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Developing and using a structured, conversation-based intervention for clarifying values and preferences for end-of-life in the advance care planning-naïve Swedish context: Action research within the DöBra research program

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ABSTRACT

Sweden has no systematic advance care planning (ACP), nor legal recognition of end-of-life proxies. We describe our experiences and reflections from a participatory action research process, aiming at developing and initially using a conversation-based, structured ACP approach among community-dwelling, older adults in Sweden. Eco-mapping and DöBra cards were used with 65 people to catalyze discussions on preferences for the end-of-life. We found great individual variation in both Eco-map depictions of social networks and prioritization of the 37 DöBra card items. The DöBra cards were concluded to be a viable tool for stimulating person-centered conversations on preferences for future end-of-life care.

Introduction

Robust knowledge about problems arising from poor communication around preferences and values related to death and dying and a lack of advance care planning (ACP), has motivated a variety of ACP initiatives. However, despite the increasing acceptance of ACP and advance directives internationally, most empirical research underlying ACP use and efforts to clarify terminology stem from the English-speaking world, limiting generalizability (Lin et al., 2018). For many years, research from non-English-speaking countries derived primarily from a few active research centers in Europe (Meeussen, Van der Block, & Deliens, 2011), although the ACP research literature has become notably more global in recent years (Lunder, Červ, & Kodba-Čeh, 2017; Radhakrishnan, Van Scoy, Jillapalli, Saxena, & Kim, 2017).

Lunder et al. (2017) point to the necessity of researchers and clinicians from different countries and cultures addressing ACP issues of relevance and interest for their stage of development. One example of the impact of local differences is that while formal legally-

binding documents for end-of-life (EoL) wishes are increasingly used in many English-speaking and European settings (Lack, Biller-Andorno, & Brauer, 2014), there is no legal precedent for this type of advance directive or formal EoL health proxies in Sweden to date. Individually-based advance directives are only briefly mentioned in the most recent Swedish national guidelines for palliative care (National Board of Health and Welfare, 2016) with focus on severely ill patients in acute situations, and not as an early and prophylactic process. Systematic ACP processes have not been implemented in general populations in Sweden, and are even rare exceptions in Swedish care settings.

While there may be individual consideration of future EoL issues in Sweden, the Swedish context itself might be considered ACP-naïve on a collective level. Without legal precedent for written documentation in the form of advance directives and a lack of fora and support for discussion of such issues (Westerlund et al., 2018), Sweden is one example of a country in which an approach other than advance directives is called for to raise early awareness and address EoL issues. In

addition, advance directives on their own have some known limitations. Even in countries with strong support for advance directives, relatively few complete them (Institute of Medicine, 2015). Decisions formulated at one point in time may not be valid later, but rather change with time, age and health status (Institute of Medicine, 2015; Meeussen et al., 2011). Advance directives often refer to medical intervention most relevant in unexpected, acute situations, which may not always be the primary issue in increasingly common "slower deaths" from chronic disease and frailty (MacKenzie, Smith-Howell, Bomba, & Meghani, 2018). In addition, family members who may act as surrogates in the future are not always routinely involved in the process of formulating advance directives, and thus may be ill-prepared for participation in collaborative decision-making when the need arises.

We, therefore, chose another approach to ACP (Houben, Spruit, Groenen, Wouters, & Janssen, 2014; Institute of Medicine, 2015), not focused on making binding decisions early on, but instead on preparation of individuals, families and professionals to be able to make "the best possible in-the-moment" decisions (Sudore & Fried, 2010), when they later become necessary. This is based on early initiation of a discussion process, and a shift from a legal, document-driven approach often with one individual in isolation, to one which engages stakeholders in more active conversations about an individual's hopes, preferences, values and care goals at the EoL. While there is a drive to foster conversations about EoL in general, there is limited research on these processes (Litzelman et al., 2017; Zachariah et al., 2014) and development of ACP interventions has been poorly described in the literature (Lin et al., 2018). A process of discussion with attention to relationships and knowledge of particular individual values (Johnson, Butow, Kerridge, & Tattersall, 2017; Winter, 2013) has been found to add important guidance for EoL care provision beyond that included in document-based advance directives. Review studies have found that conversation-based approaches can lead to better congruence between preferences for care and care actually delivered, improved quality of EoL care communication in general (Houben et al., 2014), as well as supporting patient and family confidence in dealing with EoL issues with less worry about the future and more peace of mind (Hall, Rowland, & Grande, 2019).

In the project described here, we apply a conversation-based ACP approach inspired by new public health perspectives (Lindqvist & Tishelman, 2016; Sallnow et al., 2016). This approach is in line with that described by Rogne & McCune as a "… *process of communication that facilitates individual's understanding, reflection, and discussion of their goals, values, and preferences for future health care decisions*"(Rogne & McCune, 2014, p. 228). Our approach moves from a patient-focus within health care facilities toward development of support strategies within communities, focusing on people in phases prior to sickness or diagnosis with life-limiting disease, and aiming toward providing a basis for later value-based and collaborative decision-making processes. We aim here to describe and reflect on our experiences in using a participatory action research approach in developing and initially using this structure for conversation-based ACP among older adults in the general public in a context previously unfamiliar with ACP. As there is a dearth of literature focusing on the development of ACP interventions, the experiences and lessons learned through this process can also be of value for work in other contexts where ACP is not systematically practiced or where approaches directly imported from other cultures may not be appropriate.

Materials and methods

This article is based on the process of planning, translating tools, pilot testing the tools and initially using the Swedish ACP (SweACP) intervention. We draw on data from meeting minutes, protocols and researchers' field notes, as well as discussions and interviews.

The SweACP project: aim, design, and process

This project is one of several in a larger research program, "*DöBra*"[1] , with the overall aim of diminishing avoidable suffering related to dying, death and bereavement. SweACP is a nation-wide participatory action research project, planned and conducted in active collaboration between researchers with a variety of disciplinary and professional backgrounds (ethics, ethnology, gerontology, nursing, palliative care, and social psychology) and a range of community-based interest and patient organizations. The aim of SweACP is to develop and test a systematic approach to promote discussion of values and preferences about EoL care choices before death is imminent. This is an effort to minimize distress even in relation to death-related issues, by acting prophylactically rather than reactively. The format for SweACP conversations was inspired by prior work in the United States (Lankarani-Fard et al., 2010; Menkin, 2007) and

Australia (Street, Blackford, Threlkeld, Bidstrup, & Downing, 2011). In SweACP, we focus on two overarching issues:

- Who matters? This is investigated through Eco-mapping, an established, inductive structure for graphically depicting a person in their social environment, which includes family, friends, social contacts, professional resources, etc. This diagram-based format was first developed and revised by Hartman (1995) and has been used to stimulate reflection and support discussion of choices and desires for future support in the context of life-limiting disease (Early, Smith, Todd, & Beem, 2000; Ray & Street, 2006, 2007; Street et al., 2011). An inner circle is drawn representing the person in focus. Other circles representing relationships of importance connect to the inner circle by lines indicating the strength (strong, moderate, or weak) of relationships, and either names or descriptions of their type (e.g. professional, acquaintance, close relationship, etc.). A wavy line represents tension in a relationship. We used Eco-mapping in an effort to clarify existing support and potential gaps for future EoL care, for example, to identify people/groups who can provide physical care, emotional or spiritual support, information, practical help, etc.
- What matters? This component aims at clarification of values and preferences related to EoL care provision. Based on recommendations for future research from the Australian Entrust-u intervention (Street et al., 2011), we translated and adapted GoWish cards, first developed in the United States (Menkin, 2007), for EoL values clarification. The original English-language version consists of 35 cards, each with a single priority statement based on Steinhauser et al.'s (2000) seminal research, and a "wild card" for other possible issues of importance to the person. The English version has been used in recent projects in the United States with different patient and provider groups, with positive reports (Delgado-Guay et al., 2016; Litzelman et al., 2017; Osman, El Jurdi, Sabra, & Arawi, 2018; Siefman, Brummel-Smith, Baker, & Edgerton, 2013); however, there are few studies reporting use of GoWish cards outside of care settings or in the community (Banner et al., 2019; Kuramoto et al., 2015). Cards are sorted according to the importance of personal preferences with further focus on and ranking of the 10 cards deemed most important. When referring to the translated and adapted

Swedish version of the cards, we use the term DöBra cards.

A project group was formed, with the researchers and community organizations: the Swedish National Pensioners' Organization (PRO), Sweden's Pensioner's Association, Network against Cancer, the Lung Cancer Interest Organization, Association of Relatives to Cancer Patients, and the Dementia Association. This group began to meet in September 2012 for initial planning prior to the procurement of funding and had met 16 times by January 2017, the end of the project phase reported here. The project phases are described in detail below.

The translation and adaptation process (September 2012–October 2013)

Experience from translation processes for GoWish in the United States provided the basis for the procedures used in translating the cards; we aimed for both cultural relevance and linguistic equivalence with the original GoWish in this first stage (McGreevy, Orrevall, Belqaid, & Bernhardson, 2014). A preliminary translation was done by the first and last authors, both bilingual but with English respectively Swedish as native language and discussed in two project group meetings. Particular areas for negotiation revolved around the cultural appropriateness of items originally formulated in English, and how specific versus open items should be. As Eco-mapping primarily involves a graphic representation, only translation of instructions was needed, which was uncontroversial.

After negotiating consensus about the initial translation, we made concerted efforts to consider different cultural needs and perspectives. Our ambition crystallized into aiming to develop one set of Swedish language cards that would allow adult residents in Sweden to respond to EoL issues of importance for them as individuals, making efforts to avoid systematic bias in relation to particular groups or communities. This solution meshes with strategic principles relevant in Sweden but differs from the United States, where cards have been specifically translated and adapted for different language/cultural groups.

A final step in efforts to avoid bias was a meeting with strategic advisers and the "inter-religious advisory board" which acted as an informal reference group for a municipality with a majority of residents classified as immigrants to Sweden, to elicit feedback on the translated cards and the planned project. We complemented this with an individual meeting with

the Imam of an Islamic congregation in another area of Sweden.

Finalizing the instruments and protocol (November 2013–April 2014)

In a process parallel to considering cultural appropriateness of the translation, we also discussed the preliminary study protocol and initial translated DöBra cards with different stakeholder representatives, to elicit a variety of reactions, for example, about their wording in Swedish, if new items might be important to include, and if existing items should be omitted. Whereas the original English GoWish cards have one "wild card," we increased the number in the Swedish DöBra cards to encourage exploration of what residents in Sweden might find important.

Eleven women and five men aged 59–84 years volunteered to participate in discussions as representatives of the involved community/patient organizations and through personal contacts. Discussions were held in groups of four persons, who met with the first and last authors in different settings according to participants' preferences. The first discussion was with women retirees, who made clear that they were not affiliated with any religious groups, and the second discussion was therefore held with male retirees from a Christian congregation. The third discussion was with family member representatives of the Dementia Association and the last with representatives of participating patient organizations for different cancer diagnoses. In each group, we began with an open discussion of the participants' ideas about quality EoL care, prior to each participant receiving a newly translated DöBra card deck with 35 items and unlimited wild cards, to comment on the language used in the cards and give feedback on the planned protocol for future testing. A convenience sample of 20 professionals attending the 3rd Swedish national Palliative Care conference in March 2014 also commented on the translated DöBra card items; however this was done in writing or through ad hoc comments at an exhibition of the activities of the DöBra research program.

Based on the extensive translation process and feedback on the project protocol, we made final adjustments to the DöBra cards to increase their cultural relevance, for example, broadened the English "family" term to one in Swedish meaning those who are close to an individual. The finalized research version consists of 37 items with three wild cards; the changes made through the translation and adaption process are shown in the supplemental material.

Initial research study (May 2015–January 2017)

Recruitment strategies. Rather than pre-determining a sample and confronting potential participants with unelicited issues related to death and dying, after the ethical review was completed (Stockholm #2015/106-31/5), we instead recruited participants through a process of active volunteering, in collaboration with the Dementia Association and one partner organization for retirees, PRO. The Dementia Association included a notice about the project in its membership magazine in May 2015 requesting that those interested in volunteering to participate in a research project aiming to develop a protocol to support discussions of values and preferences for future EoL care, please contact the researchers. This was repeated, along with a short article about project progress, in early September 2016. This strategy generated 23 participants throughout Sweden. PRO provided similar information about the project to several local chapters; this "trickle-down" recruitment led to 25 participants from the northern region of Sweden. An additional 12 people contacted the researchers after hearing about the project from friends and neighbors who had participated, and six more participants were recruited through direct contact with the researchers via two other community organization partners.

Interviews. A total of 61 interviews were conducted in Swedish with 66 individuals to explore the questions of who and what would matter at the participant's future EoL. Five interviews were held with couples. Data from one individual interview has been excluded from analysis; during the interview process, we noted that this participant exhibited relatively severe cognitive impairment, which might hinder appropriate understanding of informed consent. We, therefore, continued to converse but did not use these data. Table 1 presents information about the 65 participants, of whom 61 were born in Sweden, two in a neighboring Nordic country, and two outside Europe.

Analysis. The audio-recorded interviews ranged from 30–133 minutes and were professionally transcribed. The interviewer initiated analysis by listening to the recording while correcting possible transcription errors and adding non-verbal information as notes in the transcripts. The transcripts were entered into NVivo 11, a software program for qualitative data analysis, with photographs of Eco-maps and DöBra card rankings for those highest prioritized.

Table 1. Characteristics of participants in the study (n = 65).

Characteristics	n (%)
Age (years), median (range)	74 (43–95)
Sex	
Female	46 (70.8)
Male	19 (29.2)
Living situation	
Spouse	31 (47.7)
Alone[a]	33 (50.8)
With children	1 (1.5)
Education	
University	32 (49.2)
High school	13 (20.0)
Elementary school	15 (23.1)
Other	5 (7.7)
Employment status	
Retired	56 (86.2)
Employed, part-time	5 (7.7)
Retired, working part-time	2 (3.1)
Student, full-time	1 (1.5)
Employed, full-time	1 (1.5)
Self-assessed health status	
Good	49 (75.4)
Neither good nor poor	14 (21.5)
Poor	2 (3.1)

[a]Three people lived alone, but had a steady partner who resided elsewhere.

Each participant's Eco-mapping data was entered into a digital matrix, with the type and strength of relationship recorded; for example, in the case of K.G. shown in Figure 1, "wife" would have been recorded as "spouse" with "4 lines" indicating strength, and "flowers" as "other," with no strength of relationship noted. These data were descriptively summarized and reflections from the authors compiled.

The photographs of the 10 most highly prioritized DöBra cards were the basis for the analysis shown in Table 2. These data were also entered into a digital matrix, recording the order of priority for each card by the participant. The most highly ranked card was then assigned 10 points; the second card in the ranking assigned 9 points, etc. with the last of the 10 most highly ranked cards given 1 point. In the four cases in which a participant chose more than 10 cards as most highly prioritized, only the top 10 were given scores. One person prioritized six cards equally, and these data are not included in Table 2. Also, one person in an interviewed couple did not participate in the interview component using the DöBra cards. Table 2 thus presents data for 63 of the 65 participants.

The interview data is analyzed and reported upon in detail elsewhere (Eneslätt, Helgesson, & Tishelman, manuscript submitted for publication), with data presented here derived from interviews and field notes, only to exemplify our points related to the initial use and acceptability of the DöBra cards.

Results

It is important to recognize that the SweACP process is intended to allow for individually-based reflection and conversation, rather than providing information on a group level. The following presentation, therefore, focuses on breadth in responses and learning from the process of developing a systematic procedure for ACP in an ACP-naïve setting, rather than on describing group values as norms.

Who matters: Eco-mapping

The process of Eco-mapping has led us to reflect over the nature of social relationships and how they have been depicted; most notable in these explorative data is the variation in how the process of mapping has been interpreted and used, beyond the sheer number of relationships depicted by participants (total of 682 relationships among the 65 participants, between 1–31 per participant; median 10). The level of detail also varies in these interviews; some participants have given names to some or all of those on their Eco-map, whereas others drew groups labeled by role (e.g., "children with their families;" "lots more friends," "a colleague"). Figure 1 shows a replication of two Eco-maps in English translation after removing potentially identifying features.

However, there are also a number of commonalities among Eco-maps. It seems that some forms of relationships have been self-evident to include, for example, partners, children, and in-laws even when they are depicted with some degree of tension, whereas others—for example, friends, neighbors, nieces/nephews appear included only if the relationship is described as tension-free. Grandchildren have also not been depicted with any sign of tension; it is unclear in our data if this means participants had only positive relationships with grandchildren or if tenser relationships have been omitted. Depictions of relationships to partners varied from a wavy line indicating tension in conjunction with three showing a strong relationship, to ten lines illustrating a relationship's strength, on a diagram with four lines illustrated in the key as showing maximum strength. A total of 17 participants depicted tension in 29 different relationships.

The types of relationships most commonly depicted among these participants were children (by 55 participants); siblings (n = 44); friends (n = 40); and a partner (n = 35). Pets—here dogs and cats—could also be included (n = 6), and one participant included his deceased child and parents. Another drew lines
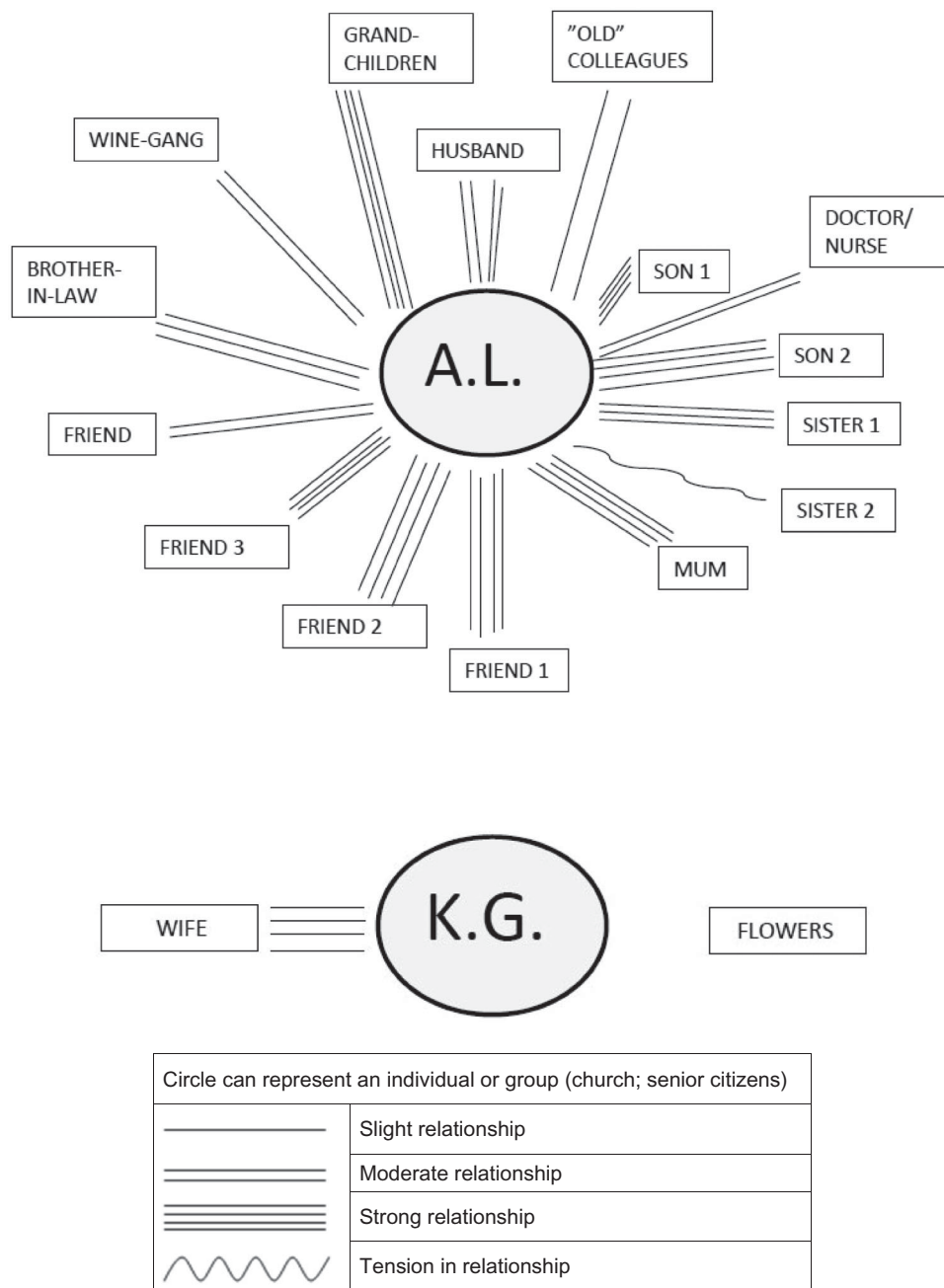
Figure 1. Examples of Eco-mapping.

representing the strength of the participant's relationship with himself; the combination of one wavy line and three straight lines was identical to his depicted relationship with his partner. As shown in Figure 1, even flowers were included by one participant, whose drawing otherwise only consisted of a spouse.

Groups were included in Eco-maps, both as formal organizations (23 participants named 47 organizations) including those through which participants were recruited, but also, for example, neighborhood organizations, religious congregations, unions and professional organizations, sports and hobby clubs.

Informal groups were depicted by nine participants in 11 forms, described as, for example, "workmates," "sauna buddies," "book club," "wine gang."

Formal care providers were included by 14 participants in 24 different relationships. Present contacts varied in how they were depicted, for example, as collectives like "community health center," "the hospital" and "the health care system" or on an individual basis, for example, "Nurse Bibbi," "my pain doctor," or "the chiropractor." Eldercare was also included in the Eco-maps of this sample of participants with a median age of 74 years, for example, "home health aides," "the

Table 2. DöBra card sorting ($n = 63$).

Card statements	No. 1–10	No. Prio 1	Points[a]
To have those I am close to around me	42	13	288
To be free of pain	41	9	288
Not being short of breath	39	5	250
To be free of anxiety	32	2	188
To maintain my dignity	32	1	181
To be cared for by staff I feel comfortable with	27	1	131
To have an advocate who knows my values	27	0	125
WILD CARD	25	8	170
Not dying alone	25	3	155
To be treated the way I want	25	0	116
To have a human touch	24	1	121
To be mentally aware	23	1	156
To be clean and neat	22	0	95
Not being a burden to those who are close to me	21	4	141
To have someone who will listen to me	21	0	113
Not being connected to machines	20	2	104
To say goodbye to important people in my life	20	0	81
To trust my doctor	18	1	73
To keep my sense of humor	18	0	85
To be able to talk about what scares me	16	0	58
To have someone who speaks my own language	12	3	72
To have lived my life to the fullest	10	4	65
To have those who are close to me be prepared for my death	10	1	51
To prevent arguments by making sure that those close to me know what I want	10	0	46
To have my financial affairs in order	9	0	43
To have my funeral arrangements made	9	0	28
To be able to help others	9	0	22
To die at home	7	1	39
To have close friends near	7	0	25
To have a doctor who knows me well	6	1	24
To be at peace with God	5	1	34
To take care of unfinished business with others	4	0	18
To pray	3	1	26
To know how my body will be taken care of after death	2	0	10
To be able to talk about what death means	1	0	7
To remember personal accomplishments	1	0	3
To know how my body will change	1	0	1
To meet with a representative of my religion	0	0	0

[a]The highest ranked card was assigned 10 points, the second ranked 9 points etc., with the last of the 10 most highly ranked cards given 1 point.

care home," and, as one man wrote, "the contact person at my wife's residential dementia unit." Notably, one participant who drew his Eco-map silently, explicitly integrated the future with the present, including "my future hypothetical legal guardian," "hypothetical future health care staff," and "hypothetical future social care staff" along with "son" and "daughter". He then explained this future planning in the interview, saying "… *there can be a lot of tensions in those relationships*". When asked if the legal guardian was for his wife who had been diagnosed with a dementia disease, he replied:

> No, for me, this is about my death here… my wife is on her way into a dementia, so I'm hoping to live another three years [laughs] but I'm not counting on having her as support in that situation… so if you get… if you have a hard time taking care of yourself, you can have a legal guardian [sic: a legal guardian only deals with financial matters in Swedish law and has no jurisdiction or familiarity with matters related to EoL or ACP]. … So I figured … that, that person could help me … (Participant #61)

This participant's clarity in the time frame he considered as well as expectations of the role of a legal

guardian, which were however not in line with the existing legal parameters for this role, made him an outlier among these participants. In these data, it became clear that participants had more difficulty in envisioning and describing their futures, than in depicting their present relationships, which also seemed challenging. While few participants were explicitly critical, in general there did not seem to be much enthusiasm about the Eco-mapping exercise, which could trigger short but unspecific comments, for example, about tensions in relationships. Our general impression was that conversations about who matters—that is, about social networks and intimate relationships—were more difficult to have than those about what mattered at the EoL.

What matters: DöBra cards

Table 2 presents the variation in ranking of the DöBra cards in three forms; the first column shows the number of times a card was prioritized among the 10 most important regardless of ranking and is the basis for

Table 3. Wild cards and their prioritizations ($n = 64$).

No. in rank	Wild card statement
1	To be able to decide myself when to end my life
1	To be able to give love to those I meet, until the end
1	To be entitled to euthanasia
1	To get to decide myself when to die
1	To have my teddy bear with me
1	To have room for my spirituality
1	To have the opportunity of assisted living
1	To have the right to end my life
2	To convey courage and confidence
2	To have flowers around me
2	To HAVE peace with God
2	To have the right to end my life myself
2	To not have any life-sustaining measures
4	To be able to eat what I like
4	To be entitled to euthanasia
5	To not be connected to machines when you don't have a life with dignity
5	To not become demented
6	To be a partner for discussion in health care all the way to the end
7	To be able to come outside
7	To have someone take responsibility for my finances
9	To get the strength to physically and mentally support my wife
10	To be able to end my life when I want to
10	To be able to stop eating when I know the end is near
10	To get help in ending my life when I want to
10	To know that someone will take care of my close ones

their presentation order, the second column indicates the number of times the card was ranked first, that is, was most highly prioritized, and the third column presents the scoring described above.

It is notable that all but one card figures in at least one participant's top 10 priorities (Table 2). The only card not chosen in the top 10 priorities of these 63 individuals involved a clear action, concerning formal religion, "*To meet with a representative for my religion.*" Both other cards explicitly related to religion were ranked among the 10 most prioritized by 5 respectively 3 people, and as first priority for one person each (Table 2).

There is also great variation among the card most highly ranked. Nineteen of 37 itemized cards were ranked as at least one person's 1st priority in this group; The cards most highly prioritized were: "*To have my family with me*" and "*To be free of pain,*" although it should be remembered that conclusions about group-level data are far from the aim of this exercise, which seeks to allow for individualization and initiation of a reflective discussion process.

The wild cards, a means for further individualizing this ACP conversation, are listed by content and ranking in Table 3. Individually formulated wild cards were used 25 times by 22 of the participants (three participants used two wildcards each). The rankings of these statements varied from 1 to 10, with 8 participants ranking a wild card highest. Eight of the wild cards explicitly mention assisted dying in some form, and an additional three seem closely related, that is, "*To be able to stop eating when I know the end is near;*" "*To not be connected to machines when you don*"*t have a life with dignity;*" and "*To not have any life-sustaining measures.*" Some wild cards reformulated already existing items, to clarify or make a point more explicit—for example, rather than the pre-formulated item "*To be at peace with God,*" one wild card reads "*To HAVE peace with God.*" Other cards communicated very individual and specific wishes, for example, "*To have my teddy bear with me.*"

The results of the card sorting shown in Tables 2 and 3 provide however little information about participants' reactions to cards as they discussed and prioritized them. Reactions varied by individual, although only a few people questioned either the benefit of individual DöBra cards or the deck as a whole. Individual items could be questioned in terms of what was meant or item relevance. One example of this was "*To be able to help others*" with the responses of those who commented this item specifically varying from "*To help others, what do they mean there*?" (Participant #8) to more extensive consideration, as in the case of this participant who reflected:

> How can I help others if I'm about to die myself? I've been a very social person and have been a volunteer, but don't know if I would be able to think about others or helping others at that point. I must say, I think this is a tricky question. (Participant #12)

Even other cards could stimulate an initial response about the difficulty in making a choice, for example, one woman (Participant #29) commented "*this is an impossible question*" when considering the card "*Not being a burden to my family.*"

Other challenges were also commented on. In response to a direct question, one woman remarked on difficulties in considering an unknown future: "*It's pretty hard, because you just don't know how you will be at that time point*" (Participant #12). Some people could comment on difficulties in prioritizing only 10 cards, as all were seen as important. The man quoted below had a somewhat different perspective, and commented the interrelationship among different items, as they are not all on the same level of specificity, saying:

> It's very hard to do [sort the cards] since some overlap with one another … there are a lot that are hard <u>not</u> to choose. But some, some take [priority] over <u>the</u> others. Like 'not dying alone'; choosing 'having those I am close to around me' means it [the first card, 'not dying alone'] doesn't have to be there [in the most important pile]. (Participant #33)

Some participants, in line with the above, grouped cards into what they viewed as similar areas, sometimes choosing one to represent the area as a whole. This could be based on what was seen as an internal hierarchy in which the item on one card could even include others, as noted above, or based on the salience of one of the cards for the individual. On the other hand, other participants did not seem to react to overlap, viewing cards individually and interpreting them in other ways.

Another issue mentioned by some participants concerned the bluntness of a few cards. It should be remembered that this study took place in a context in which ACP discussions about EoL issues are virtually non-existent and not anticipated, especially outside the health care environment. Although uncommon in interviews, a few cards could provoke a negative response. For example, one woman described her reaction to the directness of the formulation of the item "*Not dying alone*" as influencing her prioritization:

> And you know, I'm so bloody squeamish [half-laughing, half-crying]. You don't really have a lot of time to consider every card, but then it said 'dying'... and that is so very final [laughs]. The other cards aren't so definite, but that one is definite, and so I didn't choose it, I think, because the others were easier to deal with. (Participant #3)

In contrast, several participants explicitly commented that the cards were a source of support for considering potentially difficult issues. As one man explained:

> Yes, it's extremely important to be able to do something like this and update it, because I don't really give myself enough time to think through these kind of things as seriously as the way this is structured (Participant #18).

Another participant commented that the cards made the interview "*interesting,*" as she became "*curious about each card, and what will be on the next card*" (Participant #19). However, we noted that some participants had difficulties with the steps in the card sorting process, especially those whose cognitive status was affected. These individuals could struggle with the last stage of ranking their preferences, although the cards seemed to function appropriately for stimulating reflection and discussion.

One participant summarized the interview, explicitly voicing positive aspects which seemed to be appreciated by many, saying:

> I think the cards were the best part, because there were so many different alternatives, and based on

what kind of person you are and what you believe in and so on, there's something for everyone... Yes, I think that it was [for] whichever religion and whichever language and so on. I think that was considerate.... (Participant #20)

Discussion

In this article, we discuss experiences from developing and carrying out the first study with a nationally-recruited sample of 65 persons who actively volunteered to participate in testing a conversational approach to discussing ACP, in an ACP-naïve context. We found interest in participation, despite the need to take an active position by volunteering. Eco-mapping to depict social networks was met with limited enthusiasm, and discussion of social networks, particularly when they were limited, seemed to be a sensitive area. In contrast, the DöBra cards were accepted by most participants as a tool to facilitate discussions about matters of importance in future EoL situations. The cards were user-friendly and sensitive to individual preferences, making the card deck a promising tool to support person-centeredness in EoL care discussions.

As there is little written about using this adapted tool outside the United States, and one of few articles to document its' use outside formal care services, this research is of potential relevance for other situations. There are however some methodological caveats to consider. This project was conducted as a participatory action research process in collaboration with community-based organizations, which involves an ongoing process of considering rigor and trustworthiness of data from different perspectives. We did not use predetermined criteria for evaluation but have instead made efforts to describe the research process transparently, as recommended by Kingsley and Chapman (2013) as one practical means of negotiating rigor in such research. This also provides an opportunity for those interested in initiating ACP interventions in other contexts to learn from our experiences, and encouraging cultural adaptations.

Another methodological consideration is that as we did not delineate a sample in advance, we have no basis for determining the proportion of people interested in either ACP or project participation. The feedback we received from both organizations primarily involved in recruitment is that there has been much passive interest in SweACP from their members and that it has contributed to influencing their organizational agendas, as there was little prior awareness of ACP at all. Nearly 20% of participants in the study contacted us requesting to be interviewed after

hearing about the experiences of others who had already participated; this further strengthens our impression that the project was positively received. Another support for interpreting the project positively is the high degree of participation, 91%, in follow-up interviews, conducted 6–12 months later (otherwise beyond the scope of this article). Nevertheless, we caution for broad generalizations about potential uptake based on these limited data; we would argue that ACP, particularly in settings without clear guidelines for practice and communication with care providers based on such conversations, is not necessarily of benefit for all, but rather for those who are interested in engaging with EoL issues in this manner. Note that we have not positioned SweACP as part of a discourse on choice and control over the EoL (Borgstrom & Walter, 2015), but rather as a means of supporting timely communication about EoL to facilitate dealing with relevant issues, individually or with meaningful others, when the time occurs.

The project context, with a lack of structures for determining formal proxy decision-makers for the EoL, may also be one reason that Eco-mapping was not as successful as we had anticipated. While the exercise did raise issues that might lead to further contemplation and made visible a social network often taken-for-granted in detail rarely presented in the literature, some difficulties were experienced, as it seemed neither participants nor interviewers always felt comfortable with Eco-mapping. The rather short discussions which ensued might, in part, reflect inadequate probing. As few research studies report Eco-mapping in ACP conversations, it remains unclear whether interviewers should have received more training and support, or if there are tacit social norms in some cultures, making discussion of limited social networks a sensitive issue. International gerontological and nursing literature offers support for the latter interpretation, noting the stigmatizing nature of loneliness and limited networks in older age in a range of countries [see e.g., recent empirical work from New Zealand (Gott et al., 2018) and a meta-synthesis of qualitative research in English, Finnish, and German (Kitzmüller, Clancy, Vaismoradi, Wegener, & Bondas, 2018)].

Reactions to Eco-mapping may have also been affected by difficulties not only in considering one's social network at present, but also considering needs in a hypothetical future, and who one would turn to for help with these. Whereas Early et al. (2000) found the Eco-map useful with patients in hospice care, their protocol initially established participants' needs and then focused the Eco-mapping exercise on who could meet those needs. In this study, social networks were discussed on a more hypothetical level as participants were not known to be at the EoL. Eco-mapping was also found to be an appropriate tool in the Australian Entrust-u project (Street et al., 2011), but again, in that context, it was a first step in determining a legal "trusted decision maker". The lack of practical implications in contexts that do not allow for legal EoL proxies or representatives may tend to make this a sensitive theoretical exercise for all involved.

In contrast, using the DöBra cards was met with more interest and enthusiasm by participants, and generally found relatively easy to negotiate by both participants and interviewers. Although Siefman et al. (2013) concluded that the GoWish cards work as well for users experiencing cognitive impairments as those without, we found that the card-sorting component could be challenging in such situations, although the cards remained an appropriate tool for stimulating discussion.

While other studies, primarily from the United States, have also found the GoWish cards to be well-received and helpful in stimulating conversations about EoL issues in a variety of populations (Litzelman et al., 2017; Osman et al., 2018; Potthoff & Minton, 2017), there has been little prior research using the cards among community-dwelling older adults [rare exceptions include (Banner et al., 2019; Kuramoto et al., 2015)]. In this study we have also furthered knowledge about how participants respond to card statements and negotiate prioritizations, including the use of wild cards, which can inform both further use of and research on EoL conversation tools. Wild cards are not always used and have been rarely discussed in the extant literature [for exceptions, see (Lankarani-Fard et al., 2010; Lee, Hinderer, & Alexander, 2018)]. The relatively common use of wild cards in our study may be related to our protocol, raising freely formulated wishes before using the cards, but could also be an effect of sampling, where individuals with clear preferences might have been recruited to a larger extent. However, the wild cards were not addressed at all by participants in the group discussions in our final stages of instrument development, nor were issues related to assisted-death raised in those groups. This may reflect the potentially controversial and often taboo-laden nature of this discussion in contexts where euthanasia is not legal. This issue was raised relatively frequently in individual conversations, which may reflect an interest among the general public and/or a bias in our sample of

individuals who actively volunteered and may thus have a particular interest in many types of EoL choices.

Benefits with the DöBra cards thus included providing structure for a potentially difficult conversation and supporting the initiation of communication about EoL issues when couples and/or other family members were present. The DöBra cards are specifically geared to EoL care goals, rather than a broader discussion of EoL issues as is the case with other conversation tools; this meant that people did not have to formulate all relevant aspects of EoL care goals themselves, but primarily responded to existing statements. We found that the cards could open thinking about matters of importance in the EoL beyond those previously considered, and in this way serve as a form of "death education"(Corr & Corr, 2003; Doka, 2015). Another positive feature of the interview structure in general, and the DöBra cards, in particular, is that the participant had something to "do" besides talking. Holding and sorting a physical deck of cards seemed to allow participants to modulate the degree of intimacy they desired when discussing potentially sensitive issues. This differs from the eye-to-eye contact in a direct individual interview situation based on conversation alone.

One important area not addressed by this initial study is how to communicate values and preferences further. Our position to date, given the nature of this initial SweACP study conducted outside of health and social care organizational structures, is that participants "own" their own information themselves. We have documented via photographs and audio-recordings for research purposes only, participants have received their photographed ranking, and have kept the DöBra cards when so desired. This is in line with our primary intention to stimulate a continuing conversation among families and communities. However this strategy may have clear limitations, particularly, as seen through Eco-mapping and as noted by Gott et al. (2018), when support networks beyond family are lacking for many elderly, as there are significant obstacles to establishing new community-based supports in advanced age. It is therefore essential to consider how documentation and communication of values and care goals should occur for the particularly vulnerable and growing group who lack family or other advocates.

In summary, in SweACP we focus on catalyzing and facilitating discussion about the future of people's lives, with death regarded as an inevitable social process rather than a purely medical one [see e.g., Gellie, Mills, Levinson, Stephenson, & Flynn, (2015)], in line with Frey and colleagues discussion of holistic versus biomedical perspectives on palliative care (Frey, Powell, & Gott, 2013). One implication of this is that, due to demand as both professionals and the general public became aware of the DöBra cards, they have been disseminated as a social innovation via collaboration with a publishing company, to be used as people see fit, not necessarily with professional mediation, in line with their availability in the United States.

We conclude that the results of this initial ACP study among participants from the general public in Sweden were promising. Eco-mapping was met with limited enthusiasm but was useful in depicting a social context often taken for granted, whereas DöBra cards were positively received and appear to be a tool with much potential in a variety of settings. Some reasons for the relative enthusiasm with which the DöBra cards were met seem to be related to the benefits of having a hands-on tool rather than only talking, raising concrete issues often not otherwise considered, and supporting an individualized, person-centered conversation. The wild cards seem to also have facilitated conversations that are often otherwise taboo to be raised, for example, about assisted dying, without becoming the sole focus of consideration about EoL issues.

Note

1. DöBra literally means 'Dying Well' in Swedish, but is also an idiom roughly equivalent to 'awesome'.

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References

Banner, D., Freeman, S., Kandola, D. K., Meikle, M., Russell, B. K. M., Sommerfeld, E. A., … Schiller, C. J. (2019). Community perspectives of end-of-life preparedness. *Death Studies*, 43(4), 211–223. doi:10.1080/07481187.2018.1446060

Borgstrom, E., & Walter, T. (2015). Choice and compassion at the end of life: A critical analysis of recent English policy discourse. *Social Science & Medicine*, 136–137, 99–105. doi:10.1016/j.socscimed.2015.05.013

Corr, C. A., & Corr, D. M. (2003). Death Education. In C. D. Bryant & D. L. Peck (Eds.), *Handbook of death & dying* (pp. 292–302). Thousand Oaks, CA: Sage Pubs.

Delgado-Guay, M. O., Rodriguez-Nunez, A., De la Cruz, V., Frisbee-Hume, S., Williams, J., Wu, J., … Bruera, E. (2016). Advanced cancer patients' reported wishes at the end of life: A randomized controlled trial. *Supportive Care in Cancer*, 24(10), 4273–4281. doi:10.1007/s00520-016-3260-9

Doka, K. J. (2015). Hannelore Wass: Death education—an enduring legacy. *Death Studies*, 39(9), 545–548. doi:10.1080/07481187.2015.1079452

Early, B. P., Smith, E. D., Todd, L., & Beem, T. (2000). The needs and supportive networks of the dying: An assessment instrument and mapping procedure for hospice patients. *American Journal of Hospice and Palliative Medicine*, 17(2), 87–96. doi:10.1177/104990910001700208

Eneslätt, M., Helgesson, G., & Tishelman, C. Exploring community-dwelling older adults' considerations about values and preferences for future end-of-life care in Sweden. Manuscript submitted for publication.

Frey, R., Powell, L., & Gott, M. (2013). Care vs. care: 'Biomedical' and 'holistic' worldviews of palliative care. *European Journal of Integrative Medicine*, 5(4), 352–364. doi:10.1016/j.eujim.2013.02.004

Gellie, A., Mills, A., Levinson, M., Stephenson, G., & Flynn, E. (2015). Death: A foe to be conquered? Questioning the paradigm. *Age and Ageing*, 44(1), 7–10. doi:10.1093/ageing/afu116

Gott, M., Wiles, J., Moeke-Maxwell, T., Black, S., Williams, L., Kerse, N., & Trussardi, G. (2018). What is the role of community at the end of life for people dying in advanced age? A qualitative study with bereaved family carers. *Palliative Medicine*, 32(1), 268–275. doi:10.1177/0269216317735248

Hall, A., Rowland, C., & Grande, G. (2019). How should end-of-life advance care planning discussions be implemented according to patients and informal carers? A qualitative review of reviews. *Journal of Pain and Symptom Management*, 58(2), 311–335. doi:10.1016/j.jpainsymman.2019.04.013

Hartman, A. (1995). Diagrammatic assessment of family relationships. Families in Society: *The Journal of Contemporary Social Services*, 1, 111–122. doi:10.1177/104438894950760027

Houben, C. H. M., Spruit, M. A., Groenen, M. T. J., Wouters, E. F. M., & Janssen, D. J. A. (2014). Efficacy of Advance Care Planning: A Systematic Review and Meta-Analysis. *Journal of the American Medical Directors Association*, 15(7), 477–489. doi:10.1016/j.jamda.2014.01.008

Institute of Medicine. (2015). Dying in America: Improving *quality and honoring individual preferences near the end of life*. Washington, DC: Institute of Medicine.

Johnson, S. B., Butow, P. N., Kerridge, I., & Tattersall, M. H. (2017). What do patients with cancer and their families value most at the end of life? A critical analysis of advance care planning. *International Journal of Palliative Nursing*, 23(12), 596–604. doi:10.12968/ijpn.2017.23.12.596

Kingsley, B. C., & Chapman, S. A. (2013). Questioning the meaningfulness of rigour in community-based research: Navigating a dilemma. *International Journal of Qualitative Methods*, 12(1), 551–569. doi:10.1177/160940691301200129

Kitzmüller, G., Clancy, A., Vaismoradi, M., Wegener, C., & Bondas, T. (2018). "Trapped in an empty waiting room"—the existential human core of loneliness in old age: A meta-synthesis. *Qualitative Health Research*, 28(2), 213–230. doi:10.1177/1049732317735079

Kuramoto, K., Harasawa, K., Moody, S. Y., Yoshida, M., Okawa, K., Sera, N., … Sekine, R. (2015). P-74 Advance care planning awareness: Using the go wish card game to assess the modern Japanese view of life and death. *BMJ Supportive & Palliative Care*, 5(2), A66–A67. doi:10.1136/bmjspcare-2015-000978.204

Lack, P., Biller-Andorno, N., & Brauer, S. (Eds.). (2014). *Advance directives* (Vol. 54). New York, NY: Springer.

Lankarani-Fard, A., Knapp, H., Lorenz, K. A., Golden, J. F., Taylor, A., Feld, J. E., … Asch, S. M. (2010). Feasibility of discussing end-of-life care goals with inpatients using a structured, conversational approach: The go wish card game. *Journal of Pain and Symptom Management*, 39(4), 637–643. doi:10.1016/j.jpainsymman.2009.08.011

Lee, M. C., Hinderer, K. A., & Alexander, C. S. (2018). What matters most at the end-of-life for Chinese Americans? *Gerontology and Geriatric Medicine*, 4, 7. doi:10.1177/2333721418778195

Lin, C.-P., Evans, C. J., Koffman, J., Armes, J., Murtagh, F. E. M., & Harding, R. (2018). The conceptual models and mechanisms of action that underpin advance care planning for cancer patients: A systematic review of randomised controlled trials. *Palliative Medicine*, 33(1), 5–23. doi:10.1177/0269216318809582

Lindqvist, O., & Tishelman, C. (2016). Going public: Reflections on developing the DöBra research program for health-promoting palliative care in Sweden. *Progress in Palliative Care*, 24(1), 19–24. doi:10.1080/09699260.2015.1103497.

Litzelman, D. K., Inui, T. S., Schmitt-Wendholt, K. M., Perkins, A., Griffin, W. J., Cottingham, A. H., & Ivy, S. S. (2017). Clarifying values and preferences for care near the end of life: The role of a new lay workforce. *Journal of Community Health*, 42(5), 926–934. doi:10.1007/s10900-017-0336-5

Lunder, U., Červ, B., & Kodba-Čeh, H. (2017). Impact of advance care planning on end-of-life management. *Current Opinion in Supportive and Palliative Care*, 11(4), 293–298. doi:10.1097/SPC.0000000000000306

MacKenzie, M. A., Smith-Howell, E., Bomba, P. A., & Meghani, S. H. (2018). Respecting choices and related models of advance care planning: A systematic review of published evidence. *American Journal of Hospice and*

Palliative Medicine, 35(6), 897–907. doi:10.1177/1049909117745789

McGreevy, J., Orrevall, Y., Belqaid, K., & Bernhardson, B. M. (2014). Reflections on the process of translation and cultural adaptation of an instrument to investigate taste and smell changes in adults with cancer. *Scandinavian Journal of Caring Sciences*, 28(1), 204–211. doi:10.1111/scs.12026

Meeussen, K., Van der Block, L., & Deliens, L. (2011). Advance care planning: International Perspectives. In M. Gott & C. Ingleton (Eds.), *Living with ageing and dying: Palliative and end-of-life care for older people* (pp. 102–115). Oxford, UK: Oxford University Press.

Menkin, E. S. (2007). Go wish: A tool for end-of-life care conversations. *Journal of Palliative Medicine*, 10(2), 297–303. doi:10.1089/jpm.2006.9983

National Board of Health and Welfare. (2016). Nationella riktlinjer – Utvärdering 2016 - Palliativ vård i livets slutskede [National guidelines - Evaluation 2016 - Palliative care at the end-of-life]. Retrieved from http://www.social-styrelsen.se/publikationer2016/2016-12-3.

Osman, H., El Jurdi, K., Sabra, R., & Arawi, T. (2018). Respecting patient choices: Using the 'Go Wish' cards as a teaching tool. *BMJ Supportive & Palliative Care*, 8(2), 194–197. doi:10.1136/bmjspcare-2017-001342

Potthoff, M., & Minton, M. (2017). Go-wish pediatrics: Pilot study of a conversation tool in pediatric palliative care. *Journal of Pediatric Health Care*, 31(4), 431–432. doi:10.1016/j.pedhc.2017.04.012

Radhakrishnan, K., Van Scoy, L. J., Jillapalli, R., Saxena, S., & Kim, M. T. (2017). Community-based game intervention to improve South Asian Indian Americans' engagement with advanced care planning. *Ethnicity & Health*, 24(6), 705–723. doi:10.1080/13557858.2017.1357068

Ray, R. A., & Street, A. F. (2006). Caregiver bodywork: Family members' experiences of caring for a person with motor neurone disease. *Journal of Advanced Nursing*, 56(1), 35–43. doi:10.1111/j.1365-2648.2006.03977.x

Ray, R. A., & Street, A. F. (2007). Non-finite loss and emotional labour: Family caregivers' experiences of living with motor neurone disease. *Journal of Clinical Nursing*, 16(3A), 35–43. doi:10.1111/j.1365-2702.2006.01722.x

Rogne, L., & McCune, S. L. (Eds.). (2014). *Advance care planning: Communicating about matters of life and death*. New York, NY: Springer Pub. Co.

Sallnow, L., Tishelman, C., Lindqvist, O., Richardson, H., & Cohen, J. (2016). Research in public health and end-of-life care – Building on the past and developing the new. *Progress in Palliative Care*, 24(1), 25–30. doi:10.1080/09699260.2015.1101260

Siefman, M., Brummel-Smith, K., Baker, S., & Edgerton, L. (2013). Consistency of choices of end-of-life wishes using the "Go Wish" cards: A comparison of elders with intact cognition and mild cognitive impairment. *Journal of the American Geriatrics Society*, 61, S120–S120.

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*, 284(19), 2476–2482. doi:10.1001/jama.284.19.2476

Street, A., Blackford, J., Threlkeld, G., Bidstrup, B., & Downing, J. (2011). *Entrust-u: Evaluative life review and advance care planning*. Melbourne, Australia: Department of Health, Victoria.

Sudore, R. L., & Fried, T. R. (2010). Redefining the "planning" in advance care planning: Preparing for end-of-life decision making. *Annals of Internal Medicine*, 153(4), 256–261. doi:10.1059/0003-4819-153-4-201008170-00008

Westerlund, C., Tishelman, C., Benkel, I., Fürst, C. J., Molander, U., Rasmussen, B. H., … Lindqvist, O. (2018). Public awareness of palliative care in Sweden. *Scandinavian Journal of Public Health*, 478–487. doi:10.1177/1403494817751329

Winter, L. (2013). Patient values and preferences for end-of-life treatments: Are values better predictors than a living will? *Journal of Palliative Medicine*, 16(4), 362–368. doi:10.1089/jpm.2012.0303

Zachariah, F., Klein, L., Clifton-Hawkins, N., Andrews, B., McQueary, A., Dillard, G., & Gross, D. (2014). It's about the conversation": A multidisciplinary intervention to support advance-care planning. *Journal of Clinical Oncology*, 32(31), 111. doi:10.1200/jco.2014.32.31_suppl.111