Introduction

An aging population will lead to a growing number of older individuals with multiple age-related comorbidities and functional disabilities (Buurman, Frenkel, Abu-Hanna, Parlevliet, & de Rooij, 2016). These individuals are more vulnerable to acute deterioration in health, and at some point many of them will be hospitalized (Hallgren et al., 2016). Acute hospitalization of older people is associated with high 1-year mortality (Fløjstrup, Henriksen, & Brabrand, 2017). Some of these patients could therefore be considered as being in, or nearing, the end of their life. Throughout acute hospitalization, the older patient and their families are faced with decisions and tasks they may not previously have considered. These could involve discussing the end of life (EOL) along with preferences in regard hereto, such as life-prolonging treatment and cardiopulmonary resuscitation.

The older population have demonstrated a willingness to discuss EOL, and experiences of the process of dying were present among all participants. Three themes emerged during the analysis: (a) Being independent is crucial for the future, (b) Handling and talking about the EOL, and (c) Conditions in Everyday Life are Significant. Life experiences seemed to affect the degree of reflection of EOL and the decision-making process. Knowing your population of interest is crucial, when developing an approach or using an advance care plan from another setting.

Abstract

What matters at the end of life (EOL) among the older population in Denmark is poorly investigated. We used focus groups and in-depth interviews, to identify perspectives within the EOL, along with what influences resuscitation, decision making, and other treatment preferences. We included eligible participants aged ≥65 years in the Region of Southern Denmark. Five focus groups and nine in-depth interviews were conducted, in total 31 participants. We found a general willingness to discuss EOL, and experiences of the process of dying were present among all participants. Three themes emerged during the analysis: (a) Being independent is crucial for the future, (b) Handling and talking about the EOL, and (c) Conditions in Everyday Life are Significant. Life experiences seemed to affect the degree of reflection of EOL and the decision-making process. Knowing your population of interest is crucial, when developing an approach or using an advance care plan from another setting.

Keywords

end-of-life issues, death, dying, quality of life, older people, aging, decision making

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and these experiences might be useful to know when discussing EOL with an older individual. Patients, family, and care providers play a crucial role in shaping the EOL experience, and factors considered important at EOL have previously been reported among both health care providers, family, and patients as being diverse (Steinhauser et al., 2000). Patients compared with physicians tended to view the EOL with a broader psychosocial and spiritual meaning, shaped by a lifetime experience (Steinhauser et al., 2000).

Knowledge among the old population in general regarding EOL experiences, preferences, and attitude toward decision-making is, to our knowledge, lacking. What matters at the EOL, and whether the old population want involvement in this decision-making process, still remain important questions among the older population. The aim of this qualitative study of semistructured interviews was to obtain knowledge of what matters at EOL among our older population in the Region of Southern Denmark. Furthermore, we wished to identify perspectives and experiences within the EOL, along with what influence resuscitation decision-making and other treatment preferences at EOL.

**Method**

This study is reported using the consolidated criteria for reporting qualitative studies (COREQ; Tong, Sainsbury, & Craig, 2007).

**Design**

We used focus groups and in-depth interviews to explore how the older population in the Region of Southern Denmark understands and experience the term EOL. We developed a semistructured interview guide based on the literature and on experiences from clinical practice. We used the interview guide in both focus group and in-depth interviews to facilitate discussion about the following themes: quality of life in the daily living, what matters in EOL, preferences regarding treatment at EOL, and sharing thoughts and perceptions of what contributes to a good death. We used open and closed questions when appropriate in the interview (Pleschberger et al., 2011).

**Theoretical Framework**

A hermeneutic-phenomenological approach was used based on theories of hermeneutic and phenomenology (Malterud, 2002). We explored the meaning of the phenomenon by being open to what was experienced, perceived, and reported by the individuals themselves. Results were later interpreted based on the researchers’ preunderstandings. This contributed to a manifold and in-depth description of the phenomenon investigated along with different perspectives that might be relevant to the underlying construction of data (Malterud, 2002). From a hermeneutical approach, this process of interpretation of different meanings of the text is endless, but in practice, it stops when the meaning of a subject is constant and reasonable (Kvale, 1996).

**Participants and Setting**

We invited older adults from nursing homes, the emergency department, along with community-dwelling older adults from two sites, Esbjerg and Odense, in the Region of Southern Denmark. A heterogeneous purposive sampling (Curtis, Gesler, Smith, & Washburn, 2000) and snowball sampling (Atkinson & Flint, 2001) was used to include a diverse range of the older population of interest in Denmark. Participants eligible for inclusion were ≥65 years old and able to give informed consent. Participants known with any cognitive impairment, such as dementia, were excluded. Community-dwelling older adults were interviewed in focus groups, whereas older adults from nursing homes, and those patients admitted at the emergency department, were interviewed in depth individually. We aimed at recruiting older adults with different working experience to get as many perspectives as possible. Focus groups consisted of three to five participants, and each focus group consisted of participants from the same environment, for example, the same fitness team, bridge-club, or patient organization. All this was designed not only to create a safe environment for sharing opinions and experiences concerning the EOL but also to ensure the opportunity for everyone’s perspective and opinions to get shared.

**Data Collection**

We conducted five focus groups and nine in-depth interviews over an 8-month period from November 2016 to June 2017. We conducted three in-depth interviews at the University Hospital in Odense and six in-depth interviews at two nursing homes in the city and a rural area, respectively. The interview guide was developed based on our research questions and the literature (see Online Appendix 1), and tested in the first focus group in Odense that acted as a pilot test, but was, due to its quality, inspired by Kvale’s quality criteria of the interview (Kvale, 1996), included in the analysis.

All interviews, except those performed at nursing homes, took place in a convenient neutral location away from the participants’ home. We performed the interview in a quiet room without any disturbance at the emergency department. Main author S.H. was the interviewer in all the interviews and author D.N. was the observer present in all focus groups. There was no prior relationship between the participants and the interviewer. The aim was presented to the participants and the interviewer followed the interview guide but was
open to new themes brought up by the participants. All were actively involved in the interviews.

**Data Analysis**

All interviews were audiottaped and transcribed verbatim by author S.H. During the interviews field notes were made. Coding and analysis were performed systematically using the software QSR NVivo Pro 11. The analyses were inspired by using the analytical tool systematic text condensation by Malterud, developed from Giorgi’s psychological phenomenological analysis (Malterud, 2012). The main purpose was to systematically organize and compare the interpretation of data. Systematic text condensation aimed for thematic analysis of meaning and content of data across cases and involved four steps (Malterud, 2012). First step included an open minded, not systematically, reading of all the transcribed data. Authors S.H. and D.N. both read the transcripts and preliminary themes were identified independently and then discussed, and compared. In the second step of the analysis, we identified meaning units with relevant information to the research questions. This was done by fragmenting the text into meaning units and coding them with help of QSR NVivo. Coding groups were colored and represented data from both the focus groups and individual in-depth interviews. Third, meaning units were systematically organized and decontextualized from the original data form into thematic code groups. Finally, data were reconceptualized and validated and the meaning of the phenomenon was presented and reflected by the empirical data.

**Research Ethics**

All participants participated voluntarily and gave their verbal and written consent after thorough information about the study in both oral and written form. Participants had time for reflection and were able to ask any questions to the researchers before the written consent was given. Confidentiality was emphasized to all participants, along with the rules of the interview, in the beginning of each interview. They were familiar with the possibility of ending the interview with no following consequences, and only to tell and share what they found acceptable. Participants were pseudo anonymized and the initials presented in the text are fictive. There was no financial gain or compensation for participation.

**Results**

Focus group interviews lasted between 60 and 90 min, whereas the individual in-depth interviews lasted between 25 and 75 min. We interviewed 31 participants in total (22 in groups and nine individually). We interviewed 12 women and 10 men with a median age of 74 years, range 65 to 88 years, in five groups. One of the groups consisted of seven participants, because it was arranged with three couples (seen as one unit each) and one bereaved spouse. Five women and four men with a median age of 91 years, range 69 to 99 years, were interviewed individually. We started with a short presentation of each participant in each individual interview and focus group (Pleschberger et al., 2011). All participants were willing to share their experiences; many of them particularly thanked the researchers in the end of the interview for this chance to discuss and talk about death and EOL. Three themes emerged (Online Appendix 2): (a) Being independent is crucial for the future, (b) Handling and talking about the EOL, and (c) Conditions in everyday life are significant. We did achieve operational saturation within the first three of the focus groups, as the majority of the codes defining the three major themes were identified here. However, the following focus groups and in-depth interviews did add new perspectives and experiences, making our data richer. Even though total data saturation can be difficult to achieve, we were satisfied with our theoretical saturation of data (Wray, Markovic, & Manderson, 2007).

**Being Independent Is Crucial for the Future**

The first subject of conversation was about quality of life, such as what brings value into the participant’s daily life. The majority of the participants pointed out the importance of being well and independent in daily living. Most of the participants feared loss of functioning both mentally and physically, and actually some of them referred to dependency of other people as being “the end-of-life.” A 74-year-old physically self-sufficient woman said,

I would say: If I should imagine not being able to take care of my own personal hygiene . . . Then I really don’t know if I want to be here anymore.

She was, in this statement, immediately backed up by three out of four women in the group, confirming that this is where the line is drawn. One of the women expressed.

I don’t hope, that I end up needing help from other people. I would like to end my life with some dignity.

Several of the participants stated that anytime they could find themselves in the EOL, as life can change any minute when you are old.

Getting old and dying with dignity was frequently mentioned both in and between the lines by many of the participants. Several of them confirmed it is not just about life-prolongation and getting old, but instead quality in the daily living that counts.

So, quality of life for me, would mean that you can live a good life and take care of yourself in a decent way until you are not here anymore, but not that life should be prolonged in any way.
Furthermore, a good death was, by an 82-year-old male interviewed at the emergency department, referred to as

That the lights turn off [life ends], and I don’t get senile, demented, or not able to recognize myself or my children.

Dignity was furthermore connected to physical ability and being independent. A 91-year-old woman, from one of the individual interviews at the nursing home, had lost the ability of walking within the last 6 months, and she clearly stated,

I have said it many times and I still claim that if I am not going to walk again, then I rather die.

The woman underlined that she loved to walk around in the city. Being active, in and among other people and the busy life around her, made her feel alive. She explained in the interview that she never would be able to harm herself, and thus wanted to die in a natural way. This fear of losing physical ability and function was also present among the men. In one of the groups, they stated that the thought about being dependable of the primary care system, generated anxiety. The idea of moving to a nursing home, where someone could take care of them, was not something they were looking forward to, actually one of them pronounced,

“Because, when you are getting old and aren’t able to take care of yourself anymore, then you should look forward moving to a place, where someone could take care of you” . . . “But, you are not! It is terrifying.”

They argued that the cost reduction within the primary health care system along with the increasing old population had changed the terms of being old. Nursing home residents today are frail, old, and often demented, which had importance to participants view of the future and to the possibility of moving into a nursing home. An 83-year-old woman, who often was visiting her cousin in a nursing home, mentioned,

“But, when you visit her, you see a table only with demented people. They sit there and one of them is slouching more than the other” . . . “You know what? If you are not already crazy, you will be.”

A similar experience was shared by the 82-year-old man interviewed at the emergency department:

We do see it at the center [Respite care center], how they are slouching, one more than the other, there is no spirit in them anymore, they just sit there and slouch and the food is [hanging out of their mouth] . . . [sighs and do not finish the sentence]

Another worry connected to the nursing home was the fear of being left alone or to end up lonely and isolated. One woman living in a nursing home complained about the rare visits from the busy health care professionals. She often felt alone and insecure and explained,

But, if you are in a nursing home and becomes seriously ill, the care providers won’t have the time to visit, and then you die alone.

The woman argued that she would therefore, if possible, rather choose to die in a hospital than in her nursing home. Thus, as we (the researchers) talked with the participants in the interviews about thoughts regarding the future and quality of life, they naturally began talking about EOL, death, and shared their fears in regard hereto. The participants feared losing physical function, control over themselves, and identity. Those considerations were consistent among almost every participant interviewed. When asked about his physical ability, the 89-year-old man from the emergency department said,

So, it means a lot to you that you can maintain the physical function you have? (Interviewer)

“Yes” . . . “That you can do the things you want to” . . . “And should I say, be respected!” . . . “Because, when you are reaching the age I have, someone will say: “Such an old bastard.”

Handling and Talking About the EOL

Thoughts concerning the EOL became an issue in all focus groups and in most of the individual interviews. Both the youngest and the oldest participants suggested the importance of talking about death, dying, and wishes regarding treatment at the EOL with friends, family, or their general practitioner. Talking about EOL was actually reported in one of the individual interviews as being a natural thing on the way of becoming old. However, a few of the participants, mainly from the nursing homes, did not wish to think about death or the last part of their life. They explained, these thoughts could result in anxiety and depression, and therefore they wished to live in the moment rather than living with fear of the EOL.

Some of the women who lived with a spouse claimed that men in general have difficulties with discussing their wishes regarding EOL and death. One of them mentioned, as an example that when trying to talk open minded about wishes regarding life-prolongation in case of serious illness with her husband, the conversation would turn into a monolog. Regarding the sharing of EOL wishes with others, a 70-year-old woman said,

I can talk with my children about it [EOL] in a totally different way than with my husband. He is allowed to believe that we turn 150 years old, right? [She is laughing]

However, two of the five focus groups, with only men, did not live up to the women’s prior experience, as they were willing to discuss and openly talk about their
preferences regarding the EOL. Many of the men referred to the importance of talking with their families or others and sharing their wishes. A 96-year-old man, who lived in a nursing home, shared his treatment preferences regarding life-prolonging treatment and resuscitation in case if his heart should stop beating. He had decided to share his wishes by signing a living will, and by informing both the nursing home staff and his daughter, and finally he told the interviewer,

All things considered, about this life prolonging treatment and that accounts for the hospitals as well. I don’t wish this to prolong life. It’s just a good life that comes to an end.

When he was asked, whether the fear of losing the ability of taking care of himself was a reason for the above-mentioned statement and therefore greater than the fear of dying, the answer was “absolutely.”

The participants expressed the importance of having their nearest relatives close to them in the terminal phase of life. Most of them feared dying alone. Being in contact with another person, holding hands, even if this person was unknown to the dying person, was considered very important among most of the participants. “Dying in pain” was among some of the told portrayals the participants experienced as horrible and scary, and generally being kept free of pain in the end was indisputable. Some considered the hospital as the best place to die because of the short distance to a nurse or doctor if analgesia was needed compared with dying at home. The group with three men, who previously had lost their spouses, all preferred dying in a hospice. They had experiences with hospice from friends dying and referred to the calm and nice atmosphere as something totally different from the hospital.

Two out of five focus groups debated the decision-making tool “a living will” (Holm, 1994). Six of all the participants interviewed had filled out their living will, but surprisingly 25 of all the participants were not familiar with the possibility of completing a living will. The discussion in one of the focus groups became rather intense and interesting, because the participants were shocked to find out that the medical records at their general practitioner were not available for the physician working at the hospital or at the emergency department. Some of these participants had already shared their wishes regarding EOL treatment such as life-prolonging treatment and cardiopulmonary resuscitation with their general practitioner, and thought that this was “enough” to ensure that their wishes were known in the health care system. They felt despondent about how they should be able to express their wishes.

One of the men, whose spouse had been admitted several times, mentioned the frustration of receiving the same standard questions regarding smoking, drinking, family, and so on, over and over again, and suggested,

I don’t understand, why you just don’t cut out something like that [standard questions] and asks about what is really relevant [refers to EOL questions].

In continuation hereof, when asked, almost every participant in both groups and individual interviews found it natural and okay to be confronted with questions regarding their EOL treatment preferences, especially the “cardiopulmonary resuscitation question” during their admission in the emergency department. Some even said that they expected the physician to discuss EOL with the patient during the admission. However, when asked by the interviewer, a woman living in a nursing home responded:

“Would it be too transgressive if we started a conversation [regarding cardiopulmonary resuscitation] with you?”

(Interviewer)

“No, that person who would speak with me should approach carefully; what can I talk with her about?”

Participants voiced a need of caution from the physician, when talking to their patients of these EOL treatment preferences. Physicians should be aware of the discrepancies of the needs among patients, and to which degree this EOL subject is previously considered and of interest to discuss.

Some of the participants stated that the physician should be honest to the patient regarding their serious illness, even if they were dying, whereas another man found the physician’s message of terminal illness and that his wife was inevitably dying too straightforward and harsh. A woman, who previously worked as a health care worker in a nursing home, pointed out the use of humor:

We do all know what will happen one day [We shall die], we just don’t know when. So, if it is possible that you can discuss it [EOL] with some humour, then it is manageable.

Another woman suggested educated staff in the emergency department and at the hospital in general to handle these EOL conversations:

You could consider that a few people at the hospital were educated and then able to manage these conversations [EOL conversations]. They should have a good and decent psychological and psychiatric education. It must be someone with a sense of what is going on that should talk with you.

This statement was backed up by the rest of the focus group. They further talked about the possibility of registration of their wishes both at the general practitioner and at the hospital. These questions regarding EOL treatment preferences should be just as important as the many other routine questions.
Even though, many of the participants had discussed and shared their EOL decisions regarding treatment preferences, they clearly mentioned that it should be possible to change their decisions. A woman said,

“You can’t make such a definitive will.” . . . “You should look at one situation at a time.” . . . “and this [the situation] can change from 11.30 am to noon.”

**Conditions in Everyday Life Are Significant**

Living with chronic illness affected the everyday life, and many of the participants suffered from one or more diseases. Adapting the “new” terms of the diseases in life, such as taking medication along with the experience of side effects, and regular visits at the general practitioner or admission to the emergency department or hospital were common experiences among the participants. Being old had consequences such as frailty and getting sick at an older age were issues of importance for their experience of EOL. As the 87-year-old woman explained,

“I think that most people know [that you can die from a disease] and that it’s a natural thing when you are that old, then you know that this is not just something that disappears within a week” . . . “When you are that old, then you can die from it.”

The terms of living with a chronic disease were for some of the participants a clear limitation in life. A 73-year-old woman, interviewed individually at the emergency department, had experienced loss of quality in life over the past 6 months because of her chronic disease. Her illness-acceptance and insight in the future conditions of the disease was well informed and clear. She made her decisions many years ago, when she was in a better health condition, and was still determined not to prolong her life with treatment options such as admission to the intensive care unit for respiratory assistance. She calmly said,

When we are up against something that is bad [disease], then we don’t have to be afraid [of dying]. It’s not worth being alive, if you are sick.

Death was for several participants experienced as being beautiful and relieving in the case of suffering of incurable disease.

During the analysis, a pattern among participants, who had professional experience within the health care system, was recognized. Their experiences also influenced their thoughts and decisions regarding treatment at EOL. The 68-year-old man, who previously worked as a paramedic, explained some of the difficulties he experienced regarding decision-making about cardiopulmonary resuscitation in case of cardiac arrest. He had performed cardiopulmonary resuscitation on many patients and he had experienced patients being resuscitated with either major or no further complications. He said,

It is all about timing.

If the correct treatment is set in early and the cause of the cardiac arrest is reversible, then the chance of a “good outcome” is much better. That is why my answer is not that simple, he explained,

Because, if time passes by [before cardiopulmonary resuscitation is started], then it does not matter anymore. I do not intent to spend the rest of my days being a vegetable.

The 65-year-old health care worker had made decisions regarding cardiopulmonary resuscitation and EOL in general, despite her being fit and healthy and the youngest of the participants. She had written her living will and shared the wishes with her husband. She referred to her previous work experiences,

I am a health care worker and I have worked with older people in a nursing home and seen people dying in many different ways. I have also seen those older people just lying there without being able to move or do anything themselves. That is awful. I would not wish to live like that.

Many of the participants had experienced loss within close family, and most of the participants from the nursing homes had lost their spouse. Some of the participants had lost their children, and in general many of the participants had experienced loss of friends and siblings that were younger than themselves. Several of the participants were surprised of the preparation and planning for the EOL some of their friends had done regarding treatment, place of death, and the funeral. These experiences resulted in thinking of the EOL among some of the participants; especially thoughts of being the “next in line” were provoked. The 74-year-old man planned the EOL with his spouse, who had terminal cancer, and followed her wish of dying in their home. His previous experience of loss and preparation for death with her made him comfortable regarding his own EOL choices, and he stated the following:

So, I think it will be much easier [to talk about dying]. For me it has become easier, because it was a positive experience, when we [his wife and him] discussed it [wishes at EOL] before she died. When I have to go away, I will use that again.

Only a few of the participants expressed the wish of life-prolongation and cardiopulmonary resuscitation in case of serious illness. One of those was a man who lived with his seriously cognitive impaired wife, and even though he did not directly relate his treatment preferences to his wife’s dementia, it seemed to be a clear reason for his choices of treatment throughout the interview. He mentioned feeling responsible of taking care of her no matter what. During a conversation in his group about “being mortal,” he clearly stated,
I have also thought about it a lot, that my wife is demented and not able to take care of herself. If I die, how is this supposed to be managed? Because the children they do not live here [in Denmark] anymore.

Another man interviewed in the emergency department had promised his terminally ill wife to take care of her little sister. Unfortunately, she was diagnosed with dementia, and he explained the sense of guilt he had felt with the decision of moving her to a nursing home, as he was getting weaker and unable to take care of her.

The participants were not directly confronted with questions regarding religious beliefs, but in all the focus groups, the participants brought up wishes regarding their funeral. In general, everybody had planned their funeral, some more detailed than others. A few of the participants firmly believed in God and chose not to decide whether to receive treatment or not in the EOL. One of the men was brought into the emergency department with trouble breathing the night before he was interviewed. He did not make any active decisions regarding treatment, but instead he said to the interviewer,

So, what happens, may happen. I pray to God, when the situation is like to night and I do so the other days as well—talk with God.

Another man grew up in an evangelical environment and had experienced many people dying as he sat by them until the end. He shared a general observation,

It’s amazing that even the most hard-boiled atheists, don’t stay as atheists in the end.

Discussion

This study brings new insights from a diverse population of older people, by reporting a general readiness and willingness to talk about EOL and the process of dying along with sharing experiences in regard hereto. Results are discussed according to Figure 1 showing prioritized topics from the text condensation.

Thoughts considering EOL are present in the daily living among the older population interviewed. Consistent with previously reported studies (Agård et al., 2000; The Choice in End of Life Care Program Board, 2015a; Friis & Forde, 2015; Laakkonen et al., 2005; Morgan King & Prajapati, 1994), our older population showed interest in the decision-making process, either by sharing wishes and treatment preferences with their family, friends, the general practitioner, or by completing a living will. Furthermore, many of the older individuals wanted shared decision-making in case of admission to the emergency department or hospital, especially regarding questions about cardiopulmonary resuscitation and welcomed a physician’s initiative. It was important to them that the health care staff had time to meet them, showed honesty, and in some way were educated to perform this EOL conversation.

To ensure the wishes from the interviewed participants were known in case of acute illness, the majority of them had a desire for some kind of common and identical EOL tool between the general practitioner and the hospital, for example, an advance care plan. Some of the participants trusted the physician to know and make the decision regarding cardiopulmonary resuscitation. However, a Danish study from 2012 showed disagreement between patient and physician regarding cardiopulmonary resuscitation preference in one third of the cases (Saltbaek & Tvedegaard, 2012), along with another study that also indicated a mismatch between patient and physician (Covinsky et al., 2000). The challenges in the health care system with no systematic approach to patients regarding EOL preferences, like, for example, an advance care plan and the lack of a common medical record between the hospital and the general practitioner, were or became clear to several of the participants interviewed. They felt despondent in how they should be able to ensure their EOL wishes were known. A recent published meta-synthesis of qualitative studies states the importance of people’s view of life and death as key considerations, when conducting an advance care plan (Ke, Huang, Hu, Connor, & Lee, 2017). In addition, the different experiences and perspectives differ within cultures, thus indicating that these experiences should be known to the researchers or health care professionals before an appropriate advance care plan or another approach in a specific setting can be developed.

The age of the participants did not seem to affect reflections of EOL, as both the youngest and oldest participants had made decisions regarding EOL preferences, such as cardiopulmonary resuscitation and life-prolonging treatment, along with hospitalization in case of serious illness. In contrast, the large Study to Understand Prognosis and Preferences for Outcome and Risks of Treatments (SUPPORT) found that seriously ill older adults were less likely to want cardiopulmonary resuscitation, along with life-extending care compared with comfort care, compared with younger adults (Hamel et al., 2000). Our participants stated that self-sufficiency in daily living was the most important and clear measure of quality of life. Or in reverse mentioned, being dependent of others in daily living, especially in managing personal hygiene, was “the end of life.” Previous life experiences, such as working within the health care system or being close to a dying person as well as living with a serious illness were to a higher degree explained as factors influencing their decision-making process than their age alone. This was consistent with the findings from a study in a community setting from the United States (Amjad et al., 2014), whereas others justified their cardiopulmonary resuscitation preferences highlighting their experiences of a
meaningful life (Laakkonen et al., 2005). In contrast, a recent mixed-method study from the Netherlands found that half of the respondents did not have any motivation to draw up their advance directive (van Wijmen, Pasman, Widdershoven, & Onwuteaka-Philipsen, 2014). However, the most reported motivations for decision making, such as fulfilling an advance directive, were the experience of illness among a relative or friend. Furthermore, they reported that previous stated preferences, for example, limits in treatment, were changeable as they adapted to their illness and “new” situation in life. Consistent with previous studies (Lloyd-Williams, Kennedy, Sixsmith, & Sixsmith, 2007; Strömberg & Jaarsma, 2008), being physically and mentally well was pointed out by our population as crucial to maintain dignity and quality in life. Interestingly, it has recently been shown that functional disability is independently associated with death wishes among European older adults (Mellqvist Fässberg et al., 2014). Our participants also mentioned that people and their life changes over time, and this EOL plan or testament must be revisable and changeable. Ditto et al. (2003) previously reported that declines in peoples physical or psychological functioning resulted in less desire to undergo life-sustaining treatment. They further showed instability in older adults’ EOL preferences over time and thereby emphasized the challenges of the advance directives—they might reflect outdated wishes. In contrast, a recent systematic review from the Journal of the American Medical Association (JAMA) including eight studies from Europe (22% of the studies included), did report stability in EOL preferences over time among those older adults with serious illness who actually completed the directives (Auriemma et al., 2014). This suggests that an EOL plan, either advance directive or advance care plan, could benefit some of our older population, but which type of plan, the timing, and who should be considered still remains a challenge, especially in Northern Europe. The first step, and maybe the key hereto, might be to know the population of interest better.

The term “feeling responsible” to others when making EOL decisions also became clear during the interviews. Participants felt responsible to their children and other relatives, and therefore wanted to prepare the EOL and make clear decisions, to avoid any pressure or stress.
the relatives would feel by making those decisions. Studies have presented the EOL decision-making process as stressful for relatives (Bollig, Gjengedal, & Rosland, 2016; Dreyer, Forde, & Nortvedt, 2009; Givens, Lopez, Mazor, & Mitchell, 2012). The effect of the responsibility and guilt some people can feel to their relatives, when making choices concerning their EOL, should not be underestimated. Several conditions were identified as important in the dying phase by our participants. Dying with dignity did appear several times, but the participants more often mentioned what was feared instead of defining what they meant by dignity. They feared dying alone and therefore some of them preferred dying in hospital and not at their nursing home, as the nursing home was associated with a busier environment.

In general, several of the participants feared ending their days in a nursing home. Challenges in achieving good EOL care have previously been reported in a qualitative study from three nursing homes in Denmark (Gorlén, Gorlén, & Neergaard, 2013), concluding that training and better collaboration between the general practitioners and the nursing homes is needed. Being in contact with another person at the EOL is also very important (Steinhauser et al., 2000). This was consistent with our findings. Moreover, being in contact with another person in the terminal phase of life was expressed as being paramount, even if this person was unknown to them. Hospices were for several considered the gold standard for the place of death, as it reflected access to personal and physical care, being kept free from pain, and with room for their relatives. This corresponds well to the increasing deaths in hospice seen around the world and especially in the United States (Teno et al., 2013). Furthermore, a recent study from the United Kingdom reported that dying in a location like a hospital but with comfort associated with home, for example, hospice at home, was preferred in a large public engagement (The Choice in End of Life Care Programme Board, 2015a).

Both the seriously ill patients and the physical well-being older adults shared EOL wishes and experiences, willingness regarding decision-making, and similar important factors in the terminal phase of life. However, being respected as an independent individual with their autonomy intact was mostly mentioned in the in-depth interviews, both at the emergency department and nursing homes. This could partly be explained by the different characteristics among the participants, as those from the individual interviews were older and more dependable of help in activities of daily living compared with the participants from the group interviews. Supporting this hypothesis, autonomy has been shown to be diversified among older individuals regarding EOL decision making, with a more pronounced autonomy among the oldest (Winzelberg, Hanson, & Tulsky, 2005).

Our findings suggest the need for not “just” a systematic approach in securing EOL preferences, but an approach that is individual and flexible. The individuality of when or if an older person changes their EOL wishes could be related to the lived life of the individual, along with their definition of what brings value into their life. These questions might be just as important as the EOL treatment questions. Where the line is drawn in regard to not wanting cardiopulmonary resuscitation or life-prolonging treatment, along with changes in those decisions, will therefore differ between each individual. Participants in the current study stated the importance of repeated EOL conversations with educated health care professionals as the most appropriate way to secure that their wishes are known. We found this qualitative approach ideal to clarify the older participants’ EOL experiences, attitudes toward decision-making, and what they identified as being important in EOL. Despite some efforts in recruiting a diverse older population and interviewing them both in groups and in-depth in regard to their current state of health, this study has some limitations. First, this study sample is specific for Denmark and therefore lacks generalizability to other countries. Second, most of the participants who showed willingness to make decisions regarding EOL were not acutely ill; this may change in case of acute illness. However, many of the participants were chronically ill and had previously been admitted to the emergency department. Furthermore, the patients interviewed in-depth at the emergency department also stated a clear willingness in decision-making, in spite of their acute deterioration in health. Finally, both the interviewer and observer were presented as researchers within this EOL topic, which might have encouraged and reflected the participants EOL experiences especially regarding decision making. The fact that almost every participant thanked the interviewer in the end of the interview, along with the dynamic seen in the groups between participants, indicated that they found the atmosphere for sharing their experiences trustworthy and open minded.

Conclusion

The findings from this qualitative study indicate a readiness and willingness to discuss EOL preferences among a diverse group of older Danes and secure that those wishes are known in our health care system. The lived life and experiences from the older individual seemed to affect the degree of reflection of EOL and the decision-making process. This underlines the importance of knowing the population of interest, before developing a systematic approach or using an advance care plan from another setting. Health care professionals should be educated to manage these EOL conversations. As physicians, both in an acute and in a general setting, we should therefore engage patients with EOL questions. Qualitative approaches like this are lacking within our population and should be used to enhance and strengthen the development of a general EOL tool for the benefit of the individual patient and our health care system.
Authors’ Note
The study was approved by the Danish Data Protection Agency (reference: 2008-58-0035). The Regional Scientific Ethical Committees of Southern Denmark waived the study according to Danish law about qualitative research (reference: S-20162000-175). The study was conducted according to the criteria set by the Declaration of Helsinki (Kong & West, 2013). Further requirements regarding analysis or data can be provided by contacting the author: S.H., but only in respect of the Danish Data Protection Agency.

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