

## Informal caregivers' participation when older adults in Norway are discharged from the hospital

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### What is known about this topic

- Informal caregivers provide invaluable support to older patients during hospitalisation and after discharge.
- User participation in care transitions for frail older patients is challenging.

### What this paper adds

- Informal caregivers expressed a clear preference for involvement and participation during the discharge process and just over half reported that they participated in the discharge planning.
- Younger generation caregivers experienced a higher degree of involvement in receiving and providing information to hospital staff than did older generation caregivers.
- Younger generation caregivers and caregivers of patients with reduced hearing ability had higher odds of reporting co-operation with hospital staff in the discharge process.

### Introduction

The Norwegian welfare state, an example of what is commonly referred to as the Scandinavian welfare model, is built on the premise that public healthcare should be the main source of care (Esping-Andersen 1990, Johansson *et al.* 2011). The aim of the welfare state is to maximise the individual's independence

### Abstract

This paper describes the participation of informal caregivers in the discharge process when patients aged 80 and over who were admitted from home to different hospitals in Norway were discharged to long-term community care. Data for this cross-sectional survey were collected through telephone interviews with a consecutive sample of 262 caregivers recruited between October 2007 and May 2009. The Discharge of Elderly Questionnaire was developed by the research team and was designed to elicit data concerning informal caregivers' self-reported perceptions on participation in the discharge process. A descriptive and comparative analysis of Thompson's levels of participation reported by the older generation (spouses and siblings) and the younger generation (adult children and children-in-law, nieces and grandchildren) was undertaken using bivariate cross-tabulations and chi-square tests for association and trend. Analyses showed that the younger generation of caregivers received and provided information to hospital staff to a greater degree than the older generation. Overall, 52% of the informal caregivers reported co-operating with the staff to a high or to some degree. A multivariate logistic regression analysis was used to analyse factors predicting the likelihood of informal caregivers reporting co-operation with hospital staff. The odds of younger generation caregivers reporting co-operation were more than twice as high (OR = 2.121,  $P = 0.045$ ) as the odds of the older generation. Caregivers of patients with a hearing impairment had higher odds of reporting co-operation (OR = 1.722,  $P = 0.049$ ) than caregivers of patients with no such impairment. The length of hospital stay, the caregiver's and patient's gender and education level were not significantly associated with caregiver's co-operation. The informal caregivers' experiences with information practices and user participation in hospitals highlight important challenges that must be taken seriously to ensure co-operation between families and hospitals when elderly patients are discharged back to the community.

**Keywords:** aged 80 and over, hospital discharge, informal caregivers, Norway, user participation

from family and next of kin, and it implicitly suggests that older people will not have to rely on personal wealth, family or informal caregivers to cope with disease and functional decline. A study exploring filial norms, personal preferences for care and policy opinions about the proper role of the family and the welfare state found that most Norwegians agree that the welfare state should be the prime

source of care (Daatland & Herlofson 2003). Older Norwegians tend to be stronger advocates of the welfare state's responsibility than younger Norwegians (Daatland & Herlofson 2003), and they often state that they do not wish to be dependent or to be a burden on their spouse and adult children. However, the strong emphasis on the welfare state does not imply that spouses and other family members withdraw from caring tasks. Filial obligation norms are widely upheld and supported in Norway. In accordance with filial norms, the family assumes an important role in providing practical assistance, supplementing formal care services, and essential emotional support during hospitalisation and after discharge (Romøren 2001, Björnsdóttir 2002, Daatland & Herlofson 2003, Romøren & Blekesaune 2003, Dale *et al.* 2008, Johansson *et al.* 2011, EGGE – EU Expert Group on Gender and Employment 2012). The extensive involvement of spouses and adult children as next of kin entails and even necessitates their participation in care decisions.

#### User participation as public policy and ideology

User and patient participation in healthcare is an essential item on the health policy agenda in the economically developed world, including Norway (Martin 2008, Solbjør & Steinsbekk 2011). This policy and the ideology of user participation have been the subject of international research since the early 1980s (Cahill 1998). The involvement of the public, as citizens and clients, has become an important management tool in the wake of the New Public Management rhetoric introduced in 1990, with its focus on modernisation and cost-effectiveness in the public sector (Martin 2008, Johansen & Solbjør 2012).

User participation is conceptualised as participation at two levels, the system level and the individual level. User participation at the system level is mandatory in all hospital trusts in Norway (Ministry of Health and Social Affairs 2001). At the individual level, every patient has a legally established right to influence and participate in decisions regarding his or her own medical treatment in primary and specialist healthcare services (Ministry of Health and Social Affairs 1999, 2011). In Norway, the right to be present when medical treatment is administered is extended to the patient's next of kin at the patient's request (Ministry of Health and Social Affairs 1999). In the event that the patient is cognitively impaired, the right to influence and participate in decisions regarding medical treatment is transferred to the patient's next of kin or is shared between the patient and his or her kin (Ministry of Health and Social Affairs 1999). The Norwegian Patient's Rights Act (1999) also

mandates the right of patients and their next of kin to access information about the patient's health condition and medical treatment when the patient consents to this or when the situation calls for it.

#### User involvement and participation in healthcare consultations

Our understanding of participation in this study is based on the taxonomy of patient involvement and participation developed by Thompson (2007). Thompson identified five parallel, although meaningfully different, levels of professionally determined involvement that align with levels of patient-determined involvement. 'Level 0' of Thompson's taxonomy is *non-involvement* or *exclusion*. 'Level 1' involves professionals *supplying the information* they consider necessary and/or patients *seeking and receiving information*. At 'Level 2', there is a *dialogue* between patients and professionals and an exchange of information, implying that the patient himself/herself supplies information to the professionals. 'Level 3', marked by *shared decision-making*, is the level at which patients and professionals co-operate, and the patient's opinions and preferences are incorporated before the professionals make a decision. At 'Level 4' of the taxonomy, patients are *autonomous* in decision-making and professionals offer their expertise to patients to enable them to make autonomous *informed decisions*. Levels 0, 1, 2 and 3 of Thompson's taxonomy were used in the development of the questionnaire in this study. 'Level 4' was excluded because autonomous decision-making regarding discharge planning is not a feasible situation unless the patients make the atypical decision to discharge themselves against medical advice.

#### Informal caregivers' involvement and participation in care transitions

Spouses are often the first to assume care-giving responsibilities for older adults when care needs arise. If no spouse is available or able to care for a frail elderly individual, adult children and members of the extended family often take the caregiver role (Larsson & Thorslund 2002). A meta-analytic comparison of spouses, adult children and children-in-law as caregivers of older adults shows that spouses differ significantly from children and children-in-law with regard to the amount of support provided, depressive symptoms suffered and caregiver burden experienced (Pinquart & Sorensen 2011). Family members' involvement in the discharge process is found to increase family caregivers' satisfaction with discharge planning, continuity of care, feelings of preparedness

and acceptance of the caring role (Bull *et al.* 2000a) and to increase the well-being of patients and their family caregivers (Bull *et al.* 2000b).

A systematic review of barriers and facilitators to the implementation of shared decision-making in clinical practice (Gravel *et al.* 2006) revealed that time constraint was the most frequently reported barrier. The most frequently reported facilitators were provider motivation, positive impact on the clinical process and patient outcomes. Stirling *et al.* (2012) found that caregivers' and healthcare professionals' positioning of caregivers as either empowered or passive was linked to beliefs about the appropriateness healthcare professionals felt towards providing realistic information to the caregivers. This research indicates that the beliefs of healthcare professionals may lead them to filter the provision of realistic information to caregivers (Gravel *et al.* 2006, Stirling *et al.* 2012). Research exploring the collaboration between relatives of frail elderly patients and nurses in acute hospital wards in Sweden (Lindhardt *et al.* 2008) supports the notion that treating relatives as partners in decision-making rather than as passive recipients of information is important to them. Furthermore, the study calls for a mandatory involvement of relatives at the time of admission and in the discharge-planning phase to achieve an effective exchange of information and calibration of expectations regarding possible transition outcomes (Lindhardt *et al.* 2008). Another Swedish study found that longer duration in the hospital, higher education level among patients and patients and relatives being female were factors positively associated with greater reported involvement by relatives (Almborg *et al.* 2009). However, research indicates that informal caregivers' involvement in discharge planning is limited (Bull *et al.* 2000b, Driscoll 2000, Gilmour 2002, Grimmer *et al.* 2004, Gravel *et al.* 2006).

### Purpose

The purpose of this study was to describe the participation reported by informal caregivers in discharge planning when their older family member was discharged from the hospital. The three specific research questions for the study were as follows: What level of participation did informal caregivers experience in the discharge planning? Were there differences in involvement and participation among the younger generation and the older generation of informal caregivers? Did caregivers' and patients' demographic factors influence the self-reported participation of informal caregivers in the discharge-planning process?

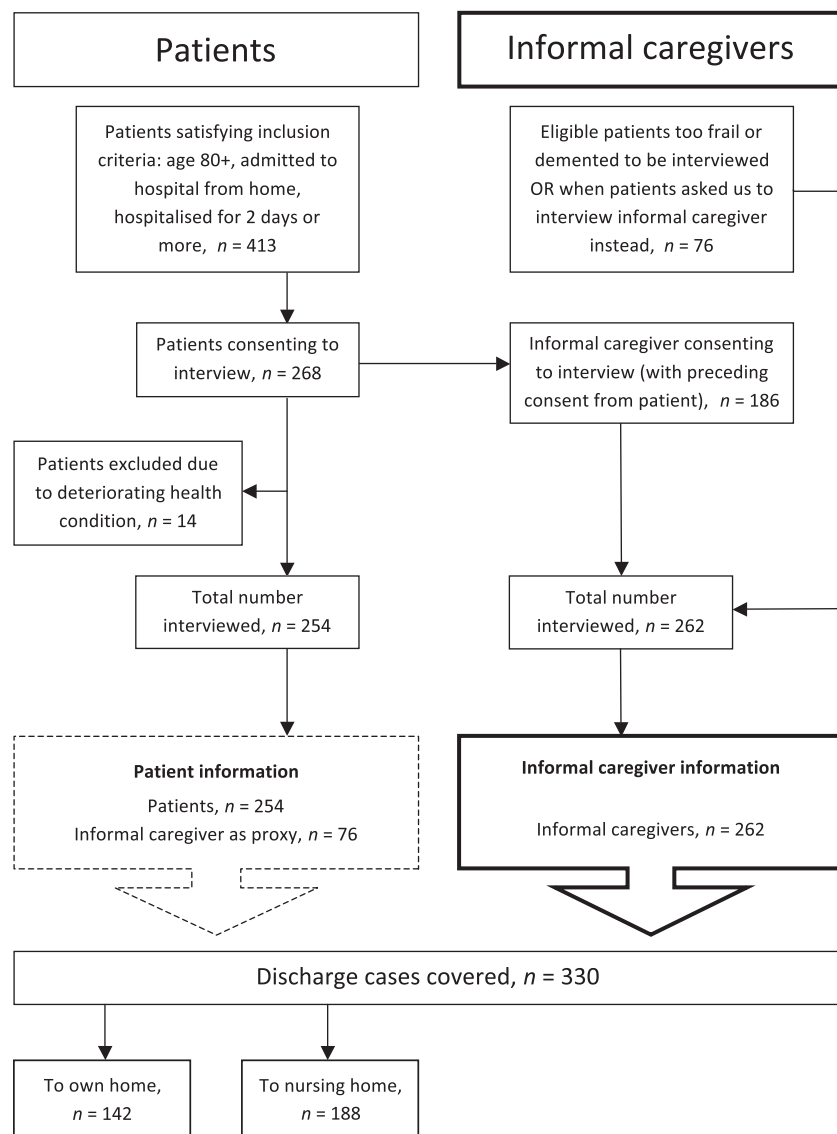
## Methods

### Design and recruitment

The study is part of a research project that collected self-reported questionnaire results for patients and close relatives of patients admitted from home to different hospitals in Norway and discharged to long-term community care. This study used a descriptive cross-sectional design with a consecutive sampling procedure (Polit & Beck 2012). In 2007, all 429 municipalities in Norway were stratified by size into three groups: small municipalities (<4000 inhabitants), medium-sized (4000–13,000 inhabitants) and large (>13,000 inhabitants). A proportionately stratified sample of 67 municipalities was drawn from the three strata (Polit & Beck 2012). Between October 2007 and May 2009, charge nurses in these 67 municipalities were instructed to consecutively identify and recruit all eligible patients for our study. The charge nurses identified 413 eligible patients recently discharged from 14 different hospitals (Figure 1). Inclusion criteria were age 80 or over, admitted to hospital from home, hospitalised for at least 2 days and adequate physical and cognitive capacity (as assessed by the recruiting nurse) to participate in the planning of their own discharge. Seventy-six of the patients were found to be too physically frail or cognitively impaired to be interviewed; in those cases, their informal caregiver was asked to participate as a proxy for the patient and to provide information as an informal caregiver. Each recruited patient was asked to identify one close relative or next of kin to be included in the study. There were no exclusion criteria for the next of kin and the number of informal caregivers recruited to the study followed from the number of patients recruited to the study. Data were collected in structured survey interviews. Geriatric nurses or geriatric nursing students conducted telephone interviews with informal caregivers within 4 weeks of the patient's discharge. As recommended by Streiner and Norman (2003), interviewers were specially trained to clarify the questions in a uniform way and to help respondents grade their answers.

### Informed consent and ethics

This study was designed in accordance with the ethical principles for medical research involving human subjects as stated in the World Medical Association's (2008) Declaration of Helsinki. Approval for the study was obtained from the South-East Norway Regional Ethics Committee for Medical Research (approval number: 17078) and all municipalities involved in the process of recruiting respondents.



**Figure 1** Flow chart of inclusion of respondents and discharge cases covered in the study.

We obtained informed written consent from each patient before interviews were initiated. When patients consented to include their informal caregiver in the study, the informal caregivers were contacted and asked if they would agree to be interviewed. The informal caregivers gave their informed (oral) consent for the interviews.

### Data collection

#### *Discharge questionnaire*

The Discharge of the Elderly Questionnaire was developed by the research team for the purpose of this study following a literature search to identify relevant studies and previously designed instruments (Foss &

Askautrud 2010) combined with qualitative interviews with elderly patients who were recently discharged from the hospital (Foss 2011). The Discharge of the Elderly Questionnaire was constructed in two versions, one for patients and one for informal caregivers. The two versions were constructed with the same content with a few target questions adjusted depending on the interviewee and the location to which the patient was discharged (home or nursing home). The questionnaires were designed to elicit data on the perceptions of the patient and the informal caregiver regarding the discharge process and the challenges after discharge. The questionnaire was tested in pilot interviews to ensure that the questions were understandable and that the questionnaire covered areas

that the respondents felt were significant. In this article, findings from the interviews with informal caregivers are reported. The patient questionnaire and patients' perspectives have been reported elsewhere (Foss & Hofoss 2011, Bragstad *et al.* 2012).

#### *Informal caregiver questionnaire*

The informal caregiver version of the questionnaire was organised in four sections: 'Demographic background', 'Participation in the discharge process', 'After discharge' and 'Summary'. In the 'Demographic background' section, informal caregivers were asked about their relationship with the patient, the patient's hospital stay and their own demographic background. The 'Participation in the discharge process' section included questions designed to measure different aspects of caregivers' involvement and participation in the discharge process. Two groups of questions were designed to measure caregivers' desire for and participation in the discharge-planning process. Four questions were designed to measure the informal caregiver's perception of information practices at the hospital. In addition, four questions measured the caregivers' perceptions of how they were treated at the hospital (Box 1). The 'After discharge' section included questions on the amount of formal and informal care provided before admission and after discharge. The 'Summary' section included questions regarding informal caregivers' assessment of assistance received from and their trust in the healthcare system.

#### **Box 1** Questions measuring informal caregiver's participation

##### Informal caregiver's desire for participation

- How important was it for you to influence the medical treatment?\*
- How important was it for you to influence the time of discharge?\*
- How important was it for you to influence how practical issues should be solved?\*

##### Informal caregiver's actual participation in the discharge process

- Thompson's participation Level 1.* Did you receive information on the kind of help the patient would receive?\*
- Thompson's participation Level 2.* Did you get an opportunity to tell the hospital staff about the patient's situation at home?\*
- Thompson's participation Level 3.* Did you participate in the decision-making on how issues could be resolved?\*

##### Informal caregiver's perception of information practices at the hospital

- Thomson's participation Level 1.* Did you receive sufficient information about the patient's medical condition?†
- In your opinion, did the patient receive sufficient information about his/her own medical condition?‡
- Did the patient want you to be present when receiving information or instructions?‡
- In your opinion, was it necessary for you to be present when the patient received information or instructions?‡

##### Informal caregiver's perception of how he or she was treated at the hospital

- Were you treated with courtesy and respect when you wanted to share decisions during the discharge planning?‡
- Did the hospital staff initiate co-operation with you?‡
- Were your opinions taken into consideration by the hospital staff?‡
- Were there any issues at the hospital that you refrained from discussing with the hospital staff?§

\*Questions were graded: to a high degree; to some degree; to a minor degree; not at all.

†Questions were graded: to a high degree; to some degree; to a minor degree; not at all; not applicable.

‡Questions were graded: to a high degree; to some degree; to a minor degree; not at all; don't know/not sure/not applicable.

§Question was graded: yes/no.

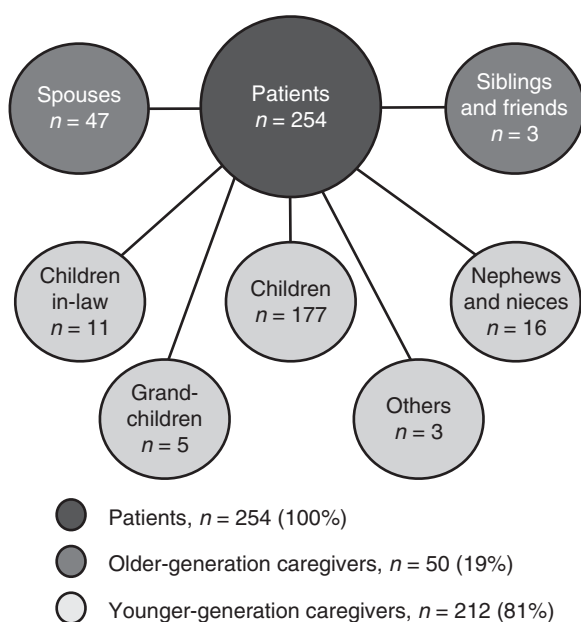
#### **Data analysis**

A descriptive data analysis was conducted on all variables to obtain frequency distributions of all categorical variables and means and standard deviations for continuous variables. The informal caregiver's relationship with the patient was recoded and the respondents were divided into two groups (Figure 2). Spouses, siblings and friends were coded as the same generation as that of the patient, the older generation. The patients' adult children, children-in-law, nephews, nieces, grandchildren and others were coded as younger generation. Bivariate cross-tabulations and Pearson's chi-square test for association were conducted with the participation variables to identify differences in participation by generation of caregiver and by gender. Bivariate cross-tabulations and chi-square tests for trend were conducted with the participation variables to investigate the informal caregiver's perceptions of how they were treated at the hospital by level of caregiver education. Questions regarding the desire for participation and actual participation were classified into four categories: 'to a high degree', 'to some degree', 'to a minor degree' and 'not at all'. Questions regarding information practices and perceptions of caregivers' treatment at the hospital were graded similarly, with an additional category of 'not applicable'. These variables were recoded to exclude all respondents who answered 'not applicable', to ensure that only caregivers who thought the question applied to their situation were included in the

statistical analyses. Prior to excluding those who answered 'not applicable', an analysis was conducted to determine whether there was a systematic pattern to these answers and whether the same respondents answered 'not applicable' on all questions. No such systematic pattern was found.

For the questions measuring Thompson's participation at Levels 1, 2 and 3 (Box 1), the categories 'to a high degree' and 'to some degree' were interpreted as participation, whereas the other two categories, 'to a minor degree' and 'not at all' were interpreted as non-participation.

Data exploration by bivariate analyses makes the analyses susceptible to false conclusions of significance as well as false insignificance, due to the lack of controlling for confounders. Thus, a multivariate logistic regression analysis was performed to assess the impact of a number of predictors, controlled for each other, on the likelihood that informal caregivers would report participation at Level 3 of Thompson (2007). The dependent variable in the analysis was self-reported co-operation with the hospital staff, dichotomised into participation and non-participation, as described above. In line with findings from earlier research on relatives' involvement in hospital discharge, we chose to include the following covariates in our logistic regression model: the patient's hearing ability (Foss & Hofoss 2011), the caregiver's generation (Pinquart & Sorensen 2011), the caregiver's and patient's gender and education level and the length of hospital stay (Almborg *et al.* 2009).



**Figure 2** The informal caregiver's relationship with the patient.

Coefficients with a  $P$ -value lower than 0.05 were considered statistically significant. Data were analysed using IBM SPSS 19 (IBM Corp., Armonk, NY, USA).

## Results

Two hundred and fifty-four patients and 262 informal caregivers were recruited for this study. The response rate for the patients was 61.5% and for informal caregivers, it was 79.4%. The empirical material in this article consisted of 262 survey interviews with informal caregivers associated with 330 patient discharge cases (Figure 1).

### Characteristics of the sample

In our sample of informal caregivers, patients' spouses accounted for 18% ( $n = 47/262$ ), 68% ( $n = 177/262$ ) were the patients' adult children, and the remaining 14% ( $n = 38/262$ ) were children-in-law, grandchildren, nieces, nephews, siblings and other friends. As shown in Table 1, 62% ( $n = 31/50$ ) of the respondents in the older generation and 63% ( $n = 134/212$ ) in the younger generation were women. The respondents' overall mean age was 60 years, and the mean age was 55 years for the younger generation and 80 years for the older generation. Our findings suggest that spouses and other caregivers in the same generation as that of the patient were notably different from the younger generation caregivers in other important traits. A larger proportion of the younger generation had been educated to a higher level than the older generation. More than three-fourths of the informal caregivers in the younger generation were gainfully employed, compared with none in the older generation. The overall percentage of informal caregivers currently living with the home-dwelling patient was 31% ( $n = 33/106$ ). Among the younger generation, only 8% ( $n = 6/77$ ) lived with the patient, whereas for informal caregivers in the same generation, the percentage was significantly higher at 93% ( $n = 27/29$ ).

### Caregiver participation in the discharge process

#### *Desired participation and actual participation*

The informal caregivers reported a clear preference for influencing medical treatment, time of discharge and the resolution of practical issues (Table 2). The respondents distinctly expressed the ability to influence the way practical issues after discharge should be solved as highly important. The desire to influence the time of discharge was important for both generations; but, for the older generation of caregivers, this was significantly less important. As shown in Table 3,

**Table 1** Characteristics of the informal caregivers by generation of caregiver

Demographic characteristics	Older generation	Younger generation	Total sample	P-value
	<i>n</i> = 50	<i>n</i> = 211	<i>n</i> = 261	
Age [years]	80.1 [6.9]	55.1 [6.9]	59.9 [12.1]	<0.001
Gender				
Female	31 (62.0)	134 (63.2)	165 (63.0)	0.874*
Male	19 (38.0)	78 (36.8)	97 (37.0)	
Civil status				
Never married	0 (0.0)	13 (6.1)	13 (5.0)	0.011†
Married or cohabiting	49 (98.0)	172 (81.2)	221 (84.3)	
Divorced	1 (2.0)	19 (9.0)	20 (7.6)	
Widowed	0 (0.0)	8 (3.8)	8 (3.1)	
Level of education				
Basic	39 (78.0)	91 (43.1)	130 (49.8)	<0.001‡
High school	5 (10.0)	38 (18.0)	43 (16.5)	
College or university	6 (12.0)	82 (38.9)	88 (33.7)	
Gainfully employed				
Yes	0 (0.0)	163 (76.9)	163 (62.2)	<0.001*
No	50 (100.0)	49 (23.1)	99 (37.8)	
Living with the patient now§	<i>n</i> = 29	<i>n</i> = 77	<i>n</i> = 106	
Yes	27 (93.1)	6 (7.8)	33 (31.1)	<0.001*
No	2 (6.9)	71 (92.2)	73 (68.9)	

Values are expressed as mean [SD] or *n* (%).

\*Fisher's exact test.

†Pearson chi-square.

‡Chi-square for trend.

§This question was posed exclusively to informal caregivers of patients discharged back to their home.

there was a statistically significant difference ( $\chi^2 = 9.79$ ,  $df = 3$ ,  $P = 0.020$ ) between male and female caregivers on the issue of influencing the time of discharge, indicating that a larger proportion of female respondents (59%,  $n = 97/165$ ) than male respondents (48%,  $n = 44/91$ ) felt that the ability to influence the time of discharge was highly important to them.

As shown in Table 2, 65% of the caregivers reported participating at Level 1, while 60% reported participating at Level 2 and 52% reported participating at Level 3. For participation at Level 2, there was a statistically significant difference between the two generations ( $\chi^2 = 8.88$ ,  $df = 3$ ,  $P = 0.031$ ), with a larger proportion of the younger generation (50%,  $n = 97/193$ ) than the older generation (34%,  $n = 15/44$ ) reporting that they were given the opportunity to provide information about the patient's home situation to the hospital staff to a high degree.

#### *Informal caregivers' perceptions of information practices at the hospital*

As shown in Table 4, the younger generation of caregivers reported receiving sufficient information about the patient's medical condition (Level 1) while at the hospital significantly more often than the older generation of caregivers. Likewise, the younger generation, compared with the older generation, reported a

higher degree of experience that the patient was sufficiently informed. However, the older generation reported experiencing a significantly stronger expectation from the patient that the caregiver should be present when the patient was receiving information.

#### *Informal caregivers' perception of how they were treated at the hospital*

The majority of informal caregivers reported that they were treated with courtesy and respect when they wanted to participate in decision-making during the discharge process (Table 5). The older generation (50%,  $n = 20/40$ ) reported that the staff did not initiate co-operation more frequently than the younger generation (66%,  $n = 126/192$ ); however, the association between the variables was not significant. A majority of the informal caregivers reported that they felt that their opinions were heard and considered to a high degree in the discharge-planning process. However, one-fourth of the respondents thought that their opinions were considered not at all or only to a minor degree. Approximately 22% of the caregivers reported that there were issues they wanted to discuss with the staff that they refrained from discussing. As shown in Table 6, the respondents with a high school degree and a college or university degree reported refraining from discussing issues with the

**Table 2** Informal caregiver's desired and actual participation by generation of caregiver

	Older generation	Younger generation	Total sample	P-value
<b>Desired participation</b>				
Medical treatment	<i>n</i> = 47	<i>n</i> = 211	<i>n</i> = 258	
To a high degree	25 (53.2)	105 (49.8)	130 (50.4)	0.606*
To some degree	7 (14.9)	50 (23.7)	57 (22.1)	
To a minor degree	8 (17.0)	30 (14.2)	38 (14.7)	
Not at all	7 (14.9)	26 (12.3)	33 (12.8)	
Time of discharge	<i>n</i> = 47	<i>n</i> = 209	<i>n</i> = 256	
To a high degree	28 (59.6)	113 (54.1)	141 (55.1)	0.018*
To some degree	4 (8.5)	46 (22.0)	50 (19.5)	
To a minor degree	6 (12.8)	35 (16.7)	41 (16.0)	
Not at all	9 (19.1)	15 (7.2)	24 (9.4)	
Solving practical issues	<i>n</i> = 47	<i>n</i> = 208	<i>n</i> = 255	
To a high degree	32 (68.1)	151 (72.6)	183 (71.8)	0.213*
To some degree	3 (6.4)	25 (12.0)	28 (11.0)	
To a minor degree	5 (10.6)	18 (8.7)	23 (9.0)	
Not at all	7 (14.9)	14 (6.7)	21 (8.2)	
<b>Actual participation</b>				
Level 1: Receive information	<i>n</i> = 45	<i>n</i> = 203	<i>n</i> = 248	
To a high degree	19 (42.2)	94 (46.3)	113 (45.6)	0.739*
To some degree	8 (17.8)	41 (20.2)	49 (19.8)	
To a minor degree	5 (11.1)	25 (12.3)	30 (12.1)	
Not at all	13 (28.9)	43 (21.2)	56 (22.6)	
Level 2: Provide information	<i>n</i> = 44	<i>n</i> = 193	<i>n</i> = 237	
To a high degree	15 (34.1)	97 (50.3)	112 (47.3)	0.031*
To some degree	11 (25.0)	19 (9.8)	30 (12.7)	
To a minor degree	3 (6.8)	18 (9.3)	21 (8.9)	
Not at all	15 (34.1)	59 (30.6)	74 (31.2)	
Level 3: Co-operation	<i>n</i> = 46	<i>n</i> = 197	<i>n</i> = 243	
To a high degree	14 (30.4)	74 (37.6)	88 (36.2)	0.423*
To some degree	5 (10.9)	33 (16.8)	38 (15.6)	
To a minor degree	6 (13.0)	23 (11.7)	29 (11.9)	
Not at all	21 (45.7)	67 (34.0)	88 (36.2)	

Values are expressed as *n* (%).

\*Pearson's chi-square.

staff significantly more frequently ( $\chi^2_{Trend} = 5.18$ ,  $df = 1$ ,  $P = 0.023$ ) than the group with a basic mandatory education level.

#### *Factors influencing informal caregivers' participation*

The bivariate analyses showed that the two generations of caregivers experienced participation at Levels 1 and 2 differently. The younger generation of caregivers experienced receiving information about the patient's medical condition (Level 1) and engaging in a dialogue to provide information about the situation at home to healthcare professionals (Level 2) more frequently than the older generation (Tables 2 and 4). Overall, only half of the caregivers reported that they co-operated with the hospital staff during the discharge process – participation at Level 3 (Table 2). In the multivariate logistic regression analysis (Table 7), two of the independent variables made a unique statistically significant contribution to the logistic regression model that explored predictors of participation

at Level 3. Controlling for the other factors in the model, the odds of caregiver participation at Level 3 were more than twice as high (OR = 2.121,  $P = 0.045$ ) for caregivers in the younger generation than for caregivers in the older generation. Patient's hearing ability was the second statistically significant predictor in this model, demonstrating that when the patient had reduced hearing ability, the caregivers' odds of reporting participation at Level 3 were more than one and a half times as high (OR = 1.722,  $P = 0.049$ ) than when the patient had no problems with hearing. The other variables in the model were not statistically significant predictors.

## Discussion

### Desired participation at the hospital

Our findings demonstrate that informal caregivers expressed a clear preference for participating in



**Table 3** Informal caregiver's desired and actual participation by gender of caregiver

	Female	Male	Total sample	P-value
<b>Desired participation</b>				
Medical treatment	<i>n</i> = 165	<i>n</i> = 93	<i>n</i> = 258	
To a high degree	85 (51.5)	45 (48.4)	130 (50.4)	0.839*
To some degree	36 (21.8)	21 (22.6)	57 (22.1)	
To a minor degree	22 (13.3)	16 (17.2)	38 (14.7)	
Not at all	22 (13.3)	11 (11.8)	33 (12.8)	
Time of discharge	<i>n</i> = 165	<i>n</i> = 91	<i>n</i> = 256	
To a high degree	97 (58.8)	44 (48.4)	141 (55.1)	0.020*
To some degree	23 (13.9)	27 (29.7)	50 (19.5)	
To a minor degree	27 (16.4)	14 (15.4)	41 (16.0)	
Not at all	18 (10.9)	6 (6.6)	24 (9.4)	
Solving practical issues	<i>n</i> = 164	<i>n</i> = 91	<i>n</i> = 255	
To a high degree	126 (76.8)	57 (62.6)	183 (71.8)	0.109*
To some degree	14 (8.5)	14 (15.4)	28 (11.0)	
To a minor degree	13 (7.9)	10 (11.0)	23 (9.0)	
Not at all	11 (6.7)	10 (11.0)	21 (8.2)	
<b>Actual participation</b>				
Level 1: Receive information	<i>n</i> = 157	<i>n</i> = 91	<i>n</i> = 248	
To a high degree	70 (44.6)	43 (47.3)	113 (45.6)	0.335*
To some degree	32 (20.4)	17 (18.7)	49 (19.8)	
To a minor degree	23 (14.6)	7 (7.7)	30 (12.1)	
Not at all	32 (20.4)	24 (26.4)	56 (22.6)	
Level 2: Provide information	<i>n</i> = 151	<i>n</i> = 86	<i>n</i> = 237	
To a high degree	75 (49.7)	37 (43.0)	112 (47.3)	0.717*
To some degree	18 (11.9)	12 (14.0)	30 (12.7)	
To a minor degree	14 (9.3)	7 (8.1)	21 (8.9)	
Not at all	44 (29.1)	30 (34.9)	74 (31.2)	
Level 3: Co-operation	<i>n</i> = 155	<i>n</i> = 88	<i>n</i> = 243	
To a high degree	58 (37.4)	30 (34.1)	88 (36.2)	0.552*
To some degree	25 (16.1)	13 (14.8)	38 (15.6)	
To a minor degree	15 (9.7)	14 (15.9)	29 (11.9)	
Not at all	57 (36.8)	31 (35.2)	88 (36.2)	

Values are expressed as *n* (%).

\*Pearson's chi-square.

discharge planning when their elderly relative was being discharged from the hospital. Most markedly, the caregivers reported a desire to influence how practical problems should be solved. Given that adult children and other caregivers provide support and help elderly patients with numerous tasks after discharge (Gautun 1999, Sand 2005, Bookman & Harrington 2007, Dale *et al.* 2008, EGGE – EU Expert Group on Gender and Employment 2012), it is reasonable for informal caregivers to desire some form of influence over such decisions. These decisions affect not only the patient's situation but also the caregiver's situation.

The desire to influence the time of discharge was less important to the older generation of caregivers than to the younger generation. The younger generation of caregivers mainly included adult children living in a separate household from the older patient. Our previous research has shown that it is important

that someone is present when the patient returns home (Bragstad *et al.* 2012). Caregivers must arrange to be present when the patient comes home and must provide support during the initial vulnerable period. These arrangements must be co-ordinated to a greater degree for gainfully employed adult children, children-in-law and extended family members than for a retired spouse in a shared household. Our findings also revealed that it was more important for women to have a say about the time of discharge. Female family members are often more involved in personal care tasks, whereas male family members help with more instrumental activities of daily life, such as grocery shopping, shovelling snow and gardening (Romøren 2001, Jegermalm 2006, Dale *et al.* 2008). Making arrangements to take on a supportive role and assisting with care tasks after discharge seem to be more important for female caregivers because the tasks they perform are of a more urgent and

**Table 4** Informal caregiver's perception of information practices at the hospital by generation of caregiver

	Older generation	Younger generation	Total sample	P-value
Caregiver received sufficient information about patient's medical condition	<i>n</i> = 46	<i>n</i> = 204	<i>n</i> = 250	
To a high degree	15 (32.6)	108 (52.9)	123 (49.2)	0.013*
To some degree	17 (37.0)	37 (18.1)	54 (21.6)	
To a minor degree	4 (8.7)	27 (13.2)	31 (12.4)	
Not at all	10 (21.7)	32 (15.7)	42 (16.8)	
Patient received sufficient information about own illness	<i>n</i> = 47	<i>n</i> = 203	<i>n</i> = 250	
To a high degree	14 (29.8)	90 (44.3)	104 (41.6)	0.042*
To some degree	16 (34.0)	60 (29.6)	76 (30.4)	
To a minor degree	6 (12.8)	20 (9.9)	26 (10.4)	
Not at all	9 (19.1)	14 (6.9)	23 (9.2)	
Don't know/not sure	2 (4.3)	19 (9.4)	21 (8.4)	
Caregiver felt need to be present when patient received information	<i>n</i> = 37	<i>n</i> = 190	<i>n</i> = 227	
To a high degree	25 (67.6)	119 (62.6)	144 (63.4)	0.187*
To some degree	8 (21.6)	29 (15.3)	37 (16.3)	
To a minor degree	0 (0.0)	20 (10.5)	20 (8.8)	
Not at all	4 (10.8)	22 (11.6)	26 (11.5)	
Patient wanted caregiver present when receiving information	<i>n</i> = 28	<i>n</i> = 140	<i>n</i> = 168	
To a high degree	13 (46.4)	82 (58.6)	95 (56.5)	0.002*
To some degree	10 (35.7)	14 (10.0)	24 (14.3)	
To a minor degree	1 (3.6)	26 (18.6)	27 (16.1)	
Not at all	4 (14.3)	18 (12.9)	22 (13.1)	

Values are expressed as *n* (%).

\*Pearson's chi-square.

**Table 5** Informal caregivers' perceptions of how they were treated at the hospital by generation of caregiver

	Older generation	Younger generation	Total sample	P-value
Treated with courtesy and respect	<i>n</i> = 34	<i>n</i> = 170	<i>n</i> = 204	
To a high degree	29 (85.3)	149 (87.6)	178 (87.3)	0.314*
To some degree	2 (5.9)	15 (8.8)	17 (8.3)	
To a minor degree	1 (2.9)	4 (2.4)	5 (2.5)	
Not at all	2 (5.9)	2 (1.2)	4 (2.0)	
Staff initiated co-operation	<i>n</i> = 40	<i>n</i> = 192	<i>n</i> = 232	
To a high degree	16 (40.0)	83 (43.2)	99 (42.7)	0.059*
To some degree	4 (10.0)	43 (22.4)	47 (20.3)	
To a minor degree	6 (15.0)	32 (16.7)	38 (16.4)	
Not at all	14 (35.0)	34 (17.7)	48 (20.7)	
Opinions taken into account	<i>n</i> = 36	<i>n</i> = 177	<i>n</i> = 213	
To a high degree	21 (58.3)	91 (51.4)	112 (52.6)	0.672*
To some degree	5 (13.9)	41 (23.2)	46 (21.6)	
To a minor degree	4 (11.1)	19 (10.7)	23 (10.8)	
Not at all	6 (16.7)	26 (14.7)	32 (15.0)	
Refrained from discussing issues at the hospital	<i>n</i> = 48	<i>n</i> = 207	<i>n</i> = 255	
Yes	9 (18.8)	46 (22.2)	55 (21.6)	0.699†
No	39 (81.3)	161 (77.8)	200 (78.4)	

Values are expressed as *n* (%).

\*Pearson's chi-square.

†Fisher's exact test.

non-postponable nature, whereas the tasks of male caregivers are often less urgent. The difference in the desire to participate in planning the time of discharge

was significant and is understandable in the light of the fact that individuals in the younger generation are often employed and live separately, so they must

**Table 6** Informal caregivers' perceptions of how they were treated at the hospital by caregiver level of education

	Basic	High school	College or university	Total sample	P-value
Treated with courtesy and respect	<i>n</i> = 96	<i>n</i> = 40	<i>n</i> = 67	<i>n</i> = 203	
To a high degree	87 (90.6)	35 (87.5)	55 (82.1)	177 (87.2)	0.059*
To some degree	7 (7.3)	3 (7.5)	7 (10.4)	17 (8.4)	
To a minor degree	1 (1.0)	2 (5.0)	2 (3.0)	5 (2.5)	
Not at all	1 (1.0)	0 (0.0)	3 (4.5)	4 (2.0)	
Staff initiated co-operation	<i>n</i> = 112	<i>n</i> = 40	<i>n</i> = 79	<i>n</i> = 231	
To a high degree	50 (44.6)	17 (42.5)	31 (39.2)	98 (42.4)	0.236*
To some degree	21 (18.8)	12 (30.0)	14 (17.7)	47 (20.3)	
To a minor degree	19 (17.0)	9 (22.5)	10 (12.7)	38 (16.5)	
Not at all	22 (19.6)	2 (5.0)	24 (30.4)	48 (20.8)	
Opinions taken into account	<i>n</i> = 106	<i>n</i> = 40	<i>n</i> = 66	<i>n</i> = 212	
To a high degree	58 (54.7)	20 (50.0)	34 (51.5)	112 (52.8)	0.659*
To some degree	21 (19.8)	11 (27.5)	13 (19.7)	45 (21.2)	
To a minor degree	10 (9.4)	6 (15.0)	7 (10.6)	23 (10.8)	
Not at all	17 (16.0)	3 (7.5)	12 (18.2)	32 (15.1)	
Refrained from discussing issues at the hospital	<i>n</i> = 125	<i>n</i> = 43	<i>n</i> = 86	<i>n</i> = 254	
Yes	19 (15.2)	12 (27.9)	24 (27.9)	55 (21.7)	0.023*
No	106 (84.8)	31 (72.1)	62 (72.1)	199 (78.3)	

Values are expressed as *n* (%).

\*Chi-square for trend.

arrange to care for their elderly relative after discharge. It is noteworthy that there was no evidence of significant differences between older and younger caregivers in their desire to participate in solving practical issues and in the medical treatment; their desire for influence on these issues was high in both groups. This finding is in line with the experiences of the patients in our study (Foss & Hofoss 2011) and contrasts with the general claim that older individuals do not wish to participate (Longtin *et al.* 2010).

### Information practices at the hospital

The older generation caregivers reported feeling less informed than the younger generation caregivers did. According to the caregivers, the patients were even more poorly informed about their own health condition. This perception was highly pronounced among the older generation caregivers. The majority of the caregivers in the older generation thought that the patient wanted them present when they received information. This may suggest a closer relationship and a stronger feeling of responsibility between spouses than between elderly patients and their adult children or extended family members. However, as shown in Table 4, the two generations provided similar reports of whether they felt that they needed to be present when information was given to the patient, indicating strong adherence to filial norms in both generations.

Our findings showed that the two groups of informal caregivers perceived information practices at the

hospital differently. Previous research on patients' experiences has shown that only one of five patients who wanted their relative present had their wish granted (Foss & Hofoss 2011). The ability to be present when the patient receives information may be a way for caregivers to ensure that important information is received and understood. Caregivers who are not present must rely on the patient to convey the information they received or must actively seek out the hospital staff to obtain the information themselves. We know that older patients are more reluctant to actively initiate co-operation with staff (Foss 2011), so the responsibility for initiating co-operation should lie with the hospital staff. However, our findings showed that the hospital staff were not always perceived by caregivers as initiators of co-operation.

In the Norwegian healthcare system, the right of patients and caregivers to be informed about a patient's health condition is clearly articulated in the legislation (Ministry of Health and Social Affairs 1999). Our findings suggest that the routines by which information was transmitted were insufficient and may have violated patients' and caregivers' rights. Information in itself is not participation; rather, it is a prerequisite for participation (Thompson 2007), and participation is hampered by a lack of information.

### Participation in the discharge process

There were differences between the generations, in favour of the younger generation, with regard to

**Table 7** Logistic regression model to assess the likelihood of caregiver co-operation with hospital staff during discharge planning

Independent variables	First outcome category: No co-operation*	Second outcome category: Co-operation*	Odds ratio	95% CI	P-value
Length of stay	117 (48.1)	126 (51.9)	1.021	0.994–1.049	0.127
Mean [SD]	11.3 [11.4]	13.3 [9.9]			
Patient gender					
Female	80 (50.0)	80 (50.0)	1.000		
Male	37 (44.6)	46 (55.4)	1.290	0.713–2.335	0.400
Caregiver gender					
Female	72 (46.5)	83 (53.5)	1.000		
Male	45 (51.1)	43 (48.9)	0.861	0.491–1.508	0.600
Generation					
Older generation	27 (58.7)	19 (41.3)	1.000		
Younger generation	90 (45.7)	107 (54.3)	2.121	1.016–4.428	0.045
Hearing ability					
No impairment	58 (56.3)	45 (43.7)	1.000		
Impairment	57 (42.5)	77 (57.5)	1.722	0.338–0.998	0.049
Patient education level					
College/university degree	6 (40.0)	9 (60.0)	1.000		
High school education	7 (46.7)	8 (53.3)	0.887	0.191–4.111	0.878
Basic education	102 (48.8)	107 (51.2)	0.553	0.174–1.758	0.315
Caregiver education level					
College/university degree	42 (51.2)	40 (48.8)	1.000		
High school education	19 (46.3)	22 (53.7)	1.354	0.604–3.032	0.462
Basic education	56 (47.1)	63 (52.9)	1.388	0.733–2.631	0.315

Values are expressed as *n* (row %).

\*The dependent variable: self-reported co-operation with the hospital staff during the discharge process (No co-operation – Did not at all or to a minor degree co-operate with the hospital staff; Co-operation – Did to some degree or to a high degree co-operate with the hospital staff) (Hosmer and Lemeshow model goodness of fit  $P = 0.398$ ) ( $n = 234$ ).

receiving information about the patient's health condition at Level 1 of Thompson (2007). The younger generation also reported participation at Level 2 more frequently than the older generation. This finding suggested that staff members engaged in dialogue with younger caregivers more than with caregivers of the same generation as that of the patient. Our findings showed that half of the caregivers reported achieving participation at Level 3. This means that only half of the caregivers reported that they co-operated with the hospital staff during the discharge process.

To us, this level of participation appeared to be low: hospital staff and the system should not be satisfied with only half of the caregivers achieving participation where this is a legally established patient and caregiver right.

The logistic regression analysis showed that younger generation caregivers had higher odds of reporting co-operation with hospital staff in the discharge process. Previous research on elderly patients and participation (Bastiaens *et al.* 2007, Foss 2011) has shown that elderly patients do not participate in a direct and outspoken manner, and this communication differs from what is expected in the efficient modern hospital. Older patients feel that they are not

heard because their attempts to participate are often subtle and cautious, and easily ignored by professionals in the busy hospital setting (Foss 2011). Younger caregivers may be more attuned to the type of participation that allows them to engage in dialogue with the staff and to be heard (Say *et al.* 2006). Furthermore, staff members may be more comfortable communicating with caregivers of their generation who exhibit a more active and empowered attitude (Stirling *et al.* 2012). Communication with older individuals can be more time consuming and arduous than communication with younger individuals, which may have detrimental effects on communication with caregivers in a busy hospital setting where the hospital staff is pressed for time.

The logistic regression analysis also showed that caregivers of patients with reduced hearing ability had higher odds of reporting co-operation with hospital staff in the discharge process. In other words, participation at Level 3 was predicted by the patient's hearing ability, demonstrating that when the patient was hearing impaired informal caregivers took on a supportive role and co-operated with hospital staff. This finding suggests that informal caregivers must be especially persistent in seeking participation to compensate for the patient's sensory loss and must

ensure participation that supports the patient's interests. Up to 60% of the population over the age of 80 has reduced hearing ability (Collerton *et al.* 2009). In the patient study (Foss & Hofoss 2011), a lack of hearing impairment proved to be important for the patient's participation in the discharge process. Advanced age is the most important risk factor for acquired hearing loss, and the prevalence of hearing loss increases with increasing longevity (Collerton *et al.* 2009). This may have implications for informal caregivers in the older generation because it is likely that a proportion of them also experience age-related hearing loss, posing a further obstacle to their success in gaining participation.

For elderly patients, hospitalisation is often the beginning of a functional decline resulting in frequent re-hospitalisation and initiating the transition from living independently to becoming care dependent and in need of nursing home placement. Informal caregivers represent an untapped resource; they can contribute to smoother care transitions by co-operating in the discharge process. Caregivers often possess important information about the patient's functional ability, ability to manage independently at home and the environment in which the patient lives. Contemporary policy initiatives in Norway (Ministry of Health and Care Services 2009, 2011) place more responsibility on the families of elderly patients to face these challenges with limited formal resources as the elderly population increases. Our findings of the experiences of informal caregivers' with information practices and user participation in hospitals highlight important challenges that must be taken seriously to ensure co-operation between families and hospitals when elderly patients are discharged.

## Conclusions

Our findings suggest that the two generations of caregivers had notably different experiences with regard to how hospital staff perceived them as participating partners in the discharge process. Participation in the sense of caregivers gaining influence and participating in the discharge planning is not common: only half of the caregivers in our sample reported participation at Level 3. Moreover, participation is dependent on the generational relationship with the patient and the caregiver's age and familial relationship. The younger generation experiences a greater degree of participation. Elderly patients who are not assisted by younger generation informal caregivers may be perceived to be at risk of missing the participation needed for a smooth transfer to their own home or to a nursing home.

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## Conflict of interest

No conflicts of interest have been declared.

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