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# **“They do what they think is the best for me.” Frail elderly patients’ preferences for participation in their care during hospitalization**

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Abbreviated title: Frail elderly patients’ preferences for participation

## ***Abstract***

**Objective:** To deepen the knowledge of frail elderly patients' preferences for participation in medical decision making during hospitalization.

**Methods:** Qualitative study using content analysis of semi-structured interviews.

**Results:** Patient participation to frail elderly means *information*, not the wish to take part in decisions about their medical treatments. They view the hospital care system as an institution of power with which they can't argue. Participation is complicated by barriers such as the numerous persons involved in their care who don't know them and their preferences, differing treatment strategies among doctors, fast patient turnover in hospitals, stressed personnel and linguistic problems due to doctors not always speaking the patient's own language.

**Conclusion:** The results of the study show that, to frail elderly patients, participation in medical decision making is primarily a question of good communication and information, not participation in decisions about medical treatments.

**Practice Implications:** More time should be given to thorough information and as few people as possible should be involved in the care of frail elderly. Linguistic problems should be identified to make it possible to take the necessary precautions to prevent negative impact on patient participation.

**Key words:** Patient participation, frail elderly, hospitalization, semi-structured interviews, content analysis.

## 1. Introduction

Health care professionals have a responsibility to involve patients in decisions concerning care and treatment. This has been accepted as ethically appropriate practice and is a part of health care legislation in many countries [1-3]. In addition, patient participation overall in decision making is associated with higher patient satisfaction and improved treatment outcomes [1 4 5].

MeSH defines *patient participation* as involvement in the decision-making process in matters pertaining to health.

It has been concluded that physicians cannot easily assume their patients' wishes to participate in clinical decision making, as patient preferences for involvement in shared decision-making tend to be varied [6-11]. Some studies show that the variability in patient choice could be anticipated from demographic factors such as age and educational level, meaning the higher the education, the higher of the desire for participation, and the older the patient, the lower the desire for participation [12-16], but this finding is not consistent [7 17].

There is abundant literature showing the benefits of patient participation [1 4 9 18-21], but as stated in the Cochrane report by Wetzels (2007) [22], the number of relevant studies found on patient participation in older patients is strikingly few, despite a highly sensitive search technique. This Cochrane report was done in the context of primary care, but what do we know about patient participation in hospital, regarding older patients?

Elkin [23] found — in the context of chemotherapy treatment of metastatic colorectal cancer — that about half the patients (n = 73; mean age 76 years) preferred a passive role in the treatment decision-making process, and Degner [8], in a study of 436 newly diagnosed cancer patients,

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found that the majority (59%) of patients wanted physicians to make treatment decisions on their behalf (n = 436, mean age 63 years).

We did not find any studies on fragile, hospitalized elderly patients. Unfortunately the western world lacks a consensus definition [<sup>24</sup>] of the “frail elderly”, who are characterized by many concomitant diseases and, often, rapidly declining health. In this study we use the most-accepted definition suggested by the Swedish National Centre of Epidemiology in 2001: It translates directly into English as “A person older than 75 years of age who has been hospitalized three or more times in the last 12 months and has three or more diagnoses in their medical records according to the International Classification of Diseases (ICD-10)” [<sup>25</sup>] (authors' translation).

The coming half-century will see a dramatic increase in the population of elderly age groups — and the group of very old is growing most rapidly in the western world, including in the United States. According to a study based on a multicenter computerized database of 70 hospitals in 25 states in the United States, 15% of emergency department (ED) visits were by patients 65 years or older. Thirty-two percent of elderly patients seen in EDs were admitted to hospital, compared with 7.5% of non-elderly patients [<sup>26</sup>]. This highly care-consuming group of frail elderly patients accounts for 13.2% of all hospital inpatient days in Sweden and consumes 19% of all costs of hospital care [<sup>27</sup>]. The frail elderly are, therefore, a very important group of patients to focus on, due to their rising number and rising economic impact on health care costs, and due to the challenge of adjusting the hospital care system to meet the needs of these patients. Little is known about elderly patients' preferences for participation in their care during hospitalization, especially the group of very frail elderly, who face many medical decisions and many hospital inpatient days, most often acutely admitted.

This study will be a contribution to research in this area.

The aim of the current study is to deepen the knowledge of frail elderly patients' preferences for participation in medical decision making during acute hospitalization.

## **2. Methods**

The study consisted of 15 qualitative interviews of fragile elderly patients. The patients had recently been hospitalized in one of two middle-sized hospitals in an area of Sweden having a total population of around 350,000 inhabitants. The hospitals are responsible for all acute hospital care in the area for all age groups.

Information about the study was distributed in the hospitals, the patients were identified by nurses and doctors as persons more than 75 years of age who had been hospitalized three or more times in the previous 12 months and had three or more diagnoses in their medical records according to the International Classification of Diseases (ICD-10).

All patients were informed about the study verbally by a nurse, as well as in writing. After giving their written consent, the patients were contacted by the first author to arrange an appointment for the interview. Exclusion criteria were difficulties in speaking and understanding the Swedish language and obvious dementia.

Before the study a semi-structured interview guide was constructed, based on the authors' clinical experience and research<sup>28</sup>. The guide was tested on one healthy and three fragile elderly persons and then revised slightly. The guide was then reviewed by a group of researchers with interviewing experience, and some further adjustments were done before it was used in the present study (see Appendix). The guide was used as a memo concerning areas to discuss and was associated with follow-up questions that were used to ensure the patients had understood the original questions.

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To further ensure the focus of the interviews was on the patients' participation in medical decision making, the interviewer explained the aim of the study before each interview.

Fourteen of the interviews were done by the first author and one by the third author. Each interview took about 40 to 90 minutes. Interviews were tape-recorded and transcribed and slightly modified from verbatim. Demographic data and data on diseases and concurrent illness were collected from the patient records.

### *2.1. Analysis*

Data were analyzed using qualitative content analysis as described by Lundman and Graneheim [29], and using both a manifest (descriptive) and a latent (interpretive) focus. No predetermined categories were used. The following stages of analysis were performed: 1) the transcripts were read through repeatedly to obtain an overall impression; 2) the interviews were scrutinized to identify significant text segments (units of meaning); 3) significant text segments were condensed to shorten the text mass and then coded; and 4) preliminary categories and subcategories were identified by clustering matching codes and by comparing similarities and differences. The preliminary categories were labeled, based on the content. During the analysis we continually reorganized the codes and the categories until the material could be divided in a natural way. We only categorized units of meaning with importance for the study. Coding and development of categories were mainly done by the first and last authors. During the process a latent interpretive category emerged — the main theme. See Table 2 for further illumination of the analytical process.

### *2.2. Trustworthiness*

To validate the results, responses to questions were further probed several times during the interview, to gain deeper understanding. Coding and development of the categories were done by

the first author. The third author read all the condensed units of meaning and also questioned the preliminary analysis. After 10–12 interviews, no new categories or subcategories were developed, but further interviews continued to increase the credibility of the study. The first author has been working as a geriatrician for about 20 years and the last author is a senior researcher in palliative care and qualitative methods.

*Table 2: Example of the analytical process:*

<b>Meaning unit (MU)</b>	<b>Condensed transcription</b>	<b>Code</b>	<b>Sub-category</b>	<b>Category</b>
Int: Did you get the help you wanted when you came to the hospital? Pat: No — not the first time. Int: No? Pat: Then I was hospitalized, and they made some tests. And then the first time a doctor came, she said that I should have warfarin. And then in the afternoon a male doctor came and said that he had heard about the plans to give me warfarin, but we should ignore that because warfarin is dangerous stuff. And palpitations are a problem in 80% of all people above 80, he said. So I had to go home again.	Pat: And then the first time a doctor came, she said that I should have warfarin. And then in the afternoon a male doctor came and said that he had heard about the plans to give me warfarin, but we should ignore that because warfarin is dangerous stuff.	Different treatment strategies between doctors	Different doctors involved in medical decision	Conditions that impair communication

### *2.3. Ethical considerations*

There was a risk that patients might identify the interviewer with the hospital care system and feel uncomfortable expressing criticism, out of fear that their candor could affect their future

care. Therefore, in the verbal and written information we were cautious to stress that no information from the interviews could lead back to the patient records and that all participation in the study was voluntary. The researchers were not in any way connected to medical care of the patients. Ethical considerations were observed according to the recommendations of the Helsinki declaration, as suggested by Wilkie [30]. The Research Ethical Committee at the Faculty of Health Sciences, Linköping University, approved the study (Dnr M104-08).

### **3. Results**

A total of fifteen patients were interviewed, three of them while still in hospital, the rest in their own homes. The patients were living in both rural districts and urban areas. Three of the patients lived in a special facility for the elderly.

Most of the interviews were done 0–2 weeks after discharge. The patients were between 75 and 96 years of age. More demographic data can be found in Table 1. The average number of hospital stays was five and a half in the previous year, meaning that the patients had a considerable experience of being admitted to and discharged from hospital. Although very ill (three died shortly after the interviews), most of the patients were able to express themselves very well, and they were willing to talk about their health care experiences.

Analyzing the interviews revealed 3 categories (figure 1):

Participation through information and communication

Barriers to communication

Preferred degree of participation

And a more latent theme:

The patients' perception of the hospital as an institution of power

The citations are identified with patient number, gender, and age, according to Table 1.

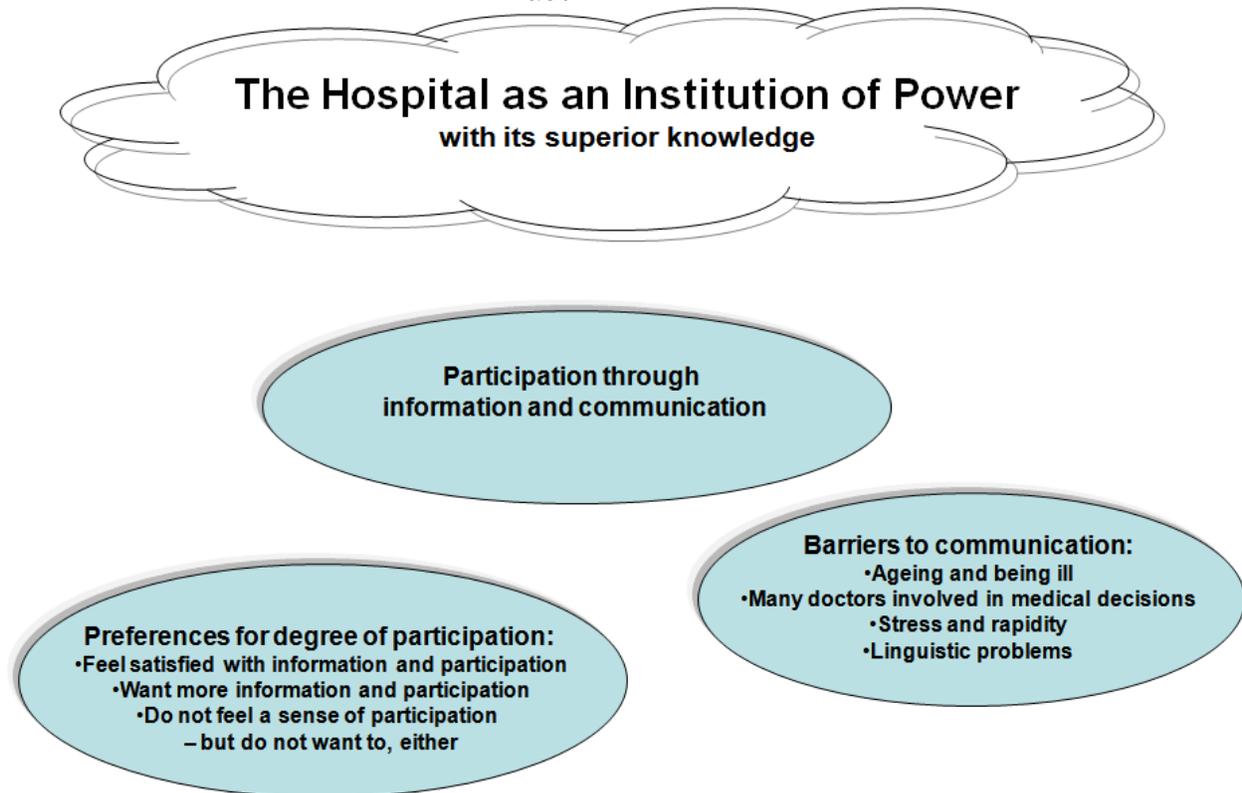


Fig. 1. Illustration of the 3 main categories together with the latent main theme

### 3.1. Participation through information and communication

To the patients in this study, patient participation in medical decisions meant the receiving of information and good communication. They wanted information about their illnesses and planned investigations, and they wanted information on the results of their investigations and the doctors' diagnostic considerations. They wanted health care staff to take the time to sit down and explain what was going to happen with them. Further, they wanted to be given the chance to be heard and to have the opportunity to express their thoughts and feelings about their symptoms and illnesses. It was important to be informed, even for those who did not wish to take an active part in the communication themselves:

Int: *What does participation in medical decision making and care mean to you?*

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*Table 1: Demographic data*

Patient No.	Age	Gender	No. of inpatient hospital admissions	Primary diagnosis	Secondary diagnoses	Home care	Marital status
1	92	f	6	Diabetes	Atherosclerosis, glaucoma, arthrosis	no	widowed
2	81	f	9	Cardiac failure	Glaucoma, cataract, atrial fibrillation, cardiac failure, diabetes, breast cancer	no	widowed
3	96	f	5	Cardiac failure	Hip fracture, gallstones, atrial fibrillation	yes	widowed
4	75	f	6	Angina pectoris	Lumbago, headache, primary hyperparathyroidism	yes	widowed
5	88	m	3	Cardiosclerosis	Inguinal herniation, angina pectoris,	no	married
6	77	f	7	Cardiosclerosis	Myocardial infarction, cardiac failure, chronic lung disease, anemia	yes	widowed
7	78	f	3	Chronic obstructive pulmonary disease	Angina pectoris, hip fracture, cardiac failure, TIA	yes	widowed
8	85	m	9	Cardiac failure	Atrial fibrillation, aortic stenosis, TIA, myocardial infarction, glaucoma	no	widowed
9	81	f	9	Cardiosclerosis	Myocardial infarction, hypertonia, chronic pain, polio, diabetes, atrial fibrillation	no	widowed
10	78	m	4	Stroke	Hypertonia, malignant melanoma, aortic insufficiency	no	married
11	81	f	4	Cardiosclerosis	Breast cancer, Parkinson disease, hip fracture	no	married
12	88	m	6	COPD	Cardiac failure, kidney stones, myocardial infarction	yes	widowed
13	86	f	3	Myocardial infarction	Collum fracture, osteoporosis, polymyalgia	yes	widowed
14	87	m	4	Prostate hyperplasia	Gastric ulcer, osteitis	no	married
15	87	f	4	Stroke	Atrial fibrillation, hypertension	no	married
<b>mean</b>	<b>84.0</b>		<b>5.5</b>				
<b>range</b>	<b>75-96</b>		<b>3-9</b>				

Pat: *I think it is when you can say what you think and feel, perhaps.*

Int: *So you feel you are participating when you can say what you feel and what you think?*

Pat: *Yes, when they listen to me. (Pat no. 15, female, 87 years)*

Int: *When they needed to do investigative procedures on you, did you participate, for example, in the decision about X-ray?*

Pat: *Yes, I knew everything that was going to happen.*

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Int: *What does patient participation mean to you?*

Pat: *That I get a description of what is going to happen.* (Pat no. 14, male, 87 years)

### *3.2. Barriers to communication*

Examining the problems with participation reveals several troublesome conditions for communication (see Figure 1).

#### *3.2.1. Ageing and being too ill*

One problem was patients' being too ill for example being too tired, being in pain or being too confused to communicate or to be interested in doing so and, thereby, to participate in their care.

Int: *Do you think you can participate in your care when you are admitted to the hospital?*

Pat: *You are so sick then, you are tired. It is good if you get some help.* (Pat no. 1, female, 92 years)

Due to advanced age and illnesses, the patients had extra difficulties understanding information<sup>31</sup> — something they were often well aware of. Many chose not to care so much about information and expressed that they were not as interested to know as they were when they were younger.

Pat: *“Well — that's obvious. When you get into hospital it can be a bit stressed, and you can get a bit confused. One is not totally perfect.* (Pat no. 3, female, 96 years)

Pat: *No, I am not really taking part in my care.*

Int: *But do you want to?*

Pat: *No. Not now, when I am this old. Perhaps when I was younger, but not now.* (Pat no. 7, female, 78 years)

#### *3.2.2. Many doctors involved in medical decisions*

Patients also had trouble dealing with continually changing doctors. New doctors appeared practically every day, sometimes with different treatment strategies. This made it difficult for the

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patient to feel confident in treatment strategies and to follow the thoughts and plans made by the doctors.

Pat: *Then I was hospitalized, and they made some tests. And then at first a doctor came. She said that I should have warfarin. And then in the afternoon a male doctor came and said that he had heard about the plans to give me warfarin, but we should ignore that, because warfarin is dangerous stuff. And palpitations are a problem in 80% of all people above 80, he said. So I had to go home again.* (Pat no. 5, male, 88 years)

### 3.2.3. Stress and rapidity

The patients gave examples of participating less when they felt the staff were stressed and when they experienced short stays in hospital, which gave little time for information to be communicated. For example, patients did not think they had the right to oppose a decision about discharge.

Int: *Did you participate in the decision about your discharge?*

Pat: *No. The doctor came. The doctor made his rounds, but I could not hear what he was saying — he was a foreigner — but that they could do no more. I had all the necessary medicines, he said.* (Pat no. 9, female, 81 years)

Int: *Please describe when you were hospitalized some time ago — the shorts hospitalizations.*

*Did you participate in the planning of your medical care then?*

Pat: *No, I did not participate then. They just wanted me to be discharged as fast as possible.*

Int: *So you did not participate in the planning of your medical care then?*

Pat.: *No — no, I did not... But the staff — they try.*

Int: *Was it the doctors that were not communicating?*

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Pat.: *Yes — but they had so much to do. A lot of patients to take care of. (Pat. no. 2, female, 81 years)*

### 3.2.4. Linguistic problems

In spite of good medical knowledge and confidence in the doctors several patients mentioned the problem of doctors speaking Swedish with an accent that made communication difficult and thus made participation difficult to achieve.

Pat: *Well, it is difficult. Foreigners have difficulties. It is one thing — they come here and don't speak the language. Perhaps they can know everything about patients but they have trouble in expressing themselves. They have a different culture. That's a problem, I think. (Pat no. 5, male, 88 years)*

### 3.3. Preferences for degree of participation

When trying to elicit the degree to which the patients wanted to participate in the medical decision making, we got three different types of answers (Figure 1):

#### 3.3.1. Felt satisfied with information and participation

This group expressed that they were pleased with the information they received which enabled them to participate to the degree they wanted, and they took the responsibility themselves, as patients, to ask questions, if they wanted to know more.

Int: *Are there ways you could participate in your care other than to become informed?*

Pat: *That's the only way to participate — to ask to learn more and to understand.*

Int: *How do you think you should be as a patient to be participating as much as possible?*

Pat: *That's up to the patient for the most part, I think. (Pat no.11, female, 81 years)*

#### 3.3.2. Wanted to get more information and participation

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Another group of patients described how they didn't get information, if they didn't ask. They expressed dissatisfaction with the low level of information they received. Some of them did not dare to speak up, while others asked many questions. They expressed the desire to get more information from their physicians.

Int: *You told me that you wanted to know more about your tests, but that you were not informed.*

*Is that correct?*

Pat: *Not without asking. It should be a natural thing that I as a patient were told without having to ask — that they sat down and told me what they have done; what they had found. I think that this should be a natural thing.*

Int: *But you have to ask first?*

Pat: *Yes, that you must. But not everyone dares to ask. (Pat no. 6, female, 77 years)*

3.3.3. Did not feel a sense of participation – but did not want to, either

Some patients expressed that they did not want to participate in their care in any way. They were pleased with a very passive role and entrusted themselves to the hospital care system.

Int: *Would you like to participate more in your care when you get to hospital?*

Pat: *No. Oh no. No, I won't. They are allowed to do what they want, as long as I get better. I don't want to participate in anything. (Pat no. 7, female, 78 years)*

3.4. *The main theme: The hospital an institution of power*

When analyzing all the interviews as a whole, a more latent theme emerged that we interpreted as the patients' perception of the hospital as some kind of an institution of power, both in terms of its competence, its hierarchy and of its doctors as people ranked higher than themselves. That the hospital was considered as an institution of power was based on the patients' perception of the hospital being more competent and, therefore, more able to make wise decisions about care

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and medical treatment. They felt that “the hospital” made the right decisions and they often expressed great confidence. The theme and categories is illustrated in Figure 1 by the cloud with this main theme overarching the three categories. Patients often did not know exactly who was making decisions about them, and when asked, often referred to “they” or “the hospital” as an institution, rather than to individuals.

Int: *Do you feel you can influence your care, for example, when you are going home?*

Pat: *When I am going home? That decision is up to the hospital. The hospital decides. Good luck, they say. Tomorrow you are going to go home in that car.* (Pat. no. 3, female, 96 years)

Some patients expressed the view that doctors, especially chief consultants, are important persons at the top of a hierarchical system who do not believe they need to communicate with patients about their care and diagnostic considerations. Especially around discharge, it seemed that the patients were overruled and not always listened to.

Int: *But who decided that you were going to a nursing home?*

Pat: *It was probably the doctor and the nurse. They thought I needed it, although I would have been better if I had gone home directly.*

Int: *What did you think yourself?*

Pat: *I wanted to go home. I said so — I wanted to go home to myself and my own stuff.*” (Pat no. 6, female, 77 years)

In spite of these conditions, most of the patients expressed great confidence in the health care they received and did not make too much effort to be informed or try to understand what was happening.

Int: *When you were in hospital, did you participate in your care and treatment?*

Pat: *My treatment? No, they do what they think they have to do. What they think is the best for me at just that time.* (Pat no. 1, female, 92 years)

## **4. Discussion and conclusion**

### *4.1. Discussion*

#### *4.1.1. Participation through communication*

According to the main result of this study participation the patients, first and foremost, means information. Patients want to be informed about investigative procedures, diagnostic considerations, their illnesses, and their treatment, and want better communication concerning their care. They want to be listened to when they are explaining how they feel or what they think about their condition, and they want to understand what is happening to them. The patients expressed their wish to be informed thoroughly — but they did not express any wish to take active part in the medical decision making. The majority defined participation as asking questions and/or obtaining information, which was also found by Sainio 2001 [15]. Our findings also accord with a study by Bastiaens of general practice in 11 European countries, which concluded that people over age 70 do want to be involved in their care, but their definition of involvement is more focused on the caring relationship, person-centered approach, and receiving information than on active participation in decision making [32]. According to other studies, in recent decades there has been a change in preferences regarding how decisions about medical treatment are made, a shift from a paternalistic model towards more shared decision making [7 14 33], with the patients taking a more active part. On the basis on our findings, together with the findings of Bastiaens (2007), it seems that a majority of elderly patients prefer *non-participation* in medical decisions, but nevertheless, good information and communication.

#### *4.1.2. Barriers to information exchange and communication*

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To obtain shared decision making requires at the least good information [<sup>34</sup>], but the results in this study reveal difficult conditions for information sharing and communication between health care providers and the frail elderly, which affects their participation. Compromising factors for good communication are the patient's own illness, having many persons involved in the patient's care who don't know the patient and the patient's preferences, differing treatment strategies among doctors, fast patient turnover in the hospitals, stressed hospital personnel, and linguistic problems with doctors not fluent in the patient's own language .

It is inevitable that hospitals will care for older patients who have hearing and vision difficulties, but the question is what measures we can take to minimize the consequences of these disabilities. On the contrary according to the patients in this study, they are treated in a stressful milieu, in which they encounter many persons involved in their care and particular patient difficulties tend to not be considered.

The differing treatment strategies among doctors and the lack of clear responsibility for treatment decisions, including discharge, makes it very difficult for patients to feel they are participating. This "collusion of anonymity" described by Balint [<sup>35</sup>] (vital decisions are made without anyone feeling fully responsible for them) is a big problem for geriatric patients with many diseases and often many medical specialists involved, with risk of both over- and undertreatment of different medical conditions [<sup>36 37</sup>]. It requires special geriatric interest and skills and good communication among health care practitioners to optimize this situation for the patient.

That so many patients expressed problems communicating with doctors who were not being able to speak the patients' own language was an unexpected result, but taking into account the

growing possibilities for migrations of doctors, for example, in the European Union countries, it should not have been a surprising finding [<sup>38 39</sup>] and is perhaps an issue to consider in the future.

#### *4.1.3. Health literacy*

Health literacy — or poor health literacy — could be part of the problem leading to low patient participation in medical decisions in our study. One definition of health literacy is given by Nutbeam [<sup>40</sup>] as “Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health.” By improving people’s access to health information and their capacity to use it effectively, it is argued that improved health literacy is critical to empowerment [<sup>40</sup>]. These patients’ physical illnesses and their decline in hearing, vision, and higher cognitive functions are associated with greater effort required to gain information about their health and/or illnesses, for example, by attending meetings or taking advantage of other educational opportunities. Also, due to the cohort effect, it is unlikely that these patients sought information through the Internet; none of our patients expressed spontaneously that they did so. All these factors contribute to poor health literacy in the frail elderly.

#### *4.1.4. Empowerment*

In the context of health care, empowerment has been described as an absence or decline of powerlessness, helplessness, alienation, victimization, oppression, subordination, and paternalism [<sup>41</sup>]. In our study we found three groups of patients according to preferred degree of participation (Feel satisfied with information and participation - Want more information and participation - Do not feel a sense of participation – but do not want to, either). This division matches the groups of patients divided according to empowerment by Edwards: empowered — non-empowered — disempowered <sup>42</sup>. The empowered patients was described as patients’ in

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control over treatment decision making and could be matched to our group of patients “Feel satisfied with information and participation”. The non-empowered patient according to Edwards was the group of patients who did not desire responsibility for making decisions relating to their health and preferred that healthcare practitioner to made decisions for them. This group could be matched our group described as “did not feel sense of participation — but did not want to, either”. The third group of patients that was described by Edwards as disempowered were caracterized as patients whose information had been regulated by health care providers and in this way had been ‘disempowered’ by limiting their ability to make choices based on (lack of) information. This could be matched to the group of patients in our study that “wanted to get more information and participation” (Table 3).

#### *4.1.5. Hospital as an institution of power*

According to our latent interpretation of the results, we found that the patients perceived the hospital care system as an institution of power with which it is not possible to argue or disagree. The patients focused on the superior competence of health care professionals as the main reason for this power, which they relied on with confidence.

Patients' perception of the hospital as an institution of power can be compared to the “power/knowledge” described by Foucault. In his view, knowledge is forever connected to power, and he often wrote them in this way: power/knowledge. His formulation has been used since the 1970s to understand the consultation or meeting between health care professionals and patients [<sup>43</sup><sup>44</sup>]. This power/knowledge, together with medical rituals such as the doctor's wearing a white coat and carrying a stethoscope, form what Foucault described as “governmentality” [<sup>45</sup><sup>46</sup>]. Governmentality is a style of power-knowledge in which growing bodies of knowledge coupled with rituals allow experts (such as doctors) to lay claim to the power of governance

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(Foucault, 1986)<sup>47</sup>. We know that some patients do not attempt to seek information or are reluctant to discuss information in consultations due to fears of presenting a challenge to health care practitioners and their medical authority [<sup>42 48 49</sup>]. According to Edwards<sup>42</sup> this is patients in the group of non-empowered patients and in this study the group of patients that “did not feel participation – but did not want to either”. The question is how many patients with this preferred degree of participation that has chosen this standpoint out of fear of challenging the medical power/knowledge? If we want to enhance patient participation we have to be aware that the hospital is perceived as a powerful institution and, therefore, should encourage involvement, especially of the frail elderly, taking in consideration all the barriers to communication listed above.

*Table 3: Preferences for degree of participation*

<b>Patients grouped according to type of preferences for degree of participation</b>
Empowered patients: Feel satisfied with information and participation - Ask questions if they want to know more
Disempowered patients: Want more information and participation - Do not always dare to ask or don't get the opportunity to ask questions (don't know who decides or are not given the time to ask)
Non-empowered patients: Do not feel a sense of participation – but do not want to, either - Prefer a passive role in medical decision making; sometimes feel too old or too ill to care

### *4.1.6. Cohort effect*

The question is whether the findings in the study are specific to our current era and cultural circumstances, including a more old-fashioned, hierarchical mode of thinking or mostly caused by the patients' being frail and very sick and thus not able to argue or question much. Having a

different cultural background from the health care staff due to age will always play a role, together with the differential in the elderly patient's knowledge of health care vis-à-vis health care personnel. Some of our patients clearly expressed that they would have participated more in medical decisions when younger. Other patients expressed their own incapacity to participate due to confusion. It thus seems possible that the preference of patients in this study for non-participation is due not to cohort effect, but more likely to age and illnesses. Search in the literature has revealed only sparse facts about the effect of age on preferences for patient participation, and the most fragile group presented in this study has not been covered in the literature to date. A study in the context of primary care [14] concluded that more informed decision making was observed in 2001 than in 1987, but that observation did not apply to the elderly. Other factors as mentioned above, including health literacy and Internet use, will change, but patients who are ill and old with mental and physical fatigue will always be in a subordinate position and find it difficult to actively participate in medical decisions. Therefore, in the authors' view, it is important to not rely on time alone to solve the problem of this group of patients being overruled and sometimes patronized.

#### *4.2. Conclusion*

The study has deepened our knowledge about frail elderly patients' preferences for participation in medical decision making and it was shown in this study that they did not express a wish to make decisions about their care and medical treatments, but they wanted to be thoroughly informed and listened to; that is, they wanted to enjoy good communication with their hospital care providers. The results differ from other recent studies in that our patients expressed a greater preference for non-participation in medical decision making. The patients perceived the hospital care system as some kind of institution of power with which it is not possible to disagree.

#### *4.3. Practice implications*

4.3.1. We must, as health care personnel, be aware of our superior position as a part of a powerful institution and do what we can to minimize the risk of patients feeling overruled, afraid of asking and being a burden.

4.3.2. More time should be given to provide information and re-information about investigations, diagnoses, medicines, and planning of health care, including discharge from hospital, especially to frail elderly patients.

4.3.3. As few people as possible should be involved in the care of the frail elderly to enhance communication and knowledge of the patients' preferences.

4.3.4. Health care staff must be able to communicate in the language of their patients or take the necessary measures to diminish the negative consequences of not being able to communicate directly with their patients.

#### *4.4. Limitations and further research*

This study was designed to deepen the knowledge of frail elderly patients' preferences for participation in their hospital care. The technique was qualitative, with in-depth interviews with rather few patients. They were able to provide much valuable information, but to get further knowledge in this area, it would be useful to conduct a quantitative study with a questionnaire to show to what extent the identified areas of concern influence patient participation and to what degree a more shared medical decision-making model is wanted by these patients. Frail elderly patients account for a rising proportion of all health care costs [27]. To ensure the greatest benefit from health care expenditures and to provide good quality health care, future research and medical education should focus on the challenges of adjusting the hospital care system to meet the needs these patients.

## **Conflict of Interest**

There are no financial or personal conflicts in this study.

*Author Contributions:* The interviews and coding were mainly done by the first author. The third author read all the condensed units of meaning and also questioned the preliminary analysis. The second author reviewed the manuscript as a whole from a gerontological point of view.

*Sponsor's Role:* The main author is an employee of the County Council of Eastern Östergötland, which financed all costs for this study.

I confirm all patient/personal identifiers have been removed or disguised so that patient/persons described are not identifiable and cannot be identified through details of the story.

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**Appendix: Interview guide**

Please describe how you are feeling today.

Please describe your last stay in hospital.

Please describe your expectations during your last stay in hospital, and describe how they were fulfilled.

Please describe what participation in medical decision making and care means to you?

Did you feel you participated in your medical decision making and care during your last/current stay in hospital?

If so, please describe in what way.

Please describe the tests and investigations you had during your last stay in hospital.

Did you participate in decisions regarding tests and investigations?

Did you want to participate in these decisions?

If so, did you get the opportunity to participate?

Did you feel that you participated in decisions regarding your medical treatment and care?

Did you want to participate?

If so, did you get the opportunity to participate?

Is there anything else you want to tell me about participation in medical decision making?