



## Patient Perception, Preference and Participation

## Elderly persons' experiences of participation in hospital discharge process

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## ABSTRACT

**Objective:** The purpose of this study was to describe older hospital patients' discharge experiences on participation in the discharge planning.

**Methods:** A sample of 254 patients aged 80+ was interviewed using a questionnaire developed by the research team. Data were collected by face-to-face interviewing during the first two weeks following patients discharge from hospital.

**Results:** In spite of their advanced age the patients in this study did express a clear preference for participation. However, there were no significant correlation between patients' wish for participation and experienced opportunity to share decisions. Hearing ability was the only significant factor affecting the chance to participate, whereas sociodemographic factors did not significantly affect on the likelihood participation the discharge process.

**Conclusion:** The actual practice of involving old people in the discharge process is not well developed as experienced by old patients themselves. The fact that factors like gender and education have little influence on participation in the oldest patients might be related to age; when you get old enough, old is all that is 'visible'.

**Practice implications:** To determine the extent of elderly patients' desire to participate, one must actively look for it both through research and in the hands-on process of discharge.

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## 1. Introduction

## 1.1. Background

Discharge of frail older patients has been shown to be associated with physical and/or psychological distress and health decline [1–3], leading to readmission to hospital [4–7], and admission to nursing home [8,9]. A considerable number of these problems have been found to be related to deficiencies in the discharge process [10].

Research indicates that one possible pathway to a discharge without adverse events would be through increased emphasis on patient participation [5,11]. Patient participation over the last two decades has become a legally stated right as well as an explicit ideology of health care professionals in many societies worldwide. Although patients' perceptions of the discharge process have been recognized as important [12], literature reviews highlight the lack of studies on patients' perspectives on the discharge process [13,14]. One possible explanation for this might be related to the fact that when it concerns older persons, participation has been

slow to evolve [15–17]. In Norway we have a highly developed welfare state, part of what is referred to as the Scandinavian Welfare State Model [13]. In Norway cooperation between hospital and municipal care is a hot topic in the discharge of elderly patients. Today there is no regulation from health authorities on how the discharge process should to be carried out. Therefore, the practice will vary according to the hospital's own initiative, but often discharge planning is minimalized. When patients are considered ready for discharge, the long-term care office in the municipality will be notified, and the patient will be discharged from hospital the next day or even the same day. The Norwegian Ministry of Health and Care Services has recently released a report to the Norwegian parliament suggesting a new health reform to increase cooperation between the hospitals and the municipalities long-term care (St.melding 47).

Considering the importance of participation in the process of discharge from hospital [5,11], clearly a need exists for insight into older patients' experiences of the discharge process. This paper focuses on older respondents' (aged 80+) experiences of participation in planning their discharge.

## 1.2. Review of literature

Although research supports the idea that the elicitation of patients' perspectives and preferences is of importance for a successful discharge [12,18–20], several studies report that

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patients are not consulted regarding their needs [17,21–23]. The lack of focus on participation in the discharge process is also reflected in research focus and a recent review of literature concluded that “the patient’s perception of readiness for discharge has rarely been included as a study variable” [13,32]. While some studies of older persons’ participation find that the respondents do feel that they have been involved in decisions regarding their discharge [17,24], others find that older patients actively or passively tend to relinquish their involvement in the processes of discharge planning [21,25]. Some authors have interpreted these findings in light of current shortened hospital stays causing vulnerable older patients to be in a state of poor health at the time of discharge, thus preventing them from actively taking part in the discharge planning [26]. Others point at an institutionalized system producing formal assessments that do not include patient participation [18,27] or cause significant communication gaps [28]. Severe stress due to worrying about their future that older persons face in a transition phase from hospital to primary care has also been highlighted as interfering with the individuals’ resources to participate [29]. Older persons might also need more encouragement to actively involve themselves in care. Some studies suggest that elderly patients do want to participate but, as they often are not “well-trained consumers” [17], they are often quite subtle in their quest for participation, with the result that their initiatives for participation might be overlooked [30]. One might expect that issues with patient participation among older patients would lead to a greater involvement for their family caregivers, but existing research indicates that private caregivers’ involvement in the discharge planning are (at best) very limited [5,31–33].

The understanding of the concept ‘participation’ has been described as ‘very broad and open to interpretation’ [34] or even as ‘blurred’ [35], and thus a clarification of the use of the term is warranted. The understanding of participation adopted in this study is based on Thompson’s taxonomy [36]. In a large-scale qualitative study Thompson identified five levels of patient-determined involvement. Thompson’s five stages are *non-involvement* (where patients are simply passive recipients of care and treatment), *being given information* (a stage that is not seen as involvement per se, but rather a requirement for being able to take part in decision-making about their own care and treatment), *dialogue* (where exchange of information between patient and clinicians takes place), *shared decision-making* (patients and clinicians cooperate to find the best solutions and the patient’s experiences that their opinions are taken into account when decisions are made. The fifth and final stage is *autonomous decision-making* for the patients. This understanding of participation was also used as a basis for the development of the questionnaire used in this study, although somewhat modified by leaving out the first and the fifth stage, as they, based on knowledge from the existing literature in the field, did not seem relevant.

### 1.3. Aim of the study and research questions

The purpose of this study was to describe older hospital patients’ discharge experiences concerning participation in the discharge planning. The specific research questions were:

- To what degree and on what level of participation did patients experience that they were allowed to participate in the planning of their hospital discharge?
- Do patients’ preferences for participation match their self-reported participation?
- Do patient gender, age, education, length of stay, orientation and memory problems and impairment of seeing and hearing affect participation in the discharge process of elderly patients?

## 2. Method

### 2.1. Setting and sample

The study is part of a larger research project funded by the Norwegian Research Council. This article reports questionnaire results on patients admitted to 14 hospitals in Norway from home and discharged to community care. Respondents who met inclusion criteria were recruited by the charge nurses at home care offices in 67 different municipalities who received patients discharged from 14 different hospitals in Norway. Inclusion criteria were: 80 years or older. The choice of elderly aged 80 and above as a target for data collection is related to the fact that this group has a pattern of hospital service use that differs markedly from other age groups. Persons 80 years or older (219,631) constitute 4.6% of the Norwegian population, and 43.3% of persons aged 70 or more; the problem of rehospitalization for this age group is increasing [37]. Adequate cognitive performance (as assessed by the recruiting nurse using judgement based on professional knowledge and experience) for taking part in the planning of their own discharge and for giving written informed consent to participate in the investigation. We did five test interviews that were tape-recorded. Findings from the test helped to identify some unclear questions that were adjusted. Furthermore, they also made us aware that elderly respondents struggled to decide between alternatives. Interviewers were trained to clarify the questions in a uniform way and to help respondents grade their answers [38]. A guide was developed and we also made a visualization of a line reflecting the alternatives to help respondents choose between alternatives. The pilot interviews were also used as a basis for the development of a 6-h training course to educate interviewers about how to help respondents choose categories and recall details of their hospital stay by linking experiences to events and using examples to calibrate the interpretation of respondents’ answers.

### 2.2. Data collection

Data were collected by face-to-face interviewing the first 2–3 weeks (mean 19.2 days) following discharge from hospital. Interviews were scheduled according to the respondents’ wishes. A total of 76 questions were asked. Interviews lasted from 30–60 min depending on respondents’ need for breaks (a number of the responders were physically rather frail), and, of course, on how much the respondents elaborated on the questions. The interviews were carried out by geriatric nurses or geriatric nurse students, who were instructed to consider the respondents’ health condition and to apply pauses accordingly. In our experience the data that respondents might have problems remembering were facts like how many days they had been at the hospital. Often these data were then obtainable from the interview with relatives with the patient’s permission.

The charge nurses at the home care offices in the different municipalities identified potential participants and obtained permission to introduce the study to older patients who met the inclusion criteria. All participants were given written and oral information that participation in the study was voluntary, that they were free to withdraw at any time during the study, that the research team was not affiliated with the hospital, that none of the data collectors were employed by the hospital, and that their decision to participate or not, and their responses, would not affect their relationship with the hospital. Approval for the study was obtained from the East Norway Regional Ethics Committee for Medical Research and all municipalities involved.

### 2.3. The questionnaire

The interviewers used a questionnaire developed for the purpose of this study. The Discharge of Elderly Questionnaire

**Table 1**  
Questions related to participation.

To what degree did you feel that the following statements describe your participation in the hospital discharge:
(1) I received information on what help I would get after discharge.
(2) I got the opportunity to tell the staff what I myself considered important in order to manage after discharge.
(3) We co-operated on how to solve different issues.
(4) Did you have the opportunity to tell what you felt was important in order to manage at home after discharge?
(5) Were your opinions taken into consideration?
(6) Were the professionals concerns the same as your concerns on the discharge?
(7) How important was it to you to influence medical treatment?
(8) How important was it to you to influence the time of discharge?
(9) How important was it to you to influence how practical issues should be solved?

All questions were graded:  
To a high degree – To some degree – To a minor degree – Not at all.

was developed by the collaborating research institutions by a process starting with a literature search that identified relevant studies and previously designed instruments [39]. The questionnaire was then tested in pilot interviews with elderly persons recently discharged from hospital to ensure that the questions were understandable and covered areas that the respondents felt were significant.

The questionnaire was designed to elicit data concerning the subjects' experiences regarding the discharge and the management of their health problems after discharge. Demographic data on age, gender, education, employment status, health and relationship of carers and medical diagnosis were also collected. The questions were designed to tap information on 10 dimensions; "Here-And-Now" (8 questions on how the patient manages after discharge), "In Hospital" (11 questions aimed at giving an overview of data on the hospital stay), "The Discharge Process" (10 questions targeting the routines of the discharge), [and] "Information" (8 questions), "Participation" (9 questions (Table 1)), "Communication" (5 questions) "The Role of Relatives" (3 questions), followed by 3 concluding questions on patients' general assessment of whether the help was as expected and according to perceived needs and of their trust in the health care system, and finally 22 questions on demographic issues, previous and current care arrangements and present functional status. The questions measuring participation were 1–4 Likert-type items. In addition there were open spaces for comments to be reported elsewhere.

#### 2.4. Data analysis

Data were analysed by SPSS 17. To check whether our data on patient participation experiences fit Thompson's hierarchical taxonomy (receiving information < dialogue < influencing decisions) we performed an analysis of the cumulativity [36,39] of patient responses to the 3 questions on whether or not the patient received information on what help he/she would get after

**Table 2**  
Patients score on questions reflecting patient participation (% (n)).

	To a high degree	To some degree	To a minor degree	Not at all	Sum
Thompson's participation level 1. Did you get information on what help you would get after discharge	35.7 (40)	21.4 (24)	7.1 (8)	35.7 (40)	100 (112)
Thompson's participation level 2. Did you get to tell the staff what you yourself considered important in order to manage after discharge?	31.3 (36)	12.2 (14)	13.0 (15)	43.5 (50)	100 (115)
Thompson's participation level 3. To what degree did you get to share decisions on how issues could be solved	27.9 (63)	14.2 (32)	20.4 (46)	37.6 (85)	100 (226) <sup>a</sup>

<sup>a</sup> All participants were asked the "Shared decision" question, whereas the "Help after discharge" question and the "Manage after discharge" question were only asked those who were discharged to their own home (and not referred to a nursing home).

discharge, whether or not the patient was able to tell the staff what he/she considered important in order to manage after discharge and whether or not the patient felt he/she influenced the decisions on how practical problems of managing at home could be solved.

The relationship of the degree of patient participation in discharge planning to how well the patient felt that he/she managed after discharge was studied by dichotomized cross-tables. The significance of distribution differences was determined by chi-squared tests.

To assess the impact on the likelihood of having influence on the discharge process of patient gender, age, education, length of stay, slightly reduced memory (vs. no problems), slightly reduced orientation regarding place, time, person, and situation (vs. no problems), reduced sight, and reduced hearing, logistic regression analyses were performed. Logistic regressions were also used to analyse the effect of patient characteristics on the experienced level of patient participation as well as to investigate the issue of whether the hospital professionals were concerned with the same issues as the patients during discharge planning.

### 3. Results

#### 3.1. Participant characteristics

During the period of recruitment (October 2007–May 2009) 413 patients met the inclusion criteria; 268 gave written informed consent to be interviewed. However, before the interview took place, the medical condition of 12 of them became aggravated in such a way that the interview appointment had to be cancelled, and 2 interviews were not completed. The final number of elderly patients interviewed was thus 254, giving a response rate of 61.5%.

The mean age of the respondents was 86.9 years (SD 4.9); 68.5% of the respondents were females, and 70% of the respondents lived alone. Slightly over 48% of the male respondents and 50% of the females stated that they had only obligatory education whereas 12.3% of the male and 4.8% of the female respondents stated that they had a college or university education.

#### 3.2. To what degree and on what level of participation did patients experience that they got to participate in the planning of their hospital discharge?

As shown in Table 2, patients did not often experience what Thompson describes as "real participation" (level 3). An absolute majority of 58% answered that they did not at all or only to a minor degree get to share decisions. For the question of having been given the opportunity to speak, the corresponding fraction was about the same (56.5%), and for the question of having received information, it was lower (43%). An analysis of the cumulativity of the across-patient response pattern behind Table 2 gave a Guttman reproducibility coefficient of 0.85. This coefficient, as well as the falling frequency of the participation levels of the two positive

**Table 3**  
Patient evaluation of importance of influencing decisions (% (n)).

	To a high degree	To some degree	To a minor degree	Not at all	Sum
How important was it to you to have influence on medical treatment?	43.2 (102)	18.2 (43)	22.5 (53)	16.1 (38)	100 (236)
How important was it to you to have influence on the time of discharge?	39.6 (93)	25.1 (59)	20.4 (48)	14.9 (36)	100 (235)
How important was it to you to have influence on how practical issues should be solved?	51.1 (118)	19.5 (45)	15.6 (36)	13.9 (32)	100 (231)

responses (“To a high degree”/“To some degree”), supports Thompson’s suggestion that there is a participation ladder which includes the following steps: (1) receives information, (2) provides input, (3) influences decisions.

The questionnaire also mapped the degree to which the patients found that their interests were taken care of, and whether they experienced that the hospital professionals were concerned with the same issues as themselves during discharge planning. On these questions we found that a higher percentage reported satisfaction. Nearly 65% experienced to a high degree or to some degree that their opinions were taken into account, and 60% of the patients stated that they to a high degree or to some degree experienced that the hospital professionals were concerned with the same issues as themselves during discharge planning.

### 3.3. Did the patients’ preferences for participation match their actual participation?

A subset of questions tapped how important the respondents felt it was to influence the different examinations and treatment, on the date of leaving the hospital, and on how practical problems after discharge were to be handled. The response distributions are shown in Table 3.

For all 3 questions, a majority of the patients said participation was highly or somewhat important, most frequently on the question of influencing how practical problems after discharge from hospital should be solved, but even medical treatment was important to over 60% of the respondents.

Another subset of questions tapped the degree to which the patients felt they had influenced the different issues. To investigate how much the patients expressed feeling of how important it was to be influential matched their actual experience of having influence, we constructed two sum-score variables. One indicated the patients’ actual degree of participation (Table 2 questions) the other patients’ estimate of how important participation was (‘Table 3 questions’). There was no correlation between the two sum-scores ( $r = 0.09$ ,  $p = 0.35$ ).

One more pair of questions made it possible to look into the match between desire and reality. Patients were asked whether they considered it important that a relative was present when they were informed that they were to be discharged from the hospital.

**Table 4**

The impact of different factors on the likelihood of patients agreeing that their opinions were taken into account (1 = agree, fully or partly, 0 = disagree fully or partly).

	B	Sig.	Exp(B)
Gender (F = 1, M = 2)	−0.047	0.88	0.954
Education <sup>a</sup>		0.22	
Basic only	−0.908	0.09	0.403
High school low	−0.599	0.28	0.550
High school high	−0.053	0.94	0.948
Hearing ability (0 = OK, 1 = Problem)	−0.822	0.03	0.440
Eyesight ability (0 = OK, 1 = Problem)	0.112	0.70	1.119
Memory ability (0 = OK, 1 = Problem)	−0.517	0.21	0.596
Orientation ability (0 = OK, 1 = Problem)	−0.177	0.76	0.838
Constant	0.637	0.37	1.891

<sup>a</sup> Reference group education = College/University.

They were also asked whether they actually were able to have relatives present when they were informed; 237 patients answered both of these questions. Of the 122 patients who wished to have their family present when information was given, less than one fourth (22%) said their wish was granted.

### 3.4. Which determinants affect participation in the discharge process of elderly patients?

The impact of a number of factors on the likelihood of being able to influence the discharge process was assessed by logistic regression. Of the independent variables in the model only hearing ability made a statistically significant contribution, as shown in Table 4.

## 4. Discussion and conclusion

### 4.1. Discussion

Our data show that participation may be regarded by Thompson [37], i.e. as more than being given relevant information and more than having the opportunity to present one’s interests. It is a three-step ladder on which the top step is co-deciding how the hospitalization and the transition from hospital to home shall take place. The scale reproducibility coefficient of 0.849 is only slightly below the 0.90-level recommended by Guttman [38] and testifies that patient responses to the 3 questions (“Did you get information”, “Did you get to relate your views” and “Did you succeed in sharing decisions”) followed a systematic pattern. Those who reported having received information may or may not have provided input concerning their personal viewpoints to hospital staff, and may or may not have participated in planning their hospital discharge. In addition, those who reported having presented their personal wishes for the discharge process may or may not have been heard. However, those who reported that they had presented their personal wishes for the discharge process by and large also reported having been informed by the hospital staff. Moreover, those who felt they had been a part of planning their own discharge process by and large also reported having presented their personal wishes for the discharge process, and said they had been informed by the hospital staff.

A review of the literature [39] showed that very few instruments are designed specifically to capture participation in the discharge process. The main focus is on the information flow from the professional to the patient and never the other way around. Few of the instruments studied/analysed to what degree the patients were invited to share their knowledge, and none of the existing instruments captured the full range of participation. In spite of their advanced age (on average age 86.9 years), the patients in this study did express a relatively clear preference for participation. This finding is contrary to the conclusions in other contemporary publications [25,41,42]. In this study 49.2% of the respondents stated that they had only completed obligatory education and the Norwegian population statistics indicate that the populations’ rate of obligatory education is 49.4, indicating no educational bias in our respondents that could affect the high inclination for patient participation. Judging from our data, to

influence effectively the planning of one's discharge from the hospital, it is imperative that the older patient have good hearing. Unfortunately, this does not apply to many persons aged 80 and above. A high percentage of patients even wished to participate in decisions on medical treatment, a dimension that is often described as being outside older patients' area of interest for participation [43]. A possible explanation is hinted at by recent reviews of instruments designed to capture patients' view of the discharge process, which indicate that the measurement of elderly patients' interest in the hospital discharge process, and their wish to participate in its planning, are insufficiently covered by the existing instruments [13,14]. To determine the extent of elderly patients' wish to participate one must actively look for it. The relative neglect of such mapping may even be a reason why the qualities of the discharge process for elderly patients have failed to improve. Research indicates that although patients' involvement in decision-making in general has increased over time, this does not hold true for older persons [44]. Judging from our data, there are no demographic factors that can be said to significantly influence patients' participation in the planning of their discharge from the hospital. This finding is quite different from what is described when analysing data on younger patients, for whom reviews of literature find that patient's participation in decision-making are associated with demographic characteristics [45–47]. It seems that factors like gender and education have little influence on participation among the oldest patients. This might be related to age; when one gets old enough, old is all that is 'visible'.

Research indicates that elderly patients often do not experience that hospital professionals have the same focus as the patients themselves during discharge [27,48]. In our study, the patients reported that hospital staff handled patients' interests pretty well. Three-fifths (65%) of the patients stated that they felt a match between their own concerns and the concerns of the hospital professionals—a fact that might also be seen as supporting the notion that professionals are able to meet older patients' requirements quite well even though staff do not (at least in the opinion of the patient) have much of a dialogue with the patients on issues regarding their discharge. Paradoxically, this bit of good news may weaken the drive for patient participation: in combination with shorter hospital stays and more severe time constraints on health professionals, the confidence of elderly patients that hospital staff acts in their best interest may keep making it easier to develop discharge plans *for* patients rather than *with* them—as described in earlier research [49]. On the other hand, if patients' needs are met without patients' participation, why is participation important other than as a legally stated right? We started out this paper by pointing at research findings that demonstrate that discharge of frail older patients are associated with adverse events that might be prevented if patients were given the opportunity to participate more in decisions during the discharge process [1–11].

#### 4.2. Conclusion

Our study support previous findings indicating that the practice of involving older people in the discharge process has been slow to develop. There are several possible mechanisms behind this, like time shortage, lack of routines and/or good procedures to make sure that older people are heard, as well as a lack of focus on the dimension of participation in instruments aimed at evaluating the discharge process. As this paper only presents findings from the patients themselves, and not their significant others, we do not know if education and other demographic and contextual characteristics of patients' next of kin would be important to older patients' experiences of participation. We assume they may.

#### 4.3. Practice implications

The data reported in this article show that elderly patients do wish to participate more fully in the planning of their hospital discharge process, and that this wish is not being met. The importance of patient participation of elderly persons is supported by the ethical imperative of participation in itself, but also by its potential for improving the standards of health care. This study points at the need for further studies specifically designed to elaborate on what happens after discharge, in the short run as well as in the long. To determine the extent of older patients' wish to participate one must actively look for it both through research and in the hands-on process of discharge.

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