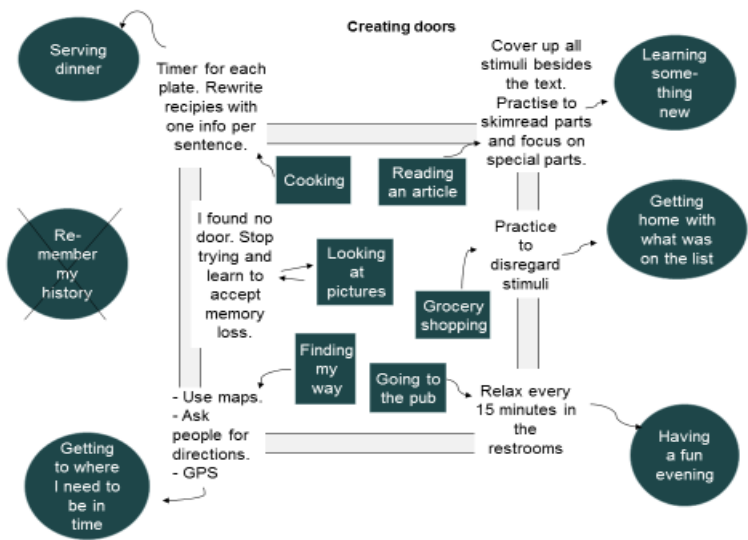

Figure 7.

Before I got sick I had plans on going into research. Now I was happy I could make coffee. If the first phases of failures and the confusion in the groan zone had not taken place I would not have been ready to accept my destiny. I needed time and help to change my mind-set and to adjust to new life expectancies. My academic research career was exchanged to an everyday life research career. The implementation of strategies had worked when making coffee during the summer. I now knew I could do it. But more prototypes for different issues in life needed to be created and it was now an iterative process going back and forth between the inspiration, ideation and implementation phase. I got *inspiration* from what didn't work in everyday life. In accepting that there were damages to my brain the search for solutions could start. *Ideation* through prototyping of tools and strategies was done together with the health care staff. One by one I learned to find and open windows and doors in my cage of glass. I still jumped into an invisible wall sometimes but the more success I experienced the more I dared to see the crashes as a challenge to further understand and handle the new me. In the process I also learned the more I exercised the better my brain worked cognitively. In 2008 I ran New York marathon, I was back working 75% and I was discovering life all over.
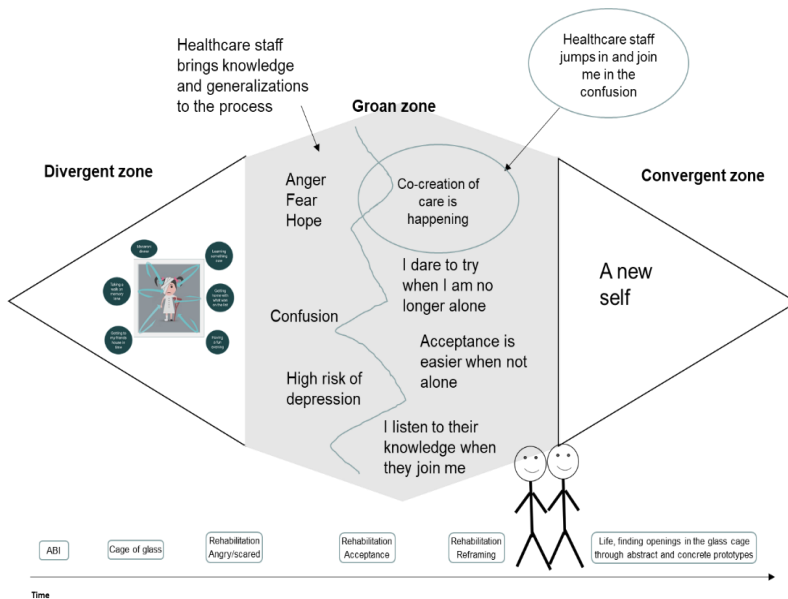

Figure 8.

Like making an orchestra play

Progressively, in 2012 my muscles stopped cooperating with me. MRI ruled out tumor and I got the diagnosis "functional muscle weakness." It was followed by a need to find new solutions to new problems. I brought my experiences from the last eight years with me and kept trying. I had to rethink everything I had been doing but I could methodologically use my experiences from before. I noticed a huge change, exercise now seemed to lessen my cognitive abilities. The old technique of running to help cognition did no longer work. It was a very lonely knowledge journey because no one wanted to join me in finding out what was really wrong and what to do about it. I got very bad mood swings which I did not understand.
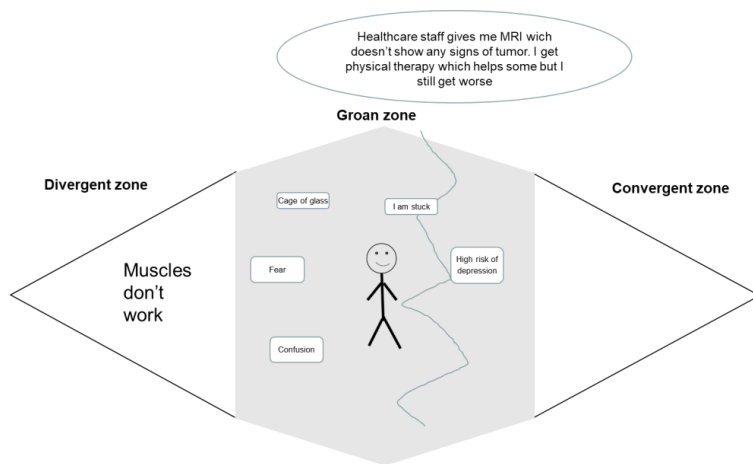
Figure 9.

In 2013 my hands started to shake a little bit and I asked to try Parkinson medication. After DaTScan indicated dopamine issues Madopark was given and I could move freely again. A new DaTScan showed no signs of Parkinson but medication helped and secondary parkinsonism was put as a diagnosis in 2014. I then got a dopamine agonist, Pramipexole, and suddenly most of my fatigue vanished. The headwind that had fought with my thoughts for more than 10 years suddenly disappeared. In studies carried out by the Nobel prize winner Arvid Carlsson a dopamine stabilizer molecule seem to help people in general with fatigue. A study of their molecule (-)-OSU6162 shows how it binds preferentially to a subpopulation of D2/D3 receptors, possibly predominantly extrasynaptic, and this may form the basis for the dopamine-stabilizing properties of (-)-OSU6162 (28). Life was back to normal, to a normal I barely remembered, before the tumor when I could think freely. I went back to the university and started my PhD studies in innovation engineering.

Stroke
In 2016 I suffered cognitive symptoms similar to those in 2004. I managed to cope through a recycling of strategies from before. I tried the different strategies. Running made it all worse, going back to only doing one thing at a time made me cope enough to live an ordinary life but my memory was vanished. In my mind I saw my research career once again disappear. Going back to previous strategies one of them had been the dopamine agonist. I tried to increase the dosage and that made the new issues almost disappear and I could continue my PhD studies. On my next yearly MRI signal disturbances was found in the back of my right frontal lobe, in insula and in cortex. It was interpreted as probable recurrence of the astrocytoma but after 11 months of no growth doctors finally decided I had suffered a mild stroke. But no one could say why and thus the fear of getting another one was eating me up. Since no one knows what happens when getting gliomas I can only rely on my beliefs which are that exercise has made me survive an astrocytoma for 14 years. I believe not running may give me a faster recurrence and a lesser chance of beating it again. However, running might shorten my aptt and risk giving me another stroke. How do you chose? I asked my doctors but from my perspective no one took me seriously until an article about stroke and pfo was published in NEJM (29). A year and a half after I suffered cognitive symptoms I got referred to a stroke specialist which jumped right into the groan zone with me. Together we discussed articles and symptoms and results from tests. In this co-creation we have found out that a pfo and low aptt could be to blame (30, 31). By closing the pfo I can relax from the fear of a relapse and continue exercise. I believe that surgery increases my chances of both long time survival and rise my cognition level through the running.

In design thinking the process of change is central. In a rehabilitative process user innovation is central. Each brain is different and patients need to find solutions to their issues. Oliviera et al. (11) studied patients' innovative behaviors and bring a patient-perspective to the innovative process. They argue;

"High patient-need coupled with low commercial activity in rare disease marketplaces creates both a need and incentive for patients and their caregivers to innovate for themselves to help them with respect to many quality of life issues."

This innovative process means changing something for the better. In my case, the diseases has made me come up with a grounded theory, Momentary contentment theory (MCT) (18, 19, 20) that in combination with the diamond of participation (14) may help others as well. As professor Arvid Carlsson put it when commenting my new brain damages in 2016 "it is like making an orchestra play" (32).

Conclusion

My rehabilitation can be described as a lifelong process, managed through different personalized strategies in the combined frame of design thinking, MCT and diamond of participation. By explaining the process of change, patients may get an understanding of what is happening and what is needed from them to move forward from an acquired brain injury. The groan zone is a scary place to be in but knowing one is not alone in combination with it being a phase may lessen the worries. MCT may help find feelings of safety in a chaos world. Looking at my successful rehabilitation through the theoretical frame of momentary contentment and design thinking the medical staff would be helped by realizing the different phases they need to explore in alliance with the patient. They inspire by making the patient realize and accept the new life, analyzing the new brain and all its possibilities. In the ideation phase the rehabilitation staff help by their generalized knowledge and by supporting the patient to personalize that knowledge. To build and modify prototypes in an iterative process towards health. Through implementation the patient tries the strategies and tools in everyday life. Here it is crucial for the staff to take one step back without disappearing. Let the patient fly but be ready to catch her when she falls. Not feeling alone is a major key to successful rehabilitation.
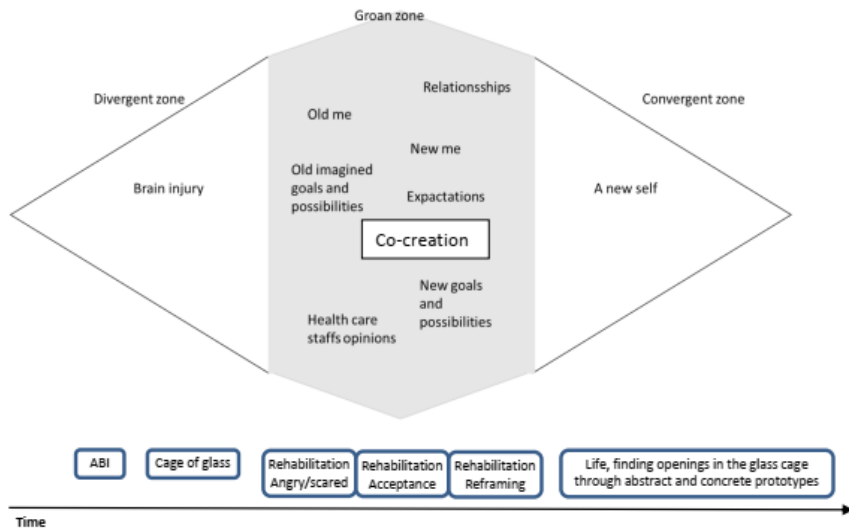

Figure 10.

Whenever one reaches true acceptance the world opens up with all kinds of possibilities. But acceptance is hard when you have no idea what you are about to accept. By dividing time into phases and understanding it is a process of learning the acceptance no longer means accepting a life within the cage of glass but rather opening up for a learning experience. You get to choose which paths to walk since you per definition have left all old tracks behind. It can be exciting like nothing else.

Ethical compliance

The authors have stated all possible conflicts of interest within this work. The authors have stated all sources of funding for this work. If this work involved human participants, informed consent was received from each individual. If this work involved human participants, it was conducted in accordance with the 1964 Declaration of Helsinki. If this work involved experiments with humans or animals, it was conducted in accordance with the related institutions' research ethics guidelines.

References

[1]   Zasler ND, Katz DI; Zafonte RD. Brain Injury Medicine, 2nd Edition: Principles and Practice. New York: Demos Medical Publishing, 2012.

[2]   García-Rudolph a, Gibert K. A Data Mining Approach for Visual and Analytical Identification of Neurorehabilitation Ranges in Traumatic Brain Injury Cognitive Rehabilitation. Abstract & Applied Analysis. 8/5/2015, Vol. 2015, p1-14. 14p.

[3]   WHO. Disabilities and rehabilitation. Accessed 2016 Feb 07. URL: http://www.who.int/disabilities/care/en/.

[4]   Momsen A; Rasmussen J, Nielsen CV, Iversen MD, Lund H. Multidisciplinary team care in rehabilitation: an overview of reviews. Rehabilitation Medicine 2012; 44: p 901-912.

[5]   Turner-Stokes L, Pick A, Nair A, Disler PB, Wade D. Multi-disciplinary rehabilitation for acquired brain injury in adults of working age. *Cochrane Database of Systematic Reviews* 2015; 12. ISSN: 1465-1858.

[6]   Turner-Stokes L, Poppleton R, Williams H, Schoewenaars K, Badwan D. Using the UKROC dataset to make the case for resources to improve cost-efficiency in neurological rehabilitation. Disability and Rehabilitation, 2012;34:22, 1900-1906.

[7]   Rittel, Horst, Webber M. Dilemmas in a General Theory of Planning. Policy Sciences, 1973; Vol. 4, pp. 155–169

[8]   Davila T, Epstein, Shelton. Making Innovation Work How to Manage It, Measure It, and Profit from It. New Jersey: Pearson Education, Inc., 2006.

[9]   Shergold P. Learning from Failure: Why Large Government Policy Initiatives Have Gone So Badly Wrong in the Past and How the Chances of Success in the Future Can be Improved. Canberra: Australian Public Service Commission, 2015.

[10]   Habicht H, Oliveira P, Shcherbatiuk V. User Innovators: When Patients Set Out to Help Themselves and End Up Helping Many. Die Unternehmung. 2012; 66(3):277-295.

[11]   Oliviera P, Zejnilovic L, Canhão H, von Hippel E. Innovation by patients with rare diseases and chronic needs. Orphanet Journal of Rare Diseases. 2015; 10:41.

[12]   Reason P, Bradbury H (Ed.). The SAGE Handbook of Action Research. Participative Inquiry and Practice. 1st Edition. London: Sage, 2001.

[13]   Zhang W, Levenson A, Crossley C. Move your research from the Ivy tower to the board room: a primer on action research for academics, consultants, and business executives. Human Resource Management. 2015; Vol. 54, No. 1. Pp. 151–174.

[14]   Kaner S, Lind L, Toldi C, Fisk S, Berger D. Facilitator's Guide to Participatory Decision-Making. San Fransisco: Jossey-Bass, 2014.

[15]   Thakur R, Hsu S, Fontenot G. Innovation in healthcare: Issues and future trends. In: (1) Subjective Personal Introspection; (2) Reliability, Mindfulness and Managing Healthcare. Journal of Business Research. 2012; 65(4):562-569.

[16]   Bates P, Robert G. Experience-based design: from re-designing the system around the patient to co-designing services with the patient. Qual. Saf. Healthcare. 2006; 15:307-310.

[17]   Brown, Tim. Change by design: how design thinking transforms organizations and inspires innovation. New York: HarperCollins publisher, 2009.

[18]   Sandén U. Nuets förnöjsamhet - en Grundad Teori med utgångspunkt i Nordnorskt vardagsliv (Today's contentment - a Founded Theory based on Northern Norwegian everyday life). Masterthesis, Lund University, 2014.

[19]   Sandén U. Momentary contentment. Exploring needs and possibilities in a psychosocial cancer context. Licentiate thesis: Lund University, 2017.

[20]   Sandén U, Harrysson L, Thulesius H, Nilsson F. Exploring health navigating design-Momentary contentment in a cancer context. International Journal of Qualitative Studies on Health and Well-being. 2017; 12(sup2): 1374809.

[21]   Sandén U, Nilsson F, Thulesius H, Hägglund M, Harrysson L. Cancer, a relational disease: exploring the needs of relatives to cancer patients. International

Journal of Qualitative Studies on Health and Well-being. 2019(1).

[22] Raman S, French T, Tulloch A. Design-led Approach to Co-production of Values for Collective Decision-Making. The Design Journal (serial online). July 28, 2017;20 (Supplement 1):S4331. Available from: Supplemental Index, Ipswich, MA. Accessed April 26, 2018.

[23] Lexell EM, Ohlsson K, Alkhed A. The group rehabilitation helped me adjust to a new life: Experiences shared by persons with an acquired brain injury. Brain Injury 3:2013.

[24] Ohlsson K, Alkhed A. Betydelsen av grupprehabilitering för personer med förvärvad hjärnskada (The importance of group rehabilitation for people with acquired brain injury). Rapport, Region Skånes universitetssjukhus, 2010.

[25] Sevetson A. Editor's Corner Change, Change, Change. Quarterly Journal of Government Information Practice & Perspective. June 1, 2005.

[26] Simon HA. The Sciences of the Artificial. MIT Press, Cambridge, Mass, 1969.

[27] Barlach A, Engberg A, Pallesen B. Interdisciplinary information design with an empowerment strategy. Stud Health Technol Inform. 2006;122:200-4.

[28] TolboomN, Berendse HW, Leysen JE, Yaqub M, van Berckel BNM, Schuit RC, Ponsen MM, Bakker E, Hoetjes NJ, Windhorst AD, Carlsson ML, Lammertsma AA, Carlsson A. The Dopamine Stabilizer (-)-OSU6162 Occupies a Subpopulation of Striatal Dopamine D2/D3 Receptors: An (^{11}C)Raclodride PET Study in Healthy Human Subjects. In: Neuropsychopharmacology 2015: 40, p 472-479.

[29] Søndergaard L, Kasner SE, Rhodes JF, Andersen G, Iversen HK, Nielsen-Kudsk JE, Settergren M, Sjöstrand C, Roine RO, Hildick-Smith D, Spence JD, Thomassen L; Gore REDUCE Clinical Study Investigators. Patent Foramen Ovale Closure or Antiplatelet Therapy for Cryptogenic Stroke. The New England Journal of Medicine, 2017 Sep 14;377(11):1033-1042.

[30] Lin CH, Kuo YW, Kuo CY, Huang YC, Hsu CY, Hsu HL, Lin YH, Wu CY, Huang YC, Lee M, Yang HT, Pan YT, Lee JD. Shortened Activated Partial Thromboplastin Time Is Associated with Acute Ischemic Stroke, Stroke Severity, and Neurological Worsening. In: Journal of Stroke and Cerebrovascular Diseases. Volume 24, Issue 10, October 2015, Pages 2270-2276.

[31] Song B, Deng W, Fisher L, Chou I, Oyer M, McMullin D, Lo E, Xu Y, Buonanno FS, Ning M. Abstract WP239: Real Time Prospective Measurement of aPTT Predicts Paradoxical Embolism in Cryptogenic Stroke. Stroke. 48(Suppl_1):AWP239, FEB 2017.

[32] Brodda, H. Hjälp mot hjärntrötthet efter skada (Helps against brain fatigue after injury). Accessed April 27, 2018 from: http://dinamediciner.se/nyheter/hjalp-mot-hjarntrotthet-efter-skada, 2017.

Paper IV

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Exploring health navigating design: momentary contentment in a cancer context

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ABSTRACT

Purpose: The technocratic and medicalized model of healthcare is rarely optimal for patients. By connecting two different studies we explore the possibilities of increasing quality of life in cancer care.

Methods: The first study captures survival strategies in a historically isolated Arctic village in Norway resulting in *Momentary contentment theory*, which emerged from analysing four years of participant observation and interview data. The second study conceptualizes everyday life of cancer patients based on in-depth interviews with 19 cancer patients; this was conceptualized as *Navigating a new life situation*. Both studies used classic grounded theory methodology. The connection between the studies is based on a health design approach.

Results: We found a fit between cancer patients challenging life conditions and harsh everyday life in an Arctic village. Death, treatments and dependence have become natural parts of life where the importance of creating spaces-of-moments and a Sense of Safety is imminent to well-being. While the cancer patients are in a new life situation, the Arctic people show a natural ability to handle uncertainties.

Conclusion: By innovation theories connected to design thinking, *Momentary contentment theory* modified to fit cancer care would eventually be a way to improve cancer patients' quality of life.

Introduction

Innovation is defined as the creation of something new that provides value to a specific customer, patient or user (Christensen, Grossman, & Hwang, 2009; Nilsson & Lindström, 2010; West, 1990). At the same time "... *innovation in health care* is defined as those changes that support health care practitioners focus on the patient by helping health care professionals work smarter, faster, better and more cost effectively" (Thakur et al 2012, p. 564). In healthcare a dominant view on innovation is that it is gained from external and formal research programs that are transferred to practice as a final step (Herzlinger, 2006). In other words, the technocratic and medicalized model of healthcare is rarely optimal for patients, but rather internally focused, that is, do not include the patient in the innovation process.

Momentary contentment theory emerges from a context where accidents and deaths are part of life and where helping each other is a necessity (Sandén, Harrysson, & Thulesius, 2015; Sandén, Thulesius, & Harrysson, 2015). In theory it has a potential fit with cancer patients where death is often a possible outcome. In order to explore the potential practical use of the theory we have identified different strategies (see results section), which in a health context may work towards

inclusion, safety and contentment. Momentary contentment theory is a classic grounded theory stemming from exploring safety and life choices within a small historically isolated Arctic Norwegian community. It shows mechanisms that have emerged from the historically rough living conditions dealing with the present moment, taking one incident at a time. This relative conception of time, however, stands in contrast to today's busy society. When helpfulness is a priority it means that people are delayed because they meet someone who needs help. In a comparative study between the various regions in Norway, Vea (2009) discusses how the prioritizing of the moment in Northern villages creates a lack of macro innovative economic thinking.

In a cancer patient study, we found a fit in both context and needs with Momentary contentment theory. The cancer patients show a fragmented way of searching for momentary contentment strategies towards inclusion, safety and a happier moment. We call this process *Navigating a new life situation*. In modern society's focus on economic growth it is hard to adopt a different way of viewing time and creating space in the moment. This may, however, be doable in order to find better ways of living with illness–adding a humanistic perspective to the technocratic medicalized model of healthcare.
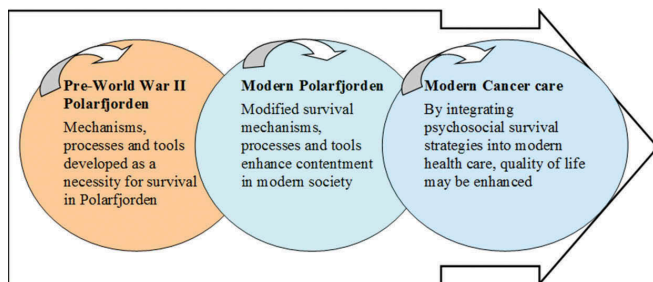
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Figure 1. A "recycling" process of psychosocial survival strategies.

Innovation potentials emerge out of the expressed needs of users and patients. Ackoff (1999) discusses problems as being a system of problems rather than isolated phenomena. Thus, solutions need to consider the whole system–a total contrast to patient testimonies in our interviews, where fragmented healthcare was an obvious obstacle to health. In Momentary contentment theory, we find a possible innovative frame of reference based in a similar context of living as for cancer patients. Our aim was to connect Momentary contentment theory and data from a cancer patient study with an innovative discourse on how to help individuals with serious illness (Figure 1). In this article we present the results as a contrasting approach we chose to call *health navigation design* where patients and their needs are at the centre in evolving health practices.

Methods

We used classic grounded theory (Holton & Walsh, 2017) to generate both studies resulting in *Momentary contentment theory* and *Navigating a new life situation*. When exploring the possibilities of connecting the two studies we chose to use design thinking and innovation theories as a means to be patient inclusive.

Research design

This article is based on two empirical research projects using classic grounded theory methodology in data collection, sampling and analysis. We started with a longitudinal observational study of a partly isolated Arctic village, complemented with interviews (Sandén, Harrysson et al., 2015). We then did a second study focusing on needs of cancer patients based on interviews. Finally, we did a third analysis connecting the two studies. In order to address the social innovation dimensions and to go from theoretical reasoning to innovation suggestions, we have adopted a design thinking perspective. Design thinking "addresses the needs of the people who will consume a product or service and the infrastructure that enables it" (Brown & Wyatt, 2010, p. 32). It was apparent in our interviews

with cancer patients that they struggled with navigating in a new and unfamiliar life situation. We chose to explore what we call *health navigation design*, that is, the design of individual patient's relationship to and communication with relatives, with other patients, with healthcare personnel, with products and with other significant people in their lives.

Data collection

Part one: "Momentary contentment"
- *Conceptualized data from four years (2010 to 2014) of interviews, talks and observations of everyday life surrounding an Arctic fjord, "Polarfjorden".* In accordance with the classic grounded theory dictum "All is data" Glaser, 1998) all written notes from observations, diaries, formal and informal interviews were coded and compared in discussions between the authors. Theoretical memos were written in conjunction with the coding and comparisons. A total of six focus group interviews and eight individual unstructured as well as semi-structured interviews were conducted. Each interview lasted between 2 and 6 hours. In order for us to capture the informant's views of their everyday lives they were asked to freely talk about their experiences. Some of the later interviews were semi-structured in order to catch a specific social aspect. We also analysed field notes from 15 targeted conversations and 50 informal, semi-structured conversations with both women and men from Polarfjorden and adjoining areas. All informants were shown the transcripts from their interview as well as of field notes from conversations and observations. They were given the possibility to suggest corrections due to misinterpretations. No informant suggested corrections.

Part two: "Navigating a new life situation"
Interviews with cancer patients. Detailed fieldnotes were collected from six focus-group interviews, two individual interviews and a follow-up individual interview with one cancer patient in 2015 (Sandén, 2016). The patients were between 20 and 70 years old, both women and men. The represented cancer illnesses

were acute myeloid leukemia, head and neck cancer, esophagus cancer, prostate cancer and bladder cancer. The interviews were unstructured and lasted between two and three hours. The question was: "Please tell me about your lives." Then the informants discussed various related topics while we as interviewers listened. In some interviews semi-structured questions, not pre-prepared, were used at the end of the interview to confirm previous analysis or to avoid misunderstandings. For example: "What did you mean when you said you didn't believe them?" A total of 19 patients who had undergone different types of cancer treatments were included. All of the patients were considered cured or in disease remission. Semi-structured interviews with a specialized cancer care nurse and a cancer care physician were also conducted. The aim of these interviews was to explore seriously ill persons' needs and concerns in everyday life and how they try to resolve them. The regional ethics committee at Lund University approved the study (Reg nr 2015:53).

Theoretical sampling

In accordance with classic grounded theory, we theoretically sampled by making new decisions regarding what the next data collection would be after each interview (Glaser, 1978).

Part one: "Momentary contentment"

We started with interviewing elderly in groups of three with the one question "Please tell me about your lives". This was a way to collect data from both what they said, how they said it and what they chose to/not to talk about. We then interviewed people in working ages to get age diversity of participants. When patterns and variations appeared in the analysis of data, we chose to collect new data as new questions arose. We continually interviewed the village's oldest individual, 97 years of age, thus collecting notes from more than 10 hours from him talking about the village from a historical point of view. His stories were at the end of the study tested against data from the local historical and story-telling literature (Bottolfsen, 1995; Lauritzen, 2005; Rørtveit, 2008).

Part two: "Navigating a new life situation"

We conducted unstructured interviews in order to let the participating cancer patients decide what they wanted to talk about. Then we did two individual interviews to see if their content differed from focus group data. We also did two follow up semi-structured individual interviews to see if our interpretations from the group discussions differed from those particular participant's views, which they did not. In these interviews we did not use a fixed form of questions, but notes from previous group discussions (Sandén, 2016).

Classic grounded theory analysis

Part one: "Momentary contentment theory"

New data was collected and analysed until further data did not provide any new information and saturation was reached. At this stage the formulated theory was modified in light of relevant existing literature (Glaser, 1998). Fieldnotes from both interviews and observations and then theoretical memos were written and drawn in various shapes and forms in the constant comparative analysis. Grounded theory focuses on incidents and memos rather than persons (Glaser & Strauss, 1967), and in this study the number of incidents coded and compared amounted to several hundred.

The memos were coded, categorized and sorted. After each interview or accrual observation new material was coded, analysed and compared with previous results until new data no longer gave new information, that is, saturation was reached (Glaser, 1998). The concepts were gradually developed to explain the informants' attitudes toward life. The core category *Momentary contentment* was finalized in May 2014 and since then, memos and fieldnotes were written without discrimination, but interpretation and analysis was done selectively towards that core category. When no new information was reached through data collection all memos were compared to find relationships between categories and concepts letting theoretical codes emerge. Eventually a grounded theory of *Momentary contentment* was generated, explained by the sub-core categories: "Doing safety", "Destiny readiness" and "Middle consciousness".

Part two: "Navigating a new life situation"

The same classic grounded theory analytical method was used as described above. After each interview, new data was coded, analysed and compared with previous data until saturation was reached. What has emerged so far is not a saturated grounded theory but a conceptual description called "*Navigating a new life situation*".

Part three: "Health navigation design"

Navigating a new life situation is compared to *Momentary contentment theory* and other research. Both memos and final analysis of the studies are compared in order to search for differences and similarities in needs and solutions, which is further discussed throughout this article.

Fit, relevance, workability, modifiability and limitations

The results in a grounded theory study are not reports of facts, but rather probability statements about the relationship between concepts or an integrated set of conceptual hypotheses developed from empirical data. Grounded theory is thus judged by fit, relevance, workability and modifiability (Glaser, 1998, p. 18). Fit

and relevance to both studies were achieved through continuous comparative analytical work. By focusing on what the informants chose as important topics we thereby allowed the main categories to emerge. The workability shows in momentary contentment theory how the core category, momentary contentment, frames our discoveries with the three main categories and explains what participants are doing to resolve their main concern. The cancer study has not lead to a new theory and has thus no workability of its own, but is used in the modifiability part. Modifiability of the studies was performed by connecting them.

Limitations are in the number of cancer patients involved and a lack of regional difference since they all come from a couple of regions in Sweden. The comparison between the two studies are, however, not based on regional area but in the context of life conditions. The regions of the cancer patients and the area where Momentary contentment theory has originally emerged are approximately 2000 kilometres apart. Momentary contentment theory has emerged from living in a context close to hazards and accidents, in so the context is similar to that of cancer patients. In order to fully know whether Momentary contentment theory has bearing on cancer patients on a more generalized level, we conclude that there is a possible fit and a need for more studies.

Theoretical frame of references

Inspiration from Fraser (2005) allows us to further argue for redistribution of resources (e.g., new innovations) to enhance abilities for recognising specific needs among individuals providing opportunities for user representation in decisions. It would add to growing personal capabilities for participation, such as in promotion of personal emancipation and control as well as social inclusion. Inclusion of a patient voice is met by involving patients starting at the very beginning of the innovation design process. True patient inclusion in innovation requires "strong leadership to challenge traditional thinking and practices; a robust commitment to collaboration and partnership working; and a willingness to invest time in establishing a culture and infrastructure which values and promotes the patient perspective" (McNichol, 2012, p. 221).

In order to design a patient-centred psychosocial care we discuss innovation possibilities based in design thinking where each individual is the starting point and they themselves express needs and solutions. This is well in line with recent discussions on innovation within research in social work (Phillips & Shaw, 2011) and the emergent perspective raised by Essén and Lindblad (2013). In such a perspective we can gain deeper insights and better understanding of each patient's context and needs, hence making a positive difference for those affected by the innovation. Christensen et al. (2009) argue that approximately 50% of consumed US healthcare is driven by physician and hospital supply, not by patients' needs or demand. This clearly supports us in the endeavour to better understand and illuminate patient needs.

Existing innovation implementation ideas include frameworks such as Rogers' (1983) innovation attributes for adoption, Glaser's (2009) prescriptive factors and van Achterberg, Schoonhove and Grol's (2008) evidence-based implementation strategies. Implementing innovation processes within social and health contexts has been difficult (May, 2013; Nilsson, 2014). Looking at design research the development within manufacturing industry has gone from product-orientation, via process-orientation, to cross disciplinary integration (Larsson, 2005). Lean thinking is a response to competitive pressure, whereas Agile thinking has to do with the sharing of resources, technologies and risks among companies (Larsson, 2005; Nagel & Dove, 1991). We argue similar needs for healthcare: a move from traditional healthcare to a cross-disciplinary care with a health focus design.

Health promoting contexts

When looking for a holistic view on health, Aaron Antonovsky's studies on health-promoting components became a natural source of data. Antonovsky developed the salutogenic theory. It connects cognition, behaviour and motivation and indicates sense of coherence (SOC) as the single most important ability to mentally survive hardship. A SOC consists of three components: comprehensibility, manageability and meaningfulness (Antonovsky, 1996); it is not bound by cultural context, but any culture can fit the concept in accordance with their culture (Antonovsky, 1996). The Momentary contentment theory emerged from applying classic grounded theory methodology to study the mechanisms behind dealing with life conditions before World War II in an isolated Arctic village where deaths, fishing boats perishing in ocean storms and tuberculosis and other diseases on shore were a natural part of life (Bottolfsen, 1995; Lauritzen, 2005; Sandén, Harrysson et al., 2015).

Both salutogenic theory and Momentary contentment theory have evolved from empirical studies of health in connection to various forms of hardship. But where Antonovsky chose to examine healthy-sick as opposing forces on a scale regarding what makes a person move towards health, our field studies have led us to focus on contentment, safety and an adaptive time perspective. An important base for momentary contentment is a surrounding frame of safety. Through altruism, cognitive tools, middle consciousness and an adaptive time perspective, a Sense of Safety is created in an otherwise unpredictable context. Sense of Safety is thus to *Momentary contentment theory* what SOC is to

the salutogenic theory. We have neither in interviews nor observations in the momentary contentment study discovered the reflection of SOC that Antonovsky presents. None of the elderly in the Arctic expressed any meaning or SOC to their hardships–quite the opposite. Instead, they demonstrated a genuine ability to place uncontrollable difficulties in a *middle consciousness*, reformulating problems into solutions and using laughter as therapeutic confirmations. In other words, they were showing adequate ways of not having to reflect on purpose and meaning. With symbolic statements like "done with it" and "this is just the way it is" the informants moved on without requesting further context and meaning.

One main difference in the origins of salutogenic theory and Momentary contentment theory is the contexts in which they were studied. Antonovsky met concentration camp survivors and explored their needs and strengths (see, for example, Kvåle & Synnes, 2013). As for Momentary contentment theory, our informants lived in a partly isolated environment where accidents and deaths were still apparent. Where salutogenic theory and SOC evolved from people in need of coping with terrible things from the past, Momentary contentment theory emerged from an environment where people need to cope with what happens in the present moment. Momentary contentment shows how nature's duality in the Arctic environment allowed hope and *destiny readiness* to live side by side in a collectivist spirit of enjoying life and feeling happy with what is; dealing with one moment after the other; placing the unmanageable in a *middle consciousness* creates a breathing space in the present–something often needed in a cancer context. Here and now the problem disappears, ready to be addressed when needed or when it becomes clear due to the need for help.

Momentary contentment theory

Momentary contentment theory explains a culture of safety, joy and living in the moment. This is attained by activity, inclusion, altruistic helpfulness, acceptance of life changing events and an ability to separate negative from positive. Momentary contentment also separates the present moment from past and future expectations and has three categorical dimensions: (1) Creating safety, (2) Destiny readiness and (3) Middle consciousness.

Creating safety

Creating safety is a social norm that brings order through activity and contributes to actually being able to influence one's own life, not only having a sense of doing so. Creating safety is based on a culture of helpfulness stemming from a time when helping out was a necessity for survival. Today it is rarely a question of life and death, but the altruistic helpfulness works contentment enhancing, both for

those who help and for those who receive help. Creating safety is also visible through group responsibilities in including individuals and in collective concerns for shared functions, such as care and a local store (Sandén, Harrysson et al., 2015).

Destiny readiness

Destiny readiness is an individual mental positioning–a way of thinking where there are no expectations that life should be easy. Destiny readiness involves cognitive preparedness helped by linguistic tools for dealing with "what is". An example is the expression "done with it", which is used as a tool to move on from dwelling on something negative. Another expression "we know where we live" is used to accept the climates' effects with, for example, recurring storms and flooding. Through linguistic expressions one can find ease in a rough situation (Sandén, Harrysson et al., 2015).

Middle consciousness

Middle consciousness is another mental positioning. It deals with worries that, despite the other Momentary contentment balancing mechanisms of Creating safety and Destiny readiness, are still present. Middle consciousness triggers a separation phenomenon; it gives an ability to switch between levels of consciousness and to place worries in a "standby" mode. In this standby mode, the healthy parts in people's lives are highlighted without denying any illnesses or disabilities. Middle consciousness, together with Creating safety, includes offering help when help can be given, but otherwise promoting a focus on health (Sandén, Harrysson et al., 2015). This ability of separating parts of life brought on by Middle consciousness has its origins in a historically needed focus on the present moment, emphasizing the strength in every human being (Bottolfsen, 1995; Lauritzen, 2005; Rørtveit, 2008; Sandén, Harrysson et al., 2015). Momentary contentment is a theory with a potential for health promotion. When reviewing previous research, the psychosocial survival knowledge behind Momentary contentment shows a general but fragmented analogy with literature on what creates happiness, joy and satisfaction, linguistically as well as cognitively and behaviourally (Bauman, 2008; Egonsson, 2011; Haller & Hadler, 2006; Norman, 1998; Sandén, Harrysson et al., 2015). The theory is further explained in an article in *Grounded Theory Review* (Sandén, Harrysson et al., 2015).

Creating the moment–Past and future are relatively easy concepts to relate to, but what about the present moment? The perception of "now" can be seen as a momentary, barely observable tile in a chronological perspective; or as a phenomenological momentary situation, free from the environment in both time and space; or, like a subjective abundant experience, like a flow of the Greek kairos. Kairos means a time

that does not follow the clock, and is perceived differently in different situations for different people. Kairos is a moment of indeterminate time in which an event of significance happens. Each now is a "critical juncture", and every critical moment is a moment of kairos. That is because every moment creates the context in which the next moment will take place. Kairos is a golden opportunity to act in different ways to influence and change one's fate, maybe just for the minute ahead or perhaps for life (Stern, 2004).

It is paramount in the Western world to establish, and relate to, a timely perspective. Studies on ex-prisoners living in dark rooms have demonstrated psychological problems and they often find a way to assess time. There is a need to find a coherent framework, regularity and predictability for the individual (Lasane & O'donnell, 2005). The social perception of time is central to a community's culture and differences in the perception of time distinguish one culture from another. The view of time within a community is often hidden, unconscious and difficult for outsiders to perceive (Levine, 1996). Momentary contentment shows how time can be viewed with various references, such as seasons, and how an integration with the annual cycle helps create contentment when living in that environment. During the dark time people in the Arctic village sleep more, while summertime without sunset means reduced sleep, increased activity and even sleepless nights: allowing oneself to get tired of the darkness and then happily face the sun. This is done on a collective basis (Sandén, Harrysson et al., 2015). Translated into a patient perspective, one can learn to allow the body to become tired of treatments, but also joyfully meet a positive test result and create space for momentary contentment. This can be hard for relatives to recognize and explanatory models might be needed since the relatives are not living with the same time horizon.

Momentary contentment and cancer patient needs

The results from interviews with cancer patients show similarities with Momentary contentment both in respect of experienced needs and perceived contexts. Both contexts have closeness to death and a need for help attached to them, and it is hard to predict who will be the next to get very ill or die. However, the cancer patient informants show different abilities in dealing with these needs. Our cancer patient study often showed a fragmented unknown life based on solitude instead of inclusion. *Creating safety* was seen in cancer patients' yearnings for altruistic actions. Many cancer patients had found ways to use activity and helpfulness as tools for feeling better. However, they expressed difficulties in balancing their need for help with wishes to provide help for others. Inclusion was found within patient groups and organisations. However, they expressed difficulties in balancing their need for help with wishes to provide help for others. Inclusion was found within patient groups and organisations. However, *competitive parlance*, that is, comparing the seriousness and differences of treatments and prognosis and discussing them in a hierarchical way, was identified in the focus groups of patients sharing the same diagnosis. This verbal competition of cancer suffering worked contrary to inclusion. Yet, when mixing patients with different diagnoses within a focus group, competitive parlance was not seen. *Destiny readiness* was visible in our cancer patient study in the concept of hope where patients expressed uncertainties, misunderstandings and inconsistencies. All patients expressed a hope that "lives within", where there is an opening for a *destiny readiness*, but many also expressed a feeling of being pushed by relatives, friends and healthcare staff towards being positive and cognitively expect hope. Thereby they also had thoughts about future fears and illness. *Middle consciousness* is apparent for cancer patients in their sporadic and fragmented attempts to navigate between feeling healthy and feeling sick with a fear of death.

Results and discussion

Momentary contentment theory explains a culture where old survival strategies and patterns of behaviour live on. We have also chosen to listen to and to analyse cancer patients' stories about their everyday lives rendering the concept *Navigating a new life situation*. Cancer patients expressed a need to navigate in a context where the illness creates a risky future as well as relational difficulties and shows a need for momentary coping strategies, for example to temporally encapsulate fear of death. In both the cancer patient navigating study and the Momentary contentment study the informants describe a life where death is a part of present life. They show similarities in needs, but where the cancer patients describe a new life situation with fragmented coping skills *Momentary contentment theory* shows how a well-developed collective external support system can create stability, a sense of belonging and security. This structure is something to fall back on when life is harsh (Sandén, Harrysson et al., 2015). Cancer patients expressed that healthcare staff continuity and knowing where to call to get help was very important to their psychosocial health. This is hard to achieve in todays' fragmented healthcare system (Nilsson, 2014) and patients lack a *Sense of safety*. Holton (2007) explains in a grounded theory how too much change can lead to a loss of autonomy and identity for many knowledge workers. Holton suggests a need of rehumanization through fluctuating support networks:

"*mutual engagement provides the arena for the release of collective creativity. It offers challenge, experimentation and learning. Mutual engagement builds confidence, commitment and energy. It enhances the bonding of network members.*" This connects to the Communities of practice, explained by Etienne Wenger (2000) as "groups of people informally bound together by shared expertise and passion for a joint enterprise–engineers engaged in deep-water drilling, for example, consultants who specialize in strategic marketing, or frontline managers in charge of a check processing at a large commercial bank". Through virtual media, communities of practice could be created from a *health navigation design* perspective, improving patient skills and increasing knowledge in how to embrace momentary contentment.

Applying destiny readiness and the complexity of hope

With a diagnosis that involves the risk of a shortened life, healthcare professionals frequently try to inspire hope. Attempts to inspire sometimes evolve into demands, thus cognitively tend to draw the patient from the present moment into thinking about an insecure future (Sandén, 2006). This is adjacent to Benzein's conclusions about hope in palliative care, which distinguishes "living with hope" from "to hope for something": "living with hope", that is, being hopeful relating to what is present; "to hope for something", that is, hoping relating to future and changes (Benzein, Norberg, & Saveman, 2001). Most of our respondents had a fairly good prognosis. However, they all shared thoughts and feelings concerning life and death. The interviews showed an importance of offering hope. But, in order for hope to be assimilated without evolving into a demand, it must comply with a person's knowledge. Since our interviews were unstructured the patients decided what to share. They rarely mentioned the word hope but the phenomenon of hope was present in their stories. When talking they rather expressed concrete and symbolic ways to handle uncertainties. We found symbolism as well as concrete examples of actions, people or issues placed in between the present moment and possible death. It could be the surgeon symbolizing a personalized hope through magnificence "he will save me" or an activity plan of what to do between today and a possible relapse. A theory of equilibrium of hope shows how people create instinctive compensatory strategies to increase the existential hope, including the denial of life-shortening information or by increasing momentary enjoyments of life (Thulesius, Håkansson, & Petersson, 2003). One way to interact with patients on this subject, in line with *Momentary contentment* (Sandén, Harrysson et al., 2015), is to accept and respect the disease, patients' knowledge and beliefs and to simultaneously accept that life with all its surprises, positive and negative, may go on. There is a need for more research on patients with possible deadly diseases, but where the present individual prognosis looks fairly good, and to position hope within a contented safety-enhancing context.

Crisis management by middle consciousness and symbolic actions

A person's subjective life situation experience is more important to subjective quality of life than the actual life situation. This refers to both medical and psychosocial factors, such as perceived health, close social relationships and perceived financial situation (Haller & Hadler, 2006). In other words, self-care and psychosocial innovations ought to be of great importance to healthcare improvements. By a *Middle consciousness* approach one can place illness in a standby mode and thereby separate sick from healthy; seeing disability when help is needed, and not seeing it when help is not needed. *Momentary contentment* indicates how it is possible to, at one point, act with helpfulness and then, at another point, treat the same person as fully fit, thus allowing all parts of a person affected by cancer to exist side by side (Sandén, Harrysson et al., 2015). In the cancer patient interviews we found small activities of health and normalcy to be symbolically helpful for patients in defining their healthy selves in relation to their illness and their symptoms. For example, while hospitalized they were doing something healthy like making a sandwich or changing clothes. This proved of great value in allowing the complete person to exist, the sick part alongside with the cancer part of oneself. Other examples were to allow fear to be expressed during a specified time frame or to keep a healthy part of social life alive while being hospitalized. These symbolical approaches were similar to *Momentary contentment* strategies but non-reflected and fragmentized. By bringing together *Momentary contentment* strategies with patient narratives we may be able to create new supportive tools; perhaps a pick and use manual in how to use different symbols, rituals and approaches in a personalized manner.

Altruism induced contentment

In a summary of various research data on altruism a strong link is found between altruism and wellbeing, happiness, health and longevity–as long as helping others does not overwhelm a person. Altruism results in positive social inclusion, in distraction from personal problems and self-centred anxiety, in increased wellbeing combined with experiences of meaning and purpose and in a more active lifestyle. People who are involved in helping others generally describe their self-esteem as better than those not involved in such activities (Post, 2005). In a setting where helpfulness is based on altruism, each situation contributes to greater

contentment for those involved. Altruism contributes to increased safety feelings for both those being helped and for those who do the helping. Each time altruism is practiced it increases a trust that you will not stand alone for future needs of help (Sandén, Harrysson et al., 2015). In our patient interviews this wish was expressed as a "need to be needed". There is a need for a supportive psychosocial context. Support groups, for example, increase patient empowerment and lead to greater participation, increased search for knowledge about the disease and generally improve the patients' abilities to navigate their disease (Weis, 2003).

Inclusive contentment

A prerequisite for Sense of Safety–a feeling of enhanced safety in a community or group–is an ongoing inclusion process. Inclusion is established when individuals have a sense of belonging to a group and perceive themselves to be a distinct and unique member of it. This must be combined with a group responsibility of including the individual, rather than the individual connecting to the group (Jansen, Otten, van der Zee, & Jans, 2014; Shore et al., 2011). If the group does not take responsibility for such inclusion, it may lead to marginalisation of people who do not fall within the behavioural norms of the group (Ytterhus, 2012).

Momentary contentment theory explains how strategies for upholding heterogeneity strengthen inclusion processes within groups. Such strategies combine belonging with authenticity and include techniques for dealing with heterogeneity (Sandén, Harrysson et al., 2015). Many of these strategies can be modified to fit modern healthcare and be implemented within patient groups. By, for example, mixing different diagnoses in a group, many of the homogeneity problems of "not fitting in", "being different" or "not being sick enough" that were apparent in our patient interviews are reduced.

Humour and contentment

There are many testimonies of conversations between doctors and patients where serious health aspects are reflected in and by humour:

> I think that what we regard as funny and what we regard as witty and sometimes sarcastic, are all part of what we regard as humorous. Whether or not something is humorous is whether or not it makes us giggle or smile or laugh. It's interesting that there is a substantial literature about the health benefits of laughter. You sometimes hear the adage that laughter is the best medicine, so putting humour and laughter together is important. (Geriatrician Cornelius Foley, NYC, in interview about palliative care and humour, Monahan, 2015)

Humour is a Momentary contentment strategy containing both laughter and affirmation. Through humour a

victimized person is drawn towards the present moment. This gives little room for dwelling and for expressions like "it will probably get better" or "time heals all wounds", described by several cancer patients as provoking. Confirmation is rather created in laughter and contributes to contentment and an inter-subjective confirmation "I know you know I know" without a need to talk about what has happened (Sandén, Harrysson et al., 2015). During the patient focus groups, we observed similar confirmations where humour was used to move on and cope with situations.

Nature brings contentment

Sceneries bring another kind of support. Momentary contentment theory shows how people's relationship to nature, although different, bring similar internal power enhancement (Sandén, Harrysson et al., 2015). The role of nature did not come up as an issue in our study of cancer patients, but there are several studies that show nature's role as a healing force (Sandén, Harrysson et al., 2015; Strang, 2007). Aside from specialized green rehabilitation stations, hospitals very often miss the point of nature's role in people's minds. Technology exists, both interactive and non-interactive, that can create environments that partially fill a similar function, for example moving panoramas. By an innovative linking of technical, medical and psychosocial knowledge we have a unique multi-disciplinary potential to contribute to better psychosocial health among patients and families.

Bridging knowledge

Above are areas of possible innovative fits between Momentary contentment strategies and cancer patients' testimonies on a general level. In order to make them become non-fragmented innovation processes these areas need to be linked together in a personalized manner for individual patients. Already existing psycho-pedagogical tools to increase knowledge about the disease show that specific and clear disease information increases patient empowerment and participation. From participation grows knowledge (Alden, 2014; Kane, 2014; Schmidt et al., 2015). There are several studies as well as patient testimonies pointing to the importance of patient participation and self-action in both diagnostic and treatment processes (deBronkart, 2011; McDonald, Bryce, & Graber, 2013). However, we argue, there is a need to design solutions as a whole and not look at each issue separately.

Future research

The presented areas, aligned in comprehensive programmes allowing patients to be active as well as interactive, are potential innovations in today's fragmented healthcare. We suggest that the modification of

Momentary contentment theory to fit with cancer patients *Navigating a new life situation* outlined in this paper is a starting point of an explorative implementation route for the presented areas into a healthcare context. There is certainly a need to further investigate active patient centred health promoting processes and structures in the continuum of care. Nonetheless, as problematized in May's (2013) studies of innovation processes within social and health contexts, resulting in the Normalization Process Theory (NPT), there are a number of difficulties when it comes to promoting change in health care contexts. The NPT is suggested to provide understanding of the actual work that goes on in the socio-political context as well as the socio-technical practices. There are both structural and process-related difficulties obstructing implementation to be addressed in general as well as in specific situations (May, 2013; Nilsson, 2014). Furthermore, as concluded by Page (2014, p. 230) "the best way to innovate is from getting people together with different skill sets and devising questions that need to be answered." Hence, it includes patients, relatives, staff, politicians and researchers as well as future, yet unknown actors. By combining *Momentary contentment theory* (Sandén, Harrysson et al., 2015) and Patient Process Orientation (Nilsson, 2014) with NPT (May, 2013) and a health navigation design perspective we suggest that contentment enhancing innovation practices such as virtual communities of practice (Wenger, 2000) or fluctuating support networks (Holton, 2007) is an approach well worth trying.

Conclusion

By analysing interview and observational data using grounded theory we found similar everyday challenges between people in Arctic Norway and Swedish cancer patients. In Arctic Norway, *Momentary contentment theory* is the grounded theory conceptualization that explains how creating a Sense of Safety and room for activity and joy in the present yields well-being. We suggest that implementing *Momentary contentment* approaches for cancer patients would help them to improve *Navigating a new life situation*. This would be achieved through an adaptive view on time in combination with cognitive tools helping patients to act on what is possible to influence and to simultaneously let go of that which is not. Thus, "space-of-moments" with a *Sense of Safety* can be created in an unpredictable context. Patients' tactics could change from today's fragmentized attempts to the concrete and explainable by a user's manual of *Momentary contentment* strategies that also would make it easier for patients, family and friends to understand the patient's situation and actions. Finally, we suggest that through a health navigation design, the contentment safety-enhancing mechanisms from *Momentary contentment theory* may contribute to capacity building and eventually enhance quality of life.

Disclosure statement

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Notes on contributors

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Authors' contributions

The first author carried out the data collection. All authors participated in the analysis and the design of the study. All authors read and approved the final manuscript.

References

Ackoff, R. (1999). *Re-creating the corporation: A design of organizations for the 21st century*. New York, NY: Oxford University Press.

Alden, D. L. (2014). Decision aid influences on factors associated with patient empowerment prior to cancer treatment decision making. *Medical Decision Making*, *34*(7), 884–898. doi:10.1177/0272989X14536780

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International*, *11*(1), 11–18. doi:10.1093/heapro/11.1.11

Bauman, Z. (2008). *The art of life*. Cambridge: Polity.

Benzein, E., Norberg, A., & Saveman, B.-I. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine*, *15*(2), 117–126. doi:10.1191/026921601675617254

Bottolfsen, Ø. (1995). *Lofoten og Vesterålens historie 1700 - 1837: Fiskerbondesamfunnet* [The history of Lofoten and Vesterålen 1700-1837: A fishing farmer society]. Stokmarknes: kommunene.

Brown, T., & Wyatt, J. (2010). Design thinking and social innovation. *Stanford Social Innovation Review*. Retrieved from http://ssir.org/articles/entry/design_thinking_for_social_innovation

Christensen, M., Grossman, J. H., & Hwang, J. (2009). *The innovator's prescription – A disruptive solution to health care*. New York, NY: McGraw Hill.

deBronkart, D. (2011). Let patients help. TED Talk. Retrieved from http://epatientdave.com/videos/ (accessed 22 February 2015).

Egonsson, D. (2011). Zygmunt Baumans levnadskonst [Zygmunt Bauman's way of life]. *Filosofisk tidskrift*, *32*(4), 3–16.

Essén, A., & Lindblad, S. (2013). Innovation as emergence in health care: Unpacking change from within. *Social Science & Medicine*, *93*, 203–211. doi:10.1016/j.socscimed.2012.08.035

Fraser, N. (2005). Reframing justice in a globalizing world. *New Left Review*, *36*, 69–88.

Glaser, B. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.

Glaser, B. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Mill Valley, CA: Sociology Press.

Glaser, J. (2009). Implementing electronic health records: 10 factors for success. *Health Finance Management*, *63*(1), 50–54.

Haller, M., & Hadler, M. (2006). How social relations and structures can produce happiness and unhappiness: An international comparative analysis. *Social Indicators Research*, *75*(2), 169–216. doi:10.1007/s11205-004-6297-y

Herzlinger, R. E. (2006). Why innovation in health care is so hard. *Harvard Business Review*, *84*(5), 58–66, 156.

Holton, J. (2007). Rehumanising knowledge work through fluctuating support networks: A grounded theory. *Grounded Theory Review*, *6*(2), 74–85.

Holton, J. A., & Walsh, I. (2017). *Classic grounded theory: Applications with qualitative and quantitative data.*, Los Angeles, CA: Sage publications.

Jansen, W. S., Otten, S., van der Zee, K. I., & Jans, L. (2014). Inclusion: Conceptualization and measurement. *European Journal of Social Psychology*, *44*(4), 370–385. doi:10.1002/ejsp.v44.4

Kane, P. (2014). A pathway to empowerment: Evaluating a cancer education and support programme in New Zealand. *European Journal of Cancer Care*, *23*(5), 668–674. doi:10.1111/ecc.12188

Kvåle, K., & Synnes, O. (2013). Understanding cancer patients' reflections on good nursing care in light of Antonovsky's theory. *European Journal of Oncology Nursing*, *17*(6), 814–819. doi:10.1016/j.ejon.2013.07.003

Larsson, A. (2005). *Engineering know-who: Why social connectedness matters to global design teams* (Doctoral thesis). Luleå University of Technology, Luleå, Sweden.

Lasane, T. P., & O'donnell, D. A. (2005). Time orientation measurement: A conceptual approach. In A. Strathman & J. Joireman (Eds.), *Understanding behavior in the context of time. Theory research and application*. Mahwah, NJ: Lawrence Erlbaum Associates.

Lauritzen, H. N. (2005). *Mitt liv som nothun. Om silda og Eidsfjorden i eldre og nyere tid* [My rough life as a fisherman. About herring and Eidsfjorden in past and present]. Sortland: Sortland kommune, SpareBank 1, Norges sildesalgslag, Norges råfisklag, Norges Fiskarlag.

Levine, R. V. (1996). Cultural differences in the pace of life. In H. Helfrich (Ed.), *Time and mind*. Seattle, WA: Hogrefe & Huber Publishers.

May, C. (2013). Agency and implementation: Understanding the embedding of health care innovations in practice. *Social Science & Medicine*, *78*, 26–33. doi:10.1016/j.socscimed.2012.11.021

McDonald, K. M., Bryce, C. L., & Graber, M. L. (2013). The patient is in: Patient involvement strategies for diagnostic error mitigation. *BMJ Quality & Safety*, *22*, ii33–ii39. doi:10.1136/bmjqs-2012-001623

McNichol, E. (2012). Patient-led innovation in health care: The value of the 'user' perspective. *International Journal of Health Care Management*, *2*(4), 216–222.

Monahan, K. (2015). An interview with Dr. Cornelius Foley: Humour, palliative care and hospice. *Social Work in Mental Health*, *13*(1), 7–16. doi:10.1080/15332985.2014.899942

Nagel, R. N., & Dove, R. (1991). *21st century manufacturing enterprise strategy: An industry-lead view*. Collingdale, PA: Diane Publishing Company.

Nilsson, F. (2014). Du måste vara frisk för att kunna vara sjuk – ett patientperspektiv på cancervården [You need to be healthy to be able to be sick - a patient perspective on cancercare]. Region Skåne. Retrieved from https://www.skane.se/Upload/Webbplatser/Utvecklingscentrum/Rapporter/Nilsson_F_2014/Rapport2014_Frisk_for_att_vara_sjuk.pdf

Nilsson, F., & Lindström, B. (2010). *Vägar till förnyelse - studier av svensk sjukvård*. Lund: Design Sciences, LTH, Lund University. Retrieved from http://www.design.lth.se/aktuellt/vaegar-till-foernyelse-studier-av-svensk-sjukvaard/

Norman, R. (1998). *The moral philosophers: An introduction to ethics*. Oxford: Oxford University Press.

Page, T. (2014). Notions of innovation in health care services and products. *International Journal of Innovation and Sustainable Development*, *8*(3), 217–230. doi:10.1504/IJISD.2014.066609

Phillips, C., & Shaw, I. (2011). Innovation and the practice of social work research. Editorial in *British Journal of Social Work*, *41*(4), 609–624. doi:10.1093/bjsw/bcr072

Post, S. G. (2005). Altruism, happiness, and health: It's good to be good. *International Journal of Behavioral Medicine*, *39*(4), 66–77. doi:10.1207/s15327558ijbm1202_4

Rogers, E. M. (1983). *Diffusion of innovations*. New York, NY: Free Press.

Rørtveit, J. G. (2008). *Folket på Vinje - En fortelling om Anna på Vinje* [The people on Vinje - a story about Anna from Vinje]. Norway, Oslo: Kolofon.

Sandén, U. (2006). *… och jag vill leva*. Stockholm: Prisma/Norstedts förlag.

Sandén, U. (2016). *På okänt cancervatten [On unknown cancer seas]*. Lund: LTH, Lunds universitet. Retrieved from http://www.design.lth.se/fileadmin/designvetenskaper/Paa_okaent_cancervatten_slutversion.pdf

Sandén, U., Harrysson, L., & Thulesius, H. (2015). Momentary contentment, a modern version of an old survival culture. *Grounded Theory Review*, *14*(2), 74–85.

Sandén, U., Thulesius, H., & Harrysson, L. (2015). Nuets förnöjsamhet - en Grundad Teori om livsval och överlevnadsstrategier [Momentary contentment - a grounded theory about life choices and survival strategies]. *Sociologisk forskning*, *52*, 3.

Schmidt, M., Eckardt, R., Scholtz, K., Neuner, B., von Dossow-Hanfsting, V., Sehouli, J., ... Spies, C. D. (2015). Patient empowerment improved perioperative quality of care in cancer patients aged ≥ 65 years – A randomized controlled trial. *PLoS One*, *10*(9), 1–21. doi:10.1371/journal.pone.0137824

Shore, L. M., Randel, A. E., Chung, B. G., Dean, M. A., Holcombe Ehrhart, K., & Singh, G. (2011). Inclusion and diversity in work groups: A review and model for future research. *Journal of Management*, *37*(4), 1262–1289. doi:10.1177/0149206310385943

Stern, D. N. (2004). The present moment as a critical moment. *Negotiation Journal*, *20*(2), 365–372. doi:10.1111/nejo.2004.20.issue-2

Strang, P. (2007). *Livsglädjen och det djupa allvaret - om existensiell kris och välbefinnande* [The joy of life and the deep gravity - about existential crisis and well-being]. Stockholm: Natur och kultur.

Thakur, R., Hsu, S., & Fontenot, G. (2012). Innovation in healthcare: issues and future trends. *Journal of Business Research*, *65*(4), 562–569. doi:10.1016/j.jbusres.2011.02.022

Thulesius, H., Barfod, T., Ekström, H., & Håkansson, A. (2004). Grundad Teori utvecklar läkekonsten. Populär beteendevetenskaplig forskningsmetod kan finna nya samband [Grounded theory develops the medical art. Popular behavioural research methods can find new patterns]. *Läkartidningen*, *101*(40), 306–310. Retrieved from http://ww2.lakartidningen.se/old/content_0440/pdf/3066_3070.pdf

Thulesius, H., Håkansson, A., & Petersson, K. (2003). Balancing: A basic process in end-of-life cancer care. *Qualitative Health Research*, *13*(10), 1353–1377. doi:10.1177/1049732303258369

van Achterberg, T, Schoonhove, L, & Grol, R. (2008). Nursing implementation science: how evidence-based nursing requires evidence-based implementation. *Journal Of Nursing Scholarship*, *40*(4), 302–310. doi:10.1111/jnu.2008.40.issue-4

Vea, J. (2009). *To kulturer: en sammenlignende undersøkelse av det vestnorske og det nordnorske kystsamfunnet : med hovedvekt på det 19. og 20. århundret.* [Two cultures: a comparative survey of the West Norwegian and North Norwegian coastal communities: with a focus on the 19th and 20th centuries]. Kristiansand: Höyskoleforlaget.

Weis, J. (2003). Support groups for cancer patients. *Supportive Care in Cancer*, *11*(12), 763–768. doi:10.1007/s00520-003-0536-7

Wenger, E. (2000). Communities of practice and social learning systems. *Organization*, *7*(2), 225–246. doi:10.1177/135050840072002

West, M. A. (1990). The social psychology of innovation in groups. In M. A. West & J. L. Farr (Eds.), *Innovation and creativity at work: Psychological and organizational strategies* (pp. 209–334). Chichester: Wiley.

Ytterhus, B. (2012). Everyday segregation amongst disabled children and their peers: A qualitative longitudinal study in norway. *Children & Society*, *26*(3), 203–213. doi:10.1111/j.1099-0860.2012.00433.x

Paper V

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Cancer, a relational disease *exploring the needs of relatives to cancer patients*

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ABSTRACT

Purpose: In this qualitative interview study we investigated the experiences of family members to cancer patients. Our objective was to explore and to differentiate their needs from the needs of cancer patients.

Methods: Five focus groups and six individual narrative interviews with 17 family members to cancer patients in Sweden were conducted and compared with 19 cancer patient interviews. Our analysis was inspired by classic grounded theory.

Results: Family members to cancer patients expressed own morbidity connected to high stress levels and difficulties in recognizing own stress due to ongoing comparisons with the cancer patient. Family members were trapped in a momentary terror-like situation where they became their sick relative's safety net. A percieved inability to improve their loved one's well being contributed to a feeling of guilt. The longing for it all to end was encumbered with shame since the end included possible death.

Conclusions: By recognizing cancer as a disease striking both body and relationships, family members are given precedence over their own struggles, differentiated from the patient's experiences. We define differences in needs between cancer patients and family members. Family members to cancer patients may be supported in developing balancing strategies towards less stress, increased safety and moments of contentment.

Introduction

Since more people survive cancer and more live longer with a chronic disease (Siegel, Miller, & Jemal, 2019) there is also an increase in family members living with cancer. Spouse caregivers show morbidity connected to high levels of stress, anxiety, potential burnout, depressive symptoms, marital distress, poor health, and unmet needs (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Goren, Gilloteau, Lees, & DiBonaventura, 2014; Lehto, Aromaa, & Tammela, 2018; Li & Loke, 2013; Sandén, 2017; Sjövall, 2011). Cancer is an illness that often requires family members to engage. Cancer is on the increase and in Sweden we struggle with providing psychosocial support to both patients and family members. Migration and possible language barriers adds to the challenge (Sethi, Williams, Zhu, Shen, & Ireson, 2017). In order to be able to provide support to affected families, there is a general need to increase and adapt family support to this emerging situation of a slowly less fatal disease.

When cancer strikes a patient it promptly becomes a health problem to fix, but when family members are struck through their relationship with the patient it eventually becomes a problem for society as increased morbidity. However, family members' needs start long before it becomes a societal problem. Jussila (2008) and Andreassen, Randers, Nyhlin, and Mattiasson (2007)

argues the inclusion of family in caring for the patient. At the same time as we agree, we argue the importance of allowing the family members to have their own relationship to the disease with varying needs and different experiences of the disease. We see a need for easy access to userfriendly self-help tools to increase safety, moments of joy and relaxation in a stressful situation.

In this study we firstly wanted to explore the experiences of family members to cancer patients. Secondly, our aim was to find ways to handle the presumed distress caused by a relationship affected by a severe disease such as cancer. Many health theories, such as Salutogenic theory (Antonovsky, 1996), Self-efficacy theory (Bandura, 1997) and Momentary contentment theory (Sandén, 2014, 2017), align in their use of coping strategies but differ in their view on control, meaningfulness and individualism. The former two are commonly referred to as implemented in Swedish health care while the latter is newer and not yet clinically tested. The salutogenic theory argue a sense of coherence, found through meaningfulness, comprehensibility and manageability. Self-efficacy has its focus on the cognitive process within the individual and his/her view on one's personal ability to take control and to cope in a situation. The momentary contentment theory is based on an acceptance of life

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as being hard and it uses three safety balancing mechanisms: Doing safety, Destiny readiness and Middle consciousness. The *meaning of hardships* is central in both salutogenic and momentary contentment theories but in different ways. Where salutogenic theory focuses on finding a meaning with what happens in life, momentary contentment theory focuses on enjoying life and an acceptance of that there often is no meaning. *Comprehensibility* is elaborated in both the self-efficacy and the salutogenic theory. In the salutogenic theory you get a sense of prediction and trust that things happen in an orderly fashion, whereas the self-efficacy theory focuses on the individual's belief in her own ability. *Manageability* is included in all three theories. The salutogenic as well as the self-efficacy theory have the individual as a focal point, whereas momentary contentment theory focuses on the group level. Our emerging objective was to illuminate ways of supporting the development of strategies to enhance psychosocial wellbeing among family members to cancer patients.

Our research questions were: What are the needs of family members to cancer patients? How do salutogenic, self efficacy and momentary contentment health theories express ways of meeting those needs? In this study the objective was to answer these questions and to suggest possible solutions to the main concern of the participants.

Method

Interviews and empirical analysis

This qualitative study builds on narrative interviews with 17 family members to cancer patients. All informants and their cancer sick relatives were above 18 years of age. They were interviewed in five focus groups complemented with six individual interviews. The interviews lasted between two and three hours each. For 15 interview participants their cancer sick loved one was still alive. We informed about the study through advertisements in social media and at primary care facilities. We asked to interview people over 18 years of age experiencing cancer as a loved one. Both parents, spouses and children to cancer sick patients responded and were interviewed. We regarded it as a strength to allow diversity in relationships. The patterns found are thus usable on a variety of family members. Further research may pin point specific needs to specific family members. New data was collected and analyzed until further data did not provide any new information and saturation was reached. All interviewees wanting to participate were accepted until enough informants to finalize the study was reached.

Unstructured narrative interviews were used as a way to let the informants decide what was important to share. It is a mode to gather data both based on what participants say, how they say it and what they choose to talk and not talk about. The method is useful when focus is on experiences revealed only when informants tell a story in their own way (Gillham, 2008). Carefully detailed field notes were written during interviews, but in accordance with classic grounded theory (Glaser, 1998) no audio recordings followed by verbatim transcriptions were done.

Our analysis was conducted with the methodological features of classic grounded theory, yet we do not claim to have reached the asymptote of a fully integrated grounded theory (Glaser, 1978). The analysis include data collection, coding, comparison and categorization. Classic grounded theory aims at explaining and conceptualizing what is going on in a substantive area. Each interview was field noted, then coded and then compared to previous interviews. Theoretical memos, a crucial part of classic grounded theory, were written after and between interviews as well as in the analysing phases, then coded and categorized and eventually sorted. Memos are a central part of the data material in accordance with classic grounded theory (Glaser, 1998). Doing a grounded theory study is a circular process of constantly comparing, coding and analyzing new data until it does not provide any new information (Glaser, 1998). The concepts were gradually developed to explain the informants' attitudes toward life. After the core category of navigating was finalised, memos and notes were written without discrimination, but interpretation and analysis was done selectively guided by the core category. When no new information was reached through data collection all memos were compared and sorted to find relationships between categories and concepts. Data from family members was further compared to data from a previous study (Sandén, Harrysson, Thulesius, & Nilsson, 2017) where 19 cancer patients were interviewed. What has emerged from the write up of the sorted memos so far is not a saturated grounded theory but a conceptual description called "Navigating cancer as a loved one". We have previously described a theoretical fit between the patient study "Navigating a new life situation" and Momentary contentment theory (Sandén et al., 2017). In this article we do the same with relatives to cancer patients. Clinical studies need to be done to explore if and how the momentary contentment theory need to be revised in order for a grounded theory of cancer navigation to emerge.

The Regional Ethical Review Board at Lund University approved the study (Reg nr 2016:219).

Fit, relevance, workability, modifiability

The results in a grounded theory study are not reports of facts but rather probability statements about the relationship between concepts or an integrated set of conceptual hypotheses developed from empirical data. Grounded theory is thus judged by fit, relevance, workability, and modifiability (Glaser, 1998, p. 18). Fit and

relevance were achieved through the continuous comparative analytical work. By focusing on what the informants chose as important topics such as information, communication and the overall pressure we thereby allowed the main categories to emerge through conceptualization. The informants were offered to read and comment on the analysis to ensure both fit and relevance. The workability is seen in how the core category of navigating explains what participants are doing to resolve their main concern. The workability of the core category is also seen in how the different categories all involve navigating in some way. The study has not lead to a new theory and has thus no workability in its own. Modifiability of the study was performed by connecting it to the cancer patient study and to health theories.

Results

Family members to cancer patients described a situation where guilt and problems in healthcare put demands on them to be alert at all times. Expressions like *"I didn't dare to get sick, who would take care of everything?"* and *"I became the safety-net"* show how the relatives put pressure on themselves to be strong and to put their own needs secondarily to the patient's. Cancer patients, when put in groups with the same diagnosis, tended to form a hierarchial order of seriousness of the disease between themselves (Sandén, 2016). This was less common among family members in our study, but when it happened, the hierarchy also followed the seriousness of the cancer, not the actual situation for them as relatives. Stress related morbidity became a part of life for family members in our study, and we wanted to provide concrete suggestions for strategies to enhance wellbeing.

Momentary terror and time juggling

Our interviews showed how family members rarely received help based on their needs, or help to express their needs. Instead their lives were tinged by obligations. They found themselves in a fragmented healthcare process expected to manage like a project leader without training or systematic support. Bandura's (1997) self-efficacy theory suggests that lack of perceived control is underpinning most forms of anxiety. Many interviewed family members expressed powerlessness towards the disease and its potentially deadly outcome. In addition family members lacked a language to describe their role in life. They used "parent" "helper" "project leader" "nurse" in attempts to capture their situation. Fivush and Merrill (2014) argue the role of language as in naming and conceptualizing experiences and feelings and thus the abstract can be made tangible. The interviewed family members struggled with reflecting upon their own situation and many experienced a terror-like momentary situation. In our earlier interviews with cancer patients many expressed an ability to separate healthy parts of their lives from the sick, and how they actually enjoyed these episodes (Sandén et al., 2017). Family members did not seem to have the same ability to juggle time, but were rather in a mood of almost constant alert. To constantly face illness and the need to both guard and manoeuvre the healthcare process takes over the present moment. Many described how they never dared to disconnect from the disease: *"One must always be on guard for possible mistakes"*.

When asked about needs, they kept returning to the patient's experiences. They were longing for it all to end, but the longing was hammered with guilt due to the unsure future of the patient. Many testified that the cancer sick person would not have survived without their effort and they were scared to let go of the constant control. Several family members described relief when resourceful palliative care arrived. Suddenly the healthcare system worked and they could somewhat relax a bit. It became evident that family members often lacked recognition for their work; linguistically, judicially and economically. Instead high morbidity and sick leave (Sjövall et al., 2009) show how society use this resource in an unsustainable way.

Doing safety

Patients "did safety" with other patients through organizations, websites, and in relationships with family and healthcare staff. Family members showed no such sense of "doing safety". Rather they expressed a need to actually be the safety net—*"I was too afraid to get sick, who would then handle everything"*. Lack of safety feelings and communion among family members made them struggle. Antonovsky (1996) stresses the need to feel a sense of coherence with what happens, something which is very difficult when the family members do not see their own needs. Knowing our place in context over time affects our inner sense of continuity and in this lies a feeling of security (Rämgård, 2006). Living with a person sick from cancer makes it difficult to feel safe in a relational continuity. Family members seemed to have no safety net and difficulties in separating themselves from the fear of cancer. They expressed needs on a general level, often arguing *"(the) health care needs to see us, we have needs"* but when asked about personal needs the most common answer was *"I don't need help personally"*. It was as if they did not see their own needs other than through their sick loved one. When healthcare resources were increased, family members experienced clusters of safety enhancing moments, which made other existing needs legitimate.

Delegitimation

Family members expressed with anger and pain how the patient sometimes got delegitimised. However, they also added to their own delegitimization by not recognizing their personal situation as painful or by adding guilt when in pain without being the one with a tumor. Ware (1992) discusses *delegitimation* experiences as when disease or pain is denied. She mentions two forms; one where people suppress experiences of illness with words like "we are all tired", and another where physicians define the experienced illness as psychosomatic. Both types means a questioning of a person's ways of thinking. However, according to Ware (1992), the second is more damaging to the patient since it includes a psychiatric illness, containing strong stigma . Several informants said that "family members need support and help", but they also answered the question "what are your needs?" with "*I don't have any needs, but other family members do*". This show how family members deny themselves of help. According to self-efficacy theory people's ability to cope with stress is linked to their belief in themselves (Bandura, 1997). Healthcare organizations need to help family members see themselves as important. Evergeti (2011) mentions how people reconstruct their images of the stigmatized self, how complex interactions reinforce homogeneity in one group and, in interactions with members of other groups, maintain differences. She shows how a reaction to discriminatory and socially excluding conditions is a significant personal identity marker as opposed to a dominant society. If being the safety net becomes an identity marker it may explain why family members show difficulties expressing their needs separated from those of their cancer sick loved one despite knowing a need exists on a generalized level.

Time horizons

"*Time is nature's way to keep everything from happening all at once*" (Wheeler, 1990, p. 10; Cummings, 1922). The social perception of time distinguishes one culture from another. Local appreciation of time within a community is often unstated, thus difficult for outsiders to perceive (Levine, 1996). Time is an issue for chronically ill people, both in regard to the disease, and to the various actions that have to be directed in consequence of the disease (Gunnarsson, 2016). Both patients and family members struggled with waiting. Waiting for answers, waiting for x-ray, waiting for treatments and waiting in waiting rooms. Both Gunnarsson (2016) and Auyero (2011) illustrated a process where patients and social recipients learn to be patient. Auyero (2011) notes that "*collective time senses are deeply intertwined with the workings of (and resistance to) social domination*" (p. 7). He lifts time as the locus of conflict, but also, and as important, of acquiescence.

If life itself is one cluster of moments, it is generally seen as shorter by patients than by family members. One explanation is that when looking at a possible death there is no imaginary life beyond that point for the patient. However to the family members there still is a life after a possible death, thus the horizon was closer to most patients. Patients and family members showed difficulties in recognizing each other's different time perceptions. Among family members it was apparent that the present moment was characterized by anxiety and guilt: "I was ashamed, I wasn't allowed to feel bad". Patients, on the other hand, had a shorter time horizon not knowing whether they would survive or not, and they experienced more moments of joy. Macduff (2006) discusses the impact of different perceptions of time on the priorities given to past, present, and future orientations. Two key dimensions in negotiating across cultural boarders are lifted: i/ differing perceptions and values of time, and ii/management of time. In a cancer context, with life and death in proximity, the perception of time changes in different ways for patients and family members. Macduff's (2006) arguments illustrate possible causes for misunderstandings in families.

Patients seem better equipped to juggle time and to disconnect from the disease and enjoy moments, thus creating new small clusters of moments. Nordenfelt (2005) describes phenomenologically how chronically ill people create parallel worlds such as that of sickness, a medical world and an everyday world. Many interviewed patients who were done with treatments described how they separated the fear of illness and death they felt during the waiting time between an examination, such as an imaging procedure, and receiving the results of the examination, from the rest of their life. They capsulated fear as a way to put the fear of dying in a cluster of moments and thus separating the illness from the healthy part of oneself. A framed space of fear is created and contributes to safety feelings outside that frame. Family members showed no such strategies, rather they uncontrollably accepted the illness as one big space of fear, longing for it all to end. This, in some cases, means that the death of their family member exaggerates feelings of guilt. "I almost look forward to palliative care".

Finding a balance?

Malterud and Hollnagel (2004) refers to Antonovsky and patients' sense of coherence in finding coping strategies for health when faced with illness. Boscherini (2017) explains Antonovsky´s salutogenesis in terms of keeping it together in the face of adversity,

manifested in the availability of resources, a supportive social network, order and familiarity and in an inspiring realization that there are important phenomena in life and nature. The philosopher Bruce N Waller (2002) argue the need for both an internal locus of control and a sense of competent self-efficacy when discussing the psychological structure of patient autonomy. Waller (p. 257) states "Those with an internal locus of control believe that their life's course is basically up to them". The interviewed relatives in our study described how their life had almost been hijacked by the disease. They also talked about being placed in a situation without proper training or knowledge, thus lacking self-efficacy:

> "You get into a double-mindedness. On the one hand, you should be a fixer, the one who can do everything, be both a nurse, an occupational therapist and a curator at the same time. On the other hand, there is no access to contact facilities with healthcare, one has to wait for other people's decisions and hope to be taken seriously."

The fact that relatives don't have the disease in their body makes it more difficult for them to balance their fear. Wallhagen and Brod (1997) showed how perceived control over symptoms had greater influence over well-being than beliefs concerning ability to control the disease itself (Wallhagen & Brod, 1997). According to Waller (2002), if one loses control in one area it may be balanced by increasing control somewhere else. In a study on mental health, researchers tried to understand the Samoan individual. In interviews they called themselves "a relational self" and mental health for "relational harmony and balance ". Another approach found in the study was the perception of well-being and how the well-being of the individual was protected by means of relational agreements with others (Tamasese, Peteru, Waldegrave, & Bush, 2005). This connects to the momentary contentment theory (Sandén, 2014) where safety is built on balancing mechanisms where individuals act within a community and adversity is faced together. To balance adversity in different ways seem to be a part of coping mechanisms in different theories. Looking at our interviews with relatives and cancer patients, balance was hard for the relatives to find.

Discussion

We have previously interviewed cancer patients and for this study family members to cancer patients. For this article we have compared the results from both interview studies, but with a family member perspective. In many interviews, focus groups and one-on-one, family members to cancer patients, described

a lonely situation where they were stuck in a terror-like situation with few breaks. Several participants expressed how they before meeting other relatives, believed they were becoming mentally ill due to their strong feelings of fear, anxiety and stress. Further, literature show morbidity among relatives and we argue a need to widen the concept of cancer where family members are affected relationally aside from the patient.

Cancer as a relational disease

Both cancer patients and family members saw cancer as a disease striking patients first and family members second, presenting a power imbalance giving patients interpretative precedence. Family members expressed more loneliness than patients did. Some felt guilt when having fun. They were *doing safety* by helping, but this was described as a lonesome effort where they never seemed to be a part of a shared collective *doing safety*. Guilt came from the notion of cancer not affecting family members directly, but through the patient. At the same time this created guilt for patients, being the carrier of the pain, i.e., the cancer. If we rather view cancer as striking everyone it meets, but differently, then family members are affected in a relational way, whereas patients are affected both bodily and relationally. If we view cancer as both a relational and somatic disease it does not give precedence to feelings of neither patients nor family members. Family members often expressed a general need for help, but seemed unable to define any needs. They had difficulties talking about their own lives with cancer without allowing the patient in between themselves and the disease.

Healthcare devote few resources directly to family members, instead they use resources due to morbidity connected to the high stress of being an informal care-giver (Goren et al., 2014). A more inclusive healthcare, asks for a changed approach to both patient processes and in regard to a broader participation of the patient's social network. Intercultural studies add language barriers as another burden to the caregiving role (Sethi et al., 2017) which also has to be considered. Goren et al (2014) states "*the need for enhancing our understanding of the caregiving experience and developing supportive and personalized multicomponent interventions for caregivers, given their pivotal role in providing support for patients*" (p. 1637). It is thus a wicked problem as defined by Rittel and Webber (1973) where both mindset, behaviour patterns and multiple societal factors are involved, and a solution would be complex. Thakur, Hsu, and Fontenot (2012) stresses the importance of understanding the challenges faced by healthcare organizations, e.g., multiple medical records of patients and incorrect doses of drugs and wrong medication. Our

study show how the consequences of such challenges, when healthcare fails, are placed on the family members to handle, making them unable to relax from the stress of being the safety net.

From guilt to pride

Momentary contentment theory shows language use as a coping strategy in reformulating problems into solutions, and, alongside, place an initial problem in a temporal state of mind—*Middle consciousness* (Sandén, Thulesius, & Harrysson, 2015) where one may use symbolic opposites to find balance. Patients already juggle between feeling sick and healthy in using symbols of health in their daily life (Sand, Olsson, & Strang, 2009; Sandén, 2017). As patients oscillate between feeling sick and healthy, family members have other opposites. Many family members expressed being alone with thoughts and feelings. They described guilt from having fun when their loved one was sick, a cognitive process where they added more guilt on themselves and quite the opposite to *Destiny readiness*, which means accepting life as it is. In some cases that means accepting death. Jonasson et al. (2011) studied men's feelings of guilt after their wife's death in cancer and concluded the importance of having end-of-life discussions within the last 3 months before her death. An opposite to guilt could be pride. Thinking "our relationship has cancer" can give legitimization to guilt and self-pity, as we are in this together—but also to pride and joy, for the navigating work that is being done. Momentary contentment strategies may be used to find a balance between being a caretaker and a project leader, and finding a workable life where there is space for just being in the relationship in spite of the disease.

The creation of cluster of moments

Mishra, Brakey, Kano, Nedjat-Haiem, and Sussmanbc (2018) asked young adult cancer patients and their primary informal caregiver about factors that made a "good day". The cancer patients referenced normalizing activities such as doing chores, leaving the house, and seeing friends and family. Whereas the caregivers did not let go of the disease but rather considered good days in relation to their loved ones' well-being, such as when they are "feeling good" and "not sick". Sand et al. (2009) showed how patients in palliative care developed useful strategies to hold off death. They described it as a cognitive and emotional pendulum that swing between extremes, where patients use the tools that suit their own concepts. Thulesius, Håkansson, and Petersson (2003) theory of equilibrium of hope shows how people create instinctive compensatory strategies to increase existential hope, such as a denial of life-shortening information or by increasing momentary enjoyments of life. We saw no such strategies among family members. In the Momentary contentment theory (Sandén, 2017), the concept *momentary* is defined as a subjective formation of clusters of moments. By dividing time into clusters of moments the burden of stressful experiences may lessen. Through separating activity and waiting into different clusters of moments one may break the waiting anxiety during part of the waiting periods. If done in communion with others a joint collective safety-net may evolve. Letting both patients and family members know when an answer is expected can create predictability. This is well in line with Lasane and O'Donnell (2005) argument that people in the Western world need to establish and relate themselves in a temporal perspective, a need to find coherence, regularity and predictability. Momentary contentment theory shows how time can be viewed from various references on a collective basis (Sandén, 2014).

From loneliness to altruistic communion

Altruism is central to life, past and present, in an interdependent relationship of those helping and those being helped. In groups, altruism means shared pride based on partially unconscious processes wherein it is hard to see our own role. Momentary contentment theory illustrates strategies of helpfulness in illuminating altruistic patterns among patients and family members. It shows the need to balance the helping in shared helpfulness, i.e., helping in the helping. Helpfulness as action and altruism as phenomenon are thus vital. Safety is created in the trust of not having to face difficulties alone (Sandén, 2014). Post (2005) describes how altruism results in positive social inclusion, in distraction from personal problems and self-centred anxiety, in increased wellbeing combined with experiences of meaning and purpose and in a more active lifestyle. A strong link is found between altruism and wellbeing, happiness, health and longevity—as long as helping others does not overwhelm a person. The help family members give, enhancing others' wellbeing, may be argued as altruistic. However, it is clear that many family members are overwhelmed and show stress and fatigue, rather than wellbeing (Sandén, 2017). Leonidou and Giannousib (2018) describe family caregivers' experienced responsibility for bringing together medical information received from different sources, organizing notes for the patient and transferring information from one doctor to another to receive the best possible healthcare. Self-imposed demands to create stability, order and safety for the sick relative also seem to stem from a touch of guilt (Sandén, 2017; Sjövall, 2011). Patients on the other hand yearn for altruistic actions, but lack strength to follow them through. Many cancer patients find ways to use activity and

helpfulness as tools for feeling better. However, they express difficulties in balancing receiving and giving help (Sandén, 2017). Both patients and family members need support in balancing their engagement.

Finding hope within

Within the concept of hope patients express uncertainties, misunderstandings and inconsistencies (Sandén et al., 2017). They convey a hope that "lives within", an opening for *destiny readiness*, but many also feel pushed by relatives, friends and healthcare staff towards being positive and cognitively hopeful. The latter usually includes moving focus towards a change and thus to the future, a future which to a cancer sick person also means fear of death. This is adjacent to Benzein, Norberg, and Saveman (2001) distinction between "living with hope" and "to hope for something". The former relating to what is present, the latter to a changeable future. Our interviews show the importance of offering hope, and to do it in compliance with life as is (Sandén, 2006, 2017).

Family members are living and acting in the moment, but since the moment often is filled with suffering they evidently wish for a future when the cancer is gone. In line with both Benzein et al. (2001) and momentary contentment theory we think that a cognitive factor of the future puts family members more in a "hoping for" mode, whereas patients are more in a "living with hope" state of mind (Sandén, 2017). To internalize the family members' "hoping for" mode into "living with hope" their momentary situation should include more of being themselves rather than being the safety net and project leader. In order to not create morbidity, it is important to find balance in the caretaker role.

Implications and suggestions for practice

We argue that healthcare stakeholders could do the following to suggest possible solutions to the main concern of the participants:

- help family members get in contact with other family members of cancer patients.
- recognize that family members have feelings separate from the person carrying the disease.
- recognize family members as affected by the disease and give them support helping them to go from guilt to pride and support them in taking care of their own needs. Teach them the difference between hoping for and carrying a hope within.
- Most importantly, we suggest that healthcare staff should recognize that family members' need to have a life of their own, and, importantly, they cannot be the continuous safety net for healthcare mistakes, errors and mishaps.

Limitations and future research

Limitations of our study sit mainly in the number of participants interviewed. Also, the regional generalizability is limited since all participants came from three different regions in Sweden. In future research a survey could be designed from the results of this interview study to explore its generalizability. Each need may also be further explored, contextualized and given new solutions.

Conclusion

Cancer affects patients and family members in different ways. The patients are physically affected, leading to relational difficulties, while the relatives are relationally affected and develop different types of morbidity.

Our interviews showed a situation where patients were seen as the primary interpreter of the disease and its impact on life. However, by recognizing cancer as a relational disease alongside with the tumor, every person affected by cancer may be given precedence over his/her own experiences and needs. Then by recognizing the differences in experiences and needs, existing and potential misunderstandings between patients and family members can be dealt with.

Skills found in different health theories may be applied in the search for better health. For example: sharing various fears of dying or being left alone, of different time horizons, and of the concept of hope versus hoping for.

The literature shows high morbidity for people living close to a cancer patient. Patients and family members have disparate needs, but they share an overall longing for a less fragmented healthcare.

Both cancer patients and family members show difficulties in expressing the specific needs that comes from being in a relationship affected by cancer. We have been able to illuminate a few specific needs.

- Family members have needs of their own, but lack insight and concepts to describe them.
- Morbidity among family members to cancer patients may be lessened by applying health promoting strategies.
- Cancer is not just a bodily disease, but a relational disease as well.

We finally argue the need for a recognition of cancer as a relational disease creating morbidity in family members. To meet these needs momentary contentment theory, as a theory built on communion and helpfulness, may be useful. In a collective setting, family members can help each other to create time and space for safety, a break from demands and a relief of pains.

Authors' contribution

The first author carried out the data collection. All authors participated in the analysis and the design of the study. All authors read and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

Disclosure statement

No potential conflict of interest was reported by the authors.

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References

Andreassen, S., Randers, I., Nyhlin, K. T., & Mattiasson, A. (2007). A meta-analysis of qualitative studies on living with oesophageal and clinically similar forms of cancer, seen from the perspective of patients and family members. *International Journal of Qualitative Studies on Health and Well-Being*, 2, 114–127.

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International*, 11(1), 11–18.

Auyero, J. (2011). Patients of the state: An ethnographic account of poor people's waiting. *Latin American Research Review*, 46(1), 5–29. Retrieved from http://lasa-4.univ.pitt.edu/LARR/prot/fulltext/Vol46no1/Auyero_5-29_46-1.pdf

Bandura, A. (1997). Insights. Self-efficacy. *Harvard Mental Health Letter*, 13(9), 4–6.

Benzein, E., Norberg, A., & Saveman, B.-I. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine*, 15(2), 117–126.

Boscherini, G. (2017). A sense of coherence: Supporting the healing process. *Architectual Design*, 87(2), 108–113.

Braun, M., Mikulincer, M., Rydall, A., Walsh, A., & Rodin, G. (2007). Hidden morbidity in cancer: Spouse caregivers. *Journal of Clinical Oncology*, 25(30), 4829–4834.

Cummings, R. (1922). *The girl in the golden atom*. University of Nebraska press. Retrieved from http://www.gutenberg.org/ebooks/21094

Evergeti, V. (2011). Discrimination and reaction: The practical constitution of social exclusion. *Symbolic Interaction*, 34(3), 377–397.

Fivush, R., & Merrill, N. (2014). The personal past as historically, culturally and socially constructed. *Applied Cognitive Psychology*, 28(3), 301–303.

Gillham, B. (2008). *Forskningsintervjun: Tekniker och genomförande*. Lund: Studentlitteratur.

Glaser, B. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.

Glaser, B. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.

Goren, A., Gilloteau, I., Lees, M., & DiBonaventura, M. (2014). Quantifying the burden of informal caregiving for patients with cancer in Europe. *Support Care Cancer*, 22, 1637.

Gunnarsson, M. (2016). *Please be patient : A cultural phenomenological study of haemodialysis and kidney transplantation care* (PhD dissertation). Lund University. Retrieved from http://urn.kb.se/resolve?urn=urn:nbn:se:sh:diva-28914

Jonasson, J. M., Hauksdóttirad, A., Nemesc, S., Surkan, P. J., Valdimarsdóttir, U., Onelöv, E., & Steineck, G. (2011). Couples' communication before the wife's death to cancer and the widower's feelings of guilt or regret after the loss – A population-based investigation. *European Journal of Cancer*, 47(10, July 2011), 1564–1570.

Jussila, A.-L. (2008). Stabilising of life: A substantive theory. *Grounded Theory Review*, 7(1), 29–42. Retrieved from http://groundedtheoryreview.com/wp-content/uploads/2012/06/vol7no1-final-2.pdf

Lasane, T. P., & O'Donnell, D. A. (2005). Time Orientation Measurement: A Conceptual Approach. In A. Strathman & J. Joireman (Eds.), Understanding behavior in the context of time: Theory, research, and application (pp. 11–30). Mahwah, NJ: Lawrence Erlbaum Associates Publishers.

Lehto, U.-S., Aromaa, A., & Tammela, T. L. (2018). Experiences and psychological distress of spouses of prostate cancer patients at time of diagnosis and primary treatment. *European Journal of Cancer Care*, 27, e12729.

Leonidou, C., & Giannousib, Z. (2018). Experiences of caregivers of patients with metastatic cancer: What can we learn from them to better support them? *European Journal of Oncology Nursing*, 32(February 2018), 25–32.

Levine, R. V. (1996). Cultural differences in the pace of life. In H. Helfrich (Ed.), *Time and mind* (pp. 119–140). Seattle: Hogrefe & Huber Publishers.

Li, Q., & Loke, A. Y. (2013). A spectrum of hidden morbidities among spousal caregivers for patients with cancer, and differences between the genders: A review of the literature. *European Journal of Oncology Nursing*, 17(5), 578–587.

Macduff, I. (2006). Your pace or mine? Culture, time, and negotiation. *Negotiation Journal*, 22(1), 31–45.

Malterud, K., & Hollnagel, H. (2004). Positive self-assessed general health in patients with medical problems.

A qualitative study from general practice. *Scandinavian Journal of Primary Health Care*, 22(1), 11–15.

Mishra, S. I., Brakey, H. R., Kano, M., Nedjat-Haiem, F. R., & Sussmanbc, A. L. (2018). Health related quality of life during cancer treatment: Perspectives of young adult (23–39 years) cancer survivors and primary informal caregivers. *European Journal of Oncology Nursing*, 32(February 2018), 48–54.

Nordenfelt, L. (2005). Om kronisk sjukdom och livskvalitet. In B. Richt & G. Tegern (Eds.), *Sjukdomsvärldar. Om människors erfarenheter av kroppslig ohälsa* (pp. 305–322). Lund: Studentlitteratur.

Post, S. G. (2005). Altruism, happiness, and health: It's good to be good. *International Journal of Behavioral Medicine*, 12(2), 66–77.

Rämgård, M. (2006). *The power of place. Existential crises and place security in the context of pregnancy* (Doctoral thesis). Lund University, Department of Social and Economic Geography, Lund. Retrieved from http://lup.lub.lu.se/record/25595

Rittel, H., & Webber, M. (1973). Dilemmas in a general theory of planning. *Policy Sciences*, 4(2), 155–169.

Sand, L., Olsson, M., & Strang, P. (2009). Coping strategies in the presence of one's own impending death from cancer. *Journal of Pain and Symptom Management*, 37(1), 13–22.

Sandén, U. (2006). … *och jag vill leva*. Stockholm: Prisma förlag.

Sandén, U. (2014). *Nuets förnöjsamhet - en Grundad Teori med utgångspunkt i Nordnorskt vardagsliv*. Lund, MA: Lund University, School of Social Work.

Sandén, U. (2016). *Navigating unknown cancerwater-loved ones* (Report). Lund: Lund University, Department of Design Sciences.

Sandén, U. (2017). *Momentary contentment. Exploring needs and possibilities in a psychosocial cancer context* (Licentiate thesis). Lund University, Department of Design Sciences. Retrieved from http://www.design.lth.se/fileadmin/designvetenskaper/ProaktivCancer/Momentary_Contentment_-_Ulrika_Sanden_-_Licenciate_thesis.pdf

Sandén, U., Harrysson, L., Thulesius, H., & Nilsson, F. (2017). Exploring health navigating design: Momentary contentment in a cancer context. *International Journal of Qualitative Studies on Health and Well-Being*, 12(sup2), 1374809.

Sandén, U., Thulesius, H., & Harrysson, L. (2015). Nuets förnöjsamhet - en Grundad Teori om livsval och överlevnadsstrategier. *Sociologisk Forskning*, 52(3), 235–256.

Sethi, B., Williams, A., Zhu, H., Shen, E., & Ireson, R. (2017). "Father is the sky. Mother is the earth:" The influence of filial piety in the caregiving experiences of mandarin-speaking Chinese caregiver-employees in Southern Ontario, Canada. *Diversity and Equality in Health and Care*, 14(2), 53–62.

Siegel, R. L., Miller, K. D., & Jemal, A. (2019). Cancer statistics, 2019. *CA: a Cancer Journal for Clinicians*, 69(1), 7–34.

Sjövall, K. (2011). *Living with cancer: Impact on cancer patient and partner* (Doctoral thesis). Lund University, Faculty of Medicine Doctoral Dissertation Series 2011:25.

Sjövall, K., Attner, B., Lithman, T., Noreen, D., Gunnars, B., Thomé, B., & Olsson, H. (2009). Influence on the health of the partner affected by tumor disease in the wife or husband based on a population-based register study of cancer in Sweden. *Journal of Clinical Oncology*, 27(28), 4781–4786.

Tamasese, K., Peteru, C., Waldegrave, C., & Bush, A. (2005). Ole Taeao Afua, the new morning: A qualitative investigation into Samoan perspectives on mental health and culturally appropriate services. *Australian and New Zealand Journal of Psychiatry*, 39, 300–309.

Thakur, R., Hsu, S., & Fontenot, G. (2012). Innovation in healthcare: Issues and future trends. *Journal of Business Research*, 65(4), 562–569.

Thulesius, H., Håkansson, A., & Petersson, K. (2003). Balancing: A basic process in end-of-life cancer care. *Qualitative Health Research*, 13(10), 1353–1377.

Waller, B. (2002). The psychological structure of patient autonomy. *Cambridge Quarterly of Healthcare Ethics: CQ: the International Journal for Healthcare Ethics Committees*, 11, 257–265.

Wallhagen, M. I., & Brod, M. (1997). Perceived control and well-being in Parkinson's disease. *Western Journal of Nursing Research*, 19(1, February), 11–25; discussion 25–31.

Ware, N. C. (1992). Suffering and the social construction of illness: The delegitimation of illness experiencein chronic fatigue syndrome. *Medical Anthropology Quarterly, New Series*, 6(4), 347–361.

Wheeler, J. A. (1990). Information, physics, quantum: The search for links. In W. H. Zurek (Ed.), *Complexity, entropy and the physics of information* (pp. 3–28). Santa Fe Institute. Studies in the Sciences of Complexity. New York: CRC Press.

Paper VI

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Breaking the patientification process - through co-creation of care, using old arctic survival knowledge

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ABSTRACT

Purpose: Cancer research and connected innovation processes often lack a major component; patient participation. We revisit three studies (a-c) in order to explore how Momentary contentment theory may be used to improve patient participation and psychosocial health. Method: We revisited data from the initial (a) classic grounded theory study on Momentary contentment, based on four years of observation and 14 interviews. It explains a way of dealing with life close to death and morbidity. In the imminence of danger the studied culture resembles the context of cancer patients. The two following studies used focus group interviews with (b) 19 cancer patients and (c) 17 relatives of cancer patients in southern Sweden.
Results: We suggest a process where cancer patients are taught to be submissive and that the support they receive from health providers may be counterproductive to contentment; a patientification process. We present alternative ways for people to handle issues such as hope, waiting, knowledge gaps and healthcare navigation while living with cancer. We introduce an alternative to patientification and passive patients where active patients create their own safety and truly participates in their care.Conclusions: We propose clinical studies to introduce such a shift from patentification to co-creation of care.

Introduction

Individualized, precision medicine is widely acknowledged in cancer treatment and research. At the same time cancer care overlooks incorporation of patient values and objective evidence into decision-making (Hirsch & Abernethy, 2013). Historically, the patient has been seen as a passive recipient of someone else's actions (Gunnarson, 2016; Sandén, 2017). Even if patients have been more involved in their care during recent decades (Bate & Robert, 2006) our informants still express a need for further developing the involvement of patients and loved ones (Sandén et al., 2017, 2019). Patient passivity contradicts the view of an innovative person using their tacit knowledge and experience to create order in a world of illness.

Momentary contentment theory (Sandén, 2017; Sandén, Harrysson et al., 2015) explains how old survival knowledge in a remote arctic village has been transformed from historically being a matter of life and death to contributing to increased contentment in current society. The theory is based on safety-enhancing activities where inclusion, helpfulness and acceptance are central parts of the culture. We have previously shown a theoretical fit between momentary contentment and a cancer patient context (Sandén et al., 2017).

Momentary contentment theory shows how a history of isolation, harsh climate, and risky occupations have created a proximity to death and need for security. The sense of control, apparent in many health theories (Antonovsky, 1996; Bandura, 1997), is in momentary contentment theory exchanged by an acceptance of life's unpredictability and explained through three main concepts:

- *Middle consciousness* is an ability to create order. When you place situations that cannot be controlled into standby mode, they can be disconnected from your consciousness without being completely repressed.
- *Destiny readiness* is an evolved acceptance and adaptation to uncontrollable events. Instead of expecting life to be easy, safety is found in the manageability of each event.
- *Doing safety* means an active approach to life where people in communion with others create their own safety. It includes a flexible view on time.

In order to illustrate the move from problems to solutions, we have designed a model, inspired by Kaner (Kaner, 2014), illustrating the submissive patientification process and our alternative approach,

which might empower and include patients as co-operative partners. The purpose of our study is thus to explore if and how Momentary contentment theory may provide solutions to issues experienced by cancer patients and their relatives in order to break the patientification process and move it towards co-creation of care.

Materials and method

Momentary contentment theory (a)

The data consists of interviews, conversations and notes from observations of everyday life in a remote village in northern Norway, from 2010 to 2014. The first author conducted a total of six unstructured and semi-structured focus groups and eight individual interviews that lasted between 2–6 hours each. In order to capture views of their everyday lives the informants were asked to freely talk about their experiences. The first author also gathered field notes from 15 conversations and 50 informal, semi-structured conversations. New decisions regarding data collection were made after each interview (Glaser, 1998). Notes from interviews and observations were written and theoretical memos were both written and drawn in different shapes and forms in the comparative process. These memos have been sorted, coded, categorized and compared to find relationships between categories and concepts using theoretical codes. After each interview or accrual observation the new material was coded, analysed and compared with previous results. Data was thus collected and analysed in stages until new data did not provide any new information, i.e., saturation was reached. At saturation the formulated theory was slightly modified in light of existing literature (Glaser, 1998). The analysis and methodology are further described elsewhere (Sandén, 2017; Sandén, Harrysson et al., 2015).

Interviews with cancer patients and relatives (b, c)

The patient interview data is based on interviews with 36 participants affected by cancer, 19 patients (study b) and 17 relatives (study c) of cancer patients in southern Sweden. Ages were between 20 and 70 years, men and women. For ethical reasons we did not collect more personal data from the participants. All of the interviewed patients were considered cured or in disease remission. The represented cancer illnesses were acute myeloid leukaemia, head and neck cancer, oesophagus cancer, prostate cancer and bladder cancer. Among the relatives, cancers of pancreas, breast, bone, kidney, lung, CNS, lymphoma, myeloma and sarcoma were present. Dementia or

major depression were exclusion criteria to participation. The interviews were unstructured and lasted 2–3 hours. In accordance with classic grounded theory (Glaser, 1998) no interviews were recorded, instead, detailed notes were taken during the interviews. The starting question was: "Please tell me about your lives". At the end of some interviews we asked questions to confirm interpretations of previous analysis to avoid misunderstandings. Questions were similar to "What did you mean when you said … ?"

We started out with an analysis inspired by classic grounded theory resulting in two published studies (Sandén et al., 2017, 2019). No new fully integrated grounded theory was generated, but a main concern of navigating in a new and unknown life situation emerged regarding both patients and relatives. Different issues related to health emerged in the data (Table I) such as waiting, delegitimation (Ware, 1992), fear, hope, knowledge gaps, loneliness and health (Sandén, 2017).

Revisiting interviews with cancer patients and relatives through momentary contentment theory

We have previously (Sandén et al., 2017) shown a theoretical fit between the contexts of cancer patients and the subjective area from Momentary contentment theory. We therefore combined the two studies (study a and b) through a design-thinking approach, but from an inductive grounded theory base. For the present study, we have moved focus from an inductive grounded theory approach to a more deductive approach where the notes from interviews with the patients and relatives are interpreted through Momentary contentment theory.

We have also brought memos from our previous studies into the new analysis work, see example in Result section "Fear and 'scanxiety' (i.e., own health

Table I. Issues that emerged from the interviews with patients (b) and relatives (c).

	PATIENTS	RELATIVES
WAIT	Taught to passively hope for good results	Learning to hope for good results
DELEGITIMATION	Health care staff patronizing patients Patient's body and life are fragmented	Hard to reach healthcare staff
FEAR	Death is always apparent	Fear of being left alone
HOPE	Learning a "hoping-for" state of mind	Hoping for good results
KNOWLEDGE GAPS	Difficulties to turn information into knowledge	Lack of information
LONELINESS	The disease creates feelings of loneliness	No one to talk to
HEALTH	A black-and-white view of being healthy or sick	Own health diminished behind the illness of the cancer sick

diminished behind the illness of the cancer sick): Waiting or preparing". In our conceptualization of the patients' stories, we searched for meanings of their whole life situations while moving between each need and concept, such as waiting, worries, relationships etc., and then we analysed the dialectical interaction between the concepts and health as a whole. An example: many patients and relatives expressed problems related to waiting. We did not see that issue in our Momentary contentment study (study a) data because the group studied solved the problem. Consequently, we reflected on how patients solved the issue of waiting and based on the reflections tried to illuminate different strategies and emergently fit these into the patient descriptions.

Multidisciplinary analysis

Our analysis is multidisciplinary and made possible through our different backgrounds. We represent medicine, social work and design engineering and have participated in the first analysis of the interviews (studies a and b) as well as in this re-analysis. First, second and third authors have participated in the emergence of Momentary contentment theory (study a). All interviews were conducted by the first author, with the last (fourth) author participating in two of the cancer patients' interviews. The third author has been involved in the immediate analysis and conceptualization of the cancer patient interviews. By applying Momentary contentment theory to the concepts gathered from the interview narratives we introduce social medicine to a new health theory.

The regional ethics committee at Lund University approved the studies (Reg nr 2015:53 and 2016:219).

Design thinking and the diamond of participatory decision-making

The concept of shared decision-making has been proclaimed as a prime approach of making healthcare decisions since the early 1980s. However, its implementation is still a challenge due to organizational and cognitive gaps between service providers of healthcare and patients (Shay & Lafata, 2015; Weston, 2001). Bridging these gaps and including user experiences are major reasons for using design thinking for theoretical and practical guidance (Mintrom & Luetjens, 2016). Design thinking has evolved from creativity techniques and for the past 20 years has been popularized and used in various contexts to solve "wicked" problems by combining practical processes with cognitive and strategic dimensions of reasoning. A central theme in design thinking is to understand the user thoroughly and to use user experiences and interpretations in the creation of solutions. Correspondingly, when design thinking is applied to healthcare, analysis is initially based on the patient's narratives for in-depth understanding of underlying patterns and needs. We use Kaner's (Kaner, 2014) pedagogical model "Diamond of participatory decision-making" (figure 1) as a device to illustrate the change processes cancer-affected people may experience. The model shows the process of decision-making among different individuals and competences involving the different perspectives, frameworks and assumptions each part has in a group. In our context, this model is adjusted to include the different issues a cancer patient has to deal with.

In this original figure (Kaner, 2014) the model shows phases that groups go through when facilitating sustainable agreements.
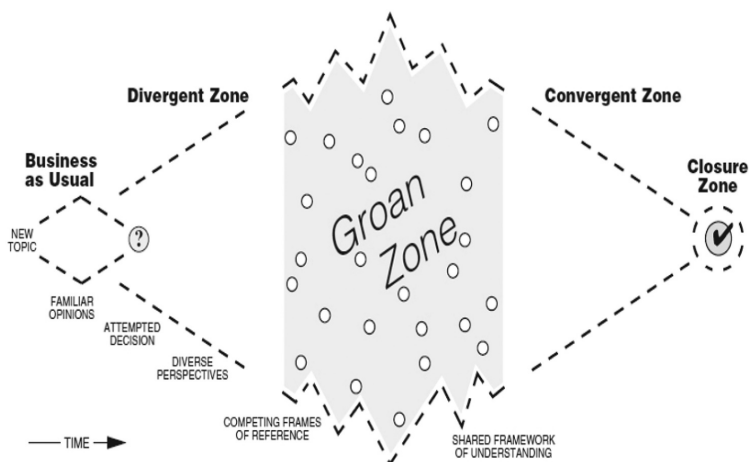

Figure 1. Diamond of participatory decision-making

In the divergent zone different perspectives become visible as a result of different expectations and assumptions, leading to competing frames of references when it comes to why, what, when and how healthcare is provided and consumed. The groan zone is per se a consequence of the diversity of perspectives, goals and knowledge that emerge in the interaction among people. Misunderstandings and miscommunications are seen as inevitable and normal in participatory decision-making (Shay & Lafata, 2015). It is through groan zones that different frames of reference meet in order to converge into a new shared frame of reference. The Diamond of participatory decision-making has been used before as an individual identity exploring tool by the first author in regard to brain rehabilitation (Sandén, 2019). Sevetson (Sevetson, 2005), refers to organizational changes while discussing a personal journey through the Diamond of participatory design, where there is personal pain in the groan zone.

Results

The patientification process

Our informants described cancer appearing in different steps, not as a straightforward process, but an iterative move towards a new life. Looking at the participatory decision-making model from a cancer patient identity perspective (figure 2), getting cancer is described by our informants as a divergent period where new perspectives are brought into their lives.

When a diagnosis is established, many patients describe confusion about whether or not they are ill; they describe it as unreal. They suddenly must involve healthcare in their everyday life and their social life changes. Studies involving 15 cancer survivors over 65 years of age show that disruptions to time and identity induce a biographical reconstruction (Hannum & Rubinstein, 2016). Other people change in the way they act towards the sick person and some relationships grow stronger; others disappear. The *groan zone* is described by our informants as three different subzones. In the first subzone the person tries to integrate the illness and its consequences into/with their identity, often expressed in relation to a shortened life span "*I have to live life, maybe all I have is this moment*". Here several patients and relatives expressed being met with fragmentation into body parts: "*I became a stick figure*". The first subzone of the groan zone is often described as a period of anxiety and disbelief.

Then, in the second subzone, when treatments start, patients are focused on surviving, and bodily reactions to treatments. Here the patients, but not the relatives, have intense contact with healthcare. The patient still must relate to their history, to the
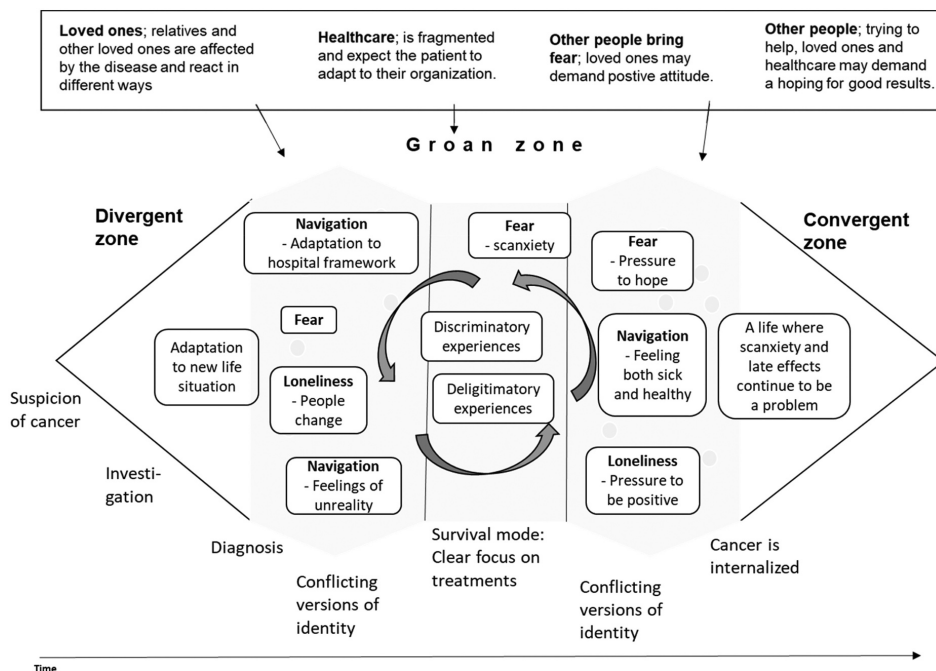

Figure 2. Patientification process

future and their relatives' view of both what has happened, what is happening and what will happen. As one informant expressed it "*How can I understand a side effect before I have lived it?*" referring to both his bodily struggles and to difficulties getting others to understand his new situation.

In the third subzone the person tries to integrate the whole experience with life after cancer or with cancer. The *convergent zone* integrates all experiences and supposedly makes cancer an incorporated part of a patient's identity; the process is seen in expressions such as "*I have started to think more about myself*" and "*I create my own space*". However, our informants seemed to struggle with the concepts of health and illness. One focus group used more than one hour to discuss whether they were ill or healthy in times of remission. Other groups shared the difficulty of integrating both health and illness with their identity and many expressed difficulties having to choose between the two. This struggle is also apparent in patients' expressions such as "*I am in a pretend-to-be-healthy mood*" or "*healthocondria*". After treatments feelings swing between the unreal and a new life. The situation facilitates a complex incorporation in the identity process of the cancer patient. The data shows a patientification process where cancer patients go through different stages in an iterative process where they learn to be a submissive, patiently waiting patient. Other people are in control of their care and

dependence, together with delegitimation experiences, pushes them towards a state of passivity. This is illustrated in figure 2, a design model based on the Diamond of participatory decision-making.

Introducing momentary contentment to reduce patientification impact

Figure 3 illustrates how strategies illuminated by Momentary contentment theory supports staying in the moment with patients feeling fewer worries and increased hope.

Instead of patient passivity, we argue an alternative approach where danger is met with personal involvement, a clear continuum of care and activities that help one getting back to the moment. Using the main concepts of Momentary contentment theory, *Middle consciousness* forms intermissions in the moment. By placing thoughts and feelings like fear in a cluster of moments, or redirecting them towards black humour, a sense of safety can be established outside of that cluster of moments (Sandén, 2017). *Destiny readiness*, accepting life as hard, contributes to a feeling of a crisis as a normal situation that must be dealt with. Through helpfulness, collective safety structures and activity, a crisis is then managed. *Doing safety* shows the possibility to affect a personal situation of any kind. A study on community-based activity groups among the elderly shows that doing activities
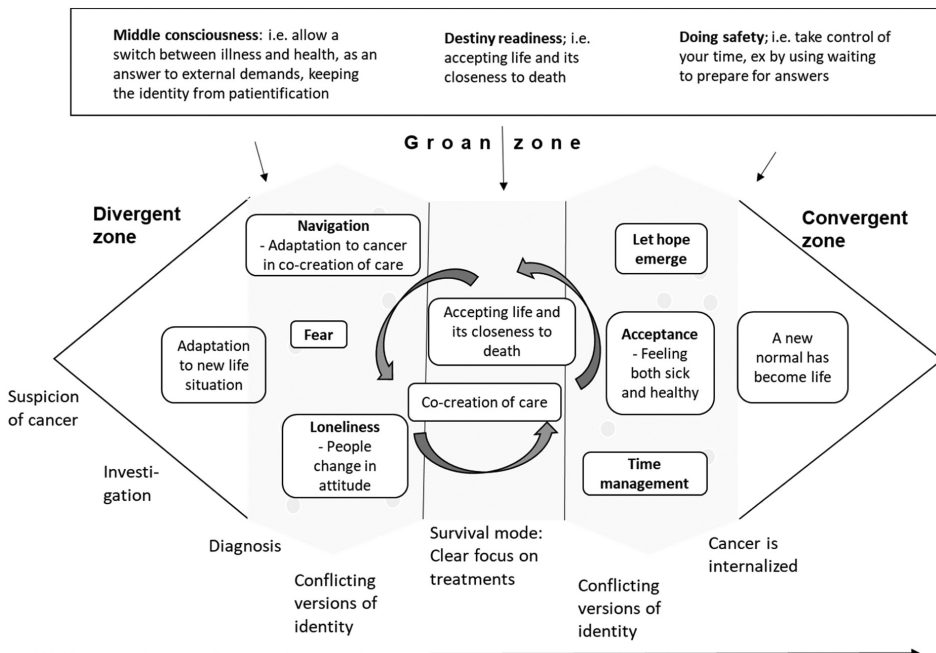

Figure 3. Momentary contentment process.

together with others enhances the positive effect of well-being as well as the motivation to keep going (Lindsay-Smith et al., 2019). Joint activities are partly a way to help each other, are partly therapy, but are also the means to have fun. The joint activities give a sense of control to do something as it cognitively creates clusters of moments, controllable episodes within an activity. With Momentary contentment theory a deeper understanding of the interview data could be gained, as shown in Table II.

Fear and "scanxiety": waiting or preparing

The distortion of time through waiting

Risks of a shortened future create emphasis on the current moment; "*I have been given a chance to rethink what is really important to me*". However, our data also shows how patients frequently put their lives on hold while waiting for answers. Time, inflicted as waiting, may disempower patients, " ... especially to be kept waiting an unusually long time is to be the subject of an assertion that one's own time (and therefore, one's social worth) is less valuable than the time and worth of the one who imposes the wait" as Schwartz (Schwartz, 1974) (p, p. 856) states. This negative situation may be balanced through medical consultation. An informant expressed this in different words: "*I had a great physician; he was calm and seemed to have all the time in the world. We talked about other things also and he told funny stories*". The opposite was also expressed, where both healthcare staff and relatives frequently tried to reduce the

distress with expressions like "don't worry" and "let's hope for the best". This may lead to two problems:

- Delegitimation. In our interviews patients talked about hypochondria when scared, thus making an adequate feeling pathological. Such expressions also cause feelings of demands being made; "*I will kick the next person who asks me to be positive*".

- Passivity. Just as the population studied in the Momentary contentment theory study tie down their outdoor furniture before an expected storm, cancer patients can create safety by preparing for different results. Telling patients not to worry encourages them to passively wait.

Further, these expressions tend to focus on the future, when scan results will be available, away from the moment, where a patient can actually *do* something about their situation. Life becomes a "negative journey" accompanied by "scanxiety", which starts a while before the scan, and persists until scan results arrive. Our informants describe how they do not know what will happen after they receive the scan results. With proper preparations they may be able to relax more and regain some control. *Waiting for imaging result. Timeline of "Scanxiety", distress reported by patients scheduled for diagnostic imaging to assess disease status. The condition, "scanxiety", is linked to decreased quality of life (*Bauml et al., 2016; Portman, 2018).

Our informants often chose to divide life into "being ill" while waiting, and "being healthy", as in survival. They showed a linear perception of time during waiting (Figure 3) and described a "hoping-

Table II. Combining concepts from patient narratives and Momentary contentment theory.

	What people said during interviews	Middle consciousness	Destiny readiness	Doing safety
Wait	Takes energy Worrisome Hard to focus on anything else Living in the future	A mindset where waiting is put in standby mode	Knowing that "shit" does happen sometimes	Preparation Doing things as distraction
Delegiti-mation	Body was fragmented, as well as body and soul were separated.	A mindset where health professionals are allowed to be Godlike "he/she will save me" and also humans as everybody else	Preparing for "shit" happens also when meeting healthcare professionals	Health professionals must learn to meet people as human beings with body, mind and soul
Fear	Stands in the way of health. Comes and goes with scanxiety	Allow hope to grow while you are afraid	Every time you become aware of having survived, hope grows	Meet fear with activity. Preparation and distraction
Hope	Important Must be logical	Hope is a state of mind	The knowledge of "shit happens" moves hope from a future good result to a calmness that you can handle anything	Doing things which help keeping mind and thoughts in the moment
Knowledge	Hard to go from informed to knowledgeable	Knowing you can handle anything creates hope	Experience-based	Learning
Loneliness	The disease creates loneliness. It is great to meet other cancer patients	Meeting others in the same situation allows life to be as it is, and no words are needed. You can stay in the middle consciousness without denying reality	Meeting others who know things can happen makes it less lonely. Reality is allowed	Reaching out to other people
Health	A black and white pendulum between feeling ill or feeling healthy	Allowing for the self to be both ill and healthy at the same time	Learning about the disease and accepting it as a part of the body	Doing new things, exploring life

for" state of mind, where hope was placed in the results. Living with hope, on the other hand, allows you to cope: "*While waiting for an X-ray result, I'm afraid, otherwise I don't think that much about it*".

Hope, time management and knowledge

The distortion of hope

For cancer patients, hope is closely connected to waiting. Being hopeful relates to feelings about what is in the present and hoping for something is related to change and the future (Benzein, 1999; Benzein et al., 2001). There is thus a difference between living with hope and hoping for something. Living with hope means an acceptance of life and a belief that you can handle future challenges.

With threat of a shortened life, healthcare professionals as well as relatives often try to enhance hope, which can lead to increased suffering (Törnqvist & Nielsen, 2011). The need to hope for a good result pressures people to cognitively move from the moment to an uncertain future. It also promotes a passive stance towards the results and the upcoming types of care taking activities. Waiting and "hoping for" are connected in their denial of the momentary reality. "Let's hope for the best" risks reducing a patient's hope by precluding activity as well as moving focus towards a worrisome future. See figure 4.

In order to allow for an incorporation of offered hope, not making it feel forced, the hope aimed for must match the knowledge a patient has. As one informant said: "*I just got angry when they obviously lied to me since I had read the [bad] statistics*".

Loneliness and companionship

In this article we show how patients are fostered and even forced into a patient identity (Figure 2). Gunnarson (Gunnarson, 2016) discusses how becoming a patient involves a transformation process from being a subject, to one's body becoming an object. One informant said: "*I walk into the hospital as a human being but walk out as a jaw*".

There are many studies on the relationship between physicians and patients. A study on identity construction of medical students shows how students grew to connect physicians as allies and patients as counterparts; some saw patients as adversaries

(Warmington & McColl, 2017). This was also detected in our interviews from a patient perspective, where one patient expressed the feeling when being treated in a condescending way: "*you and I do not belong to the same kind of people*". Another patient expressed feeling offended when talking about radiation side effects and the physician answered "*no, you don't experience side effects, they don't come until next week*".

Patients are told not to worry, when they in fact are dealing with a possibly deadly disease.

The cancer patients we interviewed expressed a need to be taken seriously when asking healthcare for help. If that did not happen, patients risked falling into self-doubt. Such self-doubt was hidden in different ways in the interview material. One was in the difference between patients and relatives, where both groups had criticism and examples of where they had not been heard:

"*I wanted to be seen, not just the tumour*".

"*No one took my symptoms seriously*".

However, as soon as criticism was put on healthcare staff the patient informants continued adding something positive to counteract a negative critique or shared experience:

"*but I shouldn't complain, they saved my life*".

Whereas the relatives seemed genuinely disappointed:

"*It's a lonely struggle to deal with the healthcare system*".

The self-doubt was also seen in how several patients described having had symptoms for years, suspecting cancer, but, not only, accepting a physician's word about the symptoms not being dangerous, but also making a hypochondriac comment about themselves, sometimes in combination with trying to avoid the risk of getting labelled as such. Similarly, Nordenfelt (Nordenfelt, 2005) discusses the importance of patient communication with their medical staff and argues that lack thereof may create feelings of insult and humiliation in a chronically ill person. This was also true for the relatives in our interviews. Several of them expressed how they thought they became mentally ill due to anxiety in the stressful situations where they had nowhere to turn. The stress of seeing a relative become more and more ill also created a horror-like situation where they wanted to help but did not know
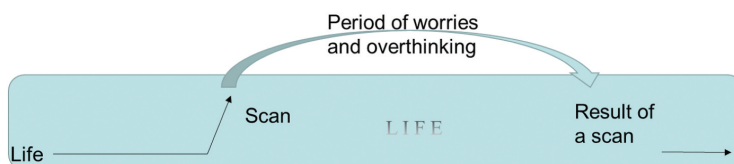

Figure 4. Illustration of "Scanxiety".

how. The frustration made many relatives hope "for it all to end", a hope that risked leading to guilt since the person suffering from cancer might not survive. All these mixed feelings together with the uncertain future affected a relative's identity and many informants expressed relief when meeting people in the same situation: *"I realized that I am not alone, that I am not crazy, that one may actually feel like I do"*. The situation was often unbearable for relatives and involved a high level of frustration. This was something the person suffering from cancer needed to relate to. As a result, both parties were at risk of assuming feelings of guilt and shame. This may explain some of the loneliness patients and relatives experience when a family member is ill, and why meeting others in shared situations provides important benefits. Several studies show that both cancer survivors and their relatives suffer from stress and depressive symptoms (Han, 2017; Lin et al., 2018; Osowiecka et al., 2019; Sandén, 2017; Sjövall, 2011). Important to note, however, is how patient informants described feelings of safety when they had been able to keep the same healthcare staff over time.

Discussion

In this article we revisit earlier used data from interviews with cancer patients and relatives where, in a deductively inspired analysis, we add Momentary contentment theory. In this re-analysis of qualitative interviews, we have found that a patientification process where patients are taught to be submissive may be reduced by a Momentary contentment approach. This includes a shift from patientification to co-creation of care. Both cancer patients and relatives to cancer patients expressed themselves in relation to each other in interviews, and both groups also emphasized the importance of their relationships, or lack thereof, with healthcare staff. Heaven et al. showed how trial identity shapes participants' understandings regarding treatment decisions and all other aspects of the trial (Heaven et al., 2006). People learn about expected values and practices, including how trial group members are expected to treat one another (Lave & Wenger, 1991). Even though identity is an individual marker it is thus formed and reinforced in relationships. The informants lift themselves in relation to the health professional team: *"no one wants to be labelled a difficult patient"*.

Patientification process

It is within relationships that patientification is strengthened and weakened. If we look at cancer patients as belonging to a cultural group within healthcare, their view of themselves will be affected when they are objectified as patients. Prejudice and discrimination are complex social phenomena negotiated through an intricate interactional web that involves initiation from the dominant group and definition and reaction from the subordinate one (Evergeti, 2011). Parsons (Parsons, 1951) discusses illness as more than a condition, as a social role, the sick person role, where the person is deprived of a reasonable claim of full legitimacy. In a patient role they are obliged to accept help from those who are specially qualified to treat illness, mostly physicians. It seems that our embodied experiences change when we become ill (Gunnarson, 2016). The fragmentation was evident in our interviews and one patient described how she lost her sense of being a human: *"I became a stick figure"*. This resembles Agledahl's (Agledahl et al., 2011) study where physicians, often without realizing, ignore existential questions. Ware discusses delegitimation and mentions two types: one where people minimize the experience of illness with words like "*we are all tired*", and another where physicians define the experienced illness as existing mostly in the patient's mind, i.e., a psychosomatic illness (Ware, 1992). Both types mean a questioning of a person's own experiences, however, according to Ware, the second one is more damaging to the patient since it includes a new illness, a psychological one, which contains a great deal of stigma. The expressions "*let's hope for the best*" and "*don't worry*" both risks contributing to delegitimation. In France, the concept of "Patientilisation" has been used to explain a patiently waiting patient (Petter-Zaugg, 2013). This correlates to the concept of clientification in social work, which includes a categorization process where a problem gets defined within the organizational frame, often in a landscape of fragmentation, specialization and individualization (Gümüscü et al., 2015). Translated into healthcare we can say, in a similar fashion, that there is a patientification process in progress.

Regaining control of your temporal space

According to Gadamer, a main task for healthcare is, in addition to restoring the sick person, and in connection with recovery, to reproduce unity with self (Gadamer, 1996). New living conditions require new social constructs, and to regain everyday life you must accept and adapt to new living conditions. Previous research on cancer patients illustrates their difficulties in balancing their new abilities where fatigue and other late effects have become a part of life, with both internal and external demands (Berger et al., 2015; Duijts et al., 2017; Van Maarschalkerweerd et al., 2019). Working full-time becomes difficult. A study of breast cancer survivors in the Netherlands shows changes in employment status 5–10 years after diagnosis (Van Maarschalkerweerd et al., 2019).
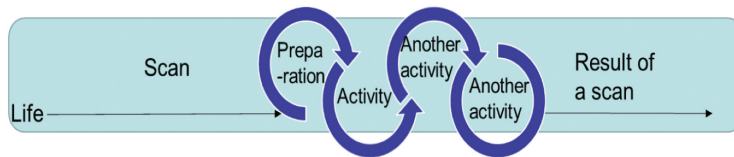
Figure 5. Overcoming Scanxiety.

According to Momentary contentment theory the view on time management and life priorities needs to be adapted to current situation (Sandén, Thulesius et al., 2015). The anthropologist Alfred Gells describes how several human periodization's have their origin in different natural phenomena that are not socially determined, such as the year and day, which unlike the socially constructed week and hour, are based on the Earth's relation to the sun (Heidegren, 2014). Likewise, we can choose to allow disease to create new accruals, which will be more adapted to real life. A natural, flexible and compliant view of time would both accept feelings of fatigue due to treatments and of joy in times of health.

By relating to the present moment as a subjective experience, not following clock time, it differs from situation to situation and between people. Life and its requirements can be adapted to a new life situation, which includes illness. Instead of the paralysing wait, patients may participate in preparations for different possible outcomes (figure 4). In Momentary contentment every moment has its own context and as such creates a possibility to influence the context in which the next moment will take place. Activity may bring a patient from a "hoping-for" state of mind to a present "living with hope". In the process patients become more involved in their care, which in several studies has shown to be beneficial (Alden, 2014; deBronkart, 2011; Kane et al., 2014; McDonald et al., 2013; Schmidt et al., 2015).

Figure 5, Overcoming "Scanxiety". By creating a cyclical perception of waiting through preparing activities, anxiety-provoking anticipation may be reduced.

Memo on overcoming scanxiety through Momentary contentment theory:

Through preparation you create a feeling "I have done everything I can do". To be able to do so you need knowledge. In preparation hope emerges, "Idohandle this". Every time you handle the situation you become more assertive that you can handle whatever comes in your way. Different outcomes during waiting become apparent when you are preparing and when they are all prepared for it is hard to dwell on them. When everything possible is done there is not much to do but to focus on something else; like having fun. That can be hard due to the loneliness, the lack of understanding. Everyone understands that you may be afraid, but it may be harder to understand your calmness. Here it helps to find others in similar situations and perhaps with similar personalities. Meeting others in the same situation allows life to be as it is and no words are needed. You can stay in middle consciousness without denying life as is.

From patientification to participation and co-creation of care

Gadamer (Gadamer, 1996) sees health as personal, an independent non-measurable balance. Antonovsky stresses the balance between generalized resource deficits and resources to determine whether something will be harmful or not (Antonovsky, 1987). This resembles Momentary contentment theory (Sandén, Harrysson et al., 2015) where health is found in the balance between the dangers in an arctic climate and the villagers' ability to handle them. Momentary contentment theory adds activity, an acceptance of different outcomes in life and a stand-by mentality (figure 5), which makes the theory usable as an antagonist to the passivity surrounding the patientification process.

It seems as patients find a way to live with hope even when the situation looks bad from the side-line. Momentary contentment theory (Sandén, 2014) illustrates an incorporation of different aspects of life as normal, including accidents and illnesses, which facilitates an internal readiness. That readiness creates a hope with no destination or change, a hope that lives within. Contrary to "hoping for a good result" this intrinsic hope moves people from anxious thoughts about what may happen in the future to a momentary acceptance of life as unpredictable and hard to control. Safety is instead reached through activity, cognitive awareness and collective helpfulness. One such activity is predictability. Together with relevant knowledge of different processes you can prepare for different results. One man stated how he managed to cope by focusing on getting well due to the information he was given about the importance of the first month "*I thought I will give everything these 30 days*". Our informants expressed the importance of not thinking of the disease when feeling healthy, stated in "*when waiting I am sick, otherwise I don't think about the disease*".

When you have cancer, it is hard to feel in control. Yet through preparations, a form of activity, a sense of control can be achieved. Activities can further be used in companionship with others to bring someone back from a negative moment, as shown in breast cancer dragon boat participants (McDonough et al., 2019). An Australian study shows how physical exercise improved both somatic and mental health among cancer survivors (Frensham et al., 2018) and a case study with exercise rehabilitation in a glioblastoma patient shows quality of life improvements (Hansen et al., 2019). To many people cancer becomes a life-long experience. Through an acceptance that different outcomes are possible one may start to prepare. In the preparation lies a subjective sense of control. Through the combination of activity and a feeling that everything that *can* be done *has* been done, patients may feel healthy in the moment, without denying the disease.

Implications for future studies replacing the patientification process with co-creation of care

In this section we have theorized our results and the implications are to be seen as suggestions that have not yet been empirically studied. We suggest these to be implemented during a clinical study. Principles for breaking the patientification process for staff in personalized cancer care are:

* Focus on each person as an individual with both unique and common needs. This supports the patient's feeling of being included in their own care.

* Support knowledge development. It strengthens the patient.

* See to that the person is included into shared decision-making. To do so the principles above must be regarded. Together they obstruct the patientification process.

* Help patients and relatives to distinguish between hoping for something and living with hope.

* Activity may be used both to prepare for different outcomes as well as to distract from passive and anxious waiting.

Strengths and limitations

Our secondary analysis of revisiting data initially collected for another analytical purpose asks for some caution. Thus, we have been observant about data that may not entirely fit the theory of Momentary contentment. We have both gone back to the raw data and to our earlier interpretations to check the data integrity against the eventuality that our new analysis may have changed the meaning of what informants shared with us. The analysis presented in this article does not contain any skewed data to create perfect fits although a grounded theory should be modifiable when new data are analysed. Hence, it may be possible that "no-fits" were left out.

The data itself also holds some limitations. Our interviews were conducted with patients and relatives after cancer survival or death, so that the narratives are constructions of memories. The interviews were conducted by one author. They were not recorded, instead, detailed notes were taken in accordance with classic grounded theory. To overcome possible bias, we have had one other author participate in two interview sessions to see how notes may differ. The differences were minor, and we regard them as having no impact on our analysis. A second way to credibility-test the data was by sending the analytical work to the participants for comments. The feedback we received confirms our data interpretations. The interview data has also been discussed among the authors, all having experience in working or living with cancer patients.

The Momentary contentment theory has not been built around, or tested empirically on, cancer patients. However, what we have done is to present a conceptual design through theorizing needs and solutions based on conceptualized cancer interview data. There is a multidisciplinary approach in our analysis, based on the research group's various disciplines where we mix engineering, medicine and social sciences as well as clinical and patient experiences.

Conclusion

Through Momentary contentment theory we introduce participation and acceptance as means to learn to adapt to new living conditions for patients with cancer. We suggest a clinical study where patients are guided into a proactive approach to concepts such as living with hope, activity, preparation and acquiring knowledge. Moreover, healthcare is assumed to be a co-creation process, including the patient based on their needs.

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References

Agledahl, K. M., Gulbrandsen, P., Førde, R., & Wifstad, Å. (2011). Courteous but not curious: How doctors' politeness masks their existential neglect. A qualitative study of video-recorded patient consultations. *Journal of Medical Ethics*, *37*(11), 650–654. https://doi.org/10.1136/jme.2010.041988

Alden, D. L. (2014). Decision aid influences on factors associated with patient empowerment prior to cancer treatment decision making. *Medical Decision Making*, *34*(7), 884–898. https://doi.org/10.1177/0272989X14536780

Antonovsky, A. (1987). *Unraveling the mystery of health: How people manage stress and stay well*. Jossey-Bass.

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion1. *Health Promotion International*, *11*(1), 11–18. https://doi.org/10.1093/heapro/11.1.11

Bandura, A. (1997). Insights Self-efficacy. *Harvard Mental Health Letter*, *13*(9), 4–6.

Bate, P., & Robert, G. (2006). Experience-based design: From redesigning the system around the patient to co-designing services with the patient. *Quality & Safety In Health Care*, *15*(5), 307–310. https://doi.org/10.1136/qshc.2005.016527

Bauml, J. M., Troxel, A., Epperson, C. N., Cohen, R. B., Schmitz, K., Stricker, C., Shulman, L. N., Bradbury, A., Mao, J. J., & Langer, C. J. (2016).*Original article: Scan-associated distress in lung cancer: Quantifying the impact of "scanxiety"*. *Lung Cancer*, October 2016, *100*, 110–113. https://doi.org/10.1016/j.lungcan.2016.08.002

Benzein, E., *Traces of hope*. Umeå University medical dissertations: N.S., 636. 1999: Umeå Univ

Benzein, E., Norberg, A., & Saveman, B. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine*, *15*(2), 117–126. https://doi.org/10.1191/026921601675617254

Berger, A. M., Mooney, K., Alvarez-Perez, A., Breitbart, W. S., Carpenter, K. M., Cella, D., Cleeland, C., Dotan, E., Eisenberger, M. A., Escalante, C. P., Jacobsen, P. B., Jankowski, C., LeBlanc, T., Ligibel, J. A., Trice Loggers, E., Mandrell, B., Murphy, B. A., Palesh, O., Pirl, W. F., Plaxe, S. C., … Smith, C. (2015). *Cancer-Related Fatigue, Version 2.2015*. *13*(8): p. 1012.

deBronkart, D. (2011). *Meet e-patient dave*. TEDxMaastricht April 2011 https://www.ted.com/talks/dave_debronkart_meet_e_patient_dave.

Duijts, S. F. A., Van Egmond, M. P., Gits, M., Van Der Beek, A. J., & Bleiker, E. M. (2017). Cancer survivors' perspectives and experiences regarding behavioral determinants of return to work and continuation of work. *Disability and Rehabilitation*, *39*(21), 2164–2172. https://doi.org/10.1080/09638288.2016.1219924

Evergeti, V. (2011). Discrimination and reaction: The practical constitution of social exclusion. *Symbolic Interaction*, *34* (3), 377–397. https://doi.org/10.1525/si.2011.34.3.377

Frensham, L. J., Parfitt, G., & Dollman, J. (2018). Effect of a 12-week online walking intervention on health and quality of life in cancer survivors: A quasi-randomized controlled trial. *International Journal Of Environmental Research And Public Health*, *15*(10), 10. https://doi.org/10.3390/ijerph15102081

Gadamer, H.-G. (1996). *The enigma of health: The art of healing in a scientific age*. Polity Press.

Glaser, B. G. (1998). *Doing grounded theory: Issues and discussions*. Sociology Press, cop.

Gümüscü, A., Nygren, L., & Khoo, E. (2015). *Bringing the family back in: On role* assignment *and* clientification in the Swedish social services. *Social Sciences*, *4*(1), 117–133. https://doi.org/10.3390/socsci4010117

Gunnarson, M., *Please be patient: A cultural phenomenological study of haemodialysis and kidney transplantation care*. Lund studies in arts and cultural sciences: 7. 2016.

Han, M. A. (2017). Stress and depressive symptoms in cancer survivors and their family members: Korea community health survey 2012. Int. J. Environ. Res. Public Health 2017, 14(9), 999; https://doi.org/10.3390/ijerph14090999.

Hannum, S. M., & Rubinstein, R. L. (2016). The meaningfulness of time; Narratives of cancer among chronically ill older adults. *Journal of Aging Studies*, Januray 2016, *36*, 17–25. https://doi.org/10.1016/j.jaging.2015.12.006

Hansen, A., Søgaard, K., & Minet, L. R. (2019). Development of an exercise intervention as part of rehabilitation in a glioblastoma multiforme survivor during irradiation treatment: A case report. 41: p. 1608–1614

Heaven, B., Murtagh, M., Rapley, T., May, C., Graham, R., Kaner, E., & Thomson, R. (2006). Patients or research subjects? A qualitative study of participation in a randomised controlled trial of a complex intervention. *Patient Education and Counseling*, *62*(2), 260–270. https://doi.org/10.1016/j.pec.2005.07.013

Heidegren, C.-G. (2014). *Tid: Sociologiska perspektiv*. 1: Stockholm: Liber(Kina).

Hirsch, B. R., & Abernethy, A. P. (2013). Structured decision-making: Using personalized medicine to improve the value of cancer care. J. Pers. Med. 2013, 3 (1), 1-13; https://doi.org/10.3390/jpm3010001

Kane, P., Jasperse, M., Boland, P., & Herst, P. (2014). A pathway to empowerment: Evaluating a cancer education and support programme in New Zealand. *European Journal of Cancer Care*, *23*(5), 668–674. https://doi.org/10.1111/ecc.12188

Kaner, S. (2014). *Facilitator's guide to participatory decision-making* (3rd ed.). Jossey-Bass.

Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation*. Cambridge University Press.

Lin, P.-H., Liu, J.-M., Hsu, R.-J., Chuang, H.-C., Chang, S.-W., Pang, S.-T., Chang, Y.-H., Chuang, C.-K., & Lin, S.-K. (2018). Depression negatively impacts survival of patients with metastatic prostate cancer. Int. J. Environ. Res. Public Health 2018, 15(10), 2148; https://doi.org/10.3390/ijerph15102148

Lindsay-Smith, G., Eime, R., O'Sullivan, G., Harvey, J., & Van Uffelen, J. G. Z. (2019). A mixed-methods case study

exploring the impact of participation in community activity groups for older adults on physical activity, health and wellbeing. *BMC Geriatrics*, *19*(1), 243. https://doi.org/10.1186/s12877-019-1245-5

McDonald, K. M., Bryce, C. L., & Graber, M. L., (2013). *The patient is in: Patient involvement strategies for diagnostic error mitigation*. 33–39.

McDonough, M. H., Patterson, M. C., Weisenbach, B. B., Ullrich-French, S., & Sabiston, C. M. (2019). The difference is more than floating: Factors affecting breast cancer survivors' decisions to join and maintain participation in dragon boat teams and support groups. *Disability & Rehabilitation*, *41*(15), 1788–1796. https://doi.org/10.1080/09638288.2018.1449259

Mintrom, M., & Luetjens, J. (2016). Design thinking in policy-making processes: Opportunities and challenges. *Australian Journal of Public Administration*, *75*(3), 391–402. https://doi.org/10.1111/1467-8500.12211

Nordenfelt, L. (2005). *Om kronisk sjukdom och livskvalitet*, in *Sjukdomsvärldar*. In B. Richt & G. Tegern (Eds.), *Om människors erfarenheter av kroppslig ohälsa* (pp. 305–322). Studentlitteratur: Lund.

Osowiecka, K., Nawrocki, S., Kurowicki, M., & Rucinska, M. (2019). The waiting time of prostate cancer patients in Poland. Int. J. Environ. Res. Public Health 2019, 16(3), 342. https://doi.org/10.3390/ijerph16030342.

Parsons, T. (1951). Illness and the role of the physician: A sociological perspective. *American Journal of Orthopsychiatry*, *21*(3), 452–460. https://doi.org/10.1111/j.1939-0025.1951.tb00003.x

Petter-Zaugg, M. (2013). *de voir autrement*. Haute Ecole Pédagogique - BEJUNE.

Portman, D. (2018). Scanxiety. *Families, Systems, & Health*, *36*(3), 415. https://doi.org/10.1037/fsh0000353

Sandén, U. (2014). Nuets förnöjsamhet - en grundad teori med utgångspunkt i Nordnorskt vardagsliv. In *School of Social Work*. Lund University. https://lup.lub.lu.se/student-papers/search/publication/4812621

Sandén, U., *Momentary contentment: Exploring needs and innovation possibilities in a psychosocial cancer context*. Department of Design Sciences, Lund Univ., Lund, 2017.

Sandén, U. (2019). Co-creation of lifelong rehabilitation design. *Brain, Body, Cognition*, *8*(4), 381–393.

Sandén, U., Harrysson, L., & Thulesius, H. (2015). Momentary contentment a modern version of an old survival culture. *Grounded Theory Review: An International Journal*, *14*(2), 74–85. http://groundedtheoryreview.com/2015/12/19/momentary-contentment-a-modern-version-of-an-old-survival-culture/

Sandén, U., Harrysson, L., Thulesius, H., & Nilsson, F. (2017). Exploring health navigating design: Momentary contentment in a cancer context. *International Journal of Qualitative Studies on Health & Well-Being*, *12*(1), 1374809. https://doi.org/10.1080/17482631.2017.1374809

Sandén, U., Nilsson, F., Thulesius, H., Hägglund, M., & Harrysson, L. (2019). Cancer, a relational disease: Exploring the needs of relatives to cancer patients. *International Journal of Qualitative Studies on Health and Well-being*, *14*(1), 1. https://doi.org/10.1080/17482631.2019.1622354

Sandén, U., Thulesius, H., & Harrysson, L. (2015). Nuets förnöjsamhet: En grundad teori om livsval och överlevnadsstrategier. *Sociologisk Forskning*, *52*(3), 235–256. https://sociologiskforskning.se/sf/article/view/18292

Schmidt, M., Eckardt, R., Scholtz, K., Neuner, B., Von Dossow-hanfstingl, V., Sehouli, J., Stief, C. G., Wernecke, K.-D., & Spies, C. D. (2015). Patient empowerment improved perioperative quality of care in cancer patients aged > 65 years - a randomized controlled trial. *Plos one*, *10*(9). https://doi.org/10.1371/journal.pone.0137824

Schwartz, B. (1974). Waiting, exchange, and power: The distribution of time in social systems. *American Journal of Sociology*, *79*(4), 841–870. https://doi.org/10.1086/225629

Sevetson, A. (2005). Editor's corner: Change, change, change. *DttP: A Quarterly Journal of Government Information Practice & Perspective*, *33*(2), 4.

Shay, L. A., & Lafata, J. E. (2015). Where is the evidence? A systematic review of shared decision making and patient outcomes. *Medical Decision Making : An International Journal of the Society for Medical Decision Making*, *35*(1), 114–131. https://doi.org/10.1177/0272989X14551638

Sjövall, K., *Living with cancer: Impact on cancer patient and partner*. Faculty of Medicine doctoral dissertation ed. 25. Lund Univ. Lund 2011.

Törnqvist, L., & Nielsen, L. (2011). *Att skapa en god vårdrelation: Relationen mellan sjuksköterska och patienter som insjuknat i cancer (To create a good caring relationship: The bond between nurses and cancer patients)*. Linné univ.

Van Maarschalkerweerd, P. E. A., Schaapveld, M., Paalman, C. H., Aaronson, N. K., & Duijts, S. F. A. (2019). Changes in employment status, barriers to, and facilitators of (return to) work in breast cancer survivors 5–10 years after diagnosis. *Disability and Rehabilitation*, *42*(21), 1–7. https://doi.org/10.1080/09638288.2018.1522554

Ware, N. C. (1992). Suffering and the social construction of illness: The delegitimation of illness experience in chronic fatigue syndrome. *Medical Anthropology Quarterly*, *6*(4), 347–361. https://anthrosource.onlinelibrary.wiley.com/doi/pdf/10.1525/maq.1992.6.4.02a00030?casa_token=QqoNdWxHPB8AAAAA%3AXzRfXdiZsFbfyRU7yZ6F2DgZpq9SlQ-WjHCEXLqGmDbg93WcBJYyLwl09R_TLU8uP01j2gOe36b-rLkA

Warmington, S., & McColl, G. (2017). Medical student stories of participation in patient care-related activities: The construction of relational identity. *Advances in Health Sciences Education : Theory and Practice*, *22*(1), 147–163. https://doi.org/10.1007/s10459-016-9689-2

Weston, W. W. (2001). Informed and shared decision-making: The crux of patient-centred care. *CMAJ: Canadian Medical Association Journal*, *165*(4), 438–439. https://pubmed.ncbi.nlm.nih.gov/11531054/

Paper VII

Pluralistic task shifting for a more timely cancer diagnosis.

A grounded theory study from a primary care perspective.

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Objective

To explore how cancer could be diagnosed in a more timely way.

Design

Grounded theory analysis of primary care physicians' free text survey responses to: "How do you think the speed of diagnosis of cancer in primary care could be improved?". Secondary analysis of primary care physician interviews, survey responses, literature.

Setting

Primary care in 20 European Örenäs Research Group countries.

Subjects

Primary care physicians: 1352 survey respondents (2013-2016), 20 Spanish and 7 Swedish interviewees (2015-2019).

Main outcome measures

Conceptual explanation of how to improve timeliness of cancer diagnosis.

Results

Pluralistic task shifting is a grounded theory of a composite strategy. It includes *task sharing* - among nurses, physicians, nurse assistants, secretaries, and patients - and *changing tasks* with cancer screening when appropriate or cancer fast-tracks to accelerate cancer case finding. A *pluralistic dialogue culture* of comprehensive collaboration and task redistribution is required for effective pluralistic task shifting.

Pluralistic task shifting relies on *cognitive task shifting,* which includes learning more about slow analytic reasoning and fast automatic thinking initiated by pattern

recognition; and *digital task shifting,* which by use of eHealth and telemedicine bridges time and place and improves power symmetry between patients, caregivers, and clinicians.

Financial task shifting that involves cost tracking followed by reallocation of funds is necessary for the restructuring and retraining required for successful pluralistic task shifting.

A timely diagnosis reduces expensive investigations and waiting times. Also, late-stage cancers are costlier to treat than early-stage cancers. Timing is central to cancer diagnosis: not too early to avoid overdiagnosis, and never too late.

Conclusions

We present *pluralistic task shifting* as a conceptual summary of strategies needed to optimise the timeliness of cancer diagnosis.

Key Points

Cancer diagnosis is under-researched in primary care, especially theoretically. Thus, inspired by classic grounded theory, we analysed and conceptualised the field:

Pluralistic task shifting is a conceptual explanation of how the timeliness of cancer diagnosis could be improved, with data derived mostly from primary care physicians.

This includes *task sharing* and *changing tasks* including screening and cancer fast-tracks to accelerate cancer case finding, and requires *cognitive task shifting* emphasising learning, and *digital task shifting* involving the use of eHealth and telemedicine.

Financial task shifting with cost tracking and reallocation of funds is eventually necessary for successful pluralistic task shifting to happen.

Introduction

Diagnosing cancer is heterogeneous, in that it depends on disease type, age, gender, socioeconomic and geographical context, and type of healthcare system [1-3]. Some cancers, such as breast cancer, colorectal cancer and prostate cancer, may be detected by screening in an early asymptomatic phase of the disease [4]. However, the majority of cancers are discovered by case finding: symptoms and signs of the cancer are assessed through consultations with health care professionals [5] and most cancer patients are first seen by a primary care physician [1,2].

Work-up of a cancer diagnosis often requires several different assessment methods, which may or may not include a physical examination [5]. These are followed by technical procedures which include diagnostic imaging techniques and blood tests [2]. A histological examination of body tissue or cells ultimately confirms the cancer diagnosis, except for some late-stage cancers, often in the elderly, which may only be discovered by diagnostic imaging or at autopsy [6].

Many countries have introduced fast-track systems for detecting cancer that are effective in improving case-finding if the symptoms and signs of patients meet specific fast-track criteria [3]. Investigations for suspected cancer can in some countries be done by centralised or specialised diagnostic services that target many diagnoses simultaneously for those patients who do not meet fast-track criteria and where case finding fails [3,7,8].

The complexity of the cancer diagnostic pathway described above implies that there are many opportunities for error and delay. These many issues need to be resolved to optimise the work-up processes involved.

The purpose of this study was to analyse, from a primary care perspective, how the timeliness

of cancer diagnosis could be enhanced. Since theories on care improvement are rare but encouraged [9] we present a grounded theory to provide conceptual hypotheses to explain how we may improve a more timely diagnosis of cancer.

Methods

Data collection

We collected data mainly from surveys of European primary care physicians. Secondarily we collected data from interviews with primary care physicians, from scientific literature data and from news articles and internet media.

We performed an online survey study of primary care physicians in 25 Örenäs Research Group centres in 20 countries between November 2015 and December 2016 (Bulgaria, Croatia, Denmark, England, Finland, France, Germany, Greece, Israel, Italy, Netherlands, Norway, Poland, Portugal, Romania, Scotland, Slovenia, Spain, Sweden and Switzerland).

The methodology and the development of the Örenäs Research Group survey is described elsewhere [3,10]. The overall response rate for the survey was 24.8%, ranging from 7.1%-65.6% between participating countries.

We also used data from an online survey by the International Cancer Benchmarking Partnership to Danish and Swedish primary care physicians in 2013 (translated from Danish by BST and from Swedish by HT) [11].

Data from a focus group interview study with Spanish primary care physicians in 2015 were

also used (translated from Castilian by BOF) [12].

We further collected data from interviews with Swedish primary care physician researchers 2015-2019 who had participated in a detailed audit of the diagnostic process from electronic health records of six hundred patients diagnosed with bowel, lung, and urinary tract cancer (translated from Swedish by HT) [13].

The Spanish focus group data were transcribed from audio recordings, while the Swedish interview data were recorded in field notes. Scientific and popular literature on cancer diagnosis, including articles and comments from online sources, was also studied in the theory generation process. The scientific literature analysed in this study is given in the reference list.

Subjects

Primary care physicians:

The Örenäs Research Group survey qualitative data were retrieved from free text comments written by 1352 respondents from 20 European countries; free text comments in the International Cancer Benchmarking Partnership survey were written by 237 Danish and 165 Swedish respondents [11]; transcribed qualitative data from 20 Spanish focus group participants [12]; and qualitative data in field notes from 7 Swedish individual interviews with primary care physicians [13]; were also used as data for the analysis.

Data Analysis

Our analysis was inspired by classic grounded theory, which is the world's most cited behavioural research method with 137,065 Google Scholar citations for its seminal publication (29 June, 2021) [14].

We primarily analysed free text survey responses to: "How do you think the speed of diagnosis of cancer in primary care could be improved?" Thus, a preformed question was the basis of our analysis which is not in line with classic grounded theory where a starting point of the analysis should not be set in advance.

Secondary data analysis of survey data, focus group data and individual interview data was done by applying the same grounded theory procedures as in recent studies following the classic grounded theory "all is data" dictum [15-20]. Classic grounded theory uses a mostly inductive approach to generate hypotheses that explains how participants in a studied area resolve their main concern. Grounded theory aims to generate conceptual theories presenting explanatory hypotheses that transcend cultural, temporal and contextual boundaries. Relevant and modifiable grounded theory concepts that work to explain what is going on should be able to fit in diverse settings and exceed disciplinary and geographical borders [14,21-27].

A classic grounded theory research conceptualises "what is going on" in the field of study by constantly comparing data during an iterative research process which involves open coding, memoing, theoretical sampling (data collection based on emerging hypotheses from the ongoing analysis), selective coding (coding and recoding particular data based on central concepts from the ongoing analysis), sorting (sorting memos according to relationships between concepts in the theory), re-sorting and then writing up the sorted memos into a working paper and eventually a publication [14,21-27].

Once the core category that explained what was going on in the data was generated, which in this study first was "pluralistic retasking", but later renamed "pluralistic task shifting", the analysis was delimited to the core category and related categories, and selective coding was done. Memoing, with the core category guiding the analytic work, then continued.

According to grounded theory rules, most of the conceptual literature was analysed at the end of the study [14,21-27].

The group of authors is multidisciplinary, comprising researchers in nursing (SH), social work and design (US), economic history (LH), and physician researchers (HT, DP, RH, TK, B O-F, ALN, BST, PV, MH). Our study was inspired by the concept of pluralistic dialogue, with numerous e-mail rounds, several telephone discussions and some face-to-face meetings knitting the group of authors together in the analytic process over a period of five years. This brought a collective intelligence perspective to the emergence of the theory [28].

A classic grounded theory study generates hypotheses for new theory based on thorough systematic analyses of large amounts of data, both empirical and interpreted, quantitative as well as qualitative. The quality of a classic grounded theory may be tried against the principles of "fit", "work", "relevance" and "modifiability" set forth by Glaser and Strauss [14] and Glaser [21-27]. "Fit" has to do with how closely concepts fit the incidents they are representing. Achieving fit requires rigorous adherence to the constant comparison process, where incidents are compared to each other and to emerging concepts. A "relevant" study deals with the real concern of the participants and captures attention. The theory "works" when it explains how the problem, or main concern of participants, is being resolved and when it accounts for most of the variation in participants' behaviour in the substantive area. A "modifiable" theory is one that is never complete but can always be further developed when new relevant data are compared to existing data. A classic grounded theory is never right or wrong, it just has more or less fit, relevance, workability and modifiability, and readers of this paper may assess its quality according to these principles.

Descriptive and narrative data from the survey part of this study have been reported elsewhere [3,10].

Ethics approval

Neither the mail survey nor the interview data in this study required formal research ethics

approval according to Swedish law, but the Regional Research Ethics Committee in Linköping gave a positive advisory statement regarding the International Cancer Benchmarking Partnership survey (Diary number 2011/495-31). Local study leads of the Örenäs Research Group were asked to either gain ethical approval or obtain a statement that formal ethical approval was not needed in their jurisdiction [3,10].

Results

Rethinking cancer diagnosis by pluralistic task shifting

In this study, based on conceptualised data from the written reflections and ideas of many primary care physicians, but also literature data, we propose that a compound strategy of "pluralistic task shifting" is the core variable that can explain what could be done to improve the timeliness of cancer diagnosis from a primary care perspective.

Table 1 gives an overview of the most important concepts in the study including the core variable Pluralistic Task Shifting and its sub-core variables.

Table 2 provides definitions of the concepts used in the study.

Table 1. Overview of the most important concepts in the theory of Pluralistic Task Shifting for a more timely cancer diagnosis.
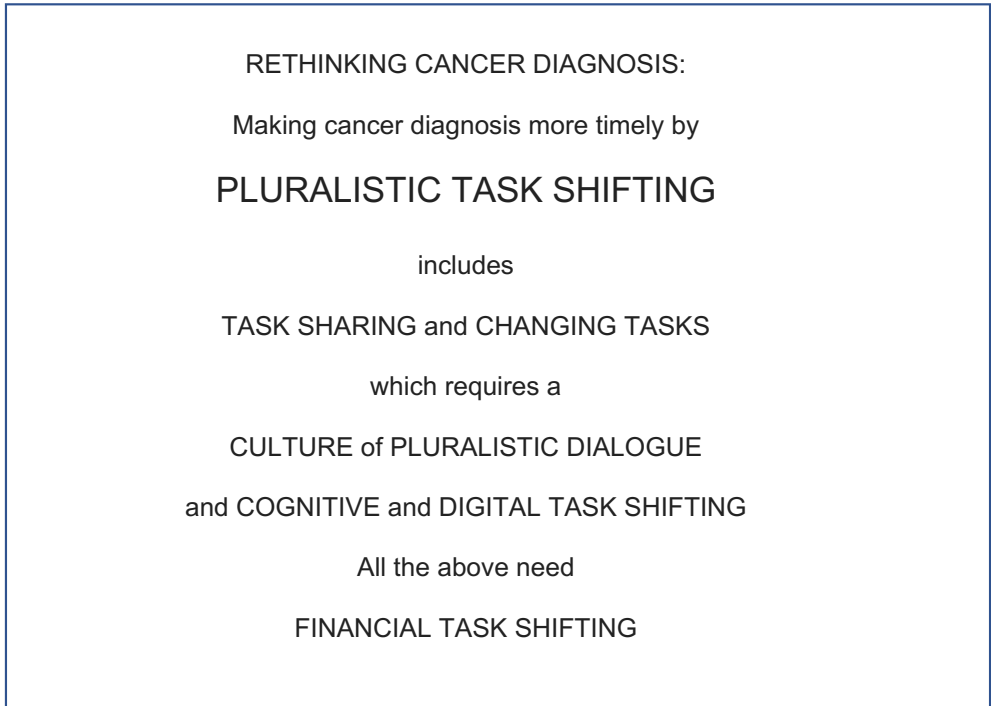
RETHINKING CANCER DIAGNOSIS:

Making cancer diagnosis more timely by

PLURALISTIC TASK SHIFTING

includes

TASK SHARING and CHANGING TASKS

which requires a

CULTURE of PLURALISTIC DIALOGUE

and COGNITIVE and DIGITAL TASK SHIFTING

All the above need

FINANCIAL TASK SHIFTING

Table 2. Definitions of concepts used in the study of the theory of Pluralistic Task Shifting for a more timely cancer diagnosis.

"Rethinking cancer diagnosis": the "main concern" of the survey participants, based on the question "How do you think the speed of diagnosis of cancer in primary care could be improved?".
"Pluralistic task shifting": the "core variable" that explains what is going on - it is a resolution of the main concern, giving an overall explanation to how the timeliness of diagnosis of cancer in primary care could be improved. "Task shifting" is the "rational redistribution of tasks among health workforce teams" mostly described in healthcare in low-income countries" according to WHO 2008 [29]. It is an "in-vivo" concept from health care. In our context, it explains how tasks such as cancer diagnosis could be improved. "In-vivo" means that task shifting is an existing concept used within the substantive area of scrutiny. Task shifting has been "emergently fitted" to the data, meaning that we have hypothesised that task shifting explains and covers what the respondents and literature data are suggesting on how to improve the timeliness of cancer diagnosis.
"Task sharing": a property of task shifting that emphasises collaboration, team working and training.
"Vertical task shifting and task sharing": a process that involves staff at *different* levels of training and competence, for example shifting from community health workers to nurses, or from nurses to physicians.

"Horizontal task shifting and sharing": a process that involves staff at *similar* levels of training and competence, for example shifting and sharing from a physician in one speciality to a physician in another one.

"Changing tasks": a property of pluralistic task shifting that explains standardised cancer diagnostic pathways and screening programmes.

"Culture of pluralistic dialogue": an evolving cooperative dialogue among professionals crossing boundaries of disciplines. It focuses on patients/clients and service delivery. It is a requirement for a successful task shifting and sharing to develop.

Pluralistic dialogue is an emergently fitted, or "borrowed", grounded theory concept explaining professionals collaborating by deconstructing and resynthesising thinking, rethinking professional responsibility and reframing team responsibility by breaking of stereotypical images [30].

"Cognitive task shifting": a property of pluralistic task shifting emphasising "thinking cancer". It includes the "fast thinking" used in intuitive diagnosis and the "slow thinking" prompted by algorithms.

"Digital task shifting": a property of pluralistic task shifting that emphasises telemedicine and eHealth.

"Financial task shifting": a prerequisite for pluralistic task shifting; it includes reallocating funds ("money to follow") and cost tracking ("follow the money").

Pluralistic task shifting is a conceptual name for the overarching pattern of behaviour suggested by primary care physicians in many countries and by literature data as a composite strategy to shrink organisational gaps, reduce structural bottlenecks and thus improve how cancer may be diagnosed in a more timely manner. "Pluralistic" implies that the diagnostic

tasks are many, and "shifting" tells us that we must change how we undertake cancer diagnosis to achieve the goal of diagnosing cancer at the right time.

Task shifting, sharing, and changing

Task shifting emerged early in the analysis to explain the multitude of reflections made by the participants in the Örenäs Research Group survey data. Task shifting has been in use for some time in health care, making it an "in-vivo" concept, and it was defined by the World Health Organisation (WHO) as a "rational redistribution of tasks among health workforce teams" mostly described in healthcare in low-income countries [29]. Task shifting fits well with how many respondents in our survey data wanted cancer diagnosis to work. Changing the focus of the tasks of primary care physicians from dealing with complaints that could be taken care of by other health care professionals to instead work more with unpacking potential cancer symptoms was mentioned by many respondents as a meaningful task shifting prioritisation from physicians to nurses. This is called vertical task shifting in the literature [31].

> "We should involve the nurses in gathering the patients' medical history"
>
> Polish primary care physician

> "We need better training of district nurses who initially assess the patient, often by phone"
>
> Swedish primary care physician

Task shifting from hospital physicians to primary care physicians is in the literature called horizontal task shifting [31] and it was mentioned by many respondents.

> "We (primary care physicians) should directly refer to investigations without involving specialists who can do follow up of the diagnosed disease, unless when there is real diagnostic uncertainty, instead of doing routine tasks that the general practitioner can handle."
>
> Danish primary care physician

Shifting the focus of cancer diagnosis tasks from secondary care to primary care is a task shift motivated by longer waiting lists for hospital specialist care, while primary care physicians can offer a more timely access.

"In hospitals the diseases stay, and the people come and go; in general practice, the people stay and the diseases come and go." [32]. This expression illustrates that primary care physicians already know most of their patients' background and this can promote timeliness of cancer diagnosis.

Task sharing as collaboration.

Task sharing between different health care professionals in primary and secondary care requires improved communication, collaboration, and true cooperation with a need for a dialogue culture (see below).

Task sharing with the public and the patients by information and teaching about cancer alarm signs and symptoms was also mentioned as a way of speeding up cancer diagnosis.

> "More time for patient education and prevention, so that patients report faster on their own with worrying symptoms"
>
> Polish primary care physician
>
> "Better health education for the population about alarm signals."
>
> Portuguese primary care physician

"Safety netting" was mentioned to ensure the communication of test results, meaning that physicians and patients share responsibility of the task of monitoring incoming results from diagnostic tests such as imaging and laboratory tests [33] as well as changed symptoms and new bodily sensations.

> "Normally, a follow-up physician appointment is booked, but I am also asking the patient to phone, that is doubled safety."
>
> Danish primary care physician

Respondents often suggested that task sharing could be achieved by use of digital tools in the form of e-mails, chat functions and overarching electronic health records, to minimise thresholds between primary and secondary care. We call this digital task shifting, see below.

Task changing by standardised diagnosis pathways.

Task changing is seen in many countries (such as Denmark, Norway, Sweden and the UK) that have introduced cancer fast-track systems for diagnosing cancer that work well if the symptoms and signs of patients meet the fast-track criteria. Centralised diagnosis procedures or specialised diagnosis services that target many diagnoses simultaneously, called Rapid Diagnostic Centres in the UK [34] and diagnostic centres in Denmark [8] and Sweden, serve patients who do not meet the fast-track criteria.

Task changing in the form of screening asymptomatic people for bowel, breast, cervical and prostate cancer is also a standardised diagnosis pathway which already exists in many, but not all, jurisdictions in the 20 surveyed countries [4].

Digital task shifting is defined as information- and communication technology (ICT)-based task sharing and shifting. Triaging using digital tools is already done by telemedicine care

providers and can improve timeliness of cancer diagnosis [35].

Telemedicine and eHealth solutions for targeting the right person to screen or to investigate, and by making better use of electronic health records, could eventually improve the cancer work-up efficiency.

> "Information and Communication Technology support directly in the patient records [is needed] - today we do not have many support tools within the electronic health records"
>
> Swedish primary care physician

Digital task shifting could be achieved by better use of e-mails, chat functions and overarching electronic health records to minimise barriers between primary and secondary care. There is a huge potential for increased care task collaboration efforts, if we make better use of the advantages of ICT and telemedicine to bridge time and place.

> "With the powerful and fast ICT of today we have the potential for ultrafast diagnosis, but we still rely on analogue slow technique"
>
> Swedish primary care physician

Pluralistic dialogue culture. Task shifting, task changing and task sharing between and within professional groups and with patients requires an attitude of rethinking where dialogue is necessary. And since the tasks are many, the dialogue must be pluralistic (see Table 2). So, creating a task collaborative dialogue work culture, where primary care physicians and specialists would meet in real life or by digital tools, was mentioned by several physicians as a way of improving task shifting and sharing.

> "By creating an informal meeting culture between GPs and specialists, so they know each other personally."
>
>> Dutch primary care physician
>
> "Allowing virtual consultations with 'end specialists' to validate malignancy diagnosis"
>
>> Israeli primary care physician

Cognitive task shifting involves rethinking attitudes to, and awareness of, diagnostic reasoning.

Caregivers and patients are learning more about cancer diagnosis and how cancer may be discovered in primary care where the vast symptom flow is mostly of a benign nature. Health care professionals may benefit from reflecting on how they perform diagnostic reasoning. According to the dual process theory of cognition, it is relevant to be aware of whether System 1 or System 2 was used [36]. "System 1" diagnostic reasoning is based on fast intuitive thinking induced by pattern recognition which involves "gut feelings".

> "Gut feeling detection depends on a number of patient characteristics.
> Either the patient signals immediately entering the room, or the patient comes with relatives, or the patient can signal by body language, facial expression, skin colour, or being a frequent attender or not."
>
>> Summary memo from focus group with Spanish primary care physicians

"System 2" diagnostic reasoning is analytic and involves slow rational thinking in algorithms, using traditional cancer case-finding diagnosis. Cognitive task shifting seeks to increase clinicians' awareness of these two systems of diagnostic reasoning. The ability to alternate between them is crucial for avoiding diagnostic delay. Hence a more timely

diagnosis can be achieved:

>"By listening carefully to patients and thus recognising possible red flags or gut
>
>feelings."
>
>Dutch primary care physician

Task shifting as time management. Good cancer diagnosis is eventually about optimal use of time. "Not too early" to avoid over-diagnosis and "never too late". Since time is a limited resource and cancer is often progressive and life threatening unless treated in time, reducing time intervals is what better diagnosis and treatment provides for cancer patients. So, task shifting cancer diagnosis should have optimal time management as a goal.

>"Time to listen to patients, better opportunity to have a quick consultation with a GP"
>
>Danish primary care physician

Financial task shifting relies on reallocation of funds from hospital care to primary care. "Following the money" and need for "money to follow" explains what underlies the necessary care restructuring to improve diagnosis timeliness. Task shifting thus involves health care reorganisation and accompanying budget rethinking or refinancing. "Following the money" means tracking costs and thereby tracing structures and processes that need to change. By "following the money" in the billing of medical procedures and tests, we have found evidence of short-sighted strategies in cancer diagnosis. These are not cost-efficient from a sustainable budget perspective.

>"Electronic Health Records…. focus too much on billing and solving how to bill most
>
>efficiently while solving the health issues become secondary."
>
>Primary care physician working in both US and Europe

As an example, primary care physicians in some countries were not reimbursed for some tests, for example prostate specific antigen, PSA. This lack of reimbursement delays cancer work-up, slows down the diagnosis process, and since cancer is more expensive to treat at a late stage than at early stages this cost more in the long term. So, by this economic logic early cancer diagnosis is always better than late; except in relation to cancers where a "watchful waiting" approach is used.

"Money to follow" indicates that refinancing, using financial incentives and billing for tests and procedures for cancer diagnosis, is necessary for the restructuring. This includes covering the costs of comprehensive training of those who will be able to have tasks shifted to them, for example nurses and healthcare assistants.

> "Increase funding for cancer diagnostic tests (tumour markers, colonoscopy, gastroscopy, radiographs) - currently, the funding is insufficient and as a result, PSA is rarely measured."
>> Polish primary care physician

A few survey respondents from countries with little screening activity wanted compulsory cancer screening.

> "Gynaecology examination and mammographic screening should be made compulsory for all women regardless of their age".
>> Bulgarian primary care physician

One primary care physician (from a context with no cancer screening available) wrote that if patients would not attend screening, they should get penalised by losing their health insurance. However, mandatory screening is a task shift that, according to several survey

respondents and the literature would risk overdiagnosis and overtreatment [37].

Task shifting nihilism. Overdiagnosis and overtreatment was mentioned by many respondents. Some were concerned that the changes necessary for earlier diagnosis could harm patients through over-treatment and unnecessary anxiety.

> "Not relevant [to diagnose cancer early]. Cancer diagnosis is a difficult balancing act between under- and overdiagnosis. Faster cancer diagnosis will also give more overdiagnosis."
>
> Danish primary care physician

But shifting the screening task from asymptomatic people to primary care patients that are "risk factor targeted" might eventually reduce the risk of overdiagnosis and increase the cost benefit. Targeting people at risk could be done by using machine learning on electronic health record data or electronic surveys [38].

Some respondents were happy with the existing diagnostic speed and were more worried about overdiagnosis and the harm that is associated with finding cancers which may not need to be treated, or if treated, would result in unnecessary suffering. This was especially true for respondents in countries, such as the UK, with fast-track diagnosis systems already in place.

Shifting diagnosis infrastructure. Faster access to tests, both imaging, endoscopic and blood tests, was mentioned by many respondents as a way of speeding up the diagnosis of cancer. This could either be part of a task shift from secondary care to primary care physicians, or task sharing between them.

In some countries primary care physicians had poor access to a lot of the cancer work-up and diagnostic procedures. They needed to rely on secondary care specialists to get testing

and imaging done, and this often resulted in long waits.

Ultrasound is an imaging option that few primary care physicians had access to. Improving access to ultrasound, either by easier referral or by primary care physicians doing ultrasounds themselves, was mentioned as a task that could speed up cancer diagnosis.

"The choice of performing ultrasound scans by yourself or funded by the National Health Fund".

Polish primary care physician

Bypassing secondary care specialists to get access to the diagnosis infrastructure was mentioned by many respondents and this task bypassing is a shift that already happens in the fast-track systems in some countries.

Point-of-care testing was available in some countries but not for all tests and in some countries with limited availability. More point-of-care testing would eventually speed up diagnosis according to many respondents, especially if cost issues could be addressed.

Task sharing between primary care physicians and secondary care specialists could be eased by "hotlines" by telephone, e-chat, or e-mail to achieve smoother and faster communication between primary care physicians and specialists. This way of overcoming long waits and delays in diagnosis is an example of digital task shifting within a dialogue culture.

To achieve all these task shifts by sharing and changing tasks in the cancer work-up processes, many respondents emphasised the need to shift or redistribute the financing, and the physical and regulatory infrastructure of the health care system in general and of primary care in particular. Also, by reducing bureaucracy, corruption, and in some countries eliminating disincentives to refer patients or perform tests was mentioned to enable task

changing and shifting to speed up cancer work-up routes.

This infrastructure shifting would help primary care to implement more point-of-care testing, facilitate the access to imaging and endoscopic procedures, and eventually improve the status of primary care.

Discussion

In this grounded theory study on how to improve the speed of cancer diagnosis an overall multivariate strategy of pluralistic task shifting emerged from the ideas of many primary care physician respondents across 20 countries and literature data. Pluralistic task shifting expands the concept of task shifting which was in forefront for the future of primary care according to the WHO:

> "...I see *task shifting* as the vanguard for the renaissance of primary health care..."
>
> Margaret Chan, WHO Director General 2006-2017

Our prime data were written suggestions in a survey from the Örenäs Research Group. Additional data came from an International Cancer Benchmarking Partnership survey, Spanish and Swedish interviewees, and literature which included a WHO report on task shifting [29]. In many Anglo-Saxon and Nordic countries, as well as in the Netherlands and Slovenia, vertical task shifting from physicians to nurses in primary care has been in place for decades, with an emphasis on chronic disease management and prevention [39,40].

The respondents' views in our study were conceptualised as pluralistic task shifting - suggesting that many things need to be done differently to achieve the goal of a more timely diagnosis for cancer patients. Task shifting and task sharing are key strategies that involve reorganising the health care workforce to provide the cancer services necessary to ease bottlenecks in the diagnostic process. Rethinking cancer diagnosis through pluralistic

task shifting could be explained theoretically as a Basic Composite Strategy [21,23,26]. Functional dimensions of task shifting are digital task shifting by optimising digital tools, telemedicine and e-health, restructuring task shifting by default assessment procedures such as cancer fast-tracks and screening, and cognitive task shifting by training and fast and slow thinking in cancer case finding. Financial task shifting, with cost tracking ("following the money") and reallocating funds ("money to follow"), are fundamental conditions for successful pluralistic task shifting.

That said, task shifting cancer diagnosis will only be achieveable if someone is willing to pay the price. Thus, pluralistic task shifting not only requires an acceptance of organisational cultural change but also requires a comprehensive health economic perspective. It is necessary to develop financial incentives to achieve a more timely diagnostic process for cancer in primary care across many countries and jurisdictions. However, these incentives are intrinsic, in the sense that if we view costs across the whole health and general economic systems, it almost always costs less to manage a cancer that has been diagnosed earlier. Thus, more money in the health care system may not be required to achieve a more timely diagnosis of cancer [41,42].

To achieve pluralistic task shifting, a change in workplace culture involving pluralistic dialogue is suggested. Pluralistic dialogue is a concept discovered in a New Zealand grounded theory of hospital teamwork [30] and became part of our theory at an early stage as an "emergent fit" (grounded theory lingo for "borrowing" either earlier grounded theory concepts or in-vivo concepts) [21,23]. Pluralistic dialogue explains how professionals succeed in collaborating by different strategies such as deconstructing and resynthesizing thinking, rethinking professional responsibility and reframing team responsibility. This eventually leads to the breaking of stereotypical images involving negotiating service provision.

In a Swedish grounded theory study of interactions between primary care physicians and patients in the context of standardised cancer pathways, "negotiating bodily sensations" explained the reconciliation of the patients' and the physicians' expertise [43] and emphasises the tasks of patients and their unique role in diagnosing cancer.

Pluralistic task shifting shares some properties with the grounded theory of balancing cancer care [44], which explains problem-solving strategies of health care professionals in sensing patients' symptom signals and gauging them against existing diagnostic and therapeutic resources. The balancing outcome is characterised by a compromise, at best an optimised situation, at worst a deceit.

An important condition for task shifting to happen is funding allocation or "money to follow". Thus, one answer to the question "Why should we be task shifting cancer diagnosis?" comes from the value-based care model [45] based on the assumption that "health systems should seek to obtain the maximum possible value for the health of people for every dollar they spend" [46]. By cost tracking ("following the money"), we can reveal costly bottlenecks and inefficient care processes. "From clinical pathways to care delivery value chains", "promoting the right care and reducing medical overuse" and eventually "turning a fragmented model into another integrated model" are processes suggested by the value-based care model [47]. Similarly, pluralistic task shifting fits with the disruptive innovations concept from a design thinking perspective on health care innovations [48] explaining how existing structures become obsolete from innovative improvements.

There are indeed problems with task shifting and we hypothesise this as especially caused by it being implemented outside of the context of a dialogue culture, as shown by Malterud, pointing to issues with patient safety when secondary care horizontally and one-sidedly shifts tasks to primary care [31].

Choosing experts, "elsewhereism" of experts, and power symmetry issues were

core concepts discovered in the seminal grounded theory "Experts vs Laymen" [49]. Digital task shifting has improved the potential for contact between caregiver experts and layman patients, and between experts in primary and secondary care, by bridging time and place [50]. This reduces or modifies "elsewhereism" and alters power symmetry, often to the advantage of the layman.

Cognitive task shifting as "thinking cancer" in every primary care consultation, was suggested by Holtedahl and includes "thinking cancer epidemiology", "thinking organ-based symptoms" and "avoiding diagnostic traps" [51,52]. This belongs to the slow analytic "System 2" diagnostic reasoning [36] which fits well with teamwork and thus pluralistic dialogue. It also aligns with the growing evidence for the use of cancer risk scores in primary care [1,53]. In Wales, "ThinkCancer!" was an educational behaviour change aimed at the whole general practice team, designed to ensure timely diagnosis of cancer consisting of teaching and awareness sessions, the appointment of a "safety netting champion" and the development of a bespoke "safety netting plan" [54].

The conclusion of a Norwegian qualitative study of vertical task shifting in a hematology department fits well with our pluralistic task shifting theory:

> "Task shifting from doctors to nurses… requires not only development of technical skills but also complex changes in organisation, clinical routines and role identity. Educational and organisational interventions to build a team-oriented culture could potentially increase the possibility of successful task shifting and stimulate nurses to take on untraditional responsibilities. Environmental restructuring to support doctors using their time in activities only doctors can perform may be needed to realise potential efficiency gains". [55]

Strengths and Limitations

This is, to our knowledge, the first grounded theory of cancer diagnosis from a

systemic strategic perspective. Strengths include the rich qualitative data and large sample size sitting behind the explanatory concepts and the contextual scope of a grounded theory. Another strength is the collaborative learning process from a diverse group of expert analysts aspiring to achieve a collective intelligence outcome. The convergence of ideas from different research angles resulted in a conceptual theory that we hope can be understood and used across multiple disciplinary perspectives.

We only collected survey data from physicians, resulting in homogeneity of the survey population. However, the shared knowledge of the 1352 primary care physicians from 20 different health systems from countries spread geographically, and the analysis of multidisciplinary literature, yielded a coherent set of data, giving a primary care perspective that was not only international, but was also derived from heterogenous sources.

There are limits that come with a grounded theory which is not factual description but a set of conceptual hypotheses yet based on a large amount of data. Not everyone agrees with the importance of this type of conceptual theoretical knowledge in a "world run by description" [56].

Another limitation of this study is that we mostly used physician survey data. Yet, the constant comparison procedures of grounded theory can compensate for particularistic bias. The different categories that emerged from attitude patterns in the survey data were repeatedly compared and carefully fitted with interview data and literature records on task shifting and sharing [57-60]. This leads us to conclude that the survey data were rich enough to allow conceptualisations that are relevant to other cultural and clinical settings.

Meaning of the study

Pluralistic task shifting may be just an academic phrase or concept, but to be

able to change structures and work processes in health care we need to change the language (and talk with each other) [61]. If we cannot formulate in abstractions what needs to be done, our arguments will be too descriptive and particularistic. By conceptualising we can better understand the world we live in and how to achieve the necessary change. "The role and value of theory in improvement work in healthcare has been seriously underrecognized" [9]. This quote argues for the utility of the grounded theory of pluralistic task shifting and eventually trying to apply it outside of the field of cancer diagnosis.

How should then pluralistic task shifting be initiated? Inspired by Elinor Ostrom, we think that improving the timeliness of cancer diagnosis is a "polycentric task" [62]. This means that many different actors must be involved in pluralistic task shifting that will only succeed through a "bottom-up" process. Thus, it needs to be initiated by primary care organisations and their patients. Those who manage and use the care on a day-to-day basis can best see where there is the most need for change and amendments.

Conclusions

Pluralistic task shifting is trying to answer the question "how may current cancer diagnosis be improved" by conceptualising the thinking of many primary care physicians as well as literature data.

Pluralistic task shifting for more timely cancer diagnosis means that many things must be done differently, by a variety of actors, to discover and act on possible cancer at the right time, to the ultimate benefit of patients and citizens. We can achieve this demanding goal by optimising the use of technology, human resources and finances reflecting the task shifting dimensions digital, cognitive, and financial task shifting within a culture of pluralistic dialogue.

As the issues around cancer diagnosis are complex, unpacking the complexities

informs our understanding of the problems. The challenge is to make this understanding help stakeholders to improve our health care systems for patients with cancer.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

All authors participated in research design as members of the Örenäs Research Group. HT was responsible for the grounded theory analysis which however was done in collaboration with input from all authors during several years. HT and MH together drafted the manuscript. All authors participated in analysis and writing and revised the manuscript for major intellectual content. All authors read and approved the final manuscript.

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Acknowledgements

References

1. Rubin G, Berendsen A, Crawford SM, Dommett R, Earle C, Emery J et al. The expanding role of primary care in cancer control. Lancet Oncol. 2015;16:1231-72.

2. Scheel BI, Holtedahl K. Symptoms, signs, and tests: The general practitioner's comprehensive approach towards a cancer diagnosis. Scand J Prim Health Care. 2015;33:170-7.

3. Harris M, Vedsted P, Esteva M, Murchie P, Aubin-Auger I, Azuri J et al. Identifying important health system factors that influence primary care practitioners' referrals for cancer suspicion: a European cross-sectional survey. BMJ Open. 2018;8

4. Zeichner SB, Montero AJ. Detecting cancer: Pearls for the primary care physician. Cleve Clin J Med. 2016 ;83:515-23.

5. Malterud K, Reventlow S, Guassora AD. Diagnostic knowing in general practice: interpretative action and reflexivity. Scand J Prim Health Care. 2019; 37:393-401

6. Tavora F, Crowder CD, Sun CC, Burke AP. Discrepancies between clinical and autopsy diagnoses: a comparison of university, community, and private autopsy practices. Am J Clin Pathol. 2008;129:102-9.

7. Hamilton W, Walter FM, Rubin G, Neal RD. Improving early diagnosis of symptomatic cancer. Nat Rev Clin Oncol. 2016;13:740-749.

8. Næser E, Møller H, Fredberg U, Vedsted P. Mortality of patients examined at a diagnostic centre: A matched cohort study. Cancer Epidemiol. 2018; 55: 130-135.

9. Davidoff F, Dixon-Woods M, Leviton L, Michie S. Demystifying theory and its use in improvement. BMJ Qual Saf. 2015;24:228-38.

10. Harris M, Thulesius H, Neves AL, Harker S, Koskela T, Petek D et al. How European primary care practitioners think the timeliness of cancer diagnosis can be improved: a thematic analysis. BMJ Open. 2019;9:e030169.

11. Rose PW, Rubin G, Perera-Salazar R, Almberg SS, Barisic A, Dawes M, et al. ICBP Module 3 Working Group. Explaining variation in cancer survival between 11 jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey. BMJ Open. 2015;5:e007212

12. Oliva B, March S, Gadea C, Stolper E, Esteva M. Gut feelings in the diagnostic process of Spanish GPs: a focus group study. BMJ Open. 2016;6:e012847.

13. Om lärande, prioriteringar och ekonomiska aspekter. Effekter av satsningen på standardiserade vårdförlopp i cancervården. Slutrapport del 2, 2019. [On learning, priorities and economical aspects. Effects of the drive on standardised cancer care pathways. Final report part 2, 2019]. https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2019-4-1.pdf (accessed June 29, 2021).

14. Glaser BG, Strauss AL: The Discovery of Grounded Theory: Strategies for Qualitative Research. Chicago: Aldine; 1967.

15. Petrazzuoli F, Vinker S, Palmqvist S, Midlöv P, Lepeleire J, Pirani A, et al. Unburdening dementia - a basic social process grounded theory based on a primary care physician survey from 25 countries. Scand J Prim Health Care. 2020;38:253-264.

16. Sandén U, Nilsson F, Thulesius H, Hägglund M, Harrysson L. Cancer, a relational disease exploring the needs of relatives to cancer patients. Int J Qual Stud Health Well-being. 2019;14:1622354.

17.   Sandén U, Harrysson L, Thulesius H, Nilsson F. Breaking the patientification process - through co-creation of care, using old arctic survival knowledge. Int J Qual Stud Health Well-being. 2021;16:1926052.

18.   Burström L, Starrin B, Engström ML, Thulesius H. Waiting management at the emergency department - a grounded theory study. BMC Health Serv Res. 2013;13:95.

19.   Thulesius HO, Scott H, Helgesson G, Lynöe N. De-tabooing dying control - a grounded theory study. BMC Palliat Care. 2013;12:13.

20.   Thulesius H, Grahn B: Reincentivizing - a new theory of work and work absence. BMC Health Serv Res 2007, 7:100

21.   Glaser BG: Theoretical Sensitivity: Advances in the methodology of grounded theory. Mill Valley, CA: Sociology Press; 1978.

22.   Glaser BG: Basics of Grounded Theory Analysis: Emergence vs. forcing. Mill Valley, CA: Sociology Press; 1992.

23.   Glaser BG: Doing Grounded Theory: Issues and discussions. Mill Valley, CA: Sociology Press; 1998

24.   Glaser BG: The Grounded Theory Perspective: Conceptualization contrasted with description. Mill Valley, CA: Sociology Press; 2001.

25.   Glaser BG: The Grounded Theory Perspective II: Description's remodeling of grounded theory methodology. Mill Valley, CA: Sociology Press; 2003.

26.   Glaser BG: The Grounded Theory Perspective III: Theoretical coding. Mill Valley, CA: Sociology Press; 2005.

27.   Glaser BG: Doing Formal Grounded Theory. Mill Valley, CA: Sociology Press; 2007.

28.   Woolley AW, Fuchs E. Collective intelligence in the organization of science. Organization Science. 2011; 22:1359–1367.

29.   WHO: Task shifting: global recommendations and guidelines. Geneva: World Health Organization, 2008.

30.   McCallin, A. (1999). Pluralistic Dialogue: A Grounded Theory of Interdisciplinary Practice. The Australian Journal of Rehabilitation Counselling, 5(2), 78-85.

31.   Malterud K, Aamland A, Fosse A. How can task shifting put patient safety at risk? A qualitative study of experiences among general practitioners in Norway. Scand J Prim Health Care. 2020;38:24-32.

32.   Blythe A "The structure and organisation of primary care" p.4. in Blythe A, Buchan J. eds. Essential Primary Care. Wiley-Blackwall, UK 2016.

33.   Nicholson BD, Goyder CR, Bankhead CR, Toftegaard BS, Rose PW, Thulesius H et al. Responsibility for follow-up during the diagnostic process in primary care: a secondary analysis of International Cancer Benchmarking Partnership data. Br J Gen Pract. 2018;68:e323-e332.

34.   Hamilton W. The future of diagnosis in general practice. Br J Gen Pract. 2020;70:319-320.

35.   Riva S, Mazzocco K, Pravettoni G. Better outcomes for cancer patients using telemedicine: health-related quality of life (HrQoL) and empowerment. In Tele-oncology (pp. 23-37). Springer, Cham. 2015.

36.   Croskerry P. Clinical cognition and diagnostic error: applications of a dual process model of reasoning. Adv Health Sci Educ Theory Pract. 2009;14 Suppl 1:27-35.

37.   Brodersen J, Schwartz LM, Heneghan C, O'Sullivan JW, Aronson JK, Woloshin S. Overdiagnosis: what it is and what it isn't. BMJ Evid Based Med. 2018;23:1-3.

38.   Hippisley-Cox J, Coupland C. Symptoms and risk factors to identify women with suspected cancer in primary care: derivation and validation of an algorithm. Br J Gen Pract. 2013 ;63:e11-21.

39.   Klemenc-Ketis Z, Terbovc A, Gomiscek B, Kersnik J. Role of nurse practitioners in reducing cardiovascular risk factors: a retrospective cohort study. J Clin Nurs. 2015;24:3077-83.

40.   Maier CB, Aiken LH. Task shifting from physicians to nurses in primary care in 39 countries: a cross-country comparative study. Eur J Public Health. 2016;26(6):927-934.

41.   Pisu M, Henrikson NB, Banegas MP, Yabroff KR. Costs of cancer along the care continuum: What we can expect based on recent literature. Cancer. 2018;124:4181-4191

42.   Birtwistle M, Earnshaw A. Saving lives, averting costs: an analysis of the financial implications of achieving earlier diagnosis of colorectal, lung and ovarian cancer. Cancer Res. UK 2014.

43.   Hultstrand C, Coe AB, Lilja M, Hajdarevic S. Negotiating bodily sensations between patients and GPs in the context of standardized cancer patient pathways - an observational study in primary care. BMC Health Serv Res. 2020;20:46.

44.   Thulesius H, Håkansson A, Petersson K. Balancing: a basic process in end-of-life cancer care. Qual Health Res 2003, 10:1353-1377.

45.   NEJM Catalyst. What is value-based healthcare? https://catalyst.nejm.org/what-is-value-based-healthcare/ (accessed: 29 June 2021)

46.   Porter ME, Teisberg EO. Redefining Health Care. Boston, Mass: Harvard Business School Press; 2006

47.   Varela J. Looking for Value-Based Community Health. Abstract Book of the 89th EGPRN Meeting, Vigo - Spain, 17-20 October 2019. https://www.egprn.org/file/7e2f297c-a9e0-42af-8a2e-cb30b04dfcdd/Abstract-Book-of-the-89th-EGPRN-Meeting-Vigo-Spain-17-20-October-2019.pdf (accessed: 29 June 2021)

48.   Christensen C, Waldeck A, Fogg R. How Disruptive Innovation Can Finally Revolutionize Healthcare. A Plan for Incumbents and Start-Ups to Build a Future of Better Health and Lower Costs; Clayton Christensen Institute for Disruptive Innovation, 2017; Available online: https://www.christenseninstitute.org/wp-content/uploads/2017/05/How-Disruption-Can-Finally-Revolutionize-Healthcare-final.pdf (accessed: 29 June 2021).

49.   Glaser B. Experts versus laymen: A study of the patsy and the subcontractor. Mill Valley, CA: Sociology Press 1972.

50.   El Morr C. "Health care virtual communities: Challenges and opportunities." Handbook of research on developments in e-health and telemedicine: Technological and social perspectives. IGI Global, 2010. 278-298.

51.   Holtedahl K. Early diagnosis of cancer in general practice: a manual. Berlin Heidelberg: Springer-Verlag, 1990.

52.   Holtedahl K. Challenges in early diagnosis of cancer: the fast track. Scand J Prim Health Care. 2020;38:251-252.

53.   Ewing M, Naredi P, Zhang C, Månsson J. Identification of patients with non-metastatic colorectal cancer in primary care: a case-control study. Br J Gen Pract. 2016;66:e880-e886.

54.   Disbeschl S, Surgey A, Roberts JL, Disbeschl S, Surgey A, Roberts JL et al. Protocol for a Feasibility study incorporating a Randomised Pilot Trial with an Embedded Process

Evaluation and Feasibility Economic Analysis of ThinkCancer!: A primary care intervention to expedite cancer diagnosis in Wales. Pilot and Feasibility Studies. 2021; 7:100.

55.　　Feiring E, Lie AE. Factors perceived to influence implementation of task shifting in highly specialised healthcare: a theory-based qualitative approach. BMC Health Serv Res. 2018;18:899.

56.　　Glaser BG. Naturalist Inquiry and Grounded Theory. Historical Social Research / Historische Sozialforschung. 2007, Suppl, 114-132. http://www.jstor.org/stable/40981073 (accessed June 29, 2021),

57.　　Olsen DS, Fevolden A. Gradual transition. Bottlenecks and task sharing in diagnostic imaging. Oslo: The Nordic Institute for Studies in Innovation, Research and Education, 46, 2013E.

58.　　Gessessew A, Barnabas GA, Prata N, Weidert K. Task shifting and sharing in Tigray, Ethiopia, to achieve comprehensive emergency obstetric care. Int J Gynaecol Obstet. 2011;113:28-31

59.　　 Robertson FC, Esene IN, Kolias AG, Khan T, Rosseau G, Gormley WB et al. Global Neurosurgery Survey Collaborators. Global Perspectives on Task Shifting and Task Sharing in Neurosurgery. World Neurosurg X. 2019;6:100060.

60.　　Robertson FC, Lippa L, Broekman MLD. Editorial. Task shifting and task sharing for neurosurgeons amidst the COVID-19 pandemic. J Neurosurg. 2020;1-3.

61.　　Wright EO. Metatheoretical Foundations of Charles Tilly's Durable Inequality. Comparative Studies in Society and History. 2000;42:458-474.

62.　　Andersson KP, Ostrom, E. Analyzing decentralized resource regimes from a polycentric perspective. Policy sciences. 2008;41: 71-93.

The art of bouncing back

Ulrika Sandén is a Swedish author and social worker. Her thesis has its origin in her experiences from living in northern Norway as well as from her own brain tumor trajectory. This is an interdisciplinary thesis about Momentary contentment theory in a cancer context.

Living with cancer requires an adjustment in many areas. Patients can in companionship with others, through an adaptive view on time management and an acceptance of life's unpredictability, create spaces of safety, humor and hopefulness.

This doctoral thesis presents Momentary contentment, a grounded theory which increases the understanding of life where time, risks and contentment explain a cultural setting of relationships making everyday life more safe and fun. The thesis illuminates a design process wherein this understanding becomes useful in a new setting, that of cancer rehabilitation.