

The Shared Decision Making of Older Adults in Healthcare

ABSTRACT

Purpose: The research question for this paper was: what are older adults' experiences of shared decision-making in a healthcare setting? This involved:

1. Exploring older adults' experiences and opinions of decision-making in a healthcare setting;
2. Understanding what shared decision-making means to older adults.

Design and Method: A qualitative study using face-to-face, semi-structured interviews with adults over 65 years. Thematic analysis was used.

Participants: Eight adults with a mean age of 76 years.

Findings: Three broad themes were identified which ascribed roles to individuals involved in decision making. This includes the way in which older adults felt they should be involved actively: by asking questions and knowing their own body. The doctors' role was described as assistive by facilitating discussion, giving options and advice. The role of the family was also explored; older adults felt the family could impact on their decisions in both a direct and indirect way. There was some confusion about what constituted a decision.

Conclusion: Older adults described what having an active role in decision making meant for them, but expected an assistive role from clinicians. They see their family as having an important role.

Research limitations/implications: This was a small qualitative study in one market town in England.

Practical implications: Clinicians should facilitate the involvement of older adults in shared decision making and consider how they can increase awareness of this. They should also involve the family in decision making.

Originality/Value: There are limited studies which look at this issue in depth.

INTRODUCTION

Shared decision making (SDM) is defined as *"a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical*

evidence and the patient's informed preferences." (Coulter and Collins, 2011). Decisions can be seen along a continuum, with patient-led decisions at one end and clinician-led decisions the other (Hoffmann, *et al.*, 2014). Charles *et al.*, (1997) identified four aspects of a shared decision: (1) involvement of at least two participants, (2) sharing of information by both parties, (3) steps taken to build a consensus and (4) an agreement being reached. Although this description of SDM focused on treatment-related decisions, it can be expanded to any healthcare decisions and is beginning to be recognised in healthcare policy (DoH, 2010; Haslam, 2016; NHS, 2015; Frosch *et al.*, 2011; Hoffmann, *et al.*, 2014).

During SDM, the clinician shares information regarding diagnosis, aetiology, prognosis and treatment. The patient shares knowledge of their own social circumstances, attitude to risk and personal values (Coulter and Collins, 2011). Due to the nature of the sharing of information, SDM is most useful where there is no superior clinical option (Hoffmann, *et al.*, 2014). An example of this would be when the national guidelines are left open to individualisation, often using the term "offer" rather than "start" a particular therapy, such as the use of statins to reduce cardiovascular risk (Barrett, *et al.*, 2016). The SDM process may involve more than two participants and family input should be considered (Charles, *et al.*, 1997).

SDM is widely beneficial. Research shows that patients wish to be actively involved in decisions, therefore SDM can increase patient autonomy and improve clinical outcomes (Coulter and Collins, 2011; Davey, *et al.*, 2002; Kashaf and McGill, 2015; LeBlanc, *et al.*, 2015; Shay and Lafata, 2015). For clinicians SDM can increase job satisfaction and for regulatory bodies SDM is an ethical imperative (Sullivan, *et al.*, 2006; Coulter and Collins, 2011). SDM is also beneficial for commissioners, reducing unwarranted variation in clinical practice and ensuring patients receive individualised care (Coulter and Collins, 2011). However, the benefits of SDM depend on who identifies the shared decision. Patient definitions of SDM differs to clinicians'. A qualitative study found four characteristics that patients considered to be constitutive of a shared decision: (1) both the doctor and the patient share information, (2) both are open-minded and respectful, (3) the need for patient self-advocacy and (4) a personalised physician recommendation (Shay and Lafata, 2014). There is some concordance between patient perceptions and those outlined by Charles (1997), but they do not

completely align. Patients perceive a shared decision when both they and the clinician agree, despite absence of information sharing or patient self-advocacy (Shay and Lafata, 2014). As a result, patient-reported SDM does not consistently align with observer-reported SDM (Wunderlich *et al.*, 2010). Patient perceptions are arguably more important because improved health outcomes are greater when SDM is patient-reported (Shay and Lafata, 2015).

Recognition of differing demographics is also essential. The older demographic is important for a number of reasons. Firstly, a large survey identified that preference to be active in decision making declined from 45 years of age (Levinson *et al.*, 2005). Additionally, older adults have higher health service utilisation than other groups (Vegda *et al.*, 2009). Finally, older people have experienced the transition in the last twenty years from a model where the patient seeks help and complies with a doctors' decision to a model where the doctor and the patient work in partnership (Kaba and Sooriakumaran, 2007). There has been some research regarding health-related SDM in older populations, but results have been mixed.

METHODS

This research aims to answer the following:

1. Explore older adults' experiences and opinions of decision making in a healthcare setting;
2. Understand what shared decision making means to older adults.

Ethical approval was gained from King's College Ethics Committee.

Sampling

Convenience sampling was used to identify participants (Andrews *et al.*, 2013). Members of a country market were approached and given an information leaflet. Those expressing interest in participation were given a copy of the information sheet and were invited to provide their details if they wanted to be contacted. The intended sample size was eight participants. It was identified that snowball sampling was necessary to achieve the sample size (Kuper, *et al.*, 2008).

Interviews

Interviews were carried out in the participants' home, allowing for adequate confidentiality. The information sheet was provided at the beginning of each interview with time set aside for questions and a consent form was signed.

A short demographic questionnaire was completed by the participant and all interviews were then semi-structured following the topic guide. All were face-to-face and conducted by the same interviewer. They were audio recorded, with participants' consent, and visual cues noted. At the end of the interview participants were asked whether they wanted anything removed from the transcript.

Methods of analysis

Each interview was transcribed in full, including non-verbal cues. Identifying features of each interviewee were removed from transcription to ensure anonymity. The initial interview was double-coded; however, later analysis was undertaken by one researcher. An inductive approach was taken (Bowen, 2016). Initial analysis fed into enquiries in later interviews. Thematic analysis using a framework was used. (Gale *et al.*, 2013). Analysis took a largely semantic approach (Braun and Clarke, 2006).

Results

Participant characteristics

Seven older people were initially interested in participation. Of these, four were interviewed. A further five individuals were identified with snowball sampling, of whom, four took part. Reasons for not participating were lack of time and being uncontactable.

The average age was 76 years (range 66 to 90 years) with six females and two males. All participants identified as White British. Educational background ranged from secondary education to postgraduate education. One participant was self-employed, one was in part-time work and the remainder were retired. Three participants self-reported chronic conditions.

The average length of interview was 36 minutes (range 21 to 52 minutes).

Thematic overview

Initial analysis highlighted the need to define the nature of decisions. Following this, three themes outlining the roles of individuals involved in SDM were explored: the patients' role, the clinicians' role, and the role of family.

Nature of decisions

Twenty-four health-related decisions were discussed across eight interviews, with considerable variation between them. The nature of the decisions discussed are listed in table 1. Categorisation was based on direct questioning (*"Who made the final decision?"*) or on the participant saying *"I decided"* or *"The doctor decided"*. It was not possible to categorise two of the decisions as they were described too briefly.

Table 1.

SDM was not a well-known term. Two participants reported hearing of SDM prior to interview. Both cases reported they had read about SDM previously. One of these participants described the term accurately:

"Well, I imagine it would be mutual, the decision, wouldn't it? The doctor would set forth the advantages and I would decide whether it was worth going through whatever the treatment it was." – Mrs E

Definitions given by participants who had not heard of SDM were varied. Three participants included family in their definition, but overall there was no consistent understanding of SDM.

Perceived role of the patient: asking questions and knowing their own body

Throughout the interviews there was a sense that participants wanted to have an active role in decisions about their health. This was expressed in a number of ways, including asking questions to their doctors and expressing that they knew their own body.

Most participants described asking questions in order to help them make a decision. In some cases, the question asking was the primary factor enabling participant decision making:

“And I remember sitting there asking him what would happen if I don’t have it. And he said “Well, the tumour will grow and grow and grow. And then you will become completely incapacitated. And then you will die.” So I went “Alright.” – Mrs G

Although, a minority of participants felt asking questions was less important:

“I’m not a chap that... who says “Well, what you gonna do then?” You know.” – Mr F

A second aspect of the patients’ role was that the participants knew their own bodies better than their doctor did. This concept was described by several participants:

“And you were the patient, but sometimes he used to treat you that, that you weren’t very bright. That you were the patient and he knew best. And I disagree with that because I think, at the end of the day, the patient knows their body better than anyone, you know.” – Mr H

Participants identified that awareness of their own bodies meant that they were qualified to make some decisions about their medical care, however, a distinction was made between when the participant was more qualified and when it should fall on the doctor:

“I think when it comes to something really medical as opposed to being mechanical, like my knees were sort of mechanical as it were. Um... so you know yourself how it’s impacting on your life and whether you actually want to have it done. And where it’s something medical, like do you stay on a drug or don’t you, and you don’t feel any different when you take it, then you take... it’s easier to take the doctor’s advice.” – Ms B

The participants’ and the doctors’ expertise were clearly described and correlate with the distribution of expertise described in the literature.

Patient expectations of the doctor’s role: assistance with decision making

The role of the doctor was discussed in all interviews. This included giving options, giving advice and explaining or discussing with the patient. Overall, participants described an

assistive role for the clinician. Additionally, many of the participants discussed the relationship with their doctor and how this impacted on their ability to make shared decisions with them.

Participants described looking at decisions as a case of choosing between options and that these should be provided by the doctor:

“It’s my body. I should be given the options. And you can only have options by discussion.” – Mrs A

Some participants expressed feelings of having no options as none sat with their personal preferences. But it was generally accepted that the clinical should provide options for the patient.

The second expectation of the doctor was provision of medical advice. Participants described expecting advice from the doctor in order to make up for a lack of medical knowledge on their part:

“Well, I expected her to give me her professional advice. Yeah, you know, I haven’t got strong ideas myself about health. Not really.” – Mrs E

But it was recognised by participants that the advice was from a medical perspective and that they still had final control over the decision:

“Although, they only advise. They can’t actually tell you what you should be doing. They advise what they medically think you should be doing.” – Mrs G

This again highlights the distribution of expertise between the patient and their doctor.

A further role of the doctor was need for discussion in order to be able to make a decision; this was described by many of the participants. One concisely explained how she would like to make shared decisions encompassing all three aspects that were identified by the participants as a whole:

“I think I would discuss it and then, um... hear what they’d got to say and what their advice was and then decide whether I... if it was something that wasn’t crucial, that it was a sort of options... then I would discuss it with them and decide whether I wanted to take that option or not.” – Ms B

Overall, these three aspects give the clinician an assistive role which, in turn, enables the active role that the older adults preferred for themselves.

Additional to the assistive roles of the doctor, there was a sense of needing to have a positive relationship to facilitate shared decisions:

“The way we’re going, where we can have any old GP, nothing wrong with GPs, but I think that as human beings we need to establish relationships.” – Mrs C

Various terms were used by participants to describe the quality of the relationship that they felt was needed with the doctor, including faith, honesty and trust. Additionally to this sense of trust in the doctor, participants also identified that there needed to be a level of respect for their doctor in order for shared decisions to be made:

“I think it’s important that you have trust and respect for your consultant or GP” – Mrs G

It was also highlighted on several occasions that the doctors’ demeanour would impact on the nature of the relationship and the ability to make a shared decision with them. As a result of the need for a relationship, some participants reported they could make decisions with their GP, but not hospital doctors. The need for a human relationship with a doctor in order to feel comfortable making a decision, and the reported lack of ability to build positive relationships between patients and hospital doctors can be identified as a patient perceived barrier to SDM.

Perceived influence of the family: direct and indirect roles

The role of the family was widely discussed. Family were frequently identified as key providers of support and significant contributors to decisions. Broadly, the role of the family was direct,

with specific input into the decision making process, and indirect, where the family impacted on the chosen option without active involvement.

Direct role of the family in shared decision making

Active involvement of family was identified by many participants who preferred to share their health problems with their relatives. Several decisions were made with the assistance of family members. Female participants frequently described the role their daughters' had in their decisions. In one participants' experience, the daughter was a key part in clinical consultations, often fulfilling the active roles ordinarily attributed to the patient:

"My daughter made notes, because I couldn't contain anything. I just couldn't take anything in." – Mrs G

In this instance, the daughter also had a large impact on the final outcome as to whether Mrs G would opt for treatment or not. A second participant described the importance of involving her daughter in the decision making:

"Because it can put things in perspective, you know, sometimes if I were to misinterpret something my doctor said I would question it with her and she'd... she'd probably take his side or, no, take his point of view and point out what he meant." – Mrs C

However, in this case, there was complex relationship as the daughter was a medical professional. While the input from the daughter was appreciated by the participant, there were also instances in which the participant reported withholding information from her daughter because she did not want to be *"lectured"* on areas of contention.

Other family members were also described to be actively involved in the decisions made by the participants. One participant reported how his brother had helped him to decide whether to have surgery done under the NHS or to go to private practice instead:

“And I was thinking of going private but then my brother said it would cost several thousands, he said, “If they’re gonna see you within two and a half weeks, there’s not much point.” – Mr H

In other instances when participants were considering the monetary implications of particular healthcare decisions, the family were described to have an active role in the decision. In some cases, the family member made the final decision. While this role was often taken on by the spouse, other family members also had input.

The family is clearly perceived to have an important role in the decision making process and SDM from the perspective of older people. Some of the family roles described by the participants align with roles outlined in Charles’ article (1997), but some of the input from family members during the interviews does not fit easily into these categories, in particular the role of the family in financing healthcare.

Indirect role of the family in shared decision making

Additionally, the family also impacted indirectly on the outcome of health-related decisions. Several of the participants described making a particular decision after considering how it would affect their family:

“So I told him I wanted him to go ahead, because I wasn’t going to put my family through that.” – Mrs A

Family values, including aspects of upbringing, were also described. The values of her mother were described extensively by one participant and informed her decision making as an adult:

“My mum was a nurse and you weren’t given, you know... today is the first day of the rest of your life. Are you going to spend the rest of your life lying down and moaning because you’re in pain with a period or whatever do you get up and get on with your life? And having been brought up like that, I am like it.” – Mrs C

The interviews highlighted the role of the family as being broad and of high importance to older adults in the context of SDM.

Summary

The results suggest a varied understanding of SDM by older adults, in part, due to lack of awareness. It also highlighted the importance of defining decisions. Throughout the interviews there was recognition of the roles of three parties within health-related decision making. The participants identified that they would like to have an active role in decision making and described ways in which this active role should be executed. They also outlined the role of the doctor, describing how they wanted to be assisted with decision making. Additionally, participants identified the relationship they had with their doctor impacted on their ability to make a shared decision. Finally, participants identified the importance of sharing decisions with family and described both direct and indirect roles for the family. Some of roles of the family have not been discussed previously.

DISCUSSION

Relevance to existing research

SDM is a sharing of expertise by both the patient and the clinician (Coulter and Collins, 2011). This research suggests that older people also recognise the distribution of expertise. Older people identified that they were experts in their own body, but indicated the medical and scientific knowledge needed to be provided by the clinician. Despite having experienced a change in medical model (Kaba and Sooriakumaran, 2007), older adults have similar perceptions of SDM to the perceptions of patients in other qualitative studies (Shay and Lafata, 2014). The importance of the patient-doctor relationship described also agrees with previous qualitative work (Shay and Lafata, 2014). Other literature has identified that SDM between a clinician and an older adult can increase trust between the patient and the doctor (Butterworth and Campbell, 2014). However, as older adults feel a level of trust and respect must already exist before making a shared decision, there is a potential reciprocal relationship between patient-clinician relationship and SDM.

Older adults in this project expressed how they had an active role in decision making, including knowing their own bodies and asking questions. This differs to a survey that found preference for an active role in medical decision making declined with age (Levinson et al, 2005). During the interviews, it emerged that older people had a preference for an active role

and, within the scope and sample of this research, there did not seem to be any declining interest in SDM with age. Levinson (2005) used a survey-based approach, but the semi-structured interview approach used in this research allowed a more in depth investigation suggesting older adults still prefer an active role.

The role of the family is a less well-documented area within SDM. Charles' initial article proposed several roles for family members and there has been some investigation into the role of the family regarding decisions surrounding dementia (Miller, *et al.*, 2016). Within this project, some participants expressed that families had taken on some documented roles, however, there were also instances in which family members were involved in ways that have not yet been described. There were several situations in which the family had a considerable role in deciding how healthcare funding, which has not yet been described. It should be noted that some literature questions the role of the family, suggesting that the family may have a negative effect on the patients' identity and autonomy (van Nistelrooij *et al.*, 2017). Further research into the role of the family may be necessary to fully understand their role and the implications that it may have.

Relevance to clinical practice and further research

This research, alongside previous work, outlines the preference of older adults for active roles in decisions (Dardas *et al.*, 2016; Miller, *et al.*, 2016). Previous studies have shown that older people are not involved in SDM to the extent that they would like (Miller, *et al.*, 2016). Therefore, facilitation of older adult involvement should become a priority within clinical practice. This would enable older adults to benefit from the higher probability of improved outcomes as a result of SDM (Shay and Lafata, 2015).

Improving awareness of SDM among older adults should also be a clinical focus as the majority of older adults are not familiar with SDM. Clinician training programmes have been shown to allow better facilitation of SDM, but the possibility of patient workshops in SDM still needs investigation (Sullivan, *et al.*, 2006; Hoffmann, *et al.*, 2014).

In light of the importance of family to decision making, clinicians should recognise that older patients may wish to involve family and should aim to facilitate discussions between family

members. Some studies have investigated the use of family meetings in the context of SDM for dementia patients (Milte *et al.*, 2015). Further research could help clinicians to involve the family to the preferred level of the patient. Qualitative research would be preferable in order to fully understand patient perceptions and preferences and should recognise the potential for direct and indirect roles of the family in SDM.

Limitations

Sample size is a limitation for this study. Recruitment, particularly of older men, proved problematic, therefore, theoretical saturation was not reached (Austin and Sutton, 2014). Additionally, the use of convenience sampling resulted in little variation in demographic characteristics. Therefore, it was not possible to compare perspectives between men and women and between ethnicities.

An unforeseen limitation was the high prevalence of participants' close contact with medical professionals. Three participants had a child practicing as a nurse, one participant had children who were doctors and a further participant had worked in several health-related jobs. It is possible that the increased awareness of medical topics may have impacted on the results of this project, particularly when discussing the role of the family, as there was overlap between roles in situations where a family member was also a healthcare professional.

CONCLUSION

This research project set out to understand the experiences and perceptions of SDM from an older adults' perspective. Interviews with older adults allowed the exploration of a number of health-related decisions and uncovered key opinions regarding decision making.

Firstly, older adults described the ways in which they felt they should be active in making decision about their health, including their sense of knowing their own body to a greater extent than their clinician. But there was also recognition of the distribution of knowledge which is key to the process of SDM. This project also highlighted a lack of awareness of SDM from the perspective of older adults. Older adults described situations in which their families

had both direct and indirect effects on their decision making and investigation into how this role can best be harnessed by clinicians to aid the decision making process would be beneficial.

In conclusion, older adults share many of the views which have been uncovered in studies of SDM in the general population, but they also highlight areas that they consider to be important and require further research or better integration into clinical practice.

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