# Too complex and time-consuming to fit in! Physicians' experiences of elderly patients and their participation in medical decision making: a grounded theory study 

Anne Wissendorff Ekdahl, ${ }^{1,2}$ Ingrid Hellström, ${ }^{1,2}$ Lars Andersson, ${ }^{3}$ Maria Friedrichsen ${ }^{2,4}$

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For numbered affiliations see end of article.

Correspondence to
Dr Anne Wissendorff Ekdahl; anne.ekdahl@lio.se

## ARTICLE SUMMARY

## Article focus

- Physicians' views and attitudes to elderly patients' participation in medical decision making.


## Key messages

- Hospital care is not well adapted to elderly patients with multimorbidity as they are a highly complex patient group to take care of.
- Taking care of elderly patients with multimorbidity often frustrates physicians by giving them a feeling of professional inadequacy.
- Remuneration systems do not allow for necessary time for communication among medical professionals and between physicians and patients or relatives. Neither do these systems support the necessary integration of care.

Strengths and limitations of this study

- The scope of the study, to the authors' knowledge, has not been clearly documented in earlier studies and is important to bear in mind when planning for future healthcare, especially as there will be a growing proportion of frail elderly people.
- Qualitative research limits generalization.
- The study was performed in a Swedish context.


## INTRODUCTION

Healthcare professionals have a responsibility to involve patients in medical decision making. This has been accepted as ethically appropriate practice for decades and is a part of healthcare legislation in many countries. ${ }^{1-5}$ The literature supports the advantages of patient participation to give better treatment results and higher patient satisfaction. ${ }^{6-12}$

Studies in the area of medical decision making show that most patients prefer shared
decision making, but that preferences are very individual. ${ }^{13}$ Several factors have influence, such as age, sex and level of education, but the relationship is not constant. ${ }^{14-17}$ Several studies have focused on older patients with cancer and chronic diseases. ${ }^{14-161819}$ Most have found a decline in the wish for involvement as patients get older ${ }^{17}{ }^{20-24}$; nevertheless, studies have shown that, overall, there is less participation than actually preferred. ${ }^{25}{ }^{26}$ One of the reasons reported for not participating is the patient feeling subordinate to the hospital as an institution of power. ${ }^{27}$

In contrast to the multitude of publications on patient participation, there is a lack of studies of physicians' preferences and behaviour related to stimulating patients to partake in decision making. ${ }^{28}$ Some studies have shown that attitudes towards involving patients range from highly positive to more circumspect and that moves towards enhancing patient involvement in decision making will depend on developing both the skills and attitudes of medical professionals. ${ }^{21}{ }^{29}$ Further influence is exerted by the conflict of demands on resources within the collectively funded healthcare system ${ }^{30}$ and the lack of time. ${ }^{31}$

In summary, we know much about the benefits of patient participation in medical decision making and something about elderly patients and their preferences related to this process. However, very little is known about physicians' thoughts and considerations regarding patient participation, particularly among elderly patients. The aim of this study was to explore physicians' thoughts and considerations of participation in medical decision making by hospitalised elderly patients with multimorbidity who are admitted to hospital.

## METHODS

This qualitative study is based on focus group interviews and grounded theory. ${ }^{32}{ }^{33}$ This method was combined with an individual questionnaire soliciting demographic data, as well as questions and statements based on barriers to participation, such as short incare time or the patient being too ill to participate in medical decision making. ${ }^{2527}$

## Setting and participants

The participants were hospital physicians in the Departments of Geriatrics, General and Orthopaedic Surgery, and Internal Medicine in two counties in Sweden. We performed one interview in each department in which there were six doctors. Each session took about an hour. For the demographics of the physicians, see table 1. Each focus group interview had six participants, and in total, 30 physicians in three different hospitals were interviewed. The departments were chosen for having a high proportion of elderly patients on their wards and represented several medical specialities. The first author of this study (AWE) is a geriatrician with more than 20 years of experience of geriatric medicine and is used to discussing participation in medical decision making with patients and relatives. The
Table 1 Demographics of the physicians
Women/men ( $\mathrm{N}=29$ ) $\quad 10 / 19$
Age groups, years $(\mathrm{N}=27)$

| $<35$ | 7 |
| :--- | ---: |
| $35-45$ | 3 |
| $46-55$ | 7 |
| $>55$ | 10 |
| Years of experience $(\mathrm{N}=29)$ | 6 |
| $<5$ | 3 |
| $5-10$ | 7 |
| $11-20$ | 13 |
| 20 |  |

last author (MF) is a nurse with experience in research and nursing in palliative care. Both these authors were present at each interview.

## Data collection

A semistructured interview guide was developed based on earlier studies, ${ }^{27}{ }^{34}$ the researchers' experiences and discussions with fellow physicians. For the complete questionnaire, see table 2. The interview guide was used when needed to ensure that key areas were discussed, and it was modified as interviews progressed to accommodate probing questions. Interviews with physicians were conducted between April 2010 and May 2011 and were performed in department conference rooms at a time chosen by the physicians. At the beginning of each interview, an investigator (MF or AWE) introduced the study and explained the focus group's objectives and process. Both investigators participated in each focus group interview, one took a more active role, the other was more of an observer. The interviews, approximately an hour in length, were tape-recorded and transcribed verbatim by the first author. The informants were asked to share their thoughts on elderly patients with multimorbidity and to describe perceived barriers and facilitators to participation.

Data collection and analysis continued until no new categories emerged and no new properties within the categories were identified. A self-administered questionnaire was collected at the end of each focus group (to avoid having the questions influence the interview), in which the physicians were asked to estimate the percentage of the presence of different barriers with impact on participation in medical decision making; they were also asked to choose the most appropriate of four different statements regarding informing elderly patients about their treatment.

Field notes were recorded immediately after each interview, including descriptions of where the interview was held, reflections on how the interview went to get a deeper understanding of what was going on and what the physicians were describing.

## Data analysis

First, there was an initial coding whereby we gave substantive names to text sequences and developed

Table 2 Semistructured interview guide

| Introductory question | ge that comes into your mind when you think about the frail elderly |
| :---: | :---: |
| Transition question | Tell us what comes into your mind when you think about patient participation in treatment decision making |
| Key question | What ingredients do you think are necessary to achieve patient participation in treatment decision making? |
| Key question | Which role (active, shared, passive) do you think that frail elderly patients prefer in treatment decision making? |
| Key question | How do you think you could facilitate communication between the frail elderly and healthcare staff (or doctors)? |
| Key question | How do you think we meet the preferences of the frail elderly regarding information about their healthcare? |
| Key question | What obstacles to participation in treatment decision making do you think are faced by the frail elderly? |
| Key question | What obstacles in the organization of healthcare do you think exist to participation in treatment decision making by the frail elderly? |
| Final question | Is there anything else that anyone feels we should have talked about? Summarising and verification |

preliminary categories. The next step involved asking questions about what was going on and making constant comparisons between and within the preliminary categories to see if the categories were well described. The aim was to obtain a focused coding, using the most significant earlier preliminary codes to synthesise and explain larger segments of data. ${ }^{32}{ }^{33}$ At the same time, an axial coding was performed to bring data together and describe the categories. ${ }^{32}{ }^{33}$ Data collection and data analysis were performed simultaneously. Integrative diagrams and memos were written throughout the process to guide thinking and to record analytical insights and interpretations.

## Rigour

At the end of each interview, one of the authors summarised the discussion for the focus group, to ensure that there were no misunderstandings. All physicians confirmed the summary. Several data collection methods were used in order to study the phenomenon from different aspects. The quantitative results were not analysed until all interviews had been completed. Two researchers (MF and AWE) did the initial coding independently. A third independent researcher experienced with grounded theory (IH) reread and interpreted the findings. Regular meetings were held to review the evolving understanding.

## FINDINGS

## Quantitative results

Twenty-nine physicians (of total 30) answered a questionnaire about the proportion of their frail elderly patients to whom different statements about barriers affecting participation in medical decision making applied. The results are shown in table 3. As can be seen, the physicians assumed that most patients were not too ill to participate in medical decision making.

In the same questionnaire, the physicians were asked to choose the most appropriate of four statements
regarding elderly patients' information about their treatment, and 23 (79\%) physicians responded. Of the responders, seven ( $30 \%$ ) believed that patients got the information they wanted about their treatment, eight ( $35 \%$ ) that patients would have preferred more information, seven ( $30 \%$ ) that patients found it difficult to

Table 3 Physicians' estimation of barriers affecting participation in medical decision making
To what proportion of your frail elderly patients do the following statements apply? $(\mathrm{N}=29)$

Number of doctors (\%)
Perceive to be too ill to participate in medical decision making

```
    0%-20% 15 (52)
    21%-40% 10 (34)
    41%-60% 4 (14)
    61%-80%
    -
    81%-100%
```

Perceive different treatment strategies between different
doctors

| $0 \%-20 \%$ | $5(17)$ |
| :--- | ---: |
| $21 \%-40 \%$ | $12(41)$ |
| $41 \%-60 \%$ | $5(17)$ |
| $61 \%-80 \%$ | $6(21)$ |
| $81 \%-100 \%$ | $1(3)$ |

Perceive to have too short incare time to participate in medical decision making

| $0 \%-20 \%$ | $1(3)$ |
| :--- | ---: |
| $21 \%-40 \%$ | $5(17)$ |
| $41 \%-60 \%$ | $5(17)$ |
| $61 \%-80 \%$ | $10(34)$ |
| $81 \%-100 \%$ | $8(28)$ |

Perceive to have difficulties in understanding the medical information you give them

| $0 \%-20 \%$ | - |
| :--- | ---: |
| $21 \%-40 \%$ | $6(21)$ |
| $41 \%-60 \%$ | $10(34)$ |
| $61 \%-80 \%$ | $9(31)$ |
| $81 \%-100 \%$ | $3(10)$ |

ask questions about their treatment and one (4\%) that the patients did not want to know about their treatment.

## Qualitative results

In the interviews, we identified two categories describing physicians' thoughts on participation in medical decision making of elderly patients with multimorbidity. The first category was called 'being challenged', which meant meeting the challenge to take care of elderly patients with multimorbidity in all its complexity. The second category was called 'being a small part of the healthcare production machine', with its bureaucratic routines and remuneration systems that do not favour elderly patients with multimorbidity. Both categories led to the core category 'lacking in time'. For an integrative diagram of physicians' thoughts on elderly patients with multimorbidity, see table 4.

Throughout the interviews, the physicians described why they could not give good care to these patients, and the overall theory explaining physicians' experiences of elderly patients with multimorbidity was that it was 'too complex and time-consuming to fit in', mostly because of lack of competence or lack of a holistic view and also because the routines in the hospital care system and in the remuneration system do not favour elderly patients with multimorbidity.

## Being challenged

To take care of elderly patients with multimorbidity and enable them to participate in medical decision making were described as a challenge. This was explained by the patients' medical and social complexity and their need of time-consuming communication with all care givers, including relatives, which gave physicians the feeling of not being able to provide a good quality of care. Other challenging circumstances included patients not clearly expressing their preferences and communicating with patients with cognitive decline.

## Having a feeling of incompetence

Physicians-apart from the geriatricians-described a feeling of not having the right competence for this patient group. They reported a lack of a holistic view, insufficient knowledge of medications, lack of competence regarding social needs and difficulties in communicating with the municipality, whose rules they did not
understand and which they viewed as overly bureaucratic.

> I: What do you think of the frail elderly as patients? R1: [Consider] an old patient with many illnesses and polypharmacy... What do we know of the long medication list? How many interactions do we miss? We do one thing at a time and do not care about the whole.
> R2: We meet them quite often; well, they are in our care system all the time, but sometimes we feel a bit stranded and do not know what to do with them.

These patients were described as being frequently admitted without a diagnosis, but rather because of vague symptoms of 'getting worse'. All physicians agreed that the frail elderly patients are time-consuming compared with other patients. They reported a feeling of not doing a good job due to lack of time. Furthermore, it was expressed as being sometimes quicker to order investigations or give treatments than to take time to discuss goal setting, consequences of investigations, pros and cons of treatments or having a more thorough discussion of the whole situation.

The patients are also in need of nursing care, which is not the main focus of the doctors. Physicians described themselves as doing 'nothing' when taking care of elderly patients, who were seen as taking time from patients with distinctive acute medical conditions.

R : We want to provide elective care-that makes good statistics. We can't have these frail elderly in need of nursing care, and on top of all, we don't really know how to take care of them or how to treat them medically, so they are totally worthless to us.

A challenge arises when patients prefer a passive or subordinate role, leaving a greater responsibility to the doctors to make decisions. Many physicians were uncomfortable with having to try to guess the preferences of the patients-and again-it could be time-consuming.

## Having to take relatives into consideration

Relatives are described as both an asset and a hindrance to good care and participation in medical decision making. Sometimes they act as an extra set of ears, able to ask questions and harbour information for a patient who is in poor condition and currently cannot assimilate

Table 4 Physicians' thoughts on elderly patients with multimorbidity

## Lacking in time

Being challenged
Being a small part of the healthcare machinery

- Having a feeling of incompetence
- At the mercy of routines
- Having to take relatives into consideration
- Having to take cognitive decline into account
- Unfit premises
- Indirect communication
- Lack of continuity
- Lack of beds
- Inadequate remuneration for elderly patients with multimorbidity
medical facts. At other times, physicians feel that relatives are 'taking over', pressing for investigations and treatments that are medically unbeneficial for the patient or against the patient's preferences. The following is an example of family members opposing information being passed to the patient, impeding the patient's own participation and creating an ethical dilemma for the physicians concerning whom to listen to:

I: You have just told me about barriers to patient participation, such as routines. Do you see other problems? R: Relatives (from several physicians at a time).
I: That came fast-tell me more.
R : Like when the mother is very ill, and the relatives do not allow her to be informed. They wish to protect her from knowing the truth.

At the same time, physicians pointed out the importance of following the wishes of patients, of not letting relatives take over making medical decisions and becoming the only ones addressed by healthcare staff.

## Having to take cognitive decline into account

To enable patients to participate in medical decision making, physicians have to give information adapted to the patients' medical condition, educational level, and not least, cognitive function, the latter being a common problem in this group. It is important to allot time, listen carefully, be polite and establish a relationship by trying to understand what is important for the patient, finding out what the patient's fears and preferences are. All this has to be done within a quite limited time frame.

The high prevalence of cognitive decline in elderly patients is giving relatives a bigger role in medical decision making compared with that needed for younger patients, necessitating communication with more people, who are not always accessible, again requiring more time than other groups of patients.

## Being a small part of the 'healthcare production machine'

To be part of the healthcare production machine means to be part of the hospital with all its routines, including communication and remuneration systems, which are badly adapted to elderly patients with multimorbidity. It also means dealing with a lack of beds and continuity, especially among physicians.

The participating physicians who worked in emergency departments made certain observations. The emergency room was described as a kind of machine 'sucking in' patients, with routines set up to start investigations, make diagnoses and admit patients, rather than send them home. Some indicated that elderly patients with multimorbidity were taking time and space from the really acutely ill patients. Multiple illnesses in one patient made it difficult to admit them to a specific department or ward, and they were described as 'hanging in the air between specialities' before finally being admitted somewhere.

## At the mercy of routines

Rigid ward routines lead to difficulties in giving individualised care. Physicians describe themselves as having little or no influence over these routines. The premises are described as noisy, frequently without adequate places or chairs for a calm conversation in a dignified environment. Much communication on the wards happens not directly with the patient, but through nurses and assistant nurses, and the physicians cannot always be sure they have got the correct information about the patient:

> R: You must often trust the information from nurses and assistant nurses-you don't have the time to talk with the patient. And often it is not even the nurse that talked to the patient herself-it could be the nurse from a previous shift. Very often this is the source of information-and it is not always correct!

Physicians felt that the rapid turnover of staff, including doctors, on the wards made it difficult to get to know elderly patients and their illnesses, resulting in a lack of continuity of care. This had greater impact on these patients, who commonly have a longer incare time. Lack of beds and time coalesced into speedy, not uncommonly premature, discharges.

## Inadequate remuneration system

The remuneration system favours easy accessibility and a high number of treated patients, making elderly patients with long incare time an obstacle to good economy and 'worthless' as cited earlier, at the same time as physicians recognize their needs. Hence, these patients are not allotted enough time for good care, including time for participation in medical decision making. As these physicians pointed out:

> R: It is not a good system we have created, not making the frail elderly feel welcome. I think that many of these patients feel unwelcome, because they are regarded by us physicians as just a cost. You are educated as a physician to take care of people, but you end up with the "knife in your back"-it is not good.

The physicians felt a frustration that 'money rules' creating ethical dilemmas when everyone is trying to avoid these patients, in spite of their needs.

## They just don't fit in

The overall theory generated by our data was that due to lack of competence, lack of a holistic view, need for timeconsuming care and communication with multiple care givers, an inadequate remuneration system and inappropriate routines, elderly patients with multimorbidity are too complex and time-consuming to fit in at the hospital, with severe obstacles to their participation in medical decision making.

## DISCUSSION

The main findings of this study show ideals conflicting with reality. It is difficult for a physician who is not
familiar with all diseases and treatment options to invite a patient to participate in medical decision making. To take good care of these patients requires consultations and referrals to multiple specialists, and as the physicians point out, there is no time to do these. The alternative is to partly ignore illnesses where the competence to address the situation is lacking, eliciting a feeling of inadequacy. Elderly patients with multimorbidity indeed form a complex patient group, and integration of their care is a central challenge for healthcare delivery. ${ }^{34}$ The increase in medical knowledge and skills has resulted in increasing specialisation, making it more difficult to have the necessary holistic view regarding elderly patients with multimorbidity.

Much of the content of the interviews revolved around physicians explaining why they were not able to provide these patients with good care and enable them to participate in medical decision making. Physicians expressed feelings of frustration and bad conscience about not being able to prioritise these patients; at the same time, some of the physicians observed that elderly patients were not ill enough to be in hospital, taking beds and time from the 'really ill' patients. We know that there is a 6 -month mortality rate of around $25 \%$ in elderly patients who have been emergently admitted during the previous 6 months. ${ }^{35}$ Thus, these patients really are ill-but still not always welcome in a hospital. The issue is whether the physicians' lack of giving priority to elderly patients with multimorbidity is more an expression of ageism, ${ }^{36}$ not finding it interesting or attractive to take care of these patients and finding it more convenient to blame the lack of time rather than admit a lack of interest.

As the system of remuneration is linked to 'healthcare production', such as rapid accessibility (ie, time taken to perform investigations or operations) and number of treated patients, the geriatric approach to treatment assumes a lower priority. Lack of geriatric competence, specifically the specialist's skills in comprehensive geriatric assessment, holistically combining physical, psychological, social and functional perspectives, is a main area of concern in the care of elderly patients with multimorbidity, with consequences such as higher dependency after discharge and higher mortality. ${ }^{37}$ In spite of political announcements on the importance of taking good care of elderly patients with multimorbidity, the remuneration systems continue to emphasise easy accessibility, rapid turnover and focus on reduced performance time, all of which hinder physicians from meeting these patients' needs.

The quantitative results presented in the tables all support the qualitative findings.

## Limitations

Although the mainly qualitative methodology in this study limits generalisation and is restricted to the healthcare system and the geographical context of Sweden, our findings do provide insight into the
problem of the decision-making process of elderly patients with multimorbidity. The range of specialities among the interviewed physicians increases the validity of our results. There are similarities and differences in all countries' remunerations systems and attitudes to elderly patients, which also limit generalisations.

## CONCLUSIONS

We describe important obstacles to participation in medical decision making by elderly patients with multimorbidity, such as physicians' lack of geriatric competence and lack of time. The remuneration systems do not allow for necessary time for communication between medical professionals and between physicians and patients or relatives. Neither do they support the necessary integration of care. Thus, taking care of elderly patients with multimorbidity often frustrates physicians by giving them a feeling of professional inadequacy, as they are unable to prioritise this common and rapidly growing patient group. This indicates that hospital care is not adapted to elderly patients with multimorbidity, who are a highly complex patient group to take care of. This has not been clearly documented in earlier studies but is important to bear in mind when planning for future healthcare, especially as there will be a growing proportion of frail elderly people.

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[^0]:    Author affiliations
    ${ }^{1}$ Department of Geriatric Medicine, Vrinnevi Hospital, Norrköping, Sweden
    ${ }^{2}$ Department of Social and Welfare Studies, Faculty of Health Sciences, Linköping University, Norrköping, Sweden
    ${ }^{3}$ National Institute for the Study of Ageing and Later Life (NISAL), Department of Social and Welfare Studies, Linköping University, Norrköping, Sweden
    ${ }^{4}$ Palliative Education and Research Center, Vrinnevi Hospital, Norrköping, Sweden

