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Health care professionals' experiences of possibilities and constraints in caring for older adults living with long-term pain in community home care

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ABSTRACT

Caring for a growing population of older adults with complex health problems in their homes is part of every-day work for many health care professionals in the world. This qualitative interview study explores the way health care professionals perceive possibilities and constraints when caring for older adults living with long-term pain in community home care in Sweden. The study aims to understand the relationship between health care professionals' subjective experiences and social structures such as the organization of care and shared norms and values in regard to their perceived space of action. Findings provide insight into how institutional structures such as organization and time, conflate with cultural notions, norms, and ideals, and how these enable and constrain health care professionals in their daily work but also create dilemmas. Findings suggest centering the meaning of structuring aspects in social organizations as a tool for reflection on priorities, improvement, and development in care settings.

Introduction and background

Caring for a growing population of older adults with complex health problems in their homes is part of every-day work for many health care professionals in the world. This qualitative interview study explores the way health care professionals perceive possibilities and constraints when caring for older adults living with long-term pain in community home care. The study thus aims to understand the relationship between health care professionals' subjective experiences and social structures. The organization of care as well as shared norms and values are aspects that need to be considered while exploring health care professionals' experiences of providing care.

The population of older adults is rapidly growing worldwide (World Health Organization, 2015). Increasing age is often associated with more complex health problems such as comorbidities (Summer Meranius, 2010) where long-term musculoskeletal pain is a common component and difficult to treat (Maxwell et al., 2008; Soldato et al., 2007; Tsang et al., 2008). Long-term pain often has an impact on mobility and ability to manage daily life independently, is associated with increased risk of falls and related injuries (Leveille et al., 2009, Stubbs et al., 2014,) and with sleep disturbance, anxiety, and depression (AGS Panel on Persistent Pain in Older Persons, 2002). Pain influences the sense of well-being and quality of life and research shows that people feel lonely when it comes to learning to live with long-term pain and illness (Charmaz, 1983, 1991, 2020; Gillsjö, Schwartz-Barcott, & Bergh, 2013). There has been an increase in research on older adults and pain for the past decades (Gagliese, 2009), there is however less research focusing on how health care professionals experience caring for older adults living with long-term musculoskeletal pain.

In Sweden as in many other parts of the world, the political intention is that people who suffer from comorbidities and complex health problems spend less time in hospitals and receive professional care in their homes (SOU, 2011). In 1992 municipalities in Sweden were trusted with the responsibility to provide long-term care for older adults (National Board of Health and Welfare, 1996). Older adults in need of support to manage their daily life get assistance from home care providers, organized within social care. If also in need of professional health care such as physiotherapy, occupational therapy, or a nurse, this is managed by the health care organization. From the perspective of health care professionals, home care has been described as challenging, both in regard to role, professional versus the role of a guest (Öresland, Määttä, Norberg, Jörgensen, & Lützén, 2008), and making difficult decisions (Furåker, 2012) but also as a balancing act handling needs, wishes and values (Janssen, Abma, & Van Regenmortel, 2014), and a limitless

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responsibility where it is difficult to distinguish between professional and personal responsibility (Jarling, Rydström, Ernsth Bravell, Nyström, & Dalheim Englund, 2020).

Results from our previous qualitative research (Berglund, Nässén, & Gillsjö, 2015) suggested that health care professionals felt they wanted to accomplish more than they could while caring for older adults with long-term pain. The situations they described left them with little room to maneuver. We thought it would add in–depth knowledge on health care professionals daily work to analyze their perceived limited social power in the context of community home care with theories that highlight individuals' perceived space of action in a specific social setting.

Theoretical points of departure

As pain is an intersubjective experience, it affects the lives of family, friends, and others around the person with it, which include health care professionals which in turn affects the experiences of the person in pain. Good (1994) referred to this as "bearing witness to the moral experience of suffering" (p. 13). Health care professionals interacting with patients "bear witness" by listening, supporting, and providing coherence and meaning to experiences. The creation of coherence and meaning however, has inherently local qualities. To care for someone has cultural aspects as shared values and notions of care, well-being, and support provide action with meaning. What people perceive as possible options are, according to the French sociologist Pierre Bourdieu (1977, 1990), deeply ingrained skills, dispositions, and habits due to life experiences, which he coined *habitus*. Habitus entails how we respond to social expectations, understand what is expected and have a "feel for the game" (Bourdieu, 1990, p. 66) within a specific context. Familiarity with social expectations is learnt and embodied, commonly by being brought up in a given context, and of being socialized into shared knowledge, norms, and values. Moral dynamics, shared norms, and values in a specific context, play an important part in what people perceive as their constraints, options, and possibilities, which in this paper will be termed their "space of action."

While the concept of habitus stresses the subconscious aspect of internalized structures, the British sociologist Anthony Giddens (1979) emphasizes peoples' ability to reflect on their options and their resistance. According to Giddens, structures include resources, rules, principles, or values which are points of departure rather than determinative for action. Giddens argues that structures both enable and constrain, which in this paper will be used as a starting-point to explore and discuss how health care professionals perceive their possibilities and constraints in every-day work.

Aim

The objective of this paper was to explore issues that health care professionals considered significant in the care of older adults living with long-term pain in community-based home care in Sweden including perceived space of action in relation to caring for these people.

Methods

Data collection and participants

In three communities in the south part of Sweden, heads of community-based home care organizations consented to participate in the present study. They, in turn, asked health care professionals that met the inclusion criteria of at least three years of experience working with older adults living with long-term pain to participate in the study. Ten health care professionals, eight women and two men, gave their informed consent. Two of the participants were occupational therapists, three were physiotherapists and five were nurses.

Data were collected through semi-structured interviews. The interviews lasted between 22 and 49 min and were conducted at a health care center where the interviewed participant was employed. Health care professionals were asked to reflect on their experiences providing care to older adults living at home with long-term pain. The participants were asked to give concrete examples of their experiences and encouraged to further develop their answers. The interviews were audio-recorded and transcribed verbatim, generating approximately 115 pages of narrative data.

Data analysis

Since our objective was to explore issues that staff felt were significant in the care they provided and described, the study was designed using a hermeneutical perspective (Ricoeur, 1981; Ricoeur, 1991). Ricoeur sees interpretation as a particular way of understanding that is applied to written expressions of experience. He argues that the construction of meaning through interpretation of text can make unfamiliar and incomprehensible experiences seem familiar and comprehensible (Ricœur, 1976; Ricoeur, 1981). Inspired by Ricoeur's ideas, our interpretation of the interviews was based partly on our pre-understanding and partly on our growing appreciation of an emerging totality that could only be understood from its parts. This meant shifting back and forth between the parts (each individual interview) and the whole (the sum of all the texts). Each interview is thus regarded as a meaningful entity, but together all the interviews can be seen as a single entity, a reading of which in turn helps deepen our understanding of each one. Our growing understanding of the setting helped us contextualize the interviews (Skinner, 2012). Further, the local care context is part of a national healthcare system that is embedded in a broader social, historical, and cultural context.

In the analysis, the concept of constraints was considered to include any structuring aspects the health care professionals referred to as important and restraining for their capability to care for older adults with long-term pain. Structuring aspects such as resources, rules, principles, and values (in the sense of Giddens, 1979) they referred to during the interview were included in the analysis. We regard structuring aspects as institutional as well as shared norms or values. While institutional and organizational aspects were rather explicit in the interviews, shared norms and values were more often implied as health care professionals discussed how they perceived and managed their daily work.

Ethical considerations

The study was designed following the ethical guidelines of research of the Declaration of Helsinki (World Medical Association, 2013). It was also approved by the Regional Ethical Review Board in Gothenburg (814–13). The participants were informed, both orally and in writing, and gave their informed consent to participate in the study. They were also informed that they could withdraw their participation at any time without explanation and (or) consequences.

Findings

Three themes emerged as significant to the health care professionals' experiences of space of action when providing care to older adults living with long-term pain in community home care: negotiating notions on pain, assessing time and space, and contesting the boundaries of home.

Negotiating notions on pain

Pain is an obvious and straightforward sign of illness and suffering but simultaneously difficult and elusive for health care professionals, as well as patients, their next of kin, physicians, and home care providers, to apprehend and communicate. Health care professionals describe a shared notion in society of a perceived "right" to live life without pain. It is an ideal that conveys common beliefs in the biomedical field of knowledge, trust in its capacity to cure illness and the expected access to and support from the health care system in contemporary Swedish society. However, the common ideal is concurrently contested, as biomedical logics tend to emphasize the difficult balance between the benefits of drugs and serious adverse effects in relation to long-term pain. Health care professionals are in their professional capacity aware of the inherent contradiction and conflict between these different perspectives and expectations:

> *…pain is so difficult… no one should have to be in pain, so it is always said, no one should have to be in pain, and it sounds easy. All you need to do is to talk to a physician and get pain relieving medication and there is always something that will help. But I don't think it works that easily, in fact I think it is difficult. You get confused by these pills, you get constipated, feel sick and dizzy and there is a huge risk of falling… (RN 1).*

The health care professional says she knows it is not possible to relieve pain completely in every situation and she gives examples of severe adverse effects these people can suffer from, such as constipation, dizziness, and nausea. She identifies a conflict between general expectations and professional pharmacological knowledge on adverse effects.

Health care professionals work in home care parallel to home care providers who assist patients in their daily life. Home care providers work very closely with their clients daily, and report to health care professionals when they observe changes in well-being. These observations can also originate from concerned next of kin or from clients themselves. One participant explains:

> *…but us nurses know that not every kind of pain is possible to ease, and we often feel trapped in a balancing act between home care providers who say we don't do enough or take the problem seriously enough…. and there is this powerlessness I feel then and when I talk to the physician, and nobody listens… so one is caught in the middle of it. (RN 2).*

Home care providers observe clients' well-being and when they report any changes to the health care professionals, they expect action and relief for the person. Health care professionals recognize the legitimacy of such expectations and in turn appeal to physicians at the health care center for support. They report pleading with physicians for more effective drugs, and physicians tending to be restrictive. While they as professionals are aware of potential adverse effects of medications, they feel hard-pressed and express frustration with the inherent contradiction of perspectives and expectations. To some extent, they share the common notion of a "right" to be relieved of pain through modern drugs yet are also familiar with the difficult adverse effects these drugs cause. Home care providers, on the other hand, have less formal education but they are close to their clients and meet them daily. The friction between an ideal and a possible outcome for each person in pain can leave health care professionals feeling frustrated and powerlessness in relation to what they can accomplish to support people in pain and reassure home care providers that they have done everything they possibly can do for the well-being of the patients.

However, a recognized way to achieve less frustration in the situation was to create a mutual understanding of the complexity of a situation by taking enough time to talk things through with home care providers:

> *There is a frustration among them, which I can understand. Home care providers work in the homes of their patients and see them in pain, and they are not relieved from pain in an ideal way. If we sit down, talk it over and explain to them [the home care providers] … their frustration disappears. (RN2).*

Health care professionals reflect on and acknowledge the importance of sitting down with home care providers, to share concerns and to reach a mutual perception of a situation. Negotiation also includes an effort to understand the situation, to explain and communicate back and forth, to relay notions of pain-relief and try to find a solution. Negotiating with home care providers, and with patients and next of kin, is thus a potential way to create a shared understanding and reduce frustration in all parties.

The organization of care implies that health care professionals rely on home care providers to observe patients and report deviations to them:

> *I collaborate with home care providers, and they tell me if something is wrong… some patients I rarely see but they [the home care providers] are really reliable and good at reporting to me if something is out of the ordinary. Then I can visit the patient and try to figure out what the current problem is. (RN3).*

Reports from home care providers that something is out of the ordinary with a client, enable health care professionals to act upon the observations. Although in separate organizations, health care professionals' collaboration with home care providers can compensate for the lack of a personal and first-hand experience of a person's condition and add to health care professionals' sense of control.

Health care professionals can also recognize the notion of a right to a pain-free life as unrealistic and therefore challenged:

> *When you have worked for many years like I have, it [the patient's situation] flows off or something like that, but I try to create a moment of wellbeing while I visit them and talk to them. I spend time with them and talk for a while, but I don't think about them incessantly, because I wouldn't last if I did. I communicate with the physicians, and I communicate with the patients and support them the best I can. (RN 3).*

Experiences over time can lead to the conclusion that to sustain oneself professionally it is important to have a pragmatic approach. Health care professionals care for people with long-term pain over extensive periods of time, which can be accomplished by keeping what they perceive to be an appropriate emotional distance. It is recognized as untenable to take on every else's suffering, as that would be a too heavy burden. Focus is instead geared towards the ability to create a moment of well-being for the person (in Swedish *en god stund*), while seeing each other and talking. Health care professionals may have arrived to administrate prescribed drugs, for therapeutic exercise or to provide tools and techniques, but they are also there to lend support by listening, affirming, and comforting. A moment of social interaction supports and, ideally, distracts the person from their pain, if only for a short while, and is regarded meaningful and caring.

Assessing time and space

To capture older adults' experiences of pain it is important to know when people want to share. Health care professionals underline the importance of being perceptive and aware that older adults often seem to think that pain is a natural and inevitable part of getting older, and therefor may refrain from verbalizing their pain. It is thus important to understand how and when people consider it appropriate to communicate pain:

> *Well, it's not until I sit down with her, she will tell me how she has worked, and she eagerly wants to share how she has worked hard, all her life. She will tell me about all the heavy machines they used and how they harvested and did the threshing and then she will also tell me about her pain. I doubt she will talk to the home care providers about it, rather I believe it is not until you sit down with her, then she will share her pain. (RN3).*

For some people, pain is subtle or in the background of other health problems and they will not share their pain until or unless health care professionals create an appropriate moment of time and space where patients feel it is socially acceptable to do so. The quote above emphasizes the need to sit down together as this makes it possible for patients to share their experiences and for health care professionals to listen carefully and assess the situation.

Health care professionals must also balance their workload and the time they have available within the organization of care, and this is reflected in how and when they decide to act:

> *If I were to ask another question there will be so much more that I need to listen to, and how can I do that? Do I have the time to listen and for how long do I need to sit here? Well, if you open up for something… you do get to a certain point in any conversation when you have to decide if you are going to say no, now I don't have any more time. I don't express myself exactly like that, but I may cut the conversation short because If I ask another question then I open for something that I cannot interrupt after only five minutes. Then I must be prepared to stay and sit there for another twenty minutes. (RN4).*

In this reflection, the conflict between the patient's needs and the health professional's schedule is apparent. Patients will share their experiences with health care professionals if they are given opportunity. Yet time is seen as a limited, constraining resource that must be assessed and divided between patients. As widely reported in western allopathic medicine, this quote illustrates deeply embedded neoliberal ideologies that structure the organization of Swedish home care, with efficiency and time management being highly valued. When to remain in a conversation with a patient or to say good-bye and leave is thus a critical choice for health care professionals to make during any meeting.

Contesting the boundaries of home

Health care professionals care for patients living at home and need to consider the meaning of home and personal integrity.

> *It is more complicated when people live at home, it's entirely different compared to when they are in a nursing care facility because then you can check on them every day. I feel I'm less in control when people need care at home, and they have more integrity, and you are like some kind of guest when you visit them. You have to make plans ahead and it must suit them, and it feels entirely different… To work in a nursing care facility is like working in a hospital… you are close to your patients all the time. (RN3).*

Home care is compared to both nursing care facilities and hospitals, where health care professionals are physically close to patients while at work and therefore can observe them continuously and for longer periods. Home care is intermittent care, and it is not possible to monitor patients constantly. The quote emphasizes the circumstance that appointments must be agreed upon and suit the patient's daily life but also that patients' integrity is more prominent at home, compared to the integrity given to them in hospital care. Health care professionals underline that if patients do not want their daily life to be interrupted by health care professionals' visits, they can decide against a proposed caring action. People in home care may prefer not to be disturbed in their daily lives, especially if they have tried a variety of procedures and cannot see the meaningfulness in another effort. In line with national regulations and notions of patients' rights to autonomy and integrity, health care professionals emphasize they understand and recognize people who draw these boundaries.

Health care professionals will nonetheless attempt to persuade the older adult they care for. It can be a professional challenge to advocate for another attempt, and this can be accomplished in different ways. When health care professionals step back and allow patients time to process a suggestion, they sometimes find that patients comply when they have thought it through. Health care professionals can also decide to intensify their persuasion and encouragement to motivate a patient to make an extra effort:

> *If I find that a patient is not really motivated […] I can try even harder to encourage him or her and say look how well you are doing, last time you could only take four steps but today you managed six steps. (Physiotherapist 1).*

Health care professionals can persuade patients to try an extra step or two, or another procedure despite high age and long-term pain, if they believe patients will gain health benefits and well-being.

Discussion and conclusion

Findings suggest that institutional structures such as the organization of care does not provide a solution or support the management of peoples' experiences of pain, but rather creates situations where conflicting perspectives appear. In Swedish society, there is a high degree of expectation and belief in the national health care system to cure illness and pain. Biomedicine is a field where "a salvational view of science" (Geertz, 1988, p. 146) is persuasive and trust in its capacity to cure illness is widespread in Sweden. In relation to long-term pain, health care professionals are aware of the inherent contradiction between the potential immediate benefit of drugs and the serious adverse effects but find that patients' needs and high expectations from next of kin and home care providers, can cause frustration in all parties and iatrogenic effects for their patients. Health care professionals' perceived space of action, in this case negotiation, potentially creates common ground where there otherwise could be conflict or frustration. According to Giddens (1979), structures are points of departure rather than determining for action, which suggest they can be adhered to or consciously put aside or opposed. Findings indicate, in line with Giddens, that health care professionals also recognize options instead of negotiation. Perceived space of action is equally apparent when health care professionals' ward off feelings of frustration, and when they talk of how they need to emotionally detach themselves from patients, actions that have been described in terms of compassion fatigue (Yoder, 2010). Other recognized possibilities are also evident when health care professionals emphasize that they can support patients by focusing on the social aspects of the relationship.

As there is rarely an immediate cure to long-term pain, findings indicate that a significant way to care for a patient is through focusing on a moment of well-being through social interaction. While health care professionals administrate drugs, provide tools and techniques or therapeutic exercise, they can also include small-talk and listening. The ability to create a moment of well-being (in Swedish *en god stund*) by taking time to talk or to listen and distract the patient from pain for a while, is identified as meaningful interaction and a recognized ideal within caring science, contributing support to the patient's experience of wellbeing (Dahlberg, Todres, & Galvin, 2009). However, when health care professionals mention aspects that they find restrain their capacity to care for older adults with long-term pain, they often refer to the structured aspects of time. It requires time to sit down with patients to have a conversation and to listen carefully as well as to support and comfort somebody. Pain assessment entails knowledge, sensitivity, and awareness of what to listen for in a conversation, but also the time needed to create a socially appropriate situation, which includes physically sitting down together, before sincere sharing can take place. Health care professionals will negotiate the time they have at hand with the task they need to perform and may choose to stay a bit longer or to abstain from asking another question, and leave. They acknowledge the importance of sitting down and allowing for a social moment to accomplish a meaningful caring encounter and this perceived space of action is thus a possibility. To ask one more question may however cause friction in relation to organizational aspects of care, such as the limitations of a busy schedule. In home care in Sweden and worldwide, time has been described as a scarce resource by both home care providers and by health care professionals (Jarling et al., 2020). Neo-liberal reforms since the 1990s have increasingly defined time management and cost effectiveness as guiding values within the Swedish welfare sector and notably in the care of older people (Palmqvist, 2022). As time is perceived as a limited and constraining resource by health care professionals, every encounter with patients brings about choices and priorities that needs to be addressed.

Individuals' rights to autonomy and integrity are values generally regarded very highly in Swedish society and patients' rights to integrity are specifically emphasized in the National Health Care Act (HSL National Health Care Act, 2017: 30). Health care professionals recognize these values as points of departure, as implied when they say they must respect a patient's wish not to be disturbed in their daily life at home. Meaningful care, therefore, must take place with patients' approval and participation. However, findings indicate that care and support can still take place although patients may previously have rejected a suggested caring action. Health care professionals' regard it as caring to insist a bit on certain actions, despite an initial lack of approval from the patient. Bourdieu's concept of habitus (Bourdieu, 1990) is useful to understand how health care professionals use seemingly conflicting social norms and expectations as points of departure while caring for older adults living at home. They have a "feel for the game", where the "game" in Bourdieu's sense means caring for someone, by experience and familiarity with society, the health care system and not least, their patients. In the present paper, health care professionals' space of action includes being persistent, to explain and motivate, and also to provide time to reflect on a suggested caring action and think it through. To persuade a reluctant patient to try something new or to encourage and motivate someone to leave their comfort zone, such as to engage in physical exercise, are sometimes necessary. Rasoal, Kihlgren, and Skovdahl (2018) describe coaxing (in Norwegian bokmål *lirke*) as the most efficient way for nurses and nurse assistants to get older patients to comply with their suggestions in Norwegian home cares. The variation of what is perceived as meaningful and possible ways to act is not without limits but specific to what is coherent and comprehensible in the particular social context.

Methodological considerations

When reading and analyzing the interviews with a theoretical focus on institutional structures as well as norms and values as structuring points of departure, inspired by Giddens (1979), it turned our attention to how health care professionals would reason and describe constraints as well as what they perceive they can accomplish in different situations. Bourdieu's concept *habitus* (Bourdieu, 1990) facilitated our understanding of how health care professionals act in apparently complex and contradictory situations when they strive to accomplish their professional objectives without losing their patients' trust and confidence. There is variation in what they can achieve when they respond to different expectations, but options are not without limits. Habitus emphasizes social reproduction and thus suggests why change, or any action what apart from what is learnt within social systems of every-day practices, is challenging to accomplish.

Limitations and future research

Although this paper is based on interviews with a relatively small number of health care professionals in Sweden, findings provide an in-depth understanding of their perceived space of action caring for older adults living with long-term pain in home care. A limitation with an interview study is the element of uncertainty regarding if study participants do in practice what they say they do. Even though the act of sitting down (and listening or having small talk) is mentioned as key to creating opportunities for health care professionals to socially interact with and support their patients, health care professionals do not sit down at every opportunity. Arguably, they cannot do so every time, and so must use some metric to determine when to. To understand what motivates health care professionals in different situations and to understand when and why a certain decision on how to act is made in a specific situation, we would like to propose that in further research interviews would ideally be complemented with periods of participant observation (see for example Kiefer, 2007: Roper & Shapira, 1999). Ethnography and participant observation would capture differences in what health care professionals say and what they do in these situations, as a starting point for further in-depth understanding.

Practical implications

Findings provide insight into how institutional structures and shared norms and values constitute a starting point for health care professionals' care and support to patients in home care with long-term pain. This creates awareness of the meaning of structuring aspects in social organizations, as a tool for reflection on priorities, improvement, and development in care settings more broadly.

Conclusions

The present study allows for an understanding of how cultural and social notions such as the necessity to sit down as a cue for social support and sharing, patients' rights to integrity and ideals related to pain, provide actions with meaning in home care. Findings also reveal that while health care professionals strive to accomplish their professional objectives, to assess and support the patient, dilemmas arise. The constraints of time and organization conflate with shared ideals, norms and values and create complex interactional situations. Health care professionals navigate through dilemmas and conflicts where a perceived acting space includes myriad, sometimes competing roles of negotiation, collaboration, intentional emotional detachment, support through conversation and listening, persistence and leaving patients room to reflect on their suggestions. Home care for older adults with long-term pain appears to reflect a liminal space not simply for those experiencing it, as Charmaz (1991) long-ago demonstrated, but also for the health care professionals who are working with them.

Declaration of Competing Interest

None.

Data availability

The authors do not have permission to share data.

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