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The tension between carrying a burden and feeling like a burden: a qualitative study of informal caregivers' and care recipients' experiences after patient discharge from hospital

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ABSTRACT

Purpose: The number of people aged 80 and above is projected to triple over the next 30 years. Expanding public expenditure on long-term care services has made policies encouraged informal caregiving. Burden of care describes challenges connected to informal caregiving.

Dependent patients report feelings of being a burden. Few studies have focused on both the experience of caregiver burden and recipients' feelings of burden. This study explores the experiences of old patients and informal caregivers in the first 30 days after the patient's discharge.

Method: A phenomenological approach was used to explore the subjective experiences of the participants. Semi-structured individual interviews were analysed thematically.

Results: The results reflect imbalance regarding care needs relative to time, social roles, physical and emotional states, and formal care resources. Four themes emerged from the interviews: 1) Bridging the gap, 2) Family is family, 3) Never enough, and 4) Stress and distress.

Conclusions: The participants face strains within their roles. The care situation has potential to be burdensome. To secure healthcare quality for old patients, the informal carer's role needs to be recognized. Informal care based on altruism and reciprocity seems to be positive, whereas informal care based on family norms might have a negative impact.

ARTICLE HISTORY

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KEYWORDS

Healthcare; elderly; informal care; quality of care; burden of care; reciprocity; equity


Background

The number of people aged 80 and above is projected to triple over the next 30 years (UN, 2019). Along with this, there is a growing concern about expanding public expenditure on long-term care services in the future (Calvó-Perxas et al., 2018; Plothner et al., 2019). Therefore, the policies of several European countries have encouraged informal caregiving to reduce public healthcare spending (Bremer et al., 2017; Calvó-Perxas et al., 2018; Pavolini & Ranci, 2008), which has resulted in a shift in responsibilities for care away from the state and onto families and individuals (Del-Pino-Casado et al., 2019; McGregor, 2001; Navarro, 2009; Pavolini & Ranci, 2008; Sakellariou & Rotarou, 2017). Thus, informal caregivers play a crucial role in supporting the health, well-being, functional independence, and quality of life of older persons (Plothner et al., 2019; Schulz & Eden, 2016). The defining characteristics of an informal caregiver typically include being a person who provides

unpaid, ongoing assistance with activities of daily living to a person with a chronic illness or disability (Roth et al., 2015). Informal caregiving ranges from assistance with daily activities and provision of direct care to helping the care recipient navigate complex healthcare and social services systems (Schulz & Eden, 2016).

Burden of care is a concept that has been discussed and acknowledged for years (Bastawrous, 2013; Carretero et al., 2009; Roth et al., 2015; Zarit et al., 1980) and describes the physical, emotional, social, and financial problems that can be experienced by informal caregivers (Bastawrous, 2013; Ringer et al., 2017; Roth et al., 2015; Zarit et al., 1980). Burden of care has been broadly classified into two dimensions: objective and subjective (Zarit et al., 1986). Objective burden of care refers to the physical effect of day-to-day tasks undertaken for the patient, such as the time invested by the caregiver while helping, supervising, and feeding the ill family member. Subjective burden of care has been seen as the psychological, social, and

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emotional impact caregivers may experience from the objective burden of caregiving (Fekete et al., 2017). A caregiver's subjective burden is defined as the caregiver's state, characterized by distress in several areas (caregiver's health, psychological well-being, finances, social life, and the relationship between caregiver and care recipient), resulting from the caregiving situation (Zarit et al., 1980). The subjective care burden has been related to increased anxiety (Cooper et al., 2007) and depression (Schulz et al., 1995; Schulze & Rössler, 2005) as well as decreased physical health (Carretero et al., 2009).

In spite of the fact that caregiving occurs within a dyadic relationship between caregiver and care recipient, less attention has been given to the care recipient's sense of having become a burden to others, and research on the relationship between formal care and that undertaken by a family member or friend tends to overlook older people's everyday experiences at the intersections of systems of care. A systematic review of clinical studies involving patients with advanced illnesses found that a large number of dependent patients reported feelings of being a burden to others (McPherson, Wilson, Murray et al., 2007a). The feeling of being a burden to others has been defined as a multifactorial (physical, psychological, and emotional) construct that may arise in dependent people due to their need for care (Cousineau et al., 2003). Frequently, these people feel both frustrated and guilty about the hardships they impose on their caregivers (McPherson et al., 2010). Based on the available evidence, the feeling of being a burden is clinically important due to the distress and suffering it causes and its negative impact on the quality of life and the patient's sense of dignity (Rodríguez-Prat et al., 2019).

As the average length of stay declines, older people are being discharged from the hospital "quicker and sicker" than before (Deniger et al., 2015; Galvin et al., 2017; Spehar et al., 2005). Although there has been increasing studies in the area care transitions for older patients and how this situation affects the patient and their informal caregiver (Gupta et al., 2019; Hvalvik & Reiersen, 2015; Jeffs et al., 2017; Lilleheie et al., 2020, 2019), there are few studies addressing how this influences feelings of reciprocity, equity and family dynamics. Furthermore, few studies have focused on the experience of caregiver burden and on recipients' feelings of being a burden (Sales, 2003). Knowledge about the experiences of older people regarding their own care and need for care is crucial to identifying and addressing issues related to the time after discharge from hospital (Hestevik et al., 2019), particularly because the transition between levels of the healthcare system and the period subsequent to hospital discharge is regarded as critical for avoiding readmission in older patients (Krumholz,

2013; Storm et al., 2014). Therefore, patients' and caregivers' perspectives on being care receivers and caregivers, respectively, may provide valuable information to guide improvements in health service quality (Noest et al., 2014). Thus, this study aimed to explore how patients aged 80 years old and above, and their informal caregivers experience being care recipients and caregivers, respectively, in the first 30 days after the patients' discharge from hospital to their own home. We wanted to explore how they perceive the informal care, how it might impact their everyday life regarding well-being and stress, and how it might impact on the relationship between informal caregivers and care recipients. This study adds important knowledge on how to improve the situation for informal caregivers and care recipients. Furthermore, it contributes towards the tailoring of education for health and social workers as well as aids competence development for health professionals delivering services to older patients during and after discharge from hospital. The study also helps to identify quality gaps in the health service and thus contributes to quality improvement in healthcare for older patients.

The first period following hospital discharge is a vulnerable time for patients (Noest et al., 2014), and their journey between healthcare sectors may provide important information that can be used to improve the quality of care.

Methods

This qualitative study is part of a larger project addressing cross-sectoral care transitions for older patients.

Design

In this study, we conducted semi-structured interviews with older patients and their informal caregivers to learn about their experiences and preferences. A phenomenological perspective attaches importance to rich contextualized descriptions based on experience. It intends to turn to the phenomenon itself, freeing itself from pre-existing prejudices (Spiegelberg, 2012). In this way, it becomes an essentially reflexive enterprise (Toombs, 2013). In addition, it demands a scientific approach to subjectivity (Natanson, 1974) as stressed by Schutz (Schutz, 1972). Phenomenology allowed us to discuss the various experiences and preferences of the interviewees regarding our research topics in light of the aim of phenomenological qualitative research. This research dealt with experiences and meanings and intended "to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place" (Giorgi & Giorgi,

2003). Our informants can illuminate the lived world, and our aim was to see things as they appeared to them.

We followed the consolidated criteria for reporting qualitative studies (COREQ) (Tong et al., 2007) (see the Supplementary File).

Setting and participants

In Norway, healthcare is mainly funded by the state and available to all residents. The hospitals are responsible for acute and specialized healthcare, while the healthcare services in the municipalities provide follow up of somatic and mental health issues (Lindahl, 2019). The municipality also administers homecare services for patients who need services due to illness, impaired health, old age, or other factors (Holm et al., 2017).

The participants in this study were recruited from an acute geriatric ward at a large hospital in Norway. Acute Geriatric wards are independent units within the hospital, dedicated to older people with acute medical disorders. The distinctive feature of acute geriatric units is the comprehensive geriatric assessment and care focusing on patients' needs, interdisciplinary work carried out by a core team of professionals (geriatrician, nursing staff trained in geriatrics, therapists, and social worker), and early planning of discharge (Baztan et al., 2009).

The inclusion criteria were patients aged 80 years and above, living at home prior to hospitalization, and were to be transferred to one of the following services: short-term stay at a nursing home or own home with health services from the municipality. Health professionals in the hospital ward identified all the patients who fulfilled the criteria. Patients unable to give informed consent were not included in the study.

Twenty-two patients agreed to participate, and 18 were interviewed twice after discharge from hospital. Three patients (n = 3) were readmitted to hospital before the interview and one (n = 1) patient changed his/her mind about participation.

We conducted the 30s Chair Stand Test (CST) to describe the functional and mental characteristics of the participants (see Table I). This test is a functional evaluation clinical test that measures lower body strength, and can be related to demanding activities in daily life (Jones et al., 1999; Millor et al., 2013). The test can predict patients survival, health status, together with hospital costs (Dumurgier et al., 2009). We also performed the Mini Mental State Examination (MMSE) to assess cognitive function (Tombaugh & McIntyre, 1992). The patient participant's ages ranged from 82 to 100 years old. The mean age was 92 years. Please see Table I for patient characteristics.

In addition, we recruited participants from the relatives of included patients. Sixteen of the 18 patients had a next-of-kin which they regarded as an informal caregiver. Thirteen of the informal caregivers who were asked to participate agreed and were interviewed approximately 30 days after the patients had been discharged from the hospital. Characteristics of the informal caregivers and relationship to the patient are provided in Table I. Caregivers ranged in age from 42 to 79 years old. The relationship to the patient varied from sons and daughters to friends and neighbours (Table I).

Data collection

The data were collected between September 2017 and March 2018. We conducted individual semi-structured interviews with open-ended questions to capture the way in which participants experienced life after the patients were discharged from hospital. We

Table I. Characteristics of participants.

No	Patient age	Patient gender	Life situation	Informal caregiver no	Informal caregivers relationship to patient (gender)
P1	90–95	F	Alone	(C1)	Daughter (F)
P2	90–95	F	Alone	(C2)	Daughter (F)
P3	82–89	F	With spouse	(C3)	Sister (F)
P5	96–100	F	Alone	(C5)	Daughter (F)
P6	90–95	F	Alone	(C6)	Granddaughter (F)
P7	96–100	M	Alone		Daughter (F)
P8	96–100	F	Alone	(C8)	Daughter (F)
P9	96–100	F	Alone	(C9)	Son (M)
P10	82–89	F	Alone		Niece (F)
P11	82–89	M	With spouse	(C11)	Wife (F)
P13	90–95	F	Alone	(C13)	Niece (F)
P15	82–98	F	Alone	(C15)	Daughter (F)
P16	82–89	F	Alone	(C16)	Neighbour (M)
P19	82–89	F	With spouse		Daughter (F)
P20	82–89	M	Alone		Son (M)
P21	96–100	F	Alone		Son (M)
P22	82–89	F	Alone		Support person (F)
P23	96–100	F	Alone	(C23)	Granddaughter (F)

Table II. Interview guide.

- 1 Could you please describe how you are experiencing your current situation?
- 2 Please describe how you have experienced the caregiver situation/caregiver role.
- 3 Please describe how you have experienced the cooperation/coordination of the caregiver tasks.
- 4 Please describe how you have experienced the homecare.
- 5 Looking back, is there anything you think should have been done differently regarding the healthcare the patient has received?

developed a semistructured interview guide with open-ended questions (see Table II) and suggested follow-up questions, such as “Can you tell me more about this?”, “What did you think then?”, “How did this affect you?”. The initial questions were based on established standards for quality in healthcare (WHO, 2020). The interview guide was modified iteratively, as the interviews and concurrent data analysis proceeded, to incorporate new information and to focus progressively on emerging themes.

The interviews with the patients were conducted one-on-one, approximately 1 week after discharge at the patient’s current residence. To capture their experiences from the whole 30-day period, a follow-up interview was conducted about 1 month after discharge. Due to their health status, three participants were only interviewed once. The interviews were performed by the first author of this article and lasted from 30 minutes to 115 minutes. The interviewer is an experienced physical therapist with extensive experience working with older patients. The first author was not involved in the treatment of the patients in the study.

The interviews with the informal caregivers were also one-on-one interviews and were conducted approximately 30 days after the patient’s discharge from the hospital. The interviews lasted from 30 to 105 minutes and were also performed by the first author. All interviews were audiotaped and transcribed verbatim by a professional transcriber. Participants’ names and other personal identifiers were removed from the transcripts.

To enable the participants to express their concerns and make their claims on their own terms, the interviewer kept her preconception out of the interview process (Alase, 2017).

Data analysis

To analyse the data we used thematic analysis (Braun & Clarke, 2006; Holloway & Todres, 2003). Initially, all the authors read the transcribed material searching for meaning and patterns. We used a thematic coding technique based on Braun and Clarke’s (Braun & Clarke, 2006) work. This approach has been widely used and accepted as robust across a wide range of disciplines, including human health research (Braun &

Clarke, 2014). It is a method for reporting patterns within qualitative data that includes six phases: familiarizing with the data, generating initial codes, searching for patterns or themes across data, reviewing themes, defining and naming themes; writing the report. Examples of the coding strategy are presented in Table III. To maximize trustworthiness and limit threats to validity, we employed the criterion for “trustworthiness” that Lincoln and Guba (1985) outlined. We met the criterion of credibility through open-ended questioning and by providing a detailed description of the methods. To meet the criterion for transferability, we present detailed and in-depth descriptive data and quote the participants in the text. To meet the criterion of dependability, each transcription was independently read, checked and coded by two of the authors (. and.) we reached final interpretations through an agreement among all four authors. To meet the criterion of confirmability, we present rich quotes from the participants that depict each theme. The initial codes were then categorized into themes. To reflect on their relevance to the research questions (Bryman, 2016), these themes were discussed and reviewed by all authors. The themes were then refined to ensure that each was meaningful and clear but distinct from other themes (Patton, 2015). Reflexivity involves critical reflection on the researcher’s impact while gathering information throughout the research process (Malterud, 2001). Researcher triangulation was used in the analytical processes and preconceptions were placed in brackets. Bracketing is a fundamental strategy in phenomenology (Dowling, 2007). In this study, different researchers’ preconceptions were placed in brackets due to examination and limitation of own prejudices (Dowling, 2007). Reflexivity was secured during the interviews, as participants were asked to elaborate their statements, both to ensure a common understanding and to achieve a detailed representation of the phenomenon. All the authors who performed the analysis were educated in the health fields and have extensive clinical experience and/or research in the field of elder healthcare.

Ethical considerations

The study was preapproved and registered by the Norwegian Centre for Research Data (No. 53110). All the patients were deemed able to give informed consent by healthcare personnel in hospital. The first author met the participants in hospital and gave them verbal and written information about the purpose of the study. They were informed that their participation was voluntary, and about their right to withdraw from the study at any stage without any affect of their current or future access to services. After the first interview, the first author asked the patients for the name of their informal caregivers as well as for permission to contact and interview them

Table III. Examples of coding strategy.

Quotation	Initial code	Subtheme	Theme
<i>They didn't talk about what they thought was wrong with me, the doctors. They didn't. They said nothing. It would have been better for me if they told me what they thought could be wrong, but they didn't. So, I don't know. I don't know what they thought. Maybe they think it's better for the patient not knowing what's wrong with them. So, I think they do it out of good will, but for my part, at least, I think it would have been better to know. I can bear hearing that I am both sick and everything. I can bear that. And I think it would have been better for me to know, rather than to go around and imagine things that might not be true. But I don't know. I think it would have been better if they told me some more. (P13)</i>	They did not tell me anything	Information gap	Bridging the gap
<i>I take a lot of responsibility for her. Makes sure she has food in the house and in the case- Drives her around a bit, so she gets her a little aired, so to speak, Not just sitting home in a chair. Takes her visiting family and stuff. Well, that's how it is these days. Drives her back and forth to the doctors and to the hairdresser and things like that. She wants me to be there a lot, due to her uncertainty, I think. (C6)</i>	I take a lot of responsibility for her well being	Bridging the formal care gap	
<i>She is the centrepiece of the family. She is the one who takes care of everyone. It is a matter of course, after the many years of care that she has given, it is important to give something back. (C21)</i>	She has always taken care of us; it is natural to give something back	Reciprocity	Family is family
<i>I used to have some help from the home care, and it was ok, but then I got a little tired of different people showing up each time, so I thought I had to take care myself. So, they offered me services, it's not that- but family is family. (P8)</i>	They offered me services, but I prefer help from my family	Family is family	
<i>But everything depends on me, after all. I hope he understands that. Often, it is taken for granted that we women should do everything. (C11) enough</i>	I must take care of everything	Care task	Never
<i>Like my sister and our son and his wife and such, you know, they have their own life and their own interests, you can't expect them to stand up for us all the time. I don't mean it either ... (P3) This is a little bit difficult for my kids to understand, you see, because they are used to me being able to manage by myself. They don't quite understand this new situation. Because they haven't seen me so helpless before, I think. They haven't seen it. So now they see me as a more helpless person. (P15)</i>	I need more help, but understand that my family has other commitments in life I need more help than I used to. It is hard for my family to understand	Care need Care need	
<i>The image I get is her standing in the hallway of death, in a way, and it's so tiring. I don't know how I can help her either, it's so hard this. She can get so angry with us sometimes. Then she can sniff at us and say, "You don't understand how I feel. You don't understand what it's like to grow old. «I don't know why she's so angry with us so often. My reason tells me that I should not take it personally, but off course I do. So, then I fight a battle against myself to manage to just be good and comfort her, then. And just say, "I understand you." (C13) distress</i>	My aunt is old and sick. She gets frustrated and angry. The situation feels distressing.	Distress	Stress/
<i>It is so despairing to be helpless. I've always been able to help myself, and suddenly I can't do anything, and I'm desperate, that is.(P13)</i>	I am helpless, and it makes me feel desperate.	Stress	

about the patients' situations. The informal caregivers were provided with verbal and written information outlining the purpose of the study before the interview. They were informed that participation was voluntary, that they could withdraw from the study at any stage and were assured that this would not affect the patients' current or future access to services. We obtained written and informed consent from all participants and guaranteed their confidentiality.

Results

The thematic analysis produced an overarching theme, "the tension between feelings of carrying and being a burden", which reflects the informal caregivers' and care recipients' multidimensional biopsychosocial experiences of an imbalance in and uncertainty regarding care needs relative to time, social roles, physical and emotional states, and formal care resources. Four themes linked to the overarching theme outlined this tension: 1) Bridging the gap, 2)

Family is family, 3) Never enough, and 4) Stress and distress.

Our findings indicated high levels of psychological distress and unmet supportive care needs among the informal caregivers and the care recipients. Our results indicated an ambiguity where the participants' experiences of care were shaped by a desire to retain a sense of independence and to avoid placing unnecessary demands on the healthcare service, family, and friends, while the informal caregivers' experiences were influenced by how caregiving had to be balanced with other life commitments. The four inter-related main themes, along with selected quotations from the interviews to illustrate the findings, are presented in the following sections.

Bridging the gap

The patients and the informal caregivers in this study expressed that they were burdened with the expectation from the health services that they, to a large

extent, were supposed to secure necessary follow-up and care themselves. Both groups of participants expressed an uncertainty due to an experienced gap in the health systems regarding their own needs and the offers they received. The patients described themselves as *helpless and dependent on help from others* (P13) to manage daily life, whereas the informal caregivers described how they felt responsible for securing the health and well-being of the patients. Both patients and informal caregivers described how the informal caregivers must *take a lot of responsibility for the patients' situation* (C6), for daily tasks, as well as for coordination of care and navigating a complex health-care service.

Both patients and informal caregivers described how they lacked information, both about the organization of the services and the patient's health condition. The lack of involvement and information made the situation demanding for all participants. For the informal caregivers, the lack of information made them experience the role of coordinator and caregiver as more burdensome. One of the informal caregivers expressed the situation like this:

They sent him home without contacting me and without asking me. I think that is quite serious and deviates significantly from how this should work. (C11)

For the patients, on the other hand, lack of information about their health condition and future made them worried and scared. One of the patients expressed how she experienced the lack of information:

They didn't talk about what they thought was wrong with me, the doctors. They didn't. They said nothing. It would have been better for me if they told me what they thought could be wrong, but they didn't. So, I don't know. I don't know what they thought. Maybe they think it's better for the patient not knowing what's wrong with them. So, I think they do it out of good will, but for my part, at least, I think it would have been better to know. I can bear hearing that I am both sick and everything. I can bear that. And I think it would have been better for me to know, rather than to go around and imagine things that might not be true. But I don't know. I think it would have been better if they told me some more. (P13)

The organization and the complexity of the services also made it necessary for patients to receive help from informal caregivers to manage their daily life. Since the patients were physically and psychologically reduced after discharge, they still needed different health services. To be able to receive necessary medical attention, they asked for help from the informal caregivers for transport and support in meetings with health personnel (e.g., with their general practitioner). Both patients and informal caregivers described how the informal caregivers assisted the patients in communicating with

health personnel. The patients also turned to their informal caregivers to get them to elaborate and translate the information they had received from the health service. This is illustrated by the quote below:

So, I called my daughter and I said, "Now you have to take care of your old mother and tell me what this is all about." Then she told me that some food could trigger this uric acid content in the blood. But, I will say it like she said it, that if you eat the way you usually do, some fish, some meat, some egg, some of this and some of that, and if you notice something or at some point recognise some of the ailments you've had, then you just have to think about what you've eaten that you haven't eaten before, and then cut it out. Yes, I thought that was a reasonable answer, so then I related to that. That was the kind of information I expected to get at the hospital. (P19)

The participants experienced a health service that did not always deliver the necessary and expected care, which increased uncertainty about the patient's situation. For informal caregivers, uncertainty about their own role led to a concern about how to balance care responsibility and their own life. Still, both informal caregivers and patients accepted the in-between role to which the caregivers were assigned by the health services, but as the following quote illustrates, some of them also questioned whether the caregivers' responsibility to secure the patients' care and follow up their medical situation was accurate:

I guess I called to make sure she was satisfying follow-up, and then I think they asked me what I thought she would need. And then I answered, maybe a little short, 'cause then I said, "You have to ask her yourself." Then I said that they had to figure it out, together with her, "because I don't know her state of health", I said. (C5)

The way the informal caregivers experienced the responsibility for bridging the gap between the services delivered and the patients' need for help and assistance made the situation burdensome for the participants. Due to the patients' condition during the first 30 days after discharge, the prioritizing and the organization of the health services made it, first and foremost, the informal caregivers' responsibility to bridge the gap.

Family is family

Both patients and informal caregivers found that the services the patients were offered were limited and not sufficiently based on knowledge about the patients' everyday life. Both groups described short visits from the homecare service and extensive use of temporary workers. The short visits did not allow time for conversations about what the patients themselves thought they needed. Nor did the informal caregivers experience any participation in the planning and design of the services offered to patients. Patients

were aware that the health service had limited resources and that this influenced the service provision. The limited services and the restricted focus on the patients' needs and involvement made the patients turn to informal caregivers for help and support in this troublesome situation. Some of the patients did, in fact, turn down services offered because they then felt more in control of the situation, and one of the patients stated: *family is family* (P8). Reported exchanges of support between family generations seemed to be grounded in reciprocity. Our informants assumed it was expected that they would repay their "debts" from earlier decades at later stages of their parents' or grandparents' lives. Both care recipients and caregivers emphasized the reciprocity in the relationship and the support that lies in a family relationship. The informal caregivers mentioned that the short visits and different personnel each time made patients feel unsafe, and this insecurity made them turn to friends and family members for help, instead. As one of the informal caregivers stated: *I do wonder if it might have anything to do with her feeling safe?* (C6).

While most of the patients were comfortable with a situation where informal caregivers took most of the responsibility for supporting their needs, others asked for more appropriate help from the services to spare their loved ones. Both patients and informal caregivers put forward the need for a specific contact person in the services, whom they could relate to when they needed help or had questions about the patient's health and situation.

Both groups of participants explained the responsibility the relatives took on in terms of reciprocity. This reciprocity enabled the participants to conceptualize the informal care as a part of the *give and take* (C1) of family relationships that are based on *mutual support* (P2) and exchange. As one grandson said it:

She is the centrepiece of the family. She is the one who takes care of everyone. It is a matter of course, after the many years of care that she has given, it is important to give something back. (C21)

The feeling of caring responsibility stemmed from love and gratitude towards their partners, older parents, or grandparents. The patients had been there for their children and helped them in earlier years; now the informal caregivers reported that they wanted to reciprocate. However, not all seemed to assume a caring responsibility, which increased the load on those who did. Often, one of the children or grandchildren living nearby and having a closer relationship with the parent becomes the primary caregiver. The feeling of duty and reciprocity depends on the relationship with the parent and the family's history. A granddaughter elaborated on her commitment to her grandmother like this:

If you've never had a close relationship, maybe have been a parent who was a little distant or, well, then, I think it might not suddenly be like everyone is there to help and support you, and "poor you" – if you never have been there for them. But my grandmother has always been there for me and for my kids. So, I don't feel any sacrifice. I feel that it is just and fair that I am there for her now, when she needs me. (C23)

This showed how care given by spouses, children, neighbours, and friends was embedded in the social relationships between the two groups of participants.

Never enough

Both patients and caregivers realized that the care demands exceeded the caregivers' personal time and resources. Due to insufficient services delivered without sensitivity to older patients' extensive need for assistance and help, the informal caregivers were left with a large number of different tasks to handle, a burden which was difficult to balance against other commitments in their life. This placed the informal caregivers in a challenging situation about which they reported having feelings of *guilt and an awareness of their shortcomings* (C6) that left them with *remorse* (C6) and a concern about whether they were able to follow up the patient's needs satisfactorily. For some caregivers, having a caring responsibility meant supervising and taking on the role of being the patient's advocate or manager, which involved mediating for the best care and treatment. Uncertainty was still there, and sometimes, the caregiver had to argue with health professionals to meet the patient's needs. These informal caregivers acknowledged that the patient's life situation and well-being (C23) depended on their ability to support them. A granddaughter described her impact on her grandmother's life situation like this:

She probably wouldn't have been where she now is without me. I don't think so. I don't think she would have been in good shape. I'm not sure whether she would have been alive, actually. In fact, I'm not sure if she would. (C23)

Some of the informal caregivers described the struggle to meet both the patient's need for help and other responsibilities. One of the informal caregivers, a daughter of a 95-year-old woman put it like this:

But I don't know if we can give her [my mother] that support every single day. We do have our own lives to live, you know. I live half an hour away and have all the children and grandchildren here that need my help as well. The biggest do not need so much help, but the little ones do. When they are ill, their parents can't be home from work, you know. So, there must be some days between the visits. Usually I visit her every other day, and then maybe skip, say, Friday and go there until Monday again. (C1)

The patients, on the other hand, were very much aware of the fact that they were *lucky* (P8) to have their informal caregivers to help them, and one of the patients stated that her *well-being depends on her neighbours' goodwill* (P16). In addition, even if several of the patients longed for extended social interaction with their informal caregivers, they recognized that their helpers had a *life of their own* (P3). This understanding made the patient, in some cases, try to limit the caregiving burden for the informal caregivers; for example, the patients *kept quiet* (P8) about some of their medical challenges and worries, or the patients would sometimes disguise their state of health to make the caregiver burden as light as possible. Anna (96) said it like this:

I've kept this to myself. I don't even talk to my daughter about it because I'm, like, I don't want to complain to her about anything unnecessary. I don't want to bother her with me having been awake for a whole night and perhaps have been exhausted when she and the kids come. Then I play awake, you see. She has enough with her own ailments, and she can't do anything about mine, so I don't think it's right to bother her with that. (P8)

In this way, some of the patients tried to spare the informal caregivers from caregiving tasks and thereby continue to secure help from family instead of help from health and social services.

Stress and distress

Both caregivers and care recipients reported experiences of negative stress based on the care responsibilities and unmet needs. Caregivers stated feelings of overload, and care recipients mentioned feelings of guilt for burdening the caregiver. Informal care was perceived as a vital stress factor when not knowing when the role would come to an end was associated with negative consequences for the well-being of both the informal caregivers and the care recipients. Both the informal caregivers and the patients described the time after discharge as a demanding and stressful situation that led to distress for both parties. As a wife of an 82-year-old man said it: *The situation is very exhausting because I have no freedom anymore. (C11)*

One of patients stated: *I can't make it. I won't be able to make it. It's too much for me to handle by myself. (P2)*

The organization of the health service caused strain for the informal caregivers and the patients that was reinforced by the undersupplied services delivered by homecare. Both groups reported different psychological stresses connected to the situation. The feelings expressed in the interviews with the informal caregivers included frustration, exhaustion, guilt, and sorrow, whereas the patients articulated feelings of

hopelessness, despair, anxiousness, lack of autonomy, and insecurity.

The situation also burdened their relationship. The patients described how they felt *helpless* and sometimes *misunderstood* (P13) by the informal caregivers. While the informal caregivers felt *exhausted* (C13) and *frustrated* (C1) due to endless tasks and demands from both the services and the patient. A daughter said:

She calls at all hours, either home to me or to her granddaughter. I say to her, "You're driving me crazy", so I'm not as patient as I should be, I must admit. I'm not patient at all because it's not the mom I used to know who is sitting there. Just complaining and sighing and complaining and sighing, almost never saying hello when I visit her. She calls and says, "Aren't you coming?" and then I say, "I was with you yesterday. I have been to work. I cannot cope. I have a life of my own, you know". (C2)

One patient described her feelings of sorrow when neither the health personnel nor her relatives were able to meet her need for help:

My children tell me, "You can't expect it. They don't have time. They have too much else to do". And they're probably right, but that doesn't help me because I am very disappointed at times. Sometimes I feel like crying. But I don't cry openly. I don't. But I cry inside. (P2)

Several of the patients reported feeling like a burden on their closest relatives in the period after hospitalization: *I'm just a burden to everyone around me. Everyone has to take care of me. It doesn't feel good. I've always been able to manage by myself (P13)*. This concern resulted in feelings of stress, anxiety, and guilt.

Discussion

The purpose of this study was to explore how patients 80 years old and above and their informal caregivers experienced the informal care situation the first 30 days after the patient's discharge from hospital. Our most important findings suggest that informal caregivers and care recipients experience an imbalance between their care needs and available resources from the health services, which indicates a quality gap in the service. The formal resources are not balanced against the participants' available time, social roles and physical and emotional states. Although the patients desired to maintain independence and equity in relation to their informal caregivers, their need for assistance and care seemed to have a negative impact on the informal caregivers' ability to balance care tasks against other life commitments. This influenced the relationship between the caregivers and care recipients. Even though both groups of participants acknowledged reciprocity as an important aspect of a family relationship, our material also revealed some ambiguity regarding

expectations and willingness to perform informal care. Due to the imbalance in care needs and available resources, both groups reported a situation filled with uncertainty and worry as well as inequity between the caregivers' and the care recipients' resources.

The caregivers and care recipients in our study experienced uncertainty and worry in different ways. Andersen et al. (2020) describe how uncertainty arises when informal caregivers perceive the health and social system's failure to deliver the expected care and treatment. This is in line with the responses of the informal caregivers in this study, who recognized the gap between the patients' needs and formal care resources. The informal caregivers reported how lack of information and support from the healthcare services contributed to their feeling of uncertainty when they mediated between the patient and healthcare professionals. The informal caregivers also expressed how they experienced extended caregiver activities after the patient's hospitalization. Several researchers have described how informal caregiving is experienced as a chronic stressor that puts caregivers at risk for physical and mental morbidity (Adelman et al., 2014; Bastawrous, 2013; Carretero et al., 2009; Del-Pino-Casado et al., 2019; Fekete, 2015; Ringer et al., 2017; Roth et al., 2015; Zarit et al., 1980). Especially around-the-clock care obligations, associated with high or increasing care needs, and care transitions (e.g., hospital to home) are substantial risk factors for caregiver burden (Adelman et al., 2014). The informal caregivers interviewed told how they experienced strain and difficulties with balancing caregiving with other life demands, and several of them described how this led to feelings of powerlessness and despair. This is in line with other researchers' descriptions of how informal caregivers, caring for an old, ill, and frail patient experiences existential, life-constraining life phenomena (Adelman et al., 2014; Zarit et al., 1980). The informal caregivers expressed this through stories of frustration and distress associated with care tasks that went beyond what they had the time and resources to handle. Research has described that when informal caregivers lack support and resources to handle their caregiver tasks, they experience greater physical and psychosocial costs, costs that might compromise the quality of care they are able to provide (Bastawrous, 2013). When the informal caregivers in our study reported extended care tasks together with limited support and information from the health services, they described how they became uncertain about their own ability to secure satisfactory care, health services, and welfare for the patients.

The care recipients in this study described an origin for their worry and uncertainty that was different from that of the informal caregivers. Several of the patients

in our study described how being dependent and responsible for creating difficulties for others caused feelings of uncertainty and worry. They mentioned these worries not only regarding the current situation but also in anticipation of future declining health. McPherson et al. (McPherson, Wilson, Murray et al., 2007a) state that the self-perceived feeling of being a burden in older patients arises as a result of dependency and the need for physical assistance (McPherson, Wilson, Murray et al., 2007a). This corresponds with the uncertainty and worries the patients experienced when not able to perform daily activities by themselves but instead had to rely on others to handle small tasks and basic needs. In another study of McPherson et al. (McPherson, Wilson, Murray et al., 2007b), participants described how the feeling of responsibility for causing hardships to others caused distress and how this impacted negatively on their self-esteem. When the patients in our study felt responsible for creating difficulties for others, this had a bearing on how they saw themselves and their sense of dignity, and they described a sensation of powerlessness. These findings are supported by other researchers who describe how the feeling of being a burden to others might be embedded in a more general construct of existential distress (Rodríguez-Prat et al., 2019; Wilson et al., 2005).

The patients in this study experienced that their health condition reduced their ability to fulfil family relationships based on mutual exchange and equity. According to McPherson et al. (McPherson et al., 2010), although equity theory was developed to understand relationship interactions in general, there is important evidence that the principles are applicable to the specific situation of caregiving interactions (McPherson et al., 2010). Equity theory focuses on determining whether the distribution of resources is fair to both relational partners. Equity is measured by comparing the ratio of contributions (or costs) and benefits (or rewards) for each person (Adams, 1963). Inequity arises when individuals give more than they receive (under benefit) or receive more than they give (over benefit) (Walster et al., 1973, 1978). In other words, equity theory predicts that individuals are motivated to restore balance in the relationship. This is done by altering the contributions given and received, and by this, they perceive reciprocity. Reciprocity is thereby one means by which equity can be restored. However, the ability to reciprocate may be affected by illness (McPherson, Wilson, Murray et al., 2007b).

When the patients in the current study reported that they experienced reduced opportunity to reciprocate and restore equity, it made some of them perceive themselves as having become a burden without the ability to maintain a balance between benefits

and contributions. They struggled to retain equality with informal caregivers and expressed despair when they couldn't. In this way, when some of the patients attempted to reduce demands on family and friends, this might be understood as an attempt to sustain a sense of independence in the face of chronic health conditions and impairments. Other researchers have claimed that not accepting care also undermines reciprocity norms. Providing and accepting care are both necessary for a relationship to thrive. Indeed, a state of inequity can be distressing for both members of the dyad (McPherson et al., 2010; McPherson, Wilson, Murray et al., 2007a). The lack of equity and the limited opportunities for restoring balance in the relationship between the informal caregiver and care recipient in this period might explain why both groups of participants expressed distress in the context of their relationship.

As mentioned above, our material revealed some ambiguity regarding expectations and willingness to perform informal care. A great majority of the informal caregivers in this study had a family relationship with the patient. According to other researchers, informal care is motivated either by altruism or reciprocity, on the one hand, or by family norms, on the other (Klimaviciute et al., 2017). Pestieau et al. (2012) claim that the concept of pure altruism relates to how children and spouses experience joy and a sense of contribution when helping their dependent relatives. Pure altruism denotes the willingness to make voluntary transfers of resources (time, money) to another person or other persons, disregarding one's own benefit (Alessie et al., 2014). Altruistic caring or caring that is based on an implicit exchange contract is voluntary, whereas informal caring induced by family norms is constrained and, as such, does not necessarily bring utility to the caregiver and may even have negative psychological and physical implications (Klimaviciute et al., 2017). While most of the caregivers and care recipients described the informal care situation as challenging, others characterized the informal care situation as more satisfying.

These findings were revealed in caregiver-care recipient relations that seemed to be based on reciprocity. This might reveal a tendency in our material, indicating that informal care responsibility motivated by reciprocity or altruism was perceived as less burdensome than in cases where informal care was performed due to necessity and duty. Researchers have claimed that the feeling of duty or reciprocity depends on the relationship between caregiver and care recipient, as well as on their family's history (Andersen et al., 2020). Informal caregivers in close relationships have been found to report less caregiver burden (Williamson & Schulz, 1990), and Tanji et al. (2008) found that increased mutuality in the

relationship between caregiver and care receiver was associated not only with lower levels of caregiver burden but also lower levels of depression in caregivers and care receivers. These findings are supported by studies showing how a caregiving situation may also be experienced as worthwhile and meaningful (Roth et al., 2015; Toljamo et al., 2012). This might lead to the conclusion that differences in family relationships can help explain the ambiguity in the material. But it also shows us how differences in motivation for informal caregiving, differences in the relationship between the caregiver and the care receiver, together with family norms and history, contribute to shaping the experience of the informal care situation for caregivers and care recipients.

Strengths and limitations

As in other qualitative research, the goal of this study was to enhance our understanding of the phenomenon being studied (Malterud, 2001). We aimed to give a voice to older patients and their informal caregivers about their experiences of the informal care situation after discharge from hospital. However, the study was limited by linguistic considerations (the informants had to understand Norwegian or English), the specific demographics, and the geographical location. Even though the findings in this study cannot be generalized, the results may be transferred to similar situations or people (Malterud, 2001). The authors of this study have backgrounds in nutrition, nursing and physiotherapy, in addition to clinical practice, leadership, quality improvement, and professional development in the health services. Throughout the study, we were conscious that our previous understanding and backgrounds would influence the research process (Creswell & Poth, 2018). We strove to interpret the data openly and to provide a transparent description of the path from the data to the results. The involvement of multiple researchers from different backgrounds may strengthen the design of a study, as they can supplement and contest each other's statements (Gale et al., 2013).

Clients with dementia or other forms of cognitive impairment were excluded from this study. If these patients and their caregivers had been included, the findings might have been different, especially since the ability to express empathy may be compromised with dementia (Hua et al., 2018; Lough et al., 2006).

The participants' vulnerable situations may have influenced the quality of the interviews. The interviewer did her best to put the participants at ease and to listen empathetically and carefully, and several participants expressed their appreciation of the opportunity to tell their story. By conducting a follow-up interview, we were able to grasp the situations and

experiences throughout the 30-day period. This may also be a strength of the study.

Conclusion

Informal caregivers play an essential role in supporting the care of older patients after discharge from hospital. Both caregiver and care receiver face strains within their roles and report various unmet needs. It has been identified that the role of carers can be a positive experience for both caregiver and care recipient. However, the informal care situation also has the potential to be burdensome and stressful, owing to the caring situation, the complexity of caring, and the relationship between the caregiver and the care recipient. To secure the quality of care for older patients, the informal caregiver's role needs to be recognized and understood by healthcare personnel to ensure that informal carers do not feel alone and isolated in their role. Informal care based on altruism and reciprocity seems to be perceived as positive and valuable for those involved and might be encouraged as a support to formal care. Informal care based on duty and family norms, on the other hand, might have a negative impact on both caregiver and care recipient, and should therefore be recognized and supported differently. To develop interventions to support caregivers and care receivers, it is crucial to understand the features of burdens and factors contributing to burdens. Health professionals should be aware of the self-perceived feeling of being a burden as well as caring being experienced as a burden and not underestimate the significance of the issue in the healthcare services for older patients. The healthcare system should not only support informal caregivers but value their input and include them as essential members of the care team.

Future research on this topic should include patients with dementia. Particularly to explore the role of reciprocity and family dynamics in relations between this patient group and their informal caregivers.

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