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Few opportunities to influence decisions regarding the care and treatment of an older hospitalized family member: A qualitative study among family members --Manuscript Draft--

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Abstract:	<p>Abstract</p> <p>Background: The drive towards patient involvement in health services has been increasingly promoted. The World Health Organisation emphasizes the family's perspective in comprehensive care. Internationally there is an increased emphasis on what patients and their family tell about the hospital experiences. However, current literature does not adequately address the question of participation experiences among relatives of older hospitalized family members. There is a paucity of research with a generational perspective on relatives' opportunities to exert influence.</p> <p>Objective: The aim of the study was to explore relatives' experiences of opportunities to participate in decisions about the care and treatment of older hospitalized family members and whether there are different experiences of influence to the relatives' age.</p> <p>Design: This was an explorative study applying individual qualitative interviews. The interviews were analysed following hermeneutic methodological principles.</p> <p>Settings: Two Norwegian geriatric wards participated: one at a university hospital and one at a local hospital.</p> <p>Participants: Twelve participants, six women and six men, were purposively selected. The relatives were aged from 36 to 88 (mean age 62) and were spouses, children and/or children-in-law of patients.</p> <p>Results: The relatives' experienced opportunities to exert influence were distributed along a continuum ranging from older relatives being reactive waiting for an initiative from health professionals, to younger adults being proactive securing influence. Older "invisible" carers appeared to go unnoticed by the health professionals, establishing few opportunities to influence decisions. The middle-aged relatives also experienced limited influence, but participated when the hospital needed it. However, limited participation seemed to have less impact on their lives than in the older relatives. Middle-aged relatives and younger adults identified strategies in which visibility was the key to increasing the odds of gaining participation. The exceptional experiences seemed to be some older carers' experiences of influencing decisions with the help of professionals.</p> <p>Conclusions: Our findings suggest that experiences of influence were limited regardless of age. However, the results indicated that participation among relatives decrease with age while vulnerability for not having influence seemed to increase with age. The problem of patient choice most clearly manifested among the older carers, which might indicate that the relatives' age sets terms for opportunities to participate.</p> <p>Keywords Adult, Aged, Aged, 80 and over, Middle Age, Decision Making, Family, Hospitals, Older People, Patient Participation, Qualitative Research</p>	
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Title Page

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Title: Few opportunities to influence decisions regarding the care and treatment of an older hospitalized family member: A qualitative study among family members

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Abstract

Background: The drive towards patient involvement in health services has been increasingly promoted. The World Health Organisation emphasizes the family's perspective in comprehensive care. Internationally there is an increased emphasis on what patients and their family tell about the hospital experiences. However, current literature does not adequately address the question of participation experiences among relatives of older hospitalized family members. There is a paucity of research with a generational perspective on relatives' opportunities to exert influence.

Objective: The aim of the study was to explore relatives' experiences of opportunities to participate in decisions about the care and treatment of older hospitalized family members and whether there are different experiences of influence to the relatives' age.

Design: This was an explorative study applying individual qualitative interviews. The interviews were analysed following hermeneutic methodological principles.

Settings: Two Norwegian geriatric wards participated: one at a university hospital and one at a local hospital.

Participants: Twelve participants, six women and six men, were purposively selected. The relatives were aged from 36 to 88 (mean age 62) and were spouses, children and/or children-in-law of patients.

Results: The relatives' experienced opportunities to exert influence were distributed along a continuum ranging from **older relatives** being reactive waiting for an initiative from health professionals, to **younger adults** being proactive securing influence. Older "invisible" carers appeared to go unnoticed by the health professionals, **establishing few opportunities to influence decisions**. The middle-aged relatives **also** experienced **limited influence, but**

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participated when the hospital needed it. However, limited participation seemed to have less impact on their lives than in the older relatives. Middle-aged relatives and younger adults identified strategies in which visibility was the key to increasing the odds of gaining participation. The exceptional experiences seemed to be some older carers' experiences of influencing decisions with the help of professionals.

Conclusions: Our findings suggest that experiences of influence were limited regardless of age. However, the results indicated that participation among relatives decrease with age while vulnerability for not having influence seemed to increase with age. The *problem* of patient choice most clearly manifested among the older carers, which might indicate that the relatives' age sets terms for opportunities to participate.

Keywords

Adult, Aged, Aged, 80 and over, Middle Age, Decision Making, Family, Hospitals, Older People, Patient Participation, Qualitative Research

38 **Background**

39 Patients are entitled to participate in decisions regarding their care and treatment, and have the
40 right to receive the information necessary to obtain insight into their health condition and the
41 content of the health care provided. The family may gain influence and participation in the
42 process of care and treatment if the patient gives his or her consent [1, 2].

43

44 This study concerns relatives' experiences of opportunities to participate in decisions about
45 the care and treatment of older hospitalized family member and whether there are different
46 experiences of influence related to the relatives' age.

47

48 In this study, we understand participation to mean “the involvement in the decision-making
49 process in matters pertaining to health” [3(MeSH-term), 4], and decision making as “the
50 process of making a selective intellectual judgment when presented with several complex
51 alternatives consisting of several variables, and usually defining a course of action or an idea”
52 [3, 5, 6]. Furthermore, we understand influence on decision making to be a phenomenon that
53 varies in extent and context in line with Thompson (2007). Thompson (2007) **described**
54 different levels of patient involvement and participation ranging from non-involvement,
55 seeking and receiving information, information-giving, possibly dialogue, shared decision
56 making and autonomous decision-making [7]. Each level depicts the “patients' relative power
57 to influence decisions” [7, p. 1302]. Achieving a particular level in one situation does not
58 automatically predict a move to the next level. The level of participation is, at any given time
59 and whatever the personal preferences, depending on health professionals, settings or illness
60 [7]. In this study, the terms influence refers to the capacity or power of relatives, by direct or

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2 61 indirect means, to impact on the decisions-making processes about care and treatment of their
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5 62 older hospitalized relative [7].
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10 64 There is a paucity of research examining family experiences in hospital, and research
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12 65 indicates that relatives' influence on health services generally is limited [8-12]. A recent study
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14 66 found that whether the relatives were next-of-kin to a spouse, a child, an adult child, a parent
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16 67 or a sibling, and whether the diagnosis was somatic or psychiatric, the experiences with health
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18 68 services seemed to be similar. They reported a lack of information, inclusion and
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20 69 collaboration in the care of their ill family member [8].
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22 70
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24 71 With respect to the relatives of older hospitalized family members, studies examining family
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26 72 experiences in hospital have mostly treated the relatives as a homogenous group [9, 10, 13-
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28 73 15]. A qualitative study on expectations, communication and care decisions among families
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30 74 and caregivers of older people, **uncovered** differences between older and adult relatives [16].
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32 75 Some of the older relatives had health or cognitive problems impacting on their ability to
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34 76 provide care for another. The adult **relatives** had concerns about their other responsibilities,
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36 77 such as family and work. Regardless of age, **being a relative of a patient in a geriatric hospital**
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38 78 **ward was stressful**. The major themes emerging from the interviews centred on the family
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40 79 caregivers' need for consistent reliable communication and involvement in care decisions
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42 80 [16].
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51 82 **Regarding exchange of information, responsibility for the patient's wellbeing in hospital and**
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53 83 **for the patient's compliance with the daily regimen, Norlyk (2012) suggested that relatives**
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55 84 **were the 'extended arms' of health professionals [17]. According to other studies on user**
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57 85 **participation among older patients, the relatives were, by patients, perceived to be 'the**
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1 86 extended arms' of themselves; they delegated decision-making to relatives [18, 19]. Some
2 87 present research emphasizes the relatives' contribution to the support and enhancement of the
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4 88 level of patient participation [20, 21]. A review of the evidence on hospital discharge planning
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7 89 for frail older people and their family, indicated that family participation could improve the
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10 90 discharge process [22]. The study on informal caregivers' participation when older adults in
11
12 91 Norway are discharged from the hospital, found that the younger relatives (mean age 55)
13
14 92 experienced a higher degree of involvement in receiving and providing information to
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16
17 93 hospital staff than did the older (mean age 80) [23]. At hospital, the younger, but significantly
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19 94 less the older, relatives reported receiving sufficient information about the patient's medical
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21 95 conditions, and the younger experienced to a higher degree than the older, that the patient was
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24 96 sufficiently informed. The study suggested that older patients assisted by older relatives,
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26 97 might be exposed to higher risk of inadequate participation needed for an appropriate
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29 98 discharge to home [23]. Furthermore, the study found that the younger generations of carers
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31 99 seemed to have better chances for exerting influence on decisions related to the care and
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34 100 treatment of their older relative, and that for the younger relatives it was imperative to gain
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36 101 influence on decisions in matters that affected their own life [23].
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42 103 This study is a part of a larger research project focusing on user participation among older
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44 104 hospitalized patients and their relatives. The first study found that older patients addressed
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47 105 their difficulties of participating by authorizing family members to act and participate on their
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49 106 behalf [18]. The second study compared and contrasted older patients' and their relatives'
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52 107 experiences of participation in decision-making processes regarding the planning of everyday
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54 108 life after discharge from hospital [24]. Participation in making decisions appeared to be
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57 109 random and limited for both patients and their relatives, and conflicting for the families as a
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59 110 whole. The decision-making processes seemed to be limited to the hospital context; **decisions**
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111 appeared to be settled without considering the patient's broader life context in which family
112 played a role. The relatives told they provided assistance to the patients on a daily basis, but
113 were side-lined even if the decisions made at the hospital affected their everyday life [24].
114 These results are consistent with previous research [5, 23, 25-27]. The results from study two
115 seemed to suggest a pattern of age-related differences; the relatives' influence and
116 participation seemed to decrease with age while vulnerability for not having influence seemed
117 to increase with age. Limited participation in decisions seemed to affect older carers' lives
118 more than the middle-aged relatives. However, this was not explored systematically in that
119 study. Consequently, the next step in the project was to analyse this issue in-depth. That is the
120 topic of this paper.

121 Aim

122 The aim of the study was to explore relatives' experiences of opportunities to participate in
123 decisions about the care and treatment of older hospitalized family members and analyse
124 whether there are different experiences of influence related to the relatives' age.

125 Methods

126 Design

127 The study had an explorative design and was informed by Brinkmann and Kvale (2015) and
128 the phenomenological hermeneutical method for researching lived experience developed by
129 Lindseth and Norberg (2004) [28, 29]. According to the latter, the most basic way to gain
130 access of human experiences is to listen to others' stories about the way they act in various
131 situations. Experience is implicit in a situation and in the story about the situation. Humans
132 organize experiences so that they answer questions like: 'what', 'why', 'who', 'how', 'with

133 whom', 'to whom' and 'for whom' [28]. The study complied with the Consolidated Criteria
134 for Reporting Qualitative Research (COREQ) [30].

135

136 **Setting and participants**

137 The empirical part of this study was conducted in 2013 in two Norwegian geriatric wards, one
138 at a university hospital and one at a local hospital. The wards offered a treatment and
139 rehabilitation program including patients aged 65 and over, with multi-morbid conditions and
140 complex health problems. In this study, the typical reason for hospitalization was acute
141 functional decline, fall or inadequate intake of fluid and food.

142

143 The inclusion criterion in the study included being a Norwegian speaking relative of a patient
144 admitted to one of the two geriatric wards. We applied a purposive recruitment strategy to
145 achieve maximum variation of the sample. The head nurses gave geriatric nurses the authority
146 to recruit relatives by a face-to-face approach when the relatives visited the wards, or by
147 telephoning relatives the nurses had met in the wards. The nurses were asked to recruit
148 relatives with different relationships to the patient, gender and age, as we assumed that these
149 characteristics might impact on the opportunities to participate in decision-making. As most
150 patients in the wards were 70 years and above, available spouses and children were of a
151 certain age. The classification of age complies with the MeSH (Medical Subject Headings)
152 terms [3] (see Table 1). In this study, the term *older* refers to the participants aged 65 and
153 over, *middle-aged* to participants between 45 and 74 and *younger adults* for participants less
154 than 45 years.

155

156 Approximately 25 potential study participants were assessed and invited to join in the study.

157 Nine relatives declined the invitation due to time pressure or of reasons we do not know;

158 sixteen relatives were enrolled in the study. The geriatric nurses provided written and oral

159 information to potential participants, who were given time to consider participation in the

160 study. Written consent was obtained and assurances of confidentiality and anonymity were

161 given. One relative declined to participate. One relative dropped out because of stress and

162 time pressure, one relative never had time for an interview appointment, and one relative

163 dropped out because the patient became sicker. Accordingly, twelve relatives participated in

164 this study. There was no relationship between the interviewers and the potential participants

165 prior to study commencement.

166

167 Four participants lived in urban communities and eight lived in rural communities. Six

168 relatives were retired from work. Six relatives were employed (see Table1). Among the

169 participants were men and women with professions related to health services and who had

170 insights into specialised rehabilitation services and deep knowledge of hospitals. They were

171 also well informed about user and patient rights. Other participants had technical practical or

172 administrative occupations.

173

174 [TABLE 1 TO GO NEAR HERE]

175

176 Table 1 show that five participants were older, six participants were middle-aged, and one

177 was a younger adult. The participants consisted of six women and six men.

178 **Data collection**

1
2 179 **Individual interviews were used to collect data.** The purpose was to obtain in-depth
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4 180 information about relatives' experiences of participation, and was conducted by the first
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6
7 181 author in 2013. **The first author, who is female, was a fulltime PhD candidate at the time of**
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9 182 **the study. She had leave of absence from work as an occupational therapist in a geriatric**
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11 183 **ward. This background might have impacted on the data collection by influencing what**
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14 184 **caught her attention in the interview situations (e.g. regarding how life circumstances might**
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16 185 **have an impact on the individual's possibilities of gaining user participation and how health**
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19 186 **services adapted user participation).**

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24 188 An interview guide **aimed to uncover experiences of user participation** was developed **based**
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27 189 **on key documents [31-33].** The interview guide is summarized in Table 2.

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31 191 Duration of the interviews ranged from 19 to 81 minutes with an average of 35 minutes. **An**
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34 192 audio recorder was used. The interviews were conducted at the preferred location of the
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37 193 relatives: four at the hospital, three at home, two at the relatives' workplace, and one at a
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39 194 near-home location. Ten relatives were interviewed while their family member stayed at
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41 195 hospital, or within a few days after the patient's discharge from hospital. Two relatives were
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44 196 interviewed respectively 11 days and nearly three months **s** after the patients stay at hospital.
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46 197 **The reason for this was time pressure on the part of the relatives.**

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51 199 The number of relatives to be interviewed was not predetermined. **The recruitment process**
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54 200 **ended when experiences of participation kept recurring in the interviews.**

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202 The interview guide was not pilot tested. The first author was trained by the supervisors, and a
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2 203 nurse trained in the craft of research interviewing was present and participating in some of the
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4 204 early interviews. After the interviews, the trained interviewer gave feedback on interview
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7 205 performance and critically discussed possible interpretations of the relatives' accounts. The
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9 206 subsequent interviews were more conversation like with the interview guide used as a check
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12 207 list to ensure addressing all relevant topics. Discussions between the supervisors and the first
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14 208 author were described and reflected on in memos [30], which were written immediately after
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16 209 each interview, and were later subjected to critical reflections by the research group. The
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19 210 memos provided additional information about the interview situation, interaction, emotional
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22 211 expressions and the relatives' accounts. All interviewers were women.
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26 213 The interviews were transcribed verbatim by the first author, including nonverbal audible
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29 214 signals such as laughter, sighs and pauses helping the researchers to comprehend the
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31 215 interviews within their particular context [30]. Researcher triangulation of data enhanced the
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34 216 credibility of the interpretation. The supervisors had different professional backgrounds and
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36 217 research experiences, which ensured a diversity of perspectives. Over time the authors
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39 218 critically discussed and reflected on the interpretations and broader perspectives and possible
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41 219 meanings were uncovered. Summarizing, to enhance the trustworthiness we have attended to
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43 220 the integrity of data, the balance between reflexivity and subjectivity (as bias enters as soon as
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46 221 a research question is asked in a particular way), and we have sought to provide a transparent
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49 222 account of all aspects of the research process [30, 34].
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54 224 [Table 2 TO GO NEAR HERE]
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226 **Data analysis**

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2 227 This study applied a phenomenological-hermeneutic analytic approach [28, 29]. The main
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4 228 tool to manage the interview texts was Microsoft word. The initial reading of the transcribed
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7 229 data aimed to gain a preliminary understanding of the phenomenon (experiences of influence
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9 230 and participation) and its context [29]. The next reading was to create an initial structure of
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11 231 meaning units, themes and subthemes in order to clarify the significant meanings in the texts.
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14 232 First, the text was divided into meaning units, i.e. shorter or longer parts of the text related to
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16 233 the research question. These were condensed into brief everyday words capturing the essential
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19 234 meanings. Condensed meaning units that were similar were then abstracted to form sub-
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21 235 themes, which were next assembled and abstracted into themes [28]. Table 3 show an
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24 236 illustration of the analytic process from interview text to themes via meaning units, subthemes
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26 237 and themes.

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32 239 [TABLE 3 TO GO NEAR HERE]

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38 241 We understand hermeneutic analysis to be an active and reflexive approach to theme
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40 242 development. Each interview text was given equal attention in the analytic process; the
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42 243 interpretations were validated by re-reading the whole text several times in light of the
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45 244 meaning units, subthemes and themes and the other way around.

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50 246 At some point an age-specific dimension emerged; participants seemed to describe different
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52 247 experiences depending on age. We searched for other patterns as well, e.g. the kind of family
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54 248 relation between relative and patient, gender, relatives being health professionals, being able
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57 249 to take leave of absence from work, and/or having the opportunity to be present in the hospital
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59 250 where user participation materialised. From our analysis, we concluded that all these aspects

251 seemed important for the experiences of participation in decision-making processes.

252 However, they played out differently depending on the age of the relatives, which we have

253 tried to capture in the findings.

254

255 **Two patterns** stood out in the texts because of the extremely different experiences of

256 participation in decisions about the care and treatment of the hospitalized family member.

257 Whereas the experiences recounted by **older relatives** reflected an invisible and **reactive**

258 attitude to participation, **the younger adult's** experiences reflected a visible and proactive

259 attitude to participation. **By a hermeneutic turn in the analysis, these two extremely different**

260 **patterns became pivots to the continued analysis, and the whole text was re-read in light of**

261 **these identified patterns.** This resulted in a continuum of opportunities for relatives to exert

262 influence on care and treatment of older family members (Figure 1).

263

264 **Ethical considerations**

265 The study was approved by **the Regional Committee for Medical and Health Research Ethics**

266 **South East Ref. 2012/1598.** To protect participants' anonymity, two hospitals were included

267 in the study. It was emphasized that participation in the study was voluntary and that consent

268 could be withdrawn at any time and without any kind of repercussion.

269

269 **Results**

270 **All relatives appeared to experience the opportunity to influence decisions about the care and**

271 **treatment of an older family member to be dependent on permission from the patient and/or**

272 **the health professionals. Being a relative with a health professional background appeared to**

273 **make no difference concerning the relative power to influence decisions. Apart from the**

274 **younger adult, who was a man, the age groups were equally distributed in terms of gender.**

275 The variety of family relationships between the relative and the patient were equally
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2 276 distributed among the older and the middle-aged groups (see figure 1). Thus, we interpreted
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4 277 the different experiences of opportunities to participate in decisions about the care and
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7 278 treatment of the patient to be strongly related to the age of the relatives.
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13 280 The relatives' experiences of influencing decisions appeared to form a continuum ranging
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15 281 from having scarcely any such experience to report, to experiences of taking control. Their
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18 282 opportunities to exert influence ranged from being "invisible and reactive" (i.e. waiting for an
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20 283 initiative from the health professionals) to being "visible and proactive" (i.e. securing
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22 284 influence). The sliding yet overlapping transitions between the different experiences of
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25 285 influence may be illustrated as in Figure 1.
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31 287 [FIGURE 1 TO GO NEAR HERE]
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37 289 Figure 1 show the continuum of experienced opportunities to participate in decisions about
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39 290 the care and treatment of older family members, and puts this continuum into the contexts of
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42 291 relationship, gender and age.
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48 293 Relatives communicated how time consuming it was to be relatives. Some of the relatives
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50 294 who were employed pointed out the necessity of being able to take leave of absence from
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52 295 work, or taking holiday time at the time their parent was admitted to and discharged from
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55 296 hospital. On a daily basis, the older carers played a large part in the care of the older family
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57 297 member, but experienced limited opportunities to influence decisions *affecting* their daily life.
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60 298 Whether the older carers were present at the hospital or not, they appeared to be "invisible"
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299 and go unnoticed by the health professionals. This indicates that taking initiative seemed to be
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2 300 a prerequisite even to get possibilities to partake. According to a middle-aged relative and the
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4 301 younger adult, visibility and presence were key strategies to increase the odds of gaining
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7 302 participation. The younger adult experienced participation by taking control himself. Those of
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9 303 the older relatives who did experience some influence seemed to be exceptional in the sense
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11 304 that a particular professional they encountered discovered and verbalised their needs and took
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14 305 action accordingly. In the following sections, the findings are described in further detail.
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18 306 **Neither seen nor heard**

20 307 The experiences recounted by the two oldest women referred to their own invisibility as well
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22
23 308 as that of the health professionals. The women led their “hidden” lives behind the four walls
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25 309 of their own home adapting to their spouses’ needs. The wives said they had limited access to
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27
28 310 transportation, and that they rarely contacted the healthcare services. When the health
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30 311 providers contacted the wives, this was generally by telephone to give information (about
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32 312 decisions made by the professionals), or ask for information related to the health of the
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35 313 patient. It therefore seemed they were dealing with faceless and nameless professionals who
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37 314 they referred to as “they” and “them”. The wives appeared unclear whether the callers had the
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39
40 315 authority to make decisions, and if so, what about. Once, one of the wives made a phone call
41
42 316 herself but her voice was not heard:

45 317 *“When my husband last returned home from the hospital, I rang the community nurses*
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47
48 318 *and asked if I could get some help. Well, that would mean we would have to employ*
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50 319 *more people, she said! But could you please come and put on the pain plaster? So they*
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52 320 *came around twice, and then they asked me if I could do it. That was all. I have never*
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54
55 321 *asked for anything else after that. Perhaps they ought to think about the person who*
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57 322 *isn’t sick as well as the person who is” (An older relative).*
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The wives asked the interviewer to help them exert influence over the healthcare services (to extend a stay in a nursing home). **They asked how ill their spouses would have to be to warrant a place in a nursing home:**

“How sick would you have to be to get into a nursing home? How far can you push yourself?! I don’t think I can take much more!”

In contrast to the older wives, **an older husband** told that he was present at the hospital almost every day. Nevertheless, he did not **feel** to be seen and heard; neither the health professionals nor his wife gave him opportunities of any kind, to participate in making decisions:

“Yes, the discharge came as a surprise. Nobody told me anything. My wife was far from healthy. I was worried. But our son is ever so kind, and moved out of his bedroom. If they had been extremely busy at the hospital, I wouldn’t have mentioned it, but there were lots of empty beds”.

Unwilling acceptance

Two of the older relatives, who were over 70 years of age at the time of the interview, and the younger adult, explicitly discussed the challenges related to patient choice. They described experiences of the patient appearing to failing not recognize the carers’ and the families’ situation when making decisions. For the older relatives, providing care involved maintaining three households: their own home, the childhood home and the mother’s flat. The relatives explained that they had little control of their own situation and no influence on the patient’s decisions. They talked about a 60-year career as carers and described how they had fought for the patient to receive appropriate care, but the system had always supported her mother,

347 whose preference was generally to refuse such care. The patient had been hospitalized two
348 years earlier and the situation had now become equally precarious. The relatives said they had
349 contacted a number of service providers, and the general practitioner, to ask if someone could
350 find an emergency nursing home bed, which reputedly was impossible. The following day a
351 temporary employee from the community nursing service managed to get her mother admitted
352 to hospital:

*“Is there no-one who can override THE PATIENT? The doctor attended to my mother
on the Thursday, and she was so poorly! Then I talk to the doctor on the following
Friday and she says ‘we cannot hospitalise a patient when she herself says no’. Says
the doctor. And then a TEMPORARY employee from the community nursing service
gets hold of an ambulance and sends my mother to hospital. I thought that was
brilliantly well done.” (An older relative)*

Exceptional experiences; being “saved” by a professional

360 Despite a general experience among the older relatives of not being seen or heard, two of the
361 relatives recounted exceptional experiences of be “saved” by professionals who saw their
362 struggles, verbalised their needs and took action accordingly. The older relatives themselves
363 related their lack of ability to take care of their own needs to their old age. They told that they
364 had difficulties asking for help and was grateful to nurses who saw their needs and acted on
365 them. According to older relatives, self-sacrifice is a particular characteristic of their
366 generation; they felt that things were different for younger people. An older relative felt
367 unable to verbalise her own needs vis-à-vis the health professionals, and was even less
368 capable of influence decisions in a way that might improve her own life, but would go against
369 her husband’s wishes:

370 *“It feels bad to talk about my husband in this way, but ... I had better use the words of*
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2 371 *the nurse in the hospital. She said that if you agree with me, she said, I would*
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4 372 *recommend that you apply for a long-term place for your husband straight away. For*
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7 373 *there is no sense in you wearing yourself out. Said the nurse. Talking like that about*
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9 374 *your husband, feels a bit, you know, you sort of feel that you need to try your very best,*
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11 375 *for as long as possible. But of course, once it starts wearing you down, it just gets too*
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14 376 *much.” (An older relative)*

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17 377 To look after the most elderly members of the family was, according to **older relatives**, an
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19 378 obligation for people of their generation, even if this was at the expense of their own lives.
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21 379 **Some** compared being responsible for **the patient** to having a child at nursery school, and said
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24 380 they had handed over a whole book to the hospital about the **patient’s** condition. **These**
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26 381 **relatives told that a** nurse had confirmed that **their** situation was intolerable and had virtually
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28 382 demanded that the primary healthcare service find a nursing home place. The **older relative**
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31 383 expressed: “The nurse took responsibility. She addressed the problem. **I was deeply pleased.**”
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35 384 **Feeling cheated: participation only when the hospital needs it**

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37 385 **Generally, the middle-aged relatives** felt that no significant **influence** had been obtained. **In**
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40 386 **an attempt to influence the care of the older hospitalized relative, they collaborated with**
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42 387 **several family members, who gathered information when visiting the patient. The following**
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45 388 statement was representative of the middle-aged relatives and their toleration of their own
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47 389 limited participation in relevant decisions:

50 390 *“It all depends a lot on your health, yes, it all depends on your current situation. Had*
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52 391 *I had a lot to cope with personally, poor health and that sort of thing, it may well have*
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55 392 *been more difficult for me to take on this role. As it was, I didn’t even reflect on it. I*
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57 393 *feel I have the competence required of a next-of-kin, and I don’t consider it a burden.*
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394 *But how it will feel in 30 years, I don't know, really. It is difficult to tell.*" (A middle-
1
2 395 aged relative)

396 All middle-aged relatives told they had assisted the hospital by providing information about
397 the patient. However, they were frustrated by the absence of follow-up dialogues. Regarding
398 other responsibilities such as family and work, the middle-aged relatives called for
399 opportunities to influence decisions about practical tasks. A relative told that the providing of
400 information had cost her a great deal; she did not want "to tell on dad". However, on the
401 hospital's request, she had given information about the patient's health and level of
402 functioning at home. In return for providing information she wanted dialogue with the
403 professionals, but no dialogue was initiated. On the contrary, referring to the patient being
404 angry and stressed on the ward, a nurse called and asked the relatives to arrange for a short
405 leave from the hospital:

406 *"With regard to the leave, the hospital collaborated with us, on their initiative. But
407 when telling them everything about dad's behaviour at home, I felt somewhat cheated
408 when I received nothing in return."* (A middle-aged relative)

410 **Strategies to increase the odds of gaining participation**

411 To get in position for participation, a middle-aged relative and the younger adult recounted
412 employing different strategies. In order to boost user participation, they strategically develop
413 interpersonal relationships with the professionals and earned goodwill and acceptance by
414 providing personal care for the patient. Furthermore, using clear communication, e.g.
415 presenting an unambiguous message to the professionals, and preparing themselves by
416 reading white papers, legislation and research posted on the internet were strategies

1
2 417 employed. This was something the older relatives did not experience to master: “*We don’t*
3 418 *have a computer, so we’re part of a generation that’s becoming extinct, I believe*”.

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8 420 The singularly most important strategy was to be visible and present in the hospital in order to
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10 421 receive and provide information: knocking on the door of the ward office, requesting
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12 422 conversations with the nurse in charge and taking part when doctors were doing their rounds.

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16 423 *“It’s all-important [to be present at the hospital] to catch what is going on. You never*
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18 424 *receive any information, there is no telephone contact, but because I have been here a*
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21 425 *lot, you get to know what you need to know. But you have to ask. So I listen out all the*
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23 426 *time.” (A middle-aged relative)*

24 25 26 27 427 **Taking control**

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29 428 **The younger adult** experienced that **the patient**, at first, excluded him from participation in
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32 429 decisions about the care and treatment, but the health professionals carefully did listen to him.
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34 430 **The younger adult** reported that he exerted influence by taking control and organising
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37 431 meetings attended by the professionals, the patient and the **relative**, and felt that he in this
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39 432 way (“no tricks, just **common sense**”) helped **the patient** to make the right decisions.
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45 434 During the interview, **the younger adult**’s main concern was how to organise a conversation
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47 435 that would allow the patient to make good choices, and he **discussed the problem of patient**
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50 436 **choice**. The son felt that the prevailing logic of choice was counterproductive, not only
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52 437 restricting the relatives’ level of participation but also the patient’s level of involvement,
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55 438 **arguing as follows**: the **son brought his mother to the general practitioner who** did not give his
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57 439 mother healthcare assistance because his mother had not chosen this for herself. **This**,
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60 440 **according to the son, indicated that the** doctor considered it to be more important to give the
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2 442 patient choice than to involve the patient and relative in conversations about best interests of
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4 443 the patient. The younger adult was of the opinion that doctors associated making choices with
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6 444 participating in decisions as if they were the same phenomenon. By focusing on treatment
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8 445 choices, the patient's opportunity to exert influence on a singular decision increased, but the
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10 446 patient's participation in a process of making decisions involving several considerations,
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12 decreased:

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15 447 *“Even though you should never interrupt a senior consultant while talking, I had to*
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17 448 *tell her that she would be better off talking about my mother's medical condition. The*
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19 449 *doctor came up with a number of different treatment alternatives, and the many*
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21 450 *options confused my mother. The doctor started the wrong way around. At any rate, it*
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23 451 *did not make for a good situation.” (The younger adult)*
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27 452 The younger adult questioned whether the focus on individual choice in user participation
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29 453 ideology did in fact compromise the ethical principles of patient care. He argued that when a
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31 454 patient was as ambivalent as his mother, who was making choices that potentially would
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33 455 endanger her own life, rather than the good decisions, then this was a moral problem.
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35 456 According to the son's reasoning, giving his mother, in her present situation, a number of
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37 457 options, could result in his mother making decisions that was contrary to her own wishes. In
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39 458 his opinion, participation by patients and their relatives would need to take place in a forum in
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41 459 which patients, the relatives and health professionals openly discuss the best interests of the
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43 460 patient.
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52 461 Discussion

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55 462 The aim of this study was to explore relatives' experiences of opportunities to participate in
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57 463 decisions about the care and treatment of older hospitalized family members and analyse
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59 464 whether there are different experiences of influence related to the relatives' age. We found
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2 466 that most of the relatives experienced low levels of user participation regardless of age. This
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4 467 is in line with existing literature [5, 8-12, 23, 25-27, 35], but contrary to the relatives'
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6 preferences of participation. Nevertheless, age did seem to impact on the relatives'
7 468 opportunities to influence decisions. In the following we discuss these findings and their
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9 469 implications.

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15 471 The older relatives in this study adopted a reactive approach to participation. In the
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17 interviews, they expressed intentions and wishes to influence decisions, but in a responsive
18 472 and reserved way. The reactive attitude exposed by older relatives might challenge the current
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20 473 participation ideology which is based on individualism and requires proactive partners in
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22 474 health care [4, 36]. The older generation's commonly held values of solidarity and community
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24 475 might conflict with such ideas [36]. The first study in the larger research project of which this
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26 476 paper is a part, highlighted the ambiguous participation on the part of older hospitalized
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28 477 patients. They seemed to gain influence through active and passive approaches [18] in line
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30 478 with previous research [36]. When older patients experienced difficulties in participating in
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32 479 decisions regarding treatment and care, they delegated decision making to the relatives and
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34 480 the professionals [18]. This kind of active and passive approaches to gain influence might be
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36 481 common features of older people, both relatives and patients.
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48 484 In our results, patient choice emerged as a possible *problem*. Some relatives experienced that
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50 485 choices made by patients (and professionals) seemed to disregard the family's needs and life
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52 486 circumstances, and imply care resources the relatives did not possess. Although the current
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54 487 participation ideology based on liberalism emphasises individuals' free choice [36-38], the
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56 488 results might indicate that the individual patient, and not the individual relative, had
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58 489 opportunities to make choices for themselves. Cash et al. (2013) claimed that the ideal of
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490 individual choice remains largely absent from policies directed at informal caregivers, and
491 that research has been limited in developing an understanding of the underlying choices, or
492 lack thereof, in providing informal care [38]. The emergence of liberalism within welfare
493 policy has, according to Cash et al. (2013), created an inequity for older carers, who are not
494 offered the same degree of choice as other older people, e.g. older patients. Due to factors
495 such as age and relationship to the care receiver, the problem of patient choice is particularly
496 the case with spousal care [38], which our study might underpin.

497
498 The younger adult questioned whether the focus on choice in user participation ideology did
499 in fact compromise the ethical principles of patient care. Mol (2008) differentiated between
500 the logic of care and the problem of patient choice with the same arguments [37]. The logic of
501 care does not construct patients as passive: “they do not primarily figure as subjects of choice,
502 but as the subjects of all kinds of activities” [37, p. 8]. This logic recognizes that patients can’t
503 be separated from family, friends and other support systems [37]. Our results indicate that
504 choices made at hospital had unintended consequences, and that the problem of patient choice
505 most clearly affected the older relatives who did not manage the care responsibility assigned
506 to them.

507
508 On the subject of making choices in matters of their own concerns, the middle-aged relatives
509 called for opportunities to influence decisions about practical tasks in order to coordinate care
510 with other family responsibilities. Relatives have no autonomous right to participate in
511 decisions about care and treatment of adult family members unless on behalf of the patient
512 [39]. However, an approach to participation by relatives of older patients, that is not merely
513 an extension of patient participation, has been suggested by an integrative literature review on
514 carer engagement in the hospital care [14]. The review argued for establishing an integrated

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2 516 model of carer engagement whereto the relatives can participate, e.g. through **information**
3 **sharing, shared decision-making, carer support and education**, and communication with the
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5 517 health professionals [14]. **In line with a study focusing on** relatives as competent collaborative
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7 518 partners [11], relatives in our study **might be interpreted as such**. However, the middle-aged
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9 519 relatives seemed to cope with experiences of low participation better than the older people,
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11 520 possibly because they could handle the consequences for themselves due to better health and
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13 521 help from **other** family members.
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20 523 **We uncovered a few exceptional experiences of user participation, in which participation was**
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22 524 **facilitated by an attentive professional who discovered the relative's need for assistance.**

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25 525 **Previous studies have reported that that the nurses' attitudes and how they approach the**
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27 526 **family are the strongest predictors for collaboration to happen [35, 40]. Valuing relatives has**
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29 527 **been shown to open up possibilities to influence decisions [35, 40]. Furthermore, "active**
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31 528 **listeners" among the staff promote family participation in the care of older patients in**
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33 529 **institutional settings [41]. This was evident in this study as well, which underscores the**
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35 530 **importance of professionals facilitating user participation among relatives.**
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43 532 **A recent study proposed that older patients in the emergency department should be treated as**
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45 533 **a specialty population in the sense that this group is a vulnerable population and should be**
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47 534 **placed in age-friendly environments and being met by specialised staff members [9]. Our**
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49 535 **study proposes that relatives of frail older patients in general, but particularly older vulnerable**
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51 536 **relatives should be treated as a "specialty population" in the hospital. By this we mean that**
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53 537 **they need special attention and involvement in decisions regarding the treatment and care of**
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55 538 **their hospitalised relative. Health professionals should be particularly aware of older relatives**
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57 539 **who need help to express their own needs for support [23].**
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3 541 A current review of available knowledge on engagement in healthcare decision making with a
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5 542 focus on older patients and their caregivers, promote the idea of patients and carers as equal
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7 543 partners, and supported the need of a discussion between them about needs and expectations
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10 544 [42]. Family meetings arranged by the hospital, have over time been found to be a robust
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12 545 format in that respect [20, 43]. Relatives have reported as most satisfying the information
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15 546 conveyed in family meetings and the subsequent discussions with the professionals [43]. Our
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17 547 study supports such forums of conversation between professionals, patient and family.
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24 549 **Limitations**

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26 550 Data saturation has been discussed as a nebulous concept, but a presumptive ideal for which
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29 551 to strive [34].The study was exploratory and the sample size limited. However, it included
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31 552 participants of a wide range of ages and with different relations to the patient, allowing us to
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34 553 explore the data from a generational perspective. We cannot claim to have achieved
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36 554 maximum variation within this limited sample. Considering that most patients in the wards
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39 555 were 70 years and over, the potential participants within the group of younger adults was
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41 556 limited. The younger adult group in this study consisted of only one participant, which is a
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43 557 limitation. Furthermore, the middle-aged relatives stood out by having many siblings and
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46 558 other family members to help, which is not always the case. The older caregivers included in
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48 559 the study did not manage the care responsibility assigned to them, which is not always the
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51 560 case. It would also have been preferable with more participants from both genders.
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57 562 The hospitals' services from which we recruited participants, experienced time constraints
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59 563 and tight fiscal management at the time of data collection (2013). This might have impacted
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564 on the nurses who recruited participants, and might have raised the possibility of selection
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2 565 bias. However, our analysis indicates that the relatives who agreed to participate provided
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4 566 balanced accounts of their experiences, comprising both negative and positive elements.
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568 **Conclusions**

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16 569 **Our findings suggest that experiences of influence were limited regardless of age. However,**
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18 570 **the results indicate that user participation among relatives decrease with age, while**
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21 571 **vulnerability due to not having influence seems to increase with age. The *problem* of patient**
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23 572 **choice most clearly manifested themselves among the older carers. This might indicate that**
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26 573 **the relatives' age sets terms for opportunities to participate.**
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30 574 **Declarations**

31 32 33 34 35 575 **Ethics approval and consent to participate**

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37 576 The study was approved by the Regional Committee for Medical and Health Research Ethics
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39
40 577 South East Ref. 2012/1598. The two geriatric wards that accepted to enroll in the present
41
42 578 study received a detailed description of the study. Potential participants were identified by
43
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45 579 nurses who had been given this authority from the wards head nurses. All volunteer
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47 580 participants signed a written informed consent. All participants might terminate their
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50 581 collaboration with the study at any time, and they were informed that such decision did not
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52 582 have any consequence.
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55 583 **Consent for publication**

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58 584 Not applicable
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585 **Availability of data and materials**

1
2 586 The datasets analysed during the current study are available from the corresponding author on
3
4 587 reasonable request.
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8 588 **Competing interests**

9
10 589 The authors declare that they have no competing interests
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12
13

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17
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21 592 **Authors' contributions**

22
23 593 IN, LJD, MK contributed to the conception and the design the study. IN collected the data,
24
25 594 transcribed the interviews and drafted the manuscript. IN, LJD, MK contributed to the
26
27 595 interpretation of the results and critical revised the manuscript. All authors read and approved
28
29 596 the final manuscript.
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37
38 599 to participate in this study. We are grateful to the relatives who participated and shared their
39
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41
42 601 the data collection.
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48 602 **Authors' information**

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50 603 Not applicable.
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26 727 **Figure legends**

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 41 732 care and treatment of older family member

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Table 1 Participants

Relatives			Patient
Relation to patient	Age of relatives	Work status	Age of patient
Wife	Older	Retired	Older
Husband	Older	Retired	Older
Wife	Older	Retired	Older
Daughter	Older	Retired	Older
Son-in-law	Older	Retired	
Daughter	Middle Age	Retired	Older
Son	Middle Age	Employed	Older
Daughter	Middle Age	Employed	Older
Son	Middle Age	Employed	Older
Daughter-in-law	Middle Age	Employed	
Son	Middle Age	Employed	Older
Son	Younger Adult	Employed	Middle Age

Table 2 Interview guide

Themes	
Being the relative of an older hospitalized family member	How are you related to the patient? Can you tell me how the patient was hospitalized and what happens when you are present? What is your situation? In your opinion, what is it important that you tell the staff and the nurses about yourself and your situation?
Participation and influence	Can you share some of your thoughts about how you have been welcomed as a relative? Are you being asked about your own experiences and wishes when it comes to the specific situation of your ill relative and its impact on your situation? What do you consider important to you and your situation? Can you tell me about your needs/wishes?

Table 3 Illustration of the analytic process

Meaning units	Condensed text	Sub-themes	Themes
<p>I was visiting my spouse every day, but did not attend the ward round. The nurses and the others were so nice, but I think that some information [from me about my husband/wife] would have been for the better; they didn't ask me about anything. (Older relative)</p> <p>If I receive all the help I am offered at home, I might as well move out myself. The last time the ambulance was here, I asked them how sick you would have to be to get into a nursing home. Someone needs to do something, try to apply for a place! (Older relative)</p>	<p>Wanting to influence decisions but being reactive in that respect.</p> <p>Taking little or no initiative to exert influence.</p>	<p>Waiting for professionals to initiate contact</p>	<p>Neither seen nor heard</p>
<p>I have phoned to all kinds of healthcare services. For thirteen years! No one has called me. Mom wants to live at home, something she has told everyone in the systems, you know. So, therefore, it has been easier for them to send her back home, of course. From where it could be, the hospital or others services. (Older relative)</p>	<p>Making a huge effort into getting adequate help from healthcare services to the patient</p>	<p>Fighting to be heard</p>	<p>Unwilling acceptance</p>

Figure 1 From invisible and reactive to visible and proactive: a continuum of influence on the care and treatment of older family members

Themes	<p>Neither seen, nor heard</p> <p>Unwilling acceptance</p> <p>Exceptional case; Being “saved” by a professional</p> <p>Feeling cheated: participation when hospital needs it</p> <p>Strategies to increase the odds of gaining participation</p> <p>Taking control</p>		
Relation to patient	Two Wives, One Husband, one Daughter and one Son-in-law	Three sons and one daughter-in-law, two daughters	Son
Gender	Three women, two men	Three women, three men	One man
Age of relatives	Older	Middle-aged	Younger Adult