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People with multimorbidity assessed for home-based rehabilitation

Supporting vulnerable and complex everyday life?

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This article examines meetings between people living a complicated everyday life with multimorbidity and an assessor responsible for providing a rehabilitation programme, home care or neither. The background to this is a health policy change towards more home-based rehabilitation and less home care, which began with new legislation in the Danish Consolidation Act on Social Services in 2015. The question raised is whether these meetings support the everyday lives of people with multimorbidity or exacerbate their already vulnerable situation, and how their agency plays a role in the assessor's decision.

The article is based on an ethnographic field study in Denmark. Twenty-six individuals with multimorbidity aged 28-86 years, applying for or already receiving home care, were studied. The article uses three cases to explore the distinct ways in which the people relate

to the assessment meeting, and how the meeting affects their vulnerable situation, while the analysis reveals the widely varying involvement of the people's agency. We find support for these people in their everyday lives with multimorbidity, when everyday life and challenges in practical daily activities are understood in context, and when the meeting is based on the people's experience of their lives. Conversely, assessment meetings that exclude their experience of meaningful everyday life and their need for help to handle their complicated life with multimorbidity result in restricted access to rehabilitation and home care. This creates inequality in access to health and social care and in the possibility to live a meaningful everyday life, which reinforces these people's vulnerability.

Introduction

Multimorbidity is from a medical perspective the characterization of life with two or more concurrent long-term health conditions (Van der Akker et al. 1996). In this article we are interested in the social situation of people living with multimorbidity, and the fact that up to 95% of home care recipients aged 65 years or more live with multimorbidity (Violán et al., 2014a, b). Our focus is then on a particular group of people living with multimorbidity who are applying for municipal care, or already receiving it. We wish to explore the meeting between care of the welfare state in Denmark and people's everyday life with multimorbidity. We understand the meeting from the point of people being in a fundamentally vulnerable situation, living a medical and social complex everyday life

Health and social policies directed at people living at home with multimorbidity are rapidly changing. In Denmark a paradigmatic shift in home care provision from 2015 has directed resources towards home-based rehabilitation, and more limited home care services. Social researchers have found that this creates higher thresholds for assistance and support (Bertelsen & Hansen, 2018; Petersen et al. 2017; Rostgaard & Graff, 2016). Our aim is to understand the assessment meetings between people living a complicated everyday life with multimorbidity and an municipal assessor that determine whether clients will receive home-based rehabilitation, home care or neither. We explore how these practices are formed in the context of the people's everyday lives, and how they can be understood in terms of helping, interfering with, and even harming the everyday lives of people with multimorbidity.

There is little knowledge of the extent to which increased home-based rehabilitation at the expense of home care can be understood as increasing the vul-

nerability of everyday life with multimorbidity. This article is based on a large ethnographic study conducted by the first author; this forms the basis for the present analysis, which was performed by both authors. In this article we focus on how vulnerability becomes an important dimension in clients' meetings with care professionals, and also an effect of assessment interventions that aim to establish home-based rehabilitation instead of home care. In the analysis we do not find people living with multimorbidity to be passive receivers or victims, but actors with different agencies to preserve and protect their everyday lives.

Background

People with multimorbidity are not a specific category within the population, although they have below average longevity (Tinetti et al., 2011). Life with multimorbidity is typically disrupted by more frequent and longer hospitalizations than the lives of people with only one long-term health condition. Furthermore, people with multimorbidity experience greater challenges in returning to their previous everyday lives as they have lower levels of functioning after discharge (PradosTorres et al., 2014). Their lives are often characterised by alternation between periods of illness requiring admission and periods when they are well enough to remain at home (Coventry, Dickens, & Todd, 2014). They often have more limited energy, which adversely affects their relationships with friends and family (Kuluski et al., 2014) in addition to education and work (Jansbøl, Anker, Nielsen & Hjarsbech, 2016).

From a social and an everyday life perspective, people with multimorbidity can thus be seen as being in a vulnerable situation, when they have difficulties in reproducing the everyday life flow of other people. Many, but not all, experience instability and challenges that place them in need of support. This will be our perspective in examining the meetings to assess these people's potential for home-based rehabilitation.

The background to this study is the paradigmatic change in the approach to health and social care in high-income countries, where people needing assistance will now mostly be offered rehabilitation as a supplement to, or replacement for, home care (Aspinal et al., 2016). In Denmark, people applying for municipal home care, or already receiving it on a short- or long-term basis, are offered home-based rehabilitation under Article 83a of the Consolidation Act on Social Services, (Social- og Indenrigsministeriet, 2014); this entails free home care and rehabilitation

as part of the Danish welfare model (Sundheds- og Ældreministeriet, 2017). In the assessment meeting, the client's rehabilitation potential is evaluated in relation to any increase in levels of physical or mental functioning or improvement with regard to particular social problems; this determines whether home-based rehabilitation or home care (or neither) are offered.

Theoretical framework

The analytical framework draws upon Schutz' phenomenological sociology of everyday life, where people's everyday life is understood to be an intersubjective world that people draw upon without noticing how the normalities of everyday life are recreated as common sense normalities in an organised world, but where pragmatic motives also play their part (Schutz, 1971a, 1970). Here everyday life is seen as the background, a structure of meaning; and against this background, the foreground of daily activities is played out. For people with a complex everyday life with multimorbidity, the associated routines, habits and pragmatic interests will be experienced as common sense normalities and as meaningful, in terms of an everyday life understanding. Schutz also describes the motive for actions as having a temporal direction, aimed at a future goal or at past situations, and in this way temporality forms the person's actions and agency in a meaningful way in everyday life (Schutz, 1971b). This has guided our analytical interest in the meaning of the temporal aspect of the person's meeting with the assessor.

Multimorbidity is clearly part of contemporary societal culture, in which diagnoses circulate and gain explanatory power in relation to various aspects of social life such as suffering, anxiety and abnormality (Brinkmann & Petersen, 2015). We are interested in experiences of vulnerability in life constructed as *"life when you have multimorbidity"*, and how these also form and become representative of the home-based rehabilitation assessment meetings. At the same time, we wish to understand meaning, agency and the everyday life experiences in the people's situatedness, within a theoretical framework of phenomenological sociology, but with a particular emphasis on vulnerability.

Vulnerability as a concept is used here to understand the situation of people as groups or individuals when they are thrown into great challenges that cannot be met on the basis of their own capabilities or the context they are in. In this perspective, vulnerability is not a characteristic of individuals, but of situations and contexts that imply or lead to vulnerability. People are understood as sharing

vulnerability as a human condition, as Fineman has illuminated in her theorization of vulnerability (Fineman, 2008, 2017). One aspect of vulnerability is related to humans as embodied living creatures in constant transformation, embedded into social institutions and relations, which may create different forms of vulnerability. Another aspect of vulnerability is seen in the way in which the state uses legislation and policy measures to support people or force them into vulnerable situations.

Sodemann, a contemporary critic of how the health system in Denmark, points out that: *"Vulnerability is something we all have. It is expressed in relationships and interactions with others; it depends on experiences, the framework and, not least, the context"* (Sodemann, 2018, p. 32). According to Sodemann, vulnerability has ontological status, as something that a person is, but it is also socially constructed in peoples meeting with the health system. Grøn views vulnerability as a phenomenon that is at stake for specific people in specific intersubjective and indeterminate situations and in her research seeks to reveal vulnerability as being involved *"in all its shadowy complexity"* (Grøn, 2016, p. 24). In these understandings, vulnerability is not synonymous with frailty or passivity, but is connected to strength and power of resistance (Sodemann, 2018), and to what Wiuff and Grøn broadly designate as agency: *"the areas in their (people's) lives in which they can act and make a difference"* (Wiuff & Grøn, 2009, p. 78).

Theoretically drawing on Fineman, and inspired also by Sodemann, Wiuff and Grøn, this article understands vulnerability as a phenomenon and concept that are, and also are created. In our theoretical interpretation, it is not possible to define vulnerability as a typification of specific citizens who are vulnerable. Vulnerability is understood as conditional on everyday life and the process of living with ongoing illness. Navigating this complex everyday life with multimorbidity entails a vulnerable balance (Jönsson, Guassora, Freil & Reventlow, 2018; Ørtenblad, Meillier & Jönsson, 2018; Rosbach & Andersen 2017; Signal et al., 2017) an involves changes to everyday rhythms, habits and normalities (Vedsegaard 2019; Röing & Sanner, 2015; White, Lentin & Farnworth, 2016). It is, however, difficult to define everyday life narrowly; more broadly, it is *"the knowledge and structures of meaning that people produce, re-establish, and draw on through all their daily, often routine, interactions and activities"* (Jacobsen & Kristiansen, 2014, p. 13); this shows how everyday life is much more than daily practical activities.

The theoretical aim of this article is to examine vulnerability and agency as present and conditional, in a complex everyday life with multimorbidity, but also as being created in relation to context and situation, more specifically in assess-

ment meetings where the focus is on how far these support everyday lives or in fact create additional vulnerability.

Methodology

The first author has conducted a larger 17-month ethnographic field study following 26 people with multimorbidity in the period leading up to, and in some cases through, a home-based rehabilitation programme. The study included 23 interviews with 26 people, including three dyadic interviews with married couples, 23 field observations of meetings between assessors and clients in their homes, 55 field observations of clients' rehabilitation practice in their home together with rehabilitation therapists and finally 25 field observations of peoples everyday life with multimorbidity. The present article is based on the 23 interviews and 23 field observations of meetings between assessors and clients in their homes. The interviews were conducted before the assessment meetings; they took 1-2 hours and were open, semi-structured, dialogical interviews with narrative elements (Kvale & Brinkmann, 2015). The observations were conducted on an 'observer-as-participant' (Gold, 1970; Spradley, 1980) basis and lasted 1-2 hours. Field notes (Emerson, Fretz & Shaw, 2011) were written during the meetings.

Participants were selected in cooperation with municipal home care services in an area near Copenhagen with a moderately high number of people categorised as having multimorbidity (Sundhedsdatastyrelsen, 2018). People were invited to participate in the study in the chronological order of receipt of their application by the assessment unit, or at the time of the planned visit by the assessor (occupational therapist, physiotherapist or nurse). The main selection criterion was multimorbidity: people with physical or mental illnesses, or both. Using the principle of purposeful sampling with maximum variation (Patton, 2015), informants included were either applying for home care, receiving it temporarily, or having received it for several years. Informed consent was obtained using oral and written information. Participants were informed of their anonymity and the possibility to withdraw their consent to participate at any time.

The participants (18 women, 8 men) were aged between 28 and 86, mostly between 66 and 75. Apart from three married couples, they all lived without a partner. The participants' socio-economic background was relatively homogeneous: they were pensioners, had applied for early retirement, or were in a sheltered job; in most cases, they had a low educational level. The participants did not differ

socio-economically from home care recipients generally (Fredslund & Rasmussen, 2018). It was challenging to obtain participants under 55 years, so for a period only informants meeting this criterion were included, and gradually a greater spread of age groups was achieved. There was generally high interest in participation; only two people declined, one because of language problems, and the other because she felt overwhelmed by the number of professionals she was in contact with in her home. One informant was excluded by the first author after the first interview, because he turned out not to be ill, just old (88 years).

Vulnerability and agency: Three cases

In the analysis we present three cases that reveal both agency and vulnerability in the meeting between assessors and people living with multimorbidity. The three cases have been chosen because they illustrate variations and nuances in the agency of the clients, the establishment of the assessment decision, and how support in everyday life with multimorbidity is experienced from the perspective of the recipient. The three cases are exemplary (Hansen & Ingemann, 2016), because they illustrate what is typical of the observed assessment meetings in the entire data, while bringing vulnerability into focus in various ways.

“But I’d like to exercise - it’s good for your body, isn’t it?”:

Marginalisation of agency in everyday life

Lis is 80 years old. She lives alone after her husband died some years ago. Lis regularly sees her two children, grandchildren and nieces, but is mostly alone in her everyday life: *“I don’t think it’s much fun to be alone, I don’t like that very much. But I don’t know – I don’t feel I should move to an old people’s home yet either”*. Lis was born in another Nordic country. She moved to Denmark while she was still young and proudly states that she worked hard to get by in this new country, and studied to be a secretary. Lis valued her work highly but when her husband became ill she stopped working: *“I thought, ‘OK then, I’ll stop at 65. I’m entitled to that’”*. When Lis retired, she became ill and was diagnosed with diabetes and later also with rheumatism. Lis narrates how she and her husband continued to travel nonetheless, and in everyday life, her husband often took on a protective role: *“He looked after*

me, and could see when I was a bit shaky". After her husband's death, Lis became concerned about the changed face of everyday life and the challenges of daily living. She once collapsed in the street when out shopping, and she wants to prevent any repetition by exercising: *"When no-one's there looking out for you, you have to do it yourself"* Lis comments with some pride. She also proudly offers her hand for a handshake when I first meet her. Although she hardly has any strength left in her hands, this welcome gesture is convincing and earnest. She holds my hands for a long time, while she emphatically says that she is very happy to receive a visit. When we enter the living room Lis moves quickly, but suddenly she sways and leans against a chair, while commenting: *"It's that diabetes and the rheumatism, they don't go well together... I have no strength any more"*. Lis has not previously had home care, but kept up everyday living through her own resources. She has now applied for help in the form of physical home-based rehabilitation. For Lis, as for several of the informants, the meeting with the assessor focuses on rehabilitation from the beginning. The assessor begins by confirming that Lis's application is for physical rehabilitation. Lis speaks eagerly: *"But I want to exercise - it's good for your body, isn't it?"* The assessor replies: *"Yes."*

In terms of her lived experiences of everyday life, Lis is proud of having looked after herself, despite challenges. At the same time, her statement expresses internalised knowledge of the right thing to say, consistent with the 'active ageing' discourse, as the assessor acknowledges. But there is also another aspect.

Lis is an example of several people in the study who have found that the complexity of multimorbidity has made everyday life more unpredictable and insecure. Lis has experienced that a rheumatism-related change of medicine meant that her diabetes suddenly became worse; she collapsed in the street. She brings this up:

"I fall over, I can't feel when my blood sugar level is too low. I was picked up again one day, by the mother of one of my son's old friends. She asked me where I lived. I said: 'I don't know'. She thought I'd had a brain haemorrhage. Before, my husband used to take care of me."

In the meeting with the assessor, Lis is mindful of the vulnerability of her everyday life. It is brought about specifically by the same unpredictable, dramatic aspect of the two illnesses, and two not very compatible medications. Lis is afraid of how the multimorbidity is developing and that other illnesses might emerge, and is worried about her solitary life without her husband's protection. When Lis mentions the episode of her recent fall in the assessment meeting, she relates it

to the purpose of the rehabilitation. She thus demonstrates agency in her wish to strengthen her legs in order to avoid future falls.

But these are not the experiences, the situation or the context that underlie the judgement of the assessor, who replies:

"When I look at you, I see a woman who looks fit and lovely for her age. You're in too good a condition compared to those who get an exercise program"

Although they both draw upon internalised knowledge about how exercising promotes good health, they have a different understanding of rehabilitation and access to it. For Lis, rehabilitation strengthens the body; the motive for action is future-oriented, aimed at avoiding falls and at taking care of herself. Temporality is present in Lis's agency, because of a possible more mobile future. Yet the assessor's motive for action in declining Lis' application for rehabilitation is driven by the past in general: Lis has hitherto taken good care of herself, and for her age, her physical appearance is 'too good' - so the rehabilitation potential is estimated to be low. Lis might not profit very much from rehabilitation, whereas other clients, younger and maybe even frailer, might benefit more. Lis is not seen in her personal vulnerable situation, but only in comparison to others, which gives her a low rehabilitation potential. The incompatible motives for action, in terms of the point in time used as the reference, mean conflicting understandings of access to home-based rehabilitation; the assessor declines the application. This meeting thus excludes Lis from rehabilitation, creating more vulnerability in her everyday life with multimorbidity. Yet Lis again shows agency, not immediately accepting the rejection: *"Look at my fingers, there's not much strength in them!"*

Lis's hands, visibly afflicted by rheumatism, match the assessor's understanding of rehabilitation access as dependent on physical appearance. Yet her hands are considered by the assessor to be without rehabilitation potential, due to her overall performance, which has low potential. So Lis is only offered guidance from an occupational therapist about using hand tools. In Lis's meeting with the assessor, it is her rheumatism that prompts the initiative taken, in the form of guidance. With a narrow focus on a single disease and on Lis's physical appearance, the vulnerability in her complex everyday life with multimorbidity becomes marginalised. The agency in her desire for rehabilitation, involving broader support for her everyday life with multimorbidity, might even be part of the reason for rejecting her application.

"I'm afraid I'll fall": Marginalising meaningfulness in everyday life

John, aged 86, and Lily, 76, have been married for almost 30 years. Lily has four children from a previous marriage. The couple often receive visits from a son, the daughter-in-law, and the grandchildren. John and Lily have had long working lives, which they enjoyed, he as a typographer and she as a nursing assistant. John has been diagnosed with diabetes and osteoporosis; after several strokes, the strength in his left leg and arm is reduced. He has been repeatedly admitted to hospital with cystitis and recently broke his hip after a fall. Until now, Lily has been responsible for practical matters at home. Recently she has had several collapsed vertebrae and has not recovered from hospitalisation with a liver disease. They get around in their flat but John is uncertain in his movements, using a walker; Lily has back pains and suffers from fatigue and nausea. Their daily activities have become challenging, and against this background they are now receiving home care temporarily. Their everyday life with multimorbidity has deteriorated. John says: *"At first, when I was ill, I cycled almost every fine day - I had freedom"*. Lily adds: *"That's been hardest for us, the loss of freedom"*. Their everyday normalities and habits have changed. John's daily trip to his allotment and Lily's frequent visits to her sister have stopped. Their interests, routines and habits outside the home have been interrupted; now they spend most of the day together at home. They argue more often, due to the disruption to the everyday normalities that are meaningful for their relationship and their respective roles. Lily says: *"Before my illness, it was me that took care of John's lunch; I can't any more"*. John values the home care they are presently receiving, because it enables Lily to spare herself in daily activities. The help supports them in everyday life; they have enough strength now to resume social activities away from home. Lily says: *"They've opened a kind of cafe in this area; we've gone down there some times"*. The temporary home care also implies helping John to use the bath. And now that Lily has been discharged from hospital, she also receives help in using the bath, with cleaning, and preparing John's lunch. The couple's meeting with the assessor is aimed at reassessing their temporary home assistance needs and rehabilitation potential.

The assessor leads the discussion, enquiring about their challenges in tackling practical activities. The daily life perspective is here reduced to practical activities viewed separately, e.g. cooking and washing clothes. This also happens in many other assessment meetings observed.

Assessor: *"I see John is practising at home; let's see if making lunch can be practised."*

John: *"Why? I can't stand up and prepare it, and can't get it onto the table."*

Assessor: *"It can be done at the activity centre; let's see if it can be done at home. It's about keeping yourself active, so you can do as much as possible."*

John: *"I'm afraid I'll fall."*

John looks down at the table. The assessor looks at John, then at Lily.

The assessor says to Lily: *"Well, don't start lifting him. You'll have to call the emergency number."*

John's fear and concern about falling over and breaking a hip again, thus burdening his wife in terms of work, and in their roles, habits and routines, makes his situation vulnerable. The approach of the assessor, however, bypasses a consideration of the whole complex situation of everyday life with multimorbidity seen in context, and avoids estimating how the balance between help and self-supported activities of the couple might create more or less vulnerability

At the meeting, the couple's possibility to maintain their everyday habits is at stake. Now that they are receiving temporary home care for practical tasks, they have strength left for social engagements away from home. This new additional strength creates stronger agency, based on a desire to resume everyday life habits. The meeting therefore hinges on whether the couple can keep their temporary home care, which can support their everyday life habits and the increased social life that they have resumed, or whether the home care will be replaced by home-based rehabilitation, skills training, or simply withdrawn.

Assessor: *"So do you think you should get what's now temporary help on a permanent basis?"*

John: *"That would be great. It's a matter of feeling secure."*

Assessor: *"So you want to have permanent help?!"*

John: *"That would be nice."*

Assessor: *"Help in bathing will be permanent. But as for making lunch, I won't take that away from you, John."*

John: *"So she (the home help) isn't coming to help with lunch any more?"*

Assessor: *"No - well, in fact yes - one of our therapists is coming to practise making food with you."*

Lily: *"I think it's very uncertain, all of it, yes, it's all so uncertain."*

The assessor tries to construct the life skill of preparing lunch as especially valuable for John, although the couple have continually expressed how they see their situation as a whole, and have to balance weaknesses against what a "secure" life is for them. By using words such as secure, uncertain and afraid, they express the perceived vulnerability of their situation, and put particular emphasis on their dependency on each other and on others. The assessor's suggestion to call the emergency services if John falls is a recognition of their risky situation, but not a recognition of their vulnerability as an overall experience of their relation to each other, to assistance and to living with multimorbidity.

For John and Lily the burden of multimorbidity entails vulnerable social isolation; their vulnerability weaves threads back to two lost pleasures: John's time spent with friends on the allotment and Lily's visits to her sister. This challenges their close-knit, isolated everyday life and marital roles, with practical activities becoming the subject of arguments. What subsequently emerges for some informants, e.g. Lis, is agency, but this does not apply to John and Lily, who instead resign themselves to the situation. In summary, the cases show that people's challenges with daily practical activities cannot be viewed in isolation; they are conditioned by the people's temporally threaded vulnerability and agency in an everyday life with multimorbidity.

Greater vulnerability is the outcome of the couple's meeting with the assessor, where John's fear is ignored. In the meeting the fear is viewed by the assessor from a practical perspective, i.e. in terms of challenges with tasks brought on by a fall at home. This objectifies John, and his anxiety prompts the assessor's instructions to Lily on the standard procedure for falls at home. Through this marginalisation of the holistic perspective of everyday life, rehabilitation focused on making lunch becomes meaningless for John; this produces a lack of consent to rehabilitation, which is also ignored by the assessor.

"I can't figure out where to start": Supporting a vulnerable everyday life with multimorbidity

Inge, aged 51, lives alone. She sees her sister several times weekly. Since childhood, Inge has suffered from asthma, allergy, and osteoporosis; at school, she struggled to keep pace with learning. At 18 she was considered eligible for an early pension and since then she has worked in a sheltered workshop. Inge has been in hospital several times due to psychotic depression; now she is an outpatient in psychiatric treatment. She also receives outpatient treatment for blood clots in both legs. Most recently her sister has helped her with shopping, cleaning and cooking. Her sister is now renovating Inge's flat. Inge explains: *"She's my anchoring point [...] I'm starting from scratch, so to speak. A new start was needed. I'll be glad when we've finished this mess"*. Inge's flat and the whole residential quarter have been undergoing major renovation. The living room is filled with boxes, furniture moved away from walls and a ladder with a paint bucket that has not been touched for a long time is standing in solitude. Inge says that the renovation stresses her, affecting her sleep. So just recently she started staying home from the sheltered workshop and the outpatient treatments. Her fixed structure and everyday habits are thus disintegrating. Inge has also stopped cooking a warm evening meal. She says that now she only leaves the flat when necessary: *"I don't feel so safe leaving my home but I do go out - I have to. Food doesn't get here by itself."* When I first meet Inge, and she invites me in, she meets me with an aura of exhaustion and despair. She opens the door, and says *"Just come in"*, while she turns her back on me in the entrance, walks ahead and sits down in the settee. While I am still standing in the hall, Inge asks from the living room whether I want coffee, and without waiting for an answer, pours me half a cup of lukewarm coffee from a thermos flask. Inge tells me that her sister passed by with the thermos flask, and that she does not make tea or coffee or prepare meals herself at present. With her sister's support, Inge has applied for help with cooking and cleaning.

Inge's meeting with the assessor starts differently from most meetings observed. Inge is invited to talk about her current everyday life:

Assessor: *"First, I'd like to hear, how are you spending your day?"*

Inge: *"I go to a sheltered workshop, twice a week for four hours, and to the psychiatrist twice weekly; I'm free only on Fridays [...], I don't go there very much now. I'm awake at night and too tired in the day [...] The workmen should have finished six months ago [...]; I tend to be at home, that's where I feel best, that's my space"*

This is an account of a life with previous routines and an everyday life flow which seem to have broken up. Inge's narrative shows how everyday life with multimorbidity is vulnerable and complex in itself; the renovation of the flat is an extra challenge. This seems to have led to Inge breaking with everyday life normalities, involving interruption of the structure, routines, habits and activities of daily life. She is trying to hold on to individual daily activities, by continuing to go shopping, but everyday life and its habits have not been re-established for Inge. The assessor asks:

Assessor: *"What would you like help with?"*

Inge: *"I can't figure out where to start."*

This inviting approach in the meeting differs from most of the observed assessment meetings, and it involves a different type of answer, a plea for help to get a "hold" on her situation. Inge's reply reflects how the breaks with everyday life routines and daily practical activities have meant that she can no longer navigate in everyday life. Inge says that she wants to re-establish her previous everyday life, including daily activities:

Inge: *"I'd like to cook again, I'm only getting rye bread now [...]; I'd like to get a normal everyday life back again."*

Assessor: *"So there's cleaning and cooking. We have to prioritise one of these first, making a plan. What would you most like to start with?"*

Inge: *"They're both important, I don't know. I'd like to be able to boil an egg, that'd be lovely."*

Assessor: *"OK, let's start with cooking."*

The starting point of the meeting is Inge's everyday life with multimorbidity; here there is an attempt to recreate in Inge the understanding and acceptance of normalities of everyday life in an organised world in terms of her own and the assessor's intersubjective understanding. For Inge, to start rehabilitation is thus a meaningful course of action, providing support for a vulnerable everyday life with multimorbidity, amid the challenge of prioritising daily activities.

In the dialogue, cooking as a daily activity is not separated from everyday life - it forms part of Inge's challenge in navigating her everyday life. Inge thus receives

support not merely for her regular activities but also for her vulnerable situation after the disruption of her everyday life flow and to help her cope in life with multimorbidity. Here, the assessment meeting does not overlook agency, but creates agency; Inge decides to prioritise cooking, demonstrating the supported goal of re-establishing a disrupted everyday life.

Discussion and conclusion

The main finding of this article is that people's challenges in handling daily practical activities cannot be viewed in isolation; rather, those challenges are conditioned by people's temporally threaded vulnerability and agency in everyday life with multimorbidity. What is found in the assessment meetings is that it is possible to support people's complex everyday lives with multimorbidity as they face challenges in daily practical activities, when their everyday lives are not reduced to discrete tasks; also, the help offered must not exclude either these people's perceptions of a meaningful everyday life or their need to be able to cope with their everyday life. Conversely, the article also finds that a one-sided focus on people's practical daily challenges, thus marginalising their complex everyday life with multimorbidity and emphasising rehabilitation potential, creates unequal access to health care and additional vulnerability among people with multimorbidity.

A further finding is that an emphasis in assessing rehabilitation potential on the person's challenges with daily activities reduces the broad concept of everyday life and increases its medicalisation (Conrad, 1992; Illich, 1982; Vabø, 2018). The person's wishes from an everyday life perspective are thus overlooked or neglected in the assessment meeting. This article concurs with Jarling et al. (Jarling et al., 2018) in finding that people become guests in their own homes, but adds that ignoring people's everyday lives and wishes, specifically at meetings in their own homes, exacerbates their vulnerable situation.

Drawing on Fineman, we see how vulnerability in the three cases is present as a human condition. However, the preventative foresight of the assessor in relation to supporting people living a complex everyday life with multimorbidity does not seem to include a recognition of their situation as vulnerable. This is true of the first two cases, where expressions of fear, uncertainty and insecurity as part of the person's situation are not acknowledged and appreciated by the assessor. The two sides of vulnerability (Fineman, 2008, 2017) also have explanatory power in the cases; the people's everyday lives are partly transformed relationally and as

embodiment and partly through policy measures and legislation. The very basis of assessment for home-based rehabilitation is transformation in people's lives of an embodied, social and relational character. In all three cases, the people have experienced radical changes in their everyday life flow, and in their relation to the world and to each other. However the new legislation on home-based rehabilitation creates even more acute vulnerability, because they may not get help unless they mobilise agency, but this is only accepted in a few cases. Vulnerability is thus both affected and created during the meeting; as Sodemann states, vulnerability is created in relations (Sodemann, 2018). As other researchers have observed (see e.g. Järvinen, Larsen & Mortensen, 2002; Mik-Meyer, 2004), the power relationship is asymmetric in the meeting between person and system, since the person, as in this study, expresses the wish that the assessor is authorised to approve or decline. So the meeting structure in itself potentially creates vulnerability among people with multimorbidity. The outcome is also significant in terms of whether the people receive support in their everyday lives with multimorbidity, or whether additional vulnerability is constructed. The health policy framework and the context of these meetings play a key role here.

In line with Schutz (Schutz, 1971a, 1971b, 1970), we see the forms of temporally threaded agency in the three cases as part of the experience and as a typical phenomenon of life with multimorbidity. The cases show how vulnerability and agency appear as temporal threads from past lived experiences to future hopes. They highlight how aspects of vulnerability and agency in everyday life find expression in the challenges of daily practical activities. In the case of Lis, this is seen in how she draws upon the agency she previously demonstrated in her move to Denmark and in her husband's illness when she applies for home-based rehabilitation. Agency stems from a hope for future rehabilitation, combating her vulnerable situation in an everyday life with multimorbidity, where practical activities such as shopping are challenging. Inge's case is the exception that accentuates the general pattern; the meeting focuses on re-establishing everyday life's habits and routines, as well as agency, supporting a complex everyday life with multimorbidity. This finding corroborates that of Ørtenblad et al.: *"In particular, patients with multimorbidity need to be involved in decisions on treatment and care; this is because the complexity of the course of their illness affects everyday life significantly; this influences prioritisations in treatment and self-administered care"* (Ørtenblad, Jönsson & Meillier, 2015, p. 98). The present article contributes to this insight by highlighting that a firm foundation in people's whole everyday life experience as the central aspect,

rather than involving people peripherally in terms of daily activities, is crucial for the assessment meeting as support for everyday life with multimorbidity, and thus enhanced access to health care.

In an extension of the discourse of the last two decades on 'active ageing' as a health policy, focusing more on active ageing in home care policy and practice, and 'stay active at home' programmes (Metzelthin et al., 2017), political interest has now turned to home-based rehabilitation, where people's rehabilitation potential is attracting increased attention. In seeking rehabilitation potential, there is a movement towards what Åkerstrøm and Pors, from an organisational perspective on welfare management, call potentialisation; this entails always striving to move beyond current status, also creating opportunities for renewal, which those involved cannot even imagine (Åkerstrøm & Pors, 2014). The meeting with the assessor is thus framed by a health policy focusing on exploring the person's rehabilitation potential. This article concludes that, for people with multimorbidity, such 'potentialisation' plays a major role in the assessment meetings. But the unequivocal focus on rehabilitation potential, related to daily practical activities, increases vulnerability.

For most clients, like John and Lily, the meeting indicates that rehabilitation potential is assessed as highly significant in relation to daily activities. The assessor ignores everyday life experiences with multimorbidity, including their complexity, favouring a focus on fragmented daily practical tasks as a basis for assessing rehabilitation potential and home care needs. This finding reinforces other research that finds a divergence between rehabilitation practices focused on simplicity and the complexity of everyday life when handling chronic illness (Sørensen, 2018), and that the significance of participation in shared social gatherings is deprioritised or ignored by health professionals (Wind, 2016). Research has also shown that home-based rehabilitation tends to be limited to an emphasis on the body and task mastery at the expense of a perspective that considers good everyday life as a totality (Vabø, 2018). This article adds that focusing solely on daily practical activities creates objectification of everyday life, many clients do not find it meaningful, it generates problems of consent, and it increases additional vulnerability. Some people therefore resign themselves rather than demonstrating agency in the assessment meeting, and in some cases like that of the couple, they find themselves without access to home care.

References

- Aspinal, F., Glasby, J., Rostgaard, T., Tuntland, H. & Westendorp, R.G. (2016). New horizons: Reablement - supporting older people towards independence. *Age Ageing* 45, 574-578. <https://doi.org/10.1093/ageing/afw094>
- Bertelsen, M. T. & Hansen, M. B. (2018). *Hverdagsrehabilitering og velfærdsinnovation i ældreplejens organisering*. Ålborg Universitet. Retrieved from https://vbn.aau.dk/ws/portal-files/portal/285943233/Hverdagsrehabilitering_og_velf_rdsinnovation_i_ldreplejens_organisering_final.pdf (accessed 10.19.19)
- Brinkmann, S. & Petersen, A. (2015). *Diagnoser: perspektiver, kritik og diskussion*. Aarhus, Denmark: Klim.
- Conrad, P. (1992). Medicalization and Social Control. *Annu. Rev. Sociol* 18, 209-241. <https://doi.org/10.1146/annurev.soc.18.1.209>
- Coventry, P. A., Dickens, C., & Todd, C. (2014). How does mental-physical multimorbidity express itself in lived time and space? A phenomenological analysis of encounters with depression and chronic physical illness. *Social Science & Medicine*, 118, 108-118. <https://doi.org/10.1016/j.socscimed.2014.07.068>
- Emerson, R.M., Fretz, R.I. & Shaw, L.L. (2011). *Writing ethnographic fieldnotes*, 2nd ed. The University of Chicago Press, Chicago. <https://doi.org/10.7208/chicago/9780226206868.001.0001>
- Fineman, M. A. (2008). The Vulnerable Subject: Anchoring Equality in the Human Condition. *Yale Journal of Law and Feminism*, 20, 1-505.
- Fineman, M. A. (2017). Vulnerability and Inevitable Inequality. *Oslo Law Review*, 4(3), 133-149. <https://doi.org/10.18261/issn.2387-3299-2017-03-02>
- Fredslund, E.K. & Rasmussen, S.R. (2018). *Ældres forbrug af sundheds-og hjemmeplejeydelser-betydende socioøkonomiske faktorer*. Copenhagen.
- Gold, R., 1970. Roles in Sociological Field Observations, in: Denzin, N.K. (Eds.), *Sociological Methods, a Sourcebook* (pp. 370-380). Butterworths, Chicago.
- Grøn, L. (2016). Old age and vulnerability between first, second and third person perspectives. Ethnographic explorations of aging in contemporary Denmark. *J. Aging Stud.* 39, 21-30. <https://doi.org/https://doi.org/10.1016/j.jaging.2016.09.002>
- Hansen, B.B. & Ingemann, J.H. (2016). *At se verden i et sandkorn, om eksemplarisk metode*. Samfundslitteratur, Frederiksberg.
- Illich, I. (1982). Medicalization and primary care. *J. R. Coll. Gen. Pract.* 32, 463-470.
- Jacobsen, H.M. & Kristiansen, S. (2014). Hverdagslivssociologiens variationer in: Hviid-Jacobsen, M., Kristiansen, S. (Eds.), *Hverdagslivet, Sociologier Om Det Upåagtede*. Hans Reitzels Forlag, Copenhagen, pp. 9-41.
- Jansbøl, K., Anker, L., Nielsen, N. & Hjarsbech, P. (2016). *Oplevelser af behandlingsforløb og sygdomskonsekvenser blandt mennesker med én eller flere autoimmune sygdomme*. KORA Det Nationale Institut for Kommuner og Regioners Analyse og Forskning, Copenhagen.
- Jarling, A., Rydström, I., Ernsth-Bravell, M., Nyström, M. & Dalheim-Englund, A. (2018). Becoming a guest in your own home: Home care in Sweden from the perspective of older people with multimorbidities. *Int. J. Older People Nurs.* 13, 1-10. <https://doi.org/10.1111/opn.12194>
- Järvinen, M., Elm Larsen, J. & Mortensen, N. (Eds.) (2002). *Det magtfulde møde mellem system og klient*. Aarhus Universitetsforlag, Århus.

- Jønsson, A.B., Guassora, A. D., Freil, M. & Reventlow, S. (2018). What the doctor doesn't know: Discarded patient knowledge of older adults with multimorbidity. *Chronic Illn.* 1-14. <https://doi.org/10.1177/1742395318796173>
- Kuluski, K., Bensimon, C.M., Alvaro, C., Lyons, R.F., Schaink, A.K. & Tobias, R. (2014). Life interrupted: The impact of complex chronic disease from the perspective of hospitalized patients. *Illness, Cris. Loss* 22, 127-144. <https://doi.org/10.2190/IL.22.2.d>
- Kvale, S. & Brinkmann, S. (2015). *Interview : det kvalitative forskningsinterview som håndværk*, 3rd ed. Hans Reitzel, Copenhagen.
- Metzelthin, S.F., Zijlstra, G.A., Van Rossum, E., De Man-Van Ginkel, J.M., Resnick, B., Lewin, G. & Parsons, M., Kempen, G.I. (2017). 'Doing with ...' rather than 'doing for ...' older adults: rationale and content of the 'Stay Active at Home' programme. *Clin. Rehabil.* 31, 1419-1430. <https://doi.org/10.1177/0269215517698733>
- Mik-Meyer, N. (2004). *Dømt til personlig udvikling, identitetsarbejde i revalidering*. Hans Reitzel, Copenhagen.
- Ministry of Health (2017). *Healthcare in Denmark - An Overview*. København. Retrieved from https://www.sum.dk/English/~media/Filer%20-%20Publikationer_i_pdf/2016/Healthcare-in-dk-16-dec/Healthcare-english-V16-dec.ashx (accessed 2.19.18).
- Patton, M.Q. (2015). *Qualitative research & evaluation methods, integrating theory and practice*, 4rd ed. SAGE Publications, Inc., Thousand Oaks, California.
- Prados-Torres, A., Calderón-Larrañaga, A., Hanco-Saavedra, J., Poblador-Plou, B. & Van Den Akker, M. (2014). Multimorbidity patterns: A systematic review. *J. Clin. Epidemiol.* 67, 254-266. <https://doi.org/10.1016/j.jclinepi.2013.09.021>
- Petersen, A., Graff, L., Rostgaard, T., Kjellberg, J., & Kjellberg, P. K. (2017). *Rehabilitering på ældreområdet - Hvad fortæller danske undersøgelser os om kommunernes arbejde med rehabilitering i hjemmeplejen?* København. Retrieved from <https://www.sst.dk/da/nyheder/2017/~media/887D8135638442D08F8C6BBA0FA4C130.ashx> (accessed 2.22.18).
- Rosbach, M. & Andersen, J.S., (2017). Patient-experienced burden of treatment in patients with multimorbidity - A systematic review of qualitative data. *PLoS One* 12, e0179916. <https://doi.org/10.1371/journal.pone.0179916>
- Rostgaard, T. & Graff, L. (2016). *Med hænderne i lommen - Borger og medarbejders samspil og samarbejde i rehabilitering*. København: KORA Det Nationale Institut for Kommuner og Regioners Analyse og Forskning. Retrieved from <https://www.vive.dk/media/pure/8841/2039537> (accessed 02.02.18).
- Röing, M. & Sanner, M. (2015). A meta-ethnographic synthesis on phenomenographic studies of patients' experiences of chronic illness. *Int. J. Qual. Stud. Health Well-being* 10. <https://doi.org/10.3402/qhw.v10.26279>
- Schutz, A. (1971a). On Multiple realities, in: Natanson, M., Breda, h. IL. Van (Eds.), *Collected Papers I - The Problem of Social Reality*. Martinus Nijhoff, The Hague, pp. 207-259.
- Schutz, A. (1971b). Common-sense and scientific interpretation of human action, in: Natanson, M., Breda, V.H.L. (Eds.), *Collected Papers I - The Problem of Social Reality*. Martinus Nijhoff, The Hague, pp. 1-47.
- Schutz, A. (1970). *On phenomenology and social relations, Selected writings*. Chicago.
- Signal, L., Semper, K., Stairmand, J., Davies, C., Millar, E., Dowell, T., Lawrenson, R., Mangin, D. & Sarfati, D. (2017). A walking stick in one hand and a chainsaw in the other: patients' perspectives of living with multimorbidity. *NZMJ* 130, 65-76. <https://doi.org/DOI: 1175-8716>

- Social- og Indenrigsministeriet (2014). *Servicebogen - Bekendtgørelse af lov om social service* - retsinformation.dk. BEK nr 1575 af 27/12/2014. URL <https://www.retsinformation.dk/forms/R0710.aspx?id=183958> (accessed 6.30.16).
- Sodemann, M. (2018). *Sårbar? - det kan du selv være, sundhedsvæsenets rolle i patienters sårbarhed*. Morten Sodemann, Odense.
- Sørensen, N.Ø. (2018). At forme sig selv på ny - modstand og frimodighed in: Øye, C., Sørensen, N.Ø. & Martinsen, K. (Eds.), *Å Tenke Med Foucault. En Bok for Masterstudiene i Helse-Og Sosialfagene*. Fagbokforlaget. Norway, Bergen, pp. 111-132.
- Spradley, J.P. (1980). *Participant observation*. Harcourt Brace College Publishers, Fort Worth.
- Sundhedsdatastyrelsen (2018). *Borgere med multisygdom*.
- Tinetti, M.E., McAvay, G.J., Chang, S.S., Newman, A.B., Fitzpatrick, A.L., Fried, T.R. & Peduzzi, P.N. (2011). Contribution of Multiple Chronic Conditions to Universal Health Outcomes. *J. Am. Geriatr. Soc.* 59, 1686-1691. <https://doi.org/10.1111/j.1532-5415.2011.03573.x>
- Vabø, M. (2018). Omsorgsarbeid i et hverdagslivsperspektiv. *Tidsskr. omsorgsforskning* 4, 276-286. <https://doi.org/10.18261/issn.2387-5984-2018-03-10>
- Van den Akker, M., Buntinx, F. & Knottnerus, A.J. (1996). Comorbidity or multimorbidity : what's in a name? A review of literature. *Eur. J. Gen. Pract.* 2, 65-70. <https://doi.org/10.3109/13814789609162146>
- Vedsegaard, H.W. (2019). Borgere med multisygdom i nye rehabiliteringsforløb - brugerinddragelse eller borgerens inddragelse? *Tidsskrift for Velferdsforskning* 22, 59-73. <https://doi.org/10.18261/issn.2464-3076-2019-01-04>
- Violán, C., Foguet-Boreu, Q., Roso-Llorach, A., Rodriguez-Blanco, T., Pons-Vigués, M., Pujol-Ribera, E., Ángel Muñoz-Pérez, M. & Valderas, J.M. (2014a). Burden of multimorbidity, socioeconomic status and use of health services across stages of life in urban areas: a cross-sectional study. *BMC Public Health* 14. <https://doi.org/10.1186/1471-2458-14-530>
- Violán, C., Foguet-Boreu, Q., Flores-Mateo, G., Salisbury, C., Blom, J., Freitag, M., Glynn, L., Muth & C. & Valderas, J.M. (2014b). Prevalence, Determinants and Patterns of Multimorbidity in Primary Care: A Systematic Review of Observational Studies. *PLoS One* 9, 1-9. <https://doi.org/doi:10.1371/journal.pone.0102149>
- White, C., Lentin, P. & Farnworth, L. (2016). Multimorbidity and the process of living with ongoing illness. *Chronic Illn.* 12, 83-97. <https://doi.org/10.1177/1742395315610392>
- Wind, G. (2016). Livet med kronisk sygdom - grundvilkår, rutine og hjemmearbejde, in: Glasdam, S. & Jørgensen, J.W. (Eds.), *Det Nære Sundhedsvæsen: Perspektiver På Samfundsudvikling Og Møder Mellem Mennesker*. Munksgaard, Copenhagen., pp. 96-105.
- Wiuff, M.B. & Grøn, L. (2009). *Sårbarhed og handlekraft, borgere og praktiserende lægers forståelse og italesættelse af sociale forskelle i sygdom og sundhed*. Dansk Sundhedsinstitut, Copenhagen.
- Ørtenblad, L., Jönsson, A.B. & Meillier, L. (2015). Komplet liv. Patientinddragelse som vej til et bedre hverdagsliv for multisyrge? *Tidsskr. Forsk. i Sygd. og Samf.* 83-101. <https://doi.org/10.7146/tfss.v0i22.20821>
- Ørtenblad, L., Meillier, L. & Jönsson, A.B. (2018). Multimorbidity: A patient perspective on navigating the health care system and everyday life. *Chronic Illn.* 14, 271-281. <https://doi.org/10.1177/1742395317731607>
- Åkerstrøm, N.A., Pors, Justine G., 2014. *Velfærdsledelse, mellem styring og potentialisering*, 1. udg. ed. Hans Reitzel, Copenhagen.

