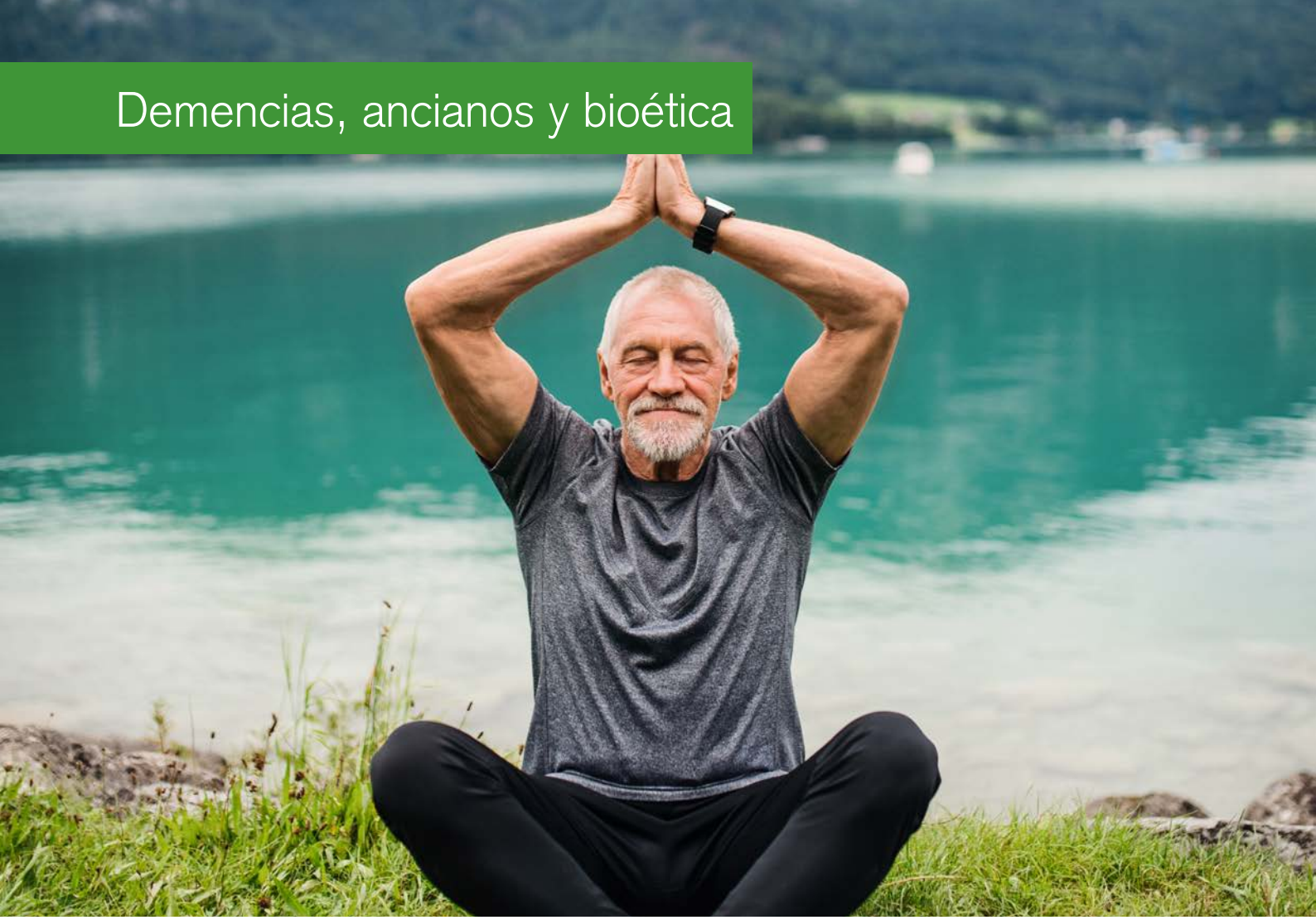

Knowing Oldest Old's Preferences May Improve their Healthcare: A Qualitative Study

Conocer las preferencias de los ancianos puede mejorar su atención médica: estudio cualitativo

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Abstract

Oldest old people's preferences are not taken into account though their importance in healthcare planning. To identify them, we undertook a qualitative study, using in-depth interviews, in a rural area of Toledo, Spain. The majority of participants rate the health care received as good. They favour building a trusting relationship with the physician, choosing to receive enough treatment to avoid the burden of suffering. They express the wish to die at home, but when an acute event occurs they want to be transferred to hospital. Knowing oldest old people health values will help to develop suitable healthcare systems.

Resumen

No se suele tener en cuenta las preferencias de los ancianos y es muy importante para la gestión de la atención sanitaria. Para identificarlos, realizamos un estudio cualitativo, mediante entrevistas en profundidad en una zona rural de Toledo, España. La mayoría de los participantes califican la atención sanitaria recibida como buena. Están a favor de construir una relación de confianza con el médico, optando por recibir el tratamiento necesario para evitar el sufrimiento. Expresan el deseo de morir en casa, pero cuando ocurre un episodio grave quieren ser trasladados al hospital. Conocer las preferencias de los ancianos ayudará a desarrollar sistemas de salud adecuados.

Key words

Aged; 80 and over; clinical ethics; patient acceptance of healthcare.

Edad; 80 años y más; ética clínica; aceptación de la atención médica por parte de los pacientes.

Fechas

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1. Introduction

The population of older people is rapidly expanding; therefore, the burden on the allocation of healthcare resources is becoming greater. The greatest population increase is observed in the oldest age group (people 90 years of age or above), which implies that the largest proportion of healthcare resources over the next decades will be dedicated to this group. Therefore, we need to reconsider which healthcare services we are delivering to a population with specific needs.

The gaps between the services provided and what really matters to the patient suggest that making healthcare decisions is not centred on the older people's individual choices. And we know that being aware of the patients' attitudes and preferences is a central part of what determines high quality end-of-life care (Lynn, 2013)

There is growing concern that the national health systems fail to deliver high quality care that is aligned with the needs and preferences of the oldest old, due to both the lack of interdisciplinary skills and specific training in the care of the older people and the coordination between sites of care (Meier, 2014). The gaps between the services provided and what really matters to the patient suggest that making healthcare decisions is not centred on the older people's individual choices. And we know that being aware of the patients' attitudes and preferences is a central part of what determines high quality end-of-life care (Lynn, 2013).

Unfortunately, there is a lack of appropriate information about the oldest old's wishes and choices for end of life care. Knowledge based on younger persons' choices may be of limited value for understanding of the end of life needs among the oldest old, yet they are generally excluded from qualitative research studies because of assumed troublesome communication. It appears that growing evidence in this approach will work to enhance healthcare for older people, and thus contribute to the design of healthcare services in accordance with their needs (Mack, Weeks, Wright, Block, & Prigerson, 2010).

The present study attempts to fill this void in knowledge by helping to understand oldest old patients' preferences with regards to end of life healthcare. The aim of this paper is to identify the preferences of oldest old people in a rural area concerning their end of life healthcare, paying particular attention to their current values and attitudes towards ageing and death, in order to deduce how their ideal healthcare would be. Our hypothesis is that we can enhance the healthcare received by oldest old patients if we know which their attitudes and preferences about healthcare are.

2. Methods

We used a qualitative method using in-depth interviews. Qualitative methods allow the study of structural relationships within the social group being investigated thus obtaining a theoretical framework from the people comments.

We chose the in-depth interview to avoid the bothersome requirement of travelling for the oldest old participants. We conducted non-structured interviews with 27 oldest old

people (see guideline in appendix). Every 90 years old or above people living at home in six small towns in a rural area of Toledo, Spain, were recruited, approached by their general practitioner, excluding those with cognitive or hearing impairment. Characteristics of the participants are shown in table. We selected the sample size through the principles of theoretical saturation. Conversations were audiotaped and transcribed literally, with interviewees consent. A detailed scrutiny of the transcripts was carried out to identify different topics, which were then coded using *Atlas.ti* software. Data collection and subsequent analysis was carried out using the methods of constant comparison of grounded theory.

Table. Characteristics of participants

Participants	N = 27
Sex	7 male, 20 female
Age range	91-102 years
Median	93.4 years
Marital status	3 single, 5 married, 19 widowed

3. Results

After coding and creating new categories, we found three major themes: 1) Coping with ageing states the wish to die or being cared; 2) attitudes towards healthcare received; and 3) preferred healthcare.

3.1. Coping with ageing states the wish to die or being cared

Those older people who have positive feelings about ageing, rate their health as good. Anyway, it is assumed that their subjective health depends more on symptoms and disabilities than on the number of chronic comorbidities they suffer (Enkvist, Ekström, & Elmståhl, 2012).

> Interviewer (I): Do you think ageing is a disease?
>
> Participant (P). 1: "No, I don´t think so… ageing is having good luck."

To engage with a positive subjective well-being they use coping strategies such as resignation, acceptance or spirituality. For example, they do not look to accelerate death, since they believe that death is determined by God or by fate, and cannot be fought against. Instead, ageing stereotypes ("ageism") or the fear of becoming a burden, deteriorate the very aged patient's satisfaction with life. In spite of their high prevalence of losses and diseases, negative feelings were less notorious in the study sample.

> P. 4: "So, if death nears, it doesn´t matter what I think. It´s God´s desire, so my opinion is of no value…"

Those oldest old people who accept ageing, and live life on a day-to-day basis, do not think about death. They make financial and funeral arrangements to lessen the burden for their children. However, older people who reject ageing show desires of death, as a means of breaking away the ties that arise with advanced age.

P. 16: "Why should I think of death? It will come alone, to everybody, at any time. It doesn´t respect anyone…"

P. 23: "Sometimes I wish to die, because I cause trouble. I need to get out of bed in the night, and I can´t walk alone. I´m boring my daughter every time…"

3.2. Attitudes towards healthcare received

For most interviewees, building a trusting relationship, having enough time and receiving information are fundamental in contact with professionals

The vast majority of participants think they receive good healthcare. They also think younger people does not deserve more consideration than older people when dying. For most interviewees, building a trusting relationship, having enough time and receiving information are fundamental in contact with professionals. However, they assume a subordinate status in which they should do what their physician says.

P. 20: "I trust my doctor a lot. If she says let's take medicine, I'd say I obey her."

3.3. Preferred healthcare by oldest old people

They desire a quick and peaceful death, free from pain and suffering.

P. 5: "A good death to me would be to go to bed at night and not wake up in the morning. And you're not in any pain".

The majority of the aged interviewees choose to receive enough treatment to avoid the burden of suffering.

P. 4: "Well, I think doctors must keep people alive, even though they are very old".

However, for a person with much lower quality of life (with impairments or disabilities), life-prolongation is not attractive. Nevertheless, they will accept symptomatic therapies in order to approach a good death.

All of the participants expressed the wish to be cared and die at home. The main reasons cited by the participants were the presence of family, and limiting mobilization of relatives. Most participants described home in symbolic terms as somewhere you could be comfortable, with the presence of personal possessions and loved ones:

I: What do you think about home?

P. 9: "It's because your love's there. Home is your life, your family, your memories".

But when an acute event occurs, many participants felt that better quality care, in a technical sense, could be provided in hospital. However, that is not their chosen site of death; they prefer to die at home.

4. Discussion

The oldest old's preferred place of death is not respected. Despite the "home" being their preferred site of death due to its symbolic meanings, the presence of loved ones, confidence and being repository of memories, the very aged do not usually die at home

Oldest old people have a high prevalence of illness and disability. Approaching the end of life, functional decline accelerates and contact with the healthcare system becomes more frequent (Somogyi-Zalud, Zhong, Lynn, & Hamel, 2000). Aging stereotypes ("ageism") or the fear of becoming a burden, deteriorate the very aged patient's satisfaction with life. However, the prevailing accumulation of losses is not associated to a significant decrease in the subjective well-being, since higher levels of happiness have been noted above all in the very aged (Márquez, Izal, Montorio, & Pérez, 2004). This apparent contradiction can be attributed in part to the coping mechanisms the elderly use to face old age, such as acceptance, resignation or spirituality (Martin, Rott, Poon, Courtenay, & Lehr, 2001).

Generally, health related quality of life does not deteriorate with advancing age because its main component, subjective health, remains stable through the process of ageing. Oldest old people value certain aspects relating to quality of life that younger people do not appreciate. Nevertheless, it is possible that health related quality of life declines at the end of life, mainly due to the fact that the prevailing functional trajectory at this time implies prolonged gradual decline, with multiple hospital admissions or moves between different care settings (Murray, Kendall, Boyd, & Sheikh, 2005).

A second reason for quality of life decline is due to the fact that the oldest old's preferred place of death is not respected. Despite the "home" being their preferred site of death due to its symbolic meanings, the presence of loved ones, confidence and being repository of memories, the very aged do not usually die at home. The majority of deaths occurs in institutions (hospitals or nursing homes) (Fischer, Min, Cervantes, & Kutner, 2013). However, it is not easy to know the preferred place of death of the very aged since there has been very little research done on the matter. We do know that they seek comfort and safety, but this could be met by different health services.

In order to define old people's preferences at the end of life, we should assess their health values associated to the concept of "good death". Their most important elements are coordinated care, adequate symptom control, having their choices respected, strengthening relationships with loved ones and achieving a sense of completion (Dy, Shugarman, Lorenz, Mularski, & Lynn, 2008). Nevertheless, preferences are highly individualized, so we should try to elicit them from each patient.

Medical literature reveal the opinion that oldest old patients think that they receive good healthcare, as we found in our study (Jaipaul & Rosenthal, 2003). However, we must be cautious when considering these results since the oldest old may not be too critical when

giving opinions, due to their low educational attainment. Perhaps in successive generations the old people may be more demanding and critical with the healthcare they receive.

A wealth of evidence indicates that many oldest old patients want to discuss issues related to end of life problems with their healthcare professionals and families, so as to be involved in their own care (Bastiaens, van Royen, Rotar-Pavlic, Raposo, & Baker, 2007). This however rarely happens, because there is a lack of communication between providers and older patients, who often fear being misunderstood or burdening loved ones, especially if there is a reluctance amongst family members to discuss end of life care (Sharp, Moran, Kuhn, & Barclay, 2013). Physicians do not accurately know patients' values and goals of care, and they maintain great decisional uncertainty after such discussions with their patients (Fischer, Tulsky, Rose, Siminoff, & Arnold, 1998). But it is very important to know the older people's health values, which they are able to express, as we confirmed in our study, since it enables the physicians to understand the individualised preferences of those they care for.

The traditional model of physician-patient interaction is paternalistic. The physician is empowered by his technical knowledge and the patient is characterized by an unquestioning belief in the physicians' expertise. This is the preferred model chosen by oldest old patients

Oldest old people may well exhibit different attitudes concerning patient involvement in medical decision-making. They appreciate a relationship that embraces values such as trust, support, and discussion of feelings. They much more appreciate the building of a personal relationship with their physician rather than acknowledge his technical expertise (Rotar Pavlic, Svab, & Wetzels, 2008). The rural setting, like that where we run our study, seems to be a good environment to initiate physician-patient communication.

The traditional model of physician-patient interaction is paternalistic. The physician is empowered by his technical knowledge and the patient is characterized by an unquestioning belief in the physicians' expertise. This is the preferred model chosen by oldest old patients, although their frequent health illiteracy raise doubts about the information they have available (Jung, Baerveldt, Olesen, Grol, & Wensing, 2003).

The medical literature assumes that older people maximize their quality of life at expense of quantity, and give more importance to comfort and symptom control rather than to life-sustaining treatments (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013). On the contrary, in our sample, we found that oldest old people interviewed chose to receive enough treatment to avoid the burden of suffering, using high technology if necessary, even though it may harm their quality of life or extend their life. Nevertheless, these preferences could be biased owing to a lack of information about suggested interventions, or a sparse communication of expected outcomes (McCarthy, Pencina, Kelly-Hayes, Evans, Oberacker, D'Agostino, Burns, & Murabito, 2008).

In any case, the older people focus their preferences on the perceived outcomes of serious illness rather than on the specific medical interventions themselves (Lum, Sudore, & Bekelman, 2015). We must therefore refocus our goals of care in order to adapt them to the oldest old expected outcomes: functional and cognitive recovery, self-sufficiency or the relieving of being a family burden. Oldest old people would prefer healthcare

services that reduce functional decline and age-related complications, which boost their capabilities and social networks. Nonetheless, they appreciate being admitted to hospital if this is crucial in the restoring of their functional abilities. Oldest old people favour flexible healthcare services, continuity of care with general practitioner guidance and adaptation of care provision to individual circumstances and preferences (Bayliss, Edwards, Steiner, & Main, 2008).

Our study is consistent with previous research which reveal that most oldest old people express the wish to be cared and die at home like the rest of the population, essentially due to fear of being alone, or of losing their independence (Hunt, Shlomo, & Addington-Hall, 2014). But as death nears and illness progresses, they want to be transferred to hospital (Lock & Higginson, 2005). They choose to be admitted to inpatient facilities when symptom control and quality of life cannot be accomplished at home, since they consider that hospitals can provide the advanced technology required in interventions.

The chosen place of care will be the one which fulfils the patient's requests and facilitates comfort and safety (Fried, van Doorn, O'Leary, Tinetti, & Drickamer, 2000). Consequently, we must target our efforts to enhance home healthcare, if we wish to satisfy these wishes.

5. Implications for practice

The results of our study have significant clinical and policy implications in order to improve healthcare for the oldest old.

The physician-patient relationship needs to evolve from traditional paternalism into a relationship that promotes patient autonomy. This relationship could change if we are able to open communication and offer more information to the older patient

Completion of advance care statements is not sufficient to elicit oldest old people's preferences in decision-making. Preferences may change over time (Collins, Parks, & Winter, 2006), so it may be preferable to begin an integral and continued process of discussion and review between patients, families and healthcare professionals, generally known as advance care planning (Lum, Sudore, & Bekelman, 2015).

Oldest old people prefer to establish a trusting relationship with their healthcare professionals and their family than to settle on decision-making, with a great desire for decisions to be made for them by competent others. The physician-patient relationship needs to evolve from traditional paternalism into a relationship that promotes patient autonomy. This relationship could change if we are able to open communication and offer more information to the older patient. We must encourage more explicit communication between patients, providers and families, through on-going discussions, focused on expected outcomes and patient's goals of care.

We should adapt healthcare services to meet the subjective needs of the oldest old patients. A healthcare system designed to look after oldest old people should be based on trends towards individual and flexible care, preventive attitude, coordinated care between health care services, prevalence of ambulatory care, assessment and monitoring

by interdisciplinary teams, continuity of care and promoting social services and caregiver support (Meier, 2014).

By investing in research on the oldest-old's preferences and promoting communication, we can deliver healthcare systems designed to deal with their specific needs. Such a healthcare system could undoubtedly enable a growing number of oldest old people to be treated and allowed to die in their preferred conditions and in their chosen place.

6. Conclusions

1. Oldest old people may wish to participate in decision-making, so we must encourage more explicit communication between patients, providers and families, through on-going discussions, focused on expected outcomes and patient's goals of care.
2. Oldest old people prefer to establish a trusting relationship with their healthcare professionals and their family than to settle on decision-making.
3. We ought to know oldest old people healthcare preferences at the end of life in order to satisfy their needs in decision-making and to build healthcare systems for the elderly.

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Appendix

Non- structured interview guideline

1. ¿Qué supone para usted ser viejo/mayor? *(What does it mean to you to be old?)*
2. ¿Cómo se encuentra usted de salud? *(How are you in health?)*
3. Cuénteme, en pequeños rasgos, qué enfermedades ha padecido. ¿Ha ingresado alguna vez en el hospital? *(Tell me, in small features, what diseases you have suffered. Have you ever been admitted to the hospital?)*
4. ¿Cómo es la relación con su médico y enfermera de cabecera? *(How is the relationship with your general practitioner and family nurse?)*
5. ¿Qué opinión tiene del hospital? En caso afirmativo, ¿cómo considera la atención que recibió? ¿Qué debería mejorarse en la atención a las personas mayores en el hospital? *(What do you think of the hospital? If so, how do you consider the care you received? What should be improved in the care for the elderly in the hospital?)*
6. ¿Ha pensado alguna vez sobre la muerte? ¿Ha hecho algún preparativo sobre ella? ¿Qué piensa sobre la muerte? *(Have you ever thought about death? Have you made any arrangements? What do you think about death?)*
7. ¿Dónde querría usted morir? *(Where would you like to die?)*
8. ¿Cómo querría que se le atendiera al final de la vida? ¿Querría que se hiciera todo lo posible por mejorarle a cualquier precio, o primaría estar más confortable antes que vivir más? *(How would you want to be cared for at the end of your life? Would you like to do everything as possible to ameliorate you at any price, or would you prefer to be more comfortable than live longer?)*