

Navigating power dynamics in engaging communities in end-of-life issues – Lessons learned from developing community-based intergenerational arts initiatives about death and loss

Max Kleijberg, Beth Maina Ahlberg, Alastair Macdonald, Olav Lindqvist & Carol Tishelman

To cite this article: Max Kleijberg, Beth Maina Ahlberg, Alastair Macdonald, Olav Lindqvist & Carol Tishelman (2019): Navigating power dynamics in engaging communities in end-of-life issues – Lessons learned from developing community-based intergenerational arts initiatives about death and loss, *Death Studies*, DOI: [10.1080/07481187.2019.1671547](https://doi.org/10.1080/07481187.2019.1671547)

To link to this article: <https://doi.org/10.1080/07481187.2019.1671547>



© 2019 The Author(s). Published with license by Taylor & Francis Group, LLC.



Published online: 11 Oct 2019.



Submit your article to this journal [↗](#)



Article views: 1181



View related articles [↗](#)



View Crossmark data [↗](#)

Navigating power dynamics in engaging communities in end-of-life issues – Lessons learned from developing community-based intergenerational arts initiatives about death and loss

Max Kleijberg^a , Beth Maina Ahlberg^b, Alastair Macdonald^c, Olav Lindqvist^{a,d}, and Carol Tishelman^{a,e}

^aDepartment of Learning, Informatics, Management and Ethics, Karolinska Institutet, Stockholm, Sweden; ^bDepartment of Sociology, Uppsala University, Uppsala, Sweden; ^cSchool of Design, The Glasgow School of Art, Glasgow, UK; ^dDepartment of Nursing, Umeå University, Umeå, Sweden; ^eCentre for Rural Medicine, Storuman, Sweden

ABSTRACT

Lack of community engagement in end-of-life issues and age-segregation in Swedish society motivated us to develop Studio DöBra, a community-based intergenerational arts initiative to support community engagement in end-of-life issues and develop intergenerational meeting places. Representatives from several community organizations formed a project group with first author MK, to develop Studio DöBra. Based on analysis of exploratory interviews with professionals involved in other, similar initiatives and data from Studio DöBra development, we discuss challenges related to power dynamics in developing initiatives to engage communities in end-of-life issues, and how these can inform the development of similar initiatives.



Introduction

Dying, death and loss affect everyone. However, with increasing professionalization in many societies, death has become less of a community concern as specialized facilities such as hospitals, hospices, and funeral homes increasingly manage affairs related to the end-of-life (EoL; Walter, 2017). Community engagement in EoL issues is important, as healthcare services have limited ability to fulfill EoL needs that are situated in and mediated by social relationships, which are often inaccessible to professionals (Kellehear, 2015).

In international comparisons, Sweden scores moderately well on quality of specialized palliative care, but low on community engagement in EoL care (Line, 2015). One reason for this may be a low public awareness of palliative care in Sweden, with taboos, fear, shame, and avoidance of issues related to the EoL named by respondents to a Swedish survey as barriers for learning more about palliative care (Westerlund et al., 2018). The low community engagement in EoL care may also be related to the fact that volunteers are not an integral part of Swedish EoL care, compared to other European countries where hospices are dependent on volunteers (Sauter & Rasmussen, 2010).

Health promotion efforts to engage communities in EoL issues may lead to developing community capacity, individual learning, and personal growth (Sallnow, Richardson, Murray, & Kellehear, 2016). These efforts have been described on a continuum of engagement from informing through empowering (Sallnow & Paul, 2015). The success of community engagement is said to largely depend on the first stages of developing equitable partnerships with community stakeholders (Sallnow & Paul, 2015; Wicks & Reason, 2009). It is therefore important to investigate ways in which these participatory processes can be navigated in order to inform development of community engagement in EoL issues.

The DöBra¹ research program in Sweden applies a health promotion approach to engage communities in EoL issues and facilitate preparation for encounters with the EoL through supporting conversations about dying, death, and loss on individual, community, and societal levels (Lindqvist & Tishelman, 2016). As part of this research program, a doctoral project with an action research design was initiated, in which first author MK, a PhD student with a design background, partnered with community-based organizations to

CONTACT Max Kleijberg  max.kleijberg@ki.se  Department of Learning, Informatics, Management and Ethics, Karolinska Institutet, Stockholm, 171 77 Sweden.

© 2019 The Author(s). Published with license by Taylor & Francis Group, LLC.

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

develop an intergenerational arts initiative called “Studio DöBra” to engage children, elderly and community organizations in EoL issues and create intergenerational meeting places.

In Sweden, most people die in old age and elderly people often live at home, dependent on home care and informal social care from their communities (Ulmanen & Szebehely, 2015). However, loss of social contacts at an older age has been found to increase risk for loneliness (Dahlberg, Andersson, & Lennartsson, 2018). Additionally, there are few intergenerational meeting places (Holmberg, Nilsson, & Weibull, 2003), and, as Walter (2017) points out, in age-segregated, ageing societies, many children are spared personal experiences related to death and loss. However, this lack of involvement of children in EoL-related conversations and exposure to death through media, may lead to unrealistic and negative assumptions about the EoL (Paul, 2015; Walter, 2017). Thus, the goal of Studio DöBra was to bring together these two age groups and support engagement in issues related to dying, death, and loss.

Context of Studio DöBra

In their systematic review, Martins et al. (2019) conceptualize intergenerational programs as “tools that allow for the exchange of resources and learning among older and younger generations” (p. 94). Prior to partnering with community-based organizations to develop Studio DöBra, we defined the younger generation as nine year-olds, based on positive experiences of similar initiatives working with this age group (Tsiris et al., 2011) as well as on literature suggesting that, by this age, children have generally developed an understanding of death as a definite and inevitable fact (Paul, 2015; Vázquez-Sánchez et al., 2019). The older generation was defined as anyone over the age of 65, to include a large group of potential participants. In Sweden, 65 is a common retirement age, with people thereafter often referred to as pensioners, seniors, or elderly. The use of the arts in Studio DöBra was supported by literature indicating that arts activities both facilitate engagement with EoL issues, topics that may be difficult to put into words (Bertman, 2015; Nan et al., 2018; Walter, 2012), and support intergenerational interaction (Lou & Dai, 2017).

Action research aims to develop knowledge *with* people rather than *on* people through action and reflection (Bradbury, 2015). Thus MK was involved in developing Studio DöBra and learning about it in collaboration with community organizations. Their collaboration was informed by principles of

community-based participatory research, adapted to the local context (Israel et al., 2017). These principles for engaging communities in research and action, guided MK and partners in critically reflecting on power dynamics between researchers and communities, maintaining equitable and sustainable partnerships, and integrating research and action to co-create knowledge useful and of value to all partners.

Given the relative silence around EoL issues in Sweden, we anticipated challenges in initiating partnerships, but were positively surprised by the organizations’ interest in engaging in the initiative. In May 2016, a representative of the urban area’s elder care bureau, with prior collaboration with the DöBra research program, suggested that MK approach the activity center for elderly in an ethnically diverse neighborhood on the outskirts of a major Swedish city, as its manager was known for community engagement and interest in developing new activities. Involvement of the local library was also suggested as this might provide a “neutral place” for intergenerational workshops. An unplanned benefit was that MK resided in this neighborhood, which made him an insider in the community, facilitating connection with community organizations.

MK first approached the local library which had just begun specializing as a children’s library; its manager and a children’s librarian agreed to participate. They had recently begun working with a neighborhood artistic organization for children, run by artists with design backgrounds. MK met with that organization’s manager and artistic director who were interested in collaborating, as was the manager of the activity center for elderly when approached. An after-school center (in Sweden these centers are typically connected to a primary school and offer activities based on national guidelines) in the area was involved through contact with the artistic organization, and a teacher agreed to formally be part of the project group, but said she could not participate in developing Studio DöBra due to lack of time.

The project group which formed consisted of MK and representatives from the partnering community-organizations. Together, the project group developed Studio DöBra and co-created knowledge about this development process through collective reflective practice. Eight children were recruited through the after-school center and eight elderly participants were recruited through the activity center for elderly people, the library, and a local assisted living facility.

Studio DöBra consisted of five weekly two-hour intergenerational workshops held on Friday

afternoons in November-December 2016. Each workshop began with an open question related to the EoL, such as “where do we end up after we die?” and “how does grief feel?” The participants explored these questions together through creating collages, sculptures, drawings, and games. During the final workshop, the participants created an exhibition, shown at the children’s library and activity center for elderly people, to tell their story of Studio DöBra by displaying what they had created, accompanied by their own explanatory texts.

Our aim in this article is to investigate approaches for navigating collaborative processes of developing community-based intergenerational arts initiatives to engage communities in EoL issues, and discuss how this can inform other initiatives aiming to engage communities in EoL issues.

Methods

Due to a lack of research literature on intergenerational arts initiatives to support community engagement in EoL issues, MK conducted exploratory interviews to learn from professionals with experience of developing initiatives sharing features with Studio DöBra, as described in Table 1. MK interviewed these professionals while simultaneously participating in developing Studio DöBra. In addition, data was generated throughout this development process, as described in Table 2. Exploratory interviews influenced Studio DöBra development, and issues arising in Studio DöBra development influenced questions asked in exploratory interviews. The empirical data thus consists of two qualitative databases, generated in parallel but interrelated processes, illustrated in

Figure 1. Relevant permissions were obtained from the UK and from the appropriate research ethics committee in Sweden.

Exploratory interviews

A total of 14 interviews with 15 individuals (one interview with 2 individuals), were conducted by MK, and focused on professional experiences of developing initiatives. Snowball recruitment was used to find initiatives of potential relevance for Studio DöBra development (Heckathorn, 2011), starting from the DöBra research program’s own network with already existing connections with relevant initiatives in Sweden and the UK. The study was also advertised in a Swedish palliative care newsletter to find other relevant initiatives, but without response. Seven initiatives were included, indicated by capital letters A-G. One to 4 participants per initiative were interviewed, depending on their availability, the initiative’s perceived relevance, and scale. For practical reasons participants from projects A, D, and G were interviewed by telephone, whereas the others were interviewed directly. The participants ranged from being relatively new to advanced in their professions. Participating artists had backgrounds in visual arts, sculpture, theater, and/or music and applied these expressions in the initiatives.

All participants signed informed consent forms prior to participation. Interviews were conducted in conversational form using an interview guide with topics ranging from developing the initiative, to its content and implications, with topics added throughout the interview process as new issues emerged during Studio DöBra development and previous interviews. MK began interviews by introducing the

Table 1. Exploratory interviews.

	Included initiatives						
	A	B	C	D	E	F	G
Inclusion criteria							
Arts-based	x	x	x	x	x	x	
Intergenerational (non-familial)	x	x	x		x	x	
Explicitly dealing with end-of-life related topics	x	x	x	x			x
Research initiatives							x
Place of initiative							
Sweden		x	x	x	x	x	
UK	x						x
Gender of individuals interviewed							
Women (<i>n</i> = 13)	3	1	2	2 ^a	1	3	1
Men (<i>n</i> = 2)	1		1				
Professions							
Artists (<i>n</i> = 3)			2	1			
Artists employed in healthcare institutions (<i>n</i> = 5)	4					1	
Pre/primary school teachers (<i>n</i> = 3)		1		1		1	
Researchers (<i>n</i> = 2)					1		1
Business developer (<i>n</i> = 1)			1				
Healthcare professional (<i>n</i> = 1)						1	

^aJoint interview.

Table 2. Studio DöBra development process.

		Studio DöBra project group partners							
		Artistic organization for children						Activity center for elderly:	
		DöBra research program: MK, PhD student, researcher	Artist-1, artistic director	Artist-2, manager	Artist-3, free-lance artist ^a	Library for children: Librarian	Activity center for elderly: Activity Manager	After school center: Teacher ^b	
Gender									
Women									
Men		x	x	x	x	x	x	x	
Planning meetings participation									
P1		x	x	x	n/a	x	x	n/a	
P2		x	x	x	n/a	x	x	n/a	
P3		x	x	x	n/a	x	x	n/a	
P4		x	x	x	n/a	x	x	n/a	
P5		x	x	x	x	x	x	n/a	
Reflective meetings participation									
R1		x	x	x	x	x	x	n/a	
R2		x	x	x	x	x	x	n/a	
R3		x	x	x	x	x	x	n/a	
R4		x	x	x	x	x	x	n/a	
R5		x	x	x	x	x	x	n/a	
R6		x	x	x	x	x	x	n/a	
R7		x	x	x	x	x	x	n/a	
R8		x	x	x	x	x	x	n/a	
Follow-up interview participation		n/a	x	x	x	x	x	x	

^aArtist-3 became involved from P5.^bThe teacher could not participate in planning and reflective meetings due to time constraints.

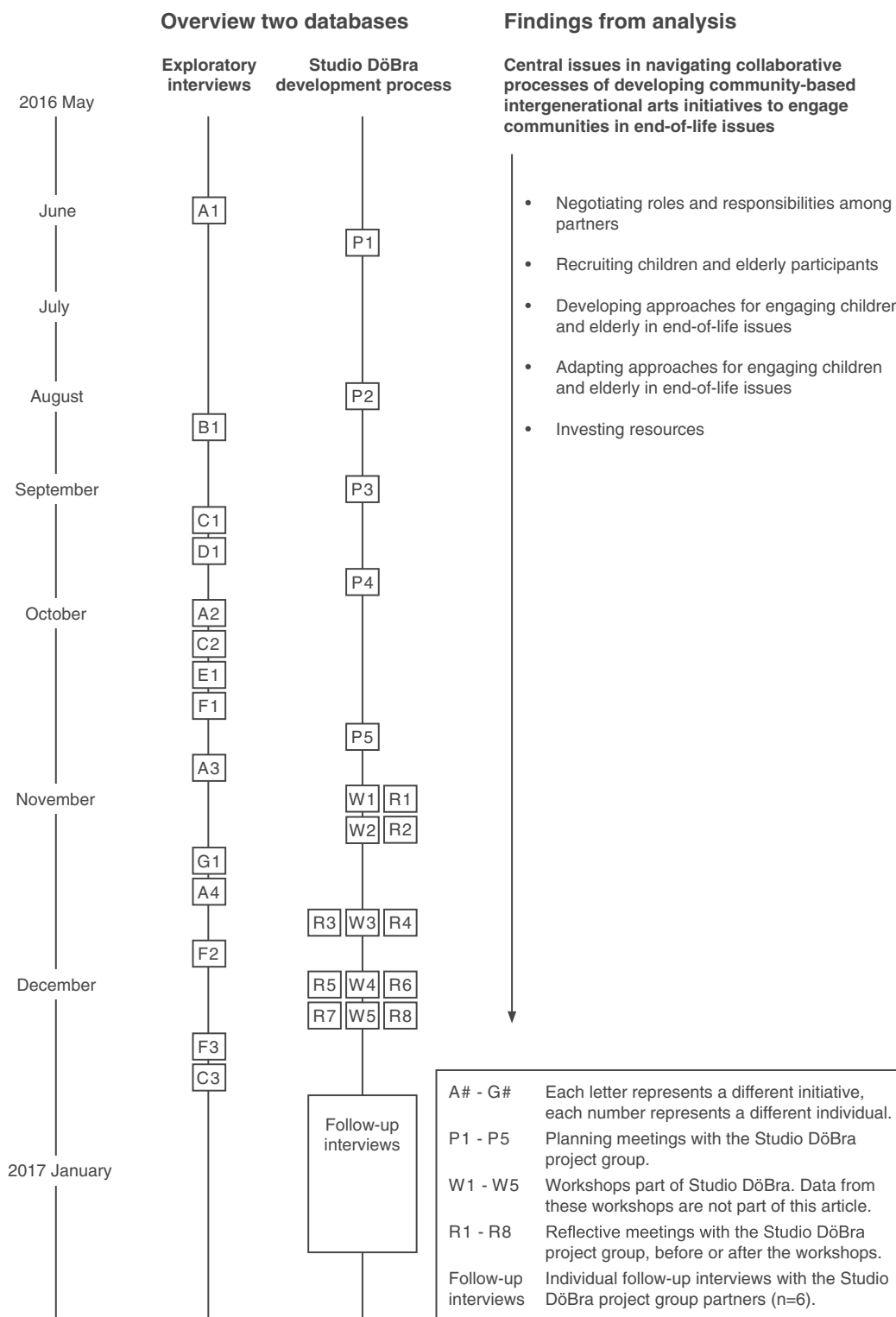


Figure 1. Timeframe of databases and findings from analysis.

ongoing Studio DöBra development, explaining that the purpose of the interview was to inform that process. The interviews were generally about one hour long, and were audio-recorded and professionally transcribed verbatim.

Studio DöBra development process

Prior to partnering in this action research project, responsible managers from the partnering community organizations gave written consent and project group partners also signed informed consent forms. As the

project group strived to co-create knowledge in this action research project, partners want to be acknowledged in some publications and presentations. In the case of this article, partners were not interested in authorship. Therefore while not strictly anonymous, names and specific locations are not mentioned and sensitive personal information is not shared here.

The Studio DöBra development process database comprises MK's reflections and qualitative data generated during development. Development took place through five planning meetings with the project group. In these meetings the group developed the content of the intergenerational workshops and defined points of action. Based on this, MK formulated agendas for planning meetings which were sent out to partners in advance. In conjunction with each intergenerational workshop, the project group held reflective meetings, which generally began with MK asking partners to reflect on how they thought the workshop had gone. Based on these reflections, the group discussed the planning for subsequent workshops. The planning and reflective meetings were audio-recorded and professionally transcribed verbatim.

Within two months after concluding the series of workshops, the children's teacher was interviewed by MK and the other project group partners were interviewed by authors CT and OL who otherwise did not participate in Studio DöBra. These follow-up interviews were in conversational form, supported by an interview guide focusing on experiences of the development process, similar to that used in exploratory interviews. In summary, this Studio DöBra development database consists of data from five planning meetings (P1–P5), eight reflective meetings (R1–R8), six follow-up interviews, as well as MK's reflections.

Analysis

Qualitative analysis of both databases was guided by interpretive description which takes in account the specific contexts relevant to the generated data, and uses both description and interpretation to develop knowledge of use for practice and application in wider contexts (Thorne, 2016). MK led the data analysis in a process repeatedly discussed and reflected on by all authors and community partners. Memos were written throughout to document ideas and decision-making.

Initially, MK read the transcripts while listening to audio-recordings, to make corrections and become familiar with the data. Preliminary ideas were noted, initiating development of a coding scheme. Data from both databases were structured chronologically using

NVivo 11 analysis software to allow consideration of interactions between databases throughout analysis. All data were repeatedly read chronologically and inductively coded, allowing for multiple codes. The initial coding scheme comprised broad categories of which five were interpreted as most central to the aim of this article: About the EoL; Collaboration and participation; Intergenerational aspects; The arts; and Recruitment. Almost all data were coded in more than one of these categories. Data in each category was again read chronologically and inductively coded into content-based subcategories. The relationships between (sub)categories were considered, (sub)categories finalized and described to reflect their content. Main categories were formulated as issues central to development of the investigated initiatives (e.g., “recruiting children and elderly participants”). Subcategories were described as challenges related to these issues (e.g., “mobility”), and as approaches to deal with them (e.g., “hosting the initiative where elderly already are”).

During this analytic process, MK met twice with the Studio DöBra project group (once together with co-authors CT and OL) to reflect on preliminary findings and deepen our collective understanding. Reflections about temporal aspects (i.e., when issues arose and how they were navigated over time), catalyzed the next, more process-oriented analytic phase. (Sub)categories (representing issues, challenges and approaches) were mapped against the chronologically-structured databases to help us identify the timing of issues, challenges, and approaches used during the Studio DöBra development process. Additionally, we found themes running through these issues which related to different power dynamics, described below.

Results

Based on analysis of the two databases encompassing data from eight different initiatives (Studio DöBra and seven initiatives investigated through exploratory interviews), we present ways in which central issues were navigated in developing community-based intergenerational arts initiatives to engage communities in EoL topics. We found that ways in which these issues were navigated to a great extent related to power dynamics among people of different ages as well as among partners collaborating to develop these initiatives. We conceptualized these partners as ‘adults-in-between’ the children and elderly people in age. We found that the adults-in-between have power over and felt responsible for these two age-groups. Power dynamics among partners related for example to

professional mandates to participate in developing these initiatives and the possibility of investing resources in its development. For each central issue, we present ways in which power dynamics influenced how it was navigated, through findings from Studio DöBra complemented with findings from exploratory interviews. When relevant, we describe ways in which the two databases influenced each other.

Negotiating roles and responsibilities among partners

Children and elderly participants were not involved in the development process of any of the investigated initiatives. Those involved in development were the adults-in-between these age-groups who were all supported through their professional mandates. Artist-1 from Studio DöBra illustrates this while reflecting retrospectively, saying:

Follow-up interview Artist-1: This is a very personal project. There is the curious me, as a 10 year old, who is creative and wants answers to things, why things are the way they are, and who I am, and why the world looks like it does, and what will happen in the future. But then there is the person who is sitting in front of you now, [40 plus] and educated, who understands that I have both resources and possibilities to make things visible and comment on that which I don't think is right and also make visible that which I think is good.

Among Studio DöBra partners, the degree of self-determination varied from the librarian needing explicit approval from a manager, to others having full agency to participate. We interpret power in this context as a professional and social mandate to develop these initiatives, which seems to be exclusive to the adults-in-between.

Throughout the planning of Studio DöBra, partners assumed roles and responsibilities in relation to their professions and mandates. The artists took responsibility for contacting after-school centers to recruit children and took a leading role in developing workshop content, while other partners reacted to and built on their ideas. The Activity Manager took responsibility for recruiting elderly participants. The Librarian played a supportive role in recruitment, having least time to spend on developing Studio DöBra. As initiator and researcher, MK had most time to spend on development. Throughout development, the group discussed MK's role, agreeing that he was responsible for research-related activities.

The children's teacher said she could not participate in the planning and reflective meetings due to

time constraints, but was able to be present during the Studio DöBra workshops. Artist-1 told about previous experiences with teachers "taking over" artistic processes. These combined factors led to the teacher having a limited role. She reflected on this retrospectively as less than optimal, saying:

Follow-up interview Teacher: Something that I maybe experienced as a little bit negative, I would say... that my participation wasn't specified. How should I be participating in this? [...] I have delivered children to different workshops (laughs), but I didn't know... and that was a little sad... how [the project group] had thought and framed [the workshops]. That would have been fun to hear, and then I could have participated in that way. Not that I would have interfered so much, because it was [the project group's] project.

Thus power among partners in this context is expressed by partners limiting the influence of the teacher, thereby leaving the artists in control of the artistic process. In exploratory interviews the teacher's role was said to vary from fitting the initiative into the school's curriculum and supporting children, to being an active part in development and facilitation, although this was not always conflict-free:

Exploratory interview A4, artist employed in a healthcare institution: At one point in the art making process, [the teacher] actually came into the project and really lectured the children on the standards of their art work... I was surprised and shocked and upset by that, and I told [the teacher] so, [...] I said, look it's not the way we work, it's not the way we look at art. [...] We do want a good artistic outcome, of course we do. But it's the process of bringing these two groups of people together that's the primary [...] reason for doing [this project].

In Studio DöBra planning meetings, decisions were based on knowledge available in the group, relevant to the issue at hand. MK was learning from exploratory interviews, and other partners had knowledge and experience from their own practice that contributed to the development. However, when the group encountered challenges (e.g., in developing ways to engage children and elderly in EoL issues), MK sometimes felt that partners expected him to take a leading role as initiator. MK struggled to find balance in his role as action researcher and initiator, because such expectations seemed to skew power relations in the project group.

In exploratory interview G1, an action researcher who had developed EoL-engagement initiatives in collaboration with schools, described dealing with a similar challenge in being addressed as an expert by partners in her researcher-initiated project. When

considering this retrospectively, she explained this as serving a purpose, as relying on her as an expert seemed to give partners confidence in developing the initiatives.

Recruiting children and elderly participants

Challenges in recruiting children and elderly people in the investigated initiatives were said to relate to the adults-in-between often feeling responsible for these two age groups; the adults-in-between also expressed difficulties in introducing the topic of death and loss to these two age-groups. In recruiting children to Studio DöBra, the project group began by seeking approval from the children's legal guardians and teacher, as they have formal responsibility for the children. The artistic organization along with MK, then introduced the initiative to children at an after-school center in the neighborhood, inviting them to participate. Afterwards the project group reflected on their own fears about raising the topic of death and loss with the responsible adults and later with the children. Despite their concerns, the project group described being consistently met with positive responses as exemplified by this excerpt:

Planning meeting P4, Artist-2: Every time we've mentioned it, it's been positive, but it's true that... I've been nervous when I emailed teachers, I always mentioned that it's a research project so that they'll think it's fun, but never the actual word or what it's about.

In an effort to recruit elderly people to Studio DöBra, the Activity Manager had chosen to talk one-on-one with potential participants, anticipating that the topic of the EoL would be sensitive. The information letter about the research project was used as a basis for recruitment conversations. However, by P4 no elderly people had yet agreed to participate. Artist-2 therefore suggested trying a more informal recruitment approach inspired by a recent encounter with an elderly person:

Planning meeting P4, Artist-2: She is somebody who would be a fantastic [participant], and there must be many others, but I think we have to meet with them, because it is so abstract to get an [information letter], and scary... But to get to hear "Hi, here we are and we have children that want to do fun things together with you, do you want to join?" that would be a whole other thing.

Through this more informal strategy, a majority of the elderly participants were recruited. In a follow-up interview, the Activity Manager reflected on unexpected challenges in recruiting elderly participants.

Some had full agendas, while others did not want to commit to participating due to health and mobility issues. She also reflected on her own fears of initiating the subject of EoL when recruiting elderly, similar to what was discussed in relation to children:

Follow-up interview Activity Manager: I didn't really expect this. But there was a fear of how to bring it up, because I know that there are many who are widows and widowers. Maybe they've experienced a lot of loss not too long ago either, so how would they react when you bring up the topic?

In exploratory interviews, challenges in recruiting children and elderly participants were also said to relate to the adults-in-between's sense of responsibility and possible fears of discussing death, as described by an artist who had recruited elderly to an intergenerational initiative:

Exploratory interview C2, artist: I met [nurses responsible for activities] at this elder center, they were very positive. But then when I said that [death is one of the topics] they said "No, no, we can't talk about death..." [they said that] it just causes anxiety. "The elderly don't want to talk about death..." So they just insisted that they wouldn't do it.

The adults-in-between acted as gatekeepers, thus illustrating their power to facilitate or hinder participation of other age-groups. Recruitment approaches were therefore often directed towards adults-in-between with responsibility for children or elderly people, for example, meeting with them, showing examples of previous projects, and/or talking about their personal EoL experiences in an effort to demonstrate the value of the initiative as exemplified by an artist saying:

Exploratory interview A1, artist employed in a healthcare institution: We also ask [the children's parents] to think about their own experience of death and dying and when was their first experience of loss as a child, and how that experience had been. So it, it just opened up lots of conversations.

Another approach mentioned in exploratory interviews, was to hold the initiative at an institution already hosting a relevant age-group, even though this may raise the threshold of participation for the "visiting" age-group.

Developing approaches for engaging children and elderly in end-of-life issues

MK initiated partnerships with community-based organizations to engage them in EoL issues. Despite this, the conversation excerpt below from P3

illustrates that partners may not have felt ownership over these issues. Artist-1 pointed out that the artistic organization's primary interest was to explore creative intergenerational interaction, while the Activity Manager described EoL issues as mainly MK's interest. This may be related to MK being the initiator of Studio DöBra and/or to their own difficulties in talking about the EoL.

Planning meeting P3, Artist-1: [...] imagine if you could work with death and life but not like... human life and death and loss, but apply it to something else. And then we thought about nature. Nature, which has a yearly cycle. Things are born and grow and then die. [...] We (the artistic organization) are interested in the [creative] process and aesthetics and what happens when an older creative person meets a younger and all that. But maybe those questions that you want to include in your research (addresses MK, referring to EoL issues)... maybe we could in the middle of all this, maybe just ask such a question, and then maybe it won't be so dramatic. So if we work with it, then maybe it will be easier to talk about it. [...]

MK: So you thought more to use nature as a metaphor for life and death and the circle of life?

Artist-1: Yes [...]

Librarian: I think it sounds like a very good introduction and a first meeting, so that it will be a gentle introduction to the theme. [...]

Activity Manager: Yes, and then it's about capturing those issues that you (MK) are interested in, [...] and then you would have created something too, imagine, maybe a flower or something.

In the excerpt above, the project group discussed approaches for exploring EoL issues in intergenerational workshops. Some partners expressed concern that it would be a potentially sensitive topic for children and elderly people, but also spoke of their own difficulties in talking about EoL issues. Approaches suggested by partners to help introduce these topics during workshops included "doing" instead of talking, and using metaphors rather than explicitly mentioning death and dying, so it "won't be so dramatic" and "easier to talk about" as suggested by Artist-1 above.

During the following planning meeting the artists presented ideas for Studio DöBra arts activities based on metaphors (e.g., flowers and time). However, given the project group's previous reflections on personal difficulties talking about death, MK initiated a discussion about whether the use of metaphors might be a way to avoid the topic rather than dealing with it explicitly. This discussion led partners to reflect on

their roles as adults-in-between in facilitating intergenerational engagement with EoL issues, and their agency in creating an open and inclusive environment for participants of different ages as exemplified by Artist-1:

Planning meeting P5, Artist-1: I realized there are lots of different theories about dying and death that are interesting. And then I thought but wait, if I would have that kind of belief, like that philosopher for example, then I would have created different kinds of ideas about the workshops, how we approach and explore it, and think in a completely different way. [...] So this was an eye opener for me.

Conversations in which partners talked about their personal experiences, beliefs and questions about dying, death, and loss seemed to facilitate the sharing of ideas about how to then approach these topics with children and elderly participants.

In exploratory interviews the use of the arts were said to offer opportunities to involve all senses instead of focusing on talking. The use of metaphors in arts activities was mentioned, as also discussed in Studio DöBra. Focusing on the process of art-making, rather than on its product, was described as facilitating intergenerational engagement. It was also said however, that sometimes compromises were made to cater to the needs of other partners:

Exploratory interview A1, artist employed in a healthcare institution: Actually the process was more important for us [than the product], so it was finding a kind of compromise on that... We were more interested in what was going on during the project, and the schools have tended to want something at the end of it to show.

The Studio DöBra project group adopted the concept of linking process and product, deciding that Studio DöBra would result in an exhibition. In exploratory interviews "be brave" was advice repeatedly given in relation to engaging children and elderly in EoL issues, exemplified by this excerpt:

Exploratory interview C2, artist: I think that if you can get children and elderly to meet and make art together about death, then I think you should let them set the guidelines... You know like that game, with the wheel, and you run with the wheel and you have a stick that you use to get the wheel rolling. If they are the wheel and you are the stick, so they get to roll, they get to... so you are like a guide. But be brave.

It can however be questioned how much room was left for children and elderly participants to influence the content of any of the initiatives we investigated, as this was determined, and thereby controlled, by the

adults-in-between. Power in this context was interpreted as the mandate to decide on the approaches used for engaging children and elderly in EoL issues and thereby the content of the initiative. In all the initiatives investigated, this mandate was exclusive to the adults-in-between.

Adapting approaches for engaging children and elderly in end-of-life issues

While the Studio DöBra workshops were ongoing the project group adapted its way of working in response to what was learned in the reflective meetings. The project group reflected on the first two workshops as having “high ambitions” with many planned activities leaving too little time for all participants to discuss. It was therefore decided to increase possibilities for participants to influence the workshops’ content by decreasing the activities planned.

In exploratory interviews the abstract nature of the EoL was described as one challenge in engaging children and elderly in EoL issues. Similarly, in a reflective meeting before the third workshop, Artist-1 expressed feeling burdened by introducing the topic of death to the participants, saying “it feels as if I talk about something without really knowing what it is”. In response, MK tried to convey that it isn’t important to have answers, but rather to “open up for conversation”.

Another challenge, explicitly mentioned in exploratory interviews A3 and A4, concerned dealing with losses occurring during the initiative. An artist pointed out how creative processes may help in dealing with the death of a participant during an initiative saying:

Exploratory interview A3, artist employed in a healthcare institution: I think it can be... it can sort of hit home, the reality of what... death is, the sort of... the abruptness of death. And what you’re left with when somebody has died. And in a creative process you’re left with something very... you know tangible of that person. And I think that can be quite helpful actually, in trying to process a loss.

Another artist pointed to the power facilitators have, to either open a conversation about a sudden loss, ignore it, or silence it, saying:

Exploratory interview A4, artist employed in a healthcare institution: It’s very important that those feelings are acknowledged and given place and given value. And not kind of... not get into protection games. [Being upset] is a natural human response. And to model that that is okay.

The third Studio DöBra workshop, on the theme of loss and sorrow, followed on the heels of these

exploratory interviews and was affected by the sudden migration of one of the participating children, a form of loss not uncommon at the involved after-school center. Influenced by the exploratory interviews, MK felt that this loss should be addressed in the workshop. The situation was dealt with by beginning the workshop with a conversation about what had happened, facilitated primarily by Artist-2, providing space for participants to express their feelings and concerns.

Investing resources

Since everyone in the Studio DöBra project group participated within the scope of their jobs, their work time was compensated. The only out-of-pocket costs were therefore for workshop materials, food, and beverages. Workshop content was adapted to the available budget. As described in exploratory interviews, other initiatives operated similarly, making a point of “using what we have”. At the final planning meeting, partners discussed how to share these costs:

Planning meeting P5, Artist-1: We all contribute with different resources. We (the artistic organization for children) contribute with hours and staff and so on, but just because we are [an artistic organization] it maybe doesn’t have to mean that we should pay for everything the whole time.

Librarian: We (the library) can surely pay for a part. We already have some material. I don’t know what you want to have. [...] I just have to check how we should invoice that... with the manager.

As this excerpt illustrates, the resources invested in Studio DöBra differed among partners depending on their mandate to participate. Investing resources seemed to be interpreted as a form of ownership:

Follow-up interview Artist-2: But we felt, regarding the question of who owns the project, [...] yes, if something happened we always checked with [MK] that it was OK. At the same time we felt a big... we owned the project as well [...], if you think about what the library has done or what [the activity center] has done, it’s anyway us who have practically and planning-wise done most.

Representatives from all collaborating community organizations talked about MK as having a leading role in Studio DöBra because he had initiated it, and that the artistic organization for children invested more resources than others. It thus seemed that power among project group partners was negotiated by having different professional mandates to initiate and/or participate in Studio DöBra’s development, and a

sense of ownership over the initiative was perceived to relate to resources invested.

Discussion

We investigated approaches for navigating collaborative processes of developing community-based intergenerational arts initiatives to engage communities in EoL issues. The combination of data from developing Studio DöBra and data from exploratory interviews based on experience from seven other contexts broadens relevance, making knowledge derived more transferable to development of other initiatives engaging communities in EoL issues (Polit & Beck, 2010). The analyzed data included process-based data from the collective development of Studio DöBra, and retrospective data with reflective accounts of experiences of past initiatives. Combining these data supported analysis of how central issues were navigated during development, as descriptions came from different perspectives and contexts. As MK conducted exploratory interviews and participated in developing Studio DöBra, he had insight into both databases and mediated the interactions between them.

We found that power dynamics between people of different ages as well as among partners, deliberately or unwittingly, facilitated or hindered community-engagement in EoL issues. In navigating these dynamics, various interpersonal differences had to be engaged with, such as age, gender, profession, and social status. In literature investigating community engagement in EoL issues, “power sharing” is described as a way of increasing community engagement (Sallnow & Paul, 2015); however, ways in which power can be shared seem to be underexplored. In discussing our findings, we found that action research literature on power in participatory processes may provide a helpful framework for thinking about ways in which power dynamics may be understood and worked with to support community engagement in EoL issues (Gaventa & Cornwall, 2015). Based on this literature we discuss three characterizations of power dynamics with suggestions for development of future initiatives.

First, power dynamics between people of different ages can be characterized as a “power over’ relationship” (Gaventa & Cornwall, 2015), which in this case means that adults-in-between have power over other age-groups. This became clear, for example, in the recruitment of children and elderly participants, where the adults-in-between with formal responsibility for these age-groups acted as gatekeepers. This finding

has led us to re-conceptualize the intergenerational character of Studio DöBra as not only engaging children and elderly people in EoL issues, but also the adults-in-between, as they played a fundamental role in making this possible due to their position of power. In development of future similar initiatives we recommend that partners engage in collective reflective practice about age-related power-structures and assumptions of responsibility, as awareness of these dynamics might facilitate recruitment of participants from different age-groups and building relationships across generations.

Second, those who developed the investigated initiatives, were able to do so because of their social and professional mandate to action. This could be characterized as “power to act” (Gaventa & Cornwall, 2015). The term adults-in-between also illustrates that their power to act was not only derived from their professional mandate (i.e., a job that allows or stimulates the development of these initiatives), but also from their social status (i.e., being the “right” age). The younger and older generations were indicated with the terms children and elderly people to illustrate that these age-groups did not have power to act in the same way as the adults-in-between, because their social status in this culture was limited due to their age.

Among the adults-in-between, teachers seemed to have a limited power to act in the investigated initiatives. This was partly explained by time constraints, but also affected by other stakeholders inhibiting their participation for a variety of reasons. One limitation of this study is that while it became clear that teachers’ participation is a contentious issue, we are unable to formulate data-based recommendations for future initiatives. It should however be recognized that limited teacher involvement may hinder anchoring of the initiative at schools. For future initiatives we therefore recommend that teachers’ level of involvement be considered in terms of benefits and risks in each specific situation.

Fear and/or insecurity about initiating conversations about the EoL with children and elderly people seemed to limit adults-in-between in their power to act. This was particularly apparent in developing Studio DöBra workshops, as it was fundamental for partners to share personal experiences, questions, and beliefs about the EoL in order to become more confident in starting conversations with others. This finding is in line with research reporting that death education programs based on the sharing of personal experiences may reduce death anxiety (Doka, 2015).

For future development of similar initiatives, we therefore propose that involved partners start with developing a collective reflective practice sharing their personal EoL experiences, questions, and beliefs, as this may increase their power to act and facilitate development of the initiative.

Third, findings from Studio DöBra development in this action research project, showed that over time, power was negotiated among partners through division of roles and responsibilities, as well as investment of resources, which also contributed to a sense of ownership. This dynamic could be characterized as “power to act in concert with others”, a relational view of power in which power is negotiated through human interaction (Gaventa & Cornwall, 2015).

One factor affecting power to act in concert with others, and a potential study limitation, was that Studio DöBra development was researcher-initiated. Community-based participatory research literature as well as literature on community engagement in EoL issues highlights researcher-initiation as a factor which might inhibit community engagement; a more desirable situation according to the literature would be if the community had initiated the collaboration (Israel et al., 2017; Sallnow & Paul, 2015). However, in the Swedish context, given the low level of community engagement in EoL issues and the relative silence around these topics, we deemed this methodological ambition unfeasible (Westerlund et al., 2018).

Studio DöBra partnerships were established in a multiethnic area in which MK, an immigrant in Sweden, also lived. MK felt that this gave him credibility as an “insider” to the community and facilitated establishing contacts and partnerships. However, another potential limitation was that MK might also be seen as an “outsider” in the community, with status derived from his background and education (Minkler, 2004). In relation to the project group, MK was an outsider due to being the initiator and being able to work full-time on Studio DöBra. Even though MK was aware of his position, findings illustrate challenges in navigating this relational power dynamic in the project group.

One challenge related to expectations—both MK’s own and from community partners—that it was MK’s role to respond to difficulties, such as how explicitly death and loss should be talked about with children and elderly participants. Instead of claiming to have answers or imposing a solution, MK tried to use his position of power to catalyze reflective discussions about the proposed approaches. Later, when the workshops were ongoing, partners adapted workshop

content to allow more opportunities for participants to discuss and direct the work themselves.

It is notable that in developing Studio DöBra, partners did not discuss the possibility of including children and elderly people in this process. This illustrates the delicate balance for MK in being both a researcher and partner. MK might have steered the process towards including these age-groups in the development process, but choose not to in an effort to equalize ownership of the process with partners. However, in retrospect, we suggest that in developing future similar initiatives, adults-in-between actively involve children and elderly people in this process, for example, by discussing preferences for art forms to work with, what they are curious about in relation to the EoL, what expectations they might have of meeting other age-groups, and preferred meeting venues. This active involvement might facilitate developing the initiative in ways geared to compensate for some of the inequalities between age-groups.

In light of our findings we argue that it is important to further our understanding of ways in which power dynamics may shape community engagement in EoL issues. Reflective practice is described as a way to uncover and deal with power dynamics between researchers and communities (Muhammad, Garzón, & Reyes, 2017), as well as in working with EoL issues (Visser, 2017). During Studio DöBra development, two types of reflective practices were attempted: an individual practice in which partners wrote reflections in notebooks provided by MK, and a collective practice through conversations in reflective meetings (R1–R8). The individual practice had limitations in that not all partners were used to writing and/or because EoL topics might be difficult to put into words (Walter, 2012). Although most researchers rely on approaches using words alone for learning, our partners might have been more comfortable with approaches better aligned with their practices. We therefore suggest that alternative approaches be explored to stimulate reflection in relation to EoL topics.

Through process-based data analysis, we became aware that the collective reflective practice through conversations did however facilitate mutual understanding and decision-making in development, thus enhancing power to act in concert with others. This can be conceptualized through theories of opening communicative spaces (Wicks & Reason, 2009) and communicative action in action research (Ahlberg et al., 2016). Our collective reflective practice opened up communicative space in which the project group

became increasingly aware of power dynamics between people of different ages. This awareness facilitated communicative action, as it informed decisions about using this power to enable rather than avoid, block, or silence intergenerational conversations about the EoL.

During the Studio DöBra development process, the collaborating community organizations began to apply the lessons they learned in their own practices. The artistic organization for children, for example, is now also including elderly people, providing intergenerational meeting places. Additionally, the project group is continuing to work together to find ways to apply and disseminate research-based knowledge, not only through peer reviewed articles, but also to other audiences relevant for the collaborating community organizations and in manners that are accessible for people with different backgrounds. These may be seen as examples of the beginning of a shift in power from researchers' initiatives to community organizations driving Studio DöBra further to co-create knowledge of value to them.

Note

1. The term DöBra is a Swedish pun which literally means dying well, but figuratively means 'awesome'.

Acknowledgements

We acknowledge the contribution of collaborating community-based organizations, the participating children and elderly people, and the parents of the children. We also acknowledge the contribution of author Olav Lindqvist, who died during the writing of this article. As one of MK's supervisors, Olav was a fundamental support in MK's doctoral project.

Disclosure statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This research was financially supported primarily by a grant from the Swedish Council for Health, Welfare and Working Life (FORTE) [grant number 2014-4071]. Investor AB financed CT's endowed professorial chair, allowing her research time on this project, and Stockholm City Elder Care Bureau has provided economic support for collaboration with the DöBra research program as a whole.

ORCID

Max Kleijberg  <http://orcid.org/0000-0003-4036-707X>

References

- Ahlberg, B. M., Maina, F., Kubai, A., Khamasi, W., Ekman, M., & Lundqvist-Persson, C. (2016). A child, a tree": Challenges in building collaborative relations in a community research project in a Kenyan context. *Action Research, 14*(3), 257–275. doi:10.1177/1476750315607607
- Bertman, S. (2015). Hannelore Wass: Insights into creative teaching and other ways of knowing when facing aging and mortality. *Death Studies, 39*(9), 537–544. doi:10.1080/07481187.2015.1079451
- Bradbury, H. (2015). Introduction: How to situate and define action research. In H. Bradbury (Ed.), *The Sage handbook of action research* (3rd ed., pp. 1–9). Los Angeles, CA: Sage.
- Dahlberg, L., Andersson, L., & Lennartsson, C. (2018). Long-term predictors of loneliness in old age: Results of a 20-year national study. *Aging and Mental Health, 22*(2), 190–196. doi:10.1080/13607863.2016.1247425
- Doka, K. J. (2015). Hannelore wass: Death education—an enduring legacy. *Death Studies, 39*(9), 545–548. doi:10.1080/07481187.2015.1079452
- Gaventa, J., & Cornwall, A. (2015). Power and knowledge. In H. Bradbury (Ed.), *The Sage handbook of action research: Participative inquiry and practice* (pp. 465–471). Thousand Oaks, CA: Sage.
- Heckathorn, D. D. (2011). Snowball versus respondent-driven sampling. *Sociological Methodology, 41*(1), 355–366. doi:10.1111/j.1467-9531.2011.01244.x
- Holmberg, S., Nilsson, Å., & Weibull, L. (2003). *Äldre i samhället - En redovisning av SOM-institutets analyser genomförda på uppdrag av Senior 2005* [Elderly in society - A report of SOM Institute's analyzes commissioned by Senior 2015] Retrieved from Göteborgs universitet: https://www.som.gu.se/digitalAssets/1393/1393424_senior-slutrappport.pdf
- Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., Allen, A. J., III, Guzman, R. J., & Lichtenstein, R. (2017). Critical issues in developing and following CBPR principles. In N. Wallerstein, B. Duran, J. Oetzel, & M. Minkler (Eds.), *Community-based participatory research for health advancing social and health equity* (3rd ed., pp. 31–44). Hoboken, NJ: Jossey-Bass & Pfeiffer Imprints, Wiley.
- Kellehear, A. (2015). Death education as a public health issue. In J. Stillion & T. Attig (Eds.), *Death, dying, and bereavement: Contemporary perspectives, institutions, and practices* (pp. 221–232). New York, NY: Springer.
- 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
- Lou, V. W. Q., & Dai, A. A. N. (2017). A review of nonfamilial intergenerational programs on changing age stereotypes and well-being in East Asia. *Journal of Intergenerational Relationships, 15*(2), 143–158. doi:10.1080/15350770.2017.1294427

- Martins, T., Midão, L., Martínez Veiga, S., Dequech, L., Busse, G., Bertram, M., ... Costa, E. (2019). Intergenerational programs review: Study design and characteristics of intervention, outcomes, and effectiveness. *Journal of Intergenerational Relationships*, 17(1), 93–109. doi:10.1080/15350770.2018.1500333
- Minkler, M. (2004). Ethical challenges for the “outside” researcher in community-based participatory research. *Health Education and Behavior*, 31(6), 684–697. doi:10.1177/1090198104269566
- Muhammad, M., Garzón, C., & Reyes, A. (2017). Understanding contemporary racism, power, and privilege and their impacts on CBPR. In N. Wallerstein, B. Duran, J. Oetzel, & M. Minkler (Eds.), *Community-based participatory research for health advancing social and health equity* (3rd ed., pp. 47–60). Hoboken, NJ: Jossey-Bass & Pfeiffer Imprints, Wiley.
- Nan, J. K. M., Pang, K. S. Y., Lam, K. K. F., Szeto, M. M. L., Sin, S. F. Y., & So, K. S. C. (2018). An expressive-arts-based life-death education program for the elderly: A qualitative study. *Death Studies*. Advance online publication. doi:10.1080/07481187.2018.1527413
- Paul, S. (2015). *Advancing education and support around death, dying and bereavement: Hospices, schools and health promoting palliative care. (Doctor of Philosophy)*, Edinburgh, Scotland: The University of Edinburgh.
- Polit, D. F., & Beck, C. T. (2010). Generalization in quantitative and qualitative research: Myths and strategies. *International Journal of Nursing Studies*, 47(11), 1451–1458. doi:10.1016/j.ijnurstu.2010.06.004
- Sallnow, L., & Paul, S. (2015). Understanding community engagement in end-of-life care: Developing conceptual clarity. *Critical Public Health*, 25(2), 231–238. doi:10.1080/09581596.2014.909582
- Sallnow, L., Richardson, H., Murray, S. A., & Kellehear, A. (2016). The impact of a new public health approach to end-of-life care: A systematic review. *Palliative Medicine*, 30(3), 200–211. doi:10.1177/0269216315599869
- Sauter, S., & Rasmussen, B. H. (2010). Voluntärer i livets slutskede [Volunteers in the end-of-life]. *Omsorg: Nordisk Tidsskrift for Palliativ Medisin*, 1, 35–38.
- Line, D. (2015, October). 2015 Quality of Death Index. *The Economist*. Retrieved from: <https://eiuerspectives.economist.com/healthcare/2015-quality-death-index>
- Thorne, S. (2016). *Interpretive description - Qualitative research for applied practice* (2nd ed.). New York, NY: Routledge.
- Tsiris, G., Tasker, M., Lawson, V., Prince, G., Dives, T., Sands, M., & Ridley, A. (2011). Music and arts in health promotion and death education: The St Christopher’s Schools Project. *Music and Arts in Action*, 3(2), 95–119.
- Ulmanen, P., & Szebehely, M. (2015). From the state to the family or to the market? Consequences of reduced residential eldercare in Sweden. *International Journal of Social Welfare*, 24(1), 81–92. doi:10.1111/ijsw.12108
- Vázquez-Sánchez, J. M., Fernández-Alcántara, M., García-Caro, M. P., Cabañero-Martínez, M. J., Martí-García, C., & Montoya-Juárez, R. (2019). The concept of death in children aged from 9 to 11 years: Evidence through inductive and deductive analysis of drawings. *Death Studies*, 43(8), 467–477. doi:10.1080/07481187.2018.1480545
- Visser, R. C. (2017). “Doing death”: Reflecting on the researcher’s subjectivity and emotions. *Death Studies*, 41(1), 6–13. doi:10.1080/07481187.2016.1257877
- Walter, T. (2012). How people who are dying or mourning engage with the arts. *Music and Arts in Action*, 4(1), 73–98.
- Walter, T. (2017). *What death means now*. Bristol, UK: Policy Press University of Bristol.
- 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*, 46(4), 478. doi:10.1177/1403494817751329
- Wicks, P. G., & Reason, P. (2009). Initiating action research: Challenges and paradoxes of opening communicative space. *Action Research*, 7(3), 243–262. doi:10.1177/1476750309336715