

Dissemination, use, and impact of a community-based, conversational advance care planning intervention: ripple effects of the Swedish DöBra cards

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Abstract

Introduction & Aim: Despite increasing interest in community-based advance care planning interventions, few studies investigate the societal impact of such initiatives. The DöBra cards, a Swedish adaptation of the GoWish cards, were first used for advance care planning conversations in a participatory action research project and later, due to popular demand, made available for purchase by the general public. We explore how the DöBra cards were disseminated and used publicly, to understand their impact in the community.

Methods: We used Ripple Effects Mapping to follow three dissemination ripples, based on interviews with 20 participants, analyzed with directed content analysis.

Findings: Key factors influencing dissemination of the DöBra cards included ‘champions’ with a mandate within their context or organization, policy documents including use of the cards, media coverage, and presentations of the cards in various settings. The DöBra cards were adapted for use individually and in groups in different private, professional, and organizational settings. Perceived benefits of the cards included acting as an icebreaker in initiating end-of-life conversations and having preformulated statements to reflect upon. Other positive experiences included discussions on different interpretations of card statements, thus opening new perspectives regarding end-of-life. The DöBra cards functioned both as means to raise end-of-life issues in different contexts, and as an end in themselves, for example, by facilitating advance care planning conversations for those with serious disease. Impact also included personal development and strengthening of private and professional relationships, with potential to affect end-of-life care.

Conclusion: The broad dissemination of the DöBra cards influenced capacity-building in dealing with end-of-life issues in communities, as the topic of dying and death was brought to agendas in new contexts.

Keywords: advance care planning, DöBra, Go wish, Go-wish, impact, participatory action research, ripple effects mapping

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Introduction

Advance care planning (ACP) has been described as a process of reflecting on and planning for future end-of-life (EoL) care, which may include discussion with others and documentation of care preferences in advance directives.^{1,2} While research and initiatives internationally have focused on varied

time points for ACP, there is growing interest in and evidence for the benefits of early ACP approaches, that is, focusing on individuals in the community who are not yet in imminent need of EoL care.^{3–6} Noonan and colleagues⁷ discuss how ‘up-streamed’ ACP initiatives can also act as a bridge between community actors and health

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professionals in new public health approaches to palliative care. Several studies report on community-based ACP interventions as successful in stimulating discussion and documentation of EoL wishes among community-dwelling, older adults.^{8–10} Interactive tools to promote reflection and discussion have been frequently used internationally in community-based ACP interventions, for example, conversation guides,^{11–13} card decks,^{14–16} and websites.^{17,18}

In Sweden, ACP initiatives are rare exceptions in the healthcare system, and there are no legal grounds for formulating binding advance directives or appointing proxy decision-makers. In the participatory action research project (PAR) ‘Advance care planning in Sweden’ (SweACP),¹⁹ we therefore initiated a structured, conversation-based intervention using the Swedish DöBra cards with older adults without imminent EoL needs (DöBra is a Swedish pun meaning literally ‘dying well’ but also ‘awesome’). The DöBra cards are a translated and adapted version of the US GoWish cards,²⁰ previously used in community settings to stimulate conversations about EoL issues.^{21–24} The DöBra cards include 37 preformulated statements of potential importance at the EoL, for example, ‘to be free of pain’, ‘not dying alone’, and ‘to pray’; there are also wild cards for users to freely formulate any other matters of importance. Users initially sort each card statement into one of three piles according to its priority—very important, somewhat important, and less important—and then rank the 10 most important cards from 1 to 10, with the first most important. This procedure has been used in previous international studies,^{20,22,23,25} and provides a basis for reflection and discussion about EoL values and preferences.

We have previously reported^{19,26} on the DöBra cards as a viable tool for stimulating reflection and discussion on EoL issues and their implications for research participants. One implication related to an increasing request for access to the Swedish cards from the general public as well as from a range of healthcare providers. The cards were therefore made publicly available as a social innovation in collaboration with a publishing company in 2018, without any financial gain to the researchers or research program; we see this broad dissemination as a first impact of the PAR project SweACP. Approximately 2000 copies have been disseminated since, primarily via physical and online bookstores, without any research-based follow-up or control.

Jimenez and colleagues²⁷ conclude that further studies assessing the impact of ACP interventions in varied populations, settings, and contexts are needed. While studies exploring the impact of community-based ACP interventions do exist,^{10,28–31} they are often limited to measuring the impact immediately following an intervention, with Seymour and colleagues³² study a rare exception as they report on community engagement activities during the year following a peer-educational intervention. Furthermore, studies exploring the impact of ACP interventions in a broad community setting beyond formal research contexts—an important feature of PAR—appear to be lacking. The aim of this article is thus to explore how the DöBra cards have been disseminated and used publicly, to provide a basis for understanding their impact in the community. We investigate this in terms of factors influencing the spread, as well as perceived benefits and limitations of the cards as they were used in these new contexts.

Methods

We were initially inspired by Ripple Effects Mapping (REM), a method used for studying community interventions after researchers have ‘left the stage’, to allow exploration of unintentional and uncontrolled impact resulting from a PAR project. REM is a method that employs conceptualization and description of the multiple layers of impact, previously used to explore the impact of single, distinct PAR projects.³³ We therefore used a modified form of REM, as specified below, conceptualizing the first ripple from the PAR project SweACP as public dissemination of the DöBra cards. Here, we explore further public dissemination and use of the DöBra cards as subsequent ripple effects of the SweACP project. At the time we began data collection, we were aware that the DöBra cards had spread to and been used independently in varied contexts in different parts of the country, but knew little of factors influencing this spread or how the cards had been used in these different settings.

Recruitment

We explore three different cases stemming from the publicly available cards, in which we followed ‘dissemination ripples’, that is, chains of dissemination. Cases were chosen based on both contextual and geographical diversity, with participants recruited from the south to far north of Sweden. Key stakeholders known to play a role in

dissemination of the cards within these cases were approached first; for case A, we contacted a woman who had organized a study circle about death-related issues which we learned about through national media coverage (A1). This case developed to focus on the spread from a nationwide interest organization for older people. For case B, we approached a man with a central role in a patient organization who had contacted the research team in 2015 as he wanted to work with death-related issues within that organization (B1). This case came to include dissemination within patient organizations as well as other community spread. For case C, two female registered nurses in a palliative care consultation team, who had previously told us they used the DöBra cards professionally (C1 and C2), were asked to participate. This case came to revolve around dissemination in healthcare and educational contexts.

Following ethical approval (Swedish Ethical Review Authority, #2019-06087), these key stakeholders were approached by e-mail or telephone, received information about the study and agreed to participate. During interviews, these key participants informed us of others who had either inspired them or been inspired by them in relation to the use of the DöBra cards. Subsequent participants were thus recruited through snowball sampling³⁴ and contacted either by the key participant who introduced them to the study and with permission conveyed contact details to ME, or contacted directly by ME via e-mail or telephone, on the advice of the key participant. These subsequent participants in turn informed us of other potential participants who were recruited in the same manner. All but two potential participants approached consented to participate in the study; these two men each stated that they had not used the DöBra cards to an extent they believed would contribute to the study. All participants signed an informed consent form before interviews.

Data collection

As noted above, the dissemination and impact we wanted to study had originated from different dissemination ripples from SweACP, which led to the modification of REM. Data were therefore collected through interviews held in conversational form by ME, a registered nurse, and doctoral student experienced in conducting qualitative interviews, who was unknown to most participants. Permission to audiotape the interviews was given by all but two participants; notes

including quotes were taken during those interviews instead, and detailed field notes were written immediately following the interview.

Interviews were conducted from March to November 2020, and focused on three main areas: the spread of the DöBra cards (to and from the participant); experiences of using the DöBra cards; and different kinds of impact directly or indirectly resulting from use of the DöBra cards. Follow-up questions were asked to ensure understanding, for example, 'Can you explain this further?'. Most interviews were conducted by telephone due to geographical distance and COVID-19-related restrictions, with two conducted face-to-face in locations chosen by the participants. Interview duration ranged from 17 to 75 min (median 39 min). Interviews were professionally transcribed verbatim and checked by ME who read the transcript while listening to the audio-recording.

Data analysis

Directly following each interview, the data generated were summarized in the form of digital maps showing the spread and use of the DöBra cards [see final, collated versions of these maps in Figure 1(a)–(d)]. Users of the DöBra cards, the context in which they had used the cards and factors influencing their spread were included in this mapping.

Interview transcripts were then further analyzed using directed content analysis.³⁵ First, a formative categorization matrix was created with preliminary categories that guided analysis, informed by our and others' previous research.^{19,36} These preliminary categories were also informed by our preanalysis understanding of data content derived during data collection. Meaning units were then extracted, coded based on similarity in content, and added to the matrix. Modifications to the categories were made as new patterns in data became apparent through continued analysis. ME had principal responsibility for analysis, with frequent discussions with the other authors to enhance credibility. During analysis, preliminary results were presented on two occasions to the SweACP project group, including a representative of one of the organizations through which the spread of the DöBra cards was explored, as well as other community-based patient and retiree organizations. Discussions with the project group supported the findings and added nuance to the presentation of the results below.

Table 1. Sample characteristics (N = 20).

Characteristics	N (%)
Age, median (range)	57 (29–81) years
Gender	
Female	17 (85.0)
Male	3 (15.0)
Living situation ^a	
Spouse	16 (80.0)
Alone	4 (20.0)
With children	4 (20.0)
Education	
University	16 (80.0)
High school	2 (10.0)
Elementary school	2 (10.0)
Employment status ^a	
Retired	9 (45.0)
Employed, full-time	9 (45.0)
Employed, part-time	2 (10.0)
Student, part-time	1 (5.0)
Self-assessed health status	
Good	17 (85.0)
Neither good nor poor	3 (15.0)
Poor	0 (0.0)

^aTotal > 100% as categories are not mutually exclusive.

Findings

We present three example cases of dissemination ripples, based on interviews with 20 individuals. As noted above, case A had its origin in a nationwide interest organization for older people and came to include interviews with one man and seven women, as seen in Figure 1(a). Case B originates from a patient organization and includes interviews with two men and two women, as seen in Figure 1(b). Case C has a focus on dissemination through formal healthcare providers and includes interviews with eight women, see Figure 1(c). In Figure 1(a)–(d), Abel's 'Circles of care'³⁷ provided inspiration for describing levels on which dissemination occurred.

Sample characteristics are summarized in Table 1. Participants are referred to by a code, chronologically denoting the interview process and used in the figures, thus providing insight into the order of data collection and dissemination ripples.

Findings are presented in the following categories: factors influencing dissemination of the DöBra cards, variations in use, perceived benefits and limitations, and impact related to use of the DöBra cards. The results are summarized in Table 2. We use illustrative quotes to clarify analytic points. Pauses are indicated by '...', omitted phrases by '[...]', and authors' comments are also within brackets.

Factors influencing dissemination of the DöBra cards

Facilitating factors. We found that one key to broad dissemination was people with a mandate in their profession or organization who promoted the cards in different contexts, that is, 'champions'. They disseminated the cards and information about their use in a range of settings, including their private and professional networks (see Table 2).

The importance of champions is particularly notable in case B, where B1 was found to be a 'super-spreader' driven by both personal and professional incentives as he disseminated the cards widely in his private network, including his wife, friends and his mother (B2) [see Figure 1(b)]. B1 also promoted the DöBra cards at various occasions within his own patient organization as well as to other patient organizations. He introduced the cards to healthcare providers and was also influential in highlighting the DöBra cards as a tool for EoL conversations in the national disease-specific care guidelines linked to his patient organization. His mother (B2) had in turn also been very active in spreading the cards, mainly in various constellations of friends, but also used them when she volunteered at a local language café in which newly arrived immigrants practiced conversing in Swedish.

An important factor influencing dissemination in case A was a health guidance document published by this national interest organization, which included a section called DöBra recommending use of the cards [see Figure 1(a)]. The document was made available to the

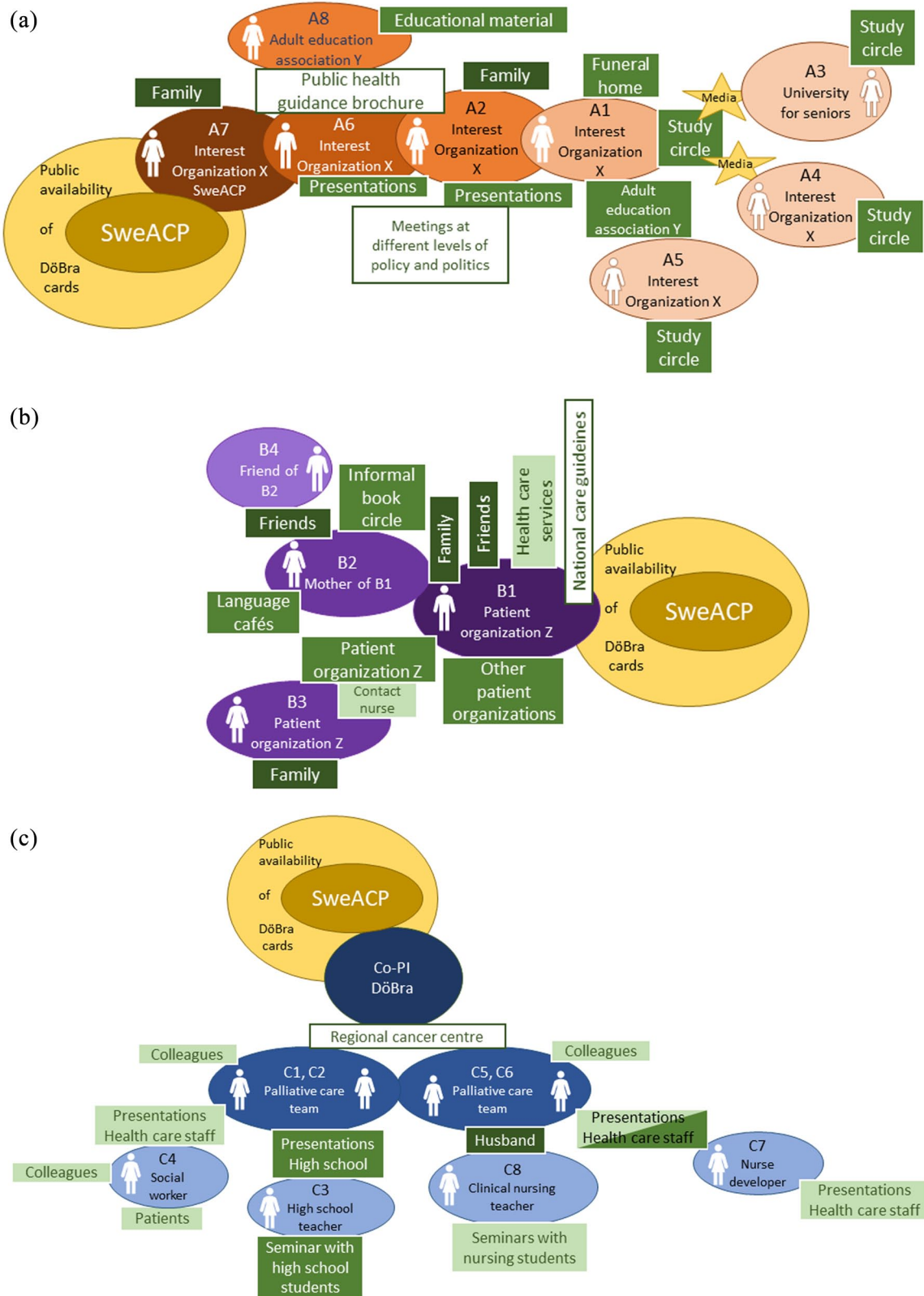


Figure 1. (Continued)

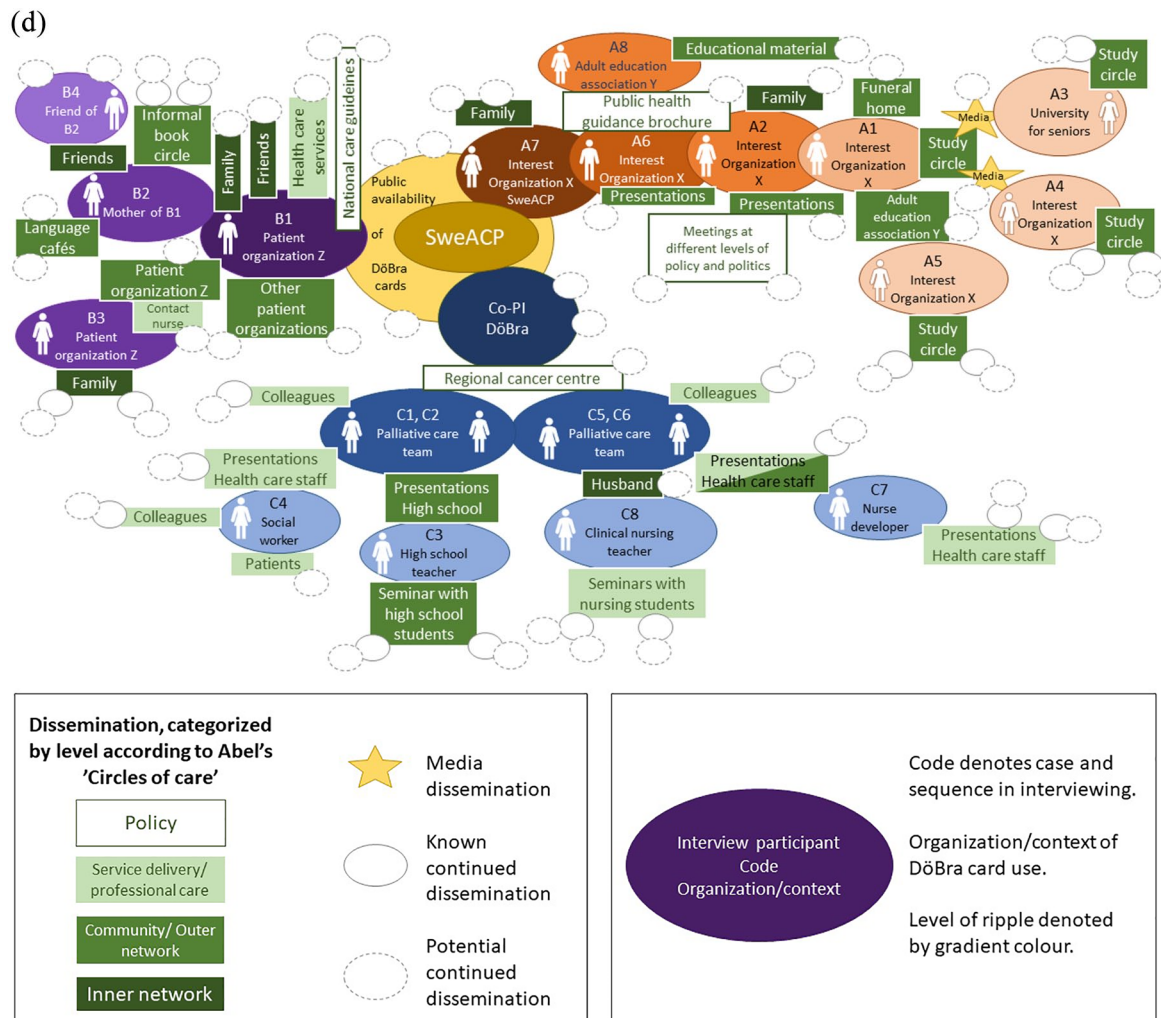


Figure 1. (a) Dissemination and use in case A. (b) Dissemination and use in case B. (c) Dissemination and use in case C. (d) Continued dissemination, known and potential.

organization’s membership of several hundred thousand through their website. Participant A7, who represented the interest organization in the SweACP project group, collaborated with A6 on the content of the document; A7 was influential in having the section about DöBra included. This collaboration also came to include A8 who designed material for organization members interested in facilitating study circles based on the topics in the document and also held courses for potential facilitators. The 2018 launching of the document entailed A6 frequently promoting the DöBra cards to the organization’s regional chapters when presenting the document. He highlighted the importance of champions and of reaching influential people with his presentations, as he said:

For example, there was [A2] in [names a region], who is very politically interested, she’s interested in issues related to health and social care, and I think that then they think this [DöBra cards] is really important and that they are happy to spread this information on, that there is this possibility and ‘shouldn’t we start something related to this subject?’

Not all participants who have been influential in spreading the cards had had personal experience of their use. Participant A6 was familiar with the cards but had never used them himself. This was also the case with A3 who organized a study circle related to death and dying in which she intended to use the DöBra cards, but due to time restraints did not actually include them in the study circle. Participant A8, who held courses for potential

study circle facilitators on the health guidance document, had never seen the cards, but described herself as nonetheless engaged in spreading information about them.

Another important factor facilitating the spread of the DöBra cards in case A was media coverage about a study circle in which the cards were used [see Figure 1(a)]. The interest organization's membership magazine, as well as local and national media reported on the 'Death Circle' study group arranged by participant A1. This inspired A3 and A4, as well as others, to start their own versions of 'Death circles' in other towns. As shown in Figure 1(d), there seems to be an extensive continued spread of the DöBra cards, which is beyond the scope of our exploration. The full circles represent cases of known spread, while the dotted circles are potential ripples suggested by our interviews, but about which we lack further information.

In case C, the main factor for dissemination was the active input of four registered nurses in two different palliative care teams (C1, C2, C5, and C6) in geographically disparate areas who used and promoted the DöBra cards in various informal and formal encounters with colleagues. They held formal presentations and workshops with other healthcare staff, some at the hospitals where they worked, but also for staff in residential care homes and even for high school students [see Figure 1(c)]. C5 described one educational event on palliative care, at which she and her colleague presented and used the DöBra cards with healthcare staff in a sparsely populated region:

We used them together ... at educational events or continuing education events we've arranged for assistant nurses working [in elder care, which is run by municipalities]. We've had presentations for, well when we were in P [a village with approximately 2000 residents] for example last year, I think there were—if there were 100 or more than 100 [people attending], I don't remember, but really very many people there.

Resistance toward use and dissemination of the DöBra cards. Some participants described how they had experienced resistance from various sources, related to either the promotion or use of the DöBra cards specifically, or related to raising issues about EoL in general. On an organizational level, some participants encountered individuals in managerial positions who were reluctant to let them spread information about or use the DöBra cards, as exemplified by A2 below. The local chapter of

her organization had prohibited her from using or providing information about the cards:

The part that is a bit unfortunate, it's that I tried to ... they usually discuss things in the working group of the district board [of the organization], and they said no, these cards should not be used in health promoting initiatives in the region. [...] There's something a little tricky when it comes to death, it seems [...] in general, the only ones who should be able to use the cards—if I generalize a lot—it was psychologists and the lot. Not just anyone in some organization should be able to use them and have a conversation [participant describing the opinion of the working group]. And there we have kind of different opinions, me and the people who were opposed. But democracy is democracy, so that was that.

Milder forms of resistance were described by other participants, as they spoke of having to convince organizational management in repeated discussions about starting study circles before receiving permission. Some spoke about resistance toward the DöBra cards from formal healthcare services and staff, something described both by patients and other healthcare professionals. Resistance was said to have been demonstrated through behaviors such as changing the topic when raised in a conversation by a patient or showing signs of discomfort when using the cards with colleagues within a healthcare organization.

Resistance was also discussed in forms of conflicts within families regarding participation in study circles about EoL issues, as described by A5:

Because some of them who came there [to a death study circle] [...] their [adult] children had said, 'you can't go there'. And then they said 'I don't give a crap, I'm going anyway because I want to know what this is all about'.

Some participants also described a form of internal resistance, for example, toward using the DöBra cards with their own families despite using them extensively professionally, or related to presenting the cards to specific people they considered vulnerable, that is, very elderly individuals or people who had just experienced loss.

Variations in use

Participants described having used the DöBra cards to reflect upon and discuss EoL issues in a range of different manners and settings: individually, with a few others, or in larger groups (see

Table 2. Summary of findings in relation to cases.

Findings/cases	Case A	Case B	Case C
Dissemination			
'Champions'	X	X	X
Policy documents	X	X	
Media	X		
Presentations (formal and informal)	X	X	X
Resistance (different forms)	X	X	X
Use			
In solitude	X	X	
With family members	X	X	^a
In group settings	X	X	X
Participant as facilitator	X		X
Participant as active attendee		X	X
For general EoL discussions	X	X	
For ACP discussions	X	X	X
Benefits (e.g. stimulating EoL conversations and modulating engagement)	X	X	X
Limitations (only cost and name mentioned)		X	X
Impact			
Personal development	X	X	X
Strengthening relationships	X	X	X
Learning about/from each other	X	X	X
Widening perspectives	X	X	X
Potential to affect EoL care		X	X
Improving professional collaboration			X
EoL issues brought to new agendas	X	X	
ACP: advance care planning; EoL: end-of-life. ^a Husband referred to as disseminator by the subsequent participant, although his wife mentions no use of cards with family.			

Table 2). Some had been active in using the cards with others, while there were also descriptions of participants acting as facilitators while others actively used the cards. The DöBra card boxes come with suggestions for their use (same as described above), although participants were

creative in modifying the use of the cards to suit their various intentions and goals.

A few participants had used the cards alone, without discussion with others. A5 speaks of this when describing how she planned the study circle:

I began to wonder how I should organize it [...] I got this card deck ... So I had it to be able to get a sense of what I was doing ... I really had to start to mull over how ... how to say that you should meet and talk about death? How do you plan something like that? So it was actually a bit tricky I thought ... Yeah, well then I wrote some points that we would include, and then this card deck was a very big help.

Some participants described using the DöBra cards in private contexts, with family and friends, first ranking the cards individually and then discussing one another's preferences. The two participants from the same patient organization, B1 and B3, met other needs in their use of the cards with family members. Instead of discussing their own preferences, the 'healthy' family member focused their ranking of card statements on beliefs about the preferences of their sick family member. This ranking was then compared to the sick family member's own ranking of preferences, and discrepancies discussed.

Participants also shared experiences of using the DöBra cards as a basis for more general discussion about EoL issues in larger groups, see Table 2. Such discussion took place in study circles about the EoL, in a seminar with high school seniors, in a language café for those with Swedish as a new language, and in a book circle, where participants discussed card statements without ranking or sorting them individually first. In other group settings, attendees had first used the cards individually to rank their own preferences for future EoL care, followed by group discussions about the attendees' varying preferences. This latter strategy for card use was predominately described in case C with various categories of health/care staff in different settings and as part of clinical education for final year nursing students.

Despite the number of healthcare staff interviewed, only one participant, a social worker (C4), mentioned using the DöBra cards with patients. She had introduced the cards to two patients who both had declined to use them. One of the nurses in a palliative care team (C5) who had been particularly active in using the DöBra cards with colleagues explained why she had never used them with patients:

We are a consultant team and so are ... those who have the closest contact with those patients we also meet, that's the home care nurse. They're the ones who get to know the patient better, and then it's perhaps more natural [to have conversations about

EoL preferences and values]. We often just meet the patients once physically, and then have mostly telephone contact with either family or the home care nurses, but I think that ... it's felt like a little too much of a distance to use them in the first meeting, just like you need to ... have time to develop a relationship maybe before you ... there's so much that needs to get done at this first meeting, just to be able to communicate some kind of a sense of security and all. I have difficulty seeing it ...

Other participants mentioned how they had taken various measures when introducing the cards to minimize the risk of upsetting others. Some described how they tried to 'feel the vibe' within a group or from an individual, to be able to judge if the time was right for presenting the cards. A3 described how she had been inspired by the 'Death Circle' held by A1, but had modified the study circle's name:

We thought it could keep people away if we called it a Death circle, we thought that no one would dare ... it was a little too direct in some way. So we called it '*Towards dusk—a circle about the end-of-life*' So that was good, I thought.

Some participants also emphasized the importance of not introducing the topic of death and dying too bluntly. This also meant that if the DöBra cards were used in a group setting, all attendees should be aware of the topic of discussion in advance. A few participants spoke of experiences of introducing the DöBra cards to individuals who were not aware of the topic beforehand who had then become uncomfortable. C3, a teacher who used the cards with high school students, said she always prepared for such potentially difficult discussions by having a backup plan in case a student became uncomfortable.

Perceived benefits and limitations

Benefits. Participants predominately described benefits of using the DöBra cards. Negative aspects were raised to a lesser degree, and only in cases B and C (see Table 2). The cards were said to be experienced as a good icebreaker in initiating conversations about death and dying, even in initial study circle sessions. Some participants highlighted that the cards presented an opportunity to talk about death-related issues they often thought about but rarely had a chance to discuss, providing them with a sense of comfort and relief afterward. Having preformulated statements to

consider, rather than only having to determine oneself what could be important at EoL, was said to be beneficial. C2 elaborated on this, saying:

But there is something that's liberating and enticing in its format, that it's already formulated for example. You don't get 10 blank pieces of paper that you're supposed to fill, but instead it's ... someone has thought ...

Another advantage highlighted was having something to do with one's hands and the physical act of moving cards around while discussing EoL preferences. Participants who had facilitated group sessions with the DöBra cards described how they had noticed that attendees could modulate their engagement and personal sharing in the groups. C4 shared her experiences of using the cards in a group of colleagues, saying:

And then maybe someone thinks that ... it's a little troubling and so, but then they just can be quiet and watch instead ... in a group of colleagues you can be, yeah well be a little laidback if you don't ...

Discussing how closely related card statements could be interpreted and valued differently by different individuals was said to be another positive feature of using the cards with others, raised by both professionals and nonprofessionals. B2 described how she sometimes had changed her prioritizations after discussing the card statements with friends:

It also changes as you go on, like when I've now talked to my friends and we've had discussions, so sort of with others, by talking with others ... I can change it sometimes, what I've written. When you talk, sit and discuss, and with friends and so and then I've sort of—*'aha! Yes, you're probably right about that, it's pretty important for me too.'* I'm going to change a little on my list, I think then, you know.

Limitations

Fewer negative aspects of the DöBra cards were mentioned. They were discussed as being too costly, both for seriously ill patients who might be struggling financially but also for healthcare services that may want to buy card decks in bulk (between €11 and 16/per deck at present; bulk cost €8). One participant described finding it challenging to introduce the cards to her study circle attendees, while others highlighted that the blunt name of the card deck, 'DöBra', might be a

hinder in introducing the cards. A few of the interviewed healthcare professionals said that they worried about being seen as frivolous by patients if introducing cards with a pun for a name. B4 spoke about how the name might suit some individuals better than others, saying:

It's a provocative name. It's brazen, but effective. It feels appealing to talk about DöBra. But it's almost a little bit unexpectedly brazen, and I'm thinking: Does it work for everyone? Those who have thought and longed to talk about this, for them it [the name] can be attractive. But what about the others, who haven't? They may well experience it as a bit provocative and almost a deterrent.

Other suggestions for improvements focused on the card statements, often suggesting adding new card items, for example, regarding assisted suicide and legal issues related to EoL.

Impact related to use of the DöBra cards

Perceived impact of the DöBra cards on an individual level was described in terms of personal development as well as effects on private and professional relationships. There were also descriptions of impact on organizational and societal level related to care provision and raising the topic of death and dying in new contexts, as summarized in Table 2 and expanded on below.

Impact on individual levels. On an individual level, some participants described impact in form of coming to peace with their own death by feeling more prepared. C1 emphasized how using the cards had been a factor in her personal development and became a way to remain in touch with her personal feelings while working as a palliative care nurse:

In one way it's good, since you think sometimes *'but oh, I'm involved in this [death and dying] so much nowadays'* [...] you're so deeply involved in other people's lives, so you just think ... well you go home and so you forget. So when you return the next morning *'what did I do yesterday?'* *'but oh, there was that difficult thing.'* And then you think, *'is there something wrong with me?'* But at the same time, when it's about you personally, that I'm going to look at these cards, then you feel that still, I seem to have ... feelings left. I'm not totally cynical, you might say.

One of the study circle facilitators highlighted how the 'death study circle' had helped an attendee cope with the recent death of her

husband. Two retired women had quite different experiences of facilitating ‘death circles’, as one of them said that she would not facilitate another circle with the same topic as it was too psychologically burdening. The other (A5) described facilitating the circle as a personal growth experience, saying:

When you start a study circle you always, you have a certain demand on you to actually steer and lead it. I was a bit anxious that I wouldn’t be ... what should I say, mature enough for the task or something like that [...] It caused me to grow myself also, that I was able to deal with that task.

Impact on private and professional relationships. Participants would often describe using the DöBra cards as affecting private as well as professional relationships. Some said that their personal relationships with family or friends had been strengthened by talking about EoL issues while using the cards. A2 described feeling comforted in knowing that she and her husband of many years had discussed these issues:

I got to know my husband better (laughs). And now we know a little bit about how we want it to be. So based on that it feels very good, I have to say. I didn’t think we were this similar, and he didn’t either. Because I thought my reflections would be very different than his, but they weren’t. And then you don’t need to wonder so much ... Because I don’t know what will happen when I get old and dement, and if I get that way or what happens. Or if you just drop dead. No matter what, we have a normal state when we think we are reasonable and have decided a little how it should be anyway. And that feels good, it feels very secure.

Another older participant described how using the DöBra cards with her friends had led them to discuss and decide upon mutual EoL support strategies since their adult children live far away. Some participants highlighted how they had learned more about those they used the cards with, both personal and professional acquaintances. The healthcare professionals interviewed especially emphasized the impact of using the DöBra cards with multiprofessional groups, for example, nurses, rehabilitation staff, and physicians. They described these sessions as providing a deeper understanding of different professional perspectives on EoL and as also making visible their own preconceived ideas about other professions. As C7 exemplifies:

And that group also started, even an older physician started talking about his own death. That doesn’t happen a lot. [...] It’s nice when one’s preconceived notions are put to shame.

Impact on care provision. Healthcare professionals also mentioned the impact of using the DöBra cards, with potential for long-term effects on care provision. Some professionals who had used the DöBra cards with colleagues in group sessions raised the importance of reflecting on one’s own EoL preferences to be able to better care for patients at the EoL. Discussing their own EoL preferences with others and realizing how different preferences can be was said to be valuable, for example, in relation to understanding different patients’ varying preferences, as well as how a patient’s preferences might change over time. Having staff of different backgrounds use and discuss the cards together was said to be a good way to learn about cultural aspects of caring for dying individuals. C6 spoke of her experiences:

Something we’ve also noted, it’s this with ... I’m thinking primarily about at the residential care homes, that there are so many different cultures mixed together, and there you can really see a ... both a difference in reasoning and that you get like an understanding of one another’s values in another way. In many cultures [...] they’ve said ‘*I’m not used to talking about this, we don’t talk about these things in my country*’ or ‘*this is taboo*’.

Another participant had a slightly different perspective, as she said the primary benefit of using the cards with other healthcare professionals was highlighting how all individuals are essentially the same, an insight she thought might prevent staff from distancing themselves from the individuals that they cared for.

Using the DöBra cards with colleagues was said to sometimes spark discussion using examples of experiences of caring for dying people. The cards were also spoken of as feasible for nonjudgmental discussions on negative aspects of care provided, as discussing card statements was experienced as less confrontative than discussing practice-based situations. C5 described receiving positive feedback from managers in the municipality after using the DöBra cards with staff working in home care services, saying:

According to what they’ve told us from home health care, their managers, they think that it’s so good to

have discussions around the cards, when you talk about approaches to dealing with people and values and such.

Another participant said the card exercise had been a good starting point for professionals from in-patient care and home care teams to discuss how they can better collaborate to meet patients' preferences in EoL care.

There were also aspects raised by nonprofessionals which had bearing on care provision. Participants who had used the cards in discussing a seriously ill family member's EoL preferences expressed how using the cards together might make the family members more satisfied with future care, by knowing that it is in concordance with the ill person's preferences. B1 said using the DöBra cards with his seriously ill wife had relieved some of his stress about being an informal proxy decision-maker in the future:

They are a really good tool for family members to actually not push their own preferences, but those of the person they care about. And we've [the patient organization] found it to be a very important thing, I've personally had a lot of anxiety since sooner or later I'm going to have to make decisions for my wife.

A few participants were not disappointed with the cards per se, but with the interaction with healthcare professionals when presenting the DöBra cards to them, pointing to a need for researchers to collaborate with healthcare services to prepare staff to meet requests from patients and their families about discussing EoL preferences.

Impact on organizational and societal levels. Although less often described, there were also indications of impact in organizations and on a societal level. Introduction of the topic of dying and death into new contexts, stimulated by media coverage, champions, or 'death circles', was frequently mentioned. This could encompass organizations hosting study circles, including the topic in policy documents, or as with A2, promoting the DöBra cards in local government meetings. A1 illustrated how other societal organizations had decided to engage with the topic of death and dying, after learning through media about the 'death circle' she organized:

I remember XXX [names place], they also contacted me pretty quickly, and there it was YYY [names

organization that arranges study circles] who were interested. And YYY got the information about the way we set it up, what we had done and so on. And of course, the woman at ZZZ [names company for funeral arrangements], she has spread it, [...] since she thought it [DöBra card deck] was so cool.

B1 described how several other members of the patient organization had become interested in raising issues of death and dying, labeling their initiatives as working with 'issues of DöBra' and were seeking to raise awareness in the patient organization's regional chapters. B1 said the DöBra cards influenced a collaborative project about EoL preferences between the patient organization and professionals saying:

But then we have the DöBra part and with the DöBra cards and quality of death, so we said to the surgeons 'but what if you got this kind of tumor yourself [...]and you know you'll have these permanent deficits in how you function, what would you choose, operation or no operation?' [...] so now we've developed a battery of questions we pose about if you got this tumor yourself [...] which is out now among all these [mentions subspecialty] surgeons in all the Nordic countries.

Some participants requested results of this study when finished, to be able to use a scientific reference when continuing their work with promoting issues of death and dying in their respective organizations.

Discussion

In this study, we explored three cases of dissemination ripples and use of the DöBra cards, to investigate the impact of the cards in a wider community setting. It should be noted that the first ripple effect from the SweACP PAR project was the call for the DöBra cards to be made broadly available to the general public due to community actors' interest in having access to a tool to support discussion and reflection about EoL issues. In the subsequent ripples investigated here, we found key factors influencing dissemination of the cards included champions with a mandate within their context or organization, policy documents including use of the cards, media coverage, as well as formal and informal presentations of the cards in various settings. However, participants also described some resistance to using or promoting the cards in different contexts. The DöBra cards were used in a range of settings, individually as

well as in groups, for ACP conversations as well as more general group discussions on EoL issues, and even in planning study circles. Perceived benefits of the DöBra cards included acting as an ice-breaker in initiating EoL conversations and having preformulated statements to reflect upon. Other positive experiences include using the cards in group settings as they supported attendees' ability to modulate their engagement according to their comfort level and allowed discussions on different interpretations of card statements, thus opening for new perspectives. The very direct name of the cards was mentioned by some as a hindering factor. The impact of the DöBra cards includes descriptions of personal development and strengthening of relationships, personally as well as professionally. On organizational and societal levels, the DöBra cards were found to have had an impact with potential to affect EoL care provision and brought the topic of death and dying onto the agenda in new settings.

This study furthers knowledge on how the GoWish/DöBra cards can stimulate EoL conversations in professional as well as less-studied nonprofessional group settings. Our findings in regard to use with healthcare professionals are in part in line with those from Osman and colleagues³⁸ study using the GoWish cards with medical students, for example, demonstrating the range of variation in EoL priorities, and stimulating reflection on how to provide personalized care. This is of importance as healthcare staff's implicit personal values can affect care provision.^{39,40} Furthermore, we also note previously undocumented aspects of use of GoWish/DöBra cards in heterogeneous professional group settings, that is, increased intercultural and inter-professional understanding among staff.

An important impact of the DöBra cards relates to bringing the topic of death and dying into new societal arenas, for example, in organizations that had not previously promoted these topics on their agendas. In this study, this included both a patient organization and an interest organization for older people, both of which had previously been reluctant to address EoL issues. This can be seen in light of how the phenomenon of 'capacity-building' is emphasized by Trickett and Beehler³³ as an important potential ripple effect of PAR projects. As noted above, in the present study, capacity-building is an indirect impact derived from the original PAR project SweACP, and a direct impact of using the DöBra cards themselves. Use of the cards has been found to build capacity and develop skills in

communities, by supporting engagement with the topic of death and dying in the wider community setting and bringing these topics into new contexts. In our data, we noted such impact in all of Abel's 'Circles of care'.³⁷ Creating supportive environments, strengthened community action, and the development of personal skills are goals emphasized also in the Ottawa charter for health promotion⁴¹ and have been used, in combination with core concepts from palliative care, in developing a field sometimes known as health-promoting palliative care (HPPC)⁴² or public health palliative care. As previous HPPC studies have shown,^{37,43,44} building compassionate networks of caring in the community can be of importance for supporting both a person with life-limiting illness and their carers.

Several participants independently raised negative aspects of having the Swedish name of the cards, 'DöBra', in the form of a pun. However, the name also seemed relatively well-known and had become somewhat of a slogan for those interested in raising awareness on the topic of death and dying, in societal organizations as well as healthcare services. Several participants labeled their interest and work with raising death awareness in their respective organizations by saying that they worked with 'issues of DöBra'. This, in combination with those participants who had not used the DöBra cards themselves but nonetheless furthered the spread of information about them, leads to questions of whether the cards might also act as a means to raise death awareness in general, in addition to their original function of facilitating ACP conversations. While we initially strived to map the ripple effects of an ACP intervention, this study shows that the DöBra cards came to be used in contexts broader than ACP, thus showing potential to strengthen community involvement in EoL issues in line with ideas within new public health approaches to palliative care.⁴³

Bornman⁴⁵ describes different aspects of the societal impact of research. While the present study describes the impact of the public dissemination and use of a tool derived from research, and not the original research per se, we find Bornman's description valuable in considering our findings. First, Bornman highlights the incalculable ripple effects of societal impact, as they may be anticipated or unanticipated and affect both the target population and beyond. In the present study, unanticipated dissemination of the DöBra cards included seminars with high school students and language cafés for newly arrived immigrants. In

these cafés, the simple language of the cards supported both practicing Swedish as well as conversations bridging different backgrounds and cultures, highlighting the universality of death and dying. Second, Bornman identified stakeholders in societal impact to include end-users, professionals, and policy makers; impact in the present study has been demonstrated among all three groups in varying degrees, even in this limited sample. Third, Bornman points out that societal impact is not always short-term; we attempt to highlight this in Figure 1(d) as we map potential continued ripple effects implied by interview data, but unable to be followed within the scope of this study. As further dissemination is still ongoing, it is plausible that ripple effects continue. Finally, Bornman highlights that the societal impact is not always positive, which demands methodological consideration of study limitations.

One methodological limitation relates to the ‘appreciative inquiry’ approach to data collection suggested in REM, which yields a sample with positive bias, with the potential to minimize reporting of negative aspects of use and impact of the DöBra cards. However, we attempted to compensate for potential bias, by not excluding participants, and including specific questions about negative aspects of the DöBra cards, even when such aspects were not spontaneously addressed by participants. Negative aspects of the DöBra cards were not mentioned by any participant in case A; however, we lack data to establish whether this is due to differences in the context of card use or other reasons. We made efforts to study diverse cases⁴⁶ of dissemination and contexts of use without forehand information about their experiences. In addition, we also made an effort to reach a broader group of card users, by emailing those who had left their contact details when purchasing the cards, asking for written descriptions about card use or nonuse. However, this initiative yielded only data from professionals, which added no new information to that presented here, and the low response rate meant the data generated was not robust enough to merit inclusion here.

Another limitation is related to the design, and questions of how three example cases relate to the broader, nation-wide dissemination of the DöBra cards. Yin,⁴⁷ referring to case study design, discusses the benefit of applying analytical, rather than statistical, generalization. Results can be strengthened by clarifying how findings from diverse cases with geographical and contextual

variation support each other in regard to analytic points, as we have illustrated in Table 2. While the first author carried out the bulk of analysis, ideas about the process and results were frequently discussed with the other authors, with the SweACP project group, as well as with researchers external to the research group. This process was deemed especially important for this study as we evaluated a research tool we had translated and adapted ourselves, in new contexts. The process provided opportunities for reflexivity in analysis and possibilities to consider and discuss rival hypotheses,⁴⁷ thus further strengthening analytical generalization.

The originally proposed REM data collection method of workshops with community stakeholders could have been beneficial to use here. Given some participants’ interest in results of this study, collecting data through workshops might both have enhanced its richness and the possibility for participants to learn from each other, despite the differences in the contexts for DöBra cards use. However, given COVID-19 restrictions and the limited computer literacy of several participants, this was carried out neither live as intended nor digitally.

There is a need for further research on how ACP interventions directed toward the general public can affect the wider community setting in different contexts. Future studies might focus on such interventions’ impact on strengthening key aspects of compassionate communities, for example, by exploring the impact on the various levels of ‘Circles of care’.³⁷ This study also highlights the need to follow long-term ‘ripple effects’ of PAR initiatives as well as of new public health approaches to palliative care, further encouraging innovative thinking about evaluation practices.

Conclusion

The broad dissemination of the DöBra cards in a variety of contexts beyond those controlled by researchers has led to capacity-building in dealing with EoL issues in the community, as the topic of dying and death has been brought to agendas in new contexts. This study demonstrates the ability of a PAR project to have a societal impact in the wider community setting.

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Research data availability

Our ethical permit prohibits us from sharing research data.

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