

# Choice, Voice, and Coproduction in Intermediate Care: Exploring Geriatric Patients' and Their Relatives' Perspectives on Patient Participation

SAGE Open  
July-September 2019: 1–13  
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DOI: 10.1177/2158244019876318  
journals.sagepub.com/home/sgo  


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## Abstract

Geriatric patients in intermediate care (IC) often do not feel involved in their rehabilitation process. We conducted interviews with 15 patients and 12 relatives to explore their experiences and preferences regarding patient participation in IC and identify types of patient participation and their potential empowering or disempowering effect. The analysis disclosed a lack of patient choice in a predetermined IC pathway. Being deserving of help meant being sick enough and was associated with the compliant patient who fits the system. Some main additional features were the need of a rehabilitation perspective and patient engagement to enable coproduction as well as the important contribution of relatives as advocates and allies. Finally, the results show the patients' vulnerable voice in the meeting with the experts' views. The study will add important knowledge on how staff can contribute to the tailoring of good interventions in IC and improve the understanding of underlying structures.

## Keywords

patient participation, intermediate care, empowerment, geriatric patients, relatives, New Public Management

## Introduction

Patient participation represents a shift in the way we view and think about health care (Andreassen, 2009; Armstrong, 2014; Berwick, 2009; Wistow & Barnes, 1993). Rooted both in the democratic rights tradition and in a market logic (Andreassen, 2009; Dent & Pahor, 2015), patient participation implies that the patient's goals, needs, and capabilities should be the guiding principle for services and interventions (Christensen & Fluge, 2016; Dyrstad, Testad, Aase, & Storm, 2015; Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014). In such, health care professionals should invite the patients to take on an active role in their care as well as in the organization of care (Berwick, 2009; Rise et al., 2013). Patient participation is today seen as an important issue in the World Health Organization's Patient Safety Strategy (World Health Organization, 2017).

In many Western countries, including Norway, the ideas of New Public Management (NPM) in health and social care gained huge political impact throughout the 1990s (Grand, 2003). The policy of deinstitutionalization along with the emphasis on cost-effective services has among other things increased the turnover of hospital patients and the work load

in the municipalities in Norway (Debesay, Harsløf, Rechel, & Vike, 2014). In addition, geriatric patients are increasing globally (World Health Organization, 2011) and the patient group can be described as having multiple and chronic diseases and high degree of frailty, requiring a holistic approach (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013). Geriatric patients often exhibit acute loss of abilities, for example, the ability to manage activities of daily living (ADL) independently, as a reaction to acute disease (Covinsky et al., 2003); thus, many of them need health care services after hospitalization (Heiberg, Bruun-Olsen, & Bergland, 2017), whereas others, due to frailty and malfunction, benefit from rehabilitation or reablement to prevent hospitalization (Hjelle, Tuntland, Førland, & Alvsvåg, 2017).

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In Norway, the mean length of hospital stay after hip fracture surgery is 5 to 6 days (Office of the Auditor General of Norway, 2013-2014). An increasingly shorter length of hospital stays is in line with international studies showing that aging patients are discharged from hospital both quicker and sicker (Deniger, Troller, & Kennelty, 2015; Organisation for Economic Co-Operation and Development, European Union, 2016; van Vliet, Huisman, & Deeg, 2017). This leads to diverse demands and needs regarding health care services in the community (United Nations Economic Commission for Europe, 2015). Intermediate care (IC) involves the services between specialist and primary health care and provides a bridging function between hospital and home for elderly frail patients (Godfrey & Townsend, 2008; Johannessen, Werner, & Steihaug, 2013; NHS Benchmarking Network, 2015; Young, 2009). IC allocates interdisciplinary and goal-oriented rehabilitation after hospitalization or for patients at risk of functional decline, often in nurse-led institution-based units in the community or in a nursing home unit, for a short time period (Pearson et al., 2015).

In line with NPM, to ensure a distinction between those who assess and those who provide the services, a purchaser-provider model has been developed in Oslo (Rostgaard, 2012; Vabø, 2012). This implies that the purchasers (the districts) assess and approve the services, whereas the providers (staff in IC) perform the services ordered on behalf of the patients. The service coincides with the policy of “aging in place,” to help elderly patients remain in their homes for as long as possible (Wiles, Lebing, Guberman, Reeve, & Allen, 2012). Transitional care involves the transfer of patients between different levels of care within the same or between locations (Dyrstad, Testad, et al., 2015); that is, in our study, transitions are addressed from hospital to IC and from IC to home. Thus, the rehabilitation perspective in IC is holistic and is supposed to be empowering (Kvæl, Debesay, Langaas, Bye, & Bergland, 2018; Pearson et al., 2015). Gibson defines empowerment as “a social process of recognizing, promoting and enhancing people’s abilities to meet their own needs, solve their own problems and mobilize the necessary resources to feel in control of their lives” (Gibson, 1991, p. 359), closely related to patient participation. Empowerment involves a change in the power relations between patients and staff to obtain participation (Pulvirenti, McGillan, & Lawn, 2014) and resonates well with person-centered care; a holistic approach that puts patients first, at the center of care, underpinned by values of respect (personhood) and established through formation and fostering of healthful relationships with patients and relatives, as well as between the staff (McCormack & McCance, 2017).

There exist currently few publications exploring geriatric patients’ and their relatives’ experiences of participating in IC (Kvæl et al., 2018). Successful patient participation is associated with satisfaction with health care services (Dyrstad, Testad, et al., 2015), a lower number of readmissions (Naylor et al., 2009), better treatment outcome (Hall, Ferreira, Maher,


Latimer, & Ferreira, 2010), and shorter institutional stay (Steihaug, Johannessen, Ådnanes, Paulsen, & Mannion, 2016). However, research reveals that elderly frail patients often do not feel involved in their own rehabilitation process (Benten & Spalding, 2008; Trappes-Lomax & Hawton, 2012). Due to the complex problems of geriatric patients, work in an IC unit demands a holistic approach, balancing practical, relational, and moral issues (Wiles, Postle, Steiner, & Walsh, 2003). However, when organizational dimensions exert pressure on the daily work situation, care as a practical routine seems to be focused on (Johannessen et al., 2013), at the expense of patient participation (Johannessen, Tveiten, & Werner, 2017). Considering the importance of patient participation in IC (Pearson et al., 2015), and the limited research related to this context, there is a need for greater insight into the construction of patient participation in IC (Benten & Spalding, 2008; Trappes-Lomax & Hawton, 2012). Thus, the aim of this study is to explore geriatric patients’ and their relatives’ experiences and preferences regarding patient participation in IC and identify types of patient participation and their potential empowering or disempowering effect. The study will add important knowledge on how staff can increase patient participation by contributing to the understanding of underlying structures in an IC setting.

### Theoretical Perspective

The European framework of patient participation provides a useful guide to understanding the experiences and preferences of patients and relatives in IC, showing underlying structures (Dent & Pahor, 2015). In this framework, patient participation can be characterized in terms of three ideal types: choice, coproduction, and voice. Thus, depending on the circumstances, patient participation can be conceptualized as empowering or disempowering (see Table 1).

Patient *choice* is the best-known term and refers to the ability to make informed choices. Choice is influenced by a market-oriented consumer logic and the NPM, according to which the patients, not the staff or system, have the authority, exercised by marketplace choices, to judge quality (Andreassen, 2009; Berwick, 2009). *Forced responsabilization* emphasizes that a forced choice is not a free, informed choice, for example, an elderly patient with cognitive impairment may feel forced to accept life in a nursing home. While *coproduction* emphasizes patient engagement in their own rehabilitation process, *paternalistic proto-professionalization* focuses more on patient compliance and is associated with a lack of practical professional wisdom (Hilton & Slotnick, 2005). *Voice* relates to the active involvement in deliberative forums and decision-making and is rooted in the democratic rights tradition (Andreassen, 2009; Rise et al., 2013). For patients to obtain a real voice, the staff has to listen and act upon what the patients are saying. The opposite case, staff assuming they know more about issues than the lay members, will lead to *manipulation*.

**Table 1.** The European Framework of Patient Participation.

Patient empowerment	Choice Patient as a consumer	Coproduction Patient as participant	Voice Patient as a citizen
	Doctors (re) design clinical services to ensure high-quality clinical practice	Doctors work with patients to enable them to self-manage effectively. Doctors also work directly with patients in the design of care pathway	Doctors work with citizens to deliver services appropriate for the local communities
	Doctors/managers decouple the formal indicators of performance, e.g., manipulation of waiting list data	Doctors are paternalistic and focus more on patient compliance than on coproduction	Doctors work with patients to enable them to self-manage effectively. Doctors also work directly with patients in the design of care pathway
Patient disempowerment	Patients have access to good information to inform individual choices. Patient/user can choose to “exit”	Patients coproduce health care services individually and/or collectively with health professionals, e.g., diabetes, self-management, home-based renal dialysis, etc.	Patients collectively have access to deliberative forums. Patients/users and citizens have confidence that their voice is listened to and acted upon
	Patients held responsible for enforced choice, e.g., involuntary service users including frail elderly patients	Patients with simplified medical vocabulary underpinning paternalistic patient–doctor relations	Patients attend advisory committees to be consulted but with no opportunity for genuine participation
	Forced responsabilization	Paternalistic proto-professionalization	Manipulation

Source. Dent & Pahor (2015, p. 547).

## Method

Qualitative interviews were chosen, influenced by critical realism, a philosophical view that states the existence of an independent reality, but claims that our knowledge of it is socially constructed. Critical realism views social phenomena as an open system where mechanisms interact at different “layers” of reality. Thus, the researcher’s focus will be on revealing the underlying structures of how meaning and knowledge are constructed (Archer, Bhaskar, Collier, Lawson, & Norrie, 1998; Clark, Lissel, & Davis, 2008).

## Settings

During 2015, the city of Oslo, Norway, has synchronized all municipal short-term services into four major institutions to meet demographic changes. The municipal districts then buy health care services from their respective IC institution. The study was conducted in three out of the four IC institutions, with a total of 350 beds, serving 12 out of a total of 15 districts in Oslo (West, East, and North, which also includes the urban areas). To make a rehabilitation plan, an initial family meeting is held within the first 2 to 3 days as a standard routine. Due to dependence in ADL, most patients come from hospitals, but some are admitted directly from their home or relocated from other IC units. Many of the patients need treatment and rehabilitation, whereas some need assessment or even palliative care. Patients in IC typically receive medical treatment, the opportunity to participate in physical and social activities to manage ADL and home assessment, in addition to follow-up services from the district after discharge to home.

## Participants

To embrace the diversity in IC, the sample was strategic. We included 27 participants, 15 patients (Table 2) and 12 relatives (Table 3), representing eight districts. Patient inclusion criteria were as follows: age >65 years, admitted to IC from hospital or from home due to acute or chronic disease and/or frailty, and dependent in ADL but with an objective of being able to live at home. We excluded patients with severe psychiatric conditions or insufficient understanding of the Norwegian language.

## Data Collection

Participants meeting the inclusion criteria were informed about the project by staff working in the IC institutions. Patients who agreed to participate were then given additional information and with their consent their chosen relative was contacted, informed, and asked for participation by the researcher responsible for data collection. Data were collected through individual interviews (April 2017-January 2018) using a semi-structured interview guide and supported by follow-up questions to initiate reflections and thick descriptions of their experiences of how patient participation was enacted in their rehabilitation process at the ICs. The main questions focused on the participants’ experiences and preferences related to participating in the transitions, during the initial family meeting and in activities in their rehabilitation process. The patients were interviewed twice to capture all the elements in the patient pathway; first time during their stay in the IC unit in their room, and second time 2 to 4 weeks after discharge in their home. The relatives were

**Table 2.** Characteristics of the Patients.

	Sex	Age	Education	Duration of stay	Diagnoses	Admitted from	IC	Admitted to
1	F	90	High	2 weeks	COPD, pneumonia	Hospital	1	Home
2	M	85	Low	23 weeks	Hip fracture, upper arm fracture, operated with hip prosthesis	Hospital	1	Nursing home
3	F	97	Low	2 weeks	Orthostatic hypotension, concussion, rib fracture	Hospital	1	Home
4	F	83	Low	10 days	Gall chronic cholecystitis, LAP cholecystectomy	Hospital	1	Home
5	M	83	Low	7 weeks	Cancer with metastases, sequela brain tumor surgery 2016	Home	2	Home
6	F	94	Low	5 weeks	Rib fracture, urinary infection, pneumonia, heart failure	Hospital	2	Home
7	F	74	Low	2 weeks	Hip fracture, operated with hip prosthesis, COPD, Dia II	Hospital	2	Home
8	F	68	Low	2 weeks	MS, blind one eye, pain syndrome	Home	2	Home
9	F	88	Low	1 week	Osteoporosis, multiple fractures in the column, pain syndrome	Hospital	3	Home
10	M	88	High	5 weeks	Forearm fracture, readmission, malfunction, and urinary infection	Hospital	3	Home
11	F	86	High	2 weeks	Femoral fracture, operated with osteosynthesis, hypothyroidism, osteoporosis	Hospital	3	Home
12	F	91	Low	3 weeks	Femoral fracture, operated with osteosynthesis, osteoporosis	Hospital	3	Home
13	F	92	Low	3 weeks	Hip fracture, operated with osteosynthesis	Hospital	1	Home
14	M	76	Low	2 weeks	Unsteadiness, walking problems, sequela former kidney operated	Hospital	2	Home
15	M	89	High	5 weeks	Dizziness, n. vestibularis inflammation, heart failure	Hospital	3	Home

Note. Age in years. Lower education: elementary school and high school. Higher education: college and university. IC = intermediate care institution; F = female; COPD = chronic obstructive pulmonary disease; M = male; MS = multiple sclerosis.

interviewed 2 to 4 weeks after patient discharge to home, except for two who were interviewed during the patients' stay due to prolonged treatment. The relative interviews were conducted in their home ( $N = 6$ ), in their workplace

( $N = 2$ ), at the IC institution ( $N = 2$ ), or in a quiet cafeteria ( $N = 2$ ). All the interviews were face-to-face, conducted by the first author who has a background as a physical therapist and broad experience within geriatric rehabilitation. The

**Table 3.** Characteristics of the Relatives.

	Sex	Age	Relation to patient	Work situation/Education	IC
1	F	68	Daughter	Retired, social worker	1
2	F	87	Sister	Retired, nurse	1
3	F	56	Daughter in law	In work, dental technician	1
4	F	50	Daughter	Disabled, bachelor in insurance	1
5	F	61	Daughter	In work, assistant deputy director, teacher	2
6	F	64	Daughter	Retired, teacher in elementary school	2
7	F	73	Support person	Retired, support person	2
8	M	71	Husband	Retired, certificate as a fitter	2
9	F	63	Daughter	Retired, teacher with university education	3
10	F	54	Daughter	In work, librarian with master	3
11	M	50	Son	In work, real estate industry, homeopath, acupuncturist	3
12	M	63	Son	Retired, political scientist	3

Note. Age in years. IC = intermediate care institution; F = female, M = male.

patient interviews lasted from 20 to 60 min, whereas the relative interviews lasted from 45 to 90 min.

### Data Analysis

The data were analyzed using thematic analysis, a widely used method for identifying, analyzing, and reporting patterns (themes) within data. Due to its epistemological neutrality, thematic analysis is compatible with a realist approach (Braun & Clarke, 2006). Initially, the authors read the interviews actively, searching for demi-regularities and patterns while taking notes. In the software HyperRESEARCH, the data were then coded and organized into meaningful groups by the first author. We also used HyperRESEARCH to identify the most dominant codes. The codes were extracted from quotes about patient participation in IC. Furthermore, the organized groups were sorted into themes (Table 4), using visual representations like mind maps. Because patients and relatives represent two different perspectives, the interviews were initially coded separately. However, in terms of the patient involvement aspect, they had a complementary function in presenting a broader picture. The sample size was guided by Malterud's model of information power (saturation), which depends on the aim of the study, sample specificity, use of established theory, quality of the dialogue, and the analysis strategy (Malterud, Siersma, & Guassors, 2015). After the 12th patient interview and the ninth relative interview, there were no new themes generated from the interviews. For completeness, we fully analyzed all the materials to ensure that information power was reached. After identifying the initial themes, the process of abduction allowed us to use the theoretical framework as a lens in abstracting the data into the further analysis, resulting in three main themes. We identified 18 initial themes, three main themes, and six

subthemes (Table 5). All the authors, with health education in physiotherapy (3), nursing (1), and nutrition (1), and extensive research and/or clinical experience in elderly health care, carried out the analysis. The first author has clinical experience from the field of IC and thus long-term involvement. The other authors provided an analytical distance to the field, thus questioning possible researcher biases (Maxwell, 2013).

## Results

### Characteristics of the Participants

Of the 15 patients interviewed, 10 were women and five were men. All were between 68 and 97 years, with an average of 85.6 years. The mean duration of stay in IC was 4.4 weeks. According to medical records, six of the patients showed clinical signs of initial cognitive impairment, that is, memory loss situations and confusion in relation to time/place. Thirteen of the patients needed municipal home care after discharge and 14 used a zimmer frame when moving inside/outside. Twelve of the patients lived alone and three lived with their spouses. The 12 relative-participants were directly related to the patients included in the study. Their age was between 50 and 87 years with an average of 63.3 years, nine women and three men. The last three patients out of the 15 included had no close relatives.

### Findings

The analysis resulted in three main themes: "Lack of choice and expectation of compliance," "The need of a rehabilitation perspective and reciprocal engagement," and "Patient participation meets experts' views," representing types of patient participation and the potential empowering or

**Table 4.** Example of Coding Procedure.

Quotes about patient participation	Code	Group	Initial themes
<i>I was well taken care of when I was a patient there. They made every effort to make me feel as good as possible and returned [home] with a good feeling. I felt understood, I felt I was a person. (Woman, 88 years)</i>	Seeing the patient as a subject	The skills of health professionals	Patient empowerment
<i>But I felt in a way that I had to chase after them [the staff], no one offered their assistance, you had to sort of check on them that what we had agreed on was in fact carried out. (Daughter, 68 years)</i>	Relatives checking out staff	Relatives role and function	Relatives as advocates

**Table 5.** Results of the Analysis.

Initial themes	Subthemes	Main themes
1. Involvement in the transition process 2. The variation of experiences 3. The vulnerable patient 4. The unsuitable patient 5. The individual needs 6. Being on hold	Like a package along a predetermined pathway Being perceived as deserving	Lack of choice and expectation of compliance
7. Reception and first impressions 8. There is nothing going on 9. The meal's role in the healing process 10. The importance of peer support 11. Patient empowerment 12. Relatives are taken for granted	The ethos of rehabilitative thinking Relatives as a necessary resource	The need of a rehabilitation perspective and reciprocal engagement
13. Agreement in goals and tasks 14. The process of patient engagement 15. Participation an unknown phenomenon 16. Safety of medical follow-up 17. Seek patient preferences through dialogue 18. Relatives as advocates	What is important to you? Leave it to the experts	Patient participation meets experts' views

disempowering impact of such participation. All the three main themes were of great prominence in the data material and are based on consensus among all the participants. Each main theme had two subthemes (see Table 5).

In general, patient participation appeared as a rather unfamiliar concept for the older patients; hence, their descriptions and narratives of the patient pathway became an important departure for the analysis. Although they mostly agreed on the same story, the relatives manifested themselves as more critical on behalf of their loved ones regarding quality of geriatric care. The relatives thus painted a more comprehensive picture of patient participation in this study.

### *Lack of Choice and Expectation of Compliance*

The analysis disclosed a lack of patient choice in a predetermined pathway. Being deserving of help meant being sick

enough, associated with the compliant patient who fits the system.

*Like a package along a predetermined pathway.* “Like a package along a predetermined IC pathway” implies standardized treatment at the expense of individualized rehabilitation where the patients possess minimal of real choice. The overall experiences of patients and relatives in IC showed great variation, from receiving holistic rehabilitation valuing the patients’ opinion to experiencing the IC as a place just for being stored away with no activities to participate in. All the participants perceived IC as necessary in the patient pathway. One daughter (50 years) said: “I think that it’s very important that everyone gets this offer [IC] when you’re so sick, it must not stop! If she [mother] had been discharged directly to home, I would have had to move in with her.” Although the participants were grateful to receive a stay in IC, most of them reported getting scant information and

time for preparation regarding the transition process to the IC unit, leaving little real choice for them on both type and place of service. “I was suddenly told at the hospital that ‘now you’re going to IC.’ I was not prepared and I did not know anything about it. But it was ok, though a bit sudden” (woman, 86 years). In addition, approximately half of all the patients felt that they were discharged and sent home too early and had little influence over the length of stay in the IC unit. Influenced by time constraints and the heavy workloads of staff, several described themselves as a “package in process” where the patient pathway was already determined and mainly based on physical criteria and without any real choice regarding the transition processes. In these cases, relatives felt powerless in the system, like forced volunteers. One daughter (64 years) stated, “Now, I think it’s quite tough. The last year she has been in and out of the emergency room, hospital, municipal acute wards, IC, home again, In and out like a package. She’s 94 years old, what about her dignity?”

*Being perceived as deserving.* “Being perceived as deserving” implies being qualified to receive a service based on physical criteria defined by professionals, and not the patients’ preferences. However, the patients wanted to be seen as a whole person. One of the patients had applied for a stay in nursing home 3 times as her health declined. It was stated that she was not “sick enough,” and even though she felt lonely and scared, had been hospitalized 3 times over the past months with subsequent IC, she was forced to live in her home. “This life, in and out of institutions. You see pictures of elderly [in nursing homes] having such a good time. And I move in and out of institutions, it’s so unfair” (woman, 94 years). The most satisfied patients (and their relatives) had uncomplicated diagnostic problems, adaptable personalities, economic, and social resources and lived in a district with engaged coordinators. The dialogue between the district coordinator and the IC unit will have a great impact on the patient participation. However, this dialogue seems random and depends on where you live. Compliance is the extent to which a patient actually follows the IC’s advice. Thus, according to some of the relatives, being deserving is also associated with the compliant patient that fits into the system. A son (63 years) stated,

She is probably a nice patient because she does not complain or set too high demands, and because she accepts things. She has a positive view of human beings, is socially committed and reflected. And she has an intention of getting well.

### *The Need of a Rehabilitation Perspective and Reciprocal Engagement*

The analysis highlighted the need of a rehabilitation perspective and patient engagement to enable coproduction as well

as the important contribution of relatives as advocates and allies.

*The ethos of rehabilitative thinking.* Rehabilitative thinking implies assisting the patients’ own efforts in achieving the optimal level of coping and functional ability, independence, and social participation (coproduction). Most of the patients experienced that the staff were friendly and service-oriented in the effort of meeting the patients’ needs. “They [the staff] were very nice all together. They were gentle and helpful and seemed interested in you. You were not just brushed off” (woman, 91 years). At the same time, more or less all of the participants reported that the health care was routinized with little thought given to daily activities that might stimulate the patients. In general, the participants called for more social and physical activity throughout the day. Except from meals and the occasional/rare training, nothing socially happened in the IC unit. The oldest participant (woman, 97 years) described a day in IC like this:

I woke up, got dressed and had breakfast. After breakfast, I lay on my bed. Then came the next meal, and then dinner. I walked into the dining room. And after that, I went back to bed again. Off course, you could sit in the living room, but I never saw anyone there . . .

Most of the relatives’ explanations for this were limited organizational resources and an overall lack of a rehabilitative philosophy. One daughter-in-law (56 years) stated,

I wish they would demand more from the patients. Patient engagement. . . , address the patients in a more motivating way. When they understand that it’s easy to say no, you have to motivate. Also, I wish there was more time for activity so that you don’t just remain passively in bed.

Furthermore, most of the participants reported their fellow patients as frail, often with cognitive impairment, being on hold for nursing home. In such cases, the IC appeared as a place for retention rather than rehabilitation, not very motivating to engage in activities or feel relatedness. The youngest patient (woman, 68 years) stated,

You have the same conversation over and over again. The conversation does not move on, and I just can’t stand it. I’ll be having dementia myself eventually if I have to sit listen to that. That’s why I’m sitting in the room.

*Relatives as a necessary resource.* “Relatives as a necessary resource” indicates the relatives’ role in struggling and voicing the patients’ rights, in addition to being a hidden resource in daily care, often taken for granted. Relatives described themselves as coordinators, advocates, supporters, and allies. Only one of the relatives lived with the patient, but most of them lived nearby or next door, they all felt a great

responsibility and had a feeling of “being on the alert,” forced to take on an active role:

This takes time. To me it is a given, even though it requires an effort, and that’s because I love my father and I have a flexible job. But not everybody has that. If I’d had small children for example . . . , then what would they do? (Daughter, 54 years)

Some of the tasks were described as obvious; however, they also felt strong expectations from the staff in IC. Examples of tasks carried out by relatives were as follows: escorting the patient in transition or to routine control at the hospital, shopping for groceries before discharge to home, washing their clothes, being a voice in family meetings, participating in home visits, and picking up necessary aids before transfer. Within these tasks, relatives might function as coproducers.

### *Patient Participation Meets Experts’ Views*

Finally, the results show the patients’ vulnerable voice in the meeting with the experts’ views.

*What is important to you?* “What is important to you” is asked during the initial family meetings in IC to voice the patients’ goals, needs, and capabilities. All the participants highlighted that it was necessary that the meeting was held early in process to clarify expectations and make a rehabilitation plan. One daughter (54 years) stated,

I felt they listened to him [the father], and they asked me as well if I had something to add. I liked that. And it’s important that the whole team is present. But I think the meeting should have been held at an earlier date [held after 1 week].

However, to have a real voice in the discussion of follow-up services and length of stay in the unit, all the participants stated that it was necessary that the district coordinator and the relatives were present, highlighting realistic information. Overall, the family meetings were considered as a forum for patients and the relatives to speak out, to let their voice be heard. “Yes, I got the impression that they listened to me, and that’s the most important thing” (man, 89 years). The participants highlighted the importance of honesty and that what is promised in terms of goals must be implemented. In some of the meetings, the patients and relatives experienced the family meeting as an organizational duty and not as a forum for their genuine voice, that is, good intentions but not so good follow-up: “I experienced the meeting as good. So, I believe the good intention is there, but when it comes to the capacity and ability to actually follow it up, I don’t think so” (daughter-in-law, 56 years).

*Leave it to the experts.* “Leave it to the experts” implies that not all patients want to participate or are able to take on an active role. The results indicate that the preferences of

elderly patients vary substantially regarding participating in decision-making, both in terms of willingness and capability. Most of the patients wanted to be offered choices and to be asked for their opinions. However, some preferred to leave any final decisions to staff and/or to rely on the experts for medical judgments. “To me participation is important, but I do not think it applies to all patients, not everyone is interested in or able to follow what is being done with them. They rather trust what the doctor says” (woman, 91 years). Accordingly, patient participation is associated with competence, sufficient information, and knowledge exchange. Most of the patients found it difficult to ask for too much help to bother the staff, afraid of being a burden. They would not complain nor bother people and this will affect their willingness to voice their needs. “It means a lot, that you do not feel like a burden” (woman, 83 years). On the contrary, the relatives stated that they need confidence, in that their voice is actually wanted. It is all about how you address the other person and how you motivate and invite into dialogue based on authentic empathy. One son (63 years) argued, “It’s about empowerment. In this case, you must give the patient an understanding and confidence that their reflections are necessary to hear. Being able to initiate a good dialogue.”

## **Discussion**

In this article, we have explored geriatric patients’ and their relatives’ experiences and preferences regarding patient participation in IC and identified types of patient participation and their potential empowering or disempowering effect. Using the framework of Dent and Pahor (2015), we have distinguished between the dimensions of choice, voice, and coproduction.

Overall, the experiences of patients and relatives in IC showed great variation, from being in an empowering atmosphere, to seeing the IC as a place for just being “stored away” in a rather disempowering way. These contradicting findings are in line with the study of Wiles and colleagues (2003), who also identified a range of experiences, associated with conflicting needs to be treated in the same place (Wiles et al., 2003). Furthermore, IC is embedded in the health care system, which is a part of the health policy. Therefore, experiences made by the participants in IC are not necessarily triggered by IC structures but by influences of policy. To give an illustration, NPM has two basic pillars: one in the bureaucratic logic focusing on efficiency and standardization and the other in the market logic with an emphasis on competition and production. Thus, the challenges for IC regarding patient participation might not be solely a conflict situated on the level of IC.

Several participants described a lack of real choice regarding the transition process with little information and time for preparation and limited influence on the length of the IC stay.



The participants described themselves as “packages in process” where the IC pathway was already determined. Furthermore, due to dependence in ADL, after acute disease they seemed to experience few other alternatives than the associated IC unit, no exit opportunity, understood as forced responsabilization, and the opposite of the free, informed choice (Dent & Pahor, 2015). The emphasis on cost-effective services along with the policy of deinstitutionalization has among other things resulted in elderly being discharged from hospital both quicker and sicker and increased the work load in the Norwegian municipalities (Debesay et al., 2014). While patients highlighted the need of sufficient information, the relatives were concerned about the organization of care. The lack of choice in transitional care is also underlined in a systematic review (Dyrstad, Testad, et al., 2015). Research states that heavy workload and time pressure constrain the participation of older people (Dyrstad, Laugaland, & Storm, 2015; Johannessen et al., 2017), functioning as a barrier in the process of empowerment.

Being perceived as deserving may mean the difference between receiving specialized services and being guided through a bureaucratic maze (Hasenfeld, 2010). To be perceived as deserving, the patients had to qualify for IC or nursing home based predominantly on physical criteria decided by professionals, at the cost of psychological and social considerations. This is in line with a recent IC study highlighting this lack of person-centered culture as a barrier patient participation (Kvæl, Debesay, Bye, & Bergland, 2019). The most satisfied patients (and relatives) had uncomplicated diagnostic problems, adaptable personalities, economic and social resources, and an intention of getting well. Thus, being deserving is also associated with the compliant and obedient patient who fits into the system and might contribute in explaining the expectations of compliance told by the participants. Our results are in line with previous research, indicating that motivated and compliant patients may receive higher levels of rehabilitation and attention (Maclean & Pound, 2000; Wiles et al., 2003) which also might account for the contradicting findings in the experiences described. A system where the compliant patient receives more, as well as patients with strong relatives, conflicts with the idea of equality and will affect the weakest groups (Tønnessen, Førde, & Nortvedt, 2011). You must be sick enough to deserve IC, but if you are too sick or complex, you will not be considered as compliant; however, this will not necessarily make you qualified for nursing home. Our findings indicate a situation characterized by limited resources, and if “you are sick enough,” you deserve a place. Nursing homes may be a competitor to IC, but patients cannot choose nursing homes freely as there are criteria to be fulfilled which are defined by experts. Thus, the market context within health care is also a risk leading to “treatment inflation” and might construct patient participation in a disempowering way (Christensen & Fluge, 2016).

The participants highlighted the need of a rehabilitation perspective and a reciprocal engagement to enable coproduction in IC. While the relatives were mostly concerned about the patients’ rights of care, the patients highlighted the aspect of being treated with dignity. Coproduction entails long-term relationships in which patients, relatives, and staff engage in dialogue (Bovaird, 2007). In reciprocal engagement, the participants are expected to take on the roles of advisers, trainers, and partners. The idea is to enable the patients to become participants in their own rehabilitation process, to obtain an individualized therapeutic and person-centered approach (Ferguson, 2007). Research underlines that the alliances between patients and health care professionals seem to have a positive influence on the treatment outcome in the rehabilitation process (Hall et al., 2010). For the patient to participate in the rehabilitation process, activities must be available to engage in, and the staff must take on a facilitator role. Most of the participants reported routinized care with little thought given to activities that might stimulate the patients, and the relatives had to step into the process of coproduction (Strøm, Andersen, Korneliussen, & Fagermoen, 2015). Even though the staff were described as friendly and service-oriented, nothing happened except meals and the occasional training with the therapist. In these cases, the IC showed itself as a place for safekeeping rather than rehabilitation. Such a lonely and boring situation, in addition to being surrounded by frail fellow patients often unable to communicate, was described as being disempowering.

The problems of patients in IC are often complex and cannot be resolved by the patient alone (Papadimitriou & Cott, 2015), but need the effort of the institutions as well as the health care professionals and their expertise and responsibility (Durose & Richardson, 2016). The results indicate that the relatives are coproducers, a necessary resource in the rehabilitation process. Research shows that relatives represent an important contribution, although often invisible, to rationalize limited resources (Strøm et al., 2015; Tønnessen et al., 2011), as well as the patients advocates of care (Dyrstad, Testad, et al., 2015). Issues addressed by the participants, such as available resources (options and time) and the competencies of the health care professionals (training, expertise, and professional orientation), are all of great relevance in the continuum ranging from coproduction to paternalistic proto-professionalism. The key to coproduction appears to be the way staff motivates patients to engage in it, an important aspect and facilitator in the social process of empowerment. Encouraging, inviting, and supporting the patients are of great importance. Increased awareness and competencies for staff to improve patient participation are also highlighted in previous research (Dyrstad, Laugaland, & Storm, 2015; Martinsen, Norlyk, & Lomborg, 2015; Milte et al., 2015).

In line with previous research (Griffith, Brosnan, Lacey, Keeling, & Wilkinson, 2004; Milte et al., 2015), the initial

family meetings in IC are much appreciated. For the patients to have a real voice, the staff have to listen and act upon what the patients are actually saying, otherwise perceived as manipulation (Dent & Pahor, 2015). However, the idea of individualized rehabilitation might conflict with the administrative rules and structures of bureaucratic organizations (Hasenfeld, 2010). The patients in this study have complex health problems, often too complex to fit into standardized formats. As a result, the staff may develop discretionary practices based on rules and previous experiences, which might represent a simplification of the patients' complex health problems (Lipsky, 2010), and constitute a barrier to real patient participation due to a lack of time (Andersen, Beedholm, Kolbæk, & Fredriksen, 2018). Our data suggest that the family meetings must be held early in the process to clarify expectations and develop a plan. It was crucial that both relatives and a district coordinator were represented to discuss follow-up services in an empowering way. Otherwise, the patients experienced the meeting as an organizational duty (Johannessen et al., 2017). The reason for this might be the limited professional discretion staff in IC actually possess. To maintain efficiency, the purchaser-provider structure aims to ensure a distinction between those who assess and those who provide the services (Rostgaard, 2012; Vabø, 2012). However, a recent evaluation of three decades with NPM in United Kingdom states that this controlling way of management leads to an increased bureaucratic and expensive administration at all levels, at the cost of the overall service resources (Hood & Dixon, 2015).

Finally, the results of the study indicate that geriatric patients report substantial variation in their preferences for patient participation, in terms of capability, interest, and willingness. This is in line with similar research (Dyrstad, Testad, et al., 2015). Some studies suggest that older patients with less education may have an increased preference for passive roles and sufficient trust in professionals and make a choice to "leave it to the experts" or relatives (Milte et al., 2015; Pearson et al., 2015). A choice to leave it to the experts is a way to participate based on trust. However, it is important that this has been explicitly clarified (Benten & Spalding, 2008). The patients highlighted the need for confidence to voice their needs. In this respect, to avoid manipulation, consultation with patients and relatives, even about their preferences for participation, is crucial (Levinson, Kao, Kuby, & Thisted, 2005). Empowerment as a social process implies recognizing, promoting, and enhancing people's abilities to meet their own needs (Gibson, 1991). It seems like staff need support to establish a rehabilitative philosophy to implement patient participation in a way that empowers patients. In addition, predictability and sufficient information seems crucial in the patient pathway. However, to succeed, the engagement of leadership is essential as well as the mentoring and empowerment of staff (Kvæl et al., 2019). Our results indicate that organizational structures shape the experiences of patient/relatives in IC. Thus, the implementation of patient

participation with an empowering effect to obtain person-centered care requires a cultural commitment from top level (McCormack & McCance, 2017).

According to critical realism, we can never be, nor should be, entirely free of preconceptions that might influence our interpretation of data. The first author held a pre-understanding that patient participation in IC is insufficient and can be improved. To ensure credibility through an on-going reflexivity, all steps in the analysis were discussed in depth in the author team and attempted presented with clarity (Morse, 2015). The study has a specific study aim, uses established theory, and has a strategic sample and emphasis reflections in the dialogue to obtain thick descriptions, all essential factors regarding information power (Malterud et al., 2015). The framework of Dent and Pahor (2015) has been a useful guide and is consistent with a rehabilitative philosophy (Kvæl et al., 2018). The types of patient participation are primarily focused on doctor-patient relations within acute hospitals. However, the authors suggest that the categories can be extended to other health care settings and staff (Dent & Pahor, 2015). The study presented has some limitations. Particular patient groups, such as patients from ethnic minorities, patients with severe cognitive impairment and aphasia, were not present in the sample, although the participants included do reflect the main users of IC. In addition, our findings essential to the three urban IC institutions included are not necessarily transferable to institutions in more rural districts or other countries. However, despite significant diversity in the design and configuration (Pearson et al., 2015), research underlines that IC is a systematic phenomenon, in that it comprises a set of services defined by its unique combination of purpose, functions, content, and structure (Godfrey et al., 2005). Thus, we believe that our findings will have great implications for staff in similar IC units.

## Conclusion

Although most of the patients are reporting benefits from their stay in IC, patient participation in this context could indeed be delivered in a more empowering way. The study indicates a gap between the outlined health policy and the clinical work in IC regarding patient participation. The analysis disclosed a lack of patient choice in a predetermined pathway. Being deserving of help meant being sick enough and was associated with the compliant patient who fits the system. Some main additional features were the need of a rehabilitation perspective and patient engagement to enable coproduction, as well as the important contribution of relatives as advocates and allies. Finally, the results show the patients' vulnerable voice in the meeting with the experts' views. Overall, we call for a more person-centered integrated care philosophy to improve outcome and experiences for persons with multiple long-term and complex conditions and their relatives in IC services. The results may inform practitioners,

researchers, and policy makers about the complexity of patient participation in IC and contribute to a greater awareness of underlying and sometimes conflicting structures such as market, bureaucracy, and psychology. In addition, the study adds important knowledge regarding how a rehabilitative philosophy and organizational commitment might increase the awareness and competencies of staff in IC to improve patient participation.

### Ethical Considerations

The study was registered and preapproved by the Norwegian Centre for Research Data. Permissions were also obtained from the Nursing Home Agency in Oslo. All interviews were audiotaped and transcribed verbatim by a professional transcriber and the first author and stored in Services for Sensitive Data, an environment in compliance with Norway's Privacy and Electronic Communication Directive. All the participants gave informed consent to participation after receiving oral and written information. This included the assurance that they could withdraw their consent at any time without consequences.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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