


## ORIGINAL ARTICLE

# What matters to older adults? Exploring person-centred care during and after transitions between hospital and home

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**Abstract**

**Aims and objectives:** To explore person-centred care provided to a group of older adults (65+) by understanding their experiences of care received, their participation in care and what matters to them during and after the transition process between hospital and home.

**Background:** Although facilitating person-centred care (PCC) has gained increasing importance globally over the last few decades, its practical implementation has been challenging. This has caused difficulties in determining its core elements and best practices. Person-centred care aims to deliver healthcare services based on individuals' preferences. Several approaches have been developed to better implement person-centred care practices. The Norwegian transitional and follow-up model, 'Holistic Continuity of Patient Care', chooses the 'What Matters to You?' approach. Other approaches include 'Shared Decision Making' and 'Continuity of Care'.

**Design:** This study employed a qualitative design.

**Methods:** Individual repeated interviews were conducted among eight participants. A hermeneutic exploratory research method was chosen. The COREQ checklist was followed.

**Results:** Three main themes related to person-centred care emerged: what matters in meetings with the individual healthcare worker, mobilising health-promoting capabilities and resources and what matters when being in the organisational healthcare system.

**Conclusion:** To participate in their own health issues, older people need to be empowered and better informed about the importance and scope of person-centred care. 'What Matters to You?' is a good focus for the direction of care but can lead to a simplified understanding of individuals' preferences. Increased focus on how care recipients' capabilities and resources affect their responding is needed.

**Relevance to clinical practice:** Ensuring that person-centred aspects are incorporated into the entire healthcare system requires better methods of engaging and empowering older adults in healthcare settings; more focus on PCC competence and skills of

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healthcare professionals as well as better integration of PCC practices into healthcare administration and policies.

**KEYWORDS**

continuity of care, hermeneutic approach, home care nursing, patient pathways, qualitative study, shared decision-making, what matters to you?

## 1 | INTRODUCTION

Placing the individual's perspective at the centre of healthcare services has become an important focus worldwide over the last few decades (Naldemirci et al., 2018). When designing healthcare to older persons, it is important to let their voices be heard (Lilleheie et al., 2019), which is the intention with the present study. Healthcare with focus on the individual's perspective is often referred to as patient-centred care or person-centred care (PCC) (Eklund et al., 2019; Kogan et al., 2016). These two terms share many similarities and are used interchangeably (Naldemirci et al., 2018); however, at a deeper level, their goals differ: whereas the former aims for a functional life, the latter aims for a meaningful life (Eklund et al., 2019). Lately, there has been a move towards using the latter term to encompass the entirety of a person's needs and preferences, beyond the clinical or medical focus (Eklund et al., 2019; Naldemirci et al., 2018). This holistic focus also includes a person's wider social and cultural background (Britten et al., 2017; McCormack, 2017; Ventres, 2017) and individual capabilities and resources (Naldemirci et al., 2018).

PCC represents a shift of focus from the traditional biomedical model that views individuals as passive targets of a healthcare system to a model that favours embracing personal choice and autonomy for those receiving health services. Thus, nurses and other healthcare workers must design their systems to suit the care recipient, rather than expecting them to adapt to the system of care (Eklund et al., 2019; Kogan et al., 2016; McCormack & McCance, 2006).

PCC is a key component of developing high-quality care (Clarke & Fawcett, 2016) and has been shown to improve health outcomes (Kebede, 2016; Tinetti et al., 2019), satisfaction (Dyrstad et al., 2015; Summer Meranius et al., 2020) and self-management in people with chronic diseases (Mavis et al., 2015). It has also resulted in reduced hospital readmission rates (Hirschman et al., 2015) and medical errors (Jansen et al., 2016). Because many older adults have complex care needs affecting their daily life, they are an ideal group to receive and benefit from PCC (Fried et al., 2020; Kogan et al., 2016).

Challenges and facilitators for implementing PCC, both in transitional and ongoing healthcare, have been reported (Jeffs et al., 2017; Nilsen et al., 2019; Olsen et al., 2020); however, literature on the delivery of PCC from the older adults' perspectives is sparse. To ensure that PCC is implemented so that the care services are designed to meet the older adult's needs, an understanding of PCC

### What does this paper contribute to the wider global clinical community?

- In order to participate in their own healthcare and treatment, older adults should be empowered and better informed about the importance and scope of person-centred care.
- 'What Matters to You?' is a good focus for the direction of care but can lead to a simplification and superficial understanding of individuals' preferences; hence, increased competence and a more comprehensive and structured approach are needed.
- Ensuring that person-centred aspects are incorporated into care, treatment and the healthcare system requires increased focus on competence and skills of nurses and other healthcare professionals, as well as adjustments to healthcare administration and policies.

from their perspective is necessary (Lilleheie et al., 2019). If the person's own perspectives of the PCC they receive conflicts with PCC intentions, the policies and practices underlying PCC may be flawed in either their design or their implementation. This study focuses on PCC in the Norwegian transition and follow-up model of 'Holistic Continuity of Patient Care (HCPC)', by exploring the experiences of a group of older adults transitioning between hospital and home, including further follow up at home.

## 2 | BACKGROUND

### 2.1 | Defining person-centred care

An interprofessional panel of experts in PCC principles and practices, gathered by the American Geriatrics Society (2016), defined PCC as care in which 'individuals' values and preferences are elicited and, once expressed, guide all aspects of their care, supporting their realistic health and life goals. It is achieved through a dynamic relationship, among individuals, others important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires' (p. 16).

## 2.2 | HCPC

The Norwegian Coordination Reform (Report no 47. (2008–2009)) of 2012 seeks to improve the coordination processes between hospitals and community health and social services. It aims to expedite and facilitate the return of individuals to their homes after hospitalisation and prevent unnecessary readmissions (Report no 47. (2008–2009)). The reform recognised older adults as a group that is particularly vulnerable to poorly coordinated transitions because of their high degree of multi-morbid conditions, general frailty and interactions across fragmented levels of the healthcare system (Report no 47. (2008–2009)). As a result, municipal healthcare services, tasked with caring for individuals in their homes, face challenges related to ensuring safe and effective care transitions and caring for people with increasingly complex medical conditions (De Vibe et al., 2016).

In response to these challenges, national learning networks – HCPC – were initiated to improve care quality and pathways for older and chronically ill persons (De Vibe et al., 2016; Nilsen et al., 2019). HCPCs were based in the municipal health services, but local hospitals were encouraged to participate because of their crucial role in facilitating hospital-home transitions.

## 2.3 | The person-centred focus in HCPC

A critical element of the HCPC's mission was operationalised through the person-centred approach, 'What Matters to You?' (WMTY), which has been implemented worldwide (De Vibe et al., 2016). WMTY represents a short slogan aiming to quickly turn the practice of municipal health workers towards involving people in their own care (Berntsen et al., 2018; Kebede, 2016; Olsen et al., 2020). This approach focuses on a shift in focus from the former more medical and paternalistic inquiry – 'What is the matter with you?' – towards a person-centred, proactive inquiry of WMTY (Berntsen et al., 2018; Hansen et al., 2018; Nilsen et al., 2019). The individual's response to the WMTY question should define the parameters of the entire care plan and process (Berntsen et al., 2018). In HCPC, the WMTY approach was used both as a cultural shift in the service given, and as a critical question on several checklists (Nilsen et al., 2019). The checklist procedures comprised critical follow-up time points along the individual's care pathway between the hospital and community, within the community and through the course of their care at home. In addition to the WMTY question, the checklists contained several aspects that were crucial to quality and continuity of care, such as medications, risk of falls and nutritional and cognitive status (De Vibe et al., 2016; Nilsen et al., 2019). The results were noted in medical records.

## 2.4 | Complementary trends to PCC

The international movement towards PCC coincides with other important trends in healthcare delivery. One key trend supporting the provision of PCC is 'Shared Decision Making', which emphasises

cooperation between care recipients and healthcare staff to weigh treatment options, discuss treatment decisions and design and implement care plans based on individual preferences (Elwyn et al., 2012; Oshima Lee & Emanuel, 2013). Elwyn has introduced a three-step 'Shared Decision Making' process: (1) 'choice talk', where care recipients receive information about having a choice and its importance; (2) 'option talk', where options are clearly explained in a language and form suited to each person and (3) 'decision talk', which involves the healthcare worker and the care recipient together making a comprehensive and shared decision (Elwyn et al., 2012).

'Continuity of Care' is another important trend related to PCC and transitions in care. It requires individuals' experiences of care to be connected and well-organised through their entire care journey (Future of Health in Alberta, 2017; Haggerty et al., 2003). Continuity of care requires healthcare personnel to attend to three components: (1) 'Informational continuity' ensures that communication of information between different providers is seamless, up to date and efficient (Future of Health in Alberta, 2017; Haggerty et al., 2003); (2) 'Management continuity' requires that healthcare services are delivered in a complementary and timely manner and are responsive to individuals' changing needs (Haggerty et al., 2003); and (3) 'Relational continuity' supports individuals' therapeutic relationships with one or more providers (Haggerty et al., 2003).

## 2.5 | Challenges of PCC in healthcare delivery for older adults

Several challenges have been identified in implementing PCC. First, involving older adults in PCC processes may be challenging, especially for those with additional problems, such as hearing loss, cognitive impairment and/or language barriers (Elwyn et al., 2012; Kogan et al., 2016). Studies show that older adults often compare their lives with those of their counterparts and, therefore, they may assume that a certain amount of pain and suffering is a normal part of ageing (Fried et al., 2020; Kogan et al., 2016). They may also have different perceptions of what and how much care and support they can expect from healthcare services, making it challenging to engage them in establishing their own PCC goals (Hvalvik & Dale, 2015).

Second, while there is a philosophical and moral commitment to delivering PCC, there is a lack of clarity and consensus on core elements of PCC in practice (Elwyn et al., 2012; Kogan et al., 2016; Naldemirci et al., 2018). Research shows that healthcare staff easily revert to traditional biomedical and paternalistic ways of treating care recipients, often without awareness of doing so (Britten et al., 2017; Moore et al., 2017; Ventres, 2017). Thus, healthcare providers may believe that they deliver PCC, when they do not (Moore et al., 2017).

Previous studies exploring PCC in transition and follow-up models such as HCPC have focused mainly on quality improvements and policy (Jeffs et al., 2017), effective models for implementing transitions (Hirschman et al., 2015; Naylor & Van Cleave, 2010) or nurses' experiences (Nilsen et al., 2019; Olsen et al., 2020). However, there is a need of studies focusing on the experiences of older adults.

## 2.6 | Aim

Given the gaps in the literature, and the importance of providing care based on the older persons' individual needs, this study aimed to explore PCC provided to a group of older adults (65 years and above), by understanding their experiences of and participation in care and what matters to them during and after the transition process between hospital and home.

## 3 | METHODS

### 3.1 | Study design

A qualitative study employing repeated individual interviews was conducted. A hermeneutic exploratory research method, grounded in Gadamerian philosophy (1990), was chosen to gain a deeper understanding of older persons' experiences (Fleming et al., 2003). According to Gadamer (1990), understanding can be achieved through dialogue between individuals, and this mutual understanding will merge into new knowledge (Fleming et al., 2003). The COnsolidated criteria for REporting Qualitative research (COREQ) checklist (Appendix S1) were followed in the study (Tong et al., 2007).

### 3.2 | Sample and recruitment

Eight older adults from three different municipalities, including two men and six women, between 72–87 years old participated in the study. Four were able to give follow-up interviews, for a total of twelve interviews (Table 1).

Home care leaders and other registered nurses from the included municipalities assisted in recruiting participants. The inclusion criteria were as follows: being 65 years or older, having been recently discharged from hospital to their homes and being followed up by home care services participating in the HCPC learning

network. We also sought to include persons of different ages and gender. Participants had various chronic diseases, including: cancer, neurological diseases, musculoskeletal disorders and/or heart diseases. None had known cognitive impairments. Despite variability in their health conditions, all participants required regular care from home care services. Participants were required to be in a relative state of health (as judged by a healthcare nurse), which would allow them to agree to participate in a second interview half a year after the initial interview.

### 3.3 | Setting

The participants lived in three different municipalities in the southern part of Norway, two of which were medium sized, with approximately 23,000 and 45,000 residents, and one small municipality with just under 6000 residents. They were included since they all participated in the same HCPC learning network and used checklists for transitions that were quite similar, including using the WMTY approach. Hence, the participants were likely to have experienced similar procedures following hospital discharge. There were, however, some differences between the municipalities regarding the organisation of the health services; notably, the smaller municipality had fewer administrative resources and general practitioners (GPs) and less bureaucracy than the two larger municipalities. The healthcare services in municipal home care were mainly delivered by registered nurses and nurse assistants, but GPs and other healthcare professions were also involved.

### 3.4 | Data collection

Older adults were invited to participate in the study by local home care nurses about 2 weeks after discharge from the hospital; interviews were conducted approximately 3 weeks after discharge. The home care nurses shared potential participants' contact information with researchers to schedule a time for the interview. Although

Participant	Gender	Age	Civil status	Living situation
A	Male	80	Married	Living in his own house with his wife
B	Female	87	Widow	Living alone in her own house
C*	Female	74	Married	Living in her own house with her husband
D*	Male	70	Married	Living in his own house with his wife
E	Female	73	Widow	Living alone in her own apartment connected to a health centre
F*	Female	72	Married	Living with her husband in a rented apartment connected to a health centre
G*	Female	84	Widow	Living alone in her own apartment connected to a health centre
H	Female	83	Widow	Living alone in her own house

TABLE 1 Background variables of the participants

\*Interviewed twice, approximately 6 months apart.

all participants consented to a 6-month follow-up interview, four were unable to participate due to rehospitalisation ( $n = 2$ ) or death ( $n = 2$ ). The interviews were conducted between 2017–2018 in the participant's home ( $n = 11$ ) or nursing home ( $n = 1$ ).

The first author conducted all interviews, following a semi-structured interview guide, addressing our primary research questions: (1) What was your experience of the care you received during your hospital stay, the transition process from the hospital to your home and the follow-up care?; and (2) What matters to you in terms of having a smooth transition, experiencing well-being and your ability to cope in your home situation? The second interview sought to determine changes in their experiences since the first interview, and how they were currently experiencing care. They were further asked if there were changes in what mattered to them since the first interview and if their home care staff managed to follow up on their previous preferences. Interviews lasted 30–60 min and were recorded and transcribed verbatim by the first author.

According to Gadamer (1990) the 'text' not only refers to the written transcript but also to taped words, written comments about the interview situation and observations made by the researcher. Therefore, the first author wrote field notes, containing observations and reflections, shortly after every interview. These were used during text analysis to give more context and comprehension to the verbal text.

### 3.5 | Data analysis

Data analysis was grounded in Gadamer's hermeneutic philosophy (1990) and it includes four steps: First, the interview text was examined as a whole. This is important in a hermeneutic approach because the meaning of the whole will influence the understanding of every other component. This first encounter with the text is always influenced by a sense of anticipation because of the researchers' pre-understanding, which should be acknowledged and identified. Second, every sentence was investigated to unearth its meaning. This stage facilitates the identification of themes that lead to a rich and detailed understanding of the phenomena. It is, according to Gadamer (1990), important that the identified themes are challenged by the researchers' pre-understanding. The software NVivo 12 (QRS International, 2020) was used to support data analysis. Third, every sentence or section was then related to the meaning of the whole text revealed in the initial phase. This step is meant to expand the sense of the text. Finally, themes that were representative of the shared understanding between the researchers and participants (both in conversations and in the text) were identified (Fleming et al., 2003).

### 3.6 | Ethical considerations

Information about the study was given to the participants both in writing and orally before the interviews began. Written informed

consent was obtained before the interviews began. All participants were assured full confidentiality, that their participation was voluntary and that they could withdraw from the study at any time (World Medical Association, 2013). Approvals from administrations of the included municipalities were collected. The Norwegian Centre for Research Data granted permission to conduct the study (reference number 51034).

## 4 | FINDINGS

The findings were organised according to three main themes, as presented in Table 2. Five sub-themes were identified and are presented under each main theme. To illustrate the meaning and validity of these themes, quotes have been added to the text.

During the interviews, participants were asked to convey what mattered to them. Many strived to give clear answers to this WMTY question, even when it was linked to a precise area of their care, such as during transitions or how they managed coping at home. Several claimed to never have heard this question before, which may be explained by the fact that it is not always asked as an explicit question, but rather integrated into a broader conversation. However, those who were familiar with the question often had difficulties expressing their thoughts about it. Several revealed that they had not understood the purpose of the WMTY approach: 'Yes, I have heard that question several times, but I cannot remember what I answered' (Participant B). Nevertheless, even if they did not answer the WMTY question directly, during the course of the interviews, they discussed – and sometimes emotionally expressed – what mattered to them.

### 4.1 | What matters in meetings with the individual healthcare worker?

Two person-centred aspects appeared to be important for the participants in meeting with the individual healthcare worker: (1) being seen and respected as a person and (2) being informed and involved in one's own care and treatment.

#### 4.1.1 | Being seen and respected as a person

Most of the participants described the care staff, both in the hospital and the community, positively. Several were enthusiastic in their gratitude towards their nurses, describing 'excellent' and 'marvellous' care being delivered by 'angels'. It appeared, however, that they felt closer to some nurses than others.

I feel especially close to the two first nurses that came to my house. They are amazing and I feel I can totally be myself with them. It is a bit hard to explain; they make me happy every time they arrive.

(Participant F)

TABLE 2 Themes and sub-themes

Themes	Sub-themes
What matters in meetings with the individual healthcare worker?	<ul style="list-style-type: none"> <li>• Being seen and respected as a person</li> <li>• Being informed and involved in one's own care and treatment</li> </ul>
Mobilising health-promoting capabilities and resources	<ul style="list-style-type: none"> <li>• Personal characteristics affecting coping abilities and well-being</li> <li>• External resources affecting coping abilities and well-being</li> </ul>
What matters when being in the organisational healthcare system?	<ul style="list-style-type: none"> <li>• Feeling safe in the healthcare system</li> </ul>

Being kind, understanding and respectful was regarded as important personal qualities of the healthcare professionals. Conversely, some participants reported dissatisfaction with nurses who were always in a hurry.

Some nurses move very quickly (gesticulating with her hands); they are doing everything so efficiently. I do not like that. Because, you know, I cannot move quickly. It is like they do not even have time to listen to me; they just move on, getting their work done.

(Participant E)

The staff's flexibility and availability were important for the participants in terms of perceiving care quality, less rigidity and freedom in their daily life. This could be related to their preferences in terms of days and the time of receiving help, changes in care according to their individual needs or simply being available when something urgent happens.

Sometimes, I cannot reach the toilet in time. I always have my mobile phone in my pocket, and I call the home care nurses immediately. Then they show up in a short time to help undress me and give me shower. This means a lot to me.

(Participant D)

#### 4.1.2 | Being informed and involved in one's own care and treatment

The potential and need to participate in decisions regarding their own health and treatment were not experienced equally among the participants. Some were clear about their needs and rights regarding being involved in decisions about themselves, such as determining their time of discharge from the hospital.

It was very important to me to return home as soon as possible after my hospitalization and not go to the rehabilitation center, as suggested. I decided that whether I live or die, I want to be at home. Although not everybody agreed, I am glad they listened to me.

(Participant C)

Others questioned the need for them to be involved in decision-making: 'I don't interfere with that; I prefer to let the experts decide'

(Participant D). One had not been involved in the decision but regretted the decision that was made in hindsight.

No, nobody asked what I felt about being discharged. I did not protest the decision at the time. But, thinking back now, I would like to protest it because I did not feel safe enough at the time.

(Participant A)

Some participants were perplexed over, or even provoked by, efforts to involve them in shared decision-making.

At the hospital they told me 'You are the one that has to decide. If you do not agree with this treatment, we cannot do anything'. But, to me, that sounds stupid. I told them, 'There is no point in me coming here to decide everything myself'. If I need help, I must receive help. If not, I could have stayed home instead.

(Participant B)

Furthermore, living with pain affected several participants, which sometimes decreased their sleep and coping abilities. However, many could not clearly express their feelings about their pain and its origins, and they did not know whether there were further treatments available to relieve their pain. Some implied that they may have not been well informed about the sources or treatment of their pain: 'At the hospital they said something about nerves in a pinch, but I really did not understand much of it' (Participant F). On the other hand, another participant reported that being well informed made difficult situations more understandable.

The cancer nurse was very good in explaining and telling me what I could expect from the chemotherapy. It made me feel prepared. Now I know that when I feel very bad/frail, it just shows that this thing is working in my body, helping me recover.

(Participant H)

#### 4.2 | Mobilising health-promoting capabilities and resources

Personal characteristics and external resources (family, friends, environment, etc.) seemed to greatly impact the participant's ability



to express his or her own preferences, to further facilitate coping ability and well-being not only in transitions but also more generally in life.

#### 4.2.1 | Personal characteristics affecting coping abilities and well-being

Conversations with the participants revealed that personal characteristics sometimes acted as a strength, and at other times an obstacle, to coping and achieving a sense of well-being. For example, one participant described her own considerable will and inner strength that facilitated her recovery.

I have been an active woman my entire life, so I decided that I should learn to walk again! I followed a training program every day; eventually, I made it.

(Participant C)

However, another participant noted that stubbornly striving towards outdated and unrealistic goals may have negatively impacted his well-being.

I swore that I would keep on using my legs and not be restricted to a wheelchair. They told me it was time to start using it, but I had decided that it was the last thing that would happen to me. I struggled so hard for so long. But the feeling of finally getting into the wheelchair was wonderful.

(Participant D)

When participants narrated their stories, they demonstrated a desire to be polite, which in PCC conversations with their healthcare providers, may work against their ability to influence their own care or achieve the outcomes they want. In the interviews, some participants exhibited exaggerated politeness, verging on excessive humbleness, which could make it difficult to explain and identify their needs.

It is not always easy to give one's opinion; often a lot should happen before I do so. For instance, I feel it is rude to express my opinion about the nurse whose behavior I do not approve, that would not be appropriate. I guess I should not tell this to you, either, but...

(Participant A)

Other participants reported that they managed to be positive and not depressed despite the challenges they faced. Some participants used humour and laughter despite facing challenging health situations. However, this emphasis on positivity and humour sometimes seemed to mask issues that would be valuable for them to share with healthcare providers, or others.

#### 4.2.2 | External resources affecting coping ability and well-being

Participants often discussed their surrounding environment as either an obstacle or a facilitator for coping. For instance, participants noted problems experienced during hospitalisation, related to the physical design of the ward, which often did not take into consideration individuals' needs. For example, some participants complained about several people sharing the same room or small and inaccessible toilets.

Some participants still lived in the same house as they did before they got older. Others had moved to houses or apartments better facilitated for older persons and recommended moving as an important decision to make as one ages. However, one's own home with its familiar surroundings and local community appeared to be important, not only to physically cope with life but also for the sense of belonging and meaningfulness. Some preferred the challenges of living in their own home over a better facilitated environment.

I know several that have sold their houses and moved into an apartment. I am sure that was the right thing to do for them. But I do not want to move. Living in my own home means a lot to me and I can cope with being here alone.

(Participant H)

Most of the participants received considerable support from spouses, children and close friends, both during their hospitalisation and in daily life after returning home. Hence, family and friends were viewed as important external resources that made a difference in managing everyday life.

My husband is taking care of me and he helps me a lot. Without him, I would need a lot more help from the healthcare services.

(Participant F)

Family and friends also seemed to promote a feeling of belonging and meaningfulness among participants. Both joy and pride were evident in their eyes when talking about their family, and the conversations easily turned in that direction.

Participants noted the importance of continuing activities that were meaningful to them, such as: attending church, singing in a choir, joining a women's club, engaging in charity work, continuing family traditions and having a pet. Such activities seemed to contribute to keeping their spirits up and enhance their ability to cope.

#### 4.3 | What matters when being in the organisational healthcare system?

When discussing being a part of the healthcare system, safety was a repetitive topic among participants. There were, however,

differences between experiences of feeling safe among individual healthcare workers (being seen, respected and included as reported in the first theme), and feeling safe during transitions and in the healthcare system in general.

#### 4.3.1 | Feeling safe in the healthcare system

Most participants reported that transitions in care appeared to follow good routines. Several reported that care providers on the receiving end of their transition were well informed both about them as individuals and their health conditions; which seemed to contribute to a feeling of safety.

Yes, when I arrived, I knew our community head nurse had contacted the hospital and explained everything about me and my condition. She knows how much help I need and stuff like that, you know. That felt good.

(Participant D)

Some participants were impressed by the coordination of different healthcare services, with multiple actors working together to ensure comprehensive and continuous care.

I have been to a lot of appointments during this period, and I have received summonses for all of them at the right time. There has been no need for nagging about appointments; everything has been seamless.

(Participant C)

Others mentioned the importance of being informed about their rights, and the help and devices available to them through the healthcare system, which could be challenging to navigate on their own.

Having comprehensive systems and routines to follow was appreciated by the participants, as they made them feel safe through transitions and in daily life. However, rigid systems could also be an obstacle to PCC.

At the hospital, they just took my medication from me. I told them that I needed to take my medication at certain times and if not, my body reacts negatively and stiffens. But many did not show up at the scheduled time to give me my medication. Eventually I got permission to control some of my medication myself, after telling them this several times. This made me scared.

(Participant F)

Participants disagreed about the importance of being treated by the same personnel, with some finding it more problematic than others to be served by many different people at home or the hospital.

It is a pity that so many different persons must visit each patient. I see new faces all the time. It is difficult having to explain your story over and over again. Even if they have seen my medical record, there are always small details that must be explained.

(Participant C)

Most of the participants described their GPs as kind and caring, but difficult to reach and build a relationship with due to their frequent replacements and heavy workloads. However, one participant reported that home care services helped address this lack of continuity in care.

I normally see my GP once a year. Otherwise, I just call the home care service if I feel bad or have an infection, and then they contact the GP. They fix everything for me. You can say that they are the link between me and my GP.

(Participant D)

Participants expressed their awareness of the municipalities' as well as the hospitals' lack of time and resources, and how that sometimes negatively affected the quality-of-care services. The critique was mainly directed towards the organising of healthcare, not the individual healthcare worker, who often received much sympathy.

Because of my special condition, I now receive help with showering twice a week, but you must not tell anyone because I am aware that they do not have the capacity to do this. The municipality cannot hire more people and it is not easy for the nurses. They have a terrible workload.

(Participant G)

## 5 | DISCUSSION

This study aimed to explore PCC provided to a group of older adults (65 years and above), by understanding their experiences of, and participation in, care and what matters to them during and after the transition process between hospital and home.

The data raise several issues for discussion. The discussion is framed with reference to relevant PCC approaches such as shared decision-making, WMTY and continuity of care, to elucidate the broad range of PCC experiences described by participants both during transitions and within healthcare practice.

### 5.1 | Important aspects facilitating shared decision-making

According to Clarke and Fawcett (2016), the PCC concept has evolved to assure people that they have full rights to participate in all aspects of their care and treatment. The widespread perception



is that people who need healthcare services are not content with healthcare staff directing their care without their input (Royal College of Nursing, 2016). This partially corresponds to our findings, as participation in one's own care and treatment was very important for several participants. However, like other studies (Paillaud et al., 2017; Pearson et al., 2015), our findings revealed that some older adults prefer limited involvement in decision-making.

Thus, it is important to emphasise the initial definition and intrinsic meaning of PCC, indicating that healthcare staff should only include individuals '...to the extent that they desire' (American Geriatrics Society Expert Panel on Person-Centered Care, 2016, p. 16). Older adults may resist involvement in PCC for a variety of reasons, including lack of energy related to health conditions, limited support from relatives or simply a lack of confidence in the healthcare setting (Dyrstad et al., 2015; Hestevik et al., 2019). Resistance may also be related to familiarity with historically more paternalistic healthcare systems, resulting in older adults (especially in the current generation) learning to be passive in their own care and to respect 'the experts' (Hestevik et al., 2019; Kogan et al., 2016; Moore et al., 2017). Hence, this resistance or lack of interest in participation in PCC may be attributed to a lack of understanding regarding the reason for this shift to a PCC approach. In this case, patients should be better prepared, through education and empowerment, to make an informed decision about their participation.

One way of empowering individuals to participate in their own care and treatment is to promote shared decision-making (Summer Meranius et al., 2020). Elwyn et al. (2012) introduced a three-step guide for this approach, including 'choice talk', 'option talk' and 'decision talk', made simple and brief for use in practice. Our findings indicate that the initial 'choice talk' of Elwyn's approach tended to be omitted. Instead, healthcare staff often directly discussed alternative options, without informing care recipients about their right to decide. Participants could perceive shared decision-making as a confusing and sometimes provoking act, wherein healthcare staff were simply shifting the responsibility for decision-making onto the individual. According to Gadamer (1990), an answer cannot be obtained without the person understanding the intention of the question. Our findings support other literature that states that older adults, and their families, need an opportunity to be prepared, educated and empowered to participate in decisions concerning their care and treatment (Dyrstad et al., 2015; Elwyn et al., 2012).

Our findings further revealed that sometimes the 'options talk' was either given little priority or was incomprehensible to the participants. This may be perceived by care recipients as jumping directly to 'decision making', without sufficient awareness of their options (Entwistle & Watt, 2013). Our findings showed some failures in communication. Several participants appeared to have limited understanding of their illness, treatment or pain; even when that information was conveyed to them. According to Dyrstad et al. (2015), the use of professional lingo by healthcare workers is a way of perpetuating paternalism and medical authority. This might exclude patients from participating by keeping them passive and making them do as they are told (Dyrstad et al., 2015; Lilleheie et al., 2019). Information

must be provided in easy-to-understand language based on patients' condition and perspective, referring to their experience of being sick (Fried et al., 2020; Hestevik et al., 2019; Lilleheie et al., 2019).

According to Fried et al. (2020), customised information is not the only issue. Individuals have a variety of beliefs and life experiences that will most likely impact their medical decisions. Healthcare staff may also assume that care recipients know more about treatment and recovery than they actually do (Hestevik et al., 2019). Hence, clarifying existing knowledge and potential assumptions is important for establishing realistic opportunities to help older adults weigh their options and make decisions.

## 5.2 | Understanding what matters to the individual

Although the purpose of the WMTY approach is to provide a short and understandable PCC slogan (Kebede, 2016), reported experiences of older adults in this study and care staff in previous studies (Nilsen et al., 2019; Olsen et al., 2020) reveal that the WMTY approach is not always easy to grasp or participate in for either party. Care staff reported difficulty in interpreting and implementing vague elements of the WMTY approach (Olsen et al., 2020), obtaining clear answers from care recipients to the WMTY question (Nilsen et al., 2019; Olsen et al., 2020) and translating individuals' answers into comprehensive goals and actions (Berntsen et al., 2018; Fried et al., 2020). Our findings support those of other studies (Entwistle & Watt, 2013; Naldemirci et al., 2018), which reveal the risk of misjudging answers and the need to be aware of communication challenges with older adults.

We found that personal characteristics, such as politeness/humility, determination, a positive attitude and having sense of humour, could both positively and negatively affect the way older adults expressed what mattered to them. For instance, strong determination could help some cope with illness, but it could cause others to avoid facing current life situations and refuse necessary adaptations. Similarly, extreme politeness could prevent them from discussing their concerns or complaints. Hence, healthcare workers cannot solely consider care recipients self-reported responses as the only input into delivering PCC; interpretation is sometimes needed (Entwistle & Watt, 2013; Naldemirci et al., 2018). According to Entwistle and Watt (2013), treating others as 'persons' requires being sensitive and responsive to their specific characteristics in the situation in which we encounter them. Our findings imply that there is a need for personal characteristics to be identified, considered and sometimes mobilised or accommodated in the delivery of the WMTY approach.

Furthermore, managing to cope physically seemed to be important to several participants, which was often linked to external resources such as suitable physical surroundings and assistance from others. In addition, participants' sense of belonging and meaningfulness were also often connected to external resources; such as their home environment and community, family, friends, pets and the ability to engage in usual activities, such as attending church.

However, sometimes established priorities might require conflicting external resources. For example, a person's desire for a familiar living environment could conflict with the wheelchair accessibility needed to maintain desired mobility. Prioritising their needs and making decisions can be a challenging task for care recipients, where facilitated guidance and help to reflect from healthcare staff can be required. Our initial PCC definition states that healthcare workers should support individuals' realistic health and life goals (American Geriatrics Society Expert Panel on Person-Centered Care, 2016). According to Miller and Rollnick (2012), healthcare staff's failure to reflect on individuals' preferences can lead to adverse PCC as the value, complexity and intrinsic worth of individuals' preferences can be lost.

Olsen et al. (2020) discovered that some staff members tend to adopt the WMTY approach, using it as a functional approach focusing on goals and actions for being physically independent. Focusing on the functional aspect was found helpful in narrowing the broad WMTY approach to something more understandable and concrete both for older adults and staff (Olsen et al., 2020). However, if establishing functional goals becomes the focus of WMTY, non-functional needs may not be accorded the same importance, making the person-centred holistic focus difficult to achieve. McCormack (2017) found that staff can become so obsessed with capturing the needs and preferences of the care recipients that they forget to listen, reflect and respond, which should remain their primary focus.

Guiding and supporting persons in identifying what matters to them is a comprehensive, time-consuming and ambiguous task for healthcare staff. This work can be facilitated by more comprehensive, clear and framed guidance for healthcare staff, including customised competence and training, to successfully work with older adults in a person-centred and holistic perspective.

### 5.3 | Facilitating continuity of PCC

The interviews revealed participants' emphases on the experience of safety throughout their care transition. We discovered that continuity in the organisational healthcare system was important for achieving this experience. This corresponds to Hudson et al. (2019) finding that continuity of care can have beneficial effects among older adults, making them feel safe, known and supported. For caregivers and healthcare administrators, there are three dimensions of continuity to consider: informational, management and relational continuity (Haggerty et al., 2003), and participants' experiences can be discussed in terms of these dimensions.

In contrast to other studies reporting lack of perceived informational continuity (Herder-van der Eerden et al., 2017; Hestevik et al., 2019; Hudson et al., 2019), our findings showed that in transitions, participants generally experienced that receiving healthcare staff had satisfactory knowledge about them. However, the information between staff members in the same unit was not always up to date, which was especially evident when new staff arrived. Some participants had to explain their stories repeatedly to help the provider

adjust the care intervention given. This can decrease individual's feelings of safety and being known, which are thought to be important factors for achieving continuity (Hudson et al., 2019).

Referring to management continuity, several participants were satisfied with the coordination of care they received from different healthcare providers and services, including following planned appointments. However, GPs being hard to reach and heavy workloads were repeatedly mentioned as challenging for the participant's continuity in treatment. Enabling continuity for older adults often requires one person (usually their GP) controlling the coordinating function (Herder-van der Eerden et al., 2017; Hudson et al., 2019). Our findings revealed, however, that home care nurses may fulfil this coordinating role by bridging different healthcare appointments and contacting GPs and pharmacies on behalf of their care recipients.

The participants appreciated good systems of care and treatment, making every day more predictable. Simultaneously, flexibility and individualised care were important, as it gave them a sense of freedom and independence. Perceiving flexibility in the service given is highlighted in other studies as a crucial factor for individuals' well-being (Hansen et al., 2018; Moore et al., 2017; Naldemirci et al., 2018). Our findings showed that rigid care systems could lead to difficulties in providing personalised, flexible care to individuals. This corresponds to findings by Nilsen et al. (2019), showing that nurses following comprehensive transitional checklists could forget important issues not mentioned in the list, which could further impede the provision of flexibility and person-centred care (Nilsen et al., 2019).

Relational continuity was historically easier to achieve when there was often just one family doctor to relate to (Future of Health in Alberta, 2017). Our current healthcare systems are more heavily specialised and fragmented, often with many different providers at several levels of care (Report no 47. (2008–2009)). Many participants found this confusing and sometimes stressful, requiring extensive effort to repeatedly build new relationships. Studies have found that limiting the number of staff interacting with care recipients and maintaining sustained contact are important factors that promote comfort and secure continuity of care (Herder-van der Eerden et al., 2017; Lloyd et al., 2018; Medina-Mirapeix et al., 2017). However, having regular but few providers does not guarantee relational continuity alone (Medina-Mirapeix et al., 2017). Our findings showed that some staff members gave their patients a sense of calm, safety and being respected, while others promoted a feeling of stress or anxiety. This may be not only related to the provider's work experience and formal competence but also to their personal competencies, such as their social and relational skills (Eklund et al., 2019; Entwistle & Watt, 2013; Moore et al., 2017; Nilsen et al., 2019).

Participants' critiques regarding healthcare staffs' and GPs' lack of time and resources were often not targeted at the individual care worker, but at their organisational system. Previous research has not only highlighted the importance of not solely focusing on the individual patient-provider level but also on organisational and political levels for the successful implementation of PCC (Eklund et al., 2019; Moore et al., 2017; Olsen et al., 2020).

## 5.4 | Strengths and limitations of the study

The study included fewer participants than was planned, facing well-documented difficulty in recruiting vulnerable older adults to participate in research studies (Jacelon, 2007; Mody et al., 2008). All eight participants volunteered to give a follow-up interview but, due to unexpected events, only four were able to do so. However, the data collected proved to be rich and informative, and are especially valuable considering known barriers to recruitment from this target group (Jacelon, 2007) and gaps in existing research on older adults' perspectives (Nilsen et al., 2019). We also believe that the findings in our study are transferable and relevant for the delivery of PCC to older adults in various healthcare settings.

One of the strengths of this study was that selected home care nurses served as a link between the researcher and the participants – allowing participants to decide whether to be included without being influenced by the researcher. While this approach could also allow the home care workers to filter out potential participants, they were specifically instructed to inform all older adults who fit the inclusion criteria and let them decide whether to participate for themselves.

Because of the participants' age and often severe health issues, their local home care service was contacted before the second interview was scheduled. This prevented us from contacting participants who were no longer in a good state of health, thus strengthening the inclusion process.

Due to the participants' difficulties in understanding and responding to the WMTY question in the initial interview, few could indicate in the second interview whether healthcare staff had followed up on their response to the WMTY question. Hence, comparing initial and follow-up interviews did not produce additional information about WMTY follow up or changes over time.

When using an analysis method based on hermeneutics, it is important to identify the researchers' pre-understandings (Fleming et al., 2003). The authors had prior experiences with older adults and community healthcare as clinicians and/or as researchers. Having field experience made it easier to talk with and understand the participants and to grasp the setting. However, a pre-understanding may also result in a fixed mindset (Fleming et al., 2003). We are also aware that this study's findings are based on the interviews and analyses conducted by the researchers and that other researchers might have focused on different aspects than we prioritised.

## 6 | CONCLUSION

The objectives of this study were to explore older adults' experiences of the care they received, and whether their experiences were in accordance with known PCC ideals. Our findings indicate that to facilitate shared decision-making, the older care recipients and their relatives must be adequately informed, empowered and prepared. Furthermore, when discussing treatment and care options with older adults, it is important to talk to them in understandable and

relatable language and encouraging them to share their experiences. Additionally, it is important to clarify the person's existing knowledge of their own health issues. Our findings also revealed that some older adults prefer only limited involvement in decision-making. Hence, it is important to include people only to the extent that they desire.

The WMTY slogan is useful in placing the person's perspective at the centre of healthcare services. However, as an approach, WMTY appears to be difficult to grasp for care recipients as well as care providers (Nilsen et al., 2019). This confusion might lead to a simplification of the approach, or attempts to define it in more understandable, but often too narrow, terms. Our findings revealed the need for greater focus and reflection on how individual capabilities and surrounding resources affect older adults' behaviour and response to the WMTY question.

The participants were, in general, satisfied with the information flow across different services. However, repeatedly explaining their story to new staff members could decrease perceived informational continuity. Regarding management continuity, home care services having a coordinating function was helpful for several participants whose GPs were difficult to access. Participants appreciated good systems in the organisation of their care, although rigid systems were found to impede continuity. The need for individuality and flexibility in care was highlighted. Experiences of relational continuity were often challenged by interactions with many different healthcare workers, which some found tiresome and stressful. Participants also described both positive and negative consequences of individual healthcare worker behaviours.

## 7 | RELEVANCE TO CLINICAL PRACTICE

Our findings highlight the importance of focusing on the organisational context, as well as the care recipient-care provider relationship, when implementing PCC in home care and transitional care. To better facilitate PCC in daily practice, the organisational structures surrounding the older adult and their providers may need to be re-defined. This can be accomplished by establishing and maintaining routines and tools to empower, engage and better integrate older care recipients in healthcare settings and decision-making. Our findings also highlight the need to decrease the number of healthcare providers involved with each care recipient. This must, however, be balanced with a focus on the competencies and behaviours of healthcare workers, and how they are received by the care recipient. We also saw a need for healthcare providers to not be so concerned with receiving actionable PCC answers, but rather to focus more on listening, reflecting, responding and mobilising individual capabilities and resources in PCC conversations with care recipients. There is a need for increased PCC competence among healthcare staff and managers to better initiate, integrate and safeguard PCC in daily practice (Ekman et al., 2011), together with implementing more formalised PCC processes. However, executing these recommendations would require more time and resources to implement PCC in practice.

Further research on the actual interaction between the care recipients and care providers, through field studies or participant observation, would be useful to better observe PCC implementation and facilitate integration of PCC into healthcare policy and practice.

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## CONFLICT OF INTEREST

There are no conflicts of interests to declare.

## AUTHOR CONTRIBUTIONS

E.R.N., B.H., U.S. and B.D. contributed to the design of the work. E.R.N. provided the data collection. E.R.N, B.H., U.S. and B.D. contributed to the data analysis and interpretation. E.R.N. with help from B.H., U.S. and B.D. drafted the article. B.H., U.S. and B.D. made critical revisions of the article. Final approval of the version to be published was accomplished by E.R.N., B.H., U.S. and B.D.

## DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions. The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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