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PhD Thesis
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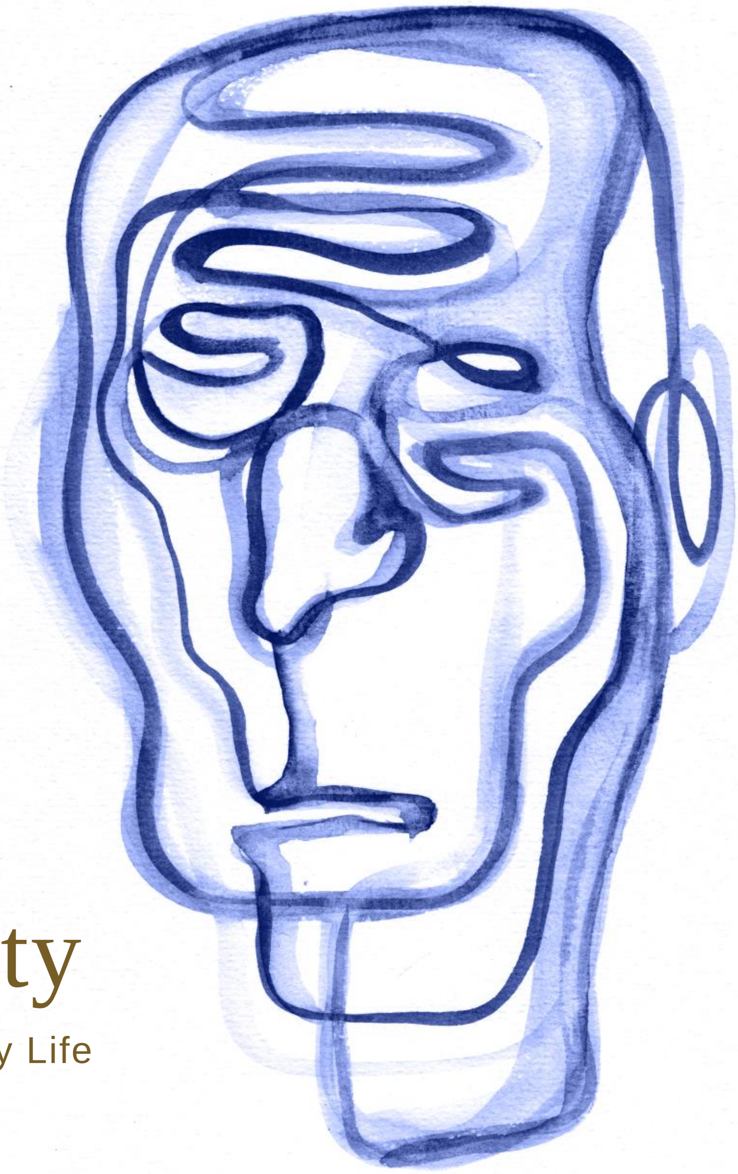

Aging with Multimorbidity

Illness and Inequity in Everyday Life

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To Peter, Selma and August
Because you are what really matters to me

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Preface

This PhD was part of an interdisciplinary research initiative on multimorbidity carried out at the Center for Research and Education in General Practice. I first became interested in multimorbidity as a medical entity when I conducted a study for the Danish patient organization, Danish Patients, in collaboration with researchers at DEFACTUM (a research consulting agency in Jutland, Denmark). The mission of the study was to examine the complexity of living an everyday life with multimorbidity, while trying to remain in the labor market. I encountered narratives of illness and coping with treatment strategies and self-care plans, which stimulated my curiosity towards investigating how multimorbidity can affect the lives of older adults who encounter the ever-burgeoning discourse on how to age well. In this dissertation, I have attempted to illuminate the experience of aging with multimorbidity from an anthropological perspective, thus contributing to the body of empirical knowledge on multimorbidity as a social phenomenon and new theoretical perspectives on illness, inequity and knowledge positions.

This study was anchored at The Research Unit for General Practice, University of Copenhagen, and The Knowledge Center for User Involvement in Healthcare, Danish Patients. The study was carried out as an industrial PhD project, which means it has been a collaboration between a university and a company. It has relevance to public health in that it adds to the existing body of qualitative research on multimorbidity meshed together with a patient organization's interest in obtaining the patient's perspectives on multimorbidity. The result of such a collaboration should enhance the possibility for a greater understanding of multimorbidity from the perspective of both General Practitioners and patients across diagnoses. It has at any rate been pivotal for me to ensure that this research was relevant both for patients and practitioners, and that it has the potential to influence policies on patient involvement, aging, and health inequities.

Working across interdisciplinary fields and representing different interests is however not without its challenges. I have elucidated some of these challenges in my articles, while others have influenced and formed me as an anthropologist in the process of conducting research in a public health field. For example, in an early draft of an article, I had written somewhere: "While respecting the epidemiological approach to health inequities, this article reckons the complexity of human being's experiences […]". During a discussion of the article at a workshop with anthropologists, I was heavily criticized for being too submissive. As a professor pointed out, they [medical scientists] would never write: "…while respecting the anthropological approach". While he received an easy laugh from the crowd for invoking the notion of the us (anthropologists) against them (the presumably dominant medical scientists) paradigm, I decided to substantiate through my articles that respecting other research approaches is not an act of submission, but a means to create the particular exclusive knowledge that comes from working within an interdisciplinary environment. This has been a key element for me in my approach, as my aim has been to take advantage of the interaction between the health sciences and the social sciences. It has been vital for me to generate a creative representation of anthropological knowledge while engaging theoretical discussions with relevance for research and clinical settings.

What I want to express with this dissertation (with its wide spectrum of theoretical approaches) is that aging with multimorbidity is saturated with experiences that are highly susceptible to individualized speculation. Hence, this thesis is not an ontological proposition about the life of older adults with multimorbidity, but more an inquiry into the contextual framework that forms the mode in which life is experienced, perceived, and interpreted by the older adult with multimorbidity. In addition, my goal has been to inspire and broaden the understanding of multimorbidity, and join the ranks of the many interdisciplinary research initiatives in multimorbidity at the Research Unit in order to generate knowledge about how we should care for older people with multimorbidity.

Chapter 1. Introduction

> *“Each patient brings to the practitioner a story. That story enmeshes the disease in a web of meanings that make sense only in the context of a particular life. But to understand that life and the illness experience it creates, we must relate life and illness to cultural context”*
>
> (Arthur Kleinman, The Illness Narratives 1988:96)

1.1 Aging with multimorbidity

March on Lolland is a cold, damp month. Winter has not yet loosened its shivering grip and barren fields surrounding villages are watery from rain or melting snow. Trees stand naked, and only once in a while does a car pass on the small, concrete streets. My first encounter with Carol is on a particularly cold March morning when she has a doctor’s appointment at the general practice that I am doing observations in. I remember a certain kind of sadness in her voice when she said I was a beam of sunlight brightening the still dark days, referring to my flowery dress, too cold for the season.

Only by the end of April, the air on Lolland will hang thick with spring. Short spells of sun will cast their deceiving promises of summer into the late afternoon. Nature will be filled with budding evidence that within weeks everything will burst into bloom. It was on such a Thursday afternoon that I met Carol again outside her wild, soon-to-be overgrown garden, her mood mirroring the luring spring. She was full of energy, excited about our trip. Tom was locking up the house, carrying two cameras over his shoulders. One, fairly large from a cheap brand, resembling my own - another, was an older digital camera with only a two-inch screen. Carol greeted me cheerfully, mocking my shiny new rubber boots. Tom only nodded his head, a man of few words, but smiled as he held the door for me getting into their car. From the backseat, I listened to their improvised tour guiding as I tried to ignore the scattering stench from the fields by now prepared with fertilizer to be sown with beets. *I cannot believe you haven’t seen Dodekalliten,* Carol blurts out as we passed a sign leading the way to the enormous columns adorning *smålandsfarvandet*, the northern sea of Lolland. We should go now, she said, but Tom turned down her suggestion. We were already late, and as chairman of the retirees‟ photo club, Carol ought to be there when the others arrived. We entered *Reventlowparken*, a museum park, as the first ones to arrive. Some confusion began; where were we to meet? Carol decided that

Tom and I should just begin to take photos, and she would wait for the rest. We would only have an hour before the public tour began. As I was struggling to take an artsy photo of what I depicted to be a bird‟s nest, two others arrived; women a few years younger than Carol aged 75. *Where is Ole* she asked them. Nobody knew. Carol decided to call him. *He has been very ill, I fear him falling, he lives alone you know, nobody to check up on him* she explained to me, leaving no doubt that she was in charge of the group, and she was taking responsibility. It turned out Ole was not feeling well, but did not need any assistance; he was just resting at home. I was surprised to find out that it was just the five of us then. From what she had told me, Carol had given me the impression of a large community group. Nonetheless, the others were in as good a mood as Carol and Tom, and pictures was taken, coffee served and Carol’s homemade cookies eaten. I began questioning my presence. This was nothing but a few older people joined in a common interest for photography. Where was the suffering, where was the thing that stood out, as my supervisor had asked me to keep an eye out for? I was soon to learn. A large group of people had now arrived, and assembled as the public tour was about to start, when Carol began feeling dizzy. Her voice became squeaky as she reached for Tom. He offered his full grown arm, still muscular from a life of carpentry, and for some moments they stood there, in what resembled a close embrace. But then, Tom could not hear the guide, and Carol insisted he should go closer. He unfolded the portable chair to comfort her, but it collapsed under Carol’s heavy weight. I hurried to her rescue, starting to feel a bit tense in the situation. Suffering from Parkinson’s disease, Carol was unable to move her body, and we stood there still in the dewy grass. *It is those darn pills. I forgot to take them. This is what happens*, she whispered to me. The sun was soon to set, and the warmth had diminished. The scarf and light jacket I had chosen to wear were not sufficient anymore, as we had stopped moving, and I began to be cold. Carol was uneasy leaning against my relatively smaller body, so she directed me to help her to the bench. Out of pure will power, she heaved her legs to walk the 10 meter distance. Once she was in place, she tried to convince me to join the tour, but I felt bad leaving her sitting by herself, and I wanted a complete experience of her struggles and crises. So, there we were, sitting on a bench, cold, silent, as we were trying to hear what the tour guide said. After 30 minutes, Tom left the tour and came to us. He had seemed torn between his first reaction to stay with Carol, and then Carol ordering him to join the others, so that he would not miss the exhibition tour that *she* had anticipated with so much joy. He did not find it that interesting, he said. We left dejected, as the tour group were walking deeper into the gardens, and drove the car in silence. Neither Tom nor Carol seemed in the mood for conversation, but I could not help asking Carol, why she did not have an alarm to remind her of the pills. *I do have one*, she sighed, *in my watch. But I never* *wear it. I don't like to be reminded that I am ill. I'm the sort of person who likes to let life absorb me to a degree where I forget everything around me*. Tom, who had not said a word since we left, took his focus from the road for just a second as he asked her, *What about that thing your doctor said, some med that you would only have to take once a day or something*. Carol started to irritate and groaned at him, *well, I couldn't take it if I was also on arthritis meds, now could I? Which I happen to be*. Then her anger seemed to recede again. *Well…Maybe it's about time that I come to terms with this new life. This new me.* (Fieldwork observations, Carol and Tom, April 2015)

Carol on the bench while the tour is on, Tom is number three from the right

The story of Carol was indeed what Kleinman describes as a story of a particular life with illnesses – here multimorbidity - set in a web of meanings. Yet, it was not a unique story. Even before I knew Carol and the other interlocutors, I knew from my previous research that some people living with multimorbidity led a burdened life with illness and numerous, sometimes conflicting, treatments and plans for self-care (Ørtenblad, Meillier and Jønsson 2015; 2017). I knew that the act of navigating and prioritizing everyday life values in a multimorbid life is no easy task (Ibid). But I was curious: which strategies did older people use to live with multimorbidity in everyday life?

According to the health discourses in Denmark, citizens are morally obligated to maintain and improve their health throughout their lives (Mikkelsen 2016:452). It is reflected in globally known paradigms of “healthy aging” (WHO 2017), which configures in Denmark with campaigns and political agendas, urging older people, regardless of whether they wish to or not, to remain healthy and active, as they would then minimize the strain on an endangered welfare system (Mikkelsen 2016:453). I wanted to learn how older people with multimorbidity, hence outside the realms of healthy aging, experienced this moral tale in their everyday lives. I wanted to go beyond what Good (1994) has termed “biomedical truths” about multimorbidity, focusing primarily on patients‟ experiences in relation to health care services (Van der Aa et al. 2017), and instead do what Kleinman urges us to; to focus on what really matters to each person (Kleinman 2006:23ff).

Thus, I will be addressing older people with multimorbidity’s dialectic movement between telling the story of illness, and presenting values or qualities of selfhood that required a different articulation from a medical anthropological point of view. Real lives lived in a collective cultural context marked by sociality, gender and encounters with health professionals among other things. I will generally refer to people with multimorbidity as *people* or *patients* when the discussion is connected to medical treatment or symptoms. When talking specifically about the older adults in this study, I will use the term interlocutors.

1.2 Biomedical versus anthropological perspectives on multimorbidity

Since the 1970s, the term ‘comorbidity’ has been used to describe the co-occurrence of medical conditions (Weaver et al. 2016:435). Originally, comorbidity was perceived as having a primary index disease with additional medical conditions, but gradually, it moved into implying the coexistence of more than one disease (van der Akker et al. 1996). This confusion led what were to become some of the leading biomedical researchers in this field to suggest a distinction between comorbidity (understood to mean having one dominant disease and then others relating to that index disease), and *multimorbidity*: having several, co-occurring diseases (Ibid).
Over the past decade, multimorbidity has captured the attention of numerous medical and social

scientists, who have showed the challenges to global health that multimorbidity presents – from a societal and economic point of view as well as on the individual level. In conducting anthropological research in a biomedical field, one of the premises is the need to adapt some biomedical terms. Without privileging the voice of biomedicine, I build my thesis on accepting multimorbidity as a useful tool to describe the challenges an individual faces when having multiple long-term or chronic diseases. Yet, despite a wide-ranging usage, the term lacks a consistent definition, which limits its usefulness in both research and clinical settings (Willadsen et al. 2016). I have chosen to follow a definition that originates in a register-based population study in Denmark, to secure relevance for my empirical field. This definition means that a patient has to have at least two diagnoses from two different groups of diagnosis; lung, musculoskeletal, endocrine, mental, cancer, gastrointestinal, cardiovascular, genitourinary (kidney) and diagnoses in sensory organs (Willadsen et al. nd). By stressing the difference in diagnoses, it highlights the complexity that the individual patient is likely to experience when navigating treatments and self-care (Shippee et al. 2012; Ørtenblad et al. 2017). Despite its heterogeneous nature, the group of multimorbid patients is said to represent 50% of the disease burden in most OECD countries (Van der Aa et al. 2017), with older adults with multimorbidity in particular having increased service utilization and higher cost (Lehnert et al. 2011, Bahler et al. 2015, Koroukian et al. 2017).

People with multimorbidity experience burdens of diseases and treatments (Shippee et al. 2012; Liddy et al. 2014; Rosbach & Sahl 2017; Ørtenblad et al. 2017) such as difficulties with self-care management (Bayliss et al. 2007, Morris et al. 2011), lower self-reported quality of life (Fortin et al. 2006, 2007; Tyack et al. 2017), and the impression of aging prematurely (Duguay et al.2014). Furthermore, as multimorbidity cannot be treated by isolating and targeting a singular unitary pathophysiological cause, patients experience issues with the health care system such as difficulties with access (van der Aa et al. 2017), lack of coherence in treatments (Noël et al. 2005; Schiøtz et al. 2016), difficulties in communicating with health professionals (McKinlay et al. 2017) and a lack of involvement in decisions (Ekdahl et al. 2010). Qualitative research has pointed to people striving to maintain their everyday life priorities (Townsend 2011; Löffler et al. 2012; Ørtenblad et al. 2017, Rosbach & Sahl 2017), and they experience difficulties in coping with symptoms, diagnoses, and health information (Bower et al. 2012). To most people, managing multimorbidity becomes a lifelong, integrated part of everyday life; interacting with both social and personal resources (Shippee et al. 2012).

It is estimated that approximately two thirds of people over the age of 65 in Western countries are multimorbid (Lim et al. 2017). Moreover, in Denmark, as in many other countries, people with low levels of education are generally more likely to develop multimorbidity (Larsen et al. 2017). Following on from this, it is often argued that there is a social gradient, and health inequity in the epidemiology of multimorbidity.

Patients with multimorbidity are a challenge for the health services, including general practice (Mair & Gallacher 2017). To Danish General Practitioners (GPs), length of consultation and complexity in treatment rise with the number of chronic conditions (Moth et al. 2012). The GPs are supposed to coordinate and follow-up on not only treatments, but also on relatives and social aspects of diseases (Grøn et al. 2007). GPs struggle with inadequate guidelines to address multimorbidity (Kristensen et al. 2017; Sinnott et al. 2013; Taylor et al. 2017), disagreement with patients on treatments (Hansen et al. 2015), and despite the indications that managing patients with multimorbidity would be easier to facilitate if they are involved in decisions regarding treatment and care (Starfield 2009; Coulter 2012), GPs experience several barriers to doing so (Sinnott et al. 2013).

Yet, multimorbidity remains a contested term. From an anthropological point of view, the notions of multimorbidity stand as social and cultural constructions (Fainzang et al. 2010:19). The current anthropological research on health conditions has its origins in the 1970s discussions on the different views of ill-health held by patients and health professionals (Eisenberg 1977; Kleinman 1980). Anthropologist and psychiatrist Arthur Kleinman‟s seminal distinction between illness and diseases (1988) has particularly resonated within medical anthropology. Kleinman points to a gap between what a patient experiences, and what the doctor treats. He argues that illness is the subjective experience of symptoms and suffering. Illness is then a cultural construction, embedded in notions of how to perceive and cope with symptoms; “the innately human experience of symptoms and suffering” (Kleinman 1988:3). Disease, on the other hand, is the problem from the health provider‟s perspective (Ibid:6). Anthropological critiques point out that the term disease tends to bring biological processes rather than individual experience to the fore, while the term illness tends to foreground the lived experience of the patient (Eisenberg 1977; Kleinman 1980, 1988). The disease-/illness distinction was adduced as relevant especially for general practice in 1981 by anthropologist and physician Cecil Helman, who argued that GPs should treat both disease *and* illness (Helman 1981:551). This distinction also caused anthropological research on chronic conditions to take into account narratives of lives and suffering, and how people struggle to make sense of those conditions (Good 1994; Mattingly 1998; Whyte 2005; 2012).

Anthropologists point to some chronic conditions as not being problematic per se – obesity, for instance, which requires a particular cultural framing to be expressed as problematic (Fainzang et al. 2010:19). This might not be comparable to chronic conditions with severe physical and mental consequences, for instance Parkinson’s disease, but the belief that the problem or responsibility lies within the individual is alike (Ibid:20). Parkinson’s disease may not have connotations of specific health behaviors, but it is understood within a moral frame in which the possibility of treatments addresses personal involvement and responsibility for self-care (Parkinson‟s Organization 2017). In this thesis, I subscribe to critiques of such implications that people are expected to or can choose to live and stay healthy through proper self-discipline (Lupton 1995; Rose & Novas 2005; Mol 2008). I use this as point of departure in my scrutinizing of living with chronic illnesses, and to argue that multimorbidity accumulates the well-described burden of chronic conditions (Estroff 1993; Manderson & Smith-Morris 2010 and so forth).

Thus, coming from two different scientific domains, I will argue that a biomedical take combined with an anthropological view on multimorbidity serves as *an opportunity to better understand the boundaries, intersections, and interactions of multiple health conditions* (Weaver et al. 2016:437). Following this approach, I aim to use multimorbidity as a critical tool for addressing more profound determinants of the everyday lives and illnesses of older adults with multimorbidity.

1.3 Aim of the thesis

I aim at producing an epistemological understanding of aging with multimorbidity. Epistemology indicates a particular mode of knowing, reflecting the researcher’s involvement in the life worlds of the study objects and the implications of this position (Hastrup 2004: 456; Tjørnhøj-Thomsen & Reventlow 2016:58). In this thesis, I conducted an ethnographic study of the lives of 14 older men and women, living with two or more chronic or long-term conditions at once, in order to explore overall:

How do older people living with multimorbidity navigate in the prioritization of treatments and self-care and incorporate illnesses in everyday life?

Self-care is a broadly used term (Godfrey et al. 2011). Here, I define self-care in accordance with the Danish disease management programs; as everyday actions taken to maintain health, obtain good quality of life and be responsible for treatment of chronic conditions (Kristensen et al. 2017). I have followed an anthropological mode of research interest, in which knowledge is acknowledged as a matter of perspective and therefore a social and relational phenomenon (Hastrup 2004:456). I asked additionally:

I. How is multimorbidity altering the older adults‟ everyday life?
II. How is the older adults‟ personal knowledge involved in planning treatments to fit into their everyday lives?
III. What role do illness and gender play in perceptions of how to age?

Yet, as anthropological knowledge is imbued by events and acts occurring in the field, so more than often we alter or extend our point of inquiry - what Hastrup names “composite attention” (Hastrup 2013a:149). During my fieldwork, new insights emerged within the ontological field of the older adults with multimorbidity’s lived experience. I began to realize, just as I had set out to investigate, what really matter to the interlocutors; I sensed that meaning and practices were perceived in relation to the context of contemporary Danish welfare schemes, inasmuch as for example insufficient care was believed to be an expression of social inequity. I also started to critically engage in my own research position, navigating different interests. Consequently, I added two questions:

IV. What is the subjective experience of health inequities?
V. How can health research be conducted empathically?

With these five questions, I enter ongoing anthropological discussions on aging, illness, knowledge positions, inequities and their interrelations. I hold theoretical conversations on ethical and methodological considerations. Each research question is discussed in a paper that offers different perspectives on how older people are trying to navigate in an everyday life with multimorbidity. Challenges, as for instance personal values and intricate treatments, which conflict with everyday priorities. I will conclude by arguing that these challenges are all closely related to the lack of a clear definition of what patient knowledge is, and how to involve such knowledge when planning individual treatment and care.

1.4 Structure of the thesis

In the first chapter, I have introduced the aim and relevance of the thesis, and framed the thesis within the main empirical object ‘multimorbidity’ as both a biomedical and a social scientific concept. Chapter 2 situates my arguments in the empirical context, setting off at the micro level, describing firstly a day in the life of Annie, and then a Danish general practice, moving into meso level taking a closer look at Lolland, and then finally looking at the macro level in discussing implications and challenges within the concept of the Welfare State. Chapter 3 presents the methods used in the thesis, with a particular section on the fieldwork on which this thesis rest. Chapter 4 presents my theoretical onset; everyday life, aging, illness and patient involvement. Chapter 5 summarizes the results, and chapter 6 provides an overall discussion combining the different results sat in relation to patient involvement. Lastly, chapter 7 concludes the thesis with perspectives on multimorbidity as a concept, drawing wires towards broader implications of the study.

Chapter 2. Empirical Context

In the following chapter, I place the thesis in the empirical context from which it has emerged. In doing qualitative research, there is a silent disjunction between what the study subject knows and the knowledge that is sought after by the researcher (Hastrup 2004:412). Describing the empirical context changing between the interlocutors' and my point of view is an attempt to bring attention to this difference and to give a voice to the participants. I try to conform to the latter throughout this thesis, especially in articles 1 and 4.

I am starting at the very local context with an example of an everyday routine, moving to a local general practice, and then situating this within the specific geographical setting and within a larger political context of welfare and aging in Denmark. This description is meant to anchor and supplement the analysis of the thesis by providing ethnographic detail and analytical excursions (Offersen 2016:30) into the local everyday life of the interlocutors. The empirical context is thus described to get a deeper understanding of the social, cultural and moral background, against which the experiences of living with multimorbidity are established.

2.1 Annie's day

Maybe Annie is not the best choice to describe an everyday in the life of an older person with multimorbidity. On our first meeting I almost choked on the lemon cake we had with the coffee, as this 85-year-old woman, amputated from hips and down, suffering from a rare blood disease that could kill her every minute along with repeated blood clots and urinary infections, smiled at me and said, "*I wish everybody my age could feel as good as I do*".

But that is the point. The anthropological attention toward the particular can gain insights in the universal (Hastrup 2004:422). Annie is not like any other of the interlocutors, yet this is true for every one of the older adults. They are unique individuals living unique lives with a unique composition of chronic diseases, which set in their context makes up the experience of multimorbidity. I cannot bring a general story of a day in a life, but Annie's day will set the frame together with the empirical context below in which we are to understand cultural and moral logics that form the interlocutors' way of thinking and acting.

So let's begin. This Sunday in late October 2017, Annie wakes around half past seven in the morning, just a few minutes before her daily morning visit from the care assistant. After being helped to get dressed, as both her legs are amputated, she takes her wheelchair to the kitchen where the care assistant has made the oatmeal ready to cook before he left. Annie finishes the oatmeal and brings it to the living room where she enjoys listening to the radio while eating. In the small case beside her plate awaits 13 pills. Annie hates swallowing pills, so she stirs them up with buttermilk. That helps. After taking out the dishes and washing the pot used for oatmeal, she starts to prepare her lunch. Today, she has been cooking goulash, potatoes, carrots and Brussels sprouts. Before lunch, she boils ginger root in water and freezes it as ice cubes, she has one of those every day and was running low, so she had added ginger to the list of groceries which were delivered yesterday. Annie has been eating ginger and powdered rose hip for the past 20 years, and is convinced that this is the reason she rarely gets any colds. When she has finished lunch, and the four additional pills, she gets a visit from her nephew and his wife, they live nearby and just came by for “a cup of coffee”, meaning a short hour of chatting. When they leave Annie goes to lie down and rest as her bottom gets sore from the wheelchair. She reads criminal novels, but gets up after an hour or so. The great-grandchild has asked for knitted, woollen socks, and if one gets a pair, the others wants a pair as well, so Annie is “fast-knitting” as she puts it. In the afternoon television airs a handball match with the local team, which she likes to watch. Before that, she has been taking in the laundry that was put out to dry in the now empty carport, the vehicle from before the amputation having been given to a grandson in need. Dinner is traditionally Danish rugbrød, open sandwiches on rye bread with different cold cuts, together with a glass of full fat milk and two pills. Around nine pm a care assistant returns, this time a familiar lady that has been there many times before, and she helps Annie getting ready for bed. Today, Annie feels exhausted, but many nights she reads some more before turning off the light. Just before sleeping Annie has the last three pills, again with milk.

If this had been a Tuesday, she would have been to the local nursing home for a gym class - even though Annie believes in the importance of exercise, the gym class serves mostly to pass the time, and to catch up with the latest local gossip. Every other week or so, she goes for some sort of check-up consultation within the health system. And so, the days of Annie do vary, but arguably, they demonstrate an everyday life with well-known routines and chores, yet with constant downturns in physical abilities. This point will be developed further in section 4.1.

2.2 The healthcare system

General practice is the corner stone of Danish primary health care, controlling access to specialists and hospitals through a referral system (Pedersen, Andersen and Søndergaard 2012). All 5.4 million Danes are registered to a default general practice, and see their GP(s) in that practice. Usually, this will be peoples' first contact with the health sector, supporting the principle that the continuity of care should be provided by a family doctor (Ibid). This makes general practice the center of the healthcare system, and I find it useful to introduce the concept here.

Most people only occasionally see their GP, but for some people with multimorbidity, a couple of contacts a month is not unusual, as GPs are meant to serve as coordinators of care for people with chronic conditions (Sinnott et al. 2013, Taylor et al. 2017). Patients may make their own appointments, and are additionally, called in to biyearly chronic disease check-ups. As already touched upon, patients with multimorbidity are especially challenging in general practice, as there is a compiled body of coordination work to be done and a lack of guidelines (Kristensen et al. 2017; Mair & Gallacher 2017).

Some miles away from Annie, in a quiet small village with just over 400 inhabitants placed in the borough of Lolland, a late 70s brick house lies next to the local church. The surrounding garden belongs to the private part of the house, whereas the parking lot in front serves the patients of the general practice that fills the other part of the house. This is one of the few solo-practices left in the area, that faces the challenge of an increasing shortage of GPs. Due to this, many Lolliks, as the people of Lolland are called, are referred to regional practices with temporarily employed GPs. General practices are organized under a decentralized structure administered by five regions. They are privately owned, but there is free access and no copay for any patients, as they are financed mainly through the tax-financed health care reimbursement scheme.

The general practice in this brick house is as the rest of the Danish general practices fully computerized in terms of patient records, prescription referrals, lab results etc. (Pedersen, Andersen and Søndergaard 2012). However, most GPs aim for a personal and holistic approach as modus operandi within the average 10-15 minutes consultations. Three of the interlocutors in this study are registered to this particular general practice, and are very fond of the GP - in fact his talent is well-known throughout most of the island. Yet, even there, consultations in general practice are sometimes challenging for a variety of reasons from both the patient perspective and from a medical point of view (article 5).

2.3 Lolland: on the outskirts of Denmark

Lolland is the fourth largest island of Denmark. It takes its name from the narrow inlets Lå (eventually spelled Lo) shaped by the tide. Fertile soil forms the flat land and makes agriculture, namely beets, the main income of the island. The median temperature varies from 0^0 Celsius in wintertime to 19^0 Celsius during the summer period. Large amounts of rain and occasionally snow not only makes weather the Danes' favorite subject for small talk, but also results in the majority of social life being lived indoors during October to April (Gullestad 1984; 1992). Close to half of the approximately 60.000 Lolliks live in the three largest towns; Nakskov, Maribo and Sakskøbing. Continuous decline in the population have created so-called "ghost-towns" of empty or deserted houses. In 2014, almost 15 per cent of the houses in the borough of Lolland were uninhabited (Regionen 2016). The decline is also visible in the still rising median age, and the number of factories that have been closed in the past 20 years.

If my interlocutors were to describe Lolland, they would highlight the breathtaking nature sights, the numerous manors, culture heritage points as Stone Age passage graves, museums, and the tourist attractions such as *Lalandia*, an indoor waterpark or *Knuthenborg*, northern Europe's largest safari park. They would tell you that Lolland could be reached in less than two hours by car from Copenhagen (and they would be wrong if you would like to avoid a speeding ticket). They would, once they knew you and it came up in conversation, reveal the truism that living in Sakskøbing is fancier than living in Nakskov, but the most fancy is Maribo, though many of the people in Maribo think too much of themselves. This would need to be understood in the light of the Danish sociality and notion of equity which in Denmark is cast as 'Sameness' (Gullestad 1992:174ff). Therefore thinking that one is better than another is considered unmannered. This talk would be in Danish with a singing intonation resembling the dialect of Fyn, the second largest island in Denmark, revealing an old affiliation.

The interlocutors could also tell you some of the history of Lolland; the great flood that took 80 souls in the fall of 1872 is still remembered in stories passed on for generations. More recently, the interlocutors from Nakskov would tell you about the former headmaster Victor Cornelins, who were awful strict and did not hesitate to use the cane. They would excuse Cornelins, though, explaining that he was taken from his family on the former Danish island of St. Croix in 1905 at the age of seven along with his sister to be exhibited in a cage in the Tivoli Gardens (Cornelins 1976). Partly proud to have known him, partly ashamed of the whole affair. The interlocutors would situate the socioeconomic decline in their life stories of changing jobs due to factory closures, or watching their kids move away from Lolland to never return except for short visits. Lolland is most easily reached by car, a good two-and-a-half hour from Copenhagen, secondly by public transportation, which would be a considerably longer affair in my experience, depending on the destination on the island, owing to poor connections of buses and trains, as my interlocutors describe the public transportation on the Island. If one comes in the autumn or fall you are met by the harsh smell of fertilizer being spread on the fields. During the winter Lolland easily interprets as a place of solitude, but if you come during the summer, you are likely surprised by the amounts of particularly German tourists, multiplying the population during the holiday season. Whenever you visited, if you placed yourself in the countryside you would be met by a stunning quietness. Only after listening for some time, you would hear bugs and birds and the wind in the trees.

As a health scholar, however, I point to Lolland as an interesting place for research, because the part of the population living with multimorbidity is one of the highest in the country (SSI 2015:5). Lolland is part of what is known to be the outskirts of Denmark, marked by low socioeconomic status, high levels of unemployment and poor population health status (Regionen 2016). The population study *LOFUS The Lolland-Falster Study* [Lolland-Falster Undersøgelsen] and *Bridging Better Health* [Broen til Bedre Sundhed] are high aiming studies, focusing on the health state of the local population, and how to improve social and medical conditions for the population (for a full discussion on the ethical implications of this, see article 4).

2.4 Aging in a welfare state

Denmark introduced the first public health care insurance in the 1890s taking the initial steps towards what we today call the welfare state, known internationally as The Nordic Model (Plough et al. 2004; Lassen and Jespersen 2017). The Nordic Model is characterized by distributing equal and free social security to all citizens, including free access and treatments in the health care sector, all financed through taxation. The Nordic Model also consists of a number of social reforms that sets the conditions for Danish citizens from birth to grave, including public pensions and assessed home helpers to help clean, wash and cook for the older who require it (Lassen and Jespersen 2017). Maybe because of The Nordic Model, Denmark is often highlighted as one of the best places in the world to grow old. Health care including home help are allocated and paid for by the municipalities and nursing homes have sliding-scale co-pay that ensures access to all. By the age of 75 the older in Denmark are offered biyearly check-ups from a municipality nurse to see if they need home care or other help.

Certainly, the welfare state entails a reciprocal relationship between citizen and state, as the state not only provides free care, but also performs regulations on citizens' lives (Vallgårda 2013). With a societal ethos of neo-liberal values such as autonomy, self-determination and individualism in Denmark, there has come a strong focus on the citizen's responsibility for self-care and following treatments (Kristensen, Lim and Askegaard 2015:491). Anthropologists have already pointed out that adult personhood in Denmark, as for many other places, is closely tied to one's ability to manage and maintain individual autonomy (Krøjier & Sjørslev 2011). The notion of aging in the welfare state revolves around the idea of choice, prevention and independence. Particularly the independence has a twofold approach as it will both support individuals' wish to be able to take care of themselves and at the same time refrain from providing governmental help by inviting them to make use of other resources such as help from a spouse or immediate family. This tends to be ironic as caring for older is not traditionally seen as the family's job in Denmark: less than three per cent of those over the age of 70 live with their children (Stuart & Hansen2006:31). Such autonomy and independence is also mirrored in the emergent global paradigm of successful aging (Lamb et al. 2017; Mikkelsen 2016:452), stressing the moral obligation for the older to maintain and manage their health and sociality, as will be discussed in article 2.

This very brief introduction to the people, the healthcare system, the place and the society draws the contours of a morally loaded life, which, I contend, works as a frame for understanding the priorities, cultural ethos and health inequities that older people with multimorbidity must face and navigate every day.

Chapter 3. Methodology

In this chapter, I describe and discuss the design and the methods used in this study and their implications for the findings. I will be going through methodological choices in my fieldwork, to show how the fieldwork, essentially carried out with writing in mind (Strathern 1991), created knowledge of particular personhoods, with a particular perspective on it (Hastrup 2013a:147). I begin with an introduction to the study design and overall methodological strategy, including a discussion of fieldwork as an anthropological method of inquiry. I attend, then, to a thorough discussion of the fieldwork; establishing a field, recruiting interlocutors and foremost conducting the fieldwork. Following this, I discuss my main analytical approaches and finally, I conclude with some remarks on the ethical considerations interwoven into the fieldwork and analysis.

3.1 Study Design

Overall methodological strategy

Investigating which strategies patients use to navigate multimorbidity treatments and everyday life priorities, I set out to conduct an ethnographic study among older people with multimorbidity living in Lolland, Denmark. Anthropologist George E. Marcus point out that "many fieldworkers today are not free in a practical sense to impose the classic conditions of fieldwork" (Marcus 2009:11). I reckon this, as it was never a possibility to move in with my interlocutors and participate unconditionally in their lives, but joining them in countless fragmented encounters over 18 months, made it possible to share enough time together to attain an understanding of an everyday life with multimorbidity.

In exploring the interlocutors' experience, I draw on conversations, formal interviews and participant observations I made with the 14 key interlocutors. Framing this contextually and relationally, I additionally draw on interviews and informal encounters with four GPs and five other health professionals in daily contact with multimorbid patients (though not all my interlocutors), three spouses, five adult children and 12 friends. However, these interviews are mainly for background info, and my main material comes from the 14 key interlocutors.

As I will show, place became central in my fieldwork, and though not consistently living at Lolland, I joined local clubs, went to fairs and events and often brought my husband and kids as we spent on/off time in our family summerhouse situated conveniently close. In the picture, my son and I are visiting a Christmas fair where I have been performing a concert with the local band.

Going places: Fieldwork revisited

In the beginning of the last century when the fieldwork pioneer Bronislaw Malinowski placed his tent at a Trobriand island and spent two years studying what had up until then been viewed as a strange and savage culture, he also laid ground for a methodological standard to anthropology. A discipline, which up until the Second World War was bound to a colonial tradition, forming regional categorizations that are still traceable in some ethnographic analysis. However, since the early 1980s, several anthropologists warned that the by then current practice of doing fieldworks reproduced distinction and *othering* (i.e. Appadurai 1986), which lead to the “crisis of representation” (Marcus & Fisher 1986). This inspired profound rethinking and rearticulating of anthropology; the positivistic attendance to fieldwork as an unproblematic means to collect ‘truths’ and anthropological representations of others was challenged, and so the validity to claim knowable truths regarding human culture, too (Okely and Callaway 1992; Speed 2006:66). In consequence, the approach towards cultures and societies as distinct and enclosed entities to be studied was dismissed, and replaced by a reflexive and temporal ethnography. Although this is the ideal that carries the present analysis, rereading the ‘representation debates’ during fieldwork I began questioning the justification of the study, and this became a methodological deliberation as discussed in article 4.

In contemporary anthropology, *fields are as emergent as are anthropological interests* (Hastrup 2013a:146). The particular field in which this study have been carried out was established through an anthropological knowledge interest on older adults with multimorbidity as the empirical object, and aging, illness and patient involvement as the guiding analytical objects. Yet Lolland, my fieldwork setting, is loaded with value. Being one of the most socioeconomically deprived areas in Denmark it is sometimes referred to in the media as ‘the arse of the rotten banana’ (Ács & Pagh 2017) alluding to the placement of Lolland in the lower bottom of the banana-shaped outskirts of Denmark. The inhabitants of course object to this ridiculous representation of what is also one of Denmark’s most beautiful nature sites with landscapes that burst with former lordly manors and cultural heritage. Almost every time I met with a new interlocutor, she or he would start to describe how wonderful a place Lolland is, as if I by virtue of being from the capital would possess demeaning notions of the outskirts. This perceived stereotyping affected the selfhood and sowed my ethnographic interest for subjective experiences of prejudices which laid ground for the analysis in article 3. Yet the truth is that Lolland was never a neutral choice for a field. It was identified based on population health status (described in 2.3), and my interlocutors were thus initially defined according to their residency.

Combining the analytical interest in place with the overall reflections on the epistemology that form the base of constituting anthropological knowledge, I follow Paul Atkinson's (2015) call for classic ethnographic fieldworks. Ethnographic fieldworks oppose the various increasing qualitative research methods often conflated with anthropological methods, yet with a profound lack of the same thorough commitment to understanding the social world of people (Atkinsons 2015). I might have been travelling only a good two hours by car, but I figuratively moved into the lives of these older people that opened their hearts and homes to me. Homes, situated far from public transportation, with no nearby places for walking, just fields and fields of beets. We went together into the deprived small towns, marked by the continuous closure of shops, leaving in most places nothing but the gas station and the local bakery. I tried to do some shopping but was left with second-hand stores carrying only out-of-fashion, cheap-quality, and left-over clothes. I went partying with visiting friends in bars where everybody else had attended the same public school. I was taken to breath-taking nature sites, I learned photography in the local retiree's club, and I visited cultural heritage monuments. I joined the local band, being by far the youngest; the only one below the age of 50, besides an 18 year-old girl just returning from maternity leave. Although it may not be reducible to the Malinowskian mise-en-scene, the experiences captured a particular sense of place, which induced the personhood of the interlocutors. Thus, I use the phrase "going places" to describe this fieldwork to underline the movement acknowledging George Marcus' (2009) many points on the fluidity of modern day fieldwork, while stressing the term 'place' to encompass and preserve the core modalities of classic anthropological fieldwork.

Anthropology at home

Denmark, and Scandinavia, remain a relatively low interest area to international anthropologists. Besides the pioneer Indian anthropologist Prakash Reddy (1991), the majority of ethnographic research in Denmark is made by – Danes. It mirrors a gradually international established subdiscipline of doing anthropology 'at home' (Fainzang et al. 2010:9). Doing fieldwork at home, therefore, is nowadays rather common, yet I believe it pertinent to discuss it a little here due to the focus on place. Still, only fifteen years ago, doing fieldwork at home was a choice which had to be defended (Jackson 1987; Madden 2010). Doing fieldwork at home, and with a permanent openness which I will briefly return to, allows for regular return visits that can rekindle the engagement and help avoiding making our interlocutors appear what Astuti calls 'cartoonish' lacking the touch of the people and lives we write about (Astuti 2017:10). The following is then to be framed in the argument, that the further away in time and space we are from the people and their lives, the easier it becomes to write ethnographies about them (Ibid.) But doing fieldwork at home, I am close to my interlocutors in time and space. Living in Copenhagen, I still share language, nationality and culture with Lolland to an extend where it is plausible to frame my presence as being culturally 'at home'. This introduces both methodological advances and challenges, specifically in considerations regarding if it is even possible for the native researcher to adequately distance oneself or if she will not be able to identify her own cultural assumptions (Hastrup 1998). However, I rarely experienced the lack of physical distance as pertinent, instead I agree with Passaro stressing that distance is primarily about theoretical stance (Passaro 1997:52).

The Danish working class to a large extent resembles my own background, but being brought up in a different time and place than my interlocutors I was continuously surprised to learn about their lives. One woman, for example, had finished school at the age of 12 after which she was sent out to serve at a nearby manor. Just the thought of leaving one's parents while still a child was so distant to me that she and I got into a lively talk about what had happened in terms of children's rights for just the past 50 years.

However fieldwork at home, is interwoven with mundane details of normal life, which also limits the participation (Cerwonka 2007). The visits and time with my interlocutors was limited by interlocutors easily getting tired and needing rest. Yet, the most significant obstacle, which I had not foreseen, was the cancellations on both sides. Having little children attending preschool meant, as most parents would recognize, numerous colds and flus. Normally, I would not perceive this as a problem, even when it meant that I too became infected. The interlocutors, however, being older and most of them also physical fragile, could not risk even a generally harmless infection, as it would be endangering them. On a few occasions, I made the call to cancel a visit due to potential infection as I was potentially carrying a virus. The older on the other hand, would sometimes call me prior to our meeting and ask for a rain check when they felt too burdened with pain or fatigue on the day. It frustrated me, I felt like I wasted time having to rearrange plans. Albeit, eventually the cancellations became a turning point to me; it was an embodied experience of how a life with multimorbidity was unpredictable and often isolated. To the interlocutors, this was to be expected. This was how things were.

3.2 Fieldwork

From late February 2015 to the end of August 2016, I conducted 18 months of on-off fieldwork consisting of participant observations, interviews and informal chats and ‘deep hanging out’ (Geertz 1998); what can roughly be put as just being present. I was ‘hanging out’ in the field in periods going from 1 day to 3 weeks. I was interviewing or participant observing interlocutors, but I also spent time just being in different locations on Lolland, sensing the geographical context that my interlocutors’ lives unfolded in.

Recruitment and establishing a field

Entering the life worlds of older people with multimorbidity requires access to a domain away from where I usually move. Worried that I would not be able to find enough participants, despite the statistically high frequency of older people with chronic conditions, I used a three-legged strategy to recruit informants: A. Through direct selection immediately following observations with general practitioners; B. through health professionals in contact with people whom might never go see their GP; and C. through snowballing, an often used strategy manifested in qualitative research as people, who know people, they can refer you to (Browne 2007).
Through a contact at the Research Unit for General Practice I was handed a list of General Practitioners who was functioning as tutor doctors for the medical students owing to the idea that already being in the range of the University’s work they would be more inclined to help me find possible participants. After sending more than 20 emails I was thrilled when the first GP invited me to come visit him two weeks from then. I thus started my fieldwork with a two-hour commute to the rural area of Lolland on a cold and icy Thursday in February 2015. I went on to do observations with three other GPs in the greater area of Copenhagen, as this was the only ones I got access to, and made observations of consultations and had informal chats on general challenges and views of patients with multimorbidity. I would often refer back to observations I made during this early state or talks I had had with GPs on particular practices when making sense together with my informants on their treatments and trajectory of diseases.

Six older patients suffering from multimorbidity was observed in consultations with the GP situated at Lolland. Three were scheduled for interviews immediately following the consultations; three were contacted by phone within the following weeks. They had all initially agreed to participate but one declined saying that he was not suitable for my study, as he was feeling fine, another declined because she was “going through a rough time” and a third kept postponing the interview. Despite my eagerness to recruit participants, I kept to the guidelines of ethics (AAA 2012) and respected rejections knowing that these particular patients had stories I would have loved to hear.

Some chronically ill Danes see their GP more frequently than others (Dalsgaard et al. 2012). During the first month of my PhD study I was often met with the statement from public health scientists and medical doctors, that the patients with multimorbidity that have regular contact with general practice are taken care of whereas the patients that the GPs never see are left alone with their untreated chronic conditions and are the ones in real need of help. I wanted to both explore and challenge this statement and it became important to me to find some of these fabled unknown patients. With the help of some competent and engaged health professionals in my professional network, I got in touch with a nurse from the regional psychiatry unit who invited and prepped two older women to participate in my study. They did not know each other and came from different parts of the region and they all contributed greatly to the material in this thesis. Additionally, two other home nurses from the municipality helped locate participants who they knew from home visits.

Finally I relied on the snowball sampling as a method for collecting participants. One informant put me in contact with his neighbor, another had a friend who was ‘even more ill’ than herself. Last but not least, as the core quality of traditional anthropological fieldworks I engaged in the local community, for instance by joining the local brass band and participating in local art clubs, went to fairs, and spent a time in the area with my family; in a summerhouse or sightseeing at local attractions. Upon joining the local band, I presented myself before rehearsal and asked if anyone by chance had chronic disease and was older than 65 years? It made all the band members burst into laughter and pointing each other out “*that goes for all of us*” they said. It was narrowed a bit when I asked if anyone had more than two chronic conditions, but three men, all eager to help me out, agreed to participate.

More than a year into the fieldwork I found myself growing o be part of the informants' life world and was challenged with when and how to leave the field. Hastrup notes "to have 'enough' ethnographic material is not a simple function of the long term, but more of the questions asked" (Hastrup 2013a:146). But when had I asked enough questions? Anthropologist Inger Sjørslev describes the act of ending fieldwork and leaving the field using the Brazilian Candomblé ritual *axexé* as an allegory. Sjørslev argues that in anthropological fieldworks closure is never complete. Instead, we form the experiences into academic knowledge just as when *axexé* transforms a deceived persons lived existence into general ancestor hood. On the other hand, Sjørslev notes, completion is not a goal for sciences (Sjørslev 2009:38), and the incompleteness may be a precondition, that she describes as "*a temporary closure in the service of a permanent openness*" (ibid). Gradually, my fieldwork moved from data collection only slightly entwined with the analysis, to being mostly days of analysis and only a few phone calls or visits to the field. I accepted that there are always more questions to ask, yet I recognized that I had by then learned so much from my interlocutors, that I needed to make at least a contemporary detachment and start the process of writing down the analysis as academic knowledge. To this day, I remain in contact with most of the informants, leaving a permanent openness.

The interlocutors

In order to study older people with multimorbidity, the inclusion criteria was that the patients was 65 years or older, had two or more chronic or long-term conditions.

In total, seven men and seven women between the age of 66 and 90 participated in the study. Two were married to each other. Their marriage gave significant substance in terms of observations of gender roles, priorities and dependency within a marriage. Three of them were playing in the local band; yet playing with them together with 16 other musicians provided insights into connotations of the interplay between multimorbidity, friendships and sociality. Only the married couple and the people playing together know each other. The majority had short levels of education, and all but one woman, still working, had public pensions as their sole income. They had between three and six self-reported chronic conditions; about half had been diagnosed with depression at some point. Some were widowed, others married, some living in single-households. They attracted no particular attention in society and as a group; older, chronic ill, mostly vocational trained, except from the stereotyped portraits of people from the lower classes, as described in article 3.

Some anthropologists struggle with moving between engaging in peoples' lives and then establishing an analytical distance (Tjørnhøj-Thomsen & Hansen 2009). In my case, my relation to some of the interlocutors became very close. Knowing their sorrows, fears, joys and life trajectory, I cared for them. They also cared for me. I named Carol my Lolland Grandma as she always spoiled me with little treats for my car rides, and she came and enthusiastically cheered at my concerts with the local band, resembling my real grandmother back home. This picture is of a lunch bag she made me along with some local honey that she wanted me to try. Yet, after each of our meetings I was scribbling down notes and thoughts, reestablishing the professional distance.

Carol, it turned out, was also oscillating positions. More than a year into our relation, she and her husband was experiencing some economic challenges and they asked to see me. *Maybe*, they said, *I could pay Carol some money for providing some sort of assistance with all the information and material that she had given me?* I refused, explaining that I neither had a budget for such a thing nor would I be able to vouch for the ethical complications of paying one participant but not the rest. She received the response perfectly well, but the situation showed that though we may have been personal, but it was a professional relation.

In addition I interviewed the interlocutors' spouses, family members and friends, as well as four general practitioners, three nurses and two nursing assistants.

Overview of key interlocutors:

Name	Gender	Age August 2016	Number of diseases (somatic/mental)	Marital status	Educational level
Lene	F	73	3/2	Divorced	Primary
Carol	F	75	3/1	Married	Secondary
Joan	F	74	4/1	Married to Henrik	Tertiary
Alice	F	85	4/1	Widow	Primary
Annie	F	82	3/1	Widow	Vocational
Hedvig	F	76	4/1	Widow	Vocational
Jane	F	72	4/0	Divorced	Vocational
Svend	M	67	4/1	Widower	Primary
John	M	77	3/1	Single	Primary
Poul-Erik	M	74	3/0	Married	Vocational
Jens	M	73	4/0	Widower	Secondary
Freddie	M	73	6/0	Divorced	Vocational
Henrik	M	79	4/0	Married to Joan	Vocational
Alfred	M	84	5/1	Widower	Vocational

Participant Observations

One way to access the participants’ experiences with multimorbidity in everyday life is through participant observations. Entering the homes of the interlocutors displayed everyday life with all its privacy, conformity and intimacy. A considerable part of social life in Denmark is lived out inside private homes (Gullestad 1984; 1992) which makes participant observations of familiar routines like watching a television show together legitimate despite an immediate lack of purpose.. After all, participant observation is about taking part in peoples' lives and observe them through shared time and social space (Spradley 1980), and watching television was a daily routine for all of the interlocutors. Yet, participant observation has its limitations. The embedded oxymoron in involvement by participating and distance by observation (Tjørnhøj-Thomsen & Hansen 2017:151) states that we cannot as participant observers fully participate in interlocutors' lives. Still, the epistemological ideal is to be present and take part in people's lives by which the participant observer gains opportunity to experience and understand the social world of the interlocutor (Ibid:152). As mentioned, I joined the local band, possible only because I have been playing the euphonium since childhood. Playing in the band gave me a subjective dimension; a condensed attention to the social practices of my interlocutors and an insight into the broad exploration of everyday life. Essentially, participant observations in this study were used as a means to make the knowledge relational by constantly letting inquiries and immediate reflections emerge within and answer to the field; an everyday life, as discussed in section 4.1. Astuti claims that "it is easy enough for a participant observer to learn what gets so eloquently and explicitly articulated in the course of social life or in the context of an interview. It is much harder to learn what people never – or very seldom, or only in certain contexts – feel the need or desire to put into words" (Astuti 2017:11). Let me give you an example:

> *I did something rather embarrassing today and I didn't even realize until it was too late. I have never talked about death with any of the interlocutors, despite the fact that they are both multimorbid and older, I guess I didn't think much about it. But then tonight *Jens* was late for rehearsal, it's the second last rehearsal before the concert, and the conductor was annoyed that we had to wait for him. He started give one of those talks about the necessity for attending rehearsals and said something like 'there's no excuse for not showing up Monday, and I burst out with what we always say in my band 'unless you're attending your own funeral'. But immediately after I said it I realized that nobody laughed like people in my own band always do, instead, people acted like they hadn't heard what I said. Freddie whispered to me "It's not funny. Last spring one of the second cornets died from a heart attack on his bike on his way here".* (Fieldnote, August 2015)

This moment exposed my ignorance and also one of the clearest differences between the interlocutors and me. To them, death was not an abstract notion. We may not have talked about it, but from then on I started noticing a subtle vulnerability underlying the selfhood they presented me in the interviews. I realized how thoughts about death, age, diseases and lack of control constituted an insecurity influencing on the interlocutors' selfhood.

In addition I conducted 5 days of observations in different general practices. These observations serve as background information and as inspiration for the interview guide (appendix 4).

In Concert.

Interviews

Though a firm believer in the value of informal conversations I also recognize not only the deep knowledge that stems from long formal interviews, but also the strategic use of these. Hence, the first meeting with a participant was always scheduled as a narrative interview (Ziebland 2013); all but one carried out at the participant's home. Joan, the one exception being also the only one still working, was initially interviewed at her workplace. I had thought that this would allow for me to see her interact with colleagues, but it turned out that she was working mostly alone being

a home-visiting social worker. Instead, we sat in a small meeting room and bonded over diabetes-diets and garden work, and she invited me to her home in the following week.
When conducting narrative interviews close attention to detail is required; not interrupting and making mental notes on what to follow up on (Ziebland 2013:4). I was asking about the development of each disease and the everyday challenges, but also plotting in life events, experiences, joys and sorrows that may have formed the perceptions and priorities of the individual. Conducting several-hour interviews with the key interlocutors gave me access to their illness narratives (Kleinman 1988). This is a far more rewarding task than it sounds; take for instance this meeting with Hedvig:

> In the house at the edge of the forest, Hedvig and I sat at her kitchen table, enjoying smørrebrød and a light beer. She was wearing a beautiful blouse with a lace collar and slacks that made her considerably large 76 years-old body look graceful despite her late polio affected joints that delayed her movements. She had been talking continuously for more than half an hour, but then a sudden silence passed as a sunbeam steered through the window. *Maybe this has nothing to do with what you are going to write about?* she asked. A little surprised I shook my head, *No, don't worry. I want your whole story.* She took a bite and then nodded: *I appreciate that. Well, more blood clusters in the lungs to come. After a while I got ill again. I got this severe cold and I still couldn't catch my breath. I had been assigned a new doctor meanwhile, the old one was to retire, I really liked him. But then when I got up there it was the nurse who listened to my lungs and she said everything was fine. My daughter then asked if she wasn't going to check on my infection numbers. But it wasn't necessary when there was nothing to be heard on the lungs. That was what she told me. The following night was really bad. We went back to the doctor, but he just sat there with his arms crossed. Then my daughter said: "My mom is really ill, I think she would like to go to the hospital". The doctor said "No we don't hospitalize people for that". So, there was nothing to do about it. Then my daughter said "I cannot take responsibility for my mother anymore" Then finally I could go to the hospital. It turned out I was running a high fever and had extremely high levels of infection so they put me on antibiotics.[...]I didn't dare to sleep alone, so I took turns sleeping over at my children's places.[...] One of the days I told my son that I was in so much pain. While he called a chiropractor whom he knew, I had to walk around in circles outside; I was in so much pain. The chiropractor said that he couldn't do anything, that we needed to call 112* [emergency call] *It turned out I had had gallstones all*

> *along.* [Alexandra: Like you had already told them when they saw you the last time] *Yes, like I told them long time ago, but they didn't listen.*

The interview lasted for a good two hours. Only interrupted by coffee-making and a short visit to the toilet, Hedvig told me her story. A story of misfortune and mistrust of the health care system. Framed in a great narrative to be listened to, topped with drama and adventures. But also a story containing knowledge about the role of family, the subjective experiences, the feeling of inequity when the 'system' did not take one seriously.

The narrative interviews were then followed up with one to three semi-structured interviews, asking questions like "what do you think a healthy life is?" and "if you could change one thing in the health care services, what would it be?", all stemming from a curiosity awoken in the life narratives. Even though reading Susan Whyte's work on managing uncertain life circumstances (Whyte 1997) had prepped me to identify agency as a core modality in the interlocutors' coping with multimorbidity in everyday life, I was still surprised to see resilience and vulnerability as a complex duality in selfhood. As I listened to experiences and reflections of the interlocutors I gained insight into the subtle ways that health inequities could present themselves. On one hand, the urge to appear independent and skilled, and on the other hand, time and again one encounters episodes of being overruled, overheard or overseen by health professionals, was often understood by the interlocutors in relation to their notion of being inferior or redundant to society. The presumed prejudges and mistreatments became pivotal to developing the concept of subjective inequity (article 3).

Sometimes I would interview the key interlocutors together with their partner; other times I would interview interlocutors together with a friend of theirs. Listening to the interactions and mutual reflections proved fruitful in uncovering emotional and moral concerns, as well as the relationship:

> Carol was sitting in her usual chair. It was late afternoon, and I was there to make an interview with her husband Tom. When I had arrived about half an hour earlier, Carol was going through an 'attack' as she calls them and was unable to move. Instead, she commanded Tom and me to brew coffee, and find some of her homemade cookies. Now we were situated in the living room, and Carol insisted that we had some coffee before Tom and I spoke. I

decided to start the interview with both of them being present. Carol was the most talkative and she had just voiced her concern for the burden that she was putting on Tom:

> Tom: *I think I'm doing fine*
> Carol: *Well, I am also thinking about the troubles moving to Bispebjerg Hospital and constantly being sent around the system. I don't want you to carry that on your shoulders, too. It's enough that you have to deal with me being here*
> Tom: *Well, ehh…what do you mean?*
> Carol: *I think I have to put my foot down and say, I need to go to Bispebjerg now*
> Tom: *It should be your rights. It can't take years to get an appointment*
> Carol: *No, but we'll see. I'm bringing Daniel* [son]; *he is really good at these things*
> Tom: *But, we can do fine ourselves…he doesn't have to…*

This episode made me reflect on how independency and remaining in control were key to how the interlocutors would like to be aging, which I analyze further in article 2. It also calls upon ethical reflections, as my interpretations and analysis of the situation are likely far from Carol and Toms', which I will get back to in the following section on ethics.

In addition to interviews with the interlocutors, I also conducted interviews with spouses as above, friends and children. The overall aim with these interviews was to gain a sense of the social context, which innately formed the interlocutor's experience of aging with multimorbidity. In the beginning they all followed an open-ended semi-structural form, as I was keen to get answers to specific things like "In which ways do your mother's diseases affect your life?" or "How is life now compared to when your wife had only x disease?" On the same note, I wanted to leave room for looking into themes emerging during the interviews. Using Spradley's elements of how to conduct an ethnographic interview, such as expressing cultural ignorance or posing mini-tour questions (Spradley 1979:55-69), I gained insight into the social context and how relations are continuously negotiated as the burden of diseases progressed. Like Christina, a daughter of an interlocutor, who shared with me some of the concerns she had regarding her dad's future:

> Christina: *I'm sure he is holding things back, to spare me from worrying. But I worry anyways. For how long can he be living in the house? I find myself more and more often*

> *thinking about "what if he fell down the staircase", his bedroom is on the top floor and I know he goes to the kitchen downstairs when he can't sleep. I can't have him living in my house, we would kill each other"*

Finally, I conducted interviews with GPs and other health professionals. They all centered on the theme of caring for and treating older with multimorbidity. Though not in the overall analytical scope of this thesis, it proved helpful to understand how their perspective was about balancing a professional treatment plan and letting the patient's preferences and priorities set the goals.

3.3 Analysis

Putting fieldwork and experience down on paper cannot but simplify and reduce it for analytical and theoretical purposes. This process is often described as a movement from field to analysis that creates the distance necessary for writing ethnography (Candea et al. 2015; Astuti 2017). Yet it is important to note, that analyzing anthropological fieldworks is an ongoing process. My analytical onset was a phenomenological focus on embodied experiences with multimorbidity in everyday life. This gradually changed over the course of the fieldwork, as my interlocutors were not as preoccupied with symptoms and physical degradations as I had imagined. Instead, I came to do a hermeneutic analysis, interpreting what they said and what I observed. Anthropologists like Kirsten Hastrup and Tim Ingold inspired me in this approach. Using the words of Hastrup the analysis and suggestions for possible theoretical connections within it, comes from my perceiving it and inferring from talks, formal interviews, participating, experiencing and being in touch (Hastrup 2004:468) with the older people with multimorbidity whom I have studied. The knowledge I produce is thus, with Tim Ingold's words: "a generous, comparative but nevertheless critical understanding of human being and knowing in the world we all inhabit" (Ingold 2008:69).

Process of analysis

All interviews were conducted in Danish, and all field notes were written in Danish. When used in articles or this thesis they were translated into English by me. As also noted by Navne, there may be inherited problems of interpretation and meaning-making in the process of translation. However, this is a challenge for anthropological knowledge production in the subjective nature, relying not only on transcribed interviews, but notes, sometimes written hours later, impressions, smells, senses and a range of other conditions to be subjectively interpreted (Navne 2017:50, Järvinen 2005).

All the data including the audio files from the interviews were processed and coded using Nvivo. Codes such as ‘feeling inferior’ were created when reading the material and then the codes were merged into themes like ‘notions of inequity’, which was then again used in the articles. A section could have several codes simultaneously. Then the analytical process of grasping these themes theoretically began. As comme-il-faut in modern-day anthropology, I have offered to send the interlocutors my articles and our transcribed interviews. In only one case did an interlocutor wish for the interview, and her reading of the transcript allowed for us to discuss the interpretation of the interview. We agreed on the general points, and she wished to go more into details on a specific case of mistreatment, which we had talked about in relation to health inequity. The then extended case was used for analysis in article 3. However, I chose to consult the remaining interlocutors in lay language, with questions like ‘am I right if I think that it’s important for you to show your doctor that you are acting accordingly to the treatments?’ we developed reflective conversations, which ensured me that I was not being over interpretive in my analysis.

Anthropological analysis are interlaced with reflexivity; a constant movement between consulting existing theories and approaches, and having theoretical conversations with peers and not least – one self. The trajectory of the analysis is never straight forward; it is like looking for that right pair of jeans, trying on numerous brands that you like, until then suddenly, the perfect fit[1]. Certainly, one can wear other clothes than jeans; this is also the case for the analysis. It would not have been wrong to look at Carol’s and the other interlocutors’ lives using narrative theories, temporality or even magic, all of which I have touched upon in the analytical search for the right fit. The right fit is thus fundamentally a subjective choice (Andersen and Risør 2014:352), and hence it is crucial to ensure transparency (Stige et al. 2009). The theories applied varied naturally, as the articles have different analytical themes. However, the overall analytical

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[1] This metaphor is inspired by Daniel Miller’s arguments in an interesting STS study on how wearing jeans in London categorizes one as ‘ordinary’ while it is most often expressed as a matter of comfort (Miller 2010)

process was inspired by the abductive analysis, as suggested by Timmermans & Tavory (2012), stating that “researchers should enter the field with the deepest and broadest theoretical base possible to develop their theoretical repertoires throughout the research process (Timmermans & Tavory 2012:180). Abductive analysis is not proposing a deductive fieldwork, but elicits theoretical innovations through a double engagement with existing theory and careful methodological steps (Ibid:181ff). Thus, I have developed my theoretical concepts to account for what anthropologist Michael Whyte told me in a conversation prior to my fieldwork: to look for “the odd thing, the thing that puzzles you” when the interlocutors share their life.

In this thesis I have not been addressing race, ethnicity or immigration issues. The interlocutors are all but one Danish born, and all were White, Danish speaking Christians. They did not experience the burden of i.e. racial discrimination or trauma from being a refugee. A comparative analysis would be interesting to do in the future, but for now, it allowed me to isolate the influence of multimorbidity on the experience of everyday life.

3.4 Ethical considerations

The fieldwork was designed and conducted in accordance with American Anthropological Associations statement of ethics (AAA 2012). This ethical codex is foremost to produce knowledge and help solve human problems without doing harm, including potential unintended consequences and impacts on individuals, communities and identities. The study was approved by the Data Protection Agency (J.nr. 2015-41-3826).

Anonymizing

All participants, from key interlocutors to health professionals, have been given alias names, and I have altered on any details that could possibly lead to identification. The participants have different names in the articles and sometimes I have changed for instance their age, number of diseases or their diagnoses as a means to disguise their identity. As some parts of the study are very personal and private, this was pivotal to me. A key that connects the aliases in the articles and the thesis will be provided upon request. Concealing identities have not influenced on any patterns of behavior or analytical attentions. Additionally, all of the key interlocutors have kept their gender when made anonymous. Only I know the identity of the participants.

Informed consent

All the key interlocutors agreed to participate in the study and gave their spoken informed consent in agreement with the ethical standard for research participation[2] . It was part of the ethical considerations that I did not make the interlocutors sign a letter of informed consent. The reason is twofold: First, older people with multimorbidity, most of them with low levels of education are likely to have low health literacy[3]. Hence, a written informed consent is inadequate, as they are better of being explained in their own terms and time, what they agree – or not- to participate in. Secondly, the oral informed consent also makes participation less formal meaning that it might seem easier to drop out of the study. The latter was important to me, owing to the well documented burden of multimorbidity (section 1.2). Upon joining the band, activities and participating in daily life interactions I presented myself and the project to properly inform about the purpose of my attendance.

Ethics in representations

In article 4, I engage in ethical discussions on representations. Much like Fainzang (2010), I report from the battleground between medical and social sciences, discussing the implications of a biomedically defined research focus. This is an important ethical discussion, and is thoroughly unfolded in the article. Another ethical area of consideration when conducting ethnography and anthropology is the matter of representation. There is consensus, that knowledge is situated (Haraway 1988) and partial (Latour 1993), which shows in the representation of the interlocutors. During my first meeting with Hedvig, I was reminded that the positions we engaged in as researcher and participants were reciprocal. I might assumedly be in power qua my privilege of representing the 'unvoiced', but Hedvig was also using my presence to tell her story:

> Hedvig: *I am so glad that you came here today. I have tried to get them to listen to my story* [as victim of malpractice]. *Finally, you can help me spread the word.*

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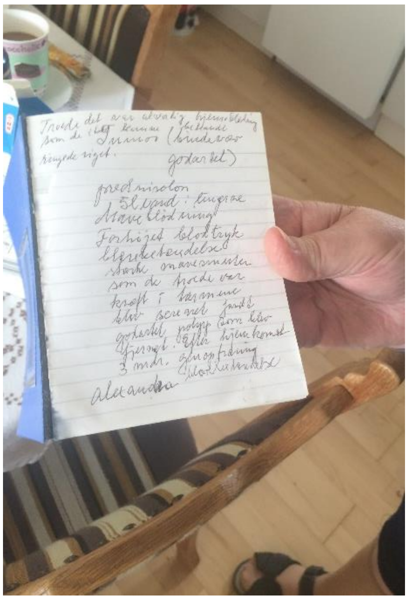
[2] Det Videnskabsetiske Komite, Version 2, December 2011

[3] Health literacy is a contested term and engaging in a discussion of it is out of the scope of this article. For now, by health literacy I mean ability and capacity to obtain, communicate, process and understand basic health information and services to make appropriate health decisions (CDC 2017a)

Picture: Hedvig's bucket list of things to share with me



Though tragic, Hedvig’s story as a victim of malpractice had little to do with my analytical object. How to handle this? I decided to listen to the story, not least because it form part of who Hedvig is and influence on her encounters with health professionals. But was I in a moral obligation of putting her story forward? Advocacy is neither a simple nor necessarily the best solution. Yet, retrenching to the realm of theory was also tenuous ethically (Speed 2006:67), since I wanted to let the interlocutors own voices be heard. I ended up letting her know that I as an anthropologist could not be the judge of whether or not she had been mistreated, but that I could give her the number of the patient ombudsman, whom I knew to be the right one to contact in such a situation due to my work at Danish Patients. She took it and I used her story as part of an analysis on the subjective health inequity (article 3).

Another aspect of representation came surprisingly from within the anthropological circles. I named my interlocutors ‘samtalepartnere’ in my first submission of article 4, but was asked to change it into informants. Having spent 1/3 of my PhD as a graduate student in the USA, I have been schooled in the American academic tradition to be cautious of words that could be confused with cultural appropriations; I was taught how the phrase ‘informants’ had implicit cultural connotations of a power relation (see Eriksen 1993; Nielsen 1996). Throughout this thesis I have used the word interlocutors, because that is what they are. They are not informants granting information; they are living subjects with agency and agendas whom I have held conversations with throughout the fieldwork.

It is one of the key principles in fieldworks that ethics and methodology are inseparable (Hoeyer et al. 2011). The above mentioned aspects have been present throughout the study. Together with considerations of whether I was being too intrusive, if the interlocutors seemed to be unease talking about certain things, if I was taking up the interlocutors’ energy from something to them more important and other related reflections, the above discussed has made up the continuous ethical attention. An attention I discussed with peers, supervisors, and not least, interlocutors.

The point being, most of all, my ethical aim in this study is to give the interlocutors voice. Not through me, but by themselves. Having the chance to spar with interlocutors about ethics and analysis has added depth and reliability to this study.

Chapter 4. Theoretical conversations

This section will draw upon the theoretical conversations on which, the arguments of this thesis rest and contributes to. In the articles I draw upon extensive and far-reaching analytical concepts; shedding theoretical light on what I contend to be the most enhancing influences on aging with multimorbidity, including: experiences of health inequity, disclosure practices and gendered approaches to the notion of successful aging. However, the articles share collective underlying theoretical premises that form the basis for the analysis; aging, multimorbidity and everyday life as empirical objects have also functioned as analytical objects implicit in the analysis. In order to situate the thesis within these premises, I begin with a discussion of everyday life as an analytical object. I move on to situate multimorbidity in a conversation on aging. Finally, I conclude with a brief discussion of my theoretical interpretation of illness and patient involvement, summing up my theoretical stance in the thesis.

4.1 Everyday Crisis

"*I thought 'this is the worse it can get' but no. It just keep going down. I believe I have got my share of disease, and yet more keep coming. Now with this new medication they may want to take away my driver's license. Tell me then what am I supposed to do? I need a car to visit my oldest daughter, there's no buses and I can't afford a taxi*" (Jane)

Whereas we might find it obvious to define 'everyday' as continuous repeated happenings and interactions, this thesis calls for attention to the chronic state of crisis in everyday life among older adults with multimorbidity. The opening quote of this chapter illustrates the convergence of everyday life and crisis. Jane's everyday life is encompassed with constant worsening in physical abilities, worries and major retrogrades of social life. With everyday life as empirical object in the thesis, I will below situate everyday life as an analytical object (Hastrup 1995).
In anthropology, the concept of everyday has been close to a modus operandi. We most often conduct participant observations situated in an everyday context. But, what *is* the 'everyday'? In his book titled *The Presentation of Self in Everyday Life* (1959) Erving Goffman does not specify the term. It seems he takes it for granted as though the meaning is well-known to the reader through his focus on social encounters in often recurring situations. Yet, discussions on the concept have emerged in the past decades. Rita Felski points to a doubleness of everyday life; being both "a mundane social world and a phenomenological relationship to that world" (Felski

2002:607). Everyday life is then in the recurring, unmomentous, and mundane events, which typically encompass activities such as eating, sleeping, getting dressed, and cooking food to mention a few (ibid). It is, "what we are, first of all, and most often" (Felski 2000:29). Yet, everyday is also a sought-after normative concept, described by Veena Das as "far from being something we might take for granted, might be thought of as an achievement" (Das 2010:376). Michel de Certeau points out, in his seminal work *The Practice of Everyday Life* (2011 [1984]), that everyday life is to be understood in the lens of the unpredictable ways that individuals form resistance to power: The worker who idles and wastes time on the job or the pedestrian who takes shortcuts to avoid a prescribed route, perform everyday tactics (de Certeau 2011[1984]:91-110). However, the anthropological and sociological approach to everyday life has been criticized as being too formalist by Michael Gardiner. He argues, that everyday life defined as a homogeneous and undifferentiated practices and attitudes, is being descriptive rather than obtaining its pivotal critical function; it fails to account for the creativity, spontaneity, and crisis that also form everyday life experiences (Gardiner 2000).

In the medical sciences, everyday life is often understood academically in the Activities for Daily Living (ADL), referring to everyday chores such as bathing, dressing, and feeding oneself (Katz et al. 1963). Particularly in regard to people with chronic diseases and older adults, ADL is used to measure the ability and the extent to which the individual can perform such activities. Though not engaging with the ADL measuring directly, independence in their ability to perform core activities was always a concern for my interlocutors.

Taking Felski's argument on the doubleness in everyday life into account, I endured the mundane tasks; having afternoon coffee, preparing lunch, waiting for someone. Yet, everyday life was corroded by not only present crisis in diseases, treatments, and relationships, but also in the discouraging predictions of what was expected to come. Here, the ADL is an interesting concept, as it rightly addresses the reasonable fears of the interlocutors that they will gradually become less able to overcome such everyday living tasks. Veena Das has worked with crisis in everyday life. For instance, she shows how sexual violence in India becomes a public everyday encounter, rooted in societal structures (Das 2013). I, too, want to call attention to crisis as present in everyday life. I am not talking about crisis as isolated periods, but crisis as a chronic state in line with Henrik Vigh's description (2008:7ff). He points to the chronic state of crisis for many people; the structurally violated, the socially marginalized and poor, and the chronically ill (Ibid). Thus, it is meaningful in this context not to talk about everyday lives but everyday crisis.

A similar point comes from Cheryl Mattingly in her study among African American families, whose everyday lives are filled with uncertainty, drama, and turbulence. To them, a mundane everyday life is sought after; it is an achievement (Mattingly 2013:323).

Multimorbidity complicates everyday life. Lisbeth Ørtenblad, Lucette Meillier, and I have shown how the burden of treatments entail dilemmas and conflict within family and social life, work life, and in encounters with health professionals. Our interlocutors, vocationally trained adults aged 18-60 with multimorbidity, felt a cumulative crisis in everyday life being boggled down not only by the diseases themselves but also by the various treatments (Ørtenblad et al. 2015; 2017). Health care delivery has become progressively more fragmented, complex, and difficult to manage (Coulter 2013:6). The present study adds to the understanding of everyday crisis in moving beyond descriptions, arguing that everyday crisis is not only degeneration and conflict as an everyday experience, but it also forms the background of the lives of the elderly with multimorbidity. It is the emotional, yet pragmatic state of mind from which people make sense of events, encounters, and mundane life. Carol's statement exemplifies this: "*It's like with the cane, once you've had it for some time you'll have to accept it to say: well, then this is how it is. I accept it because I want to be as independent as I can.*"

4.2 Intersections of aging and multimorbidity

Aging and gerontology are influential fields in anthropology (see for instance Bateson 2010; Harper 2008; Hyde and Higgs 2016; Kaufman 2015; Lock 2013; Wentzell 2013; Oxlund & Whyte 2014; Whyte 2017; Lamb 2013, 2017 to name a few). Aging, however, is quite a broad term. Though the experience of aging, getting older day by day, is universal, the biological age and the expectations towards the older vary widely within different cultural systems.

I have defined aging as being older than 65 years of age. It is a pragmatic choice taken because 65 is the official retirement age in Denmark, and 65< appears to be the most frequent definition of 'older' in the medical literature (ie. Salive 2013; Wolf et al. 2002). Though not the primary focus, aging is a concern to the interlocutors because society in many ways does not harmonize with increased longevity. Especially, when it is combined with multimorbidity. I find it important to set the scene of population politics which forms expectations towards old age in general.

The global population is aging, which calls for new developments to ensure good health and independency (Christensen et al. 2009). Sarah Lamb's study of governmental institutions providing care for the older in India, filling out a role that traditionally belongs to the family, shows how this results in conflicts about values and practices between societal models and ideals of the good life (Lamb 2013). A similar opposition can be traced between societal ideals and individual practice in policies of healthy aging and the reality of older with multimorbidity. As briefly touched upon in section 2.4, people have a moral obligation to maintain and improve their health, especially in older age as a reciprocal relation to the Welfare state (Mikkelsen 2016:452). In this regard, Lamb has showed ways in which this paradigm is based on neoliberal ideals of personhood (Lamb 2014). Martha Holstein and Meredith Minkler point to successful aging as an idealistic form, which is supported by unarticulated normative values and assumptions about old age (2003). Following this, critical gerontologists have highlighted that policies are not taking frail older people into account (Boudiny 2013), not including important self-care activities such as napping (Venn & Arber 2012), and marginalizing the physically inactive (Ranzijn 2010) and socially isolated older people (Mikkelsen 2016). In a Danish context, Aske Lassen discusses the formations of aging policies, their effects and how they interact with and are interpreted by the older in their everyday life (2014). He points to the notion of activity as an abolishment of aging, creating specific ideals about a 'good' senior life (Lassen 2014). Such perspectives highlight how aging is formed discursively through a neo-liberal logic that requires the ideal older to remain healthy, revealing an underlying normative value imposed in the encouragement for physical and social activity. This was central for my interlocutors, as their multimorbidity was preventing them from attaining that much desired successful aging. Instead, they came up with alternative interpretations of successful aging, which they were able to fulfill. Particularly the men had something to say about aging with multimorbidity, which they associated with notions of masculinity. This is thoroughly discussed in article 2.

However, based on my experience in the field and leading back to the precious section, I suggest that focusing on the vulnerability and frailness in my interlocutors may risk overlooking the agency and detailed practices to overcome and live with crisis in everyday life. I find, that giving voice to the interlocutors is the best way to grasp how aging is perceived, when one also suffers from multimorbidity. As Alfred, age 84 puts it:

> *"Why would I complain about being old? I can assure you, with all of my defects, I'm just happy to be alive. Growing old is a privilege."*

4.3 Managing Uncertainty, Disease or illness?

In investigating everyday life with multimorbidity, I draw on the anthropological attention to the social and cultural circumstances within which illness are experienced. As an anthropologist, I carry a theoretical baggage. To me, understanding multimorbidity has been formed by reading anthropological literature on managing uncertain life circumstances in relation to illness (Singer 2009; Whyte 1997; Steffen et al. 2005; Weaver, Barrett and Nichter 2016) and medical literature on the burden of diseases and treatments (i.e. Shippee 2012; Rosbach & Sahl 2017;Starfield 2006). One may dare to say that I have attended multimorbidity from both the illness and disease perspective, described in 1.2, so I will explain how this distinction directed my analytical and empirical attention.

Although seminal for the field of medical anthropology, the distinction between illness and disease does not translate well into the Danish language, where one term, ‘sygdom’, describes both. Without challenging the incontestable groundbreaking perspectives that a focus on illness has; bringing forth the everyday challenge with how to understand and live with disease, I wish here to unite illness and disease within my theoretical approach to understanding a life with multiple chronic conditions. As Kleinman & Fitz-Henry point out, it is indisputable that our subjectivities have a biology, but they are also influenced by history, culture, politics, emotions and relations (Kleinman & Fitz-Henry 2007:53). Along that line, one of the critiques of ‘diseases’ is that “it assumes that diabetes in a Manchester patient is the same as diabetes in a New Guinea tribesman” (Helman 1981: 548). Then why stress the usefulness of treating multimorbidity as disease? Do I thereby risk overseeing personal, cultural, and social factors? Rather, I want to point to the connection between the two; disease and illness. It is true, that illness is the subjective response to being un-well (Eisenberg 1977; Kleinman 1980), but the diseases, the medical categorization of symptoms, is the answer and explanation that most of the interlocutors have sought after in the period up until diagnosed. In his article on disease and illness in general practice, Cecil Helman calls for general practitioners’ attention to treat *both* disease and illness (Helman 1981). Today, more than 35 years later, many general practitioners *do* in fact treat both. Patient centeredness has become a standard point of reference, and about half of the general practitioners in Denmark are treating patients in accordance with a bio-psych-social disease approach, encompassing the psychological and social aspects of diseases (Gannik and Guassora 2011). Meanwhile, the interlocutors are referring to the disease part of multimorbidity when they talk about the numerous treatments, consultations, check-ups, and self-care prescriptions that are attached to each diagnosis.

Thus, the illness-disease distinction does not make analytical sense in the case of multimorbidity. Consequently, though attending to multimorbidity as an illness overall, I also use disease to gain insights into the more medical aspect of my interlocutors' lives. Additionally, I distinguish using the term 'condition' to describe the long-lasting irreversible loss of physical and sometimes mental abilities, while using the term 'diseases' when it is related to diagnoses whether it be specific diagnoses or the challenges in having numerous varying diagnoses. In this regard, having multiple chronic conditions becomes a disorder (Fainzang et al. 2010:20), which affected my approach to multimorbidity.

Asking the question "how does multimorbidity alter the older people's everyday life", anthropologist Susan Whyte (2005) helped me think of illness as an uncertainty, practiced in what she has termed "the subjunctive mood." In her study of Nyole people from Eastern Uganda dealing with misfortune (bodily disorders, discomfort, anxieties, prospects of death), she turns her focus to the subjunctivity with which the Nyole situate their concerns and address this adversity. Whyte argues that a situated concern makes room for different propounds; for instance saying that someone is suffering from AIDS in Eastern Uganda implies that they are unlikely to be cured, whereas saying that they are possessed by spirits means something can be done to help (Whyte 2005: 257). The subjunctive mood then is about the way an individual experiences uncertainty and how they deal with the problem (Ibid: 251). To view multimorbidity as a state of concern has been a prominent lens in the analysis of everyday life with multimorbidity as both illness and disease. In particular, I was inspired by the subjunctive mood to understand the agency with which multimorbidity was altered. It led me to develop the concept of tuning (article 3), but it also helped me to gain a more holistic view on suffering from multimorbidity. If I may take the reader back for a moment to the story of Carol in the beginning of this thesis: This is a story about illness – the subjective and social response to being ill. Carol has to relinquish the tour as she is literally left behind the others. It is, however, also a story about disease; had Carol not had the other diagnoses, she could have had another type of medication, which did not require such timely intake. However, what was most important to Carol in the story is the concern for the future, and the subjunctive mood that she acts on it. There is no happy ending to this story. Carol alters the multimorbidity with an acceptance of her misfortune, stating "*this is the new me.*"

Drawing on scholars working with uncertainty (Whyte 2005; Steffen et al. 2005) helped me render explicit what matters to the interlocutors the most in their everyday values. However, such personal values are not always attributed meaning in a medical setting, which I will delve into below.

4.4 Patient involvement

Alexandra: *Some of the things that I write about are patient involvement, you know, when you get to be part of decisions in your own treatment. Have you tried something like that?*
Alice: *No, I know nothing about such things. Whenever there is something, I just get some medications.*

Owing to my association with the Knowledge Center for User Involvement in Healthcare, my initial questions were inquiries about how and when older people with multimorbidity were involved in planning their treatments to fit their everyday life and personal values. As described elsewhere, this inquiry took a slightly different turn, yet the theoretical approach to involving patients unites the different arguments in the thesis. Therefore, before I end this overarching theoretical section, I turn to the literature of patient involvement.

Understanding peoples' experiences with illness, prioritizing treatments, self-care in everyday life, and encounters with health services, is crucial both because this is a profound component to improve healthcare and because it matters hugely to the individual (Coulter et al. 2014). Applying such experiences when planning for the individual patient's treatment and care is what I, in this thesis, define as patient involvement (Jacobsen, Pedersen and Jønsson forthcoming).
In health care, the concepts of participation and involvement emerged within the medical ethics as assigning honesty and respect for individual autonomy (Beauchamp and Childress 2009[1979]). Medical ethics started as a protest and rationalization on the WW2 concentration camps, the Tuskegee-scandal (CDC 2017b) in the US, and the use of organs from deceased patients without consent (Bauchner and Vinci 2001), but is also referred to as a reaction towards a paternalistic health care system. Until recent decades in the past century, patients were expected to demonstrate trust in the doctor's skills and the doctor was portrayed as the omniscient expert making decisions without any input from patients or relatives whatsoever (Jønsson et al. 2015).

However, user involvement in health care is not rooted in the health services but stems from a political concept of public participation in society and democratic institutions. In 1969, Sherry Arnstein made a model for participation, a ladder with eight different steps of involving citizens in political activities (Arnstein 1969). Notwithstanding the model, the question of how to organize participation and involving remains. Regarding participation in health it also has a misleading normative form, putting full participation and control as the end-goal, which most patients oppose as they do not wish to carry full responsibility for decisions (Tritter and McCallum 2006; Jønsson et al. 2015; Sinding et al. 2011). Conflating involvement with reassigning responsibility is a point I would like to challenge, and will return to. Arnstein is useful here, though, with the purpose of underscoring that participation and being involved in healthcare is not about doctors providing better information, but about challenging doctor patient relations and the rights and duties belonging to each role, respectively. Building on the dawning attention towards adherence and the increasing demands from patients, ‘informed consent’ became a legal requirement in the 1990’s, its current formulation being established in 1998[4]. Nonetheless, informed consent is not patient involvement because it builds solely on informing the patients, not taking their personal values, preferences, and attitudes into account.

Albeit, patient involvement is still largely a conceptual term and lacks consistent implementation in most realms of health care services. A study among Danish health care professionals reveals that most consider patient involvement as pertinent in providing good care (Jønsson et al. 2013). Thus, it is not a matter of will. Rather, the lack of systematic practices and guidelines often makes involving patients a task depending on the health professional and time constraints (Nyborg 2015). Allegedly, it is also a matter of upholding a professional identity and authority (Jacobsen et al. 2015).

Following the increasing interest on patient involvement (Jønsson et al. 2015), methods and aids to facilitate patient involvement have developed. The English National Health System has launched the slogan ‘no decision about me, without me’ stressing the importance of patients being involved in health decisions (Department of Health 2012). Additionally, part of preparing patients to be involved in decision making and coping with diseases in everyday life is solved

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[4] The Health Law [Lov nr. 482 af 1. juli 1998]

through the *healthtalk* homepage. The idea is to provide free, reliable, and recognizable knowledge about specific health issues through ordinary people sharing their stories and experiences (healthtalk.org). *Healthtalk* is currently not in Denmark, and there is no similar initiative. Instead, patient involvement is investigated in applied studies such as The User Involving Hospital [*Det brugerinddragende hospital*](ViBIS 2018) or Center for Shared Decision Making [*Center for Fælles beslutningstagning*](cffb.dk). When it comes to evaluating and measuring patient involvement and good quality of care public discourse and research projects have increasingly turned their focus from clinical results and numbers on morbidity and mortality to also include patient reported outcome (Shi 2012).

Angela Coulter has, in a seminal review, investigated methods for patient involvement (Coulter 2012). Initially I was inspired by Shared Decision Making (SDM), a process in which patient and health professional together find the best option for treatment (Coulter 2012:82). Using evidence-based information about options and uncertainties, often through patient decision aids, a shared decision is made. However, much of the evidence on SDM has focused on major health decisions, and relates directly to situations which involve a choice sensitive to individual preference (Ibid: 83). In observations in general practices I realized that this was seldom the case. Instead, GPs would refer me to patient-centeredness as their method of choice for involving patients. In Danish general practice, patient involvement on an *organizational* level is to a great extent about patient satisfaction and suggested methods for involving patients are feedback and treatment centered around the patient, as specified in, for instance, the British Medical Associations guideline for involving public and patients on an organizational level (BMA 2015). Apart from that, involving patients *individually* in general practice is mostly practiced as patient-centered care. Patient-centered care has been suggested as a means to enhancing the communication between doctor and patient (Stewart 1995; Ha and Longnecker 2010). The consultation in Danish general practice aims at a patient-centered approach revolving around patients' personal values. Yet there is still confusion about what patient centered means (Mead & Bower 2000) and how to incorporate patient knowledge into daily clinical encounters (Coulter 2012). Consequently, general practictioners often miss cues about patients' personal values, concerns, difficulties, and other stressors that might influence on health (Mjølstad et al. 2013; Wittink, Barg and Gallo 2006 ; Zhou et al. 2015).

I then turned to the literature on patient communication, in particular Lim and colleagues' (2016) study of what patients perceived as the greatest boundaries for communication between patients with multimorbidity and health providers. Owing to this, I began addressing involvement as an exchange of knowledge, identifying key factors that I, in cooperation with physicians Reventlow and Guassora, would categorize as important for the consultation, but which was never disclosed. I have addressed this specific problem in article 5.

Chapter 5. Collected findings

The following chapter presents the overall research results, connecting aspects of the five articles which each answering a different research question. Only the main results have been included. Additional arguments and theoretical discussions can be found in the respective article's manuscript.

The results of the thesis, though separated into different arguments in the articles, are in the empirical life worlds of the interlocutors coherent yet entangled in experiences. For instance, I separate arguments of discarded patient knowledge and subjective health inequities, though to the interlocutors they are not always divided experiences. I do so, because it grants me the opportunity to engage in a deeper, more thorough theoretical discussion within each main result. This is also the reason why I have decided to include five articles in this thesis. Each puts forth unique perspectives on living and coping with multimorbidity, aiming for a more holistic understanding of the interlocutors' lives.

5.1 Dramatizing priorities of everyday life

In accordance with the literature, multimorbidity seemed to affect the older adults' lives in a negative way; burdening them with treatments and symptoms that influence their social lives and force them to prioritize personal values and preferences over treatment adherence. For instance, Poul-Erik, who knew he ought to get some exercise and had been assigned to exercise sessions with other older men by the municipality, did not end up going as the classes were at 6pm and that had been dinnertime for Poul-Erik and his wife for the past 30 years (see article 4). Other times, social relations and values were weighted over adherence to treatments. For instance, one of the female interlocutors felt torn between doing what was best for her diseases and performing domestic chores, which she saw as a form of reciprocity in her marriage and a necessary part of her role as a wife. This is presented in details in the monologue in article 1, *The Robin. A monologue of aging with chronic diseases*, where I attempt to experiment with ethnography as a means to promote a more holistic picture of what an everyday life with multimorbidity looks like to an older person in rural Denmark. Framed by current discussions on ethnographic representations, article 1 is a theatrical manuscript for a monologue narrating the perspective of an older woman with multimorbidity. She is a composition of three of my interlocutors, where I have selected situations and stories with the artistic purpose to produce a piece of art. Yet, as all of the lines and stories are taken directly from my ethnographic material, this is not a fictive play. Article 1 thus blur the genres of academia and art, building on the tradition of ethnographic theatre and following a recent trend in anthropology to dismiss traditional representations and explore analytically what becomes when data is presented in a different way. In the monologue, I bring forward first-hand narratives of prioritizing between everyday life and multimorbidity treatments and care. Through the story of 'Betty' I show balancing everyday values and treatments as a common experience permeating aging with multimorbidity. This is the first academic work, to my knowledge, on everyday life with multimorbidity, which narrates the emotional banalities with an empathetic voice set in an analytical framework of writing up real experiences; showing the importance of such banalities in an everyday life with multimorbidity. Some of the challenges that I touch upon in the monologue may have gendered connotations to it; especially when Lene discloses to the audience that she cannot leave her husband and she needs to keep him satisfied by being a good wife, because she physically depends on his presence. Many of the women in this study mentioned the importance of relations, but not with a particular reference to their gender. On the contrary, the male interlocutors emphasized gender in what they perceived as the challenging circumstances of aging and the incapability of achieving goals of 'successful aging', which I will delve into below.

5.2 Men have gendered expectations to successful aging

In this study, the notion of successful aging as a discourse informed the public mindset but also individual everyday practices, affecting both the male and female interlocutors' perception of aging. However, in conversations on the process of aging, the men kept referring to gender. In article 2, *Gendered expectations: How older men with multimorbidity attend to successful aging*, I present how the men stressed that it was not just a question of aging but of aging as a man. They compared their present physical and mental capabilities to what they had been capable of when they were younger. Yet, it was experienced as a challenge to uphold an identity that for many was based on a former occupation as vocational workers requiring physical strengths. Instead, they associated alternative trails of aging as especially 'manly'. However, these trails still mapped onto the core components of successful aging (Rowe & Kahn 1987; 2015). Especially independency was stressed among the male interlocutors. Yet, as many were unable to be fully independent due to their multimorbidity, they transformed independency into 'being in control.' They also highlighted social engagement as important for older men, but distinguished between chosen social engagement mostly as hobbies, which they praised as healthy, and social engagement forced upon them by the municipalities, which they rejected.

They also read gendered expectations onto their health practices, most of them tending to manage their multimorbidity treatments and self-care with varying enthusiasm depending on the time and place. For instance, the tradition of cake at the weekly band rehearsal was prioritized over diabetic diets. Yet, on other occasions, some stressed how life as a retiree had provided time for local rides on the bike. Although the men were not able to fully live up to the notion of successful aging, they assessed their process of aging in accordance with self-initiated parameters, thus constituting a concept of male aging that they could fulfill. With Article 2 I intend to elucidate that discourses on successful aging may structure people's framework of reference for aging, yet it does not necessarily determine or define them.

In line with the interlocutors negotiating life conditions, I will continue to demonstrate how the interlocutors experience prejudice and how they negotiate that experience by means of agency in the following section.

5.3 Health inequity as subjective notion of inferiority in health encounters

In article 3, *Tuning Lives: Revisiting Health Inequities*, I argue that we need to adjust our focus in order to fully understand inequities in health. I explore how living the social determinants of low levels of education and low-income, the interlocutors read prejudice into encounters and interactions with health professionals. They consistently felt associated with inadequate health behavior because of their social position as belonging to the lowest social classes. For instance, some interlocutors felt that they were not afforded the same flexibility as people with higher education. John felt as if his medical adherence was not acknowledged because of prejudice towards people working on the harbor, which he felt made health professionals solely focus on his potential alcohol consumption. Others read stereotyping into cases of mistreatment, anticipating that the doctors had not done their best since the patient was "just a silly old woman." In Article 3, I argue that such subjective experiences form part of what I define as subjective health inequity: self-referentially enclosed understandings of experiences and encounters with health professionals. Subjective health inequity works as a supplement to current epidemiological understandings on health inequity drawing attention to the individual experience of perceived inequity. Yet, as is already well described in the anthropological literature, subjectivities form agency (Ortner 2005: 34) and the interlocutors reacted to subjective health inequity in varying ways by adjusting their behavior and taking precautions to differentiate themselves from the social determinant stereotype. In the article, I show how some interlocutors took precautions to appear as well-informed and adherent patients displaying responsible health practices. Others stressed their independence by refusing to accept financial aid. Others made sure that their appearances were optimized to avoid associations of being drunk because of the hassle walking or they would bring family members to make visible their network and resources. Using a musical metaphor, I name these practices that mitigate subjective health inequity *tuning lives*. Although it differs from Alfred Schutz's (1964) concept of tuning, which focuses on the musician's, composer's, and beholder's feeling of collective flux, his theory of what goes on in shared time and space resembles the interlocutors' aspirations for tuning their lives to be in flux with society. Tuning, thus, refers to the actions taken by patients because of the feeling of subjective health inequity. Addressing health inequity through the analytical lens of subjectivity and tuning brings forth a less explored side of health inequities, including within the medical literature.

Subjective health inequity as a concept enlightens how the interlocutors experience social determinants that help categorize them as a potential burdensome group. Their perception of stereotyping and prejudices stems from discourses about health practices among people with low levels of education and low income, but it also coincides with much of the contemporary medical and medical-anthropological research, which I will critique in the next section.

5.4 Health as a morally weighted research topic

During my fieldwork, the question of how to define a healthy life became omnipresent. The interlocutors had different perceptions of how to lead healthy lives than did the health authorities. Thus, I present in Article 4, *The Unhealthy: An anthropologist's encounter with older people with multimorbidity*, how 'health' manifests as a morally weighted concept. I embark on a journey of self-reflective critique and ethical considerations on doing medical anthropology and representations, reproducing biomedical notions of healthy and good lives. The knowledge that health researchers produced, including within this thesis, when studying Lolland, was unalterably creating an 'us', joining forces for a healthier population on Lolland, and a 'them', the unhealthy and irresponsible ones. Although the interlocutors acknowledged biomedical-grounded health advices and treatments, they did not always want to follow them. One woman knew that sleeping with an oxygen mask was the best treatment for her sleep apnea, yet she refused to do so since it annoyed her and was very inconvenient from her perspective. In Article 4, I tend to this disjuncture by suggesting a new concept of empathetic knowledge production as a research position requiring constant reflection on the questions asked and the answers given when doing social science research in a medical field. 'Empathetic' refers to the anthropologist’s responsibility to make practices, experiences and narratives understood within the specific local context. When health practices are embedded in a moral framework, I show the need for anthropologists to remain critical towards normative groundings. While the interlocutors are considered unhealthy, it soon became clear that they themselves felt healthy, in terms of conducting lives that felt meaningful. Hence, I aim to enforce knowledge production that entails an epistemological focus on situational existence. Similar to Article 1, this methodological article contributes with a focus on the proximity between researcher and interlocutor, and between lived experience and research produced knowledge. It is also a contribution to the current literature[5] on research ethics at the intersection of medical and social sciences.

The focus on questions and resistance towards becoming good docile citizens emerged through the social exchange between the interlocutors and me as an ethnographer. Meanwhile, the same people who would not adhere to all treatments would still, in encounters with health professionals, tune in, as described above. I argue that both are forms of regaining control over one’s life, to be understood in a temporal and relational context. I will move on to how this translates into a consultation setting below.

5.5 Patient knowledge is situational and relational

Definitions of what constitutes patient knowledge vary, and we embark on Article 5 with the underlying question of how to actually involve patients in decisions and planning of treatments so that it fit the everyday life of the individual, in particular if there is no consensus of what patient knowledge is, and hence, of what should be shared during the consultation. In encounters with their GP, the interlocutors had different notions of what kind of personal knowledge to disclose, and why. Some of these notions were intertwined with subjective health inequity, but in Article 5 I turn from the overall strategies and experiences to a more detailed inquiry of what, then, interlocutors chose to disclose, or not, in consultations with their GP. In the article “*What the doctor doesn’t know”: Discarded patient knowledge of older adults with multimorbidity*, we focus on discarded patient knowledge, taking advantage of my ethnographic position in the interlocutors’ everyday life. During fieldwork I was told personal information such as relational

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[5] A few brilliant articles are guiding the way, see for instance Baarts (2009) and Svendsen (2009)

crisis or shameful acceptance of sexual decline, which the interlocutors said they had not shared with their GP. Generally, such personal knowledge was discarded for disclosure if the interlocutors considered it to be out of the realms of medicine. Thus, interlocutors categorized consultation subjects to be only within the biomedical sphere. Additionally, some interlocutors decided not to share doubts or insecurities in regards to treatments, because they were afraid it would make them appear ignorant.

However, from a medical point of view, some of the knowledge that interlocutors said they had not disclosed during consultations may have had an influence on the choice of consultation topic, or the treatments and care that were referred. We describe the discarded knowledge thoroughly in article 5, arguing that it is to be considered patient knowledge, although not immediately recognized as important by patients themselves. Alignment on what patient knowledge is, thus, established as an essential means to facilitate patient involvement. We suggest that the discarded patient knowledge ,in some cases, hold key information to what really matters to the individual and that patient involvement methods should be developed with this in mind.

5.6 Summing up

The findings presented here direct attention to the lived experiences of challenges with health inequity, involving patient knowledge in planning treatments to fit everyday lives, and moral implications for people unable or unwilling to be docile older citizens with multimorbidity. By illuminating various ways to age with multimorbidity, I have produced knowledge on how particular sociocultural systems shape and affect health practices and disease management in everyday life. This knowledge will hopefully inspire policymakers and General Practitioners to acknowledge the challenges described within this thesis, by involving patients in the individual planning of treatments and care. How exactly, will be unfolded in the following chapter.

By engaging in conversations with anthropological and medical theories of everyday life, aging, illness, and patient involvement, I have come to understand the underlying premises of a life with multimorbidity. The theories applied in the analysis of the articles may render visible different aspect of living with multimorbidity, yet empirically, they are all intertwined.

Chapter 6. Discussion

In this thesis I have used various perspectives to look at aging with multimorbidity. Positioning myself in an everyday context among older adults suffering from multimorbidity paved the way for a substantiated analysis of how multimorbidity affects life trajectories in old age and what role the health services play. Referring to the overall aim of the thesis, I provided a vicarious immersion into aging with multimorbidity, which has brought to light entangled experiences of managing diseases in everyday life. Together the analysis and discussions form the epistemological argument that to understand the challenges of aging with multimorbidity, especially for people from lower social positions, we need to remain reflexive on the conditions under which we acquire and constitute our knowledge. My purpose was twofold: first, I wished to produce academic insights and knowledge on aging with multimorbidity contributing with new theoretical and methodological stances. The analytical findings in this regard complement the existing knowledge on multimorbidity, aging, health inequity, ethical research conversations, forms of representation and patients' knowledge disclosure practices. Second, I aimed to offer anthropological perspectives on caring for older adults with multimorbidity, by putting my interdisciplinary position as a social scientist in a medical and public health environment (conducting an industrial PhD for the umbrella organization of Danish patient organizations) to use.

In this chapter, I will first discuss power and inequity as themes that run across the findings, and then I will collate the arguments of the thesis into discussions on patient involvement and its relevance for policy and general practice. I will conclude with reflections on the strengths and limitations of the study.

6.1 Power Relations and Inequities in Everyday Life

In the articles I discuss the interlocutors' actions in terms of knowledge disclosure practices and tuning lives. Looking at social subjects through their practices in the world, I was inspired by feminist scholar Sherry Ortner's practice theory (1984); her focus on the production of subjectivities informs my analysis when I speak of agency. Sociologist Anthony Giddens attempted to unite the theories of social life into what he called structure and agency: the latter notion refers to freedom to act within the system of power that is settled in the subject's body (Giddens 1979, 1984). This is very similar to Ortners 'practice' and serves to explain the interlocutor’s ability to engage with others and their life circumstances by responding to the demands of a particular situation. Yet, if one looks at the way in which P9 in Article 5 is trying to appear well-informed as a means to get the best treatment, it is an intentional agency that comes as a response to a perceived power relation. I thus find it useful to discuss the underlying power struggle between society and individual (Ortner 1984).

Neither age, illness, social class nor gender are neutral categories; they are associated with different power relations, and they interact (Collins 1998; Phoenix and Pattynama 2006).
As for power relations in age, I have argued that neo-liberal discourses and policies of “successful” or “healthy” aging produce notions of certain personhoods as ‘irresponsible’ and ‘burdensome’ (Section 4.2, Articles 1, 2 and 4). In addition, the collected findings in this thesis point to aging having connotations regarding both a physical and psychological fragility, as specified in Carol’s story: Carol gradually loses her physical functions and social connectedness, and has to leave the retirees’ photography club. Although not always explicitly mentioned, many of the interlocutors gave the impression that they felt as if they had lost some of their former societal status in the process of aging. For instance, some of the men in Article 2 whose physical strength had diminished felt that their former skills were not valued in the present. I thus raise new perspectives, building on the growing body of research on aging in Denmark (Lassen 2014; 2015; Lassen and Moreira 2014; Lassen and Jespersen 2017; Oxlund and Whyte 2014; Mikkelsen 2016), adding to the understanding of people’s ambivalent attitudes towards successful aging, by arguing that we need to incorporate *past time* in perceptions of aging. This thesis has pointed out how aging is not an isolated experience but is a life course stage, in which connections to former identities, to some, become crucial.

In this thesis I have identified how some men experience aging and refer to gender when explaining certain health practices, but there is also an implicit power relation involved: structural gender inequities in health, which limit access to health services and contribute to morbidity and higher mortality rates among women, are well-described, especially in less developed countries (WHO 2015; Okoije 1994). However, gender inequities in health also affect men's health, resulting in reduced longevity, inadequate self-care and higher health risk behavior (WHO 2015; Mahalik et al. 2007; O'Brien et al. 2005; Sen & Östlin 2008). It has been argued that the notion of hegemonic masculinity causes the majority of men to access health services less frequently than women, and consequently men have poorer health status (Courtenay 2000). This thesis refines this position, both confirming that some men do not see their GP very often, but also contributing with examples of older men going for regular check-ups in general practice (see Article 5).

Power relations and inequities in regards to social class are explicitly discussed in Article 3, and constitue a well-known problem in anthropological literature (Marx *in* Parkin 1979, Weber 1995[1905]). Karl Marx was particularly interested in the relations between the dominating capitalists and the dominated working class. He defines capitalists as the ones who own the productions and hire people, and the working class as the ones who own nothing but their labor (Parkin 1979). Max Weber has a slightly different approach, focusing on social categorizations in the sense that life options are allocated depending on an individual's opportunity for accessing valuable societal resources (Weber 1995[1905]). These two classics may seem outdated with regard to the contemporary analysis in this thesis; however, despite the Danish ideal of equity and egalitarialism (Merrild 2018), Marx and Weber form the basis for our current understanding of social classes. Social classes are collected positions in a societal structure in which persons are grouped based on material and cultural criteria, and that grant or deny access to particular advantages (Dahlgren and Ljunggren 2010:13). What I want this thesis to contribute with, in studies of class, power and inequity, is the agency that people possess owing to their social class. Anthropologist Anne Mia Steno use the term 'dribble' to describe how Danish working-class youth, struggling to acquire an education, move on a bodily and relational level in the institutional and educational system, navigating the options to break with the intended structure (Steno 2015). Adding to this perspective, I have suggested the term *tuning* to describe the intentional agency that is carried out as a different act with the one purpose – to avoid subjective health inequity (Article 3).

Understanding and responding to issues of illness and treatments in terms of the interaction between society and policies, discourses and individual perceptions, experiences, behavior and meaning, I place myself within the *critical* medical anthropology (Singer 1995:81). This holistic and temporal concern with features of social life and knowledge, such as with culturally and socially constituted systems of meaning, is particularly anthropological, and in this thesis I use this position to add to the number of studies exploring bio-power and health subjectivities (Lupton 1995; Rose and Novas 2005, Rose 2007). I do so with special regard to constructions of knowledge. In 1978 Foucault outlined what he called "biopower", and here I have focused on his notion of "biopolitics" as something that operates through technologies of normalization, facilitating classification and control of the social body (Foucault, Senellart and Burchell 2008).

Inspired by Foucault, Lupton (1995) demonstrates how health promotion discourses act as moral regulations, drawing distinctions between ‘civilized’ and ‘uncivilized’ behavior. This leads to a representation of certain social groups as uncontrolled (Lupton 1995), developed into the concept of ‘healthism’ by Kristensen and colleagues (Kristensen, Lim and Askegaard 2016, described in Article 3). This thesis enters the conversation of such biopolitics from a slightly different angle, using the concept as a gateway for understanding the subjective notion of health inequity: on the one hand by looking into health practices in terms of hierarchy, as in Article 3, and on the other hand by considering when and how an ‘other’ is established as subordinated, inferior and excluded. That led me on the methodological quest for empathy, which is described in Article 4.

As such, the constitution of knowledge is also imbued with power and inequity, and this very study seems to be situated within such a knowledge position. As I have illustrated, there is an inherent power relation in studying people whose health practices are deemed inadequate by the established medical world. This position creates a binary opposition between *us*, the health researchers, having the answers, and *them*, the research objects, acting ‘wrongly'. This is thoroughly discussed in Article 4, but the notion of ‘right’ and ‘wrong’ knowledge can be traced into the disclosure practices of the older people. Adding to the literature on patient knowledge and disclosure practices, I illuminate how patients evaluate whether information were to be shared in the consultation with GP on parameters of biomedical relevance. Thus, they implicitly, and likely unwillingly, reproduce notions of us and them, right and wrong knowledge.

Summing up on the power and inequality aspect, I have illustrated how power relations in part of the analysis are analytical objects, whereas at other times, they have been implicit underlying premises. My point is not to provide extended theoretical discussions of power, but to shed light on the way that we talk about power, which is at odds with what people are actually experiencing: people do not see themselves as agents; they are not parsing categories. I surmise that our categories and theories do not stand up to the lived experience of aging with multimorbidity, and I believe that we need to shift the conversations. Instead, I argue that the different aspects of aging with multimorbidity is incompletely described through only analysis developed around concern for power. For instance, it may be argued that my concept of tuning lives could also be seen through the lens of resistance, but I suggest that it is not agency directed *against* biopower – it is more a form of being in the world, owing to the linkages between selfhood and society.

6.2 Patient involvement of older adults with multimorbidity

This thesis illuminates that older adults with multimorbidity, especially from the lower social classes, are still not receiving care that is tailored to their personal values, priorities and preferences, despite the fact that such patient knowledge has become pertinent owing to the chronicity in diseases, which has made illness part of everyday life. This is particularly important with regard to multimorbidity. As the number of an individual's chronic conditions rises, the burden of symptoms, treatments, self-care and even risk of premature death, increases (Shippee et al. 2012; Fortin et al. 2006, 2007; Bayliss et al. 2007). If treatments and self-care plans are to improve the lives of people with multimorbidity, policy makers as well as health professionals, including GPs, need to incorporate patient experiences. My intention is not to criticize the GP's approach, but to enlarge it to also encompass knowledge, concerns and priorities that the patients may not immediately express themselves. This leaves two questions: *Who are to be involved?* and *How are we going to involve them?*

From my prior work with patient involvement, I knew of the myth that patients who are older, severely ill or with low health literacy are not capable of being involved (Jønsson et al. 2013; see also Legare & Thomson-Leduc 2014). The patients' lack of interest in being involved is often used as an explanation when health providers talk about why they do not involve patients (Jønsson et al. 2013). Alice in Section 4.4. states that she does not have the knowledge necessary and does not express any further interest in gaining such knowledge. Then why talk about patient involvement in this case? Relating the question to the findings of this study, all the interlocutors have plans, fears, preferences, considerations, doubts and so on, which affect, if not directly then indirectly, their treatment adherence. Wensing and Baker (2003) argued that patient involvement should depend on considerations including the type of patient, suggesting that patients' ability and willingness to be involved should determine the level of involvement (Wensing and Baker 2003). Back then, more than a decade ago, it was often reported that less than 50 per cent of patients wished to be involved (Benbassat and Tidhar 1998; Guadagnoli and Ward 1998), but times were changing. Qualitative studies revealed only minor reservations about participation (Jenkins et al. 2001; Edwards, Elwyn and Smith 2001), yet today the assertion that patients do not wish to be involved remains a barrier, which I have encountered several times during this study. I suggest that it is a rhetorical matter, assuming that patient involvement in general practice is, as the collected findings have shown, a question of adapting treatments and self-care to fit into daily life, so that adherence can be enhanced. Sam, in Article 4, has been referred to an exercise program offered by the municipality, but despite his intention to participate, he drops out: the course coincides with dinner time and is therefore too inconvenient.

Another example is from Article 1, where Betty has trouble adhering to all the self-care she has to perform. If she and her doctor had only talked about the underlying cause of the lack of adherence, then the doctor might have been able to find another, more effective solution together with Betty. In Article 5 the interlocutors discard knowledge, and explain it by turning around the involvement, stating that for instance P3, P5 and Px did not find it necessary to involve their GP in this sphere of their lives. A similar point is made by Lim and colleagues, showing that what patients perceive to be pertinent to disclose depends on the relationship with the health provider, and there are barriers for disclosing knowledge relating to anxiety, stigma, embarrassment and the notion of certain information not being important (Lim et al. 2016).

Summing up the numerous stories of everyday lives with multimorbidity that come into view in this thesis, it is worth noticing that all interlocutors have priorities, considerations, personal values and a sociality, all of which are proven to have an effect on adherence (Loh et al. 2007). What I discovered during fieldwork was that patients make pragmatic, rational decisions and priorities regarding their self-care and treatment, although not always in accordance with the health provider’s intention or prescription. Everyday life considerations tended to carry more weight than following treatments if there was a conflict between the two. In her study of pregnant Danish smokers, Mette Bech Risør offers a similar argument: “Health promotion programs and health science are as embedded in local contexts as any other knowledge practices; they are performed by human actors engaging in human relations, and I find it necessary to take into account different complex levels of social interaction” (Risør 2003:79-80). In Article 2 I point towards some particularities for the men, which I suggest should also be considered when involving them in general practice. However, I do not have sufficient material on gender differences regarding specific attitudes towards involvement. Thus, for now, I will simply draw attention to the possibility of gender disparity when planning involvement in the future.
So, respecting that some people may prefer not to be involved, there should be an active and systematic *option* for engaging patient knowledge when planning care. This leads to the next leg of argumentation – the question of how, then, to engage patient knowledge from older adults with multimorbidity and perhaps poor health literacy.

As mentioned previously, SDM is not necessarily the right choice of method for involving patients in general practice. In settings where the provision of care is mainly through conversation, as in general practice, professionals rely heavily on patients' ability to engage in such conversations. SDM is only relevant for facilitating these conversations when there is a particular preference-sensitive choice of treatments (Kunneman et al. 2016). In other words, patients engaging in decisions need to keep in mind the argument of this thesis: how patients categorize knowledge.

Much of the involvement literature tends to view consultation as "an episodic dyadic encounter" rather than a "longitudinal complex relationship" (Elwyn 2004: 288). This objection is particularly relevant in a Danish general practice setting, where every citizen is assigned to a GP and the GP claims to know the patients, particularly the ones with multimorbidity, owing to their frequent visits in general practice (Mjølstad et al. 2013). Recognizing that healthcare decisions are distributed continuously in everyday life across time and space outside the consultation (Rapley and May 2009), and that such decisions involve different actors in different terrains and temporalities, is critical for practicing patient involvement in general practice. This thesis shows, in accordance with anthropological and sociological literature (Rapley 2008; Clinch and Benson 2013), that the decisions and priorities regarding care in everyday life, which the interlocutors take, are not cognitively autonomous, they depend on either social relations, human and non-human actors and personal values. The question is how to use this patient knowledge?

Wetzels et al. (2015) made a randomized trial to evaluate the effects of a leaflet aimed to help older patients prepare for consultation in general practice, but found no relevant effects on involvement or patient satisfaction (Wetzels et al. 2015). Throughout the fieldwork I asked the interlocutors if they would like to have some sort of preparation for the consultations. Some did write down questions or notes for the consultation, but none found the idea of a leaflet helpful. I also presented them with different approaches to this, including showing them the website healthtalk.org, where patients may find stories similar to their own, to help them prepare for consultations, treatments or living with specific diseases. Many found the website interesting, though some, including Alice claimed they would not know how to use it. Maybe Alice did in fact not want to be involved in planning and decisions regarding care? Or maybe she did. Alice really only cared about two things: animals and her garden. She was no longer able to keep an animal, so what bothered her the most was that she had lately had such difficulties with walking that she had not been to the garden. Usually, she would have had coffee outside in the garden for an hour a day, but now she did not dare walk out there. Is this relevant for the planning of her care? For her GP? I do not have the answer. However, I would need to return to the paradigm of biopower, to frame the patient involvement that some of the interlocutors feel they lack. The story of Lily in Article 3 sheds some light on this, underlining her desperation for an answer that she does not get. Also, one woman complained, which became part of the story of Betty in Article 1, that her doctor did not help her get an appointment at the hospital, and this would have been pivotal to her. This story illustrates that patient involvement is not necessarily sought after in by patients as participation in decision making. This is somewhat similar to the point ethnographer Anne Marie Mol (2008) makes, when she argues for two kinds of logic: that of choice and that of care. Mol stresses that the autonomy individuals are entitled to in the *logic of choice* is not necessarily good care, despite its promise to make patients free from a normative perception of passivity. On the contrary, the *logic of care* does not underline autonomy, but sheds light on the practices of daily life and the attempts to make these more liveable through ‘good’ care (Mol 2008:84ff). I build on Mol’s arguments, then, when I say that we need a language for patient involvement that can address the need for time in consultations, help to navigate intricate treatments and consider everyday values in care planning and so forth. To Carol, patient involvement, is about health providers engaging actively in the navigation of treatments. We need to keep such differences in mind. Additionally, her story is a story of power relations. Carol tunes her life to the doctors’ expectations (see Article 5), and yet, in the end, she cannot break the wall of power. The notion of being inferior in comparison to health providers is something than runs across the findings of this study, and is discussed particularly in Articles 1, 3, 4 and 5.

Returning to the scheme of patient involvement, I have argued that patient knowledge, even though not always recognized as relevant by patients (Article 5), is the key to involving patients in their individual treatment and care planning. With this, I would like to point to the necessity of being aware of power constellations. The findings show that the consultation room is not a neutral place, it is a place, essentially, where one sort of knowledge is weighted (at least by patients) higher than another, and until this changes, we cannot fully say that we involve the patients. This is especially true for older patients with intricate multiple chronic conditions, who are already subject to perceptions of underlying prejudices against them owing to their educational and income level.

6.3 Strengths and Limitations of the Study

I conclude with reflections on the strengths and limitations of this study. Originally, I had planned to do more systematic observations of the doctor-patient relationship, inquiring about patient involvement in general practice. I did not succeed in getting access to enough GPs, and nor did the interlocutors invite me to go along with them to see their GP, either because they did not think of it or because they considered a particular visit irrelevant for me. "*It was just a check-up, I have them four times a year. We [the doctor and her] barely speak*" as Anita explained to me when I said that I would have loved to have gone with her, on hearing that she had come straight from a doctor's appointment. Along these lines it soon became clear that involvement in the consultations in general practice was not an immediate concern for patients or GPs. The latter said in interviews that they did, in fact, already involve patients, stating how their consultations were patient centered, and always began by asking the patient what he or she had come to see the GP for. For some time it felt meaningless even to discuss patient involvement in the study, until gradually I became aware of the sort of knowledge that was never shared with the GP. I began listening to narratives of encounters with health professionals identifying points of involvement or lack of involvement. This has formed the joint argument of the thesis, but it is a one-way perspective, which does not involve the perspectives of the GPs or other health professionals.

Situating the study in an empirical object of everyday life, and allowing a year and a half for conducting fieldwork, gave me the advantage of time. I had the chance to follow the interlocutors through ups and downs regarding illnesses in everyday life. In some cases I was also the witness of an accelerating decline, bringing multimorbidity suffering to the front row. With others, I saw plans emerge and being played out: Joan finally had her garden arranged, Ole was able to participate in that much desired hunt, the forthcoming birth of a grandchild was announced, followed by anxiety due to suspected disease, but to everyone's relief the child was born healthy. Time also added an aspect of trust. Had I relied on single interviews, I might not have gained the confidentiality that is needed for acquiring a sense of everyday life as it is: in the beginning my interlocutors made a great deal out of my visits, preparing, arranging and making sure that I did not leave without having "*some good information*" as Lene said. Near the end, I witnessed frustrations openly played out, and on more than one occasion I held someone's hand as they cried with sorrow, with fear of the future or with grief over a lost spouse. Hence, the time aspect affected the kind of information that I got from the interlocutors. This has, in particular, had an influence on the data and analysis that I have used in Article 5; inquiring what kind of knowledge that the older adults did not disclose to their GP was possible only because of the established confidentiality and time frame that made such knowledge accessible to me.

However, the data collected was inevitably formed by me as an ethnographer. Every ethnographer carries features that can somehow affect their relation to the interlocutors (LeCompte and Schensul 2015:145). When the local newspaper did an Article on me joining a band, I realized my physical appearance was not neutral, as the headline read “The grey-haired folks have blonde company” [De grå toppe har fået blond selskab].

Picture to the left: “The Grey-haired folks have blonde company”. Picture to the right: “Age doesn’t mean a thing”
(Folketidende Sep 15 2015)

Being a young woman probably helped to get the older men to participate (I know, because they all made jokes simulating illness so that I would visit them), yet it undoubtedly also made some of the men try to impress me, stressing only their well-being and energy, and leaving out important details. As time passed, however, I obtained access to more nuanced insights, which in Gofmann’s words could be described as ‘backstage’ – behavior freed from the expectations and norms that shape our behavior in public (Goffman 1959).

Lastly, I will argue that there are several different aspects of aging with multimorbidity, but it was never the intention for this thesis to claim that all older people with multimorbidity necessarily experience subjective inequity, for example, or have knowledge that they decline to share with their GP. That being said, I wish to make just a few remarks on the significance of the inclusion criteria of illness and age, which lay the ground for the study. My interlocutors had a mean age of 76, as of August 2016, and were chosen because they were multimorbid. Multimorbidity accounts for 63 percent of 75-79 year-olds in Denmark (Friis et al. 2013). 11 out of 14 interlocutors had none or a low level of education, which is consistent with the research showing that multimorbidity is most frequent among people with a low level of education (Eriksen et al. 2015). They had at least three chronic conditions, yet the diagnoses varied considerably. Danish population-based studies have found that some diseases come in clusters, meaning that specific combinations are more frequent than others. As an example, 38 percent of people with diabetes also suffer from hypertension (Friis et al. 2013). Seven of my interlocutors had diabetes, and six of them were medicated for hypertension, which constituted an overrepresentation compared to the population studies. My point is not that my interlocutors need to be representative, but that the variations in their diseases are not important for this study. Instead, when looking at aging with multimorbidity, I focus on the burden associated with the number of different diseases, not the specific diagnoses. This is a point I will develop in the concluding perspectives, reflecting on the term multimorbidity. For now, the group of interlocutors, however small in number compared to quantitative studies, reflects how multimorbidity is distributed most heavily in Danish society.

Chapter 7. Concluding perspectives

This final chapter will draw together the main conclusions, followed by critical reflections on the term multimorbidity. I end this thesis with the story of Carol, who also opened the thesis, lastly summing up the perspectives of the thesis.

7.1 Summing up conclusions

In this thesis, I have offered analytical perspectives on perceptions of illness and inequities in everyday life among older adults with multimorbidity. Positioning myself within the life worlds of older people suffering from multiple illnesses, this thesis speaks from the patient's perspective. I have explored how multimorbidity is experienced, encompassed and intertwined in everyday lives from an individual point of view. I have argued that multimorbidity positions aging in a framework of illness and experiences of inequity. To conclude, I offer five original contributions:

1) How to use art as an instrument in conjuring emotion and showing the importance of banalities from everyday life with multimorbidity in an academic setting
2) How notions of successful aging are affected by older men's multimorbidity and gendered values and perceptions
3) A refined theory for understanding health inequities on an individual level; introducing the coherent concepts of *subjective health inequity* and *tuning lives*
4) A critical contribution to research ethics in health research for medical and social sciences, proposing an empathic research position that allows for different perspectives on health to thrive simultaneously
5) A discussion of what constitutes patient knowledge and disclosure practices proving relevant to future involvement of patients in general practice

Firstly, I propose ethnographic theater as a method for foregrounding individual experiences and perceptions without fragmenting them, but by presenting them as full narrative stories composed by the researcher from the collected material. This method is rather new, as ethnographic theater is with few exceptions (i.e. Bluebond-Langer 1978; Saldaña 2003) used as a co-design method, and this particular piece has the academic environment on conferences and meetings as its target audience. It is meant for interpretation and analysis, and is thus a new experimental means of presenting ethnographic data.

Secondly, I argue that neo-liberal notions of how to age successfully are particularly hard to live up to for older men with multimorbidity. Their illnesses puts Rowe & Kahn’s framework with emphasis on maintaining health (Rowe and Kahn 1987; 2015) out of reach. I show how this enforces new interpretations of successful aging, that additionally has gendered expectations to it. This is one of the first studies that investigates how older men with multimorbidity attend to successful aging, in particular in a Danish context, where the neo-liberal values are widespread, as described in 2.4. In article 2 I argue that discourses on successful aging may structure people’s framework of reference for aging, yet it does not necessarily determine or define them.

Thirdly, I propose two new theoretical concepts contributing to the understanding of the interplay between social determinants and health inequity on an individual level. I argue that health inequity should also be understood as individual experiences of perceived injustice or maltreatment, resulting in what I name *subjective health inequity*. Drawing on this particular framework, I contend that there is agency connected to subjective health inequity, and that actions taken to embody or eclipse prejudices and stereotypes that result in unequal treatment are best understood as *tuning lives*.

Fourthly, medical anthropologists must constantly reflect on how fieldwork produces and represents its empirical objects. I suggest the perspective of *empathic research*, referring to the anthropologist’s responsibility to make practices, experiences and narratives understood within the specific local context. This thesis with its multifactorial approaches attempts to do just that.

Finally, I offer a discussion of patient knowledge, in which I elevate overlooked aspects of personal life, which are not necessarily recognized as knowledge worth disclosing by patients, but which might alter planning of care and thus help achieve better adherence. Shedding light on how patients categorize and constitute patient knowledge through an inquiry into what is not disclosed to the GP, I contend that a collective notion of patient knowledge is necessary for involving patients in planning care and treatments.

Based on these novel insights, I conclude that aging with multimorbidity is a phenomenon loaded with morally valued expectations from both the individual and society. Sometimes these expectations clash, and I have shown that most of the times the strong part wins; societal discourse frames older adults with multimorbidity as losers, a perception also taken on by individuals in the study. This perspective contributes to the vast amount of anthropological literature on power relations with the particular focus on subjective perceptions of power-relations.

I began the thesis by asking how older adults navigate and prioritize within treatments and self-care and encompass illnesses in their everyday life. In short, the answer to my overall research question is this: They do what they believe is best for them, either medically or socially, and they struggle and tune to fit the cultural norms, sometimes altering notions of for instance successful aging. Yet, throughout this thesis I have argued that it is also not quite that simple. I have illustrated a range of aspects that influence how one ages with multimorbidity, and I have adduced the individual perspective; though no man is an Island, experiences are interpreted individually. This confirms the underlying normative approach of this thesis: that one should look for what really matters to the patients, and I shall therefore argue that what really matters to the individual needs to be part of planning future care for people aging with multimorbidity.

7.2 Conceptualizing multimorbidity

Before concluding, I would like to return to the concept of multimorbidity. As I have described in the introduction, multimorbidity is an increasingly growing field of interest for researchers, though it encompasses multiple understandings and connotations owing to a lack of consistent definitions. Although I have used multimorbidity to describe the state of two or more diseases from at least two different groups of diagnosis (Willadsen et al. nd), I am inconsistent in the use of the term within the articles. Article 3 is targeted at an international medical anthropological audience, among whom the term multimorbidity is a relatively vilified term. To avoid spending too much space on the argument of the term itself, I instead refer to the interlocutors as suffering from *multiple chronic conditions*. This points to a sort of semiotic rhetoric depending on the context of usage; while multimorbidity in a clinical setting refers to the number of diseases within an individual, in research it also positions the researcher within scientific fields or interests. Here, I would like to examine some of the limitations and strengths in the term multimorbidity.

As anthropologists, we are not obliged to accept the medical categories, which might be considered too remote from our empirical and analytical objects (Whyte 2012:66). But as part of an interdisciplinary research environment, I consider it an unnecessary impediment to merely reject medical terms. To the interlocutors in this study, diagnoses matters, and having multiple diagnoses can impede or complicate treatment, which have direct influence on their life. So let me set out with the medical aspect on multimorbidity:

What's in a name? So referring to poor Juliet's suffering in Shakespeare's Romeo & Juliet, one of the most seminal articles on multimorbidity begins (van der Akker et al. 1996). When it comes to the phenomenon of having multiple chronic conditions, a growing problem worldwide, it is important to have a common language to discuss the specific challenges it entails. As I have stated in the introduction (1.2), treatment of patients with different chronic conditions is complex and intricate (Noël et al. 2004; Schiøtz et al. 2016), and the transfer of information from one specialized unit to another is far from optimal, owing to the remnant 'doctrine of singular etiology' described by Dubos (Dubos 1959). Time after time, many of my interlocutors describe repeating or correcting information on their diagnoses and treatments, simply because this knowledge is not sufficiently transferred from one health provider to another (the organizational aspects of this are out of the scope of this thesis). This is in particular a problem that relates to the number of simultaneous chronic conditions, and in that sense, there is a certain pivotal pragmatism in having a joint umbrella diagnosis of 'multimorbidity' when looking into particular problems owing to this.

Albeit, the concept of multimorbidity is understood as a particular state of complex chronicity; suffering from concurrent and sometimes intricate conditions. There is a lack of constancy in the use of the term. Willadsen and colleagues found in a review of 163 articles that 115 articles operated with individually constructed definitions. However, all articles had 'diseases' in their definition, and in 37 percent of the articles, the cut-off point for multimorbidity was two or more conditions (Willadsen et al. 2016). In another article, Willadsen and colleagues argue that in order to capture the challenges with multimorbidity, the definition needs to consider the type of diseases. They suggest that the complexity in multimorbidity is less apparent when the diseases are too alike (for instance two types of heart conditions), and hence adduce that multimorbidity is having at least two chronic or long-term conditions or diseases from at least two different categories of diseases (Willadsen et al. nd). This is the definition as formerly stated that I rest this thesis upon.

Multimorbidity is rarely an isolated problem. Rather, it is situated in a complex mix of biology, sociality, economy and other life circumstances. Thus, an anthropological critique of multimorbidity serves to illuminate the pitfalls in the term: Recently, anthropologist have been pointing to the importance of taking into account multiple determinants of health such as harmful endemic conditions (Weaver, Barrett and Nichter 2016:435, 437), and that causality and context are inextricably connected (Andersen & Risør 2014:346). Accordingly, multimorbidity is approached by anthropologists in a much more holistic framework. Merrill Singer proposes that the term *syndemic* should replace multimorbidity as an epidemiological category that can entail both health and social problems (Singer 1996). The notion of syndemic is used recently by Mendenhall (2016) in her comparative analysis of comorbidity among marginalized groups in India, South Africa and the US. Her argument is that a concept like syndemic, contrary to comorbitidy (multimorbidity), can analytically foreground the structural and political inequities that underlie the distribution of diseases (Mendenhall 2016: 464ff). However, as pointed out by Manderson & Warren (2016), the concepts of multimorbidity and syndemic need to be understood empirically (Manderson & Warren 2016:481), and they suggest the need to understand a life with multimorbidity through the term 'recursive cascades': the interaction between bodily immobility, social isolation and resource limitations (Ibid: 492, fig 1). Thus, they complicate the idea of a syndemic approach (Ibid:491).

Margaret Lock has argued, "Recognition that all medical knowledge and practice is historically and culturally constructed…[…] is essential" (Lock 2001:480). Emily Mendenhall adds onto this by arguing that comorbidity (and multimorbidity) should not be treated the same cross-culturally (Mendenhall 2016:463), which suits well my arguments on the subjective experiences in this thesis. As mentioned earlier, Merrill Singer suggests we look at this as a syndemic state; using an epidemiological category to describe the interplay of diseases and social conditions: "A syndemic involves a set of enmeshed and mutually enhancing health problems that, working together in a context of noxious social and physical conditions, can significantly affect the overall disease burden and health status of a population" (Singer 2009:xiv). Although an inspiring springboard for my inquiry, especially into the role of the socioeconomic, I have found limits to this use, first and foremost the lack of recognition of the term 'syndemic' used in this regard among the epidemiologist that I collaborate with on finding ways to care for multimorbidity. Second, too broad a focus might exclude the individuality in how illness structures and challenges everyday life. Among medical anthropologists multimorbidity is rarely used; instead they call for new terms to account for the synergies in broader critical and biosocial frameworks (Weaver, Barrett and Nichter 2016:435). Additionally, when Manderson and Warren (2016) suggest looking at the interplay of disease and social conditions as "recursive cascades and chronic conditions" (Manderson and Warren 2016: 479), they add a certain timeframe, moving between past and present, to the experience of diseases, which I have not necessarily found in this study. To the interlocutors in this study, the diseases are always present, though some diseases feel more central than others. Carol was suffering from Parkinson's disease, arthritis and a digestion related disease along with on-off depressions. However, it was always Parkinson's disease that was centered in her illness narratives:

> "*Mr. Parkinson, I call the disease that, he is the one that bugs me. 'Go away Mr. Parkinson,' I usually say when things get too bad. I also have some arthritis, which is bothering me, and then the thing with my stomach. But those two are not really a concern, because Mr. Parkinson takes up all the space*" (Carol)

This is a particular pattern when Parkinson's diseases is part of a multimorbidity diagnosis; that it has the most strong effect on the health related life quality (Vertrano et al. 2016; Brettschneider et al. 2013). In such cases it may be more useful to talk about co-morbidities than multimorbidity, stressing the one disease centered.

However, the interlocutors never identified themselves as 'multimorbid' or 'comorbid', though some referred to themselves as "chronicians" [kronikere], which is mostly regarded a health provider term for the patients with chronic conditions, whom in some cases are very experienced and attentive towards symptoms and treatments. Albeit, to all interlocutors, diseases and illnesses were very present in their everyday life; materialized in medications, treatments, self-care plans and worries about the future and their life circumstances. How does multimorbidity as a concept relate to these lay people's everyday experience of living with multiple chronic illnesses? Looking at multimorbidity through this lens illuminates how dimensions of multimorbidity are shaped by policies, subjectivities and life conditions. In this thesis I have shown how this affects the individual experiences and attending to aging with multimorbidity, and I believe there is an important point to make about the term multimorbidity in this regard:

Multimorbidity does not (yet) have the same negative connotations as do many of the diseases the interlocutors suffer from, for instance, 'life-style diseases' such as chronic respiratory conditions, obesity, type 2 diabetes and cardiovascular conditions. 'Life-style disease' as a concept has been criticized for implying that people can stay healthy through proper self-discipline (Lupton 1995). My arguments throughout this thesis have been similar, although criticism is aimed at successful aging and social determinants. In relation to the term multimorbidity, the lack of negative connotations may lead the concept to serve as a heuristic tool, because it encompasses the extra suffering in terms of multiple illnesses and treatments that need to be adhered to without taking on connotations of morality.

7.3 Sketching a closing image

To end this thesis, I return again to Carol, sitting in her favorite chair on our last encounter a cloudy summer day in July 2016. Since we first became acquainted a year and a half ago at Carol's general practitioner, her multimorbidity had progressed and that decline materialized in the little keybox outside the door containing the key for the home care assistant to lock herself in with. By then, Carol was dependent on assistance getting in and out of bed and bathing, as Tom did not have the physical abilities to manage anymore. The retirees' photoclub had languished since Carol no longer had the energy to organize photo events, and her friends I met at a dinner she hosted were increasingly turning away, she felt. On that particular day, Carol teared up as she told me about her latest challenges while revising and adjusting her expectations for the remaining years of her life:

> "*Sometimes I can't help but think "what will become of me when I get more ill? How will I be able to get in and out of bed?" But I have to tell myself that I will have to wait and see. It's like with the cane, once you've had it for some time you'll have to accept it to say "well, then this is how it is. I accept it because I want to be as independent as I can". Now, we were supposed to go on a holiday this summer, but I don't know if I can do it. I don't think I can. I told Tom. But he doesn't really believe that I can't. If we go then he will have to socialize with the others and go on the tours alone. He's not gonna like that. But he has to. He has to realize this is how it is because I will never be able to do all that again. I have come to face the fact that I can't. I didn't use to be like that. Remember that time you went with me to take photos of the sculptures in the park. And I had to give up? That was the first time. From here on it's going down*" (Carol, July 2016)

Carol's Parkinson's disease has progressed and she and Tom are considering if she should have invasive brain surgery. They might still have that opportunity; Carol's doctor said they would be willing to make an exemption for the suggested maximum age of 70. Bringing the concept of multimorbidity into this setting, it may not capture what is really the concern of Carol; the accumulating degradation in physical ability, and as she mentioned later that day, the fear of her future mental abilities as Parkinson's also affects cognitive skills.

Or maybe multimorbidity is exactly the right term to describe what is going on? Carol would not be so concerned with the Parkinson's had it not been for her other diseases preventing her from new medications other than the brain surgery. And if it had not been for the Parkinson's disease, she might have paid a lot more attention to the other diseases. Also, the depression she has suffered from is linked to having multiple chronic conditions. Although her quote is mostly about the consequences of multimorbidity, I believe that the last sentence "*from here it's going down*" in all its sadness is a concise expression of the inevitable in living with multimorbidity: the chronicity and acceptance that despite treatments and care, life will never again be without illness.

Still, the trajectory of Carol's story is a densely intertwined mix of multimorbidity, aging and additional life circumstances. From Carol's words above about negotiating and navigating multimorbidity in everyday life, I adduce how her priorities and values are enacted, renegotiated and contested in multiple ways. How, then, to live? What to do with what matters the most in one's life? Together, Carol and the other interlocutors' lives form a collective knowledge in this thesis on the individual experience for one of the most pressing health challenges in years to come. Looping back to Kleinman in opening the introduction, I hope for this knowledge to a call for GPs, researchers and policy makers organizing care to the acknowledge illness experience and its social consequences for the patient (Kleinman 1988:250) when planning care for people aging with multimorbidity.

With this thesis I have attempted to add an epistemological understanding of aging with multimorbidity, attending not only to the practices of everyday life with multimorbidity but also tracking the various ways in which knowledge is constituted, be it in research or the individuals forming of personal information into patient knowledge. By no means do I claim to adduce ontological truths and answers; my contribution is of a different kind. I hope that the articles and the collective arguments of this thesis on illness and inequities in everyday life will provide theoretical perspectives that can enter both health research and ongoing public conversations about aging, multimorbidity and patient involvement. If epidemiological statistics tell the importance of rethinking care for older adults with multimorbidity, then this thesis may conclude that aging with multimorbidity is not an isolated phenomenon to be studied or treated. Rather, we need to incorporate aspects of inequity, subjectivity and gendered experiences of aging when attending multimorbidity. This thesis offers a language for such aspects that can inform future research and policies.

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Summary

An increasing number of older adults are living with multimorbidity. People with multimorbidity experience challenges in managing several, often intricate, treatments and self-care recommendations and have difficulties in communicating with health professionals. Furthermore, they experience a low quality of life, and strive to maintain their daily priorities and adhere to treatments, which can affect their social and personal resources.

This thesis focuses on individual experiences of aging with multimorbidity through ethnographic fieldwork among 14 older adults living in Lolland, Denmark. The overall aim is to understand how older people living with multimorbidity navigate treatments and self-care, and how they incorporate and prioritize these in their daily lives.

The ethnographic study design consisted both of participant observations and of individual interviews. The 14 key interlocutors were followed with regular field visits, semi-structured interviews and informal conversations while respondents/others went about their everyday activities.

The findings are analyzed in five papers forming the main argument of this thesis.

Paper 1 *The Robin. A monologue of aging with chronic diseases*
This article proposes ethnographic theater as a unique way of producing academic knowledge about individual experiences of living with multimorbidity as a full narrative story. In living with multimorbidity, social relations and values were sometimes prioritized over adherence to treatments. For instance, one woman defied medical advice by continuing to do domestic chores, such as baking bread, because it felt to her like the only way to perform her role as a ‘wife’. I bring forward first-hand narratives like this – prioritizing between everyday life and multimorbidity treatments and care, through a theater monologue. The lead character is compounded of three of my interlocutors, narrating the influential emotional banalities with an empathic voice, aimed at an audience of researchers and policymakers in the field. The monologue is meant for interpretations and analysis, and is thus a new experimental means of presenting ethnographic data.

Paper 2 *How older men with multimorbidity relate to successful aging*
In this article (co-authored with Ann Dorrit Guassora and Susanne Reventlow), we show that the notion of successful aging as a discourse informed not only the public mindset, but also individual everyday practices, affecting both male and female interlocutors' perceptions of aging. In conversations on the process of aging, the male interlocutors, contrary to the females, kept referring to gender; they associated certain trails of aging as especially 'manly'. The men referred to skills they used to possess. They experienced it as a challenge to uphold a self-image, relying on their notion of masculine values, such as physical strength or particular talents from their former jobs. They also highlighted social engagement for successful aging although only by own choice such as a hobby and not social engagement that was forced upon them. Independence was also stressed as important for aging with success, even though many were unable to be fully independent due to their multimorbidity. Instead they transformed independence into 'being in control'. Additionally they associated successful aging with staying as healthy as possible with multimorbidity. The men thus self-assessed health practices based on slightly altered parameters compared to the discourses, constituting a healthy and successful aging which they could fulfill. The article illuminates how the notion of successful aging may structure the men's framework of reference for aging, yet it does not determine or define them as individuals, as they themselves construct their own versions/ interpretations of how to age 'right'.

Paper 3 *Tuning Lives: Revisiting Health Inequities*
In this article I show how the social determinants of low levels of education and low-income made the interlocutors feel judged by their health behaviors because of their social position. For instance, some interlocutors felt that they were not given the same flexibility as people with higher education. From examples like these I argue that we need to adjust our focus in order to fully understand inequities in health. I suggest the concept of subjective health inequity – self-referentially enclosed understandings of experiences and encounters with health professionals – as a means to understand individual perceptions of inequity in health. In the article, I demonstrate how the interlocutors reacted to subjective health inequity in multiple ways, including regulating behavior and taking precautions to differentiate themselves from the stereotype of lower social classes. I introduce the term *tuning lives* as a means to analytically understand this particular form of agency. Addressing health inequity through the analytical lens of subjectivity and tuning brings forth a lesser known side of health inequities, which has received very little attention in medical literature. Subjective health inequity and tuning lives are

coherent theoretical concepts contributing to the understanding of the interplay between social determinants and health inequity on an individual level.

Paper 4 *The Unhealthy: An anthropologist's encounter with older people with multimorbidity*
In this article I demonstrate how the interlocutors' perceptions of how to live healthy lives were different from those of the health authorities. I illuminate 'health' as a morally weighted concept, through self-reflexive critique and ethical considerations about my own research. Following this, the article shows how the knowledge that health researchers produced unintentionally created an 'us', joining forces for a healthier population on Lolland, and a 'them' – the unhealthy and irresponsible lay people. I tackle this disjuncture by suggesting a research position called empathic knowledge production, requiring a constant reflection on the questions asked and the answers given when doing social science research in a medical field. I show how the interlocutors are considered unhealthy by health authorities, despite the interlocutors themselves feeling healthy in terms of living lives that they felt were meaningful and feeling that they did well within the actual premises of their life conditions. This article thus brings forth epistemological knowledge on how research on health practices is embedded in a moral framework and stresses the anthropologist's responsibility to make practices, experiences and narratives understood within the specific local, temporal and relational context.

Paper 5 *What the doctor doesn't know": Discarded patient knowledge of older adults with multimorbidity*
In the fifth paper (co-authored with Susanne Reventlow, Morten Freil and Ann Dorrit Guassora) we were interested in why certain aspects of the interlocutors' lives were not taken into account when planning treatments and care. We started an inquiry into disclosure practices of the interlocutors and realized that they deliberatively chose which information to share with the GP and which not to share. In the article we show how personal information was discarded for disclosure if it was 1) considered irrelevant, meaning out of the biomedical sphere, 2) too private including information that may lead to GPs' judgment, and finally 3), some interlocutors decided not to share doubts or insecurities with regard to treatments, because they were afraid it would make them appear ignorant. In the article we argue that such discarded information may alter the focus or even outcomes of the consultation with the GP, and hence we conclude that this sort of knowledge is to be considered patient knowledge. Alignment on what patient knowledge is, is an essential means to facilitate patient involvement. We suggest that patient involvement methods should be developed to facilitate disclosure practices.

To sum up, the articles described above provide a comprehensive understanding of what it means to an individual to age with multimorbidity. This thesis illustrates that aging with multimorbidity is a phenomenon loaded with morally valued expectations from both the individual and from society. Moreover, the thesis illustrates a range of aspects, which influence how individuals age with multimorbidity.

In conclusion, the thesis offers perspectives on patient involvement and the concept of multimorbidity. I stress the need for a language of individual patient involvement, which, based on the results of this thesis, goes beyond patient preferences and values to include discarded knowledge and perceptions of inferiority stemming from underlying power relations. I follow up on this with a discussion on the usefulness of the term multimorbidity by concluding that, for now, the term has the advantage of lacking moral connotations in the public discourse.

For future research and practice, this thesis has implications on how to address problems in aging with multimorbidity by acknowledging the subjectivity in health inequities and categorization of what to share with the GP, and that aging, gender, inequity and illness are intricate in everyday lives of older people and should be addressed as convergent concepts.

Dansk resume

Et stigende antal mennesker lever i dag med flere kroniske sygdomme samtidig, kaldet multisygdom. Særligt den ældre del af befolkningen har multisygdom. Mennesker med multisygdom oplever udfordringer i at håndtere de mange, ofte modstridende, behandlinger og egenomsorgsplaner, og har problemer med at kommunikere med sundhedssystemet. Derudover har mennesker med multisygdom lavere livskvalitet, og kæmper med at fastholde deres personlige værdier i hverdagen, mens de samtidig skal følge behandlinger, der ofte interagerer med både sociale og personlige ressourcer.

Denne artikel-baserede afhandling ser på individuelle oplevelser af hvad det vil sige at være ældre med multisygdom. Den bygger på et etnografisk feltarbejde blandt 14 ældre på Lolland. Det overordnede formål er at forstå, hvordan ældre med multisygdom navigerer og prioriterer i behandlinger og egenomsorg, mens de samtidig tilpasser sygdommene til deres ønskede hverdagsliv.

Den etnografiske undersøgelse består af både deltagerobservation og individuelle interviews. De 14 nøgleinformanter er fulgt i op til 18 måneder gennem jævnlige besøg i felten, interviews og uformelle samtaler samt deltagelse i deres hverdagsliv.

Hovedfundene fra undersøgelsen er analyseret i de fem inkluderede artikler.

Artikel 1 *Rødkælken. En monolog om at aldres med multisygdom*
Artiklen her eksperimenterer med etnografisk teater som en genre til at skabe akademisk viden om individuelle oplevelser med at leve med multisygdom fortalt gennem en personlig historie. Ofte bliver sociale relationer og personlige værdier prioriteret over behandlinger, hvis de er gensidigt udelukkende. For eksempel valgte en kvinde at fortsætte med huslige pligter som bagning, selvom det forværrede hendes sygdomme, fordi det var den måde hun bedst kunne være 'kone' for sin mand. I artiklen bringer jeg sådanne valg som førstehåndsfortællinger om at vælge mellem hverdagslivets værdier og behandlinger i en teater monolog. Hovedpersonen er sammensat af tre af mine informanter, som tilsammen beretter om vigtigheden af følelser og tilsyneladende banaliteter. Fortalt af en empatisk stemme, er monologens målgruppe forskere og beslutningstagere inden for ældre og sundhedsområdet. Monologen er tænkt som en måde at

præsentere data, der skaber rum for øjeblikkelig analyse og derved diskussion, og er altså en nytænkning af og eksperimentering med vidensformidling.

Artikel 2 *Hvordan ældre mænd med multisygdom forstår succesfuld aldring*
I denne artikel (skrevet med Ann Dorrit Guassora og Susanne Reventlow), viser vi, hvordan ideen om succesfuld aldring påvirker både den offentlige diskurs og individuelle praksisser hos både mænd og kvinder. I samtaler med informanterne om aldring, fremhævede mændene - modsat kvinderne- køn som betydningsfuldt. De henviste til særlige mandlige måder at ældes på, ofte ved at referere til deres tidligere kunnen. Mændene oplevede det som udfordrende at opretholde en selvforståelse bygget på deres ide om maskuline værdier såsom fysisk styrke, eller særlige evner tillært i deres forhenværende erhverv. De understregede også vigtigheden af socialt engagement; dog kun de ting de selv havde valgt, som for eksempel en hobby, og ikke sociale tiltag som de følte blev trykket ned over hovedet på dem. Uafhængighed var også understreget som afgørende for en succesfuld aldringsoplevelse, selvom mange ikke kunne være fuldt uafhængige af hjælp og behandlinger på grund af deres multisygdom. I stedet blev uafhængighed til et ideal om at forblive i kontrol over sit eget liv. Derudover associerede mændene succesfuld aldring med at være så sund som muligt i deres situation. Mændene skabte derved deres eget parameter for, hvornår aldring var succesfuld, med mål som de -i modsætning til diskursen om succesfuld aldring- kunne nå. Artiklen kaster lys på hvordan ideen om succesfuld aldring måske nok strukturerer mændenes referencerammer for aldring, men de lader sig ikke nødvendigvis definere eller fastlægge som individer af referencerammen. I stedet skaber de deres egne versioner af hvordan man ældes med succes.

Artikel 3 *Samklang: Nye forståelser af ulighed i sundhed*
I denne artikel viser jeg hvordan sociale determinanter som lavt uddannelsesniveau og lav indkomst får informanter til at føle at deres sundhedsvaner og egenomsorg blev bedømt ud fra deres sociale position. Eksempelvis følte mange informanter, at de ikke fik samme behandling som mennesker med højere uddannelsesniveau. Jeg argumenterer derfor for i artiklen, at vi skal udvide vores forståelse af social ulighed. Jeg foreslår begrebet subjektiv ulighed i sundhed som en selvforstærkende lukket fortolkning af oplevelser i og mødet med sundhedssystemet. Med begrebet håber jeg at kunne sætte fokus på individuelle fortolkninger af ulighed i sundhed. I artiklen præsenterer jeg informanters reaktioner til sådan subjektiv ulighed i sundhed. Jeg fremhæver, hvordan de tilpasser deres adfærd og tager forholdsregler for at vise, at de ikke tilhører den stereotype gruppe af lavt uddannede med 'dårlig' sundhedsadfærd. Jeg forklarer

dette ved at introducere begrebet samklang (tuning lives). Metaforisk forsøger informanterne at stemme deres instrument til at opnå samklang med omgivelserne og samfundets forventninger. Denne måde at tilgå ulighed i sundhed viser en forholdsvis ubeskrevet side af uligheden, særligt i medicinsk litteratur. Subjektiv ulighed i sundhed og samklang skal forstås som teoretiske begreber, der kan bidrage til forståelsen af samspillet mellem sociale determinanter og ulighed i sundhed på individ-niveau.

Artikel 4 *De Usunde. Sundhedsantropologens møde med multisyge ældre på Lolland*
I denne artikel præsenter jeg, hvordan informanternes opfattelse af et sundt liv ikke nødvendigvis stemmer overens med sundhedsvæsenets. Jeg fremhæver at sundhed er et moralsk ladet begreb gennem en selvkritisk og reflekterende rejse ind i mit eget studie. På denne måde viser jeg, at sundhedsforskning til stadighed skaber et 'os', forskerne, de sunde og rigtige, og et 'dem', de multisyge, usunde og forkerte. Denne skævhed foreslår jeg løst med begrebet empatisk vidensproduktion, som er en etisk forpligtelse til konstant at reflektere over de spørgsmål vi stiller og de svar vi får, når vi laver sundhedsforskning. Jeg viser, at informanters opfattelse af sundhed relaterer sig til at leve et meningsfuldt liv og føle sig veltilpas efter omstændighederne. Artiklen bringer derved en epistemologisk opmærksomhed på vidensproduktion i sundhedsstudier, og sætter streg under antropologens forpligtelse til at gøre praksisser, oplevelser og fortællinger forståelige i den specifikke lokale, historiske og relationelle kontekst.

Artikel 5 *Det min læge ikke ved: Ældre multisyge's frasorterede patientviden*
I den femte artikel (skrevet med Susanne Reventlow, Morten Freil og Ann Dorrit Guassora) undersøgte vi, hvorfor nogle aspekter af informanternes liv ikke blev overvejet, når der blev planlagt behandling. Vi begyndte at undersøge hvad informanterne delte med deres læge, og hvad de ikke delte. I artiklen viser vi, at informanter frasorterer at fortælle personlige detaljer til deres læge 1) hvis de regner det for irrelevant eller uden for det medicinske område, 2) hvis de regner det for at være for privat og eventuelt vil udstille dem over lægen samt 3) hvis de mener, at deres usikkerheder og tvivl vil få dem til at fremstå som ignorante. I artiklen argumenterer vi for, at sådan frasorteret viden kunne have haft en indflydelse på fokus i konsultationen eller planlægning af behandling med den praktiserende læge, og derfor skal regnes for at være patientviden. En fælles forståelse af hvad patientviden er, er afgørende for at kunne inddrage patienter. Vi foreslår, at patientinddragelses metoder bør udvikles til at kunne facilitere patientviden som ellers er frasorteret.

De ovenfor beskrevne artikler bidrager med en bred forståelse af hvad det vil sige for den enkelte at blive ældre med multisygdom. Denne afhandling illustrerer, at det at blive ældre med multisygdom er et fænomen, som er ladet med moralske forståelser og forventninger fra individet selv såvel som fra det omgivende samfund. Afhandlingen viser desuden en række aspekter, der har indflydelse på hvordan den enkelte aldres med multisygdom.

Som konklusion giver afhandlingen perspektiver på patientinddragelse og multisygdom som begreb. Jeg fremhæver manglen på et sprog for patientinddragelse, der baseret på resultaterne i denne afhandling, løftes fra patientens præferencer og værdier, til også at inkludere frasorteret viden og følelsen af at være underlegen i det implicitte magtforhold mellem læge og patient. Jeg følger op på dette ved at konkludere at multisygdom som begreb har en række udfordringer, men at det for nuværende er særlig anvendeligt, fordi der endnu ikke er skabt negative konnotationer til det at være multisyg.

Afhandlingen spiller ind i fremtidig forskning og praksis ved at adressere problemer i aldring med multimorbiditet som anerkender det subjektive aspekt af ulighed i sundhed og den individuelle sortering i hvad man som patient fortæller sin læge. Derudover viser afhandlingen, at aldring, køn, ulighed og sygdom er sammenflettet i den enkeltes liv, og derfor i forskning og praksis bør adresseres som sammenhængende fænomener.

References

van de Aa, M.J., van der Broeke, J.R., Stronks, K. and Plochg, T. (2017) Patients with multimorbidity and their experiences with the healthcare process: a scoping review. *Journal of comorbidity*. 7(1):11-21

AAA (2012) America Anthropological Association: Principles of Professional Repsonsibility. Retrived January 11, 2015 from http://ethics.americananthro.org./category/statement

Ács, A. and Pagh, S.(2017) “Lovestorm” How a Local Community Reclaims Positive Public Perception by Using Social Media *Proceedings of the 4th European Conference on Social Media*

Van den Akker, M., Buntinx, F., Knottnerus, J.A. (1996) Comorbidity or multimorbidity. *European Journal of General Practice* 2(2):65-70.

Andersen, R.S. and Risør, M.B. (2014) The importance of contextualization. Anthropological reflections on descriptive analysis, its limitations and implications. *Anthropology and Medicine* 21(3):345-456

Appadurai, A. (1986). Theory in Anthropology: Center and Periphery. *Comparative Studies in Society and History*, 28(2), 356-374.

Arnstein, S. (1969). A Ladder Of Citizen Participation. *Journal of the American Institute of Planners*, 35(4), 216-224.

Astuti, R. (2017). On keeping up the tension between fieldwork and ethnography. *HAU: Journal of Ethnographic Theory*, 7(1), 9-14.

Atkinson, P. (2015) *For Ethnography*. London: Sage

Bahler, C., Huber C., Brüngger, B. and Reich, O. (2015) Multimorbidity, health care utilization and costs in an elderly community-dwelling population: a claims data based observational study. *BMC Health Services Research* 15(1):23

Baarts, C. (2009) Stuck in the middle: research ethics caught between science and politics. *Qualitative Research* 9(4):423-439.

Bateson, M. C. 2010. *Composing a Further Life: the Age of Active Wisdom*. New York: Knopf.

Bauchner, H., & Vinci, R. (2001). What have we learnt from the Alder Hey affair?:That monitoring physicians’ performance is necessary to ensure good practice. *BMJ : British Medical Journal*, 322(7282), 309–310.

Bayliss, E.A., Ellis, J.L. and Steiner, J.F. (2007) Barriers to self-management and quality of life outcomes in seniors with multimorbidity. *Annals of Family Medicine* (5);5:395-402

Benbasset, J. P. D., & Tidhar, M.(1998). Patients' preferences for participation in clinical decision making: A review of published surveys. *Behavioral Medicine*, 24, 81-87.

Beauchamp, T.L. and Childress J.F. (2009[1979]) *Principles of biomedical ethics.* 6th edition. New York: Oxford University

Bluebond-Langer, M. (1978). *The Private Worlds of Dying Children*. Princeton: Princeton University Press

BMA (2015) file:///C:/Users/svd105/Downloads/plg_publicpatientinformationtoolkit_ Jan2015%20(1).pdf accessed March 1 2018

Boudiny, K. (2013). "Active ageing": from empty rhetoric to effective policy tool. *Ageing and Society*, 33(6), 1077–1098. http://doi.org/10.1017/S0144686X1200030X

Bower, P., Harkness E., Macdonald, W., Coventry, P., Bundy, C. and Moss-Morris, R. (2012) Illness representations in patients with multimorbid long-term conditions: Qualitative study. *Psychology and Health*, 2012;27(10):1211-26. doi: 10.1080/08870446.2012.662973.

Brettschneider, C., Leicht, H. Bickel, H., Dahlhaus, A., Fuchs, A., Gensichen, J., Maier, W., Riedel-Heller, S., Schäfer, I., Schön, G., Weyerer, S., Wiese, B., van Den Bussche, H., Scherer, M. and König, H-H. (2013) Relative impact of multimorbid chronic conditions on health-related quality of life--results from the MultiCare Cohort Study. *PLoS ONE*, 8(6), E66742.

Browne, K. (2007) Snowball sampling: using social networks to research non-heterosexual women, *International Journal of Social Research Methodology*, 8:1, 47-60, DOI: 10.1080/1364557032000081663

Candea, M., Yarrow, T., Trundle, T., & Cook, J. (2015). *Detachment, essays on the limits of relational thinking*. Manchester: Manchester University Press.

Cerwonka, A. (2007). Nervous conditions: the stakes in interdisciplinary research. In Malkki,L. ed. *Improvising theory: Process and Temporality in Ethnographic Fieldwork*. Chicago Univeristy Press.

CDC (2017a) https://www.cdc.gov/healthliteracy/learn/index.html Accessed March 21 2018

CDC (2017b) https://www.cdc.gov/tuskegee/timeline.htm Accessed March 21 2018

Christensen, K., Doblhammer, G., Rau, R., and Vaupel, J. W. (2009). Ageing populations: the challenges ahead. *Lancet*, 374(9696), 1196–1208. http://doi.org/10.1016/S0140-6736(09)6146-4

Clinch, M., and Benson, J. (2013). Making information ‘relevant’: general practitioner judgments and the production of patient involvement. *Social Science & Medicine*, 96, 104-111.

Collins, P. (1998). It's All In the Family: Intersections of Gender, Race, and Nation. *Hypatia*, 13(3), 62-82.

Cornelins, V. (1976). *Fra St. Croix til Nakskov, et livs eventyr*. Fredericia: Frimodt.

Coulter, A. (2012) Patient engagement – what works? *Journal of Ambulant Care Management* 35(2):80-89

Coulter, A. (2013). Understanding the experience of illness and treatment. In Ziebland, S., Coulter, A., Calabrese, J.D. and Locock, L. (eds). *Understanding and using health experiences, improving patient care.* Oxford: Oxford University Press.

Coulter, A., Locock, L., Ziebland, S., & Calabrese, J. (2014). Collecting data on patient experience is not enough. *British Medical Journal*, 348(7951), 15-17.

Courtenay, Will H. (2000) "Constructions of masculinity and their influence on men's well-being: a theory of gender and health" In: *Social Science & Medicine* Vol. 50 (2000) p. 1385-1401

Dahlgren, Kenneth & Ljunggren, Jørn (2010) ”Klasse: Begrep, skjema og debatt”.I: Dahlgren & Ljunggren (red.) *Klassebilder. Ulikhet og sosial mobilitet i Norge*. Oslo: Univeristetsforlaget. s. 13-27.

Dalsgaard EM, Vedsted P, Fenger-Grøn M, Sandbaek A, Vestergaard M. (2012) Socioeconomic position and contact to general practice among persons with diabetes”*Prim Care Diabetes*. Dec;6(4):313-8. doi: 10.1016/j.pcd.2012.06.002. Epub 2012 Jul 17.

Das, V. (2010). Moral and Spiritual Striving in the Everyday: To Be a Muslim in Contemporary India. In A. Pandian & D. Ali (Eds.*) Ethical Life in South Asia*. Bloomington and Indianapolis: Indiana University Press

Das, V. (2013). Violence, crisis, and the everyday. *International Journal of Middle East Studies*, 45(4), 798-800.

De Certeau, M. (2011[984]). *The Practice of Everyday Life* (3.rd ed.). Berkeley: University of California Press.

Department of Health (2012) https://www.kingsfund.org.uk/publications/articles/consultation-response-liberating-nhs-no-decision-about-me-without-me Accessed March 4 2018

Dubos, R. (1959) *Mirage of Health: Utopias, Progress, and Biological Change*. New York: Harper and Brothers

Duguay, C., Gallagher, F. and Fortin, M. (2014) The experience of adults with multimorbidity: a qualitative study. *Journal of comorbidity* (4):11-21

Edwards A, Elwyn G, Smith C. (2001) Consumers' views of quality: identifying the consultation outcomes of importance to consumers, and their relevance to 'shared decision-making' approaches. *Health Expectations*;4:151–61

Eisenberg, L. (1977). Disease and illness Distinctions between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry*, 1(1), 9-23.

Ekdahl, A., Andersson, L. and Friederichsen M. (2010) They do what they think is best for me. Frail elderly patient's preference for participating in their care during hospitalization. *Patient education and counseling.* 80 (2010): 233-240

Elwyn, G. (2004) Arriving at the postmodern medical consultation, *The European Journal of General Practice*, 10:3, 93-97, DOI: 10.3109/13814780409044542

Eriksen, L., Statens Institut for Folkesundhed, & Sundhedsstyrelsen. (2016*). Sygdomsbyrden i Danmark, risikofaktorer (Risikofaktorer)* Kbh: Sundhedsstyrelsen.

Eriksen, T. (1993). *Små steder - store spørsmål, innføring i sosialantropologi*. Oslo: Universitetsforlaget

Estroff, S. (1993). Identity, Disability and Schizophrenia: The Problem of Chronicity. In *Knowledge, Power and Practice: The Anthropology of Medicine and Everyday Life*, Edited by: Lindenbaum, Shirley and Lock, Margaret. Berkeley: University of California Press.

Fainzang, S., Hem, H. E., and Risør, M. B. (2010). Introduciont. In: Fainzang, S., Hem, H. E., and Risør, M. B.(editors) *Taste for knowledge : medical anthropology facing medical realities*. Pp. 11-23

Felski, Rita. (2002). Everyday Life. *New Literary History: A Journal of Theory and Interpretation*, 33(4), 607-808.

Fortin, M., Bravo, G., Hudon, C:, Lapointe, L., Almirall, J. and Dubois, M.F. (2006) Relationsship between multimorbidity and health-related quality of life of patients in primary care. *Quality of life research.* Feb; 15(1):83-91

Fortin, M., Dubois, M.F., Hudon, C., Soubhi, H. and Almirall, J. (2007) Multimorbidity and quality of life: a closer look. *Health Qualitative Life Outcomes* 2007;5:52

Foucault, M., Senellart, M., & Burchell, G. (2008). *The birth of biopolitics : lectures at the college de france*, 1978-79. Retrieved from https://ebookcentral.proquest.com

Friis, K. H., Pedersen, M. B., Larsen, F., & Lasgaard, M. (2016). A national population study of the co-occurrence of multiple long-term conditions in people with multimorbidity, Denmark. Copenhagen: Sundhedsstyrelsen

Gannik, D. E., and Guassora, A. D. (2011). Samspil mellem sygdomsbegreber og organisering af sundhedsvæsenet. *Ugeskrift for Laeger*, 173(11), 807-811.

Gardiner, M. (2000). *Critiques of everyday life*. London New York: Routledge.

Geertz, Clifford. (1998). Deep Hanging Out. *New York Review of Books*, 45(16), 69-72.

Giddens, A. (1979). *Central problems in social theory, action, structure and contradiction in social analysis (Contemporary social theory).* London: Macmillan.

Giddens, A. (1984). *The constitution of society, outline of the theory of structuration.* Cambridge: Polity Press.

Godfrey, Christina M, Margaret B Harrison, Rosemary Lysaght, Marianne Lamb, Ian D Graham and Patricia Oakley (2011) Care of self – care by other – care of other: the meaning of self-care from research, practice, policy and industry perspectives . *Int J Evid Based Healthc* 2011; 9: 3–24

Goffman, Erving (1959) *The Presentation of Self in Everyday Life.* Edinburgh: University of Edinburgh Press

Good, B. (1994) *Medicine, Rationality, and Experience: Anthropological Perspective.* Cambridge: Cambridge University Press

Grøn, L., Obel, J. and Bræmer, M.H. (2007) *Tovholder i Praksis*. DSI: Rapport 2007.04

Guadagnoli, E. and Ward, P. (1998) Patient participation in decision-making. *Soc Sci Med;*47:329–39.

Gullestad, M.,(1984) *Kitchen-table society: a case study of the family life and friendships of young working-class mothers in urban Norway,* Oslo: Universitetsforlaget.

Gullestad, M. (1992) *The Art of Social Relations. Essays on Culture, Social Action and Everyday Life in Modern Norway.* Oxford: Oxford University Press

Ha, J. F., & Longnecker, N. (2010). Doctor-patient communication: A review. *Ochsner Journal,* 10(1), 38-43.

Hansen, H., Pohontsch, N., van der Bussche, H., Scherer, M. and Schäfer, I. (2015) Reasons for disagreement regarding illnesses between older patient with multimorbidity and their GPs – a qualitative study. *BMC Family Practice* (2015) 16:68

Haraway, D. (1988) Situated Knowledge: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist studies* 14(3):575-599

Harper, S. and R. Goodman (2008). *Ageing in Asia*. London: Routledge.

Hastrup, K. (1995). *A Passage to Anthropology: Between Experience and Theory*. London: Routledge.

Hastrup, K. (1998). Kulturel Forståelse: Mellem sprog og erfaring. *Kulturstudier*, (1), 47-64.

Hastrup, K. (2004) Getting it right. Knowledge and evidence in anthropology. *Anthropological Theory* (4);4: 455-472

Hastrup, K. (2013a) Scales of Attention in Fieldwork: Global Connections and Local Concerns in the Arctic. *Ethnography*. 14(2): 145-164

Hastrup, K. (2013b) Vi bebor mangfoldige verdener – eller? Imod udsagnet. *Tidsskriftet Antropologi* 67:41-47.

Helman, C. (1981). Disease versus illness in general practice. *The Journal of the Royal College of General Practitioners*, 31(230), 548-52.

Holstein, M.B. and Minkler, M. (2003). Self, Society, and the "New Gerontology". *Gerontologist*, 43(6), 787-796.

Hyde, M., & Higgs, Paul. (2016). *Ageing and globalisation* Bristol, UK: Policy Press.

Høyer, K., Jensen, A. and Mohr, K. (2011). På rejse ud i etikkens farlige vådområder. *Nordiske Udkast*, 1 & 2, 104-107.

Ingold, T. (2008*) Anthropology is not ethnography*. Proceedings of the British Academy (154), pp. 69-92

Jackson, A. (1987). *Anthropology at home* (A.S.A. monographs ; 25). London.

Jacobsen, C., Martin, H., & Baker, V. (2015). Who knows best? Negotiations of knowledge in clinical decision making. I: *Tidsskrift for Forskning i Sygdom og Samfund*, Vol. 22; 67-82

Jacobsen, C., Pedersen L. and Jønsson, A.R. (Forthcoming) Patientinddragelse – fra patientens perspektiv. In: Jørgensen, K. (edt) *Patientinddragelse – i et sundhedspolitisk, sundhedsprofessionel og brugerperspektiv*. København: Samfundslitteratur

Jenkins L, Britten N, and Barber N (2001) *Improving doctor-patient communication about drugs. Final Report to the Department of Health.* London: GKT Concordance Unit

Järvinen, M. (2005). Interview i en interaktionistisk begrebsramme. In M. Järvinen & N. Mik-Meyer (Eds.) *Kvalitative metoder i et interaktionistisk perspektiv: Interview, observationer og dokumenter* (pp. 27-48). København: Hans Reitzels Forlag.

Jønsson, A.R., Nyborg, M. Pedersen, V., Pedersen, L. Wandel, A. and Freil, M.(2013) *Sundhedsprofessionelles forståelser af patientinddragelse. En kvalitativ undersøgelse*. København: ViBIS

Jønsson, A., Baker, V., Jacobsen, C., & Pedersen, L. (2015). Brugerinddragelse: forhandlinger af autoritet, relation og viden. *Tidsskrift for Forskning i Sygdom og Samfund*, 0(22). doi:http://dx.doi.org/10.7146/tfss.v0i22.20817

Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of Illness in the Aged The Index of ADL: A Standardized Measure of Biological and Psychosocial Function. *JAMA.* 1963;185(12):914–919. doi:10.1001/jama.1963.03060120024016

Kaufman, S. (2015). *Ordinary medicine, extraordinary treatments, longer lives, and where to draw the line.* Durham London: Duke University Press.

Kleinman, A. (1980) *Patients and healers in the context of culture*. Los Angeles: University of California Press.

Kleinman, A. (1988) *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books.

Kleinman, A. (2006) *What Really Matters: living a moral life amidst uncertainty and danger*. Oxford: Oxford University Press

Kleinman A. and Fitz-Henry (2007) The Experiential Basis of Subjectivity: How Individuals Change in the Context of Societal Transformation In Biehl, J., Good, Byron, & Kleinman, Arthur. (eds) *Subjectivity, ethnographic investigations*. Berkeley, California: University of California Press.

Koroukian, S.M., Schiltz, N.K., Warner, D.F., Sun, J. Stange, K.C., Given, C.W. and Dor, A. (2017) Multimorbidity: constellations of conditions across subgroups of midlife and older individuals, and related Medicare expenditures. *Journal of comorbidity* 7(1):33-43

Kristensen, Dorthe, Ming Lim and Søren Askegaard (2015) Healthism in Denmark: State, market, and the search for a “moral compass”. *Health* 20(5):485-504

Krøijer, S. and Sjørslev, I. (2011) Autonomy and the spaciousness of the social in Denmark: the conflict between Undomshuset and Faderhuset”. *Social Analysis*. 55(2):84-105

Kunneman, M., Montori, V. M., Castaneda-Guarderas, A., & Hess, E. P. (2016). “What Is Shared Decision Making? (and What It Is Not)” *Academic Emergency Medicine*, 23(12), 1320-1324. doi:10.1111/acem.13065

Lamb, S. (2013). In/dependence, Intergenerational Uncertainty, and the Ambivalent State: Perceptions of Old Age Security in India. South Asia: *Journal of South Asian Studies*, 36(1), 65-78.

Lamb, S. (2014). Permanent personhood or meaningful decline? Toward a critical anthropology of successful aging. *Journal of Aging Studies*, 29, 41.

Lamb, S. (2017). *Successful Aging As a Contemporary Obsession, Global Perspectives*. New Brunswick, NJ: Rutgers University Press.

Larsen F.B., Pedersen M.H., Friis K., Glümer C. and Lasgaard M. (2017) A Latent Class Analysis of Multimorbidity and the Relationship to Socio Demographic Factors and Health-Related Quality of Life. A National Population-Based Study of 162,283 Danish Adults. *PLoS ONE* 12(1): e0169426.

Lassen, A. (2014). *Active Ageing and the Unmaking of Old Age: The Knowledge Productions, Everyday Practices and Policies of the Good Late Life*, University of Copehagen, PhD 252.

Lassen, A. (2015). Keeping disease at arm's length – how older Danish people distance disease through active ageing. *Aging and Society* 35(7), 1364-1383.

Lassen, A. and Moreira, T. (2014). Unmaking old age: Political and cognitive formats of active ageing. *Journal of Aging Studies,* 30, 33.

Lassen, A. and Jespersen, P. (2017) Getting old and keep going: The motivation Technologies of Active Aging in Denmark. In Lamb, S. (Ed.). Successful aging as a contemporary obsession : global perspectives. New Brunswick, NJ: Rutgers University Press

Latour, B. (1993) *We have never been modern*. Cambridge, MA: Harvard University Press
LeCompte, M and Schensul, J. (2015) *Ethics in Ethnography: A Mixed Methods Approach* Lanhan: AltaMira Press

Légaré, F. and T hompson-Leduc, P. (2014) “Twelve myths about shared decision making” Patient Education and Counseling , Volume 96 , Issue 3 , 281 - 286

Liddy, C., Blazkho, V. and Mill, K. (2014) Challenges of self-management when living with multiple chronic conditions. *Canadian Family Physician* 2014; 60:1123-33

Lim C, Berry ABL, Hirsch T, Hartzler AL, Wagner EH, Ludman E, et al. (2016) “It just seems outside my health": How Patients with Chronic Conditions Perceive Communication Boundaries with Providers. *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*; Brisbane, QLD, Australia. 2901866: ACM; 2016. p. 1172-84.

Lim, C.Y., Berry, A.B.L., Hirsch, T., Hartzler, A.L., Wagner, E.H., Ludman, E.J. and Ralstron, J.D. (2017) Understanding what is most important to individuals with multiple chronic conditions: a qualitative study of patients’ perspectives. *Journal of General Intern Medicine* Dec;32(12):1278-1284. doi: 10.1007/s11606-017-4154-3. Epub 2017 Aug 28.

Lock, M. (2001). The Tempering of Medical Anthropology: Troubling Natural Categories. *Medical Anthropology Quarterly*, 15(4), 478-492.

Lock, M. (2013). *The Alzheimer conundrum, entanglements of dementia and aging.* Princeton, N.J: Princeton University Press

Loh, A., Leonhart, R., Wills, C. E., Simon, D., & Harter, M. (2007). The impact of patient participation on adherence and clinical outcome in primary care of depression. *Patient Educ Couns,* 65(1), 69-78. doi:10.1016/j.pec.2006.05.007

Lupton, D. (1995) *The Imperative of Health: Public Health and the Regulated Body.* London: SAGE

Löffler, C., Kaduszkiewicz, H., Stolzenbach, C-O., Streich, W., Fuchs, A., van der Bussche, H., Stolper, F. and Altiner, A. (2012) Coping with multimorbidity in old age – a qualitative study. *BMC Family Practice* (13)45

Madden, R. (2010). *Being ethnographic, a guide to the theory and practice of ethnography*. London: SAGE.

Mahalik, J., Burns, S. and Syzdek, M. (2007) Masculinity and perceived normative health behavior as predictors of men's helath behaviors. *Social Science & Medicine* (64) p. 2201-2209

Mair, F.S. and Gallacher, K.I. (2017) Multimorbidity: what next? *British Journal General Practice* 2017; 67 (659): 248-249.

Manderson, L., & Smith-Morris, C. (2010). Introduction: Chronicity and the experience of illness. *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness,* 9780813549736, 1-18.

Manderson, L. and Warren, N. (2016) “Just one thing after another”: Recursive cascades and chronic conditions. *Medical Anthropology Quarterly* (30);4:479-497

Marcus, G. (2009) “Introduction” In: *Fieldwork is not what it used to be*. Edited by Faubion J. and Marcus, G. Ithaca: Cornell University Press

Marcus, G. and Fischer, M. (1986) *Anthropology as a Cultural Critique. An Experimental Movement in the Human Sciences.* Chicago: University of Chicago Press.

Mattingly, C. (1998). In Search of the Good: Narrative Reasoning in Clinical Practice. *Medical Anthropology Quarterly* 12(3):273-297.

Mattingly, C. (2013). The Moral Perils of a Superstrong Black Mother. *Ethos* 42(1): 119-138.

McKinlay, E.M., Morgen, S.J., Gray, B.V., Macdonald, L.M. and Pullon, S.R.H. (2017) Exploring interprofessional, interagency multimorbidity care: case study based observational research. *Journal of Comorbidity* 2017; 7 (1):64-78

Mead, N., & Bower, P. (2000). Patient-centredness: A conceptual framework and review of the empirical literature. *Social Science and Medicine*, 51(7), 1087-1110.

Mendenhall, E. (2016) Beyond comorbidity: A critical perspective of syndemic depression and diabetes in cross-cultural contexts. *Medical Anthropology Quarterly* (30);4:462-478

Merrild, C. (2018) Social Differences in Health as a Challenge to the Danish Welfare State. In: Bendixsen, S., Bringslid, Mary Bente, & Vike, Halvard (eds*) Egalitarianism in Scandinavia, historical and contemporary perspectives (Approaches to social inequality and difference*). Cham, Switzerland: Palgrave Macmillan. Pp. 181-200

Mikkelsen H.H. (2016) Unthinkable Solitude: Successful Aging in Denmark through the Lacanian Real. *ETHOS: Journal of the Society for Psychological Anthropology* 2016;44(4):448-463.

Mjølstad, B.P, Kirkengen, M.,Getz, L G. and Hetlevik, I. H. (2013). What Do GPs Actually Know About Their Patients As Persons? *European Journal for Person Centered Healthcare* 1:149-160.

Mol, A. (2008). *The logic of care, health and the problem of patient choice*. Abingdon, Oxon: Routledge.
Morris, R.L., Sanders, C., Kennedy, A.P: and Rogers, A. (2011) Shifting priorities in multimorbidity: a longitudinal qualitative study of patient’s prioritization of multiple conditions. *Chronic Illness* 7(2): 147-161

Moth, G., Vestergaard, M. and Vedsted, P. (2012) Chronic care management in Danish general practice – a cross-sectional study of workload and multimorbidity. *BMC Family Practice* 2012 (13):52

Navne, L. (2017). *Careography, practices and experiences of life and death in a Danish neonatal intensive care unit*, Ph.D. thesis, University of Copenhagen.

Nielsen, F. (1996). *Nærmere kommer du ikke, håndbok i antropologisk feltarbeid.* Bergen: Fagbokforlaget.

Noël, P.H., Frueh, B.C., Larme, A.C. and Pugh, J.A. (2004) Collaborative care needs and preferences of primary care patients with multimorbidity. *Health expectations* (8):54-63

Nyborg MJG (2015). *At se mennesket i patienten - En antropologisk undersøgelse af hvordan patientinddragelse forstås og praktiseres af danske sundhedsprofessionelle*. Speciale. Institut for Antropologi. Københavns Universitet

O'Brien, Rosaleen, Kate Hunt & Graham Hart (2005) 'It's caveman stuff, but that is to a certain extent how guys still operate': men's accounts of masculinity and help seeking. *Social Sciences and Medicine* (61), p. 503-516

Hebsgaard Offersen, S. (2016). *Aiming for the ordinary, exploring everyday life experiences of bodily sensations and symptoms in the Danish middle class*, PhD dissertation. Århus University.

Okoije, CE (1994) "Gender inequeties of health in the 3rd world" In: *Social Science & Medicine* Vol 39(9), p. 1237-47

Okely, J., & Callaway, H. (1992). *Anthropology and autobiography* (A.S.A. monographs ; 29). London: Routledge.

Ortner, S. (1984). Theory in Anthropology since the Sixties. *Comparative Studies in Society and History*, 26(1), 126.

Ortner, S. (2005). Subjectivity and cultural critique. *Anthropological Theory*, 5(1), 31-52.

Ortner, S.B. (2006) *Anthropology and Social Theory: Culture, Power, and the Acting Subject* Durham: Duke University.

Oxlund, B., & Whyte, S. (2014). Measuring and Managing Bodies in the Later Life Course. *Journal of Population Ageing*, 7(3), 217-230.

Parkin, F.(1979) *Marx's Theory of History: A Bourgeois Critique*. New York: Columbia University Press

Parkinsons Organization (2017) https://parkinson.dk/livet-med-parkinson/træning accessed march 15 2018

Passaro, J. (1997) “You Can´t Take the Subway to the Field!”: “Village” Epistemologies in the Global Village. In J. Gupta, Akhil and Ferguson, ed. *Anthropological locations: boundaries and grounds of a field science*. California: University of California Press.

Pedersen, K.M., Andersen J.S. and Søndergaard, J. (2012) General Practice and Primary Health Care in Denmark. *American Board Family Medicine*, Vol. 25, suppl 1; 34-38 doi: 10.3122/jabfm.2012.02.110216J

Phoenix, A., & Pattynama, P. (2006). Intersectionality. *European Journal of Women's Studies*, 13(3), 187-192.

Ploug, N., Henriksen, I., & Kærgård N. (2004). *Den Danske Velfærdsstats historie*. København: Socialforskningsinstituttet.

Ranzijn, R. (2010). Active ageing--another way to oppress marginalized and disadvantaged elders?: Aboriginal Elders as a case study. *Journal of Health Psychology*, 15(5), 716-23.

Rapley, T. (2008). Distributed decision making: the anatomy of decisions-in-action. *Sociology of health & illness*, 30(3), 429-444

Rapley, T., & May, T. (2009). *Evidence and risk: the sociology of health care grappling with knowledge and uncertainty. Shared decision-making in health care. Achieving evidence-based patient choice.* Oxford University Press, New York, 53-58

.

Reddy, G. (1991). *"Sådan er danskerne!", en indisk antropologs perspektiv på det danske samfund*. Mørke: Grevas Forlag.

Regionen (2016) Definition af yderområder.https://regionalt.erhvervsstyrelsen.dk/definition-af-yderomraader Accessed March 3 2016

Risør, M.B. (2003) Practical reasoning as everyday knowledge: health, risk and lifestyle in health promotion and the everyday life of pregnant smokers. *Folk*. Vol. 45 (2): 61-85

Rosbach, M., and Andersen, J. S. (2017). Patient-experienced burden of treatment in patients with multimorbidity – A systematic review of qualitative data. *PLoS ONE*, 12(6), e0179916.

Rose, N. and Novas C. (2005) “Biological Citizenship” In *Global Assemblages: Technology, Politics and Ethics as Anthropological Problems*, edited by A. Ong & S.J. Collier, 439-463. Malden, USA: Blackwell

Rose, N. (2007) *The politics of Life itself. Biomedicine, power and subjectivity in the twenty-first century.* Princeton: Princeton University Press

Rowe, J. W. and Kahn R.L. (1997) Successful aging. *Gerontologist* 37(4):433-40.

Rowe, J.W. and Kahn, R.L. (2015) Successful Aging 2.0: Conceptual Expansions for the 21st Century. *Gerontologist.* Vol. 70:593-596,.

Saldaña, J. (2003). Dramatizing data. *Qualitative Inquiry*. 9(2), 218-236

Salive, M.E. (2013); Multimorbidity in Older Adults, *Epidemiologic Reviews*, Volume 35, Issue 1, 1: 75–83, https://doi.org/10.1093/epirev/mxs009

Schiøtz, M.L., Høst, D. and Frølich, A. (2016) Involving patients with multimorbidity in service planning: perspectives on continuity and care coordination. *Journal of Comorbidity*, (6);2:95-102

Sen Gita & P. Östlin (2008) Gender inequity in health: why it exists and how we can change it *Global Public Health* (3):1-12

Shi L. (2012) The Impact of Primary Care: A Focused Review. *Scientifica Volume* (2012), Article ID 432892

Shippee, N.D., Shahab, N.D., May, C.R., Maird, F.S. and Montori, V. (2012) Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *Journal of Clinical Epidemiology* (65);10:1041-1051

Schutz, A. (1964) *Collected Papers II.* The Hague: Martinus Nijhoff

Sinding C, Miller P, Hudak P, Keller-Olaman S & Sussman J. (2011). Of time and troubles: Patient involvement and the production of health care disparities. I: *Health* 16(4); 400-417.

Singer, M. (1995). Beyond the Ivory Tower: Critical Praxis in Medical Anthropology. *Medical Anthropology Quarterly*, 9(1), 80-106.

Singer, M. (1996) A Dose of Drugs, a Touch of Violence, a Case of AIDS: Conceptualizing the SAVA Syndemic. *Free Inquiry in Creative Sociology* 24:99-110

Singer, M. (2009). *Introduction to syndemics, a critical systems approach to public and community health.* San Francisco: Calif: Jossey-Bass. Pp. xiii-xvii

Sinnott, C., Mc Hugh, S., Browne, J. and Bradley, C. (2013) GP's perspectives on the management of patients with multimorbidity: systematic review and synthesis of qualitative research. *BMJ Open* 2013; 3:e003610

Sjørslev, I. (2004). On Leaving the Field: Closure and Continuity as Seen through the Lens of the Candomblé Axexé Ritual. *Folk: Journal of the Danish Ethnographic Society*, 46-47, 11-40.

Speed, S. (2006), At the Crossroads of Human Rights and Anthropology: Toward a Critically Engaged Activist Research. *American Anthropologist,* 108: 66-76. doi:10.1525/aa.2006.108.1.66

Spradley, J. (1979). *The ethnographic interview* Belmont, CA: Wadsworth Group

Spradley, J. (1980). *Participant observation.* Fort Worth: Harcourt Brace College.

SSI (2015) *Borgere med multisygdom*. København: Statens Serum Institut and National Sundhedsdokumentation og IT: afdeling for sundhedsanalyser

Starfield, B. (2006). Threads and yarns: Weaving the tapestry of comorbidity. *Annals of Family Medicine,* 4(2), 101-3.

Starfield, B. (2009) Primary care and equity in health: the importance of effectiveness and equity of responsiveness to peoples' needs. *Humanity and Society,* 2009 (33): 56-73

Steffen, V., Jenkins, Richard, & Jessen, Hanne. (2005). *Managing uncertainty, ethnographic studies of illness, risk and the struggles for control* Cph: Museum Tusculanum.

Steno, A. M. (2015). *Ungdomsliv i en Uddannelsestid: Kønnede, klassede og tidsbundne driblerier i og mellem erhvervsuddannelser*. PhD Thesis Roskilde Universitet .

Stewart, M. (1995). Effective physician-patient communication and health outcomes: A review. CMAJ : *Canadian Medical Association Journal = Journal De L'Association Medicale Canadienne*, 152(9), 1423-33.

Stige, B., Malterud, K. and Midtgaarden, T. (2009) Towards an Agenda for Evaluation of Qualitative Research *Qualitative Health Research* 19(10), 1504-1516

Strathern, M. (1991) *Partial connections Savage* Md: Rowman & Littlefield.

Stuart, M., and Hansen, E. (2006) Danish Home Care Policy and the Family: Implications for the United States. *Journal of Aging and Social Policy* 8(3–4):27–42.

Svendsen, M. N. (2009) Kritisk engageret videnskab: Erfaringer fra forskning om gen- og forplantningsteknologierne. *Tidsskrift for Forskning i Sygdom og Samfund* 10:37-57.

Taylor, C. J., Harrison, C., Britt, H., Miller, G. and Hobbs, F.D.R. (2017) Heart failure and multimorbidity in Australian general practice. *Journal of Comorbidity* 2017; 7 (1):44-49

Timmermans S, Tavory I. (2012) Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis In: *Sociological Theory* 30(3):167-86.

Tjørnhøj-Thomsen, T., & Hansen, H. P. (2009). Overskridelsens etik: Erfaring, analyse og repræsentation. I K. Hastrup (red.), *Mellem Mennesker: En grundbog i antropologisk forskningsetik* (1 udg., s. 223-249). København: Hans Reitzels Forlag.

Tjørnhøj-Thomsen, T., & Hansen, H. P. (2017). Ethnographic Fieldwork. In K. M. Facey, H. P. Hansen, & A. N. V. Single (red.), *Patient Involvemnet in Health Technology Assessment*. Springer Nature Singapore: Springer. DOI: 10.1007/978-981-10-4068-9

Tjørnhøj-Thomsen, T. and Reventlow, S. (2016). Kvalitative metoder. I M. Grønbæk, S. Reventlow, & B. B. Jensen (red.), *Forebyggende sundhedsarbejde* København: Munksgaard .

Townsend, A. (2012) Applying Bourdieu's theory to accounts of living with multimorbidity. *Chronic Illness* 8(2):89-101

Tritter, JQ & MCCallum A. (2006). The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy* 76:156-168

Tyack, Z., Kuys, S., Cornwell, P., Frakes, K-A. and McPhail S. (2017) Health-related quality of life of people with multimorbidity at a community-based, interprofessional student-assisted clinic: Implications for assessment and intervention. *Chronic Illness* ahead of print

Valgårda, S. (2013) *Health Politics: Theories and Analyzis.* Copenhagen: Munksgaard

Venn, S. and Arber, S. (2012), Understanding older peoples' decisions about the use of sleeping medication: issues of control and autonomy. *Sociology of Health & Illness*, 34: 1215-1229. doi:10.1111/j.1467-9566.2012.01468.x

Vetrano, DL, Foebel, AD, Marengoni, A, Brandi, V, Collamati, A, Heckman, GA, Under, G. (2016). Chronic diseases and geriatric syndromes: The different weight of comorbidity. *European Journal Of Internal Medicine*, 27(C), 62-67.

ViBIS (2018) https://danskepatienter.dk/vibis/om-vibis/vores-projekter/det-brugerinddragende-hospital accessed march 1 2018

Vigh, H. (2008) Crisis and Chronicity: Anthropological Perspectives on Continuous Conflict and Decline, *Ethnos*, 73:1, 5-24, DOI: 10.1080/00141840801927509

Weaver, L.J., Barrett, R. and Nichter, M. (2016) Special section on comorbidity: introduction. *Medical Anthropology Quarterly* (30);4:435-441

Weber, M (1995[1905*]) Den protestantiske etikk og kapitalismens ånd*. Oslo: Pax [1905 Die protestantiske Ethik under der 'Geist' des Kapitalismus, Tübingen: J.C.B. Mohr]

Wensing, M. and Baker, R. (2003) Patient involvement in general practice care, *The European Journal of General Practice*, 9:2, 62-65, DOI: 10.3109/13814780309160404

Wentzell, E. (2013). *Maturing Masculinities, Aging, Chronic Illness, and Viagra in Mexico.* Durham: Duke University Press.

Wetzels, R., Wensing, M., van Weel, C. and Grol, R. (2005), A consultation leaflet to improve an older patient's involvement in general practice care: a randomized trial. *Health Expectations,* 8: 286–294. doi:10.1111/j.1369-7625.2005.00354.x

WHO (2015) Gender. Fact sheet N°403. August 2015 Available online: http://www.who.int/mediacentre/factsheets/fs403/en/

WHO (2017) http://www.who.int/ageing/active_ageing/en/ Accessed march 21 2018

Whyte, S. R. (1997). *Questioning Misfortune: The Pragmatics of Uncertainty in Eastern Uganda*. Cambridge: Cambridge University Press.

Whyte, S. R. (2005). Uncertain undertakings: Practicing health care in the subjunctive mood. In V. Steffen, R. Jenkins, & H. Jessen (Eds.), *Managing Uncertainty: Ethnographic studies of illness, risk and the struggles for control* (pp. 245-264). København: Museum Tusculanum.

Whyte, S. (2012). Chronicity and control: Framing 'noncommunicable diseases' in Africa. *Anthropology & Medicine*, 19(1), 63-74.

Whyte, S. R. (2017). Epilogue: Successful Aging and Desired Interdependence. In . S. Lamb (Ed.), *Successful Aging as a Contemporary Obsession: Global Perspectives* (pp. 243-247). Piscataway: Rutgers University Press.

Willadsen, T., Bebe, A., Koster-Rasmussen, R., Jarbol, D. E., Guassora, A. D., Waldorff, F. B., Olivarius, F. (2016). The role of diseases, risk factors and symptoms in the definition of multimorbidity - a systematic review. *Scand J Prim Health Care*, 34(2), 112-121. doi:10.3109/02813432.2016.1153242

Willadsen T., Siersma V., Nicolasdóttir D., Køster-Rasmussen R., Jarbøl D., Reventlow S., Mercer S. and Olivarius, N. (nd) "The effect of multimorbidity on mortality for prevalent combinations: a 15-year longitudinal registry-based nationwide Danish population study"

Wittink, M. N., Barg, F. K., and Gallo, J. J. (2006). Unwritten Rules of Talking to Doctors About Depression: Integrating Qualitative and Quantitative Methods. *Annals of Family Medicine*, 4(4), 302–309. http://doi.org/10.1370/afm.558

Wolff, J., Starfield, B. and Anderson, G. (2002)Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. *Archives of Internal Medicine* 162(20):2269-76.

Zhou, Y., Lundy, J., Humphris, G., & Mercer, S. (2015). Do multimorbidity and deprivation influence patients' emotional expressions and doctors' responses in primary care consultations?--An exploratory study using multilevel analysis. *Patient Education and Counseling*, 98(9), 1063-70.

Ziebland, S (2013) “Narrative interviewing” In *Understanding and Using Health Experiences: Improving patient care,* edited by S. Ziebland, A. Coulter, J.D. Calabrese, and L. Locock, Oxford, UK: Oxford University Press.

Ørtenblad, L., Meillier L. and Jønsson, A.B.R. (2017) Multi-Morbidity: A Patient Perspective on Navigating the Health Care System and Everyday Life. *Chronic Illness.* Ahead of print.

Overview of the articles

	Title	**Authors**	**Publications Status**
Article 1	The Robin. A Monologue of Aging with Chronic Conditions	Jønsson, Alexandra B. R.	Under review in *Qualitative Inquiry*
Article 2	How Older Men with Multimorbidity Relate to Successful aging	Jønsson, Alexandra B.R.; Ann Dorrit Guassora and Susanne Reventlow	Submitted to *Journal of Gerontology: Series B social sciences*
Article 3	Tuning Lives: Revisiting Health Inequities	Jønsson, Alexandra B. R.	Submitted to *Medical Anthropology Quarterly*
Article 4	The Unhealthy. An anthropologist's encounter with older people living with multimorbidity on Lolland	Jønsson, Alexandra B. R.	Accepted for publication in *Tidsskriftet Antropologi*, Vol. 77, special issue on ethics. To be published in Danish. (Original article in Danish, Appendix 1)
Article 5	What the doctor doesn't know: Discarded patient knowledge of older adults with multimorbidity	Jønsson, Alexandra B.R.; Susanne Reventlow; Morten Freil and Ann Dorrit Guassora	Under review in *Chronic Illness*

Article 1

The Robin: A Monologue of Aging with Chronic Diseases

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Abstract

In this article, I argue that an ethnodramatic monologue is a valuable method for producing knowledge that complements current research into living with chronic diseases. Inspired by discussions on ethnographic representations, I present a monologue of an older woman with chronic diseases. The monologue has been performed for a live audience, and several future performances are also booked, but this article is inasmuch an experiment on the textual presentation of a theatrical monologue. The protagonist is written up from three of my interlocutors from my doctoral anthropological fieldwork among the older with chronic diseases in rural Denmark. Drawing on my former training as a method actor, I have consolidated notes, interviews and observations to create a piece of art displaying my research. This article thus blends the genres of social sciences and the arts; building on the tradition of ethnographic theatre.

Introduction

In Didier Fassin's discussion of the boundaries between ethnography and fiction, his starting point is Marcel Proust's infamous quote about true life as "True life, life finally discovered and illuminated, the only life therefore really lived, is literature; *that life which, in a sense, at every moment inhabits all men as well as the artist"* (as cited in Fassin, 2014, p.40). Fassin argues, that the often overseen ending; *inhabits all men as well as the artist,* should be understood as a claim that each life lived possesses the traits of an artwork (Fassin, 2014, p.40). I have always been interested in portraying the life of the common man. Artistically, as a trained actress and academically, as a social scientist. This has until now been two separate spheres of my life however, so upon beginning fieldwork for my doctoral thesis on the everyday life of the older people with chronic diseases, I did not imagine that part of the product would end up being a monologue. I did, however, set out to investigate, put in a very basic way, why these older people with severe burdens of illness, who are stigmatized, financially instable, and socially rejected (Tyack et al., 2017; Rosbach & Sahl, 2017; Ørtenblad et al., 2017) simply did not consider suicide? This is a very strong statement in social sciences, but an interesting point-of-departure artistically, in line with the works of Eugene Ionesco, Jean Jenet, Jean-Paul Sartre and Samuel Beckett, just to mention a few. They are all characterized as writing 'absurd theatre' embracing existential philosophy by portraying the ugliness of a meaningless life. As in Beckett's "Waiting for Godot" (1965) a desolate hope accompanies Estragon's opening line to Vladimir: *"Nothing to be done"*. Yet, unlike Beckett's passive characters, my interlocutors turned out to possess agency and free will, and to stick to a world view that insisted on finding the positive in life. They were torn between keeping up their spirits and feeling the structural, organizational and social discrimination that detached them from their former lives and social worlds. How could I possibly portray these people, fragmented in academic theoretical articles and orbiting themes like gender and inequity that were not part of their own vocabulary? One of the most prominent writing icons, sociologist Laurel Richardson, remarks with self-irony that it tends towards narcissism to spend years on research that no one ends up reading and which makes no difference but to the author's career (Richardson, 1994, p.924). It made me reflect if we as ethnographers owe it to our interlocutors to expand our audience, making the knowledge accessible in other ways? The answer, I contend, was there as I turned to look into alternative forms of composing ethnography.

The ethnographic genre has been enlarged during recent years to include poetry, drama, autoethnographies and performances, just to mention a few. According to Richardson, distinguishing between 'creative' and 'analytical' would be wrong, as experimental writings are still valid representations of social life (Richardson, 1994, p. 930). While we in ‘traditional’ ethnographies put emphasis on the subjective nature of the findings, I subscribe to the claim of scientists that creative writings have the courage to display how the product is inseparable from the producer (Bochner & Ellis, 1996).

This article seeks to explore the medium of ethnographic plays by first framing the play in an academic context and elaborating on analytical aspects in the themes of the play, and secondly presenting the play in the pure manuscript form. I will not present an analysis of the monologue itself, as part of the experiment is to see how it, as raw material presented, is perceived. I wish not to predispose the reader by elaborating on how to understand the main character; my aim is to let the reader herself interpret and analyze the play. Thus I aim to use a theatre monologue as a *method of understanding* (Denzin 2014, 2017) lived life with chronic diseases.

Living with multimorbidity

Multimorbidity, at its broadest definition, means having two or more chronic conditions at the same time. The number of people living with multimorbidity is rising owing to better treatments and prolonged lifespans (van der Aa, 2017). Approximately more than half the population above the age of 65 has multimorbidity in the Western world (though numbers are rising in other parts of the world, too) (Koroukian et al., 2017). To people with low levels of education, managing and prioritizing several, sometimes conflicting, treatments is so difficult that they sometimes end up dropping out of treatment. Until this point, most research on multimorbidity has been biomedical or epidemiological - looking into causalities, compliance, representation statistics and how to plan treatment for this diverse group of patients (i.e. Moth et al., 2012; Salive, 2013). A few studies, including my own, have looked at multimorbidity in an everyday perspective, doing qualitative research on how and when relationships, priorities, work-life and quality of life are affected by multimorbidity (Ørtenblad et al., 2017; Jønsson, 2017a). However, all of the academic work produced on multimorbidity seems to be insufficient in describing the actual life of the older people with multimorbidity. Analytical approaches tend to enhance a particular theme in the material, intensifying a particular phenomenon of everyday life without much ado about the rest. This is a premise of traditional academic writing, but I was searching for a way to present my data without guiding my readers in a predetermined analytical trajectory.

The thing that most often characterizes a life with multimorbidity is the complexity. A complexity that cannot be described to the fullest with a specific focus on i.e. health inequities (Jønsson, forthcoming). I contend that I need to put forth the interplay of all these challenges and how they interact to truly represent my interlocutors. As such, I make a phenomenological approach in describing and letting the protagonist reflect upon embodied experiences. This is an approach that allows for taking emotions and physical symptoms into account as the mise-en-scène.

Cultural context

One thing, which one of the most prominent medical anthropologists, Arthur Kleinman, urged us to do, was to interpret the experience of disease and illness within a cultural context (Kleinman, 1988, p. 96). In order to fully understand the social distress caused by Betty having to decline the invitation to a family event we need to set the story within the Danish cultural notion of social activity as successful aging. Denmark is a social democratic welfare state with free access for all to health services, paid through taxes. Certainly, the welfare state relies on a certain kind of social contract - providing free care while simultaneously placing regulations on citizen's lives (Valgårda, 2013). Additionally, the generation of the baby-boomers have reach the age of retirement, and are starting to threaten the welfare system, which is not geared towards this rising number of patients. Much focus has been therefore on how to cope with the aging population (see further in Mikkelsen, 2016; Lamb, 2014; Boudiny, 2013). Still, the process of aging itself is subject to morally loaded discourses. This entails a senior life with social relations and an active social life as key to successful aging. Though some people resist such morally implied notions of how to age (Mikkelsen, 2016), the interlocutors in general mirror themselves in this discourse. In other words, they measure the success of their aging lives against particular ideas about how actively they participate in the community and how socially attached they are to family, friends and community. This means that not only does the protagonist Betty's decline of the invitation contradicts her own wish to participate and her family's expectations of her, it also entails moral implications of aging in a 'wrong' way. Betty's remark "*I don't want pity from anyone*" is an attempt to restore dignity and to self-present against social activity as resistance towards the discourse of successful aging.

Methods

The material used in the monologue was collected during my doctoral medical-anthropological fieldwork among older people with multimorbidity in rural Denmark. The fieldwork was carried out from February 2015 to August 2016 and consisted of participant observation, interviews and deep hanging out (Geertz, 1998). Situated in a specific socioeconomically deprived area of Denmark, I became a part of the local community. This allowed me to observe the interlocutors in various settings, in addition to meeting with most of them frequently. I spent time with the older people in their homes, at social events, and community fairs and observed their encounters with various health professionals. As the older people were eager to show me their life and introduce me to their relatives, I also got to know some of the interlocutors' spouses, adult children and friends. A few only spoke to me a couple of times, as they felt too exhausted and burdened to participate more than that. Ironically it was these interlocutors that made the biggest impression on me, as it was their lives and their feelings of hopelessness that drove me to portray what a life with multimorbidity is to some fragile, older people.

Ethnography as theatre

Richardson describe experiencing ethnography through *creative analytical practices* (CAP) which covers all work that has moved outside conventional social scientific writing (Richardson, 1994, p. 929). Choosing the drama as a form of expression provides the opportunity to reconstruct the sense of my fieldwork, and the everyday life of the older people I was following. It allows me to make conflicting voices be heard, to give a voice to the unspoken pain, and to portray embodied frustrations in an absurd staged melt-down - compounded by memories, senses and retrospect considerations. Theatre has throughout history always reflected the moral order of the surrounding society (Saldaña, 2003, p. 230-231). The drama as genre can display a multi-sited, emotionally meaningful representation that can recapture the experience and represent the individuals more than standard writings (Goodall, 2000, p.116).

Schechner, a theatre director, staged rituals of indigenous people to blur the boundaries between anthropology and theatre. He described six points of contact between the two disciplines, underscoring Victor and Edith Turners work on performing ethnography and emphasizing the (anthropological and cultural) importance of looking at the context of the performance, i.e. the rehearsals (Schechner, 1985). However, most contemporary ethnographic theatre comes with an educational use in the form of forum theatre, or constructed in other ways in collaboration with the participants. Mienczakowski points out how to use theater with the emancipatory purpose of providing insights and giving voice to the participants (Mienczakowski, 1995). By using the words, stories, and advice of persons with schizophrenia or alcohol dependency, his ethnographic theatre seeks a methodology to tell the truth as his interlocutors see it. Moreover, participants were involved in the creative process, through either commenting on the script or being presented with excerpts from the play. Torguet et al. (2013) discuss how to convey ethnography through theatre improvisations. Using the indoor climate in Denmark as starting point, they reveal how theatre can help facilitate the provocative role of ethnography that might be at play when presented to critical stake-holders. Goldstein et al. (2014) presented 30 questions that need to be asked when performing research-informed theatre. To them, research-informed theatre and performed ethnography are methods that turn ethnographic data and texts into theatre, drama, and scripts which are either read aloud by a group of participants or performed before an audience (Goldstein et al., 2014, p.1).

I differ somewhat from these, in my way of using ethnography as theatre. I adhere to Johnny Saldaña's definition: "*ethnotheatre employs traditional craft and artistically techniques of formal theatre production to mount a live performance event of research participant's experiences and/or researchers' interpretation of data for an audience*" (Saldaña, 2003, p.218). The interlocutors have not been involved in any sense in the design of the script; it is built upon my field notes and experiences from 18 months of fieldwork in rural Denmark. Though meant to be performed at conferences, hence the ten minutes format, it is also meant to be read in the pure form of a script, and not necessarily as Saldaña points out to be performed live. It is not intended to be performed for the participants or their peers, because although it is an artistic piece it is nevertheless written with an academic purpose. Bridging the academic genre and its print culture with the art of absurd theatre I create a play that presents anthropological findings. Thus, I can present complex anthropological knowledge to otherwise fairly infrequent readers of anthropological journals. I am (re)presenting a set of meanings to an audience both as a qualitative researcher and as an artist. Yet, I follow Saldaña's call for ethnodrama to be aesthetically pleasing and sound (Saldaña, 2005, p.31). In performing, I rely on my professional acting training and years of theatre experience, but as a written monologue I have enhanced the script with notes on movement and props, to insure that the text is interpreted in the mode I intended (Saldaña, 2005).

This approach was introduced in the health sciences in 1978 by Myra Bluebond-Langer, who wrote her monograph *The Private World of Dying Children* (1980 [1978]) partly as a theatre script. Bluebond-Langer uses both composite and individual characters; all based on her fieldwork among children with leukemia, their families and hospital staff. As the play unfolds we are shown how the children are aware that they are dying, but withhold this knowledge to spare their parents. Reading Bluebond-Langer was highly inspiring to me, though her script was never meant to be performed. Instead, she uses it in a traditional anthropological way as a piece of ethnography to which she refers her analysis.

I find that the monologue I have written can generate new questions and discussions by embodying the lived experience. It is thus an attempt to contribute to the understanding of older people living with multiple chronic conditions. It is meant to be performed, and now I turn to see in this article if the representation works as well in form of a printed manuscript.

Dramaturgical Considerations

The art of playwriting is not the same as creating a dramatic narrative, since ethnotheatre needs to employ the media and convention of a theatrical production (Saldaña, 2003, p.219-220). One of anthropology's grand old men, Victor Turner, has experience of merging theater and anthropology, together with friend and theatre director Schechner. Turner notes that anthropologists are not qualified to investigate acting techniques. Anthropologists focus on stasis rather than dynamics, and the context of the play rather than the performance as a relationship with the audience (Turner, 1985, p.xii). Here my background as an actor bridges these two areas of knowledge. I have acted professionally on stage and screen since the age of 13. As a young woman, I studied method acting at the Lee Strasberg Theatre Institute, and never imagined I would do anything else but acting until a rather tortuous trajectory placed me as an anthropology undergraduate in my mid-twenties. Nonetheless, my acting training has always served me well when doing fieldwork and presenting work at conferences. As Saldaña notes, theatre practitioners possess several skills that are prerequisites for qualitative research. As a trained actor, I have an enhanced emotional sensibility for understanding 'characters', thus seeing through the lens of my interlocutors' perspective. I have also gained years of experience in storytelling and plotting, which is useful in writing engaging narratives (Saldaña, 2003, p. 229). The last brick for staging myself as an actor-anthropologist hybrid was laid when a conference called for the end of 'boring conference-papers' and urged the presenters to make use of alternative methods. I turned to my past and performed an early version of The Robin. The reception was overwhelmingly positive. I was encouraged to refine the play and started to search the academic literature for inspiration. Initially, I came up with The Robin because I felt it expanded my possibilities for representing my interlocutors in a more holistic way. Consequently, I applied dramatically and theoretically informed analysis to the play afterwards. The dramaturgical considerations and applied analysis is therefore written partly in retrospect, but they reflect thoughts and contemplations from the very beginning of the process.

By setting it in the private life of an older woman with multimorbidity staged in a tragicomic everyday story I reveal the inspiration from Bertol Brecht. The dramaturgical use of tragicomic is a means to show the absurdity in Betty's life. Humor, then, is used to stress her social suffering and loss, yet the audience recognizes the exaggeration. It is a dramaturgical component of satire, which also helps creating a revue-like gallery, presented as 'types' (a representative of a group) rather than a specific character. It means that Betty is not to be taken necessarily as one specific person, but more as a representation for older women with multimorbidity in Rural Denmark. Another trait borrowed from Becket is sense and a state as the course of action, just like the clowns waiting for Godot (Becket, 1965). The Robin has no redemption and it illustrates the point of the inconsolable in living with multimorbidity. Another dramaturgical choice is when Betty speaks directly to the audience while the problems accumulate and she is paralyzed, as Becket's character Winnie in Happy Days (Becket, 1970), who just sits and talks throughout the play until she is buried in garbage. Such beautiful artistic ideas are not present in The Robin. Firstly because my talent cannot measure up to Beckett's, and secondly, because Betty still has to be recognizable. In order for the play to have the intended influence on an academic audience, it needs to balance the characterization and dramaturgical presented problems while still being plausible.

Every scene in The Robin is based on notes from fieldwork observations or interviews. Lines are directly transcribed from interviews, but are in some places worked on with an artistic purpose. Betty is a composite character which represents and speaks the collective realities of its original sources (Saldaña, 2011, p.17). It is thus neither fiction nor documentary, but something in-between. Doing ethnotheatre comes with an obligation to create not just an informative, but also entertaining experience for the audience (Saldaña, 2003, p. 220). As such, you cannot merely repeat what has been said in interviews: you need to creatively and strategically edit and select transcripts in order to maintain the full narrative that emerged throughout the fieldwork.

The Robin is meant to be performed as an approximately 10 minute monologue. It is a showcase of three women through a composed solo narrative revealing both personal and social insight. Using one actor for several parts, I am searching for the *verfremdung* effect of Bertol Brecht, as a means of forcing the audience to consider the drama by distancing the actor from the characters. Another way to enforce this is that the actor will be carrying a mask. It creates a distance that eases the transformation between actor and researcher, as the monologue is always presented as a research project and not a commercial piece of art.

Overall, the dramaturgical intention with The Robin is to present ethnography that portrays everyday life with multimorbidity, without analyzing or commenting on the material. Thus, it is up to the audience to interpret how we are to comprehend Betty's life. However, I must admit to a more underlying cause. I believe that we need a discursive showdown on the subject of social aging, and likewise more accurate support for the people with multimorbidity who wish to remain socially active despite their physical disability. I hope to change the current state of living with multimorbidity by creating and performing a text that will move and persuade people, especially policy makers and health professionals, to action (Denzin, 2013, p.391).

Ethical considerations

After my first performance of the monologue some in the academic audience raised the concern that I was writing three different female interlocutors as one character in my writing. This is both an artistic and an academic choice. Let us keep in mind that there is no such thing as an innocent textual staging (Richardson, 1994, p. 925), likewise in traditional written ethnography. Anthropology has addressed the issue of representation in onerous debates; some anthropologists think that we should never side with those in power, and that we need to offer alternative points of view from those prevailing in current societies (Vargas-Cetina, 2013, p.3ff). Other anthropologists believe our discipline needs to further the causes and enhance the lives of our interlocutors. In the past, anthropologists were representing the interlocutors not only by describing them in large books, but also through exhibitions and speaking for them at public audiences (Ibid.). It led to the representation crisis arising in the 1980s, forcing anthropologists to decide that there was no more need for anthropologists to act as representatives of other people. But given that anthropology is still a representational discipline in giving meaningful depictions of the world, what are the implications of our ethnographic presentations? I will make the argument that questioning the ethical considerations of ethnographic theatre reflects an implicit understanding of traditional ethnographic representation as 'true', and intrinsically authentic. An understanding that I believe most anthropologists would refrain from. Our knowledge production is always subjective, so why object to writing three actual persons as one fictional person? I assume the key is in the author's claims in the text. Yes, it would be a serious misrepresentation if I said that the monologue is a direct translation of an interlocutor's life. This is, however, not the case. The play is in its etymological meaning involved in a silent conversation with fictive works of great playwrights. It does deal with real peoples' real experiences but it is presented in a fictive way to highlight the disjunctions in the women's everyday life. I have consolidated notes, interviews and observations to combine life vignettes, insights and epiphanies; creating a plot and a storyline that fits the theatrical format (Saldaña, 2003, p. 221). Ethically, this fictive turn and combining the personalities of three women secures the level of anonymity when presenting intimate details of local people in their own culture. Bearing in mind that my fieldwork was done 'at home', and that one of these women could very well attend a performance of mine together with friends or relatives. Neither the women nor the relatives should be able to recognize and identify the women. If they were to do so, I would have broken my promise to make sure that the information they gave me would not be traceable. There might be different opinions on this, but for me writing the three interlocutors as one using direct transcripts from our interviews and observations is the ethical choice.

The Robin

Main character Betty, a 68 years-old woman suffering from Parkinson’s disease, arthritis, diabetes and a rare blood disease. A sturdy woman of great vitality with a characteristic tremor in her hand and stiffness in her movements. Her characterization must be carefully created not to become a parody. She has endurance, and as her suffering makes her unwittingly self-reflecting, she encompasses a fragile tenderness and also a cruel bitterness.

Scene 1.

Betty’s living room. One of those heavily furnished rooms displaying a former life through pictures of grandchildren and carefully selected bric-a-brac. Centered is an out-of-style heavy armchair and tiled table in the cheap uniform quality that is common in the working class homes. Front stage stands a walking frame, props hidden underneath. Betty is sitting in her chair at the rise of the curtain, she is sipping coffee and, slowly, looks out of the window (an open frame) and starts talking as if she was answering a question

BETTY

Well, it all began in 1989 when I was diagnosed with diabetes. I had nearly died, you know? But then I started working again, at the post-office. And everything was fine until a few years before my retirement. I started having trouble sleeping, and my face was sometimes…I looked like I was wearing a mask. Turns out I had Parkinson’s disease. Then soon after they found out I had arthritis, right here, in my collar bone (*lightly*) I mean, I’ve never even heard of that. Who has arthritis in their collar bone? So. I went in and out of hospitals at that time, and then my legs started swelling, that was the blood disease I told you about. Only one in 100.000 has it! Yes. I think that’s it, that’s the diseases I’ve got.

Betty gets up from the chair, comes front stage to demonstrate

BETTY

(cont.) There's so much I have to do. I have to do 100 of these (*shows arm movement*) and 100 of these (*sits on walking frame, lifts one leg at a time*). And all the meds I have to take. I don't need any help, I am organizing them by day and time myself. And of course I have to eat a specific diet for the diabetes, but my husband Kirk and I, we don't really believe that. See, my fridge is full of cheese and bread and juice and cake, and I am doing fine. To be honest, I'm not doing all of the exercise either. I mean. I know it helps, I know it does. But I just don't get around to do it. I know it's stupid, you must think I'm really stupid, but I keep forgetting. Maybe it's because I feel so bombarded by the things I have to do. Physiotherapy twice a week, it takes up all my energy. I fall asleep on the bus on my way back. I am so tired, I can't stay awake. I even sleep when I watch TV. I don't know but maybe it's being resistant that takes my energy. And it's so confusing, all the things I have to do, I don't know which is most important. It really confuses my head. My GP, he listens and listens, and is so and so understanding and empathic, but what can I use that for? I need him to ACT. I needed HIM to call the hospital. I can't get through but he could do something, he could help me find a way in this, sort it out. But they all make it even worse

Scene 2.

Scene is memory and is formed as absurd theatre using different voices and children costume props to illustrate characters.

Betty takes a stethoscope and a nursing ornament from underneath the walking frame. She stands in turn on the right and left side of the armchair. Shifts voice and prop with character. The scene is intended *to leave a very chaotic impression and should be performed non-realistically.*

DOCTOR 1

The patient is expected to experience severe loss of physical functioning due to the progressiveness of the disease. Here, take a pamphlet *(throws pamphlet at chair)*

DOCTOR 2

The patient must adhere strictly to the treatment plan or she will suffer from septic shock. Please read and adhere *(throws pamphlet at chair)*

NURSE

Don’t forget that we always work patient-centeredly

DOCTOR 1

The patient seems unable to grasp the severity of the disease and the utter importance of resting daily *(throws pamphlet at chair)*

DOCTOR 2

You need to understand that if you don’t do your exercise every day you will soon lose all mobility *(throws pamphlet at chair)*

NURSE

She doesn’t understand. (*goes behind chair, pats the invisible Betty on the shoulder*) There, there now. I hear your frustration, but you need to understand that the Doctors are very busy people and from what you’re telling me, your symptoms are not severe enough to get an acute consultation.

Yes, I know we have three months of waiting lists for regular consultations, but really, there’s nothing I can do. Okeydokey, now cheer-up. You’re doing fine.

DOCTOR 1

Who gave you these tablets? They can kill you, you need to stop immediately!

DOCTOR 2

Did you stop with the tablets? If you don’t take them you could very well end up dead!

NURSE

Now, we have committed ourselves to involving patients at this ward, so can you please tell me on a scale from 1 to 5 how much better you feel now compared to before treatment?

Scene 3.

Betty, now back in character throws away the doctor and nurse props. She screams, her scream melts in with Verdi’s Messa Da Requiem:Dies Irae, Dies Illa. As the music fills the stage, she is doing a choreographed meltdown ripping up pamphlets; she is suddenly young again, filled with powers and rage. When the music stops she lies down on stage.

BETTY

(*From the floor)* I would never tell my daughter how I truly feel. *(Slowly raises)* Why should she be burdened with that? She has enough worries already.

Betty brushes off as she stands up, walking to the front stage, picking up a dish brush and starts washing a glass. This is a symbolic act and should not resemble real cleaning; the movements are exaggerated, constant.

BETTY

When I first met Kirk the diabetes wasn’t really a big thing. I took my meds and lived on. It was after my first husband had passed away. That I met Kirk I mean. But then the Parkinson’s and all the other things came around. I sometimes feel like I’ve cheated. Like I’m not the wife that he chose to marry. He doesn’t really get how little I can actually overcome. Then he starts complaining that he has to do all the cleaning and grab water for me all the time because I get so thirsty. I don’t want him to leave me. I can’t afford that, if he is not around there’s no other way than me going to one of those public nursing homes. I can’t bear the thought of that. So I keep him pleased the way I can. I do the dishes, I bake cookies, I make pickles and jam and I cook good old fashioned meals. It’s really bad for my arthritis to do this *(holds her hand like she is doing the chores)* but really, that’s my only option. I have to always figure out what is most important.

Betty returns to her chair, picks up one of these old-fashioned pocket calendars

BETTY

I had to decline the invitation for his granddaughter’s birthday party. I don’t have the energy. I know it’s hard for his family to understand.

Betty voices the other characters in a high-pitched marking tone.

KIRK’S DAUGHTER IN-LAW

Did you hear that Betty isn’t coming? I can’t believe how selfish that woman is, that birthday party is so important to Emily

FRIEND
Why? She seemed fine last time I saw her

KIRK’S DAUGHTER IN-LAW
I think it’s a matter of motivation. She obviously doesn’t care about our side of the family

FRIEND
If she really feels that bad, can’t she just go and rest somewhere and then come back?

BETTY *(back in character)*
Leave in the middle of dinner to go rest? How would YOU feel about that? I don’t want to take away the attention from Emily, it’s her day. And I don’t want pity from anyone

Betty sees someone she knows. She gets up, start waiving at them. The scene is memory.

BETTY
Alison? Aliiisooon? *(Runs a few steps, out of breath, looses her cane, walking a bit like she’s drunk, talks in a drawled manner)* Oh, hi Alison. How are you? I just wanted to say hello. How are the kids? Oh me, I’m fine, everything taken into consideration, everything is fine. I’m just, I’m a little late with my meds today, so I’m experiencing a bit of a challenge here *(to the audience)* She thinks I’m drunk. I’m not, I forgot my pills this afternoon. *(To Alison)* Maybe you could come by some day for a cup of coffee? I really want to

show you the new handicrafts I've been working on. Yes, I know, you're busy, a grandchild takes up so much of your time. Maybe next week then? Ok, call me. You'll call me right? *(to audience)* She never did. Like most of my friends. Maybe they can't stand all the diseases. Maybe seeing me reminds them that they themselves are old and sick.

Betty picks up her cane. She walks the stage slowly as she talks. When she comes to the part about the Robin she uses her hands to make it visual to the audience.

Scene 4.

BETTY

I have these experiences at night, it is like I am sitting next to myself. That period when I had to pee all the time. I was drinking water and then peeing. Drinking and peeing. All night. I peed, I don't know, maybe 10 times a night. Then I had a feeling like I was just pouring water in to this sheet and it poured right out. I told myself it wasn't me, and then suddenly it felt like I was hovering under the ceiling and was looking at a sheet. One night, Kirk was at his son's house up north, he was staying overnight and I woke up during the night, looking down on myself. I was so terribly afraid. I called the health department in town, I told them, I'm hallucinating and I am very afraid, but they told me they couldn't just come around to check on me. I have never felt so alone. I also get these weird impressions. The other day I was sure that two Bosnians were interviewing each other in the attic. I knew it wasn't true, but I went up anyways to check, I don't know, maybe there was a radio or something. Nothing. That's the reason I can get a higher dose of medicine. But I don't tell them about the hallucinations, because then they will take away my meds. So I have learned to accept seeing things that aren't real. And then there was

> the Robin. It was right here in this room, on that rug. It matched so perfectly well the Persian colors and patterns. I thought, this bird, I knew it wasn't real, but it felt like it had come to comfort me. And then the strangest thing happened. The Robin had sat completely still but then it just flew out the open window, it had been real all along. One day, I thought, I too, will be flying out an open window.

Betty raises from the chair, she goes to look for the Robin outside the window, front audience. Slowly Mozart's Requiem in D minor, XI starts playing. Betty puts her hands on the window, she seems captured, the frame becomes bars and that is how we leave her: imprisoned by her multimorbidity.

THE END

Conclusion

In contrast to traditionally written ethnography the ethnotheatre brings forth the experience. The reader and/or live audience get a sense of the pressures of living with multimorbidity, rather than being told how to analytically grasp such pressures. Similarly, it highlights the experience of suffering, navigating, prioritizing, struggling, succeeding and failing, that altogether could be termed polyvocal emotional experiences (Görlich, 2016, p.532). When performed for a live audience the responses showed curiosity and were mostly positive. As already mentioned, some raised ethnical concerns about the dramatization of fieldwork material. However, in general, medical doctors were intrigued and have booked performances for research meetings and seminars to come. Anthropologists though, found it a little harder to accept the implied criticism of the inability of written ethnography to portray lived life -a critique, albeit, that I never intended. After the performance, the feedback mainly centered on the advantages on 'getting to know' a character, not just bits of transcripts used in articles. Lastly, one raised the question if I could have done this had I not been an actor prior. I contend, that ethnotheatre should be performed by a professional group, because a bad performance of an otherwise serene piece can still ruin the audience's experience (Saldaña, 2011, p.17). This call for collaborations between theatre professionals and ethnographers, which in my belief would bring forth a beautiful collection of easily accessible knowledge to peers as well as the public.

As this article is an experiment in itself I cannot conclude on whether the monologue as a written text fulfills the purpose of a holistic and deep description of lived life with chronic diseases, but I can hope for responses from the community of researchers blurring disciplines and experimenting with genres. However I must stress here at the end that the performance of the monologue is also a product of the commitment I made to change the world for the fragile older people I have come to know through my fieldwork. Performing for an audience of medical scholars that would not usually engage with anthropological literature I have the chance to make an actual emotional impression and prepare policy makers and health professionals to be more responsive to older people with multimorbidity. I thus follow Norman Denzin’s call (2016) to be involved in developing new methodologies for representation with the hope of social justice.

References

Van de AA, M.J., van der Broeke, J.R., Stronks, K. & Plochg, T. (2017). Patients with multimorbidity and their experiences with the healthcare process: a scoping review. *Journal of comorbidity.* 7(1),11-21

Beckett, S. (1965). *Waiting for Godot*. London: Faber & Faber

Becket, S. (1970). *Happy Days. A Play in Two Acts.* New York: Grove Press

Bluebond-Langer, M. (1978). *The Private Worlds of Dying Children.* Princeton: Princeton University Press

Bochner, A. and Ellis, C. (1996). Talking over ethnography. In: Ellis, C & Bochner, A (eds) *Composing Ethnography. Alternative Forms of Qualitative Writing*. USA: AltaMira Press

Boudiny, K. (2013). 'Active ageing': from empty rhetoric to effective policy tool. *Ageing Society,* 33(6), 1077-1098

Denzin, N. (2013). Performing methodologies. Qualitative Social Work 12(4), 389 – 394

Denzin, N. K. (2014*). Interpretive autoethnography* (2nd ed.). Thousand Oaks, CA: SAGE.

Denzin, K. (2016) Critical Qualitative Inquiry. *Qualitative Inquiry* 23(1), 8–16

Denzin, N. K. (2017). *Performance [auto] ethnography: Critical pedagogy and the politics of culture,* 2.e. New York: Routledge.

Fassin, D. (2014). True life, real lives: Revisiting the boundaries between ethnography and fiction. *American Ethnologist,* 41(1), 40-55

Geertz, C., (1998). *Deep hanging out.* The New York review of books, 45 (16), 69.

Goldstein, T., Gray, J., Salisbury, J. and Snell, P. (2014). When Qualitative Research Meets Theater: The Complexities of Performed Ethnography and Research-Informed Theater Project Design. *Qualitative Inquiry,* 20(5), 674-685

Goodall, H. L., Jr. (2000). *Writing the new ethnography.* Walnut Creek, CA: Alta Mira

Görlich, A. (2016) Poetic inquiry: understanding youth on the margins of education. *International Journal of Qualitative Studies in Education,* 29(4), 520-535

Jønsson, A. (2017a). Empowering older with chronic diseases can optimize their treatment. *Fox International Fellowship 2017 Policy Brief Series*. https://foxfellowship.yale.edu/sites/default/files/files/Joensson.pdf

Jønsson, A. (forthcoming). Tuning Lives: Revisiting Chronic Diseases and Health Inequities. Submitted to *Medical Anthropology Quaterly*.

Kleinman, A. (1988). *The Illness Narratives. Suffering, Healing and the Human Condition.* USA: Basic Books

Koroukian, S.M., Schiltz, N.K., Warner, D.F., Sun, J. Stange, K.C., Given, C.W. & Dor, A. (2017) Multimorbidity: constellations of conditions across subgroups of midlife and older individuals, and related Medicare expenditures. *Journal of comorbidity* 7(1), 33-43

Lamb, S. (2014). Permanent Personhood or Meaningful Decline? Toward a Critical Anthropology of Successful Aging. *Journal of Aging Studies* (29), 41-52

Mienczakowski, J. (1995). The Theater of Ethnography: The Reconstruction of Ethnography into Theater with Emancipatory Potential. *Qualitative Inquiry*, 1(3), 360-375

Mikkelsen H. H. (2016) Unthinkable Solitude: Successful Aging in Denmark through the Lacanian Real. *ETHOS: Journal of the Society for Psychological Anthropology*. 44(4), 448-463.

Moth, G., Vestergaard, M. & Vedste, P. (2012) Chronic care management in Danish general practice – a cross-sectional study of workload and multimorbidity. *BMC Family Practice* (13), 52

Richardson, L. (1994) Writing. A method of Inquiry. In: Denzin, N. and Lincon,Y. (eds) *Handbook of qualitative research* . Michigan: Sage Publications, pp. 923-948

Rosbach, M., & Andersen, J. S. (2017). Patient-experienced burden of treatment in patients with multimorbidity – A systematic review of qualitative data. *PLoS ONE*, 12(6), e0179916.

Salive, M. E. (2013) Multimorbidity in Older Adults. *Epidemiologic Reviews*, 35 (1), 75–83,

Saldaña, J. (2003). Dramatizing data. *Qualitative Inquiry*. 9(2), 218-236

Saldaña, J. (2005) *An anthology of Reality Theatre*. Walnut Creek, CA: AltaMira Press

Saldaña, J. (2011) *Ethnotheatre: Research from Page to Stage*. UK: Routledge

Schechner, R. (1985). *Between Theater and Anthropology.* Philadelphia: University of Pennsylvania Press. Pp. 3-33

Torguet, R., Friis, P. and Buur, J. (2013). User Ethnography as Theatre. *Participatory Innovation Conference. Track II: Design Anthropology and Social Innovation*, pp. 213-221

Turner, V. (1985). Foreword. In: Schechner, R. *Between Theater and Anthropology*. Philadelphia: University of Pennsylvania

Tyack, Z., Kuys, S., Cornwell, P., Frakes, K-A. & McPhail S. (2017) Health-related quality of life of people with multimorbidity at a community-based, interprofessional student-assisted clinic: Implications for assessment and intervention. *Chronic Illness* ahead of print

Valgårda, S. (2017). *Sundhedspolitik: Teorier og analyser*. (1 udg.) København: Munksgaard

Vargas-Cetina, G. (2013) Introduction: Anthropology and the Politics of Representation. Vargas-Cetina, G. (ed.) *Anthropology and the Politics of Representation* .Alabama: University of Alabama Press

Ørtenblad, L., Meillier, L. and Jønsson, A. (2017) Multi-morbidity: A patient perspective on navigating the health care system and everyday life. *Chronic Illness*. Ahead of print.

Article 2

How Older Men with Multimorbidity Relate to Successful Aging

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Introduction

Successful aging has been a key agenda for policies regarding older people since the late 1990's, encouraging individual maintenance of physical and social well-being as moral obligations (Lassen and Jespersen 2017; Lassen and Moreira 2014). Successful aging also appears under related labels as "active aging" or "healthy aging," building on the seminal work of Havighurst (Havighurst 1961), and Rowe & Kahn (Rowe and Kahn 1997; Rowe and Kahn 2015). To Rowe and Kahn, individual agency and independence is core to the successful aging project. Their MacArthur model encompasses three principal components for the individual to act on: maintaining a low risk of disease and disability; maintaining one's mental and physical functioning; and engaging in life (Rowe and Kahn 2015). Inasmuch, paradigms of successful aging turn discourses of aging as a natural process of decline upside down, and stresses health and well-being as essential components of how to age successfully.

The power of individual agency is emphasized in the vision of successful aging. Such a vision resonates with notions of responsibility and the ideal of independence favored in Denmark as well as in many other countries in the Global North. Denmark, an affluent welfare-state, provides tax-financed social services and health care with free access to all citizens, known as the Nordic Model (Lassen and Jespersen 2017). However, the rise of the aging population challenges the Nordic Model, and reforms and initiatives have been launched to reduce the use of services. Consequently, an aging policy focusing on independence and responsibility for one's own health has emerged (Lassen and Jespersen 2017). According to the dominant discourse, citizens not only have the capacity but also the moral obligation to maintain and improve their health (Kristensen, et al. 2016). This constitutes neoliberal notions of personhood (Lamb 2014), where adult personhood is closely tied to one's ability to manage independence and autonomy (Kroijer and Sjorslev 2011).

The concept of successful aging is not without critics, however. Firstly, researchers have pointed towards the individual notion of successful aging as being subjective and fluctuating within different cultures (Feng and Straughan 2017). Secondly, older adults unable or unwilling to engage in the ideal of successful aging are perceived as burdensome and portrayed as irresponsible (Lassen and Jespersen 2017; Mikkelsen 2016). In the critique of the latter, the prevailing successful aging paradigm is found to be profoundly ageist, displaying human conditions as frailty, vulnerability, and dependency as the opposite of success; that is, signs of failure (Lamb, et al. 2017).

To the participants in this study, the successful aging ideal may become even more remote as they suffer from multimorbidity, having at least two chronic diseases (van den Akker, et al. 1996). Multimorbidity comes with several, often intricate, treatments, and it often results in difficulties in navigating and managing treatments and self-care (Bayliss, et al. 2003; Rosbach and Andersen 2017; Ørtenblad, et al.).

Matters of gender also affect health (Mahalik, et al. 2007; O'Brien, et al. 2005; Sen and Ostlin 2008). Since the late 1990's, gender-relation theory scholars have suggested that hegemonic masculinity is a significant factor for male health inequities (Courtenay 2000; Mahalik, et al. 2007; Sen and Ostlin 2008). For instance, it has been argued that social practices like risk behavior and delayed reactions to symptoms are tools for performing masculine ideals owing to a notion of hegemonic masculinity that places the whole arena of health in a feminine sphere (Cameron and Bernardes 1998; Courtenay 2000). It has also been argued that performing this hegemonic masculinity causes the majority of men to access health services less frequently than women, and that consequently their health is poorer (Courtenay 2000; O'Brien, et al. 2005). Studies have shown that men conceptualize manhood and health as interconnected goals, and define health broadly and in alignment with other aspects of life (Farrimond 2012; Griffith, et al. 2016; Ravenell, et al. 2006). Although this may be true to some degree, it is also a stereotype that oversimplifies health behavior and presents men as a homogenous social group (Griffith, et al. 2018). For instance, in a Danish setting, a study showed men to cope with cancer by being persistent and outgoing in searching for help and talking about their disease (Michaelsen and Kristiansen 2017).

Gender is, however, interesting in intersection with age. Although it is being argued that older men's health is closely linked to gender and perceptions of masculinities (Courtenay 2000), little is known about how older, chronically ill men relate to the concept of successful aging. Independence is a core value of successful aging, yet when the older men's notion of independence as a masculine trait stresses one's sovereignty, it is often perceived by health authorities as a health-damaging concept; associated with avoidance and ignorance about health (Smith, et al. 2007). This generates a query towards how gendered expectations to health care come into play when it relates to the older generations.

In this article, we examine how older men with multimorbidity relate to successful aging. By doing so, we aim to bring about an insight into the key elements of what creates subjective notions of successful aging. Among these notions are the gendered expectations, social engagement, and health practices. The present paper is part of a larger study on the everyday lives of older, chronically ill Danes on a low-income. This paper's particular focus on exploring the men's perception of successful aging, specifically, was formed by the consistency of the male participants referring to their gender when reflecting upon health practices, but the main study also entails female key interlocutors.

Methods

This ethnographic study focused on older men and women with multimorbidity, living independently on the island of Lolland, Denmark. Fieldwork was carried out from February 2015 to August 2016 by the first author. The study was reviewed, and approval was granted by the Danish Data Protection Agency (#2015-41-3826). Informed consent was given verbally in connection with recruitment. In this pap, we focus mainly on the results and discussions of consecutive interviews and field notes from observations with the seven participating men, aged 66 to 84, retired, and living with multimorbidity. The female participants add to this study by virtue of their underlying presence in the analysis, as their lack of gendered explanations in aging and health makes the men’s reference to gender stand out. On one occasion, we draw on material including a female interlocutor, married to a male interlocutor.

Setting

The study was conducted on Lolland, a sociodemographically deprived area of Denmark. Being the fourth largest island in Denmark, Lolland is inhabited by approximately 60.000 people, the mean age being among the highest in the country. 45 % of the population suffers from more than two chronic conditions (Poulsen, et al. 2013).

Recruitment

The inclusion criteria for participants were that they had to be 65 years or more, and that they had to have two or more chronic conditions requiring ongoing medical attention. The first selection of participants took place through observations in consultations with GPs, where they had agreed to the first author being present and subsequently contacting them. They were called by phone within the following week to ask if they were interested in participating in the study. The second round of selection happened more gradually, as health workers suggested further potential participants. If these people met the inclusion criteria, they were contacted by phone, and an interview was scheduled. Nine men and eight women were contacted, out of which seven men and seven women, aged 66 to 90, with three to six chronic conditions each, agreed to participate. Two men and one woman declined based on lack of energy or time. Information about the study was given to participants during the initial recruiting and again before the first interview. All participants were guaranteed anonymity and confidentiality.

Participant Characteristics

Table 1 shows background characteristics of the men participating in the study. They all came from an ethnically Danish background. This was not an inclusion criteria but a coincidence, partly expected because of the demography where the majority of the population (87.5 %) are of Danish ethnicity. The participants all had a self-reported low income, having state pension as their only financial support. The influence of the social class will be discussed in the strengths and limitations section.

Study Design

The first author, a trained social anthropologist, conducted an ethnographic fieldwork following the men for a six to eighteen month period, depending on when they joined the study. After a participant's consent, the study started with an individual narrative interview (Ziebland 2013), which would take between one and two hours, using the participant's narrative to understand their medical history and life experience. In the following months, two to six follow-up, semi-structured interviews with each participant were conducted, taking from 30 minutes to two hours. In addition, several informal interviews and talks were conducted in person or by phone. Using a flexible interview guide, participants were interviewed about the following topics: background, development of diseases, ongoing treatments, social relations, good and bad experiences with health services, hobbies, food habits, and attitudes toward aging, health, and self-care. All interviews were conducted in the participants' private homes. The fieldwork also included participant observation, as the first author took part in social arrangements, doctor's appointments, and started playing in the local brass band along with several of the participants and their friends. This provided an opportunity to observe the participants' social connectedness and interactions. In general, the men were very keen to share their experiences with the researcher.

Data analysis

All recorded interviews were transcribed, fieldnotes were written according to memory at the end of the day. Data were analyzed abductively: Abductive analysis is appropriate to identify new patterns of meaning and to enrich theory through the process of constant revisiting data and theory, defamiliarization, and alternative casing (Timmermans and Tavory 2012). The authors first read the transcripts and notes thoroughly and marked the keywords. A summary of the participants' gender, age, diseases, education, and civil status was made. Then the transcripts and notes were coded using NVivo. In order to obtain a deeper understanding of the data, the codes were divided into sub-codes, and patterns of meaning emerged. These patterns were discussed and reflected upon. One of them, the role of gender in health, enforced by the men when asked about health practices, social relations, and aging, was considered a major part of the men's experience, and became basis for this article. Parts of transcripts could have more than one code assigned (for example, both 'masculinity' and 'care seeking'). Subsequently, more detailed analysis was undertaken by the first author who repeatedly revisited data and theory. For this paper, we examined responses to

1. How do you experience the process of aging?
2. What relations do you have, and what do they mean to you?

Distinct quotes and observations that answered these questions were coded together with contextual details that might influence the content of the data. We used the abductive approach to identify concepts and associations of health and aging and possible theoretical understandings that may explain how older, chronically ill men on a low-income in Denmark relate to health and aging.

Results

The men in this study answered the questions on social relations and managing multimorbidity in a way that maps onto the core components of successful aging. Still, they did not fit current perceptions of successful aging and instead gave alternative, gendered interpretations of the life they aspired for, being older men with multimorbidity. We organized the results with the inclusion of nuances found in the men's attention to successful aging; gendered expectations; social engagement; and health practices presented by selected cases and quotes.

"Aging as a man"

James was a retired house painter in his early seventies, living alone in a small town house after having been widowed some years ago. One day during the fieldwork, the first author and he got into a conversation on aging. When asked directly how he experienced the process of aging, he answered, *"It's different for men, you know. Yes, you grow older, but you're still a man; still strong and the one that helps out with practical issues."* This expression coined what the men all experienced; that it was not just a matter of aging, but of aging as a man. Being an older man came with the same gendered expectations that they had had of themselves as younger men, and which were sometimes difficult to fulfill with their current physical capabilities, living with multimorbidity.

Particularly gendered expectation was connected to independence. For example, Douglas, an 84-year-old man, stated that it had been his wife who had managed the household health. When he was widowed, he was left for the first time with a responsibility that he had never encountered before: "*I have to keep track of all the pills, three times a day I take pills, and then I have to remember doctor's appointments and check-*ups. […] *it's a lot of work. But, I'm a grown man; I can take care of myself.*" This sort of independence supports the societal focus on healthy aging where taking responsibility for one's own treatment is considered the ideal health behavior. However, another type of independence was also stressed by the interlocutors; a sort of sovereignty, being able to make decisions on one's own behalf, including resisting certain treatments and advices. Aaron, a 72-year-old man suffering from late effects of polio along with several other chronic conditions, continued smoking and drinking five to ten beers a day despite strong warnings from his doctor. He said this was him being independent and explained, "*I do what I think is best, and that's not necessarily what the doctor says. So I am supposed to take these little white pills for pain, but they make me feel nauseous, so I just don't. Who's better at deciding that than me?"* Louis coined it like this, letting out the visitation officer from the municipalities who had been visiting, "*I'm an adult. I don't need people like her* [visitation officer] *to tell me how to live my life. You* [ethnographer] *said you wanted to know about the good life in old age? I have one word for you: independence!*"

Independence was a concept both men and women praised and regularly brought up in conversations about the good life as an older man. It was, however, not always possible for them to be fully independent due to their chronic diseases, and instead it was referred to as being "in control," a control which was acted out, for instance, when Paul, one leg amputated, spent his savings buying an electric scooter to transport himself to the pub.

Values of aging as a man were sometimes visible in encounters with the ethnographer, a younger woman. For instance, when the men wanted to enforce their physical strength. One afternoon she offered to help carry the groceries home, but Douglas refused, saying, "*No way I'm letting a little girl carry my bags. Do I look like a jelly bean to you? I will be carrying my own bags right down to my coffin* [laughing]."

Successful aging and social engagement

When asked about relations, the older men described different aspects of their social engagement. The capability to maintain social relations, though regarded as important for life quality, was presented by the older men as a particularly rare talent for a man. Henry, a widower with several diseases including diabetes, a blood disease, and prostate cancer, explained during one of the ethnographer's visits how difficult life had become without his wife:

> "*Well, I lost my wife about a year ago, so well, when you're invited out for something, it's ok, you know, but at home, it can be a little monotonous. We used to dine occasionally with Michael and his wife, but it rarely happens now that I'm alone. I don't know why, I just can't call and ask friends over a Friday or Saturday night. My wife used to handle that, I don't know why, I just can't.*"

Henry attributed gender into keeping up social relations as an inherent female character trait by explaining for the different roles he and his wife had had.

However, the men enforced their social engagement and masculinity through interests and hobbies that they considered masculine, for instance hunting. Peter, a 66-year-old retired factory worker, played hunting horn, which allowed him to join the hunts at the manors, an exclusive club, as the horn blower. When the ethnographer asked Peter if his wife had been hunting, he laughed and said, "*no, no, hunting is not for women.*" To him, participating in hunts was a core value in his life, and it was intertwined with successful aging. He said, "*The most important thing for me, as I get older, is that I will still be able to participate in the hunts. The day I'm unable to do that, I might as well just lay down and die.*" This was a common concern; growing old and suffering from multimorbidity made it difficult to maintain the social engagement, and the men of this study were forced to prioritize. Peter explained that, because he suffered from fatigue, he had had to choose between horn lessons or attending a cooking class for older adults with diabetes. He had wanted to learn how to cook, but the horn lessons were pivotal for his role in the hunts.

All the interlocutors had diverse forms of self-initiated social engagement; some went to enjoy the company and a few beers at the local pub, others enjoyed their hobbies, and one preferred the company of his wife. These kinds of social engagement were articulated and presented as being the essence of what these men had been looking forward to spending their retirement years on. On the other hand, the social engagement organized by the municipality was regarded with skepticism. James was always present at band rehearsals, but he refused to take part in the activity program that the municipality had presented to him: "*What would I be doing there? I don't need to join a conversation club, I'm not a woman,*" he stated, thus referring back to engaging in social relations as a female character trait.

Health practices

The topic of health practices was part of the aging process because of the men's multimorbidity, which required them to adhere to a number of treatments and self-care plans. Our study participants had different ways of relating to the care that their diseases required. To the participating men, following treatments and managing self-care were mainly a question of tailoring and prioritizing what would be possible. They expressed notions of aging successfully with multimorbidity as a matter of finding the right balance between engaging in treatments and not interfering too much in everyday life by continuing to live as they had always done.

In social settings, such as a band rehearsal or a holiday celebration, some men would ignore their treatment plans, explaining that they did not want to cause trouble asking for special diets. Bob explained, "*We have "recess-cake" when rehearsing, that's a tradition. I'm not going to change that.*" Other men, like Peter, explained their lack of medically defined healthy behavior with self-ironic, gloomy forecasts: "*At my age, death is knocking - might as well have fun, right?*" Hence, treatment adherence became the opposite of what was considered fun. The women, who, on the contrary, were careful to keep their sugar intake at a minimum, if for example they had been diagnosed with diabetes, did not make such statements. Yet, Peter was a member of the diabetes patient organization, a firm reader of their magazine and trying to keep up with new treatments: "*Being a member gives me a lot of great info, and then I can sort it myself,*" he explained.

Some men did also express gendered perceptions in relation to their health practices. Especially when treatments or healthcare advices were in opposition to how a participant lived, such health behavior would be explained in regard to gender. James described his eating habits as 'traditionally Danish,' meaning fatty, high cholesterol meals. He had been advised by his doctor to eat a more healthy diet with less sugar in it, and during a home visit, where Danish pastry was side to the coffee, he was asked by the ethnographer why he was not adhering to this. He shrugged his shoulders and said, "*I guess I'm not that good at taking care of myself. I guess it's because I'm a man. Women, you know, they are a damn sight better at this than men. They know what to eat and stuff, and they always talk to each other and check up on one another. Men don't know how to do that.*" When the men compared their health behaviors to those of women in general, they stressed that women were superior in living a healthy life because of the traditional gender roles that most had been brought up with: traditionally, women were in charge of the household health and well-being, while men were focusing on being financial providers. This approach was common for both the female and the male interlocutors:

> Interviewer: "*I'd like to hear if there is a difference in how men and women cope with diseases.*"
> Louis: "*There is definitely a difference. I am more laid back than you* (wife) *are.*"
> Wife: "*That's what I was about to say. Louis is more relaxed and tends to react to things as they come along. I'm very good at worrying.*"
> Interviewer: "*Why is that?*"
> Wife: "*Women are more concerned, generally. Men are better at just taking things from the bottom-and-up!*" *(Louis & June, November 2015)*

Most of the participating men had developed multimorbidity over the past decade. They were still comparing themselves to younger versions of themselves when describing their priorities and behaviors. For example, in response to the question of health practices, Louis compared his physical strength and mobility to what he had been able to do at the age of 20. He said, "*I used to be able to climb on high ladders, I don't anymore. One gets older; you have to be more active to stay healthy. Do exercises on a more regular basis. I often go for a bicycle ride; back in the days, I wouldn't have thought of doing that, I wouldn't have had the time.*"

Bodily decline was an expected companion in late life, but it did not coincide with a perception of living the life one wanted to. James had been a local league swimmer but did not have the energy to swim anymore. Instead, he stressed his mental capabilities, stating, "*You know, I'm even better at crosswords now than I used to be. Not everything about getting old is bad.*"

Discussion

It is still inadequately exposed how the concept of successful aging is constituted among those unable to live up to the criteria. Scholars have argued that successful aging constitutes neoliberal notions of personhood (Lamb 2014), and in a Danish context, how this enacts portraits of older people, unable or unwilling to perform adequate health practices, as irresponsible and burdensome (Lassen and Jespersen 2017; Mikkelsen 2016).

This study, however, points to an important fact when talking about the ideal for successful aging. The participants proved unable or unwilling to measure up to successful aging; owing to multimorbidity, they could not remain healthy, and their health practices, including social engagement, were not adhering with the Rowe and Kahn framework. Instead, the men assessed their aging and health in accordance with their self-initiated parameters and gendered explanations. In doing so, they were able to live up to their own expectations and experience a self-reported good life. This process is also reflected in studies on self-reported health, where participants rate themselves higher on parameters of successful aging than when they are being rated in accordance with the Row and Kahn framework (Strawbridge, et al. 2002).

Looking at health practices, the participants, like the men in Griffith and colleagues' study (Griffith, et al. 2018), viewed 'health' to be about everyday practices, priorities, and abilities. Older men and women use similar, wide-ranging frames of reference, when making health judgments (Zajacova, et al. 2017). However, this article points to gender specific perceptions of successful aging: Some men read identity into masculine workplace norms and define themselves according to their jobs (Kilmartin 2007), and therefore, older men may experience their inability to remain on the labor market as a challenge to their masculinity (Emslie, et al. 2004; Oliffe, et al. 2013). This, along with the multiple chronic conditions, which they suffer from, challenges their identities; keeping up the identity of the strong sailor is difficult, when one is amputated and limited in movement due to COPD. Additionally, managing, navigating, and prioritizing within often intricate treatments are tasks that require different skills from what the participating men have acquired in their working careers. Their evaluation of their own worth is challenged when they retire, and skills which were highly appreciated at their jobs do not translate to their lives as retired, chronically ill, older men with low incomes.

Some men associated aging and health with feminine values, and had difficulties adjusting to treatments and self-care recommendations for health practices. This has already been discussed by a vast amount of researchers (Dolan 2011; Thompson, et al. 2012). Yet, other men were more pragmatic about health practices, trying to adhere to diets or be active members of patient organizations, for instance. We wish to emphasize the individuality and diversity among even just this relatively small group of men, as these contradict the categorization of 'men' as a homogenous group. However, the participating men for the most part shared a conception of masculine values, which cannot be segregated from their age. As these men are *older,* their narratives need to be considered within their generational context: In interviews, they stressed that they had lived with more traditional gender roles, according to which men were generally the financial providers, while women were in charge of the health and the social life of the family. Such masculine values translated as incompatible with successful aging. Courtenay emphasizes that masculinity tends to be defined in ways that marginalize for instance health practices which may contribute positively to health (Courtenay 2000). Following this, we argue that the participating men in this study relate to aging in ways that differ from society's concept of successful aging, and thus, ironically, marginalize practices that may contribute positively to the core concepts of their own idea of successful aging: striving for independence, being able to engage in hobbies, or prioritizing life quality over treatment adherence.

While there was considerable overlap with previous research on older men's perception of successful aging (Griffith, et al. 2018; Lassen and Moreira 2014; Mikkelsen 2016), this study highlighted the intersection of age and gender with multimorbidity. According to the dominant successful aging discourses, health is a critical aspect of successful aging. The fact that they have multiple chronic diseases reduces the participating men's possibilities of meeting society's political goals of aging. However, we argue that the results show how the men are at their best within a framework that considerably overlaps with the components of Rowe and Kahn's concept of successful aging, whether or not they champion the components. The men in this study emphasize healthy behaviors and independence along with social engagement, albeit on their own terms. They construct their own experiences of successful aging in terms of independence, of being in control, of engaging in self-initiated hobbies and social arrangements, and in terms of balancing treatments and everyday life.

Focusing on older men with multimorbidity has facilitated the identification of the unique approaches for this particular population group, and thus it has been helpful in the location of resources and strengths that could be the foundation for improving health and minimizing the male health inequity. Such insights could be used to improve and adjust the existing offers from health services, so that they can improve their ability to meet the needs of older men with multimorbidity.

Strengths and Limitations

The results are based on a long-term ethnographic fieldwork, a method that brings about a deep understanding of the participants' lives. However, the results may vary between men from different socioeconomic backgrounds. We did not foreground the role of the socioeconomic background in the analysis, but it is being addressed elsewhere. The results are not to be understood as generalizable interpretations, but rather as knowledge about how the social and cultural context creates a framework that affects and determines men's health practices.

References cited

Bayliss, Elizabeth A., et al.

2003 Descriptions of Barriers to Self-Care by Persons with Comorbid Chronic Diseases. Annals of Family Medicine 1(1):15-21.

Cameron, Elaine, and Jon Bernardes

1998 Gender and Disadvantage in Health: Men's Health for a Change. Sociology of Health & Illness 20(5):673-693.

Courtenay, W. H.

2000 Constructions of masculinity and their influence on men's well-being: a theory of gender and health. Soc Sci Med 50(10):1385-401.

Dolan, A.

2011 'You can't ask for a Dubonnet and lemonade!': working class masculinity and men's health practices. Sociol Health Illn 33(4):586-601.

Emslie, Carol, Kate Hunt, and Rosaleen O'Brien

2004 Masculinities in Older Men: A Qualitative Study in the West of Scotland. The Journal of Men's Studies 12(3):207-226.

Farrimond, H.

2012 Beyond the caveman: rethinking masculinity in relation to men's help-seeking. Health (London) 16(2):208-25.

Feng, Q., and P. T. Straughan

2017 What Does Successful Aging Mean? Lay Perception of Successful Aging Among Elderly Singaporeans. J Gerontol B Psychol Sci Soc Sci 72(2):204-213.

Griffith, Derek M., et al.

2018 "Health is the Ability to Manage Yourself Without Help": How Older African American Men Define Health and Successful Aging. The Journals of Gerontology: Series B 73(2):240-247.

Griffith, Derek M., et al.

2016 Masculinity in Men's Health: Barrier or Portal to Healthcare? *In* Men's Health in Primary Care. J.J. Heidelbaugh, ed. Pp. 19-31. Cham: Springer International Publishing.

Havighurst, Robert J.

1961 Successful Aging1. The Gerontologist 1(1):8-13.

Kristensen, Dorthe Brogård, Ming Lim, and Søren Askegaard

2016 Healthism in Denmark: State, market, and the search for a "Moral Compass". Health 20(5):485-504.

Kroijer, Stine, and Inger Sjorslev

2011 Autonomy and the spaciousness of the social in Denmark: the conflict between Ungdomshuset and Faderhuset.(Essay). 55(2):84.

Lamb, S.

2014 Permanent personhood or meaningful declineO± Toward a critical anthropology of successful aging. Journal of Aging Studies 29(1):41-52.

Lamb, Sarah, Jessica Robbins-Ruszkowski, and Anna I. Corwin

2017 Introduction

Successful Aging as a Twenty-first-Century Obsession. *In* Successful Aging as a Contemporary Obsession. Pp. 1-24. Global Perspectives: Rutgers University Press.

Lassen, Aske Juul, and Astrid Pernille Jespersen

2017 Getting Old and Keeping Going

The Motivation Technologies of Active Aging in Denmark. *In* Successful Aging as a Contemporary Obsession. Pp. 141-153. Global Perspectives: Rutgers University Press.

Lassen, Aske Juul, and Tiago Moreira

2014 Unmaking old age: Political and cognitive formats of active ageing. Journal of Aging Studies 30:33.

Mahalik, James R., Shaun M. Burns, and Matthew Syzdek

2007 Masculinity and perceived normative health behaviors as predictors of men's health behaviors. Social Science & Medicine 64(11):2201-2209.

Michaelsen, Jette Joost, and Maria Kristiansen

2017 Maskulinitet og sygdom. Nordisk sygeplejeforskning (03):182-194.

Mikkelsen, Henrik Hvenegaard

2016 Unthinkable Solitude: Successful Aging in Denmark Through the Lacanian Real. Ethos 44(4):448-463.

O'Brien, R., K. Hunt, and G. Hart

2005 'It's caveman stuff, but that is to a certain extent how guys still operate': men's accounts of masculinity and help seeking. Soc Sci Med 61(3):503-16.

Oliffe, John, et al.

2013 Masculinities, Work, and Retirement Among Older Men Who Experience Depression. Qualitative Health Research 23(12):1626-1637.

Poulsen, Inger , Rikke Engell, and Rita Ortiz

2013 Sundhedsprofil 2013 Region Sjælland og kommuner - "hvordan har du det".

Ravenell, Joseph E, Waldo E Johnson Jr, and Eric E Whitaker

2006 African-American men's perceptions of health: a focus group study. Journal of the National Medical Association 98(4):544.

Rosbach, Michael, and John Sahl Andersen

2017 Patient-experienced burden of treatment in patients with multimorbidity – A systematic review of qualitative data. PLOS ONE 12(6):e0179916.

Rowe, J. W., and R. L. Kahn

1997 Successful aging. Gerontologist 37(4):433-40.

Rowe, John W., and Robert L. Kahn

2015 Successful Aging 2.0: Conceptual Expansions for the 21st Century. Pp. 593-596, Vol. 70.

Sen, G., and P. Ostlin

2008 Gender inequity in health: why it exists and how we can change it. Glob Public Health 3 Suppl 1:1-12.

Smith, James A., et al.

2007 “I've been independent for so damn long!”: Independence, masculinity and aging in a help seeking context. Journal of Aging Studies 21(4):325-335.

Strawbridge, William J., Margaret I. Wallhagen, and Richard D. Cohen

2002 Successful Aging and Well-BeingSelf-Rated Compared With Rowe and Kahn. The Gerontologist 42(6):727-733.

Thompson, L., T. Reeder, and G. Abel

2012 I can't get my husband to go and have a colonoscopy: gender and screening for colorectal cancer. Health (London) 16(3):235-49.

Timmermans, Stefan, and Iddo Tavory

2012 Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis. Sociological Theory 30(3):167-186.

van den Akker, Marjan, Frank Buntinx, and J. André Knottnerus

1996 Comorbidity or multimorbidity. European Journal of General Practice 2(2):65-70.

Zajacova, A., S. Huzurbazar, and M. Todd

2017 Gender and the structure of self-rated health across the adult life span. Soc Sci Med 187:58-66.

Ziebland, S.

2013 Narrative interviewing. *In* Understanding and Using Health Experiences: Improving patient care. S. Ziebland, A. Coulter, J.D. Calabrese, and L. Locock, eds. Oxford, UK: Oxford University Press.

Ørtenblad, Lisbeth, Lucette Meillier, and Alexandra R Jønsson

Multi-morbidity: A patient perspective on navigating the health care system and everyday life. Chronic Illness 0(0):1742395317731607.

Table 1: Participant Characteristics

Name	Age	Educational Level	Marital Status	Number of Physical Diseases	Number of Mental Diseases
James	71	Short	Widow	4	1
Bob	78	None	Single	3	1
Peter	71	Short	Widow	4	0
Paul	71	Short	Divorced	4	0
Louis	78	Medium	Married	4	0
Douglas	84	Short	Widow	5	1
Aaron	72	Short	Single	3	0

Article 3:

Tuning Lives: Revisiting Health Inequities

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Abstract

Discourses on health inequities have focused on the link between poor health practices and social determinants. This article argues that the current understanding of health inequity can be refined by focusing on the individual experience of perceived inequity. Perceptions of social class prejudice and unequal treatment in the healthcare system are common among older adults with low levels of education and low income. This article proposes to understand such experiences as *subjective health inequities*; self-referentially enclosed understandings of experiences in encounters with health professionals. Within this framework, this article draws particular attention to a second proposed concept of *tuning*. Tuning is a conscious act intended to mitigate experiences of subjective health inequity by differentiating oneself from stereotypes. Ultimately, this article aims to show how health inequity is conceptualized and acted upon by individuals through the lens of subjective health inequities and tuning.

Keywords Health Inequities; Subjectivity; Social Determinants; Tuning; Chronic Illnesses;

Introduction

Despite universal access to healthcare, social inequality in health is rising in Denmark. Social health inequality manifests in differences in health status, risk of contracting diseases, disease prognosis, and life expectancy, linked to particular social determinants (Diderichsen, Andersen and Manuel 2011, 24-28). WHO defines social determinants as “the conditions in which people are born, grow, live and age, and the wider set of forces and systems shaping the conditions of daily life” (WHO 2018). Following the seminal analyses of the Whitehall studies (Marmot et al. 1991) and the Black Report (Townsend, Davidson and Whitehead 1998), a body of research has amply confirmed that in affluent welfare states like Denmark, the most predictive social determinants of health are *education* and *income* (Devaux 2015). For instance, people with low levels of education have a life expectancy ten years shorter than people with high levels of education (Mackenbach et al. 1997). Additionally, people with lower socioeconomic status are more likely to develop chronic diseases, and they benefit less from treatments (Marmot et al. 1991).

However, in this article, I argue for a supplement to what I contend is an over-simplified approach to understanding health inequities, with outcomes linked to social determinants tracked in easily-categorized variables. Instead, I propose and describe a new concept – *subjective health inequity* – as a framework to theorize and investigate health inequities. *Subjective* refers to the self-referentially enclosed understanding of encounters and experiences embedded within a particular individual’s socio-cultural context. Within this framework, I draw particular attention to my second proposed concept of *tuning lives* as the means by which individuals navigate and respond to experiences of subjective health inequity. Tuning as an intentional action accounts for the precautions and adjusted behaviors made in response to subjective health inequities.

My aim is to add nuance to current conceptualizations of health inequities in affluent welfare states, focusing on individual perceptions of inequity and demonstrating how these perceptions affect their options for strategic, culturally-appropriate health practices.

I define subjective health inequity as an individual experience perceived as unequal in treatment. In this perspective, subjective health inequity works in micro-level social interactions and shapes the patient’s perception of health encounters. Using this approach, I hope to supplement deterministic variables by acknowledging the subjective, fluid and transformative nature of health inequities.

Empirically, the article examines the experiences of older, chronically ill adults with low socioeconomic status living in rural Denmark. In that area, the number of older adults living with multiple chronic conditions is rising, challenging the current fragmented, single-treatment approaches (Region Sjælland 2013). People with low levels of education find it especially hard to navigate and prioritize often complex treatments (Ørtenblad, Meillier and Jønsson 2017), and these patients have higher mortality rates (Willadsen et al. nd), which makes this study setting apposite for inquiries about subjective health inequities.

Approaching the lives of older, chronically ill adults through the lens of subjective health inequity brings forth their individual experiences: I describe how the interlocutors in this study view themselves in relation to discourses of social determinants and health behavior, such as through reading prejudice into encounters and interactions with health authorities.

Yet, as anthropology has long shown, people are not passive victims of systems of power.

The interlocutors experiencing subjective health inequity use different strategies to navigate the perceived prejudice. Focusing on the subjective experience, I follow Ortner's argument, to see "*subjectivity as the basis of "agency", a necessary part of understanding how people (try to) act on the world even as they are acted upon*" (Ortner 2005, 34). Drawing inspiration from performing music, I suggest that the notion of tuning offers an avenue to understand agency and subjectivity in relation to health inequities.

One of the ways in which I connected with the interviewees was through music, as during my study I joined the local brass band. Playing an instrument in a band or orchestra takes practice and experience. During one evening session when the musicians struggled to fine-tune their instruments, I realized that the adjustments they made in their daily lives were mirrored in the kind of tuning they did with their instruments: tuning is the musician's individual task of adjusting the pitch so that it is in tune with the other musicians, in order to correctly harmonize with one another. In relation to subjective health inequity, tuning is the act of individual agency to navigate perceived prejudices. Outside rehearsal, these individuals were tuning their lives by adjusting to cultural expectations of good health behavior and distancing themselves from social determinants associated with inadequate health practices.

'Tuning in' as a concept has been used by phenomenologist Alfred Schutz to describe playing or listening to music as a non-linear but tangible relationship between performers, audience members, and the composer (Schutz 1964, 173). To Schutz, such relationships in music are a phenomenon that resonates with his philosophical enterprise. While not simultaneous, this particular social relation in music unites the performer and the composer in a conversation, similar to a face-to-face conversation (Yu 2014, 236). Building from this concept, I demonstrate how my interlocutors tune their lives to feel less inferior in health encounters and more 'in tune' with their cultural context, creating a temporary, collective experience of harmonious

conversation, just as Schutz’s musicians. Here, tuning lives is the agency that stems from subjective inequity.
Throughout my analysis, I stress the entanglement of subjective health inequity and tuning, recalling Arthur Kleinman’s claim that “*illness becomes embodied in a particular life trajectory, environed in a concrete life world”* (Kleinman 1988,31). Through narrated experiences, life stories and everyday life observations, I explore subjective health inequities and the process of tuning lives.

Subjectivity and subjective health inequity

Subjective health inequity examines the experiences of people who, by education level and income parameters, belong to the lowest socio-economic classes, indicators which are further associated with poor health behaviors and poor health status. It is *subjective* because it is a personal perception of events and experiences, and it is an *inequity* because it is interpreted as unequal treatment owing to prejudices against the lower social class, regardless of whether the existence of prejudice or the provision of unequal treatment is proven to be true. In the social sciences, multiple and competing perspectives thrive in the exploration of subjectivity and theories of how people’s inner worlds are constituted (Yu 2013, 349). Despite these multiple approaches, subjectivity generally refers to the ways people perceive themselves through systems of power and economic constraint (Yu 2013, 349-350). Subjectivity has an inherent double meaning. People are subject to social and economic conditions, while also forming ideas and acting upon the same conditions: “*subjectivity is not just the outcome of social control or the unconscious; it also provides the ground for subjects to think through their circumstances and to feel through their contradictions*” (Biehl, Good and Kleinman 2007, 14). However, subjectivity is never stable or fixed. Individuals are subject to multiple discourses in many realms, and as with identity, subjectivity is contextual, shifting and contradictory. Scholars have focused on health and subjectivity in various cultural settings (i.e. Ortner 2005; Biehl, Good and Kleinman 2007). I use the concept of subjectivity to map when and how social differentiation and inequality are part of the complexity of personal subjectivities.

Furthermore, the *formation* of subjectivity constitutes an important part of this discussion. Looking at health in relation to this formation of subjectivity, two analytical approaches have dominated: identity politics and biopower (Whyte 2009, 6). Regarding identity politics, the interlocutors in this study are not confined to a specific group, nor do they make claims or assert their rights as a group; instead, they do what they can to avoid association with health inequity, as I shall return to. Therefore, identity politics is not a good fit for discussing the formation of subjective health inequity. Instead, when looking at the formation of subjective health inequity, which is a necessary step in arguing for its existence, the notion of *biopower* is a more meaningful concept to explore. Biopower, as introduced in Michel Foucault's work, views the shaping of subjectivity through technologies, bodily practices and power relations (Foucault 1976). Biopower works subtly to shape subjectivity; Foucault points to how political technologies subtly control the entire population, enforcing an individual's responsibility to maximize health. Such implicit biopowers are part of contemporary ideological expressions of health behavior, also called "healthism". In an article on responses to health messages in Denmark, Kristensen and colleagues (2016) explore how health has become an identity marker, with the inherent potential to apportion blame and moral judgement; it excludes those unable or unwilling to obey the dictates of healthism (Kristensen, Lim and Askegaard 2016, 500). Following this, subjective health inequity emerges within such implicit biomedical-oriented powers and moralities; it lays ground for the interlocutors' perceptions of not belonging to the same world as others, which induces assumptions and consciousness about processes that lead to health inequities.

The Setting

The study is set on Lolland, the fourth largest island of Denmark. Half of the 60,000 inhabitants live in three main towns: Maribo, Sakskøbing and Nakskov, which are surrounded by extensive, flat fields of beets, agriculture being an important income source for area residents. Other residents live in the countryside or in small villages. From October to March, Lolland is a cold, damp place with barren fields, but come spring and summer, the island turns a lavish green, and tourists double the population, seeking nature and white beaches. Yet, situated on the outskirts of the country, Lolland is a socioeconomically deprived area, with the lowest median income and highest prevalence of chronic diseases in the country (Region Sjælland 2013).

Denmark, an affluent welfare state of 5.6 million people, builds on the Scandinavian Model, with welfare schemes covering the entire population financed through taxation, which provides universal access to healthcare (Kristensen, Lim and Askegaard 2016, 490). Equity is considered a core value and major strength of the Danish health care system, and Danes have a deeply embedded understanding of their unquestionable right to the highest quality treatment available (Høybye and Tjørnhøj-Thomsen 2014, 306). However, the rise in the aging population has developed into a concern as it is expected to strain the capacity of the Danish health and welfare sector. The number of older people with multiple chronic conditions demanding ongoing medical attention is growing, which is reflected in increased health service utilization and higher costs (Bahler et al. 2015). To manage the rising challenge of scarcity of health services, policies have been developed to keep the older population healthy by following treatment plans at home and taking responsibility for self-care (Otto 2013:131). Thus, encouraging proactive health and fitness is today employed as the main public health strategy to minimize the strain on the health system (Mikkelsen 2016, 452; Vallgårda 2001). In particular, preventing lifestyle diseases is emphasized by the Ministry of Health and Prevention and the municipalities, who together focus on healthy diets, smoking cessation, healthy alcohol consumption, and exercise (Danish Health and Medicine Authority 2018).

The focus on health equity echoes a societal ethos of neo-liberal values such as autonomy, self-determination and individualism, which is seen across the Global North. In Denmark, adult personhood is closely tied to one's ability to manage and maintain independence and autonomy (Krøijer & Sjørslev 2011). Hence, if one does not enact responsible health behaviors, persons may be excluded from the responsible health hegemony (Rose and Novas 2005, 451). Health behavior becomes not only an individual choice, but a window to moral character, through which people judge themselves and others (Kristensen, Lim and Askegaard 2016, 494-5). For the rising numbers of the aged population, this emphasis on personhood and moral character is also seen in the paradigm of healthy aging. Healthy aging as a concept promotes independence, with physical and social activity as the primary drivers (Lamb, Robbins-Ruszkowski and Corwin 2017). At the same time, health and illness practices that do not meet health-enhancing expectations are often considered to demonstrate lack of knowledge and understanding (Merrild, Vedsted and Andersen 2016, 548-550), which is part of the subjective inequity, as I shall return to.

Methods

The article is based on data collected through ethnographic fieldwork, which I conducted from February 2015 through August 2016. Following fourteen older adults for a period of up to eighteen months (depending on when they entered the study) provided the opportunity for deeper insights into the interlocutors' experiences and daily lives with multiple chronic conditions. All interlocutors were interviewed in depth at least twice. Interviews were conducted in narrative style (Ziebland 2013) and would generally last between one and two hours. Interviews were recorded and transcribed verbatim. I also carried out interviews with three spouses, four adult children, fourteen friends of the interlocutors and four general practitioners, two home nurses and two other health professionals. These interviews provided context and additional perceptions of particular events and experiences. Additional informal interviews and talks often took place in the community, such as while waiting in a hospital ward, driving in a car, or having dinner. The fieldwork also included participant observation as I took part in social arrangements, fairs, doctor's appointments, and my activities as a musician in the local brass band along with some of my key interlocutors and their friends.

The including criteria was 65+ years of age, living on Lolland, and having at least two chronic conditions requiring ongoing medical attention. The older men and women had either heard of my project through a social worker or a friend, or I had contacted them directly after observation of a consultation with their general practitioner. Seven men and seven women joined the study as key interlocutors based on inclusive sampling, meaning whoever agreed to participate and fulfilled the formal requirements was included in the study. The individuals were between 66 and 90 years old, and had been diagnosed with between three and six chronic conditions. Most common was diabetes type 2, hypertension, ischemic heart disease and various forms of arthritis, but the majority of participants had at least one disabling chronic disease, such as Parkinson's disease, or were living with limb loss post-amputation. In addition, about one-third were diagnosed with mental illness, most often depression, though anxiety and schizophrenia were also represented.

Though not listed as inclusion criteria, six of the men and five of the women had low levels of education. All interlocutors except one were retired, and defined themselves as having low income when asked to describe their economic position compared to the rest of society. Most interlocutors were on public pensions, which is the rights-based state pension that every Dane is paid after retirement. Only a few interlocutors had savings or private pensions adding to their income. Based on educational level and income, the interlocutors belong to the lowest two (out of five) social class quintiles in Denmark (Jul 2012).

In general, the older people were very keen to share their experiences with me, and the interviews often developed into longer, informal social interactions. Seeing them in social settings, such as in the band or at dinner with their friends, and listening to their perceptions of what outsiders (especially doctors) would think of them, inspired me to look at health inequalities through the lens of subjectivity.

The analysis was carried out abductively (Timmermans & Tavory 2012), meaning I alternated between reviewing empirical data and identifying corresponding theoretical approaches. The theme of *experiencing health inequity and acting upon it* was identified in the empirical data, and resonated with concepts of subjectivity and agency, and the data found expression through these analytical objects and theoretical approaches, as previously introduced and as will be developed further below.

The study was approved by the Danish Data Protection Agency (J.nr. 2015-41-3826) as required for all social scientific studies in Denmark. All informants are represented by alias names, and their diseases and age have been altered in order to secure anonymity. All fieldwork was carried out in Danish and citations and notes were translated into English by the author.

Subjective inequity: Living the social determinants

Public discourse of health behavior and health inequity

Although health inequality and inequities are not an overt outcome of social determinants, poor health behaviors, especially tobacco smoking, alcohol consumption, physical inactivity, obesity and diet, all of which are linked with development of diseases and premature death, are overrepresented among people with low levels of education and low income (Diderichsen, Andersen, Manuel 2011, 98-100). In Denmark, this knowledge has become common knowledge due to popular media's increased focus on socioeconomically deprived people. The television show "Busted in Nakskov" (my translation) narrates the lives of families from Lolland on welfare, struggling with finances, health, addiction, and housing, and in some cases fighting against municipalities trying to forcibly remove children from their families' homes (Tv2 2015). It has been heavily criticized for exhibiting and holding up for ridicule the lives of the poor and uneducated. After these criticisms, Danish national television broadcast a documentary on health inequalities in 2016. In the documentary, citizens from two different parts of a medium-sized city with thirteen years' difference in expected life span were interviewed and followed in everyday life settings. A general practitioner treating patients from both areas explained:

> "*The people living in area A can take care of themselves* […] *They can follow treatments, handle medications, change lifestyle. It easily sounds as if the people living in area B are stupid, but they're not. They just have different basis for acting*" (DRDK 2016, my translation)

The doctor may stress that people who experience inequities in healthcare are not stupid, but in public discourses during the fieldwork it was generally assumed that people with low social positions lacked personal competence when they failed to live up to the moral strictures of healthy living.

Stereotyping the lowest social classes

‘Social determinants’ was not a phrase that easily slid off my interlocutors’ tongues, but they turned out to have a great deal to say about prejudices toward people from the lower classes. They described the intrinsically degrading nature of belonging to a societal group considered “hard to reach”; the ones that are depicted in the media as subaltern, having “different basis for acting” as the doctor above stated. As a result, the interlocutors drew sharp distinctions between socioeconomically deprived people and themselves, although they were from similar lower classes by income level. James, a 71 year-old widower, poured coffee in my mug as we sat in his living room, preparing for a first interview. He asked if I had seen “Busted in Nakskov”, commenting that as an inhabitant of Nakskov he felt offended by the depiction of the town and its people:

> “*We are not all like that. Yes, there are some people who are in very vulnerable positions, but just because we don’t have higher educations doesn’t mean that we are irresponsible and stupid.*” (James)

Yet the continued stereotyping and negative associations with lower working-class health behaviors had resonance in the interlocutors’ self-images. The interlocutors with low levels of education recognized themselves in the social determinants of poor health. Many knew that being older and having several chronic conditions, while also having low levels of education and income, indicated a statistically higher risk of having more diseases and dying prematurely. Many of the interlocutors revealed an understanding of how one is supposed to act and behave as a patient, and they also shared a common history of feeling stereotyped, dismissed and having moral judgment inscribed upon their identities. One such individual was Barbara, diagnosed with diabetes, COPD and severe allergies, who stated that she saw a cause and effect judgment from health professionals:

> “*It’s been like this always, you’re placed in a box the minute you walk into the doctor’s office. They see chronic diseases, they see sick leave and then they just assume that I make bad choices.*” (Barbara)

Living the stereotype

The interlocutors' attempts to live up to the cultural expectations and practices of 'good' health behaviors were experienced as subjective inequity if they felt rejected by doctors and health professionals. Body language and tones of voice were interpreted to mean that the interlocutors had already been deemed unable to follow treatments and attain a healthy lifestyle.

To higher educated people, health authorities are also frequently perceived as paternalistic (Jacobsen, Martin and Baker 2015, 75-78). What is worth noticing is that the low-educated, chronically ill older adults in this study, contrary to i.e. the participants in Jacobsen and colleagues' study, associated the paternalistic approach with humiliation – an unvoiced, apparent insult to their intellectual capabilities.

Owing to this, the interlocutors anticipated that their health practices were not afforded the same flexibility as people with high levels of education or high income. Elvin was a 72 year-old man living alone in a small townhouse on the outskirts of Nakskov. He had been working at the dock since the age of sixteen and was valued by his peers for his physical strength and his reliability. Elvin had an inherent dislike for doctors, who he felt were patronizing toward him and failed to acknowledge his diabetes self-care, which he managed along with three other chronic conditions. In our first meeting, Elvin listed numbers randomly, including his blood sugar level and blood pressure level, and went on to describe which medications he was to take at what time. He had even developed a trick himself: if his blood sugar levels were too high at nighttime, he would eat a chocolate and by the morning, his blood sugar level would be normal. It was a little compensation for the sweets that he could no longer have, and it also tasted better than the glucose tablets that would normally be prescribed in that scenario. However, he did not feel that the health professionals acknowledged how well he was managing his chronic conditions. Instead, he felt as if doctors and nurses belittled his efforts and persisted in asking about his alcohol consumption, which was especially annoying as he had not touched alcohol for almost 30 years.

> *"It's because I worked at the harbor. There is so much prejudice about people working at the harbor, they think I'm unable to take care of myself. So they don't even listen."* (Elvin)

Elvin's experience highlighted the disjuncture between his attempts to act culturally appropriate by following treatments and thus live up to the notion of healthy aging, and then the prejudice that he felt he was met with. When I asked, he said that though the health professionals never mentioned his work, he assumed that was why they persisted in thinking his health behavior was inadequate to address his chronic conditions.

Some interlocutors also read inequity into mistreatment. Lily, an older woman with both legs amputated at the hip, pulled her wheelchair to the table to cut me a piece of homemade cake, and recounted:

> *"That thing with my arms, the first time I had the blood clots and my hand was completely blue. They just sent me home, even though it turned out to be blood clots and my hand might have to be cut off. I thought that was I being treated very unequal because they didn't listen to me*[…] *So the boys* [her sons] *just said I should complain. They filed a complaint for me. I was told that I would come to meet the doctor before they proceeded. I really wanted that: to ask him how he could say that I had nothing but cystitis, when my hand is all blue and I have so much pain in my arm. Then they said that he had left the unit, nothing to do* […] *I wanted to ask the doctor that question. But they didn't let me."* (Lily)

It was a story, in part, of anger: anger that the health care system would not provide her what she wanted the most – an explanation. Yet Lily had no wish to have control over the situation; a long life as a farmer's wife had taught her that for the most part things were out of her hands. This was true especially with doctors, to whom she anticipated she was nothing but an "*old, silly woman*".

During the fieldwork period, the persistence of acts of agency to mitigate these experiences of inequity became apparent, drawing my attention to precautionary measures performed to ensure that the interlocutors were distinguished from marginalized groups of socio-economically deprived people. As already stated, none of my interlocutors seemed willing to identify with that group. Instead, they distanced themselves from the dominant perception of the link between inadequate health practices and social determinants by demonstrating their adherence to treatments. Below, I will describe how this became apparent when the interlocutors worked toward feeling as if they belong to society in a manner that transcends these apparent class-based prejudices.

Tuning Lives

Tuning, as I define it, is *an act of agency that allows the interlocutors to operate as subjects negotiating situations in which they perceive prejudice; tuning is furthermore a reflection of an internalized notion of social position*. If and when something in the medical treatments went wrong, or treatments and self-care were prioritized in a different way than the health professionals wanted (for example: forgetting a pill, giving low priority to exercise, declining diets or smoking cessation regimes), the interlocutors felt condemned. They felt as if social determinants were blamed for these mistakes and different priorities, somehow taking away their ability to act and think independently. They opposed such perceived prejudices by stressing their uniqueness and their dissimilarities to the stereotypes, by tuning their lives within a given situation. *Tuning* was the *action* taken when *feeling* subjective health inequity.

This argument builds on a central premise: it is the lived experience that explains agency and why the interlocutors tune their lives in particular ways. Tuning takes different forms. In the following I explore, through exemplary cases, the particulars of how life tuning is practiced.

"I speak Doctor language"

Martha, a retired social worker, did not associate herself with her social determinants, though she acknowledged that some might focus on her education and low income. She managed the perceived risk of being stereotyped by taking control of her treatments. Martha, a once-tall, now stooping, overweight and authoritarian older woman, had spent almost 40 of her 69 years helping people with disabilities. This granted her some insights into health services which, she explained to me, came in good use now that she was so dependent on treatments herself. With poorly-concealed pride she told me how health professionals usually judged her at first, but when they entered into conversation with her, they realized that she spoke "doctor language"; this was her expression for adopting the right medical terms and appropriate behavior and attitude during consultations:

> *"I am her favorite patient. Most of the others, they don't understand anything, but I can feel that she thinks, "Ooh, here's that smart woman" when she sees me. I had to promise her that I would come back to them* [after a transfer to a different ward], *ridiculous. It's because I understand what she is saying, I understand my disease and I can comment on the treatment in Doctor language. I reckon none of the other patients are doing that. The best is when a new nurse I haven't met before sees me. I mean, she will think that I'm just another old lady, and then when I start talking, they are all like 'wow'."* (Martha)

Martha tunes her life to the medical world by presenting herself as an intelligent, responsible patient, nothing like the stereotype of older adults with chronic conditions from the lower social classes. I asked her if this resulted in better treatments, which she confirmed:

> *"Because it's prestigious to have patients that can spar with you professionally, and who maybe dare question your work. Not too provocative, you just need to trick them* [doctors] *a little, show an interest in their lives."* (Martha)

Yet Martha did not always behave in a responsible way, health-wise. She did not always take her medication on time, though she told her doctor so. On more than one occasion she forgot her pills while I was present, and I witnessed the unfortunate effects of her diseases. She explained that she would rather let life absorb her and afterwards take the punishment of being unable to move, due to the delayed effect of her medication. She refused to tell the doctor because "*it would ruin their image of me*"; thus her disclosure practices were a very pragmatic and controlled action, revealing only what she wished to reveal, and it was therefore not a matter of personality but a tuning strategy.

Displaying Responsible Health Behaviors

Another way of tuning was through purposeful and timely displays of responsible health behaviors. An example of this is Nancy, an overweight older woman suffering from post-polio syndrome, along with a history of blood clots in her lungs, heart and head. In addition, she had what she herself wrote off as minor issues: diabetes (type 2), some arthritis and obesity. Nancy, having raised three children and cared for her dying husband, had always been in charge of the family's health. One afternoon, we were sitting in her living room eating cream buns she had brought for us. She kept her pills in glasses arranged on a beautiful old silver dish, being very scrupulous about taking the medication on time and in the right dose**.** Nancy recounted how she made sure to present herself as a responsible patient when it came to her medications. From an observation of a consultation with Nancy's general practitioner, it became clear how this was a very hands-on strategy. During the consultation, Nancy vocalized how great she was at doing her exercise and taking her medication correctly, on time and in relation to a meal, and strictly attending all of her appointments. Afterwards, Nancy told me about the necessity of drawing attention to enacting a healthy lifestyle. On our way back from a doctor's appointment she explained that if she did not vocalize her resources she would not receive equal treatment:

> "*When you meet a new doctor, they will look in their papers and see, 'OK, old lady, obese, worked at the post office', and then they will think of me as a hopeless case. So yes, it's very much on purpose that I tell her all the things I do."* (Nancy)

Nancy could not ground her suspicion of people from the lower classes receiving unequal treatment in any particular experience. Rather, she felt that if she did not adhere to a certain treatment plan she would be condemned based on her low level of education, instead of given leeway based on an assumption that her actions were intentional choices or priorities. My argument here is not to conflate Nancy's strategies with high health literacy. Tuning is not ex nihilo; rather, it emerges within a context of subjective inequity and perceived prejudices an individual wishes to avoid. In that sense, Nancy was tuning, fitting into society by distancing herself from others of her same social class who might have been incapable or unwilling to follow treatments.

"I paid it all by myself"

The small apartment was filled up with cigarette smoke, and the table beside the bed, where I was offered a chair, was filled with pill bottles. Stephen, a 70 year-old retired storehouse clerk confined to his wheelchair, told me he was doing his best to keep to a restricted diet, cut down on alcohol, and take his 52 pills a day. Stephen knew that he may look like the stereotype of people in low socioeconomic circumstances, but he made sure to explain to me that he was nothing like that. To the contrary, he had savings from a life of hard work, and he was an independent citizen, not draining any additional resources from the state. On every visit he told me, using many of the same words, how he himself had paid for all of the aids that were needed for living in a wheelchair:

> *"I could ask the municipalities, but no. Why would I? I'm not one of those losers constantly asking for help. I don't need any help. Everything you see here, I paid for myself. The health services* [in the municipality] *wanted to lay out mats so that I could drive over the doorsteps, but it didn't work. So, I asked a carpenter, and paid him to raise the floor all over the apartment. 30,000 DKR it cost me."* (Stephen)

Stephen suffered from a number of conditions, including COPD and diabetes, which are associated with lifestyle issues such as smoking and inactivity, and which are also often used in stereotypes of lower-class health behavior (i.e. Tv2 2015). Yet he had some savings (though most had been used for the new floor) and he believed this to be a far truer indicator of his social class than any of the other determinants. To Stephen, economic independence, however minor, conferred high social status. He reinforced this independence as a way of tuning, thus ensuring that he was not mistaken for who he described as ‘losers’, his word for those of low socioeconomic status.

Optimizing Self-Presentation

Often, participants complained that their chronic conditions drained their energy and made them conspicuous in public. Some felt the lack of energy was apparent in their appearance, making them look constantly sick. Others had diseases or side effects resulting in issues such as tremors, gait abnormalities, or partial facial paralyzation, which they felt caused people to judge them. While such experiences may be common to many people suffering from chronic conditions, my interlocutors read prejudice and disdain into the experience due to their experiences of subjective health inequity. Consequently, many tuned their lives by optimizing their physical appearance prior to encounters with health professionals. Joyce was such an example. Her home had a distinct smell to it, a mixture of cigarette smoke and artificial lemon from cleaning products. The past two decades of her 70-year life she has been unable to work due to generalized pain, though she was also diagnosed with anxiety after a blood clot in the heart three years ago, and her post-polio syndrome effects gave her a lurching gait that troubled her. She suspected that people would assume her to be drunk, mistaking her for an alcoholic, which was her greatest fear. She found only one solution: overdressing to manage the impression that she gave. Anticipating she would not be mistaken for a drunk if dressed in ironed dresses and sporting flawless hair, she would even go grocery shopping dressed well and wearing neatly-applied makeup. She told me proudly about her strategy:

> *“Last time when I went to see my doctor, he didn’t believe I was ill. He couldn’t tell from looking at me! I had to tell him, with me you can’t tell if I’m in pain or feeling ill.”* (Joyce)

Lastly, a way of optimizing one’s image was to make family and network visible. Lily, who was previously described, silently protested the stereotypical picture of lonely older people (see Mikkelsen 2016, 449) by deliberately bringing family members, most often her sons, to doctor’s appointments. This, she explained, was meant both as a help to keep track of the often intricate treatments, but also to stress that the health professionals should not just forget about her; her sons would make sure she got the treatment she needed. Though none of the sons were medically trained, to Lily, their presence was necessary for a positive outcome.

Discussions

This article has explored how contemporary discourses about health behavior linked to social determinants may contribute to subjective feelings of health inequity. For the past 30 years, epidemiological and public health studies have illustrated that high-risk health behavior as well as chronic and psychiatric diseases are more frequent among people with low levels of education and low income (i.e. Marmot et al. 1991). Anthropologists have taken a different approach: drawing attention to the complexity of people's experiences and challenges with health inequities in local contexts, studies have focused on unequal power formations in health access, and structural explanations, such as social and economic conditions influencing health behaviors (i.e. Moon et al. 2015; Mendenhall 2016; Duke 2017). Some argue that when notions of agency are overemphasized, focus is drawn away from the life circumstances actually shaping health and illness practices, because agency assumes that people are able to change their health behavior if only they have the knowledge to do so (Merrild, Vedsted and Andersen 2016, 548-549). Yet looking at agency as a core concept within the experiences of the interlocutors in this study leads to the understanding of how life circumstances shape health practices, and not least how they are used as a basis for action by individuals in an everyday context. The ethnography in this article has shown that to some extent, people possess the capacity to enact change in their health practices, although it may be altered in ways that health authorities would not encourage: as in the case with Martha, she was disclosing only her adherent health practices to her doctor, but not her carelessness with taking medications on time, nor did she change that behavior. Chenhall and Senior (2017) elegantly discuss social determinants of health within Ngukurr, an Indigenous community in Australia. Ngukurr residents, who were also aware that they were being judged for their choices, shifted agency depending on the context the health behavior occurred in: for example, Ngukurr residents would remove soft drinks when a picture was taken because they were "bad" health choices, or opposite, highlight the cultural value of sharing in a staged picture depicting children sharing a soft drink (Chenhall and Senior 2017, 6-10). Despite the many differences between the residents of Ngukurr and those of Lolland, it is useful to stress the alikeness of agency relating to experiences of prejudice and judgment from others, for both the residents of Ngukurr and the interlocutors of my study. Inspired by these parallels, I have aimed to inquire into the kinds of subjectivities produced by agency, following the work of Ortner (2005) and Biehl and colleagues (2007). This line of inquiry then returns to the main thesis of the article, that some individuals from the lower classes, despite free and equal access to health care, experience subjective health inequity as a state of mind that interprets social encounters in a frame of unequal treatment.

Returning to the paradigm of biopower, contemporary geopolitical challenges in affluent welfare states have given rise to new liberal policies, with a reorganization of power devolving to individual moral obligations, as in e.g. healthy aging policies. With such policies, the interlocutors in this article have been found to experience significant constraints; while novel constructions of health behavior recode the duties and expectations society has of older adults, the interlocutors find themselves prejudged as unable to live according to contemporary cultural expectations and moral regimes. The development of subjective health inequity has arisen in part from what Rose names ‘somatic ethics’, which has provided room for collective discourse on how to physically enact health practices (Rose 2007, 5-6). Somatic ethics in this setting reorganizes relations between individuals and health professionals and are, I argue, the biopolitics formation that leads to subjective health inequity.

I have shown the nuances of how the interlocutors experience subjective health inequity. Some expected less-adequate care due to their working class background; they felt patronized and met with indifference, as in the case with Elvin, whose doctor failed to recognize his strict management and adherence to the diabetes diet. Others felt categorized as socioeconomically-deprived people. What I prefer to emphasize here is the subjectivity with which interlocutors read a cultural experience as divesting them of the option of culturally or socially appropriate behavior: they are simply out of tune. Thus, I have argued that interlocutors respond to the subjective health inequity by tuning their lives. When first introduced by Schutz, ‘tuning’ or ‘being in tune’ described the social relation that unites audience, musician and composer, though they may be centuries apart, which Schutz argues to be as vivid as a face-to-face conversation (Schutz 1964,171-172). The interlocutors in this study tune their lives to achieve a temporary feeling of collective harmony with society. According to Schutz, people in tune can also share spatial harmony: “the other’s facial expression, his gestures in handling his instrument […] gear into the outer world and can be grasped by the partner immediately”. This resonates with what takes place in encounters between the older, chronically ill people of Lolland and, for instance, their GPs. Martha interpreted the doctor’s expressions and adjusted her movements and words to tune herself into the world of the GP by disclosing all the (from a medical point of view) ‘right’ aspects of her health behavior, using appropriate wording.

The development of the concept of tuning lives owes a great deal to Erving Gofmann’s seminal work *The Presentation of Self in Everyday Life* (Goffman 1956). Using his arguments on, for instance, management of impressions could also have benefitted the analysis; however, I have found tuning to be more appropriate for understanding the attempt to fit in as an outsider, in this particular case in relation to health practices and social determinants.

Rather than viewing subjective health inequity and tuning lives as simply an explanatory theory, I suggest that the notion of subjectivity paired with agency has the potential to better illuminate the individual experience of health inequity, thus supplementing epidemiological causality studies. Drawing on ethnography, I have been able to recognize the patterns and diverging individual processes that subtly alter health practices of the interlocutors in this study. The concepts of subjective health inequity and tuning lives are theoretical tools through which we can grasp health inequity as molded by the cultural and social contexts of each individual.

Conclusions

Addressing health inequities through the analytical lens of subjectivity led to the argument that people are well aware of their social class and feel a need to distance themselves from representations of the lower classes and their presumably inherently poor health behaviors. This distancing, I contended, was manifested in an active agency, which I have termed tuning. I have attempted to explore an aspect of health inequity that is less-frequently described, at least in medical literature. However, I do not claim subjective health inequality to be a phenomenon that extends to all older people with low levels of education, nor that they are all tuning their lives per se. Instead, the lens of subjective health inequity can help reveal the frame of reference that leads some older, chronically ill, vocationally-trained adults to experience what they perceive to be prejudice in health encounters.

The concepts of subjective health inequity and tuning can be further unfolded and may help inform interventions targeting health inequities. Thus, forming and developing inequity conceptions and knowledge may eventually have an impact on policies of care and treatment for older people with chronic diseases and low levels of education. With the hope of a symphony to come, this article could be but the first movement in a composition.

References

Bähler, Caroline, Carola Huber, Beat Brüngger and Oliver Reich (2015) “Multimorbidity, health care utilization and costs in an elderly community-dwelling population: a claims data based observational study”. *BMC Health Services Research* 15(1):23

Biehl, João, Byron Good and Arthur Kleinman (2007) “Introduction: Rethinking Subjectivity” In *Subjectivity*, edited by J. Biehl, B. Good and A. Kleinman, 1-24. Berkeley: University of California Press.

Chenhall, Richard and Kate Senior (2017) “Living the Social Determinants of Health: Assemblages in a Remote Aboriginal Community”. *Medical Anthropology Quarterly*. doi:10.1111/maq.12418

Danish Health Authorities [Sundhedsstyrelsen] (2018) *Sundhedsstyrelsens forebyggelsespakker*. Copenhagen: Sundhedsstyrelsen.

Devaux, M (2015) “Income-related inequalities and inequities in health care services utilisation in 18 selected OECD countries”. *The European Journal of Health Economics* 16(1):21-33.

Diderichsen, Finn, Ingelise Andersen and Celie Manuel (2011) *Ulighed i sundhed - årsager og indsatser*. København: Sundhedsstyrelsen.

DRDK (2016) ”Uligheden i sundhed stiger”. *Danish Radio* website, May 22. Accesed March 9, 2018. https://www.dr.dk/nyheder/indland/uligheden-i-sundhed-stiger-de-daarligst-stillede-doer-aar-tidligere#!/

Duke, Michael R. (2017) “Neocolonialism and Health Care Access among Marshall Islanders in the United States”. *Medical Anthropology Quarterly*, 31: 422–439. doi:10.1111/maq.12376

Foucault, Michel (1976) *The History of Sexuality* Vol. 1 New York: Pantheon Books, Pp. 140

Goffman, Erving (1956) *The Presentation of Self in Everyday Life*. Edinburgh: University of Edinburgh Press

Hoybye, Mette & Tjørnhøj-Thomsen, Tine (2014) “Encounters in Cancer Treatment: Intersubjective Configurations of a Need for Rehabilitation”. *Medical Anthropology Quarterly*. 28. 10.1111/maq.12063.

Jacobsen, Charlotte. B., Helle Max Martin and Vibe Baker. (2015) “Who knows best? Negotiations of knowledge in clinical decision making”. *Tidsskrift for Forskning i Sygdom og Samfund*. (22): 67-82 http://dx.doi.org/10.7146/tfss.v0i22.20820

Jul, Jonas S. (2012) *Inddeling af befolkningen i sociale klasser* [Classification of the Population in Social Classes] Copenhagen: Arbejdernes Erhvervsråd

Kleinman, Arthur (1988) *The illness narratives: suffering, healing, and the human condition*. New York: Basic Books.

Kristensen, Dorthe, Ming Lim and Søren Askegaard (2015) “Healthism in Denmark: State, market, and the search for a "moral compass"”. *Health* 20(5):485-504

Krøijer, Stine and Inger Sjørslev (2011) “Autonomy and the spaciousness of the social in Denmark: the conflict between Undomshuset and Faderhuset”. *Social Analysis*. 55(2):84-105

Lamb, Sarah, Jessica Robbins-Ruszkowski, and Anna I. Corwin (2017) “Introduction. Successful Aging as a Twenty-first-Century Obsession” In *Successful Aging as a Contemporary Obsession*, edited by Sarah Lamb, 1-24. Global Perspectives: Rutgers University Press.

Mackenbach, Johan, Anton Kunst, Adriënne Cavelaars, Feikje Groenhof and José Geurts (1997) “Socioeconomic inequalities in morbidity and mortality in western Europe”. *The Lancet* 349(9066):1655-1659.

Marmot, M. G., S. Stansfeld, C. Patel, F. North, J. Head, I. White, E. Brunner, A. Feeney, A. Marmot, M. G. Smith and G. Davey (1991) “Health inequalities among British civil servants: the Whitehall II study”. *The Lancet* 337(8754):1387-1393.

Mendenhall, Emily (2016) “Beyond Comorbidity: A Critical Perspective of Syndemic Depression and Diabetes in Cross-cultural Contexts”. *Medical Anthropology Quarterly*, 30: 462–478. doi:10.1111/maq.12215

Merrild, Camilla, Peter Vedsted and Rikke Sand Andersen (2016) “Situating Social Difference in Health and Illness Practices”. *Perspectives in Biology and Medicine*, Vol. 59 (4): 547-561.

Mikkelsen, Henrik (2016) “Unthinkable Solitude: Succesful Aging in Denmark Through the Lacanian Real”. *Ethos* (44); 4, pp. 448-463

Moon, Graham, Grant Aitken, Paul Roderick, Simon Fraser and Gill Rowlands (2015) “Towards an understanding of the relationship of functional literacy and numeracy to geographical health inequalities”. *Social Science and Medicine* 143:185-93.

Ortner, Sherry (2005) “Subjectivity and cultural critique”.*Anthropological Theory*, (5);1:31-52

Otto, Lene (2013) “Negotiating a healthy body in old age: preventive home visits and biopolitics” *International Journal of Ageing and Later Life*, Advance access, doi: 10.3384/ijal.1652-8670.11168

Region Sjælland (2013) *Sundhedsproftil 2013 for Region Sjælland og kommuner* [Health Profile 2013 for Region South and the municipalities]. Sorø: Region Sjælland

Rose, Nikolas and Carlos Novas (2005) “Biological Citizenship” In *Global Assemblages: Technology, Politics and Ethics as Anthropological Problems*, edited by A. Ong & S.J. Collier, 439-463. Malden, USA: Blackwell

Rose, Nikolas (2007) *The politics of Life itself. Biomedicine, power and subjectivity in the twenty-first century*. Princeton: Princeton University Press

Schutz, Alfred (1964) *Collected Papers II.* The Hague: Martinus Nijhoff

Timmermans, Stefan and Ivo Tavory (2012) “Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis” *Sociological Theory* 30(3):167-186.

Townsend, Peter, Nick Davidson and Margaret Whitehead (1988) *Inequalities in Health: The Black Report and the Health Divide*. Harmondsworth, UK: Penguin.

Tv2 (2015) *På røven i Nakskov*. [Busted in Nakskov] Television show. Season 1 aired 2015 on Danish national channel Tv2

Vallgårda, Sigrid (2001) “Governing people’s lives. Strategies for improving the health of the nations in England, Denmark, Norway and Sweden”. *European Journal of Public Health*. 11 (4):386-392

WHO (2018) Social determinants of health. Key concepts. WHO website. Accessed 3/9/18 http://www.who.int/social_determinants/themes/prioritypublichealthconditions/en/

Whyte, Susan (2009) “Health Identities and Subjectivities: The ethnographic challenge”. *Medical Anthropology Quaterly* (23); 1, 6-15

Willadsen Tora, Volkert Siersma, Dagny Nicolasdóttir, Rasmus Køster-Rasmussen, Dorte Jarbøl, Susanne Reventlow, Stewart Mercer and Niels de Fine Olivarius (nd) “The effect of multimorbidity on mortality for prevalent combinations: a 15-year longitudinal registry-based nationwide Danish population study” (submitted to Clinical Epidemiology).

Yu, Chung-Chi (2014) “Mutual Tuning-In Relationships and Phenomeneological Psycology” *The Interrelation of Phenomenology, Social Sciences and the Arts. Constributions to Phenomenology* 69. DOI 10.1007/978-3-319-01390-9_16

Yu, Yeon Jung (2013) “Subjectivity, Hygiene, and STI Prevention: A Normalization Paradox in the Cleanliness Practices of Female Sex Workers in Post-Socialist China”. *Medical Anthropology Quarterly,* (27): 348–367. doi:10.1111/maq.12050

Ziebland, Sue (2013) “Narrative interviewing” In *Understanding and Using Health Experiences: Improving patient care,* edited by S. Ziebland, A. Coulter, J.D. Calabrese, and L. Locock, Oxford, UK: Oxford University Press.

Ørtenblad, Lisbeth, Lucette Meillier and Alexandra Ryborg Jønsson (2017) “Multi-morbidity: A patient perspective on navigating the health care system and everyday life”. *Chronic Illness* doi: 10.1177/1742395317731607. [Epub ahead of print]

Article 4

The Unhealthy: An anthropologist's encounter with older people living with multimorbidity on Lolland

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Abstract

Based on ethnographic research among chronically ill older people in Lolland, the article demonstrates how ‘health’ as a morally weighted concept is reproduced by the fieldworker. Recognition of such positionality emerges gradually throughout the author’s fieldwork, and the article shows how increasing critical awareness is reflected in the fieldwork itself. It is argued that medical anthropological studies require constant reflection on how the fieldworker produces empirical objects. Owing to this, the perspective termed ‘empathic research’ is introduced; ‘empathic’ refers to the anthropologist’s responsibility to make practices, experiences and narratives understood within the local context. The analysis stresses the need for anthropologists to remain critical towards positioning and normative groundings within the research project and seek knowledge on how individuals are embedded within a society and within a specific cultural and political frame of time and politics. Following this, a focus on social inequality in health must entail a commitment to engage in the world. The discussion establishes grounds for an empathetic way of collecting knowledge that entails an epistemological focus on situational existence.

Introduction

"*Medical anthropology is at the margin of medicine; it is also at the margin of anthropology*". Kleinmans infamous words (Kleinman 1995:1) frame the fieldwork that in this article will become the object of a self-reflective and critical analysis of anthropological knowledge production within dominating health discourses. In this article I will introduce a research method that I refer to as *empathic knowledge production*. *Empathic* points to the anthropological call to make local practices, experiences and narratives understood within their own context. This approach is highly inspired by the critique raised against what is often referred to as the ontological turn (see Sausdal & Vigh 2013; Hastrup 2013b; Højbjerg 2013). A critique that stresses focus on situational existence as anthropology's modus operandi (Sausdal & Vigh 2013:116). Fieldwork, participation and conversations with men, women and children should in my point of view aim to show differences in human lives within a specific sociocultural and political context. Anthropologists then work as interpreters of human health behavior that shows why and how people do as they do (Brown & Inhorn 1996:198). Yet as medical anthropology is at the margins of biomedical research, ethical challenges occur when trying to shed light on our informants' lives. Doing anthropology in biomedical fields could mean looking into the ways that local sociocultural factors affect both the self-monitoring of the body and understanding the symptoms (see Oxlund & Whyte 2014). Unfortunately the research aim that is most often defined in a biomedical framework reflects an intertwining of anthropology and medicine (Rhodes 1996:159). Anthropologists Sharon Kaufman and Lakshmi Fjord discuss Medicare in an analysis of the treatments offered to people with liver diseases - an analysis that encompasses a matrix of how to live (Kaufman and Fjord 2011:212).They lack an ethical reflection of their own positioning within biomedicine., yet, awareness of this is growing. Danish anthropologist Mette Nordahl Svendsen stresses the need for a critical, yet engaged research outset in showing informants' resistance as a condition of knowledge production that can be used to voice critiques in the empirical material: exposing epistemological differences between researcher and informants clarifies any opposing interests (Svendsen 2009). Highly inspired by Svendsen's discussion of critical engaged research my intention is to connect biomedical preconceptions to my own research and methods.

This article brings focus to empathic knowledge production in studies of how people meet and understand health regimens. Empathic knowledge production scopes the analysis to encompass considerations for health discourses having an impact on the anthropological project design, and possible consequences thereof. In the following article I will highlight the trajectory of ethical considerations that came to be over the course of time and during interactions with the informants, but also during analysis and discussions with peers and theoretical dimensions of health, ethics and ontology. To what end must we steer the analytical attention as anthropologists navigating an ocean of expectations; identifying health barriers in the lives of our informants, arising from our collaborators and political agendas? In this article I will argue that empathic knowledge production could be an answer.

I will be showing the way in which my recognition of my own biases dawns throughout the process, as they reveal themselves during the fieldwork, and how this forms a new critical awareness of ethical challenges. I will be arguing that health research always carries implicit moral imperatives, by showing how a biomedical view on health permeates my study. By highlighting the fact that my portrayal is formed from this biomedical view I am asserting that *firstly*, studies in your own culture also require constant reflection of how we create our empirical object. *Secondly*, I point out that the analytical object is constituted by occasionally conflicting interests. So I show how, months into the fieldwork, I still focus on smoking, diet and exercise - knowledge that is sought after by my biomedical colleagues. Thus neglecting what really matters to my informants in an everyday life with multimorbidity[1]. These understandings form the basis of a more general discussion of medical anthropology, and it is my intention to frame this within my own failures and experiences.

Bridging better health

Denmark is characterized by a rural area with lower socioeconomic status levels, and where the population has relatively poorer health than in the urban areas. These areas have low income levels and a decreasing population. 16 out of 98 Danish boroughs or municipalities are situated in these areas, constituting a total of 11 percent of the Danish population (Regionen 2016). Lolland is the lowest ranking municipality measured by life expectancy, income, levels of education and unemployment - and suffers from the country’s highest prevalence of chronic conditions (Region Zealand 2016a). Statistically, Lolland is one of the most socioeconomically deprived areas in Denmark, and due to its demography, the prevalence of multimorbidity is particularly high (Larsen et al. 2013). It seems obvious when focusing on multimorbidity to conduct fieldwork on Lolland.

Owing to the poor public health profile, Lolland and the neighboring island of Falster have set the goal to provide “better health for more people” in the years to come. Epistemological research and applied programs are implemented and studies in health behavior, relations and aging are conducted. My own PhD study focusing on everyday life with chronic diseases is part of this effort. I look into how older people with multimorbidity manage the burden of diseases and treatments in everyday life. I explore how they navigate often conflicting treatments and how everyday life is affected when one must constantly prioritize following this and that doctor's advice - or maybe just not following it at all. Over 18 months I visited, observed and interviewed seven women and seven men aged between 66 and 90, suffering from various chronic conditions. The fieldwork, carried out on Lolland in 2015-2016 is a collaboration between the Research Unit for General Practice at the University of Copenhagen and the Knowledge Center for User Involvement in Health Services[2]. But who has the right to define a healthy life, and what is one to do upon realizing that you are caught up between conflicting interests: the assigner's aspiration to improve the biomedical health versus the people that neither can nor will improve health in this sense?

I am connected to LOFUS (The Lolland and Falster Study), the most extensive public health study in rural Denmark ever, involving more than 100 associated researchers. LOFUS collaborates with *Bridging better health*, a development program in the Zealand Region that hopes to improve health and minimizing health inequity on Lolland and Falster. *Bridging better health* is a partnership between the municipalities, the Region of Zealand, and general practitioners on Lolland and Falster. *Bridging* is used both figuratively and literally, referring to the bridge connecting Zealand with Lolland and Falster. The bridge that I, together with research colleagues, need to cross to go "down" to the islands - , eager to improve their health. We are but pieces in a larger political puzzle, which, despite the presumably well-meaning intentions, is working towards changing the behavior of the unhealthy (Region Zealand 2016a, 2016b). Thus in referring to a *we*, working for better health at Lolland, an *other* is implied - irresponsible, unhealthy and different from this hegemony. The knowledge that I produce is thus morally constituted, which leads me to ask: who has the right to define what healthy is?

Whose research ethics?

More than 1600 years ago Saint Augustine's mother was put in a dilemma similar to what many medical anthropologists experience during their fieldwork. Saint Monica asks: "In Rome they fast on Saturday, but not in Milano. In Milano, they fast on Sunday. *What is the right thing to do?*" Saint Ambrose answers: "When I am here I do not fast on Saturday, when in Rome I do fast on Saturdays" (Saint Augustine, letter 54, 2.3). I found myself in this dilemma when my ethics was challenged as the interlocutors deliberately ignored their biomedical treatments. A woman declined sleeping with her oxygen-mask. She found it too troublesome to attach and it ruined her otherwise good mood. I could not help but think she did the wrong thing, as she was experiencing an increasing fatigue due to lack of sleep and her diseases accumulated for the same reason. What was the right thing to do?

Ethical issues relating to an individual's self-care and socially sanctioned norms is a well-known challenge in anthropological fieldworks. Extensive research ethics guidelines have been made for the researcher to be critically aware of her own positioning. Yet it is somehow inadequate, as the research ethics are still perceived within an institutionalized and normative approach rather than a way of relating researcher and interlocutor (Davis 2010:15-17). An individual's response to discourses and directions for acting, such as treatment plans, is inasmuch ethical acting in itself, according to Michel Foucault. Man cares for himself by striving for his optimal self (Foucault 1988:18). However, during my fieldwork I experienced explaining and apologizing for my normative morally loaded perspectives in self-reflective moments with an ethical agenda of wanting to 'do what's best' for the interlocutors. I asked the women with the oxygen mask if she did not find it better to feel rested even though it (the oxygen-mask) may be a little annoying. Reading through this transcription, made me reflect on what exactly research ethics are to me as an anthropologist and social scientist. Inspired by current discussions (Hastrup 2004b; Baarts 2009; Davis 2010) I contend that anthropological research ethics are about how we produce knowledge about local forms of lived life and in my field specifically, how health practices unfold in particular settings. The answer was laid out 1600 years ago: we need to understand actions in their local context.

Anthropologist Kirsten Hastrup is pointing to the ethical obligation embedded in the epistemological representation of the interlocutors' world (Hastrup 2004b: 469). As such, she argues for an ethical approach that differs from ontology as it is more than just a description of lived life. It is also loaded with power, because it theorizes interlocutors' agency and resistance that is not necessarily articulated by the interlocutors themselves (ibid). Power and biopower, means used by society to control public health (Foucault 1979[1976]), is in the relation between state and citizen just as it is between anthropologist and study subject. My duty here is not to engage in a discussion of such power, but I am merely acknowledging the relevance of reflections on health issues within the biomedical field. Instead I follow Hastrup's call for advocacy on an ethical standpoint, which acknowledges the interrelated implications between ethics and epistemology (Hastrup 2004b:470). Positioning my study as empathetic I place an ethical duty to explicitly account for experiences, narratives and practices - not only through descriptions but also through theory and interpretations that remain true to the reality of the interlocutors.

Multimorbidity as a research area

Multimorbidity is defined as having two or more chronic conditions simultaneously. People suffering from multimorbidity have a lower quality of life than their peers (Noel et al. 2005), and everyday life with multimorbidity is burdened with symptoms, decreased physical ability and time-consuming treatments (Ørtenblad et al. 2015, Høstrup and Jønsson 2017). Having one chronic condition increases the risk of developing more chronic conditions and hence multimorbidity comes into play (van der Akker 1998). Multimorbid people die younger than people with one or no chronic conditions (Tinetti et al. 2011). Multimorbidity is also associated with an accumulating burden of treatments owing to the number of diseases, which calls for complex treatment strategies considering each individual disease. It leads to a vast amount of treatments to adhere to for each patient (Smith et al. 2010; Shippee et al. 2012) and comes with severe economic challenges for the society (Wolff et al. 2002; Glynn et al. 2011).

Multimorbidity is most frequent among older people, which causes even more challenges, as the population is aging owing to better treatments and prolonged lifespans. The use of health services is greatest among the older, and the older you are, the more at risk you are for developing chronic diseases. In Denmark, more than half the population above the age of 65 has multimorbidity (Larsen et al. 2013).

My project thus fit into a political and societal challenge. The rising number of patients with multimorbidity places the Danish health services in a fragile position, organized as it is into highly specialized units targeting single diseases (Reventlow et al. 2013). Multimorbidity is both caused by and leads to health inequities (Lawson et al. 2013) - owing to health inequity increasing with the number of diseases (Barnett et al. 2012).

Taking a starting point in my fieldwork I draw upon the four cases of people living with multimorbidity. The cases exemplify how health discourses are often perceived as an undefined demand to lead a certain life, which cannot always be attained. These four people navigate in different ways between treatments and biomedical goals set by their doctor, and their own priorities; spiritual, in terms of their relationships, or for simply feeling good. When treatments and exercises are dismissed it can, however, lead to a worsening of symptoms and diseases. This is perceived negatively by health authorities. Following the four cases I aim to show how I subconsciously reproduce this approach - like in sitting across from Lenny, suffering from COPD, an invalidating lung disease, who smokes seven cigarettes during my two hour visit. In my notes I wrote that Lenny would definitely find it easier to get out of the house on his three-wheeled bike as he wishes to, if only he stopped smoking.

The Unhealthy

Prior to my discussion of the juxtaposition between the notion of health that I come to represent, and the notions of health that my interlocutors adhere to, I would like to introduce the reader to four older people. They can be healthy or unhealthy. It depends on the eye of the beholder.

Lenny, the former grocer

Lenny is a 71 years-old man, recovering from alcohol abuse, and suffering from diabetes, COPD and an amputated leg. He was born and raised in a small town on Lolland but had lived most of his adult life in the Copenhagen, until his divorce when he decided to go back. He used to work as a grocer, spending more than 70 hours a week at a medium-sized grocery store, as head of the meat section. In his own words, he is not afraid of hard work. He had to stop working due to the amputation of the leg owing to his diabetes, yet sometimes he moonlights for a friend who owns a small local store where he can do cashier work sitting down. He lives in a small house by himself, alone since his dog was put to sleep by the municipalities during his last stay at the hospital. “Nothing to it… it needed to be done ...since he could not care for it, being away”, he explains. He smokes 40 cigarettes a day and drinks 5-6 beers, but he never touches strong liquor. He explains to me that he used to be a heavy drinker, but that now things are under control. Only seldomly does he get a visit from family, but a girlfriend comes by daily for a chat. When the weather holds and he can manage it, he takes his tricycle to the local club at the harbor. According to himself he rarely does what his doctor tells him to and he does not want to stop smoking, but he takes his medication as prescribed. Most important to Lenny is his self-presentation and image, as someone making his own money and living independently. Too much focus on his diseases makes him feel “like I am being castrated”. To Lenny, whatever little amount of money that he has managed to save is of utmost importance as it allows him to buy a round of beer in the club, and pay the girlfriend to clean “because cleaning is not a man’s job”.

Dee, the artist

At Dee’s house the fireplace is on year-round, and a red cat lies on the carpet enjoying the warmth. Dee is a 69 years-old woman suffering from Parkinson’s disease, arthritis and a stomach disease. She lives with her husband in a small farmhouse and is still an active part of the local community. She used to organize events and start up new clubs, but now the advance of her diseases has forced her to cut down on activities. Yet she remains a focal point in the community. She keeps herself informed on neighbors’ welfare and health. On several occasions, during fieldtrips with Dee and the local culture clubs, I experience how she is calling to check on someone who has not turned up, to check if they might be in need of assistance or help. Hence, Dee provides peace of mind to many of the local inhabitants, despite her own physical disabilities, and the people we meet greet her with warmth. Dee has to take her medications on time, but she often forgets. When asked why she does not set an alarm to remind her, she answers that she refuse let the disabilities control her life. Her Parkinson’s diseases is getting worse because of the arthritis, but she neglects her exercises because she prefers to use whatever little energy she has on her grandchild and her art projects. This seems at first glance to be pragmatic prioritizing in treatments and everyday life, however by looking closer once you get to know Dee you see an image of an older woman who is not capable of keeping up with her treatments despite her attempts to adhere. The diseases are causing both anxiety and sorrow but Dee feels as if neither the doctors nor the municipality health workers are willing to help her, and she is in her own words “*too proud to be begging*”.

Sam, the musician

Sam usually serves traditional Danish smørrebrød and a little something for the sweet tooth when you are visiting. His home is decorated with family photos, mostly of his only child, the daughter. Her graduation picture has the prime spot on top of the fireplace. Proudly, he explains that she is the first in the family to graduate high school. Sam is 73 years-old and suffers from hypertension, arthritis, diabetes type 2 and has some troubles with his right arm. During our first interview, he concludes that I probably cannot use him since he is not really ill. I try to explain that it does not matter how severe the diseases are, that it is more a question of living with chronic conditions and attitudes towards health, and together we decide to include him. Not least, I adduce, because of our common love of smørrebrød. Sam is obese - he and his wife eat a lot of sweets and traditional soul food. They live in a large house with two dogs, in a small village surrounded by fields. In general, Sam struggles to find the motivation for doing the exercises he is recommended: “*I know it’s good to get some exercises. But it’s damn difficult to find the time and the will. When you don’t have time for it, it’s not gonna happen, and if you don't have the will to do it you won’t find the time.*” Instead, Sam spends the days at band rehearsals, walking the dogs, and being at home with his wife. “I’m the type of person who just likes to be at home”. For whatever reason, walking the dogs does not seem to be considered exercise by Sam’s doctor when he refers to their conversations. Instead, he says, he promised the doctor to attempt attending the group exercises they have discussed. He does go for the first couple of weeks, but then he drops out. It begins at 6 pm and that is dinnertime, so he and his wife agree that it is too inconvenient.

Jimmy, The Worker

The 78 years-old Jimmy is suffering from diabetes, bad congestion, arthritis and has had two clots in the heart. He was once diagnosed with painter's syndrome but it was cured, he tells me. He too plays in the local brass band, tolerated by the others but never really a part of the group. Socializing with others does not come easy to him and he prefers to keep his own company a little distant from the others. Once in a while one of the musicians addresses him and he answers politely, shy. He rarely talks, but he and I connect as we both play the euphonium and are seated next to each other when I enter the band in the beginning of my fieldwork. Our interviews contain long passages about the repertoire and opinions on the conductor. After some time, Jimmy agrees to a visit and interview in his home. Entering his small but neat and clean house, where he lives with his dog, my prejudices about older men living alone are shown to be groundless. He does not have any children and the ex-girlfriend ran off with the neighbor a few years ago. At one point she wanted to get back together, but Jimmy was not interested - "*I'd prefer his* [the dog's] *company, him you can rely on*". Jimmy does whatever the doctor tells him to, and knows all of his diseases by numbers. He is vocationally trained and struggles to get recognized as being responsible by the health services. He does not smoke, he adheres to the prescribed medications and he walks the dog daily.

Common to the four people I have presented here, is that they are considered too unhealthy or incapable to perform adequate self-care. At least from the point of view of the health professionals, whom I met during participant observations. Despite Jimmy's attempt to adhere to treatments he often misunderstands what the doctor is saying, which result in a deterioration of the diseases. Both Lenny and Sam have health behavior that conflicts with the biomedical notion of a healthy lifestyle, while Dee ought largely to take better care of herself and her treatments. Yet, they share a self-reported high quality of life owing to their deliberate prioritizing in treatments and everyday life. Their notions of health entail 'hanging with the guys', continuing to do handicrafts, eating good food with the wife, and being alone. It sometimes comes with a downward prioritizing of treatments, but as I shall argue, this is not necessarily unhealthy.

Is it possible to study health?

It is not long before I start to get a bad feeling about my fieldwork position. While looking into treatment strategies and self-care and presenting my study I am often asked by colleagues why the interlocutors are not taking better care of themselves; exercising, eating healthy foods, taking their medication accurately, reacting to potential symptoms and so forth. Readily, I reply that the Lolliks (Lolland natives) I am studying are doing their own pragmatically grounded self-care.

They have other types of resource than are generally recognized and their priorities may seem wrong when looked at through a biomedical lens, yet they are based upon reflective considerations. That remained my statement until one day Lenny discloses to me "*I have been smoking my whole life. I don't see the necessity of suddenly becoming healthy*". In that moment, the air thick with cigar smoke, I realize that my attempt to explain and defend the interlocutor's health behavior is still merely a reproduction of the moral imperative implied in analyzing health behavior from a dichotomous approach, distinguishing between 'right' and 'wrong'. Lenny's decision does not represent a certain type of self-care. He is just not interested in quitting smoking.

Experiences like the one above sets the scene for my ethical and moral considerations. How am I to navigate between the desire to respect the autonomy and self-management of Lenny, while also doing research intended to eventually help Lenny and others like him to gain more quality of life, without the burden of his lung disease restraining him from leaving the apartment? It becomes particularly challenging when I am faced with an assignment interlaced with economic and political governmentality. I find myself in a landscape of moral imperatives, in which can/shall/will becomes ruling altruisms: in the back of my head I hear the public health argument, that people suffering from multimorbidity should perform better self-care *for their own sake*.

My fieldwork thus exemplifies how anthropologists steer simultaneously between scientific rules and ethical challenges to behave ethically towards the people we study. This duality is forced by the anthropological method, assuming both humanitarian empathy and genuine scientific practices. A field of tension that the fieldworker has to learn to navigate within (Hastup 2004a:419).

The anthropologist as translator of culture

"Dear Kirsten, thank you for helping me out. As I wrote, I am in lack of two women for my study, they need to be above the age of 65, have at least two chronic conditions, preferably a mental disorder too. And of course, they have to be living in Lolland. I would like to visit them at home or have an informal chat at another location where they feel secure. After that I figure I'd be in regular contact with them, visiting etc. throughout the next year. Naturally, they can withdraw from the study anytime if they are too overburdened. PS: perhaps you can allure them stressing that I will be bringing smørrebrød or cookies for the interview, haha. Best wishes, Alexandra" (Mail for local gatekeeper, June 2015)

The correspondence above exposes my naivety that I gradually come to realize as I begin to reflect upon my perceptions about the interlocutors. Anthropology bases itself on establishing another to study, only this is a term loaded with value and containing potential conflicts. During the 1980s the representation debate started blooming due to a wish to dismiss the formation of differentiation - it argued taking people's own voices and making them into commercial goods (see Marcus and Fischer 1986). This debate stressed language as a focal point for attention - both unknown language; mother tongue and the tacit knowledge ought to be translated into words by the author (Hastrup 2003:216). Today, the solution applied most often is a discussion on the researcher's positioning and considerations on representations; yet knowledge about the other is still produced within a context of time, place and politics (Fabian 2002). The anthropological discipline, or myself at least, still carry a normative notion of the other; as can be seen in my mail to Kirsten.

Does this mean that none of my material can be used? Far from it. It only presupposes a constant reflection on how and why my empirical object is constituted in this particular way, and the consequences thereof. The philosopher G.C. argues that knowledge is never neutral, and always contains underlying interests. According to Spivak this means that knowledge is to be understood as exported goods from the West to the rest of the world, with the aim of economic gain. Thus she argues that the subaltern other has no possibilities for political representation other than through an intellectual, turning the subaltern others into tacit subjects (Spivak 1988). While Spivak is concerned with the subaltern groups of post-colonial societies, her argument can hold water in our own society if we accept the premise of influence on society being represented only by intellectuals. It might be a little too much, but let us stick to the notion of representation even of local knowledge and narratives require an intellectual 'translator':

"At first I saw that they wrote in Kulturejser something about not allowing for people who could not walk independently […] then I thought I might as well give it a go and I wrote them – Dear Kulturrejser, I have been on this and this tour, and it was very exciting […] and I would love to do it again, but I'm only capable of doing this and this. I can only walk with a stick or holding on to my husband. He can go on some of the long walks, and I can join on the shorter walks, and then I can get a taxi home or whatever […] then they wrote me back that with this attitude I was more than welcome. That was very sweet of them. So I can go even though I can't walk independently. That's OK…well, that's the acute crisis you're getting here" (Dee, interview summer 2015)

Dee is highly engaged in disabled people's rights and she is keen on telling about her experiences. Her point is that people who are not as good as her at asking for what they are entitled to are not getting any help. The above story that she is telling is a way for her to illustrate that you can still lead a good life while suffering from multimorbidity. The last remark about the acute story, she later explains, is that she knows that it might not be relevant for my study, but she has to tell me because maybe I can use it to help other people struggling with the same issues as her.

A study from 1990 shows that groups or individuals with few scientific and social resources are attracting researchers by definition, while groups and individuals with higher levels of these types of resources will have a tendency to be more suspicious or reserved in contact with a researcher (Scott et al. 1990). I adduce that the above interview with Dee calls attention to researchers the risks of presenting our interlocutors as a passive, homogeneous other. Thus we also risk limiting the analytical potential by upholding clear-cut defined groups, and by overlooking connections between such groups and the rest of society (Olwig 2002). Following on from this, we are also obligated to remove the romantic notion of saving the other. The raison d'etre of anthropology must rather be confined to researching how problems are constituted in various cultures and societies (Jöhncke 2003:29).

The rise of self-criticism

As the fieldwork progresses so does my sympathy for the interlocutors, their lives, and priorities. It is manifested in an accumulating critical dissociation from the general political focus and attempt to assure more equity and "uniform public health" [en ensartet folkesundhed] (Region Sjælland 2016a). Following a night of band practice with the local band I noted:

I arrive at the largest school in Nakskov where band rehearsals are held. Dorte greets me and apologizes for the functional shape of the place. First floor hosts a now closed public swimming pool, and the building is in general worn down from wear and tear. The assembly hall is built in old-school classic style and has great acoustics for playing. Band members are setting up music stands. All but a two are men. They speak in the usual hardcore jargon though they seem to hold on to themselves in my present, still fairly new in the band. During the break I ask if there is anyone above the age of 65 who has chronic diseases as I would like to interview them for my study – they all point at each other and laugh. "It's all of us" they say. Henry brought cake, they do it in turns, and we drink beer from the bottle while eating. A couple of men I have been interviewing and whom I know to be diabetics are refraining from having the cake with a "no thank" you loud enough for me to hear. It seems simulated, especially as I have seen them eating cake many times before. Is it because of my presence?

In interacting with interlocutors I have stressed that I study the health choices and priorities one make in everyday life with chronic diseases. I have not formulated it as a focus on social inequity or working-class older people, which it was not intended to be in the beginning. Still, I think that the above exemplifies some of the considerations interlocutors have upon agreeing to participate in a health behavior study. I believe that my very presence as a researcher frames a specific moral ethos for the interlocutors to navigate in, subconscious or not. A stereotype of underdevelopment and unhealthy lifestyle associated with areas like Lolland facilitates the interlocutors to question their actions: "*We are just not good at taking care of ourselves, down here… [the illnesses] are probably my own fault*" Max says. As I have argued, the public perception of illnesses are associated causally with unhealthy food habits, smoking, obesity, lack of exercise and a lack of understanding of one's own diseases. This is a perception that my interlocutors seem to have adopted.

Danish anthropologist Charlotte Baarts describe her fieldwork among providers of complementary treatments in Denmark as being caught between the perception of health in the field and biomedical established 'truths' (Baarts 2009:430), a tension I recognize. Once again I start to question if I am actually establishing a de facto biased relation and determine my interlocutors as 'underdogs'? According to Baarts, qualitative researchers are always in a biased relation with 'the underdog', meaning the party who has the least academic or social resources (Ibid: 423). Although my interlocutors are not defining themselves as fragile or lacking resources, their position in society are reflected when they meet the 'overdog', as this story show:

> Alexandra: *So you don't always believe what the doctor is telling you?*
> Jimmy: *No, not always. Sometimes it's like they don't really care.*
> Alexandra: *Can you try to explain that?*
> Jimmy: *It's just this sense that I get. Like one time…when I worked I slept no more than five or six hours a day, I got up at 5 in the morning and drove to work, but nowadays as I read the paper in the late morning I sometimes fall asleep. I told him [the GP] that I felt very tired during the day, but he just said "Oh well, you have to keep your age in mind". Later, another doctor told me that it has something to do with the injections I get at the hospital, but my own doctor, he just brushed me aside.*

My project began like many other medical anthropological studies as a clinical relevant study, bringing anthropological insights to contribute to solutions of clinical, biomedical problems

(Rhodes 1996:165). Now I am moving towards a critical anthropological study focusing on the political and socioeconomically structures making up the health services and defining the character of care.

Deliberately, I change my title from ‘medical anthropologist’, which to me carries close connotations to a biomedical frame of understanding disease, to the more holistic ‘health anthropologist’. Likewise, I change the way I name the participants from ‘informants’ to ‘interlocutors’[3]. None of those terms are mine, but these are just the current developments in anthropological writings. It might be next to nothing, but it is a start, at least.

Empathic Knowledge Production

Despite the above point of view I am still personally anchored within biomedicine. I truly believe that if the arthritis doctor told my interlocutor that more exercise would alleviate symptoms, he is right:

On my way from interview with Sam. While we were preparing lunch he told me, that he hasn’t been doing the exercises the doctor told him to, because he doesn’t see the point of them. I think he might feel that they are too ‘yoga-like’. I tried to dig deeper into this, but he insists that he gets all the exercise he needs from walking the dogs, even though that doesn’t really do anything for his arm, and I am pretty sure that it is a trumpet-related injury that needs to be rehabilitated. (Field note, winter 2015)

The above note is recorded after a visit with Sam, who suffers from hypertension, diabetes, arthritis and something not-diagnosed with the arm. I still believe that it would have a positive effect if Sam did his exercises. He does not care to, yet he does not want to stop playing so he has come to terms with the arm. That is my point, though. Empathic knowledge production does not mean for us to agree with out interlocutors. Conversely, it would not be ethical to disregard our research interests or personal beliefs due to our interlocutors’ priorities (Baarts 2009:431). Instead, I call for us to make room for taking into account interlocutors’ opinions *while* doing ethical research. In my study it means a renewed focus on organizational reasons for and individual consequences of inequities in health while staying aware as not to be reproducing notions of what defines resources or ‘wrong’ health and social behaviors. As noted, any anthropological analysis will always contain an implicit contrast between what others know about themselves and their life worlds, and the knowledge that the anthropologist seek for (Hastrup 2004a:412). While I refer to research on the burden of multimorbidity, the interlocutors share stories of having a good life ‘in spite of diseases’, of feeling neglected and inferior in health services, and of marital consequences of being chronically ill.

Conclusion

It is not the intention of this article to make studies of health invalid or speak against large research initiatives. Thus I need to stress two things. *Firstly*, that social and health inequities are well-suited areas for anthropological studies, using focus on particularities to create a far more nuanced understanding of what inequity means. Existing parameters on education and income (see Sundhedsstyrelsen 2017) are liberated from normative understandings and replaced with knowledge on the individual's belonging and contribution to collectives and society. I argue that despite this article's self-critical journey, a focus on health and inequities is an anthropological obligation, which we should use to engage in the world. *Secondly*, it is not my point to create fear of contact with political and morally loaded fields. The anthropological methods are not only establishing but also developing analytical fields. It means that the knowledge we produce is not only shedding lights on people's lives but also directly interfering with their life worlds through interventions and policies (Hastrup 2004a:419). It goes both ways. The people we study also have agency as individuals or groups trying to get a political or economic agendas through in participating in research (Baarts 2009:425).

Taking a starting point in my fieldwork among older men and women from Lolland suffering from multimorbidity, this article has looked into the juxtapositions of health research: health is presented within a moral frame, which I unreflectively have partly reproduced, that opens to the different stands of biomedical understandings of health and the people who are living with or against such understandings. The overall argument is, that research ethics in health studies are foremost an ethical and empathic consideration of such juxtapositions.

Keeping the balance between revealing epistemological differences and practicing anthropology anchored within biomedical health perceptions are forming the ways in which we do fieldwork and the questions we pose the interlocutors. Empathic knowledge production is the premise that can create a more unified understanding of biomedical terms such as multimorbidity, when it is discussed in an empirical context of everyday life and experience. The task is to produce knowledge in constant dialogue with ethics and self-reflections. I have tried to turn four people's stories and my own self-critique into an academic discussion with the hope of pointing to underlying principles and logics guiding the priorities of older people with multimorbidity. Acknowledging that this cannot be done alone, I hope that my research will contribute to policies that create better opportunities and quality of life when living with chronic diseases. No matter what understanding of health you adhere to.

Notes

1. In recent years, the demography is changing. People no longer die from but live with chronic conditions, owing to more and better treatments. As a consequence, a rising number of people are living with two or more chronic conditions. Today, about 30 percent of Danish adults have multiple chronic conditions (Larsen 2017). Having several chronic conditions at once complicates treatment and self-care and makes large demands of the individual in terms of adherence and overview. To attend to this rising public health challenge, many researchers now operate with the term ‘multimorbidity’ (Frølich et al. 2017). There are several definitions, in this article I adhere to the broadest: two or more chronic conditions within a patient (van der Akker et al. 1996:69). The severity of the diseases is not important for this particular study.
2. The project is an industrial PhD from 2014-2017. Besides the Ministry of Research and Innovation, the project is funded by Helsefonden, The General Practice Fund, Region Zealand, and The Research Unit for General Practice and Danish Patients.
3. To an American audience this might seem odd as ‘informants’ have long been dismissed as term for participants. But in Danish ‘informanter’ is still comme-il-faut and ‘samtalepartnere’ are rarely used. In fact, the editors made me change the wording in the Danish article back to ‘informanter’ (informants) instead of ‘samtalepartnere’.

References

van den Akker, M., F. Buntinx & J.A. Knottnerus

1996 Comorbidity or multimorbidity: what’s in a name. A review of literature. European Journal of General Practice 2:65-70.

van den Akker, M., F. Buntinx, J.F. Metsemakers, S. Roos & J.A. Knottnerus

1998 Multimorbidity in general practice: prevalence, incidence, and determinants of co-occurring chronic and recurrent diseases. Journal of Clinical Epidemiology 51(5):367-75.

Baarts, Charlotte

2009 Stuck in the middle: research ethics caught between science and politics. Qualitative Research 9(4):423-439.

Barnett, K., S.W. Mercer, M. Norbury, G. Watt, S. Wyke & B. Guthrie

2012 Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. The Lancet 380(9836):37-43.

Brown, Peter & Marcia Inhorn

1996 Disease, Ecology and Human Behavior. In: T. Johnson & C. Sargent (eds.): Medical Anthropology. Contemporary Theory and Method. Pp. 187-214. Westport, Connecticut: Praeger.

Davis, Michael

2010 Bringing ethics up to date? A Review of the AIATSIS ethical guidelines. Australian Aboriginal Studies 2:10-21.

Fabian, Johannes

2002 [1983] Time and the other: how anthropology makes its object. New York: Columbia University Press

Foucault, Michel

1979 [1976] The History of Sexuality Volume 1: An Introduction. London: Allen Lane.

1988 Technologies of the self. In: L. Martin, H. Gutman & P.H. Hutton (eds.): Technologies of the Self. A seminar with Michel Foucault. Pp. 16-50. Amherst: University of Massachusetts Press.

Frølich, Anne, Frede Olesen og Inge Kristensen

2017 Introduktion og generelle forhold. I: A. Frølich, F. Olesen & I. Kristensen (red.): Hvidbog om multisygdom. Dokumentation af multisygdom i det danske samfund – fra silotænkning til sammenhæng. S. 15-17. Virum: TrygFonden.

Glynn, L.G., J. Valderas, P. Healy, E. Burke, J. Newell & P. Gillespie

2011 The prevalence of multimorbidity in primary care and its effect on health care utilization and cost. Family Practice 28(5):516-23.

Hastrup, Kirsten

2003 Sproget. I: K. Hastrup (red.): Ind i verden. En grundbog i antropologisk metode. S. 207-227. København: Hans Reitzels Forlag.

2004a Refleksion. Vidensbegreber og videnskab. I: K. Hastrup (red.): Viden om verden. En grundbog i antropologisk analyse. S. 409-425. København: Hans Reitzels Forlag.

2004b Getting it right. Knowledge and evidence in anthropology. Anthropological Theory 4(4):455-472.

2013 Vi bebor mangfoldige verdener – eller? Imod udsagnet. Tidsskriftet Antropologi 67:41-47.

Højbjerg, Christian K.

2013 Den ”ontologiske vendings” utilstrækkelighed. Imod udsagnet. Tidsskriftet Antropologi 67:29-34.

Høstrup, Helle & Alexandra Ryborg Jønsson

2017 Livet skal leves mens man har det. I: A. Frølich, F. Olesen & I. Kristensen (red.): Hvidbog om multisygdom. S. 21-27. Virum: TrygFonden.

Jöhncke, Steffen

2003 I den gode sags tjeneste? Om antropologi, stofbrugere og lodrette forbindelser. Tidsskriftet Antropologi 45:29-47.

Kaufman, Sharon & Lakshmi Fjord

2011 Medicare, Ethics, and Reflexive Longevity: Governing Time and Treatment in an Aging Society. Medical Anthropology Quarterly 25(2):209-231.

Kleinman, Arthur

1995 Writing at the Margin: Discourse Between Anthropology and Medicine. Berkeley: University of California Press.

Larsen, Finn Breinholt

2017 Multisygdom – hvad er problemet? I: A. Frølich, F. Olesen & I. Kristensen (red.): Hvidbog om multisygdom. S. 27-35. Virum: TrygFonden.

Larsen, Finn Breinholt, Karina Friis, Mathias Lasgaard, Marie Hauge Pedersen, Jes Bak Sørensen, Louise Margrethe Arildsen Jakobsen & Julie Christiansen

2013 Hvordan har du det? Sundhedsprofil for regioner og kommuner. Region Midtjylland: Center for Folkesundhed.

Lawson, Kenny, Stewart Mercer, Sally Wyke, Eleanor Grieve, Bruce Guthrie, Graham Watt & Elisabeth Fenwick

2013 Double trouble: The impact of multimorbidity and deprivation on preference-weighted health related quality of life a cross sectional analysis of the Scottish Health Survey. International Journal for Equity in Health 12:67.

Marcus, George & Michael Fischer

1986 Anthropology as a Cultural Critique. An Experimental Movement in the Human Sciences. Chicago: University of Chicago Press.

Noel, Polly Hitchcock, B. Chris Frueh, Anne C. Larme & Jacqueline Pugh

2005 Collaborative care needs and preferences of primary care patients with multimorbidity. Health Expectations 89:54-63.

Olwig, Karen Fog

2002 The ethnographic field revisited: Towards a study of common and not so common fields of belonging. In: V. Amit (ed.): Realizing Community: Concepts, social relationships and sentiments. Pp. 124-145. London: Routledge.

Oxlund, Bjarke & Susan Whyte

2014 Measuring and Managing Bodies in the Later Life Course. Journal of Population Ageing 7(3):217-230.

Rabinow, Paul

1994 Introduction. In: P. Rabinow (ed.): Michel Foucault – Ethics: Essential work of Foucault 1954-1984. Pp. 11-42. London: Penguin Books.

Regionen

2016 Definition af yderområder. https://regionalt.erhvervsstyrelsen.dk/definition-af-yderomraader

Region Sjælland

2016a Broen til Bedre Sundhed http://www.regionsjaelland.dk/Kampagner/broen-til-bedre-sundhed/Sider/default.aspx

2016b Lolland Falster er mulighedernes land http://www.regionsjaelland.dk/nyheder/Sider/Lolland-og-Falster-er-mulighedernes-land.aspx.

Rhodes, Lorna Amarasingham

1996 Studying Biomedicine as a Cultural System. In: T. Johnson & C. Sargent (eds.): Medical Anthropology. Contemporary Theory and Method. Pp. 159-173. Westport, Connecticut: Praeger.

Sausdal, David & Henrik Vigh

2013 Den ontologiske blænding. Om den ontologiske vendings metodiske og politiske problemer. Tidsskriftet Antropologi 67:101-121.

Scott, Pam, Evelleen Richards & Brian Martin

1990 Captives of Controversy: The Myth of the Neutral Social Researcher in Contemporary Scientific Controversies. Science, Technology and Human Values 15(4):474-94.

Shippee, Nathan, Nilay Shah, Carl May, Frances Mair & Victor Montori

2012 Cumulative complexity: a functional patient-centered model of patient complexity can improve research and practice. Journal of Clinical Epidemiology 65(10):1041-51.

Smith, Susan, Siobhan O'Kelly & Tom O'Dowd

2010 GPs' and pharmacists' experiences of managing multimorbidity: A 'Pandora's box’. British Journal of General Practice 60(576):285-294.

Spivak, Gayatri C.

1988 Can the Subaltern Speak? In: C. Nelson & L. Grossberg (eds.): Marxism and the Interpretation of Culture. Pp. 271-313. Basingstoke: Macmillan.

Sundhedsstyrelsen

2011 Ulighed i sundhed. Årsager og Indsatser. http://www.sst.dk/~/media/F674C77308FB4B0CA00EB038F17E239B.ashx

Svendsen, Mette Nordahl

2009 Kritisk engageret videnskab: Erfaringer fra forskning om gen- og forplantningsteknologierne. Tidsskrift for Forskning i Sygdom og Samfund 10:37-57.

Tinetti, M., G. McAvay, S. Chang, A. Newman, A. Fitzpatrick, T. Fried & P. Peduzzi

2011 Contribution of multiple chronic conditions to universal health outcomes. Journal of the American Geriatrics Society 59(9):1686-91.

Wolff, Jennifer L., Barbara Starfield & Gerard Anderson

2002 Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. Archives of Internal Medicine 162(20):2269-76.

Ørtenblad, Lisbeth, Alexandra Ryborg Jønsson & Lucette Meillier

2015 Komplekse liv: Patientinddragelse som vej til et bedre hverdagsliv for multisyge? Tidsskrift for Forskning i Sygdom og Samfund 22:83-101.

Article 5

What the doctor doesn’t know: Discarded patient knowledge of older adults with multimorbidity.

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Keywords

patient knowledge, patient involvement, patient communication, multimorbidity, aging

Abstract

Objectives

The involvement of patients with chronic diseases in treatment and care planning requires knowledge about the patient's everyday life. This article explores older adults with multimorbidity's disclosure practices of such knowledge.

Methods

This was an 18-month ethnographic study among 14 older adults with multimorbidity living in a socially deprived area of Denmark. An abductive analytical approach was applied, focusing on perceptions of patient knowledge.

Results

Older adults with multimorbidity have various reasons for not disclosing personal knowledge. The results present three different domains of what we termed discarded patient knowledge. The domains are: 1. Knowledge that from participant's perspective has no direct biomedical relevance; 2. Knowledge considered too private; and 3. Knowledge assumed to position one as inferior.

Discussion

Participants' disclosure practices showed that personal knowledge is sometimes not recognized as being important for healthcare by participants themselves. Participants sort and disqualify knowledge, judging it within frames of biomedicine and hence adapting to a biomedical disease model. If the experiences or knowledge could have influenced the understanding of the patients' problem and provided different solutions, we argue that it should be understood as patient knowledge, though discarded by patients themselves.

Introduction

The number of older adults living with two or more chronic conditions, known as multimorbidity, (MM) is rising worldwide (1, 2). Older adults with MM are associated with poor health status and severe economic strains on healthcare systems (3, 4). Yet, health services are not addressing the complex needs of this group (5), and everyday life is seldom taken into consideration when planning treatments and self-care, despite dilemmas relating to individual priorities in managing MM in everyday life (6). Following this, to the older adults, managing MM becomes progressively more complex and difficult with the number of intricate treatments and self-care approaches (5, 7, 8). While medical adherence is of particular clinical importance to older adults with MM (9), general recommendations to older adults also account for the treatment and prevention of chronic conditions. For instance, older adults (age >65) are recommended to perform aerobic, muscle-strengthening and flexibility activities in order to prevent and treat diseases and disablement (10). Likewise, the nutritional status of older adults are an important factor for healthy aging (11). A low BMI status in particular endangers older adults to whom, for reasons relatively unknown, weight loss is related to increased risk of death (12). Older adults with MM may have low adherence or drop out of treatments owing to difficulties encompassing treatments and general health recommendations into everyday life (6). One explanation for the poor health outcome for older adults with MM could be the lack of involvement of patients' individual experience of living with MM (6). However, the viewpoints of older adults about difficulties in managing MM are a crucial domain of knowledge that includes personal and social factors, life goals and everyday priorities. Medical knowledge is crucial for treatments, but it needs to respond to the patients, and this requires a deep knowledge of their perspectives (13, 14). Following this, research has shown that patient adherence is improved when communication between health professional and patient involves patient knowledge (15-17). Patient knowledge is here defined as an individual's knowledge on personal experience with diseases, values and preferences (18). This definition constitutes patient knowledge ranging from bodily experiences of minor symptoms that the patient recognizes as harmless, to knowledge about family relations that affects adherence.

Involving patient knowledge, in essence, builds on the philosophy of bringing health professionals' pathophysiological treatments together with the life worlds of the patients (19). However, little is known about patients' reasons to self-disclose (statements made about one's personal knowledge and experience) (20) or withhold patient knowledge, especially in the context of older adults with MM. This study sought to understand patients' discarding of and reasons for (not) disclosing patient knowledge to their General Practitioner (GP) as a process of sorting and categorizing patient experience.

Research conducted so far has focused on disclosure practices during the consultation (21-23). Lim et al. show in a study that patients with MM have various disclosing practices, relating to perceptions of what is pertinent to disclose, interpersonal relationship with the health provider, and limitations in communication (20). Additionally, studies have explored impediments for patients to share knowledge with physicians, showing barriers to disclosure to include stigma, anxiety, embarrassment and patients' thinking that certain information is not important (21, 24).

The present study is set among older Danish adults with MM. Contributing to the body of research we investigated how the participants categorized particular aspects of everyday personal knowledge. If disclosing such knowledge could have had an influence on the diagnosis, treatment or focus during the consultation from a medical point of view, we place it within a domain of discarded patient knowledge and present the participants' reasons for not self-disclosing it.

With medical anthropologists Arthur Kleinman's remark on including the cultural context that illness narratives and perceptions are emerging within (19), the results are found through a medical-anthropological study of 14 older patients with MM. Thus, this article presents important understandings for involving patient knowledge in the future care of older adults with MM.

Methods

The study was designed using ethnographic methods. Ethnographic methods are well-suited to investigate what matters to patients in everyday life as it allows for longitude in-depth studies of individual choices and priorities (25). Ethnographic methods also enables the attention towards tacit enactment of routines and things done, as a form of knowledge articulation (18). Thus, healthcare behavior and adherence can be seen in the midst of an everyday life prioritizing within treatments, self-care and personal values such as relationships or hobbies.

Ethics

Participants received information about the study during recruitment and again immediately before the first interview and gave informed consent verbally. Names and ages have been altered to assure anonymity. The study did not need ethical approval according to Danish research guidelines, but was approved by the Danish Data Protection Agency (#2015-41-3826).

Data collection and participants

Data was collected through 18 months of anthropological fieldwork exploring everyday life of older adults with multimorbidity in February 2015 to August 2016 conducted by the first author. Seven women and seven men were included based on criteria of age > 65 and diagnosed with two or more chronic conditions requiring ongoing medical attention.

Patients were contacted through observations in general practice consultations, and immediately following the consultation asked if they were interested in participating. A home visit and interview was scheduled within the following weeks with seven participants. Building on this, the following participant selection happened as a snowball sampling, as both health professionals and participants referred adults that they knew fulfilled the inclusion criteria and might be interested in participating. Upon granting permission these adults was then contacted by phone by the first author, and an interview and home visit was scheduled. In total, eight women and nine men in the age range of 65-90 were contacted. Seven women and seven men agreed to participate. They had between three and six chronic conditions, and approximately two thirds of the participants had both somatic and mental conditions, mostly depressions, which influenced on their daily lives. Additional background characteristics of the participants are shown in table 1.

The fieldwork started with a narrative interview (26) of one to two hours focused on the participant's perception of their medical history and life experience. Following this, follow-up interviews were conducted with each participant, lasting from 30 minutes to two hours. Additionally, numerous informal talks and chats were also included in the data. Participants were interviewed using a flexible interview guide about the following topics: background, development of diseases, ongoing treatments, and social relations, good and bad experiences in health services, hobbies, food habits, alcohol consumption, medication, and self-care. Details on health and well-being, and daily life in situ worked well for articulating knowledge that is tacitly enacted though routines and other things. After the first author got to know the participants a little better, she started to be curious about certain things, for instance, how conflicts in the family would affect the mood and the attitude towards self-care. Participants were then directly asked if they would share such conflicts with health professionals, and their reflections on whether they did or not.

Interviews were carried out in participants' homes. To get a better understanding of the social and local context the fieldwork also included participant observation as the first author were present in parts of the participants' social lives. The participant observations made it possible to collect data concerning participants' everyday routines, and interviews provided information on interactions with the health system. Interviews were transcribed, and field notes and observations were written from memory (27).

Data analysis

A qualitative abductive analysis approach was used to analyze data (28). The transcripts and notes were coded using NVivo. In this process the analysis focused on the identification of meaningful parts. The codes was divided into sub-codes to obtain a deeper understanding of the data, and patterns of meaning emerged. The authors then discussed and reflected on these patterns. Parts of transcripts would regularly have more than one code assigned.

One participant (P1) had described his hobbies as spheres of his private life “which the doctor doesn’t know”. This lead to an inquiry about the realms of patient knowledge and their disclosure practices of personal knowledge. The analysis was then situated within a theoretical framework of patient knowledge.

Pols argues that patient knowledge is a particular form of knowledge that comes from experiencing and living with diseases. That knowledge is both consciously and subconsciously used and developed in patients’ daily practices in order to live with their diseases(18). Therefore to Pols patient knowledge is co-shaped in medical practices, influenced by encounters with health services and technologies as a particular knowledge form generated from a first person perspective situated in the conduct of everyday life and across contexts of social practice(18). In a report on shared decision making Coulter and Collins suggest using patient’s knowledge of their values, preferences, attitudes towards risk and everyday life in general to involve patients in decisions about treatment and care (29). This moves patient knowledge into a more private and personal sphere of everyday life experience, not necessarily in direct association with managing disease. However, as suggested by Lim et al. the *everyday personal* knowledge is not necessarily understood by patients as patient knowledge (30). Building on these three approaches, we set the analysis on patient knowledge as knowledge ranging across a continuum moving from being practical experiences translated into knowledge useful in daily life with diseases, to being everyday life experience and personal knowledge on for instance social relations, immediately detached from disease. It is important to notice though, that in our definition, in order for experience to become knowledge, it has to have a perceived medical effect for the understanding of the patient’s problem or management of diseases. The medical effect was evaluated by the two authors with a medical doctor background.

Based on this, we use the term ‘discarded patient knowledge’ to define boundaries of what patient knowledge is and how patients categorize relevant and irrelevant knowledge. Thus, discarded patient knowledge can be enactments or articulations of values and preferences in relation to what matters most to patients in their lives.

Results

The results present three different domains of discarded patient knowledge and the participants' reasons for not disclosing it to their GP. On different occasions, a participant could be expressing none or all of the reasons for not disclosing patient knowledge within these domains. We organized the results with the inclusion of nuances; acknowledging that the older adults with MM had different perspectives and reasons in constituting patient knowledge and in their disclosure practices.

Knowledge that from participants' perspective had no direct biomedical relevance

Besides the regularly scheduled follow-up checks on chronic diseases, the participants said they would contact the GP for, essentially, concerns about symptoms, things that were going in the wrong direction with their treatments or experiencing physical or mental illness. In the wake of such thinking, the participants said that they articulated only what they perceived as somewhat biomedically relevant. Such concerns would according to participants hinder disclosure if they were not GP-able; meaning a problem worth the medical attention of the GP (23).

When describing why and how often he saw his GP, an older man said:

> "*I go there a couple of times a year, for my regular check-ups. A week prior I've measured my blood pressure, you know, morning and nighttime, I write it down. Then he checks the numbers and also, I've had a blood test taken so that he can check up on my cholesterol and what else they want to check on. Those are great numbers, he says and well, that's it. I don't bother him anymore than that*" P4

On the contrary, P4 said in an interview that he had not told his GP about the concern that his sore arm and shoulder were preventing him from walking the dogs, which was a great loss to him. He explained to the first author that a sore arm was nothing serious and that it was just part of aging.

When P1 was asked to describe what he would initiate a consultation with his GP for, beside the regular check-ups, he explained:

> “*Well, you know, something like if you get an infection or maybe, it’s important to be aware of cancer symptoms, they can catch it early. I haven’t tried that though. I think last time I went to see her* [the GP] *besides the controls was last year when I had pneumonia*” P1

Here, P1 lists conditions with immediate biomedical relevance. When asked what he would not then see his GP for he said:

> “*Everything else* [laughing]. *No, you see the doctor for health issues. Nothing else*”.

Participants would mostly ascribe to the idea that a GP are within the biomedical sphere and many participants hence perceived that only problems of a biomedical character would be welcome in the clinical encounter. Their demarcation of biomedical was individual. Additionally, many participants would not want to burden others including their GP, and they would avoid taking up the GPs time unnecessarily, as described by P14:

> *“I would hate to be a burden to anyone. I don’t want my children to be saddled with my illness. And my GP, no, no, I would never encumber him with little things, not as long as I can take care of myself”.* P14

In reality, it meant that some of the participants did not see their doctor for what they considered minor things, i.e. a pain in the stomach or a continuous headache. Many participants said they would not bring up problems that they did not perceive as biomedically relevant.

Knowledge considered too private

In some regards, some of the participants had limits to what they wished to share with their GP. Despite many participants expressing a trusting relationship with their GP, to some, aspects of their everyday life were considered too private to share.

One of the themes running through the participants’ consideration of private knowledge was related to sexuality. P11 said that some topics like sexual problems would be too taboo to be revealed to a GP unless it was in direct association with a disease. P2 felt unease talking about it with others than his GP, but said in an interview that he was suffering from impotence. He had spoken to his GP about it, because it was related to his prostate cancer. Another man, P3, was experiencing mild incontinence. This was not disclosed to his GP since P3 had seen on the internet that incontinence was a chronic condition, and that the solutions would be aids like special underwear or adult diapers, none of which he would ascribe to. He then felt no need to share this problem with his GP. It only came up in the interview by coincidence as the first author was introducing herself and her former research on urinary incontinence treatments for older men, which lead to a talk of possible aids. When asked if he had not asked his GP about alternative solutions, P3 explained he felt it was a private problem that did not need to be shared with the GP.

Another type of patient knowledge that was not disclosed due to privacy was crisis in personal relations. For instance, P5, an older man said that he did not share with his doctor, that he had an ongoing conflict with his son:

> *"…we have never fought like this, it's really taking my energy, I can't sleep, I twist and turn all night. I know that I can be stubborn, but I really feel he owes me an apology. The thing is, I miss him. He would come by for lunch, you know with beer and smørrebrød* [traditional Danish food]*….I don't eat very much these days, I've always been like that, losing appetite if something is wrong"* P5

According to P5, his GP voiced concern about his low weight during a prior consultation, to which P5 had answered that he would make sure to eat better. However, P5 explained to the first author that he was still struggling with loss of appetite and did not see what else to do about it but add some extra butter in the meals and add cream in his coffee.

Not disclosing family-related conflicts were not just due to privacy concerns but also the perceived consequences of such crisis. A participant, whom is anonymized as Px, said about his wife suffering from multiple sclerosis, in a confidential moment with the first author, that he felt his life would be a lot easier if he lived alone. He explained:

> Px: *It is a burden at night-time when she can't get out of bed. Then I have to get up and lift her legs out of bed, it's quit a task*
> Interviewer: *And does this affect your diseases?*
> Px: *No, well, yes. I still exercise*
> Interviewer: *Where is she* [spouse] *then, she can't be alone can she?*
> Px: *Well it isn't until lately that she has gotten so ill. I don't know how we're going to manage. Then it is a nursing home or something.*

The participant later explained that he was not bringing this issue up with his GP or anyone else, despite the fact that he was about to give up his exercise, because his wife could not be home alone. He felt guilty that he was sometimes annoyed with his wife, but he believed he was making the right priority. When asked if he had discussed other possibilities to help him handle the everyday challenges, he refused angrily and said:

> *"Our private challenges are nobody else's business".* Px

However, a few participants said that they told their doctor everything. They could not think of anything to keep from the GP, though, as already described, they would only share patient knowledge if they felt it pertinent. Albeit, it was individual how much and why some patient knowledge was considered too private and some would in interviews reflect that it changed over time, depending on their relation to their GP.

Knowledge assumed to position one as inferior

In some cases, confusion and insecurity indicated a lack of knowledge regarding treatments and self-care but this was not voiced, as participants feared perceived judgment from the GP. When asked why she had not told the GP about her confusion concerning the intricate dietary prescriptions for diabetes and her AK treatment, P12 said: "*I don't want to look stupid*". This attitude of concealing insecurity and confusion was reflected in similar situations when brought up during interviews or observations. P7, an 84 year old retired vocational worker, would confuse his medications but did not tell anybody. One day, when the first author was visiting and began to read labels on the pill glasses she asked if one pill that P7 had pointed out as once a week was not in fact intended for once a day. It lead to a conversation of the confusing nature of the pills, but P7 refused to ask his GP for help as he was afraid to seem incapable of following "*simple treatment plans"* and be regarded as stupid.

One woman, P9, described how she would try to appear well-informed as a means to getting the best treatment, at the expense of articulating worries or insecurities:

> *"GPs always like adults who are smart, so I make sure to mention that I myself have been working in the health care system. He knows that I am one of those patients that he can really reach, and then he will make an effort to help solve my problem. If I have something I am worried about, like the cough you saw me with last week, I would always just check the internet myself , and then if I go see the*

> *doctor, I will not be all like 'something is wrong, I don't know what it is'. That's not who I am".* P9

For P9, remaining in control of her self-presentation led her to mitigate doubts and insecurities by checking the internet beforehand or simply not disclosing such insecurities.

Another type of fear, which led participants to not self-disclose knowledge, was circumstances or ideas that participants perceived as "banal", and described a fear of judgment as an impetus to keeping silent about it. P2 had had diabetes for more than 40 years and takes his disease very seriously. He carefully managed his blood sugar levels and made sure to report any abnormality in measurements to his GP, and he claimed that his GP always praised him for doing a great job managing the diabetes. Yet, he had anxieties about hospitals and was frightened to be hospitalized. During a hospitalization in 1977 he had what he perceived to be an out-of-body experience, looking down at himself, going through a tunnel of light. He explained that he felt as if he had died for a moment, only to return knowing that death was waiting for him. It had let him since then to do whatever possible to avoid hospitalization, but he had not told the GP why:

> P2: *Maybe I should have told the nurse back then, but I didn't. It was years before I told my friends.*
> Interviewer: *Did you tell your GP?*
> P2: *No, no I know it's stupid, and I should just forget it*
> Interviewer: *Do you think it has an impact on your health, this experience?*
> P2: *Hm…I don't know. I still have that fear of hospitals, so I'm not telling if for instance the levels* [blood sugar] *are too high because I don't want him to refer me to the hospital, and I prefer to just wait and see on my own. Then off course if it gets out of control I will call him* [GP]. *I have been to the hospital since then, I just really try to avoid it.*

Albeit, participants had a range of strategies to avoid being displayed as ignorant. There was incongruence between the belief that the GP could help you, and then not wanting to voice concerns or insecurities that perhaps would bring attention to non-adherence, which participants associated with not understanding treatments.

Discussion

In accordance with previous research (20, 21), we found that there are limits to what participants disclosed to their GP. We then found that these limits could be understood within three types of knowledge domains: 1. Knowledge that from participants' perspective had no direct biomedical relevance; 2. Knowledge considered too private; and 3. Knowledge assumed to position one as inferior. The knowledge domains were presented with participant's reasons for not disclosing, adding to the current research on disclosure practices and patient knowledge.

In research, self-disclosure practices have evolved around consultation studies, focusing on patients' unvoiced agendas (21), or patients' self-disclosure in therapy (22). Such studies show that whereas most patients disclose some personal and private information, there is a significant proportion of knowledge that remains concealed. Patients conceal knowledge for several reasons; for instance they worry about judgment (31) or they find that it is not pertinent to disclose (20, 23). While these studies have laid the groundwork for understanding self-disclosure practices, we suggest looking at what is not self-disclosed as particular domains of patient knowledge in the context of involving patients.

Pols stresses that patient knowledge should not be separated from medical knowledge, as patients are medically socialized when living with chronic conditions that form an integral part of their knowledge(18). On the subject of knowledge stemming from daily life experiences, Coulter & Collins describe patient expertise as knowledge on how disease and treatment impact on one's everyday life, attitude towards risk, and values and preferences (29). Following this, we suggest patient knowledge to be both practical knowledge used to cope with diseases but also knowledge and experiences that does not necessarily relate to diseases, but have a great influence on the way one manages MM. Such knowledge could for instance be to know that attending a grandchild's wedding would be prioritized over treatment advice to rest, or it could be the experience, that doing a certain amount of muscle-strengthening activity is too much to overcome in everyday life.

'Discarded' implies that knowledge on everyday life, values and preferences is not necessarily recognized immediately in relation to diseases. Hence, knowledge consisting of mundane or private details of personal life presented by the participants in the results section is discarded patient knowledge because it is not recognized as relevant to self-disclose. Yet, these domains of knowledge are enacted in everyday life and may influence health related decisions and hence have clinical relevance. For instance, when P4 does not disclose that his sore arm hinders him in walking the dog, as he places the problem as a part of aging and hence not pertinent to discuss with the GP. However, from a clinical point of view, walking the dog could for P4 be an important part of health: referring to the recommendations of the American College of Sports

Medicine and the American Heart Association, which have been used as a model for the Danish recommendations, virtually all older adults should be physically active. For those with chronic conditions, they should be physically active in what they are capable of doing to treat the conditions and to reduce the risk of developing further conditions (10).

Our results show that the older adults in this study establish personal experiences and lay explanatory models (19) as a component of treatment and self-care (19, 32), though not always sharing this type of patient knowledge. For that reason, all domains of patient knowledge are crucial parts of evidence based medicine, which requires “a bottom up approach that integrates the best external evidence with individual clinical expertise and patients' choice” (14), patient centered approaches acknowledging patients’ personal values (33-35) as well as patient involvement, requiring patients to disclose values and preferences in regards to treatments and care (36).

Following this argument, we raise the question of how patients are involved in planning their own care with the GP: how is it possible for GPs to involve patient knowledge adequately in care and treatment, if the patients sometimes refrain from disclosing what turns out to be important knowledge? That is a great challenge, not least for older adults with MM that discard knowledge, and whom are at greater risk of having low adherence and of dropping out of treatments (37) . However, our results show that although many GPs are conducting patient-centered consultations from a biopsychosocial perspective (34), the participants in this study seem to adapt a narrow biomedical understanding of disease and care, omitting patient knowledge they consider to be out of the realms of biomedicine. According to the biopsychosocial disease model, diagnosis should include both biological, psychological and social circumstances to aim at a more holistic approach (38, 39). In the setting of general practice, the GP relies heavily on patients to engage in conversations, describing the problem etc. This points to an inverted version, where the patient is the one involving the GP in their lives. It does also point to older adults anticipating an implicit power relation, where the GP retain a significant level of control into what is being discussed (40). Anticipating such power relations might affect what is being disclosed, as results show how some older adults are trying to be socially competent and live up to what they perceive doctors to expect; a focus on biomedically-defined diseases and treatments. Some older adults in this study believe, that in order to get the best treatment they need to be ‘good patients’ by avoiding taking up too much of the GPs time or challenging their authority (41). The results presented show how older adults with MM chose to disclose patient knowledge only related to presumed biomedical relevance, thereby second-guessing the physicians reasoning (23). This points towards patients going through processes of classifying what patient knowledge is. The participants make judgments on what they believe is welcome in the clinical encounter, framing their knowledge within arrays of biomedicine. Hence, a majority of the older adults in this study sorted and discarded knowledge judging it within frames of biomedicine, thus adapting to a biomedical disease model.

While GPs might feel they understand patient’s needs, this is often not the case (13, 42, 43). Older adults with MM’ disclosure practices showed that patient knowledge, which could have led to a different understanding of the problem and hence different solutions, was not always disclosed. Patient knowledge, and especially discarded patient knowledge, could form a basis of understanding the complex web older adults navigate within when they try to cope with MM in a cultural and social world (44-47) .

Strengths and limitations

Focus in this article has been solely on patients’ perspective. Reflections over disclosure practices only came to light because of the design of the study, including the first author’s inquiry about certain observed aspects of the older adults’ everyday life. The reporting may have characteristics similar to other cultural settings and may be comparable also to older adults living with single chronic conditions. A limit to this study is that the study design, for practical reasons, did not include the perspective of GPs. GPs position themselves differently on the spectrum of the bio-psycho-social disease model (17, 48, 49) demanding different disclosure practices from patients. Future studies on perceptions of patient knowledge and disclosure practices should include this aspect.

Implications for practice

Helping older adults with MM to manage their diseases requires them to disclose relevant knowledge on aspects of their personal and everyday lives. Recognizing and acknowledging that not all patient knowledge is disclosed, helps GPs better understand where to look if the situation is unintelligible to the GP or difficult to solve. This article thus helps define the blurred boundaries of what patient knowledge is, and how patient categorize to disclose to their GP. This is an important aspect when trying to involve patients’ perspectives in planning care for MM.

References

1. Willadsen TG, Bebe A, Koster-Rasmussen R, Jarbol DE, Guassora AD, Waldorff FB, et al. The role of diseases, risk factors and symptoms in the definition of multimorbidity - a systematic review. Scandinavian journal of primary health care. 2016;34(2):112-21.

2. Violan C, Foguet-Boreu Q, Flores-Mateo G, Salisbury C, Blom J, Freitag M, et al. Prevalence, determinants and patterns of multimorbidity in primary care: a systematic review of observational studies. PLoS One. 2014;9(7):e102149.

3. Marengoni A, Angleman S, Melis R, Mangialasche F, Karp A, Garmen A, et al. Aging with multimorbidity: a systematic review of the literature. Ageing research reviews. 2011;10(4):430-9.

4. Bähler C, Huber CA, Brüngger B, Reich O. Multimorbidity, health care utilization and costs in an elderly community-dwelling population: a claims data based observational study. BMC Health Services Research. 2015;15(1):23.

5. Ploeg J, Matthew-Maich N, Fraser K, Dufour S, McAiney C, Kaasalainen S, et al. Managing multiple chronic conditions in the community: a Canadian qualitative study of the experiences of older adults, family caregivers and healthcare providers. BMC geriatrics. 2017;17(1):40.

6. Ørtenblad L, Meillier L, Jønsson AR. Multi-morbidity: A patient perspective on navigating the health care system and everyday life. Chronic Illness.0(0):1742395317731607.

7. Rosbach M, Andersen JS. Patient-experienced burden of treatment in patients with multimorbidity – A systematic review of qualitative data. PLOS ONE. 2017;12(6):e0179916.

8. Shippee ND, Shah ND, May CR, Mair FS, Montori VM. Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. Journal of Clinical Epidemiology. 2012;65(10):1041-51.

9. Patton DE, Cadogan CA, Ryan C, Francis JJ, Gormley GJ, Passmore P, et al. Improving adherence to multiple medications in older people in primary care: Selecting intervention components to address patient-reported barriers and facilitators. Health Expectations. 2018;21(1):138-48.

10. Nelson ME, Rejeski WJ, Blair SN, Duncan PW, Judge JO, King AC, et al. Physical activity and public health in older adults: recommendation from the American College of Sports Medicine and the American Heart Association. Medicine and science in sports and exercise. 2007;39(8):1435-45.

11. Chernoff R. Nutrition and Health Promotion in Older Adults. The Journals of Gerontology: Series A. 2001;56(suppl_2):47-53.

12. Pamuk ER, Williamson DF, Serdula MK, Madans J, Byers TE. WEight loss and subsequent death in a cohort of u.s. adults. Annals of Internal Medicine. 1993;119(7_Part_2):744-8.

13. Coulter A. Understanding the experience of illness and treatment. In Understanding and Using Health Experiences: Improving patient care. . In: Sue Ziebland, Angela Coulter, Joseph D. Calabrese, Locock L, editors. Understanding and Using Health Experiences: Improving patient care. Oxford, UK: Oxford University Press; 2013.

14. Sackett DL, Rosenberg WMC, Gray JAM, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. BMJ. 1996;312(7023):71-2.

15. Martin LR, Williams SL, Haskard KB, Dimatteo MR. The challenge of patient adherence. Therapeutics and clinical risk management. 2005;1(3):189-99.

16. Guassora AD, Gannik D. Developing and maintaining patients' trust during general practice consultations: the case of smoking cessation advice. Patient Educ Couns. 2010;78(1):46-52.

17. Broholm-Jørgensen M, Guassora AD, Reventlow S, Dalton SO, Tjørnhøj-Thomsen T. Balancing trust and power: a qualitative study of GPs perceptions and strategies for retaining patients in preventive health checks. Scandinavian journal of primary health care. 2017;35(1):89-97.

18. Pols J. Knowing Patients:Turning Patient Knowledge into Science. Science, Technology, & Human Values. 2014;39(1):73-97.

19. Kleinman A. Patients and Healers in the Context of Culture. . Berkeley: University of California Press; 1980.

20. Lim C, Berry ABL, Hirsch T, Hartzler AL, Wagner EH, Ludman E, et al. "It just seems outside my health": How Patients with Chronic Conditions Perceive Communication Boundaries with Providers. Proceedings of the 2016 ACM Conference on Designing Interactive Systems; Brisbane, QLD, Australia. 2901866: ACM; 2016. p. 1172-84.

21. Barry CA, Bradley CP, Britten N, Stevenson FA, Barber N. Patients' unvoiced agendas in general practice consultations: qualitative study. BMJ. 2000;320(7244):1246-50.
22. Farber BA. Patient self-disclosure: a review of the research. Journal of clinical psychology. 2003;59(5):589-600.
23. Heritage J, Robinson JD. Accounting for the visit: giving reasons for seeking medical care. In: Maynard DW, Heritage J, editors. Communication in Medical Care: Interaction between Primary Care Physicians and Patients. Studies in Interactional Sociolinguistics. Cambridge: Cambridge University Press; 2006. p. 48-85.
24. Julliard K, Vivar J, Delgado C, Cruz E, Kabak J, Sabers H. What Latina Patients Don't Tell Their Doctors: A Qualitative Study. Annals of Family Medicine. 2008;6(6):543-9.
25. Goodson L, Vassar M. An overview of ethnography in healthcare and medical education research. Journal of Educational Evaluation for Health Professions. 2011;8:4.
26. Ziebland S. Narrative interviewing. In: Ziebland S, Coulter A, Calabrese JD, Locock L, editors. Understanding and Using Health Experiences: Improving patient care. Oxford, UK: Oxford University Press; 2013.
27. Dewalt K, DeWalt B. Participant observations. A guide for fieldworkers. Walnut Creek, CA: AltaMira; 2002.
28. Timmermans S, Tavory I. Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis. Sociological Theory. 2012;30(3):167-86.
29. Coulter A, Collins A. Making Shared Decision-making a Reality. No decision about me, without me. . London: Kings Fund; 2011.
30. Lim CY, Berry ABL, Hirsch T, Hartzler AL, Wagner EH, Ludman EJ, et al. Understanding What Is Most Important to Individuals with Multiple Chronic Conditions: A Qualitative Study of Patients' Perspectives. Journal of General Internal Medicine. 2017.
31. O'Kane AA, Rogers Y, Blandford AE. Concealing or Revealing Mobile Medical Devices?: Designing for Onstage and Offstage Presentation. Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems; Seoul, Republic of Korea. 2702453: ACM; 2015. p. 1689-98.
32. Green AR, Carrillo JE, Betancourt JR. Why the disease-based model of medicine fails our patients. Western Journal of Medicine. 2002;176(2):141-3.
33. Naik AD. On the road to patient centeredness. JAMA Intern Med. 2013;173(3):218-9.
34. Epstein RM, Street RL, Jr. The values and value of patient-centered care. Ann Fam Med. 2011;9(2):100-3.
35. Hanyok LA, Hellmann DB, Rand C, Ziegelstein RC. Practicing patient-centered care: the questions clinically excellent physicians use to get to know their patients as individuals. The patient. 2012;5(3):141-5.
36. Coulter A. Patient engagement--what works? The Journal of ambulatory care management. 2012;35(2):80-9.
37. Wallace E, Salisbury C, Guthrie B, Lewis C, Fahey T, Smith SM. Managing patients with multimorbidity in primary care. BMJ : British Medical Journal. 2015;350.
38. Balint M. he Doctor, His Patient and the Illness. London: Pitman; 1957.
39. Engel GL. The need for a new medical model: a challenge for biomedicine. Science (New York, NY). 1977;196(4286):129-36.
40. Fasulo A, Pino M. Sharing knowledge and shaping identities in healthcare interactions. Patient Education and Counseling.99(6):875-7.
41. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Education and Counseling. 2014;94(3):291-309.
42. Bente Prytz Mjølstad ALK, Linn Getz, Irene Hetlevik. What do GPs actually know about their patients as persons? . European Journal for Person Centered Healthcare. 2013;1(1):149-60.
43. Rozenblum R, Lisby M, Hockey PM, Levtizion-Korach O, Salzberg CA, Lipsitz S, et al. Uncovering the blind spot of patient satisfaction: an international survey. BMJ quality & safety. 2011;20(11):959-65.

44. Heisler M. Eliciting Personal Values of Patients with Multiple Chronic Conditions: Why and How. Journal of General Internal Medicine. 2017.

45. Ratanawongsa N, Karter AJ, Parker MM, Lyles CR, Heisler M, Moffet HH, et al. Communication and Medication Adherence: The Diabetes Study of Northern California. JAMA internal medicine. 2013;173(3):210-8.

46. Loh A, Leonhart R, Wills CE, Simon D, Harter M. The impact of patient participation on adherence and clinical outcome in primary care of depression. Patient Educ Couns. 2007;65(1):69-78.

47. Arnetz JE, Almin I, Bergström K, Franzén Y, Nilsson H. Active patient involvement in the establishment of physical therapy goals: Effects on treatment outcome and quality of care. Advances in Physiotherapy. 2004;6(2):50-69.

48. Kristensen MAT, Hølge-Hazelton B, Waldorff FB, Guassora AD. How general practitioners perceive and assess self-care in patients with multiple chronic conditions: a qualitative study. BMC Family Practice. 2017;18(1):109.

49. Davidsen A, Reventlow S. Different approaches to understanding patients in general practice in Denmark: a qualitative study2011. 209-26 p.

Appendix 1:

Article 4 (original version in Danish)

De usunde

Sundhedsantropologens møde med multisyge ældre på Lolland

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Introduktion

”Medicinsk antropologi befinder sig i udkanten af lægevidenskaben, men også i udkanten af antropologien”. Kleinmans berømte ord (Kleinman 1995:1; min oversættelse) sætter rammen for mit feltarbejde, som jeg her vil bruge som udgangspunkt for en (selv)kritik af mødet mellem antropologisk vidensproduktion og dominerende sundhedsdiskurser. Jeg vil i denne artikel introducere en forskningsposition, som jeg kalder *empatisk vidensproduktion*. Med empatisk referer jeg til antropologiens ansvar for at gøre lokale praksisser, erfaringer og udsagn forståelige i deres kontekst. Denne tilgang er inspireret af kritikken af den ’ontologiske vending’ i antropologien (se fx Sausdal & Vigh 2013; Hastrup 2013; Højbjerg 2013), en kritik der som antropologiens modus operandi fremhæver fokus på det situationelle i menneskers eksistens (Sausdal & Vigh 2013:116). Feltarbejde, samtaler og deltagelse i dagligt liv med mænd, kvinder og børn har i min optik til formål at vise forskelligheder i måden mennesker lever på, i en specifik sociokulturel og politisk kontekst. Men med den medicinske antropologis positionering i udkanten af medicinsk forskning opstår en række etiske dilemmaer i forsøget på at kaste lys på vores informanters levede liv. Som medicinske antropologer interesserer vi os eksempelvis for måden, hvorpå lokale sociokulturelle faktorer spiller en rolle med hensyn til at monitorere kroppen og forstå symptomer (se fx Oxlund & Whyte 2014). Antropologer fungerer altså i den medicinske forskning som fortolkere af menneskelig sundhedsadfærd, der viser, hvorfor og hvordan mennesker gør, som de gør (Brown & Inhorn 1996:198). Problemer i sundhedsantropologisk forskning skyldes ofte, at medicinsk antropologi og biomedicin er tæt sammenvævet, og som Lorna Rhodes påpeger (Rhodes 1996:159), arbejder mange antropologer i dag, godt nok i udkanten af, men i biomedicinske settings eller studerer problemer, der er defineret i biomedicinske termer. Eksempelvis diskuterer Sharon Kaufman og Lakshmi Fjord, hvordan Medicare, den gratis, amerikanske sundhedsforsikring for de fattigste amerikanere, skaber en forestilling om, hvordan de syge skal leve manifesteret i beslutninger om hvilken behandling leversyge tilbydes (Kaufman & Fjord 2011:212). Men de to forskere berører ikke etiske problemstillinger i deres egen positionering i biomedicinen. Opmærksomheden findes dog: I en dansk kontekst diskuterer eksempelvis Mette Nordahl Svendsen nødvendigheden af kritisk engageret forskning, idet hun viser, hvordan modstand fra informanter, som et vilkår i vidensproduktion, kan bruges produktivt til at gøre en eventuel kritisk position empirisk forankret. Ved at blotlægge epistemologiske forskelle mellem forsker og informanter tydeliggøres eventuelle modsatrettede interesser (Svendsen 2009). Stærkt inspireret af Svendsens diskussion af ’kritisk engageret forskning’ er det min intention at koble biomedicinske forforståelser op på min egen forskning og metode.

Artiklen her fokuserer på empatisk vidensproduktion i forhold til studier af, hvordan mennesker forstår og omsætter sundhedsbudskaber. Empatisk vidensproduktion er tænkt som et analytisk udgangspunkt for overvejelser over, hvilke konsekvenser dominerende biomedicinske diskurser i sundhedsforskningen har for det antropologiske projekt. Som det vil blive tydeligt i det følgende, er mine etiske refleksioner opstået over tid og i interaktion med både de mennesker, hvis liv jeg fulgte og her beskriver, og i samproduktion med kolleger og antropologiske forskningsfelter om sundhed, etik og ontologi. Hvordan og hvortil skal vi styre den analytiske opmærksomhed mellem vores biomedicinske samarbejdspartneres forventninger om, at vi kan identificere sundhedsbarrierer i vores empiriske objekters livsverdener? I artiklen her vil jeg argumentere for, at empatisk vidensproduktion kunne være et svar.

Undervejs vil jeg fremhæve den gradvise erkendelse af min positionering, som opstår i feltarbejdet, og vise, hvordan min stigende kritiske bevidsthed fører til en ny indsigt omkring etik i studiet. Jeg vil argumentere for, at der i sundhedsforskning ligger et moralsk imperativ, ved at vise, hvordan den biomedicinske forståelse af sundhed gennemsyrer mit projekt. Ved at fremhæve hvordan min repræsentation ubevidst påvirkes af denne biomedicinske forståelse, viser jeg, *dels* at studier i eget samfund (også) kræver en konstant refleksion over skabelsen af det empiriske objekt, og *dels* at det analytiske objekt ofte skabes af forskellige aktører med modsatrettede interesser, og at antropologen ubevidst kan komme til at producere viden *for* snarere end *om*. Jeg vil således vise, hvordan jeg et godt stykke inde i feltarbejdet stadig fokuserer på rygning, kost og motion, en viden som efterspørges af min opgavestiller, snarere end at finde frem til det, der egentlig har betydning for mine informanter, når det kommer til en hverdag med multisygdom[1]. Disse indsigter lader jeg danne baggrund for en mere generel diskussion af etik i sundhedsantropologien, og jeg vil, bevidst provokerende og selvudstillende, sætte dem som analytisk ramme.

Broen til bedre sundhed

Danmark har en række yderområder med socioøkonomiske udfordringer og en dårlig sundhedsprofil. Yderområder er karakteriseret ved lav erhvervsindkomst og svag befolkningsudvikling. 16 ud af de 98 danske kommuner kategoriseres sammen med småøerne som yderområder, svarende til 11 % af Danmarks befolkning (Regionen 2016). Lolland er en af de lavest rangerende kommuner, når man måler på levetid, indkomst, uddannelsesniveau, og har relativt høj arbejdsløshed og høj forekomst af kroniske sygdomme (Region Sjælland 2016a). Statistisk set er Lolland en af de socioøkonomisk mest udfordrede kommuner i Danmark og har på grund af sin demografiske sammensætning en større andel af multisyge end gennemsnittet. Det er derfor oplagt, at mit feltarbejde foregår på Lolland, for multisygdom, som jeg undersøger, stiger med alderen og forekommer oftere blandt mennesker med en ufaglært, faglært eller kort boglig uddannelse end blandt højtuddannede (Larsen et al. 2013).

Som følge af den ringe sundhedsprofil er *"bedre sundhed til flere borgere"* et regionalt mål for Lolland og Falster de kommende år. Der laves befolkningsundersøgelser, målprogrammer, indsatser og forskes blandt andet i livsstil, familierelationer og ældre. Mit ph.d.-projekt om hverdagsliv med kronisk sygdom er en del af denne storstilede indsats, der på sigt skal kunne forbedre den lokale befolknings sundhedstilstand. I mit studie ser jeg på, hvordan ældre mennesker med multisygdom håndterer sygdomsbyrde og behandlinger i hverdagen. Jeg undersøger, hvordan de navigerer i ofte modsatrettede behandlingsforløb, og hvordan dagligdagen tager sig ud, når man derfor hele tiden skal prioritere mellem at følge den ene eller den anden læges råd, eller simpelthen helt lade være. Gennem 18 måneder har jeg besøgt, interviewet og brugt tid sammen med 7 kvinder og 7 mænd i alderen 66-90 med forskellige kombinationer af mere eller mindre behandlingskrævende kroniske sygdomme. Feltarbejdet, der fandt sted på Lolland i 2015-2016, er et samarbejde mellem Videnscenter for Brugerinddragelse i Sundhed og Forskningsenheden for Almen Praksis.[2] Men hvem har retten til at definere et sundt liv, og hvad stiller man op med sin forskning, når man indser, at man er fanget i modsatrettede interesser: opgavestillernes ønske om at bedre den biomedicinske sundhed versus de mennesker, som ikke kan eller vil forbedre denne sundhed?

Jeg er tilkoblet Lolland-Falster Undersøgelsen (LOFUS), der er det mest omfattende befolkningsstudie i et landområde i Danmark nogensinde, med op mod 100 forskere tilknyttet. LOFUS arbejder også sammen med programmet "Broen til Bedre Sundhed", et udviklingsprogram i Region Sjælland, der går ud på at skabe mere sundhed og mindre ulighed på Lolland og Falster. Broen til Bedre Sundhed er et samarbejde mellem kommuner, region, erhvervsliv og praktiserende læger på Lolland og Falster. *Broen* kan også forstås helt bogstaveligt som Farøbroerne, der forbinder Sjælland med Lolland og Falster, og som har fragtet mig og en række andre forskere 'ned' for at undersøge, hvordan vi forbedrer den lokale befolknings sundhedstilstand. Vi er brikker i et større politisk spil, der, uden at jeg her vil så tvivl om intentionerne, arbejder bevidst på at ændre adfærd hos dem, som er karakteriseret som usunde (Region Sjælland 2016a, 2016b). Det, at der er et *vi*, som arbejder for at skabe bedre sundhed på Lolland, konstruerer en *Anden*, der er uansvarlig, usund og forskellig fra, hvad der igen fremstilles som et homogent *os*. Den viden, jeg finder frem til, er således moralsk konstitueret, hvilket leder mig frem til spørgsmålet om, hvem der har retten til at definere, hvad der er sundt.

Forskningsetik – for hvem?

For mere end 1600 år siden blev Skt. Augustins mor stillet over for det dilemma, som mange sundhedsantropologer møder i deres feltarbejde. Skt. Monica spørger: "I Rom faster de om lørdagen, men ikke i Milano, der faster de om søndagen. *Hvad er det rigtige at gøre*?". Skt. Ambrosius svarer: "*Når jeg er i Milano, gør jeg som de gør i Milano, men når jeg er i Rom, gør jeg som de gør i Rom*" (Augustine, brev 54, 2.3). Jeg oplevede dilemmaet i min egen etik og mine deltageres, når de åbenlyst ignorerede biomedicinske behandlinger. En kvindelig deltager ville ikke sove med sin iltmaske. Hun syntes, den var besværlig at tage af og på, og at den ødelagde hendes humør. Jeg syntes, det var et forkert valg, fordi hun blev sløv om dagen, og hendes sygdomme blev forværret. Hvad var det rigtige at gøre?

Etiske problemstillinger, der relaterer til individets omsorg for sig selv og socialt sanktionerede normer, er en velkendt udfordring i antropologiske feltarbejder. Det er forsøgt løst med forskningsretningslinjer, der skal hjælpe forskeren til at forholde sig kritisk til egen positionering. Dette forekommer dog utilstrækkeligt, idet forskningsetik stadig fremstilles som en institutionaliseret, normativ tilgang mere end en praksis mellem mennesker; forsker og deltager (Davis 2010:15-17). Individets frie respons på forskrifter om hvad de bør gøre, såsom behandlingsplaner, er i sig selv etiske handlinger, ifølge Michel Foucault, fordi mennesket ved at drage omsorg for sig selv søger det bedste for sig selv: "etik er bevidst ageren i frihed" (Foucault 1988:18, egen oversættelse). Men jeg oplevede undervejs i feltarbejdet at undskylde mine normative moraliserende perspektiver over for mig selv med en etisk agenda om at 'hjælpe' mine informanter. Selvom 'hjælpen' ikke var bogstavelig, havde den en virkning i min tilgang. Jeg spørger i et interview kvinden med iltmasken: "*Ville det ikke være bedre at være frisk, selvom den* [iltmasken] *er lidt besværlig?".* Gennemlæsning af transskriptionen af dette interview fik mig til at reflektere over, hvad jeg konkret forstår ved forskningsetik. Godt hjulpet på vej af allerede eksisterende diskussioner (se fx Hastrup 2004b; Baarts 2009; Davis 2010) vil jeg derfor påstå, at antropologisk forskningsetik handler om, hvordan vi producerer meningsfuld viden om lokale former for levet liv, og hvordan sundhedspraksisser udfolder sig i konkrete sociale situationer. Svaret lå allerede i Skt. Ambrosius svar: Vi skal forstå handlinger i deres lokale kontekst. Kirsten Hastrup pointerer netop, at vores etiske forpligtelse ligger i en epistemologisk repræsentation af informanters verden (Hastrup 2004b:469). Hermed opstiller hun et etikbegreb, der ikke er ontologisk, fordi det ikke nøjes med en at beskrive oplevelsen af væren-i-verden, og derfor indeholder magt, fordi det teoretiserer informanters agens og modstand, som ikke nødvendigvis er tydelig for dem vi studerer (ibid.). For magten, biopower, altså måden samfundet kontrollerer sundhed og sygdom i befolkningen på (Foucault 1979[1976]), findes i relationen mellem stat og borger, antropolog og subjekt. Her er mit ærinde ikke en diskussion af magten, men blot at anerkende, at det er relevant med refleksioner i det biomedicinske felt over sundhedsproblemstillingers sociopolitiske indlejring. I stedet vil jeg igen følge Hastrups opfordring og advokere for et etisk standpunkt, hvor vi anerkender de gensidige implikationer mellem etik og epistemologi (Hastrup 2004b:470). Ved at positionere mit projekt som empatisk sætter jeg en etisk forpligtelse op for mig selv og mine medforskere til at tydeliggøre erfaringer, oplevelser, fortællinger og praksisser ikke kun gennem beskrivelser, men også gennem teori og fortolkning, der stadig er tro mod informanternes virkelighed.

Multisygdom som forskningsfelt

Har man mere end to kroniske eller langvarige sygdomme på en gang, er man det, der kaldes ’multisyg’. Mennesker med multisygdom har nedsat livskvalitet (Noel et al. 2005), og hverdagen med flere kroniske sygdomme bliver belastet af smerter, nedsat bevægelighed, og tid der skal bruges på behandlinger (Ørtenblad, Jønsson & Meillier 2015; Høstrup & Jønsson 2017). Har man først én kronisk sygdom, er risikoen for at udvikle nye forhøjet (van der Akker et al. 1998), og multisyge dør tidligere end gennemsnittet (Tinetti et al. 2011). Multisygdom er også forbundet med en større sygdomsbyrde, fordi man har flere sygdomme på én gang, og det kræver komplekse behandlingsstrategier, hvor der skal tages hensyn til hver enkelt sygdom. Det medfører en anseelig mængde af behandlinger for den enkelte (Smith et al. 2010; Shippe et al. 2012) og store samfundsmæssige omkostninger (Wolff et al. 2002; Glynn et al. 2011). Multisygdom forekommer også hyppigere blandt ældre, og det er i sig selv et voksende problem, fordi vi lever længere og længere, og andelen af ældre i befolkningen vokser. Sygehusforbruget er stigende og størst i de ældste aldersgrupper, og desto ældre man er, desto større er risikoen for kroniske sygdomme. I Danmark har over halvdelen af befolkningen over 65 år multisygdom (Larsen et al. 2013).

Mit projekt rammer derved ind i en politisk og samfundsmæssig problemstilling. Det stigende antal patienter med multisygdom stiller nemlig det danske sundhedsvæsen, der i dag organisatorisk og fagligt er målrettet en specialiseret indsats rettet mod enkeltsygdomme, over for en stor udfordring i de kommende år (Reventlow et al. 2013). Multisygdom er både præget af og bidrager til social ulighed (Lawson et al. 2013), idet uligheden forstærkes desto flere samtidige sygdomme, man har (Barnett et al. 2012).

Med udgangspunkt i mit feltarbejde fremdrager jeg fire menneskers historier om et hverdagsliv med sygdom. De eksemplificerer, hvordan sundhed opfattes som et udefra defineret krav til en bestemt livsstil, som det ikke altid er muligt eller ønskeligt at efterkomme. Disse fire mennesker navigerer på forskellig vis i deres hverdag mellem på den ene side behandlingsplaner og mål, der er sat i samarbejde med for eksempel lægen, og på den anden deres egen tilgang til, hvad der er vigtigt at prioritere; det kan være det spirituelle, familierelationer eller handle om at ”være glad”. Når behandlinger eller øvelser vælges fra, kan det imidlertid skabe forværring i de kroniske sygdomme, og det opfattes som noget negativt af systemet rundt om den enkelte: læge, kommune, hospital. I forlængelse af disse fire menneskers historier vil jeg vise, hvordan jeg ubevidst reproducerer denne forestilling, når jeg fx sidder over for Hans, der lider af kronisk obstruktiv lungelidelse (KOL) og når at ryge syv cigaretter under et af mine besøg på godt en time. Her har jeg skrevet i mine noter, at Hans virkelig ville få nemmere ved at røre sig, som han gerne vil, hvis han skruede ned for smøgerne.

De usunde

Forud for min diskussion af modsætningsforholdet mellem den sundhedstænkning, jeg repræsenterer i mit projekt, og de forståelser af sundhed, jeg møder hos informanterne, vil jeg introducere læseren til fire mennesker, som er både sunde og usunde – afhængigt af øjnene, der ser.

Hans, den gamle købmand

Hans er en 71-årig mand med tidligere alkoholmisbrug, diabetes, amputeret ben og KOL. Han er født og opvokset i en lille landsby på Lolland, men boede en del af sit voksenliv på Sjælland, indtil han blev skilt og flyttede tilbage. Hans er tidligere købmand og arbejdede i sin tid 70 timer om ugen og siger om sig selv, at han ”*ikke er bange for at tage fat*”. Han måtte stoppe med at arbejde på grund af benet, men arbejder sommetider lidt ”*sort*” for en kammerat, hvor han kan sidde ned. Han bor alene i et lille hus, efter at hans hund blev aflivet af kommunen under hans sidste lange indlæggelse. Det mener Hans ”nu også var det eneste rigtige at gøre”, for han var der ikke til at tage sig af den. Hans ryger dagligt cirka 40 cigaretter og drikker 5-6 øl, men han rører ikke stærk spiritus mere. Han fortæller, at han tidligere havde et alkoholmisbrug, men nu har han det under kontrol. Familien ser han kun sjældent, men han har dagligt besøg af en veninde, og når vejret tillader det, tager han sin elscooter ned i den lokale klub. Ifølge Hans følger han sjældent lægens råd, og han har ikke lyst til at stoppe med at ryge, men han spiser sin medicin, som han skal. Det vigtigste for Hans er at opretholde en form for social status som en, der tjener sin egne penge og lever et frit liv uden hjælp. Hvis der bliver for meget fokus på sygdommene, ”*føles det, som om jeg bliver kastreret*”. For Hans er den lille opsparing, han har, vigtig, fordi den giver ham råd til at kunne give en runde øl og betale veninden for at gøre rent – ”*for det er altså arbejde for kvindfolk*”.

Karin, kunstneren

Hjemme hos Karin er der ild i pejsen næsten året rundt, og den røde huskat slænger sig dovent foran varmen. Karin er en 69-årig kvinde med Parkinsons, gigt og en mave-tarm sygdom. Hun bor alene i et istandsat bondehus og er meget engageret i det lokale kulturliv. Tidligere var hun altid den, som lavede nye klubber, arrangerede udstillinger og ture, men nu er hendes sygdomme så fremskredne, at hun har måttet skære ned på aktiviteterne. Alligevel er hun samlingspunkt for lokallivet. Hun har styr på naboerne og ved, om nogen er syge. Ved flere lejligheder, mens Karin og jeg er ude til arrangementer sammen, oplever vi, at nogen ikke er mødt op, og Karin ringer til vedkommende med det samme, hvis nu han for eksempel er faldet og ligger alene og har brug for hjælp. På den måde er Karin, på trods af fysiske begrænsninger, en tryghed for mange, og når vi møder de lokale, bliver der hilst hjerteligt. Karin er afhængig af at tage sin medicin til tiden, men glemmer det ofte. Når jeg spørger, hvorfor hun ikke sætter en alarm, så hun kan huske det, forklarer hun, at hun ikke vil lade sygdommen styre sit liv. Hendes Parkinsons forværres også af gigten, men hun laver ikke de øvelser, hun skal, fordi hun hellere vil prioritere de få timer i døgnet, hun har lidt energi, på sit barnebarn og sine kunstprojekter. Det, der fremstår som meget bevidste prioriteringer i forhold til sygdomme og hverdagsliv, bliver dog, når man kender Karin, til et billede af en kvinde, der gør sit bedste for at passe sygdommene, men ikke magter det hele på en gang. Karins sygdomme volder hende både sorg og stor angst, men hun føler ikke, at kommunen eller lægerne vil hjælpe hende, og hun er med egne ord ”for stolt til at plage”.

Klaus, trompetisten

Klaus serverer altid smørrebrød og ”lidt godt til dessert”, når man er på besøg. Overalt i hjemmet hænger fotos af datteren, særligt indrammet står hun med studenterhue på reolen. Han forklarer stolt, at hun er den første i familien, der blev student. Klaus er 66 og døjer med forhøjet blodtryk, gigt, diabetes type 2 og noget ”vrøvl” med den ene arm. Under vores første interview forklarer han, at jeg nok ikke kan ’bruge’ ham, for han er ikke rigtig syg. Jeg forklarer ham, at jeg faktisk er ligeglad med, hvilke sygdomme han har, og at det for mig mest handler om hverdag og sundhed, og så beslutter vi sammen, at han nok kan bruges. Jeg tror, det hjælper, at vi har samme forkærlighed for smørrebrød. Klaus er overvægtig, og han og konen spiser meget kage og ”gammeldags dansk mad”. De bor med deres to hunde i et stort hus i en landsby omgivet af marker. Klaus gider generelt ikke lave de øvelser, lægen siger, han skal: ”*Det er jo altid godt at røre sig og få noget motion. Men det kniber sgu lidt med lysten og med tiden. Når man ikke har tid, så får man ikke gjort det, og når man ikke har lyst, så får man ikke tid*”. I stedet bruger Klaus sin tid på at spille i det lokale brassband, på hundene, og på at være derhjemme med konen: ”*Jeg er jo sådan en, der godt bare kan lide at være hjemme*”. På trods af at Klaus går med hundene, lader hverken han eller lægen til at opfatte det som ’rigtig’ motion, når Klaus refererer deres samtaler. I stedet fortæller han, at han har lovet lægen at prøve at komme lidt til holdtræningen, de har talt om. Det går også fint de første par uger, men det starter kl. 18, og det er spisetid hjemme hos Klaus, så han ender med at droppe det. Både han og konen syntes, at tidspunktet var vældig ubelejligt.

Lille Benny, fabriksarbejderen

’Lille Benny’, som han bliver kaldt, er en 78-årig mand med diabetes, tidligere blodprop i hjertet, dårlig fordøjelse, og gigt. Han har tidligere haft ’malerhjerne’, men det er ifølge ham selv væk nu. Han spiller også i det lokale brassband, hvor de andre tager hensyn til ham, men i mine observationer er han ikke rigtigt en del af gruppen. Han har svært ved at indgå i det sociale og står oftest alene lidt væk fra de andre. En gang imellem taler en af de andre til ham, og så svarer han, men ellers passer han sig selv. Han siger sjældent noget, men han og jeg opnår en særlig kontakt, da vi spiller samme instrument i brassbandet, jeg starter i som en del af feltarbejdet. Mange af vores interviews har lange passager om, hvilke numre vi skal spille, og hvad vi mener om dirigenten. Med tiden åbner Benny sig, og jeg får lov at komme hjem og besøge ham. Mine fordomme om enlige ældre mænd bliver gjort til skamme, da jeg træder ind i et velholdt og rent lille byhus, hvor Benny bor alene med sin hund i en større by på Lolland. Han har ingen børn, og ekskæresten *”skred med genboen”* for fem år siden. Benny fortæller, at hun gerne ville have ham tilbage på et tidspunkt, men det ville han ikke: ”*Så er det noget andet med ham her* (hunden), *ham ved jeg, hvor jeg har*”. Benny gør alt, hvad han får at vide, han skal af lægen, og han kan huske alle sine sygdomme i tal, altså, hvad hans blodtryk er og skal være, osv. Benny har arbejdet som ufaglært hele sit liv og synes generelt ikke, han bliver taget seriøst af sundhedsvæsenet. Han ryger ikke og får daglig motion med hunden, ligesom han spiser sin medicin, som lægen har foreskrevet.

Fælles for de fire mennesker, jeg her har trukket frem, er, som jeg har prøvet at fremstille i beskrivelsen af deres sygdomme og pasningen af dem, at de regnes for usunde eller dårlige til at passe på sig selv – i hvert fald ifølge 'systemet', menneskeliggjort i de sundhedsprofessionelle, jeg mødte i projektets deltagerobservationer. Selvom Benny gør, hvad han skal, så forstår han sjældent, hvad lægen siger, og det ligger til grund for mange misforståelser, som resulterer i en forværring af sygdommene. Også Hans' livsstil er usund ligesom Klaus', mens Karin primært burde være bedre til at passe på sig selv. Hvad de har til fælles er også, at de, hvis man kigger på prioriteringer, og hvad der har betydning for dem i hverdagen, træffer nogle *bevidste* valg og har en høj selvoplevet livskvalitet. Deres ideer om sundhed handler om henholdsvis at kunne være sammen med 'gutterne', at fortsætte sit aktive kunstnervirke, at spise og hygge med konen og at være sig selv. Somme tider medfører det en nedprioritering af behandlinger, men jeg vil argumentere for, at det ikke nødvendigvis er usundt.

Kan man studere sundhed?

Der går ikke lang tid inde i feltarbejdet, før jeg får en dårlig smag i munden. Jeg kigger på behandlingsstrategier og egenomsorg, og når jeg fortæller om mit projekt, bliver jeg ofte spurgt af kollegaer, hvorfor mine informanter mon ikke gør *det rigtige,* altså motionerer, spiser sundt, tager deres medicin korrekt, reagerer på symptomer og så videre. Beredvilligt svarer jeg, at de lollikker, jeg følger, faktisk har alle mulige former for ressourcer og træffer nogle valg, måske ufornuftige set fra en biomedicinsk synsvinkel, men fra deres egen synsvinkel velovervejede og pragmatiske egenomsorgsvalg. Sådan ser jeg det, indtil Hans en dag i sin tilrøgede stue siger til mig: "*Altså nu har jeg jo røget hele mit liv, så jeg kan ikke se, hvorfor det er så vigtigt at være så helvedes sund*". I det øjeblik, med cigarlugt hængende i tøjet, går det op for mig, at mit forsøg på at forklare –måske endda forsvare – mine informanters sundhedsvalg stadig er en reproduktion af det moralske imperativ, der ligger i at analysere sundhedsadfærd ud fra en dikotomisk tilgang, hvor noget er rigtigt, og andet er forkert. Hans' valg er ikke et udtryk for egenomsorg. Han gider bare ikke stoppe med at ryge.

Det er erfaringer som ovenstående, der danner baggrunden for mine etiske og moralske overvejelser. Hvordan navigerer jeg for eksempel mellem ønsket om på den ene side at respektere Hans' autoritet og selvbestemmelse over eget liv og på den anden side bedrive forskning, der kan hjælpe Hans (og andre) til en bedre hverdag, så han ikke er så generet af sin KOL og måske kan komme lidt uden for lejligheden igen, som han så gerne vil? Dette bliver særlig problematisk, når jeg står med en konkret stillet opgave, der ikke er uafhængig af økonomiske og politiske styringer. Jeg finder således mig selv i et landskab af moralske imperativer, hvor kan/skal/vil bliver styrende i altruismens navn: i mit baghoved lyder det sundhedsfaglige argument om, at de multisyge skal forbedre deres egenomsorg, *for deres egen skyld*.

Mit feltarbejde bliver altså et eksempel på, hvordan vi som antropologer færdes med både forpligtelser over for videnskabelige spilleregler og etiske fordringer om at optræde moralsk i forhold til de mennesker, vi studerer. Denne dualitet er bydende tvunget sammen af den antropologiske metode, der forudsætter både humanitær medleven og god videnskabelig praksis, et spændingsfelt som den feltarbejdende antropolog må lære at leve i (Hastrup 2004a:419).

Antropologen som oversætter

*"Hej Kirsten, tak fordi du vil hjælpe mig. Jeg mangler som sagt to kvinder til mit ph.d.-studie; de skal være over 65 og have mindst to kroniske sygdomme – gerne også en psykisk lidelse. Og så skal de selvfølgelig bo på Lolland! Jeg vil gerne have lov til at besøge dem derhjemme eller eventuelt snakke med dem et andet sted, hvor de føler sig trygge. Derefter regner jeg med at have jævnlig kontakt med dem, med besøg osv. det næste års tid. De kan naturligvis altid sige nej undervejs, hvis det bliver for meget. PS: Du må lokke dem med, at jeg har kage eller smørrebrød med, haha. Mange hilsner, Alexandra" (*Mail til lokal gatekeeper, juni 2015).

Ovenstående mail udstiller min naivitet, som jeg gradvist erkender, fordi jeg begynder at reflektere over min forestilling om informanterne. Antropologien baserer sig på, at der er *en anden* eller *noget andet* at studere, men det er et begreb, der er ladet med værdi og potentielt konfliktfyldt. I 1980erne blussede repræsentationsdebatten op, foranlediget af et ønske om at frigøre sig fra skabelsen af *andethed*, idet der blev argumenteret for, at den etnografiske beskrivelse undertiden fratog folk deres egen stemme og tingsliggjorde dem (se fx Marcus &Fischer 1986). Debatten fremhævede sprog som en opmærksomhedsfaktor, både fremmedsprog, modersmål og den tavse viden, der skal omsættes til ord af forskeren (Hastrup 2003:216). Løsningen synes ofte i dag at være en diskussion af forskerens positionering og overvejelser omkring repræsentation, men viden om *den anden* produceres stadig i en kontekst af tid, rum og politik (Fabian 2002), og vores fag, eller jeg selv i det mindste, har stadig en normativ forestilling om *den anden,* som man kan analysere sig frem til i min mail til Kirsten Vil det så sige, at jeg slet ikke kan bruge det materiale, jeg har indsamlet? Nej, langt fra. Men det forudsætter en konstant refleksion over, hvordan og hvorfor mit empiriske objekt tager sig ud som det gør, og hvilke konsekvenser det har. Filosoffen G.C. Spivak argumenterer for, at viden aldrig kan være neutral, og at viden rummer bagvedliggende interesser. For Spivak betyder det blandt andet, at viden kan forstås som en eksportvare fra Vesten til resten af verden med den hensigt at opnå et (oftest) økonomisk udbytte. Hun viser således, at *den svage anden* kun har mulighed for politisk repræsentation gennem en intellektuel, og gør dem derved til subjekter uden reel mulighed for at kunne tale for sig selv (Spivak 1988). Spivak taler om de subalterne grupperinger i kolonisamfundet, men hvis vi følger præmissen om, at det er de intellektuelle, der har taleindflydelse i samfundet, så efterlader det en stor gruppe mennesker uden reel mulighed for indflydelse – også i vores eget samfund. Det er måske en overmodig konklusion, men lad os lege med tanken: at repræsentation, også af lokal viden og narrativer, forudsætter en intellektuel 'oversætter':

> *" Først så jeg, at de havde skrevet i Kulturrejser, et eller andet med at de ville ikke have folk med, som ikke var selvhjulpne og kunne gå selv* […] *Så tænkte jeg, at jeg lige ville gøre et lille forsøg, så skrev jeg til dem: "Kære Kulturrejser-medarbejder. Jeg har været sådan og sådan afsted, og det har været spændende* […] *Og det vil jeg meget gerne igen, men jeg kan ikke mere end sådan og sådan. Jeg kan kun gå med en stok eller min mand under armen. Han kan tage nogle lange ture, og jeg kan tage nogle korte ture, så kan jeg tage en taxa hjem, eller hvad jeg nu kan […] Så skrev de tilbage, at hvis jeg havde den holdning, så var jeg hjertelig velkommen. Det var da meget sødt. Så jeg må godt tage med, selvom jeg ikke kan gå. Det er fint nok … Ja, nu får du den akutte krise"* (Karin, interview sommer 2015).

Karin, som taler her, er også dybt engageret i handicapforhold og vil meget gerne fortælle om sine erfaringer. Hendes pointe er, at folk, der ikke er så gode til at "råbe op" som hende, ikke får nogen hjælp, og i den ovenstående historie vil hun illustrere, at man altså sagtens kan gøre ting, selvom man er syg. Den sidste sætning hentyder måske til, at hun forestiller sig, at jeg ikke finder det relevant, men at hun altså bare er nødt til at fortælle det, underforstået, at jeg måske kan fortælle andre om hendes erfaringer.

Et studie fra 1990 viser, at grupper eller individer med få videnskabelige eller sociale ressourcer per definition vil tiltrække forskere, mens personer med flere ressourcer vil have en tendens til at møde forskeren med en vis reservation eller mistro (Scott et al. 1990). Jeg vil mene, at interviewet med Karin viser, at vi som forskere stadig skal være opmærksomme på risikoen for en fremstilling af vores informanter som en homogen, *passiv* anden. Derved risikerer vi at indsnævre det analytiske potentiale i forskningen ved at skabe afgrænsede grupper og overse sammenhængen mellem grupperne og resten af samfundet (Olwig 2002). I forlængelse heraf bør vi også fjerne romantiseringen af eller trangen til at redde den anden. Antropologiens raison d'être må snarere være at undersøge, hvordan noget bliver defineret som et problem i det studerede samfund (Jöhncke 2003:29).

Selvkritikken spirer

Som feltarbejdet skrider frem, vokser min medleven i mine informanters liv og giver sig til kende i en tiltagende kritisk stillingtagen til det overordnede politiske fokus og opbakning til at sikre mere lighed og "*en ensartet folkesundhed*" (Region Sjælland 2016a). Efter en prøve med det lokale brassband har jeg noteret følgende:

Jeg ankommer til den største skole i Nakskov, hvor orkesteret øver. Dorte tager imod mig og undskylder, at der ser sådan ud. I underetagen er en nu lukket svømmehal, og bygningen bærer præg af slid og brug. Oppe i aulaen, der er af den gamle og fine slags med en god akustik, er orkestermedlemmerne ved at stille op. Med få undtagelser er de alle ældre mænd. Der er den sædvanlige brassband jargon, som er hård og lummer, selvom de ikke helt tør være så grove i mit nærvær endnu. I pausen nævner jeg, at jeg gerne vil tale med nogen, som er syge og over 65, og de griner og peger hinanden ud – det er nærmest alle. Carsten har kage med – det er hans tur – og vi drikker øl af flasken, mens vi spiser. Et par af de mænd, jeg har interviewet siden sidst, og som jeg ved har diabetes, siger nej tak til kagen så højt, at jeg ikke kan undgå at høre det. Det virker påtaget, især fordi jeg har set dem spise kage før uden overvejelser. Er det til min ære?

I mine møder med deltagerne har jeg ikke lagt skjul på, at jeg er der for at undersøge, hvilke sundhedsvalg man træffer, når man har mange kroniske sygdomme. Jeg har ikke italesat det som et fokus på syge og socialt udsatte, hvad det egentlig heller ikke er tænkt som, men ovenstående eksempel viser måske de overvejelser, det giver at sige ja til at medvirke i et sundhedsforskningsprojekt. Jeg vil mene, at min blotte tilstedeværelse i forskningsregi er medvirkende til at rammesætte nogle specifikke moralske handlerammer, som mine informanter så bevidst eller ubevidst navigerer i. De specifikke stereotyper af tilbageståenhed og usund livsstil, der forbindes med Danmarks landdistrikter, faciliterer nemlig skyldsspørgsmålet, der

følger de multisyge. *”Vi er nok ikke så gode til at passe på os selv hernede…* [sygdommene] *er da nok min egen skyld*”, siger Ove på 72 om de kroniske sygdomme, han har udviklet de sidste 10 år. Som jeg har vist, forstås flere af sygdommene af det offentlige danske sundhedsvæsen kausalt i sammenhæng med usund kost, rygning, overvægt, manglende motion og manglende sygdomsindsigt, og denne forklaringsmodel lader mine informanter til at have adopteret.
Som den danske antropolog Charlotte Baarts beskriver sin oplevelse af at gøre feltarbejde blandt alternative behandlere i Danmark, finder jeg også mig selv fanget mellem feltets sundhedsopfattelser og den biomedicinske som det sande regime (Baarts 2009:430). Og igen slår det mig – er jeg i gang med at indgå i en de facto partisk relation og gøre mine informanter til ”*the underdog*”? Baarts skriver, at kvalitative forskere altid er i et partisk forhold med ’the underdog’, altså den part som har færrest akademiske eller sociale ressourcer (op.cit.423). Selvom mine deltagere ikke nødvendigvis vil anskue sig selv som ressourcesvage, reflekteres deres position i samfundet i mødet med ’overhunden’, i det følgende eksempel manifesteret i lægen:

> *Alexandra:* Så man tror ikke altid på, hvad lægen siger*?*
> ’*Lille Benny’:* Nej, ikke altid. Engang imellem føles det som om, de er ligeglade.
> *Alexandra:* Prøv at forklare det!
> *’Lille Benny’*: Det er bare sådan noget, jeg føler. Fx nu her det sidste år... fx da jeg arbejdede, der sov jeg ikke andet end fem-seks timer og stod op kl. 5 om morgenen og kørte på arbejde, men nu kan jeg da godt sidde om formiddagen og slumre lidt og kan godt falde i søvn, mens jeg sidder og læser avisen. Så jeg sagde, at jeg følte mig lidt træt engang imellem. Så sagde han: ”Nå ja, men du skal også tænke på, hvor gammel du er”. Senere har jeg fået at vide, at det har noget at gøre med de indsprøjtninger, jeg får på Næstved Sygehus, men han sagde bare dét der.

Mens mit projekt i tråd med mange andre sundhedsantropologiske projekter startede som et klinisk anvendeligt studie, der med antropologisk indsigt skulle bidrage til løsning af kliniske, biomedicinske problemer (Rhodes 1996:165), bevæger jeg mig altså nu mere i retning af et kritisk medicinsk-antropologisk studie, hvor de politiske og økonomiske kræfter, der skaber det medicinske system og bestemmer karakteren og omfanget af dets virkninger, har min opmærksomhed.
Jeg ændrer bevidst min titel fra ’medicinsk antropolog’, som jeg finder tæt knyttet til en biomedicinsk forståelsesramme, til det mere holistiske ’sundhedsantropolog’. Ligeledes ændrer

jeg i løbet af projektet den mundtlige omtale af deltagerne i projektet fra 'informanter' til 'samtalepartnere', om end jeg her for overskuelighedens skyld stadig bruger betegnelsen 'informanter'. Ingen af begreberne er mine, jeg følger blot sundhedsantropologiens nyeste diskurser. Det er måske en lille dråbe i havet, men det er et sted at starte.

Empatisk vidensproduktion

Trods ovenstående standpunkt kan jeg ikke sige mig fri for personligt at befinde mig dybt forankret i det biomedicinske videnssystem. Jeg tror oprigtigt på, at hvis gigtlægen har sagt til min informant, at mere motion vil mindske generne fra gigten, så er det rigtigt:

På vej hjem fra interview med Klaus. Mens vi gjorde frokosten klar, fortalte han, at han ikke har lavet de øvelser, lægen har sagt, han skal, for han kan simpelthen ikke se, hvorfor det skulle hjælpe, og jeg tror måske, han føler, det er sådan lidt for yogaagtigt. Jeg prøvede at prikke lidt til ham, men han holder på, at han får den motion, han skal, når han går med hundene, selvom han jo ikke får rørt sin arm der, og jeg er ret sikker på, at det er en spille-[trompet]-skade ligesom Peters (Feltnote, vinter 2016)

Ovenstående er indtalt efter besøg hos Klaus, der foruden forhøjet blodtryk og sukkersyge type to har noget gigtlignende i højre arm og skulder. Jeg tror stadig på, at det vil hjælpe Klaus, hvis han lavede sine øvelser. Men han gider ikke, og han har desuden ikke lyst til at stoppe med at spille, så han har bare affundet sig med, at ”*den arm er dårlig, sådan er det*”. Men det er lige netop pointen. Den empatiske vidensindsamling betyder ikke, at vi nødvendigvis må være enige med vores informanter. Tværtimod vil det ikke være etisk korrekt at tilsidesætte vores forskningsinteresser til fordel for vores informanters prioriteringer (Baarts 2009:431).
I stedet bør vi søge at finde veje til at tale om informantens interesser, *mens* vi bedriver etisk forsvarlig forskning. I mit studie af social ulighed i sundhed betyder det eksempelvis, at jeg fokuserer på organisatoriske årsager til og individuelle konsekvenser af social ulighed set i et samfundsperspektiv, samtidig med at jeg må have en opmærksomhed mod ikke at reproducere forestillinger om, hvad ressourcer er, eller hvem der er belastet socialt og sundhedsmæssigt i sin adfærd. I praksis vil der i enhver antropologisk analyse altid findes en implicit kontrast mellem det, de andre ved om sig selv og deres verden, og så den viden, der søges af antropologen (Hastrup 2004a:412). Mens jeg henviser til forskning om, hvor stor en byrde det kan være at have multisygdom, fortæller jeg informanternes historier om at have et godt liv 'på trods', om at

føle sig overset og nedgjort af læger på grund af førtidspension, om ægteskabet, når der kommer en tredje partner i form af alvorlig sygdom, og så videre.

Konklusion

Det har ikke været min hensigt med artiklen at ugyldiggøre sundhedsstudier eller tale imod at arbejde for større undersøgelser. Det er derfor væsentligt at understrege to forhold. *For det første* er social ulighed i sundhed et oplagt felt for antropologien som fag, fordi vi med vores blik for det partikulære skaber en langt mere kompleks forståelse af, hvad ulighed betyder. De eksisterende parametre på uddannelse og indkomst (se Sundhedsstyrelsen 2011) befrier vi fra forforståelser, for i stedet at skabe viden om det enkelte menneskes indlejring i og bidrag til fællesskabet. Jeg mener altså, uanset den forudgående kritik af min egen skabelse af det analytiske og empiriske objekt, at et fokus på social ulighed, her i sundhed, er en forpligtelse, vi som antropologer bør tage på os og dermed bruge vores fag til at engagere os i verden. *For det andet* er det ikke mit ærinde at skabe berøringsangst over for politisk og moralsk ladede felter. Vores antropologiske praksis skaber og udvikler det konkrete sociale felt, der studeres. Det betyder, at den viden, vi producerer, ikke kun afdækker menneskers liv, men nogle gange indirekte griber ind i deres livsverden blandt andet gennem udformning af interventioner og retningslinjer (Hastrup 2004a:419). Det gælder i lige så høj grad den anden vej, hvor dem, vi bedriver forskning på, skal forstås som aktivt handlende individer eller grupper, der lige så vel kan have en politisk eller økonomisk dagsorden, som de ønsker at fremme ved at medvirke i forskningen (Baarts 2009:425).

Med udgangspunkt i mit feltarbejde blandt ældre mænd og kvinder med multisygdom på Lolland har artiklen undersøgt modsætningsforhold i sundhedsforskning: Sundhed fremstilles moralsk befæstet, hvilket jeg ubevidst har reproduceret delvist, og det at udføre et studie som led i en større undersøgelse åbner op for et modsætningsforhold mellem (her) sundhedstænkningens repræsentanter og så de mennesker, der studeres. Artiklens argument er derfor, at forskeren skal forholde sig etisk til sådanne modsætningsforhold i studier af sundhed og sygdom. Balancegangen mellem at blotlægge epistemologiske forskelle og praktisere antropologi, hvor studiet er forankret i biomedicinske forståelser, former den måde, vi gør feltarbejde på, og de spørgsmål, vi stiller vores informanter. Empatisk vidensproduktion er det vilkår, der kan skabe en mere nuanceret forståelse af biomedicinske begreber, som fx multisygdom, når det forankres i en empirisk kontekst af hverdagsliv og patientoplevelser. Opgaven må være hele tiden at søge viden i takt med en stillingtagen til etik og selvrefleksion. Jeg har forsøgt at omforme fire menneskers historier og mine egne refleksioner til akademisk viden og håber at kunne pege på de underliggende logikker og organisatoriske forhold, der er med til at forme multisyges livsverdener. I erkendelse af ikke at kunne gøre det alene håber jeg, at min forskning vil bidrage til på sigt at kunne skabe bedre vilkår for at leve livet med kroniske sygdomme. Sund eller ej.

Noter

1. I de seneste år er der sket store ændringer i den voksne befolknings sygdomsmønstre. Med flere og bedre behandlinger er kroniske sygdomme ikke længere noget, man dør af, men noget man lever med. Det betyder, at flere og flere mennesker lever med mindst to kroniske eller langvarige sygdomme. I skrivende stund regner man med cirka 30% af den voksne befolkning i Danmark (Larsen 2017). At have flere sygdomme på én gang komplicerer behandlingen og stiller store krav til den enkelte. For at kunne leve op til denne stigende sundhedsudfordring, operer mange medicinske og samfundsfaglige forskere med begrebet 'multisygdom' (Frølich et al. 2017). Der findes forskellige definitioner; her i artiklen følger jeg den brede definition: mindst to kroniske eller langvarige sygdomme til stede samtidig hos en patient (van den Akker et al. 1996:69). Sygdommenes karakter er ikke afgørende her, idet det er mængden af behandlinger og uoverskueligheden i hverdagen, jeg her forholder mig til.

2. Projektet er udformet som et erhvervs-ph.d.-studie, der forløb i perioden 2014-2017. Foruden Innovationsfonden og Danske Patienter, har også Forskningsenheden for Almen Praksis, Fonden for Almen Praksis, Helsefonden, Oticonfonden, Joseph Fox International Fellowship og Region Sjælland finansieret studiet på forskellig vis.

Litteratur

van den Akker, M., F. Buntinx & J.A. Knottnerus

1996 Comorbidity or multimorbidity: what's in a name. A review of literature. European Journal of General Practice 2:65-70.

van den Akker, M., F. Buntinx, J.F. Metsemakers, S. Roos & J.A. Knottnerus

1998 Multimorbidity in general practice: prevalence, incidence, and determinants of co-occurring chronic and recurrent diseases. Journal of Clinical Epidemiology 51(5):367-75.

Baarts, Charlotte

2009 Stuck in the middle: research ethics caught between science and politics. Qualitative Research 9(4):423-439.

Barnett, K., S.W. Mercer, M. Norbury, G. Watt, S. Wyke & B. Guthrie

2012 Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. The Lancet 380(9836):37-43.

Brown, Peter & Marcia Inhorn

1996 Disease, Ecology and Human Behavior. In: T. Johnson & C. Sargent (eds.): Medical Anthropology. Contemporary Theory and Method. Pp. 187-214. Westport, Connecticut: Praeger.

Davis, Michael

2010 Bringing ethics up to date? A Review of the AIATSIS ethical guidelines. Australian Aboriginal Studies 2:10-21.

Fabian, Johannes

2002 [1983] Time and the other: how anthropology makes its object. New York: Columbia University Press

Foucault, Michel

1979 [1976] The History of Sexuality Volume 1: An Introduction. London: Allen Lane.

1988 Technologies of the self. In: L. Martin, H. Gutman & P.H. Hutton (eds.): Technologies of the Self. A seminar with Michel Foucault. Pp. 16-50. Amherst: University of Massachusetts Press.

Frølich, Anne, Frede Olesen og Inge Kristensen

2017 Introduktion og generelle forhold. I: A. Frølich, F. Olesen & I. Kristensen (red.): Hvidbog om multisygdom. Dokumentation af multisygdom i det danske samfund – fra silotænkning til sammenhæng. S. 15-17. Virum: TrygFonden.

Glynn, L.G., J. Valderas, P. Healy, E. Burke, J. Newell & P. Gillespie

2011 The prevalence of multimorbidity in primary care and its effect on health care utilization and cost. Family Practice 28(5):516-23.

Hastrup, Kirsten

2003 Sproget. I: K. Hastrup (red.): Ind i verden. En grundbog i antropologisk metode. S. 207-227. København: Hans Reitzels Forlag.

2004a Refleksion. Vidensbegreber og videnskab. I: K. Hastrup (red.): Viden om verden. En grundbog i antropologisk analyse. S. 409-425. København: Hans Reitzels Forlag.

2004b Getting it right. Knowledge and evidence in anthropology. Anthropological Theory 4(4):455-472.

2013 Vi bebor mangfoldige verdener – eller? Imod udsagnet. Tidsskriftet Antropologi 67:41-47.

Højbjerg, Christian K.

2013 Den ”ontologiske vendings” utilstrækkelighed. Imod udsagnet. Tidsskriftet Antropologi 67:29-34.

Høstrup, Helle & Alexandra Ryborg Jønsson

2017 Livet skal leves mens man har det. I: A. Frølich, F. Olesen & I. Kristensen (red.): Hvidbog om multisygdom. S. 21-27. Virum: TrygFonden.

Jöhncke, Steffen

2003 I den gode sags tjeneste? Om antropologi, stofbrugere og lodrette forbindelser. Tidsskriftet Antropologi 45:29-47.

Kaufman, Sharon & Lakshmi Fjord

2011 Medicare, Ethics, and Reflexive Longevity: Governing Time and Treatment in an Aging Society. Medical Anthropology Quarterly 25(2):209-231.

Kleinman, Arthur

1995 Writing at the Margin: Discourse Between Anthropology and Medicine. Berkeley: University of California Press.

Larsen, Finn Breinholt

2017 Multisygdom – hvad er problemet? I: A. Frølich, F. Olesen & I. Kristensen (red.): Hvidbog om multisygdom. S. 27-35. Virum: TrygFonden.

Larsen, Finn Breinholt, Karina Friis, Mathias Lasgaard, Marie Hauge Pedersen, Jes Bak Sørensen, Louise Margrethe Arildsen Jakobsen & Julie Christiansen

2013 Hvordan har du det? Sundhedsprofil for regioner og kommuner. Region Midtjylland: Center for Folkesundhed.

Lawson, Kenny, Stewart Mercer, Sally Wyke, Eleanor Grieve, Bruce Guthrie, Graham Watt & Elisabeth Fenwick

2013 Double trouble: The impact of multimorbidity and deprivation on preference-weighted health related quality of life a cross sectional analysis of the Scottish Health Survey. International Journal for Equity in Health 12:67.

Marcus, George & Michael Fischer

1986 Anthropology as a Cultural Critique. An Experimental Movement in the Human Sciences. Chicago: University of Chicago Press.

Noel, Polly Hitchcock, B. Chris Frueh, Anne C. Larme & Jacqueline Pugh

2005 Collaborative care needs and preferences of primary care patients with multimorbidity. Health Expectations 89:54-63.

Olwig, Karen Fog

2002 The ethnographic field revisited: Towards a study of common and not so common fields of belonging. In: V. Amit (ed.): Realizing Community: Concepts, social relationships and sentiments. Pp. 124-145. London: Routledge.

Oxlund, Bjarke & Susan Whyte

2014 Measuring and Managing Bodies in the Later Life Course. Journal of Population Ageing 7(3):217-230.

Rabinow, Paul

1994 Introduction. In: P. Rabinow (ed.): Michel Foucault – Ethics: Essential work of Foucault 1954-1984. Pp. 11-42. London: Penguin Books.

Regionen

2016 Definition af yderområder. https://regionalt.erhvervsstyrelsen.dk/definition-af-yderomraader

Region Sjælland

2016a Broen til Bedre Sundhed http://www.regionsjaelland.dk/Kampagner/broen-til-bedre-sundhed/Sider/default.aspx

2016b Lolland Falster er mulighedernes land http://www.regionsjaelland.dk/nyheder/Sider/Lolland-og-Falster-er-mulighedernes-land.aspx.

Rhodes, Lorna Amarasingham

1996 Studying Biomedicine as a Cultural System. In: T. Johnson & C. Sargent (eds.): Medical Anthropology. Contemporary Theory and Method. Pp. 159-173. Westport, Connecticut: Praeger.

Sausdal, David & Henrik Vigh

2013 Den ontologiske blænding. Om den ontologiske vendings metodiske og politiske problemer. Tidsskriftet Antropologi 67:101-121.

Scott, Pam, Evelleen Richards & Brian Martin

1990 Captives of Controversy: The Myth of the Neutral Social Researcher in Contemporary Scientific Controversies. Science, Technology and Human Values 15(4):474-94.

Shippee, Nathan, Nilay Shah, Carl May, Frances Mair & Victor Montori

2012 Cumulative complexity: a functional patient-centered model of patient complexity can improve research and practice. Journal of Clinical Epidemiology 65(10):1041-51.

Smith, Susan, Siobhan O'Kelly & Tom O'Dowd

2010 GPs' and pharmacists' experiences of managing multimorbidity: A 'Pandora's box’. British Journal of General Practice 60(576):285-294.

Spivak, Gayatri C.

1988 Can the Subaltern Speak? In: C. Nelson & L. Grossberg (eds.): Marxism and the Interpretation of Culture. Pp. 271-313. Basingstoke: Macmillan.

Sundhedsstyrelsen

2011 Ulighed i sundhed. Årsager og Indsatser. http://www.sst.dk/~/media/F674C77308FB4B0CA00EB038F17E239B.ashx

Svendsen, Mette Nordahl

2009 Kritisk engageret videnskab: Erfaringer fra forskning om gen- og forplantningsteknologierne. Tidsskrift for Forskning i Sygdom og Samfund 10:37-57.

Tinetti, M., G. McAvay, S. Chang, A. Newman, A. Fitzpatrick, T. Fried & P. Peduzzi

2011 Contribution of multiple chronic conditions to universal health outcomes. Journal of the American Geriatrics Society 59(9):1686-91.

Wolff, Jennifer L., Barbara Starfield & Gerard Anderson

2002 Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. Archives of Internal Medicine 162(20):2269-76.

Ørtenblad, Lisbeth, Alexandra Ryborg Jønsson & Lucette Meillier

2015 Komplekse liv: Patientinddragelse som vej til et bedre hverdagsliv for multisyge? Tidsskrift for Forskning i Sygdom og Samfund 22:83-101.

Tak til

Temaredaktionen og reviewere for god, konstruktiv kritik, som har hjulpet med at skærpe og teoretisere artiklens argumenter.

Resume:

Med udgangspunkt i feltarbejde blandt ældre på Lolland med flere samtidige kroniske sygdomme vises, hvordan forestillingen om sundhed som noget moralsk befæstet ubevidst reproduceres af antropologen. Erkendelsen af denne positionering kommer gradvist, og artiklen viser, hvordan en stigende kritisk bevidsthed afspejles i feltarbejdet. Der argumenteres for, at medicinsk-antropologiske studier kræver en konstant refleksion over skabelsen af det empiriske objekt. Derfor introduceres *empatisk vidensproduktion* som forskningsposition. Med empatisk refereres til antropologiens ansvar for at gøre lokale praksisser, erfaringer og udsagn forståelige i deres kontekst. Artiklen fremhæver antropologens forpligtelse til at forholde sig kritisk over for normative indlejringer i sit projekt og i stedet søge at skabe viden om det enkelte menneskes indlejring i og bidrag til fællesskabet set i en kontekstuel og subjektiv optik. Der argumenteres for, at et fokus på social ulighed, her i sundhed, er en forpligtelse, vi som antropologer bør tage på os og dermed bruge vores fag til at engagere os i verden. Det foreslås, at empatisk vidensproduktion som forskningsstrategi med fokus på de situationelle eksistenser kan modvirke berøringsangst over for politisk og moralsk ladede felter.

Søgeord: forskningsetik, empatisk vidensproduktion, feltarbejde, multisygdom, Lolland

Keywords: research ethics, empathic knowledge production, fieldwork, multimorbidity, Denmark

Forfatteroplysninger

Alexandra Brandt Ryborg Jønsson er uddannet antropolog fra Københavns Universitet i 2011. Hun har siden forsket i og skrevet om multisygdom og patientinddragelse. Hun er ph.d.-studerende ved Danske Patienter og Forskningsenheden for Almen Praksis, Københavns Universitet.

Appendix 2:

Information for recruitment of interlocutors

INVITATION TIL DELTAGELSE I FORSKNINGSPROJEKT

Jeg er

Alexandra Jønsson, antropolog, PhD studerende

Jeg søger

Mennesker på Lolland med mindst 2 kroniske sygdomme over 65 år

Du skal

- Interviewes af mig – hvor og hvornår det passer dig.
- Hvis jeg må, vil jeg meget gerne med dig til læge og andre besøg i sundhedsvæsenet.
- Jeg vil også meget bruge noget tid sammen med dig i hverdagen – med på besøg hos venner/familie, til fritidsinteresser, med ud og handle osv.

DU VIL VÆRE HELT ANONYM – *og du kan når som helst sige, at du ikke vil deltage længere*

Du eller dine pårørende kan altid ringe til mig og høre mere: +45 [redacted]. Ellers ringer jeg til dig om en uges tid.

Om projektet:

Multisygdom er at have mindst to kroniske eller langvarige sygdomme. Multisyge har nedsat livskvalitet, døjer med smerter og forringet funktionsevne. Samtidig indgår de i mange forskellige behandlinger, som både er tidskrævende og kan virke uoverskuelige. Det betyder, at mange ikke har overskud til at deltage i sociale arrangementer og må også ofte aflyse aftaler med familie eller venner. Det påvirker hverdagen i en negativ retning og kan blandt andet føre til ensomhed og depression.

Projektet vil undersøge, hvordan multisyge sammen med egen læge kan inddrages i beslutninger om behandling og øge sin egenomsorg, altså valg og adfærd i forhold til de forskellige sygdomme. Samtidig vil der være fokus på eventuelle kønsforskelle i graden af inddragelse.

Studiet er designet som et antropologisk kvalitativt studie. Projektet udføres som et samarbejdsprojekt (erhvervsph.d. studie) mellem Danske Patienter og Forskningsenheden for Almen Praksis, Københavns Universitet, med støtte fra Uddannelses og Forskningsministeriet.

Appendix 3:

Participant Information

Deltagerinformation om deltagelse i PhD projekt

Hverdagsliv med multisygdom. Fokus på patientinddragelse, almen praksis og kønsforskelle

Tak fordi du vil deltage i en antropologisk undersøgelse, i forbindelse med mit PhD projekt

Du vil blive interviewet og gerne fulgt i din hverdag, hvor denne deltagerinformation vil blive uddybet, og hvor du kan stille de spørgsmål, du har til undersøgelsen. Du er velkommen til at tage et familiemedlem, en ven eller en bekendt med.

Husk at du når som helst trække din samtykkeerklæring tilbage, uden begrundelse. Det er kun mig, der ved hvis du trækker din deltagelse tilbage, ingen andre får noget at vide.

Formål

Formålet er at finde ud af, hvordan man lever med mange sygdomme på en gang. Hvad gør mennesker for at få det bedst mulige liv, når hverdagen er fyldt med smerter, behandlinger, bekymringer osv.

- Du vil altid være fuldstændig anonym. Jeg ændrer dit navn, alder, hvor du kommer fra, familie osv.
- I alt 14 personer bliver udvalgt til at blive fulgt.
- Jeg besøger dig eller vi mødes hvor du vil
- Jeg interviewer dig og optager det på bånd. Det er kun mig og min studentermedhjælp, der hører det.
- Jeg vil også gerne med dig til forskellige ting, fx fritidsinteresser. Jeg vil gerne have det hyggeligt med dig.

Nytte ved studiet

Når du deltager er du med til at skabe viden om, hvordan man som multisyg får det bedst mulige hverdagsliv. Du kan hjælpe mig med at finde ud af, hvordan man selv er inddraget i behandlingen, og hvad det er vigtigt at tage hensyn til.

Udelukkelse fra og afbrydelse af studiet

Hvis du ikke har lyst til at deltage længere, kan du når som helst sige stop.

Oplysninger om økonomiske forhold

Projektet er et erhvervsphd-projekt i samarbejde mellem Danske Patienter og Forskningsenheden for Almen Praksis, på Københavns Universitet.

- Danske Patienters Videnscenter for Brugerinddragelse i Sundhedsvæsenet har taget initiativ til projektet, som er formuleret og planlagt af mig
- Projektet bliver betalt af Ministeriet for Forskning og Innovation, Helsefonden, Region Sjælland og Danske Patienter.
- Projektet får økonomisk støtte fra ovenstående uanset hvad resultaterne bliver
- Projektet må ikke modtage støtte fra Medicinalindustrien
- Deltagere i projektet deltager frivilligt, og får ikke løn. Ved enkelte lejligheder kan jeg give kage eller kaffe, men der må ikke gives gaver af materiel karakter.

Adgang til forsøgsresultater

Resultaterne bliver analyseret i min PhD afhandling som er færdig vinter 2018.

Du er altid meget velkommen til at kontakte mig på email aj@vibis.dk
eller min mobil [redacted]

Med venlig hilsen

Alexandra

Appendix 4:

Interview guide patients

Interview med multisyge (tilpasset)

Tak fordi du vil deltage. Hvad går det ud på, hvad vil jeg spørge om, anonymiseret, behøver ikke svare, ok med optagelse?

INTRO

Navn, alder, uddannelse,

SYGDOMME

hvilke sygdomme har du, hvilken fik du først, hvordan startede den, hvad skete der da du så fik den næste, er der nogen sygdomme der fylder mere end andre i dit liv, hvad skete der i dit liv på de tidspunkter, arbejde, familie, socialt liv

BEHANDLINGER

Hvilken medicin tager du, hvornår, hvad skal du ellers gøre, skal du spise noget særligt, hvor tit er du til kontroller, hvad er sværest ved behandlingerne, Hvad har behandlingerne gjort for dig / ved dig, Blev noget overset, som har haft konsekvenser for din sygdom, Brug af medicin, ændring/udvikling i det, hvordan har du det med at tage medicin, bruges andet end lægemidler, Hvordan håndterede du de udfordringer der fulgte sygdom på det tidspunkt, hvis du kunne ændre noget i sundhedsvæsenet hvad skulle det så være?

LIVSHISTORIE

Hvor er du født, familie, partner, børn, hvad har du arbejdet som, hvor længe har du boet her, har din familie sygdomme, hvordan var din barndom, Hvordan var dit liv før du blev syg / fik diagnosen. hvad har det betydet i dit liv,

HVERDAGSLIV

Prøv at beskrive en helt almindelig dag, en almindelig uge. Hvad er du optaget af lige nu? Hvordan påvirker sygdommene det, er der forskel på hvordan og hvornår sygdommene påvirker "dit liv"? Oplever du vanskeligheder i hverdagen; får du hjælp i hverdagen/af hvem, Hvilken betydning har det, at der er flere symptomer/sygdomme (for familie, netværk, arbejdssituation, økonomi, behandlinger, mentale og fysiske tilstand/formåen)

ALDRING

Hvordan er det at blive ældre, hvad er et godt ældreliv, hvad synes du er et sundt liv, lever du sundt? Hvad gør du for at have det godt, undgå forværring i sygdomme/at nye sygdomme kommer til, Hvilke håb har du for fremtiden; tilfreds med situation, ønsker om forandring, drømme for fremtiden

ULIGHED

Hvad er ulighed i sundhed? Har du oplevet at være udsat for ulighed i sundhed?

KØN

Er der forskel på mænd og kvinder når det kommer til sundhed? Sygdomme? Behandling? Socialt liv? Andet? Hvordan? Hvorfor?

AFSLUTNING

Tak for din tid, er det noget andet jeg skal vide?

OPFØLGENDE INTERVIEWS:

Mange samme spørgsmål; vil gerne have bredt belyst.
Spørg fra ”hverdagsliv” og ned, helst med referencer til tidligere samtaler +

SIDEN SIDST

Er der sket noget siden sidst (følg op på interview), har du været til lægen eller lignende, hvordan går det med…(personlige livsdetaljer)

Appendix 5:

Interview Guide Health Professionals

Introduktion

Tak fordi du vil deltage. Hvad går det ud på, hvad vil jeg spørge om, anonymiseret, behøver ikke svare, ok med optagelse?

INTRO

Navn, alder, uddannelse, hvad er dit speciale/ansættelsessted

PATIENTER MED MULTISYGDOM

Kan du prøve at beskrive, hvad der karakteriserer patienter med multisygdom

Kan du komme i tanke om en patient, hvor multisygdom havde en betydning, fx gjorde behandlingen mere kompleks?

Kan du komme i tanke om en patient, hvor multisygdom ikke fyldte noget?

Er der nogen patientkarakteristika, som er særligt udfordrende, eller gunstige ved patienter med multisygdom? (vær ikke bange for generaliseringer; det kunne være at det er nemmere med patienter som selv er uddannet inden for sundhedsvæsenet osv)

Kan du udbyde det, gerne med nogle eksempler

Hvad er efter din opfattelse de største udfordringer ved multisygdom?

Hvordan finder man ud af, hvad patienten fejler ”ved siden af”

PATIENTVIDEN & FAGLIGE UDFORDRINGER

Hvordan finder man ud af, hvad der er vigtigt for patienten?

Hvordan vil du definere patient viden?

Hvad er forskellen på patienters viden og din viden

Hvad er relevant viden? Hvad er ikke?

Er det noget i dette møde som udfordrer din faglighed? Hvordan håndterer du i så fald dette?

AFSLUTNING

Tak for din tid. Info om projektets videre forløb mm.

Inden vi slutter vil jeg gerne høre, om du synes der er noget jeg har glemt at spørge om.

Er der nogen anbefalinger, forslag, opmærksomhedspunkter du gerne vil give videre ?

Corrections for the printed version:

p. 33 deceased instead of deceived

p. 39 overlooked instead of overseen

p. 42 assured instead of ensured

p. 112

Article 1 has been published in Qualitative Inquiry

Article 2 awaiting review scores in Journal of Gereontology: Series B social sciences

Article 4 has been published in Tidsskrift Antropologi

Article 5 has been accepted for publication in Chronic Illness