

# Studio DöBra – Creating spaces for engaging with end-of-life issues and interacting across generations through community-based arts activities



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## **STUDIO DÖBRA**

Creating spaces for engaging with end-of-life issues  
and interacting across generations  
through community-based arts activities

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# Studio DöBra – Creating spaces for engaging with end-of-life issues and interacting across generations through community-based arts activities

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## IN MEMORY OF MARJA AND OLAV

*Livet är ju bra underligt alltså*

*Det finns ju ingenting som är så vanligt som att födas*

*Och ändå är det världens underligaste händelse när jag får ett barnbarnsbarn.*

*Det finns inget vanligare än döden,*

*Och ändå är det katastrof varje gång det inträffar*

*Det är underligt*

Intervjuцитat från en deltagare i DöBra Ateljé

# ABSTRACT

**Background:** Studio DöBra was a community-based arts initiative about dying, death, and loss, involving children (9 years old) and older adults (most 80+) as participants. The goals were to support community engagement with end-of-life (EoL) issues and create opportunities for interaction between children and older adults. Studio DöBra was developed and studied in a collaboration between academic and community partners as part of the Swedish DöBra research program. It was informed and motivated by the Swedish context with an aging population, an age-segregated society, and a lack of community-engagement in EoL-issues. In Studio DöBra a community-based health promotion approach to EoL-issues was applied, based on the idea that these issues can be of concern to everyone, regardless of age. A variety of different arts activities were used as EoL-issues may be difficult to put into words.

**Aim:** The overall research aim is to investigate the processes and impacts of developing, facilitating, and participating in Studio DöBra. A secondary aim is to investigate the experiences of professionals developing and facilitating initiatives that share characteristics of Studio DöBra.

**Methods:** Studio DöBra was developed and investigated in a community-based participatory action research (CBPAR) process, with qualitative data generated throughout. Two iterations were developed (2016 and 2017-18) in different cities in Sweden. As the academic partner, I worked in collaboration with different community-organizations, e.g., organizations for children, older adults, and artistic organizations. Each iteration involved eight children and eight older adults in a series of five arts workshops addressing EoL-issues. Parallel to the first Studio DöBra iteration, I conducted exploratory interviews with professionals with experience from seven different initiatives that share characteristics of Studio DöBra. In 2018-19, together with community-partners from both iterations, we developed the Studio DöBra Toolbox, to document and disseminate findings to the general public; anchor lessons learned with management and local politicians; and inspire others to develop similar initiatives.

This thesis is based on four articles. In Article I, the collaborative process of developing community-based intergenerational arts initiatives to engage communities in EoL-issues was investigated based on exploratory interviews from other projects and data from the first Studio DöBra iteration including follow-up interviews with community-partners. In Article II, follow-up interviews with older adults, children, and children's parents were used to investigate how children and older adults motivate their participation, their experiences of participating, ways in which they were affected by participation, as well as how parents reflect on their child's participation. Data analyses in articles I and II were guided by interpretive description. The aim of Article III was to explore mechanisms in arts activities that support community engagement with EoL-issues. An abductive analysis was carried out, using participant observation data from the arts workshops, follow-up interviews with participants and partners, and partners' reflective meetings held in conjunction with each workshop, along with play theory. In Article IV, the aim was to investigate the impact of the Studio DöBra CBPAR process for partners, focusing on impact as both process and product. This was done through framework analysis expanding on Banks et al.'s (2017) theory of co-impact, based on longitudinal data from Studio DöBra, spanning 4.5 years.

**Findings:** In developing Studio DöBra and similar initiatives, partners navigated power dynamics among partners and between people of different ages (I, IV). Partners were conceptualized as the "adults-in-between" the children and older adults in age, with power over and a sense of responsibility for these two age-groups, which could lead partners to deliberately or unwittingly,

facilitate or hinder participants' engagement with EoL-issues (I). Furthermore, partners were all supported by their jobs to develop Studio DöBra and the other investigated initiatives, however, they had different mandates and degrees of self-determination, which informed roles and affected their sense of ownership (I, IV).

Children's and older adults' personal EoL-experiences and perceived lack of intergenerational interactions appeared to inform their motivation and participation in Studio DöBra. Some older adults were motivated by a desire for social connections and activities to counteract an increasing feeling of loneliness. Parents were generally positive about their child's participation. Children and older adults seemed to act as individuals with agency in bonding across generations and in creating spaces for engaging with EoL-issues, both in Studio DöBra and in their social networks. They also seemed to appreciate learning about the ways others reflected about EoL-issues in Studio DöBra. Some parents and older adults spoke of having learned that they can talk with children about these issues. Although participants expressed a desire to maintain new intergenerational connections, challenges which seemed to relate to a lack of agency hindered this. (II)

Modified play theory was used to explain four mechanisms in arts activities that support intergenerational engagement with EoL-issues: 1) The creation of a "Studio DöBra magic circle", i.e., the spatial and temporal boundary separating the Studio DöBra workshops from "ordinary life", created a space for intergenerational engagement with EoL-issues. 2) When facilitating, the partners tried to balance restrictions and freedoms in the topics, processes, and products of the arts activities. Determining restrictions and freedoms seemed to provide partners with a sense of control. When restrictions and freedoms appeared to be well-balanced, participants were independent in both the arts activity and engaging with EoL-issues. 3) Partners and participants approached EoL-issues through imagination and real-life experiences to deal with the potentially sensitive, abstract, and personal nature of these issues. 4) After each Studio DöBra workshop series ended, there were indications of a continuing sense of community, as shared experiences and products from arts activities seemed to bond participants. (III)

Through the Studio DöBra CBPAR process, a conceptual model was developed that distinguishes three types of impact, i.e., impact on individual and group development, action-oriented impact, and strategy-oriented impact. The model describes impact as process as these types of impact are reciprocally interrelated and evolve from each other. Impact for Studio DöBra partners included developing interest, confidence, and skills in relation to intergenerational interactions and engagement with EoL-issues through arts activities, which partners applied in various ways in their professional practices and social networks. Furthermore, the Studio DöBra Toolbox was used in efforts to anchor lessons learned at higher levels of power, and initiate spinoff projects. (IV)

**Conclusion:** This thesis contributes to an understanding of ways in which community-based intergenerational arts initiatives can be developed and facilitated to engage community-organizations, older adults, children, and their parents in EoL-issues and stimulate intergenerational interaction. It also adds insight into ways in which impact can be understood as both product and process in CBPAR, and particularly in Studio DöBra.



# POPULÄRVETENSKAPLIG SAMMANFATTNING

Döende, död och sorg berör oss alla, ung som gammal, men att prata om dessa ämnen kan vara svårt. Dessutom, i vårt samhälle med en åldrande befolkning finns det få generationsöverskridande mötesplatser. Målet med projektet DöBra Ateljé, en del av forskningsprogrammet DöBra, var att med hjälp av olika konstnärliga aktiviteter skapa möjligheter för möten mellan barn och äldre, men också stödja engagemang kring frågor som rör livets slut. Samarbetspartners i detta projekt har varit jag som doktorand samt olika samhällsaktörer. I gruppen har bland annat aktivitetsledare, kulturproducenter, konstnärer, och fritidspedagoger ingått. Projektet har en deltagande aktionsforskningsansats som innebär att vi samarbetspartners tillsammans har utvecklat och genomfört DöBra Ateljé och kontinuerligt dragit lärdomar av det vi har gjort för att ständigt förbättra vårt arbete.

Två omgångar av DöBra Ateljé har genomförts: en i Skärholmen 2016 och en i Halmstad 2017–18. I varje omgång deltog åtta barn (9 år) och åtta äldre (de flesta över 80 år) i en serie om fem träffar. Dessa deltagare arbetade tillsammans med konstnärliga aktiviteter som på olika sätt berörde döende, död och sorg. En träff handlade om frågan "var hamnar man efter livets slut?" Vid denna träff svarade deltagarna på frågan genom att skapa olika resedestinationer. Sedan byggde de en farkost och lekte att de besökte de olika destinationerna. I en annan träff arrangerade deltagarna och samarbetspartners en begravning för en död fågel, bärandes egengjorda sorgband. Samarbetspartners från båda omgångarna skapade 2018-19 en online DöBra Ateljé verktygslåda. Den innehåller handfasta tips för hur man kan genomföra generationsöverskridande träffar om döende, död och sorg. Verktygslådan beskriver också några av de konstnärliga aktiviteter som gjordes i DöBra Ateljé. Verktygslådan är kostnadsfri och tillgänglig via [www.dobra.se](http://www.dobra.se). Verktygslådan kan bidra till fortsatt utveckling av generationsöverskridande konstnärliga aktiviteter om döende, död och sorg.

Det övergripande syftet med detta forskningsprojekt har varit att undersöka processerna och effekterna av att utveckla, genomföra och delta i DöBra Ateljé. Det gjordes genom att exempelvis dokumentera planeringsmöten och generationsöverskridande träffar. Dessutom genomfördes uppföljningsintervjuer med samarbetspartners, deltagande barn och äldre, och barnens föräldrar. Jag har även genomfört utforskande intervjuer för att lära från hur andra har arbetat med likartade projekt i Sverige och Storbritannien. All data analyserades med kvalitativa metoder. Avhandlingen består av fyra artiklar som berör olika delar av projektet.

I artikel I utforskas utvecklingsprocesserna av både DöBra Ateljé Skärholmen och andra projekt som har likheter med DöBra Ateljé. Vi fann att de som genomförde dessa projekt i ålder var "vuxna-mitt-emellan" barnen och de äldre, med både makt över och en känsla av ansvar för dessa två åldersgrupper, något som styrde deras beteende. Olika mandat och förutsättningar påverkade samarbetspartners roller i DöBra Ateljé och hur mycket var och en kunde bidra till projektet. Detta tycktes ha påverkat deras känsla av ägandeskap. I DöBra Ateljé reflekterade vi samarbetspartners tillsammans över våra egna erfarenheter och frågor kring åldrande, döende, död och sorg. Det var ett led i att överkomma hinder och öka vår handlingskraft i utvecklingen och genomförandet av konstnärliga aktiviteter om livets slut för barn och äldre.

Artikel II baseras på uppföljningsintervjuer med barn, äldre och barnens föräldrar. Syftet var att undersöka hur barn och äldre berättar om varför de deltog, deras erfarenheter av att delta, hur de påverkades av deltagandet, samt hur barnens föräldrar reflekterade över deras barns deltagande. Både barn och äldre beskrev att de ville delta i DöBra Ateljé på grund av personliga erfarenheter kring död och sorg och för att de saknade generationsöverskridande möten.

Föräldrarna var generellt positiva till sitt barns deltagande. Barn och äldre agerade med handlingskraft i samspelet över generationer och skapade utrymmen för att engagera sig i frågor som rör livets slut, både i DöBra Ateljé och i sina egna sociala nätverk. Deltagarna uppskattade att lära sig om hur andra reflekterade över döende, död och sorg. Vissa föräldrar och äldre påtalade att de hade lärt sig att det är möjligt att prata med barn om dessa frågor. Barn och äldre verkade relatera till varandra som individer i stället som en del av en åldersgrupp. Deltagarna uttryckte en önskan om att upprätthålla de nya generationsöverskridande relationerna, men deras beroendeställning tycktes vara ett hinder. Resultaten indikerar vikten av att skapa generationsöverskridande möten för att motverka både ålderssegregation och negativa åldersrelaterade stereotyper.

I artikel III var syftet att utforska mekanismer i konstnärliga aktiviteter som stödjer engagemang för frågor som rör livets slut. I analysen av data från DöBra Ateljé använde vi oss av lek teori. På så sätt fann vi fyra mekanismer: 1) En "DöBra Ateljé magisk cirkel" kan beskrivas som den rumsliga och tidsmässiga gräns som skiljer konstnärliga aktiviteter från "det vanliga livet". Den skapade utrymme för att engagera sig i frågor som rör livets slut. 2) I de konstnärliga aktiviteterna försökte samarbetspartners att balansera begränsningar och friheter i ämnena, processerna och produkterna. Det tycktes främja partners' känsla av kontroll. När begränsningar och friheter verkade vara välbalanserade, blev deltagarna mer oberoende när de utförde de konstnärliga aktiviteterna, och blev mer självständiga i sitt engagemang i frågor om livets slut. 3) Både partners och deltagare använde både fantasi och personliga erfarenheter när de engagerade sig i frågor som rör livets slut i samtal, skapande och lek. 4) Efter att DöBra Ateljé omgångarna avslutats fanns tecken på en fortsatt känsla av gemenskap bland deltagarna och samarbetspartners, som delvis möjliggjordes av att de delade upplevelser och konstnärliga produkter.

I artikel IV var syftet att undersöka den deltagande aktionsforskningsprocessens påverkan utifrån samarbetspartners perspektiv, med fokus på påverkan som både process och produkt. Genom analys av data från hela processen över 4,5 år, kan denna artikel bidra till teorier om påverkan vid deltagande aktionsforskning. Vi har utvecklat en modell som skiljer på tre typer av påverkan, påverkan på individ-och grupputveckling, handlingsinriktad påverkan och strategiinriktad påverkan. Modellen beskriver påverkan som process genom att illustrera hur dessa tre typer är relaterade till och bygger på varandra. För samarbetspartners i DöBra Ateljé innebar påverkan en utveckling av intresse, självförtroende och färdigheter i förhållande till att genomföra generationsöverskridande konstnärliga aktiviteter om livets slut. Samarbetspartners har även börjat att tillämpa lärdomar på olika sätt i sina arbeten och sociala nätverk. DöBra Ateljé Verktyglåda har använts för att förankra lärdomar hos beslutsfattare samt för att initiera spinoff-projekt.

Denna avhandling bidrar till en förståelse för hur lokala generationsöverskridande konstnärliga projekt kan utvecklas och genomföras för att stödja engagemang kring frågor som rör livets slut och stimulera generationsöverskridande möten. Det ökar även förståelse för hur påverkan i deltagande aktionsforskning kan ses som både produkt och process, särskilt i DöBra Ateljé.

# POPULAIRWETENSCHAPPELIJKE SAMENVATTING

Sterven, dood en verlies zijn onderwerpen die ons allemaal aangaan, jong en oud, maar erover praten kan moeilijk zijn. En vergelijkbaar met veel andere landen met een verouderende bevolking, zijn er weinig intergenerationale ontmoetingsplaatsen in de Zweedse samenleving. Het doel van DöBra Atelier<sup>1</sup>, een onderdeel van onderzoeksprogramma DöBra, was om met verschillende kunstactiviteiten mogelijkheden te creëren voor interactie tussen kinderen en ouderen, maar ook te ondersteunen in het aangaan van onderwerpen gerelateerd aan het levenseinde. Partners in dit project waren ikzelf – als academisch partner – en verschillende maatschappelijke organisaties. De groep bestond onder meer uit activiteitenleiders voor ouderen, cultuurproducenten, kunstenaars en pedagogen van naschoolse centra<sup>2</sup>. Het project is een participatief actieonderzoek, wat inhoudt dat we met elkaar DöBra Atelier hebben ontwikkeld en gefaciliteerd. Een onderdeel daarvan is dat wij gedurende het project voortdurend lessen trokken uit wat we hebben gedaan om zo ons werk steeds te verbeteren.

Er zijn twee iteraties van DöBra Atelier uitgevoerd (2016, en 2017-18) dit gebeurde in verschillende steden in Zweden. In elke iteratie namen acht kinderen (9 jaar) en acht ouderen (de meeste ouder dan 80 jaar) deel aan een reeks van vijf workshops met kunstactiviteiten die op verschillende manieren de onderwerpen sterven, dood, en verlies behandelden. Eén workshop ging over de vraag “waar beland je na het levenseinde?” De deelnemers beantwoordden deze vraag door verschillende reisbestemmingen te creëren. Daarna bouwden ze een voertuig waarmee ze naspeelden dat ze naar de verschillende bestemmingen reisden. In een andere workshop hielden deelnemers en partners een begrafenis voor een dode vogel, waarbij zij zelfgemaakte rouwlinten droegen. Met partners van beide iteraties hebben we in 2018-19 een online Toolbox ontwikkeld. Deze bevat tips voor het ontwikkelen en faciliteren van intergenerationale kunstactiviteiten over sterven, dood, en verlies. De Toolbox beschrijft ook enkele kunstactiviteiten uit DöBra Atelier. De Toolbox is gratis beschikbaar in het Zweeds en Engels via [www.dobra.se/en](http://www.dobra.se/en). De Toolbox kan bijdragen aan de verdere ontwikkeling van intergenerationale kunstactiviteiten over sterven, dood en verlies.

Het algemene doel van dit promotieonderzoek was om de processen en impact te onderzoeken van het ontwikkelen, faciliteren en deelnemen aan DöBra Atelier. Dit werd gedaan door het documenteren van het ontwikkelingsproces en de intergenerationale workshops. Ook nam ik follow-up interviews af met partners, deelnemende kinderen en ouderen, en de ouders van de kinderen. Daarnaast heb ik ook verkennende interviews afgenomen om zo te leren hoe anderen hebben gewerkt aan gelijksoortige projecten in Zweden en het Verenigd Koninkrijk. Alle data zijn geanalyseerd met kwalitatieve methoden. Dit proefschrift bestaat uit vier artikelen.

In artikel I worden de ontwikkelingsprocessen onderzocht van zowel de eerste iteratie van DöBra Atelier en andere projecten die overeenkomsten hebben met DöBra Atelier. Degenen die deze projecten uitvoerden hebben we de “volwassenen-tussenin” genoemd, in leeftijd tussen de ouderen en kinderen in. Zij hadden macht over en een gevoel van verantwoordelijkheid voor deze twee leeftijdsgroepen, dit beïnvloedde hun gedrag. Verschillende mandaten en voorwaarden waren van invloed op de rollen die partners hadden in DöBra Atelier en hoeveel elk van hen kon bijdragen. Dit beïnvloedde hun gevoel van eigendom over het project. In DöBra

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<sup>1</sup> DöBra Ateljé in het Zweeds. DöBra is een woordspel, wat letterlijk *goed sterven* betekent en figuurlijk equivalent is met *gaaf*.

<sup>2</sup> Ongeveer 80% van de Zweedse kinderen van 6 tot 9 jaar gaan naar naschoolse centra waar pedagogen, gebaseerd op nationale richtlijnen, educatieve vrijetijdsactiviteiten organiseren (Skolverket 2019, 2021).

Atelier reflecteerden partners over ouder worden, sterven, dood en verlies. Dit maakte ons daadkrachtig bij het aanpakken van uitdagingen in het ontwikkelen en faciliteren van kunstactiviteiten voor kinderen en ouderen over het levenseinde.

Artikel II is gebaseerd op follow-up interviews met kinderen, ouderen en de ouders van de kinderen. Het doel was om te onderzoeken hoe kinderen en ouderen vertellen over waarom ze meededen, over hun ervaringen van hun deelname, de gevolgen van deelname en hoe de ouders van de kinderen reflecteerden op de deelname van hun kind. Zowel kinderen als ouderen gaven aan dat ze wilden deelnemen aan DöBra Atelier vanwege persoonlijke ervaringen met dood en verlies en een gebrek aan intergenerationale interactie. De ouders waren over het algemeen positief over de deelname van hun kind. Kinderen en ouderen handelden met daadkracht in de intergenerationale omgang en in het creëren van ruimte voor het aangaan van onderwerpen gerelateerd aan het levenseinde, zowel in DöBra Atelier als in hun eigen sociale netwerk. De deelnemers waardeerden het te leren over het perspectief van anderen op sterven, dood en verlies. Sommige ouders en ouderen benadrukte dat ze hadden geleerd dat het mogelijk is met kinderen over deze kwesties te praten. Kinderen en ouderen leken met elkaar om te gaan als individuen in plaats van een onderdeel uit een leeftijdsgroep. De deelnemers spraken erover dat zij hun nieuwe intergenerationale relaties in stand wilden houden, maar hun afhankelijkheidspositie lijkt een obstakel te zijn. Deze bevindingen geven het belang aan van het ondersteunen van intergenerationale omgang om zowel leeftijdssegregatie als negatieve leeftijdgerelateerde stereotypen tegen te gaan.

In artikel III was het doel om mechanismen te onderzoeken in kunstactiviteiten die ondersteunen bij het aangaan van onderwerpen gerelateerd aan het levenseinde. Bij de analyse van DöBra Atelier-data hebben we speltheorie toegepast. Op deze manier vonden we vier mechanismen: 1) een "DöBra Atelier magische cirkel" kan worden omschreven als de ruimtelijke en temporele grens die de kunstactiviteiten scheidt van "het gewone leven". Hierdoor ontstond ruimte voor het aangaan van onderwerpen gerelateerd aan het levenseinde. 2) Partners probeerden beperkingen en vrijheden te balanceren in de onderwerpen, processen en producten van de kunstactiviteiten. Dit leek hun gevoel van controle te bevorderen. Wanneer beperkingen en vrijheden in evenwicht leken, waren de deelnemers onafhankelijker bij het uitvoeren van de kunstactiviteiten en het aangaan van onderwerpen rond het levenseinde. 3) Zowel partners als deelnemers gebruikten zowel verbeeldingskracht als persoonlijke ervaringen bij het aangaan van onderwerpen rond het levenseinde tijdens gesprekken, creatie en spel. 4) Na afloop van de DöBra Atelier iteraties waren er tekenen van een voortdurend gemeenschapsgevoel onder de deelnemers en partners. Dit leek mogelijk gemaakt door de gedeelde ervaringen en de producten van de kunstactiviteiten.

In artikel IV was het doel om de impact van het participatieve actieonderzoeksproces vanuit het perspectief van partners te onderzoeken, met een focus op impact als proces en product. Door analyse van gegevens uit het 4,5 jarig durende proces, kan dit artikel bijdragen aan theorieën over impact door participatief actieonderzoek. We hebben een model ontwikkeld dat onderscheid maakt tussen drie soorten impact: impact op individuele en groepsontwikkeling, actiegerichte impact en strategiegerichte impact. Het model beschrijft impact als een proces door te illustreren hoe deze drie typen aan elkaar zijn gerelateerd en op elkaar bouwen. Voor partners in DöBra Atelier was impact gerelateerd aan de ontwikkeling van interesse, zelfvertrouwen en vaardigheden voor het uitvoeren van intergenerationale kunstactiviteiten over het levenseinde. Partners zijn in hun werk en sociale netwerken ook begonnen met het op verschillende manieren

toepassen van de lessen. Daarnaast is de Toolbox gebruikt om lessen te verankeren bij besluitvormers en om spin-off projecten te initiëren.

Dit proefschrift draagt bij aan een beter inzicht in de manier waarop intergenerationele kunstactiviteiten kunnen worden ontwikkeld en gefaciliteerd om zo de betrokkenheid bij kwesties rond het levenseinde te ondersteunen. Het vergroot ook het inzicht in de manier waarop de impact van participatief actieonderzoek zowel als product en proces kan worden gezien, voornamelijk in relatie tot DöBra Atelier.



## LIST OF SCIENTIFIC PAPERS

- I. Kleijberg, M., Ahlberg, B. M., Macdonald, A., Lindqvist, O., & Tishelman, C. (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*, 1-14. <https://doi.org/10.1080/07481187.2019.1671547>
- II. Kleijberg, M., Ahlberg, B. M., Hilton, R., & Tishelman, C. (2020). Death, loss and community - Perspectives from children, their parents, and older adults on intergenerational community-based arts initiatives in Sweden. *Health and Social Care in the Community*, 28(6), 2025-2036. <https://doi.org/10.1111/hsc.13014>
- III. Kleijberg, M., Hilton, R., Ahlberg, B. M., & Tishelman, C. Play elements in intergenerational arts activities as mechanisms to support community engagement with end-of-life issues. [Submitted manuscript]
- IV. Kleijberg, M., Hilton, R., Ahlberg, B. M., & Tishelman, C. Impact as process and product in community-based participatory action research - Analysis of longitudinal data from an initiative to engage communities in end-of-life issues. [Submitted manuscript]

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## **LIST OF ABBREVIATIONS**

CBPAR	Community-based participatory action research
EoL	End-of-life
PAR	Participatory action research

## PROLOGUE

When I started this doctoral project five years ago, I was often asked why a young person like me would be interested in research about aging, dying, death, and loss. Although this question might have been asked out of curiosity, to me, it illustrates the age-segregated society we live in, where younger and older people often live separated lives and are expected to have different interests. As a teenager and in my early twenties, I worked in residential elder care while I studied industrial product design in the Netherlands, where I was born. Interacting with the residents was meaningful to me and I recognized that if I live long enough, I might find myself in their position. These experiences led me to consider what an age-integrated society might be like, and how I, with my design background, could contribute to improve quality of life at the end of life.

To further explore this interest, I studied for a master's degree in experience design at Konstfack in Stockholm, in 2011. I began to think about design in a different way, from solving every-day problems through designing new products, to addressing “wicked issues” through transdisciplinary collaboration. In my master's thesis project, I explored social norms related to aging and proposed a new way of thinking around age and aging— “an ageless state of mind”.

After graduation, I worked with social entrepreneurship and innovation projects at the Unit for Bioentrepreneurship at Karolinska Institutet and at the Stockholm School of Entrepreneurship. In 2014, I became involved as a research assistant in the DöBra research program, led by Carol Tishelman and Olav Lindqvist. DöBra consists of an interdisciplinary group of people who, through participatory action research, aim to support conversations about dying, death, and loss on individual, community, and societal levels. In this new context I learned that research can be action, and action can be research, which I saw as an extension of my design practice. Together with Carol and Olav, I shaped my curiosities into a research plan for a doctoral project.

During this process, my mother died of cancer. This deeply painful experience made the abstractness of death almost tangible for me. I still find it difficult to put words to these experiences. I also noticed how some people were struggling to find ways to support me in my grief. During a work-trip to London with Carol and Olav, I learned about how arts activities were used to support conversations about dying, death, and loss in a project with school children visiting hospice patients at St. Christopher's Hospice. This led to my curiosity about ways in which arts activities might help to engage with the unspeakable. This doctoral project is a result of these formative experiences.

# 1 INTRODUCTION AND AIM

This doctoral project is part of the Swedish DöBra research program based at Karolinska Institutet and Umeå University. In Swedish, *DöBra* is a play on words, literally meaning *dying well* but figuratively equivalent to *awesome* (Lindqvist & Tishelman, 2016). The research program consists of various projects that all apply a “new public health” approach to facilitate preparation for encounters with end-of-life (EoL) issues through supporting conversations about dying, death, and loss on individual, community, and societal levels (Lindqvist & Tishelman, 2015a). New public health is characterized by a health promotion approach which sees people as active participants in their own health and focuses on education and empowerment informed by the Ottawa Charter for Health Promotion (World Health Organization, 1986). To support health promotion in relation to EoL-issues, the various DöBra projects apply different forms of participatory action research (PAR), characterized by developing knowledge *with* rather than *on* or *about* people, through cycles of action and reflection (Bradbury, 2015).

This thesis is based on one project under the DöBra program’s umbrella, a community-based participatory action research (CBPAR) project called Studio DöBra (DöBra Ateljé in Swedish). Studio DöBra was a community-based arts initiative about EoL-issues, involving children (9 years old) and older adults (most 80+). Its goals were to support community engagement with issues related to dying, death, and loss, and create opportunities for interaction among children and older adults. Arts activities were applied to support intergenerational engagement with dying, death, and loss, which are issues that may be difficult to put into words (Walter, 2012). Studio DöBra was developed and studied in a collaboration between academic and community partners, informed by CBPAR principles (Israel et al., 2017).

This thesis is based on the components illustrated in Figure 1. A first Studio DöBra iteration was developed in 2016 in Skärholmen, in collaboration with community-organizations, i.e., an artistic organization for children, an activity center for older adults, a children’s library, and an after-school center. Parallel to developing Studio DöBra Skärholmen, I conducted an exploratory interview study with professionals with experiences of initiatives that share characteristics of Studio DöBra. These interviews and the Studio DöBra development process informed each other. In 2017-2018, a second Studio DöBra iteration was developed in Halmstad, based on an initiative from the municipal organization for culture in collaboration with the municipal organization for elder care, an after-school center, and me. This iteration was informed by lessons learned from Studio DöBra Skärholmen. In 2018-2019, community-partners from Skärholmen and Halmstad and I together developed the Studio DöBra Toolbox, to document and disseminate findings to the general public, anchor lessons learned with management and local politicians, and inspire others to develop similar initiatives.

Figure 1. Overview of the components of this thesis



## 1.1 RESEARCH AIM

The overall research aim of this thesis is to investigate the processes and impacts of developing, facilitating, and participating in Studio DöBra, a community-based intergenerational arts initiative about EoL-issues. A secondary aim is to investigate the experiences of professionals developing and facilitating initiatives that share characteristics of Studio DöBra.

The following research questions are addressed in this thesis (Roman numerals throughout the thesis indicate corresponding articles):

1. How can community and academic partners develop Studio DöBra or similar initiatives to support engagement with EoL-issues and/or intergenerational interaction? (I, IV)
2. How do children and older adults motivate their participation in Studio DöBra? How do they reflect on their experiences of participation and ways in which they were affected by their participation? How do children's parents reflect on their child's participation? (II)
3. How can arts activities support community engagement with EoL-issues? What role can facilitation have in these arts activities? (I, II, III)
4. How can impact in a CBPAR project be conceptualized? What is the impact for community and academic partners of participating in this CBPAR process? (IV)

The Studio DöBra CBPAR process was an effort to develop knowledge that is of use and of value to both academic and community-partners (Israel et al., 2017; Wallerstein et al., 2017).

## 1.2 A NOTE ABOUT TERMINOLOGY

I wrote this thesis framework using the first-person point of view, as I took this opportunity to give a reflective account of the CBPAR process, in line with its theoretical perspective. I use the term *partner(s)* to refer to those who worked together to develop Studio DöBra and learn about it, i.e., representatives of community-organizations and myself. Where relevant, I use the terms *community-partner(s)* to refer to representatives of community-organizations, and *academic partner* in reference to myself. I use the term *project group* to refer to the group of partners who developed each Studio DöBra iteration. Each iteration had a project group, and I was the only person who was part of both groups. I use the term *participant(s)* to refer to the children and older adults who participated in the Studio DöBra iterations. I use the term *child(ren)* to refer to the 9-year-old participants. In the project groups, the Swedish equivalent *barn* was used. I use the term *older adult(s)* or *older participant(s)* to refer to participants of 65 years and older. In the project groups, the Swedish term *äldre* was used. As a noun, *äldre* refers to older people, and as an adjective translates to older. Initially I used the term *elderly* as I was under the impression that it was the most correct translation. However, as I wrote Article I, I began to realize that the term *elderly* is controversial as some perceive it as stigmatizing (Ayalon & Tesch-Römer, 2018). I therefore follow the American Psychological Association style 7<sup>th</sup> edition, which suggests using the term *older adults* even if older adults refer to themselves as *elderly* (American Psychological Association, 2020). I use the term *parent(s)* to refer to the children's legal guardians, while recognizing that not all legal guardians are necessarily parents and vice versa. I use my initials (MK) in tables and data excerpts. I use the term *EoL-issues* here in a broad sense to denote any topic, question, experience, etc. relating to dying, death, and loss. I use the term *loss*, rather than *grief* or *bereavement*, to be inclusive of non-death related experiences of loss.

## 1.3 A NOTE ABOUT ILLUSTRATIONS

This thesis contains illustrations of intergenerational interaction during the Studio DöBra arts workshops, such as the cover illustration. I drew these based on photographs I took during the workshops. Partners, participants, and parents have given their written consent for the use of the photographs when presenting the project. In this thesis however, I chose to use illustrations of these photographs, for several reasons. Making illustrations was part of the analysis for Article III in which I examined the photographs. This way of engaging with the data helped me to focus on details and see connections between visual data and word-based data e.g., audio recordings and transcripts. Some illustrations are combined with quotes from interviews or conversations, where using photographs might compromise confidentiality. Furthermore, I used photographs to facilitate interviews with children and older adults after each Studio DöBra iteration. One older adult, upon seeing herself in a photograph, said, "I look like a witch". This made me recognize that being represented through photographs in something as permanent as a printed thesis may be sensitive for some participants. Additionally, the workshops have a timeless quality as they apply non-digital artforms and deal with aging, dying, death, and loss, topics that are always relevant. By using illustrations, I hope to better capture this timelessness.

## 2 BACKGROUND

Studio DöBra is based on literature, prior research, and theories primarily related to three areas: Health promotion in relation to dying, death, and loss; Using arts activities to support community engagement in EoL-issues; and Creating spaces for intergenerational interaction. In this chapter, I review each area in relevance to this thesis and discuss ways in which Studio DöBra relates to these respective areas.

### 2.1 HEALTH PROMOTION IN RELATION TO DYING, DEATH, AND LOSS

The ways we die, grieve, and care for those who are dying and grieving, change as society changes. In many aging societies, most people now die in old age (Walter, 2017). According to Walter (2017), currently about 10% of all deaths are sudden, while 90% of deaths involve prolonged dying trajectories with terminal illnesses, organ failure, and/or frailty in old age. Through professionalization and specialization, hospitals, hospices, funeral homes, therapists, etc., increasingly manage EoL-related affairs (Walter, 2017). However, these services are often limited in their ability to fulfill EoL-related social and spiritual needs, because many of these needs are situated in and mediated by social relationships and are therefore often inaccessible to professionals (Abel et al., 2013; Kellehear, 2015). Additionally, aging populations are challenging the financial feasibility and sustainability of healthcare services (Kellehear, 2014; Sallnow et al., 2012). Furthermore, it is argued that healthcare services often fail to reach vulnerable and/or marginalized groups (Abel & Kellehear, 2016; Lindqvist & Tishelman, 2016; Reimer-Kirkham et al., 2016).

Many aging societies are also age segregated (Paul, 2015; Walter, 2017). Thus, as most people die in old age, and as EoL-related issues are increasingly managed by institutions rather than in communities, many children today are spared EoL-experiences. This may lead to unrealistic and negative assumptions about death, and a lack of knowledge and preparedness in relation to EoL-issues later in life (Abel et al., 2013; Paul, 2015; Walter, 2017).

Sweden's context is similar to that described above, with an aging and age-segregated society (Krekula & Johansson, 2017; Nilsson, 2002) and increasing professionalized and specialized EoL-care (Lindqvist & Tishelman, 2016; Line, 2015). A difference compared to many other European countries, is that Sweden has less community engagement in EoL-issues (Lindqvist & Tishelman, 2016; Line, 2015; Westerlund et al., 2018). This is reflected in Swedish EoL-care in which volunteers do not play an integral part, while in many other European countries EoL-care facilities, such as hospices, often rely on volunteers (Sauter & Rasmussen, 2010). A recent study surveying specialized palliative care facilities in Sweden, Belgium, and the UK, found that 20% of the Swedish services reported having volunteers working in their service, compared to about 93% in both Belgium and the UK (De Vleminck et al., 2021). Additionally, respondents in a Swedish survey mentioned taboo, fear, shame, and avoidance of EoL-issues as barriers inhibiting awareness about palliative care (Westerlund et al., 2018). Eldercare has also changed in the past decades with declining numbers of residential care



beds (Ulmanen & Szebehely, 2015). Thus home care services, and extensive use of social networks are coordinated in efforts to meet care needs (Ulmanen & Szebehely, 2015).

Walter (2017) argues that the developments described above require a change in the ways we deal with dying, death, and loss. It is argued that palliative care and the hospice movement contribute to this change in relation to those dying of terminal illnesses, but that further development is needed, particularly in relation to those dying in old age (Abel & Kellehear, 2016; Walter, 2017). At the turn of the century, Kellehear (1999) suggested a public health approach to address these issues, based on the notion that dying, death, and loss are primarily social issues that concern everyone.

Kellehear (1999) based this approach on the Ottawa Charter for Health Promotion (World Health Organization, 1986). The Ottawa Charter is often linked with the emergence of new public health, denoting a shift from disease prevention to health promotion with a focus on achieving equity in health (Baum, 2016a; World Health Organization, 1986). The charter defines health promotion as “the process of enabling people to increase control over, and to improve, their health” (World Health Organization, 1986). The World Health Organization (WHO) defines health as “a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity” (World Health Organization, 1998). In the context of health promotion health is interpreted as a resource for everyday life, rather than a state of being (World Health Organization, 1986). The charter defines five points of action, which are still referred to as the basis of health promotion initiatives, i.e., build healthy public policy, create supportive environments, strengthen community actions, develop personal skills, and reorient health services (World Health Organization, 1986). The charter emphasizes that health promotion is everyone’s responsibility, not just that of healthcare services, (World Health Organization, 1986), which makes it a transdisciplinary issue (Leavy, 2011). It also emphasizes that health promotion is not something that is done *to* people, but *with* people, to develop solutions and approaches relevant to local communities (Baum, 2016a).

By applying the five action points of the Ottawa Charter to EoL-issues, Kellehear described health promoting palliative care, with the objective of enhancing a sense of control and support for those who are dying, grieving, or are providing care (Kellehear, 1999). Creating supportive environments in relation to EoL-issues not only relates to the physical EoL-care environments, but also to creating supportive social environments in communities and social networks. This also pertains to strengthening community actions and developing personal skills, which are needed to create these supportive environments. Reorienting health services in relation to EoL-issues aims to e.g., achieve equity-informed palliative care, include vulnerable and marginalized groups such as homeless people, and people with diverse ethnic backgrounds (Reimer-Kirkham et al., 2016). Building healthy public policy aims to support these efforts (Abel et al., 2013).

Some health promoting palliative care efforts are initiated by and or based in service delivery, e.g., palliative care institutions developing their services, and/or educating and involving communities in EoL-issues (Abel et al., 2013; Paul, 2016; Tsiris et al., 2011). Other

initiatives take a community-based approach, commonly referred to as compassionate communities or cities (Abel et al., 2013; Kellehear, 2019; Librada-Flores et al., 2020). Compassionate communities are defined as communities that recognizes EoL-care and grief as everyone's responsibility and seek to create support in various settings, e.g., schools, workplaces, meeting places, care homes, and social media (Abel & Kellehear, 2016; Horsfall et al., 2020).

This relatively young field is gaining traction internationally (Archibald et al., 2016). In their systematic literature review assessing the impact of health promotion approaches to support community action in EoL-issues, Sallnow et al. (2016) found that these approaches may make practical differences, support individual learning and personal growth, and develop community capacity. However, the lack of evaluations of the impact of these type of approaches has been pointed out (Collins et al., 2020; Sallnow et al., 2016). Furthermore, literature in this field is dominated by studies on efforts initiated by or linked to healthcare institutions (Collins et al., 2020; Noonan et al., 2020; Sallnow et al., 2016). This thesis thus can contribute to this field with findings from a community-based initiative, and evaluation of impact.

### **2.1.1 Death education**

In health promotion efforts “death education”, a term referring to learning about dying, death, loss, and EoL-care, is being used to involve communities in EoL-issues and develop personal skills (Corr & Corr, 2003; Doka, 2015; Noonan et al., 2016). Corr and Corr (2003) differentiate between formal death education which may take the form of an organized course with pre-defined learning outcomes for example for healthcare staff, and informal death education through the sharing of personal EoL-related experiences. While there is little research about the implications of death education, existing research shows benefits of experiential rather than didactic programs (Doka, 2015). According to Kellehear (2014), death education based on the sharing of personal experiences has the potential to reduce a sense of isolation in bereavement and opens up for possibilities for social support.

Paul (2015) points to literature arguing that death education should be incorporated in the school curriculum to educate children in dealing with EoL-issues. Involving children in EoL-related conversations may help challenge unrealistic and negative assumptions about death (Paul, 2015). However, Paul (2015) found that “teachers often lack the confidence to do so.” The Schools Project at St. Christopher's Hospice in London, was developed in recognition to these challenges (Hartley, 2012), and was an inspiration for Studio DöBra. The Schools Project began in 2005 and is still ongoing. In this project, 9-year-old children are invited to the hospice to meet with patients and engage in arts activities together to stimulate conversations about dying, death, and loss (Hartley, 2012; Hartley & Kraus, 2008; Tsiris et al., 2011). The Schools Project is framed as a health promotion initiative to engage communities in EoL-issues (Hartley, 2012) and a form of death education aligned with teaching objectives related to loss and transition described in the UK National School Curriculum (Hartley, 2012; Tsiris et al., 2011). Through an informal evaluation of the project,

facilitators reported positive outcomes such as “normalizing death and dying” and “creating and sustaining healthy relationships” (Tsiris et al., 2011).

### **2.1.2 Positioning Studio DöBra in this field**

Studio DöBra is positioned here as applying a health promotion approach to EoL-issues. I use this term rather than health promoting palliative care as Studio DöBra is a community-based initiative, in which the term palliative care might lead to misinterpretations. The term compassionate community would be a better fit but is difficult to translate in a way that resonates with the Swedish context. In relation to the Ottawa Charter, Studio DöBra particularly focuses on the action points of creating supportive environments, strengthening community action, and developing personal skills. As noted above, the Schools Project at St. Christopher’s Hospice in London was a first source of inspiration for Studio DöBra. However, whereas the Schools Project is initiated by and takes place in a healthcare institution, Studio DöBra is community-based. This provides an opportunity to engage community-organizations in EoL-issues without healthcare institutions mediating the engagement. Additionally, by engaging community-organizations who do not traditionally deal with EoL-issues, Studio DöBra may contribute to community engagement. While the Schools Project was supported by national teaching objectives related to loss and transition as noted above, such learning objectives are not standard in Sweden (Skolverket, 2019).

Studio DöBra involved children and older adults who were not receiving specialized palliative care, to stimulate early engagement with EoL-issues. This is based on ideas about engaging children in EoL-issues to counter unrealistic and negative assumptions about death. Furthermore, by bringing together age-groups who do not often interact in today’s age-segregated society, and supporting their collective engagement with EoL-issues, these groups might be able to learn from each other through informal death education, i.e., sharing experiences.

Prior to partnering with community-organizations, I planned to involve 9-year-old children and older adults from age 65. The choice to include 9-year-olds was based in part on positive experiences from the Schools Project in London of working with this age-group (Tsiris et al., 2011). The choice was also informed by literature on the development of a child’s understanding of death which suggests that from age eight/nine, children have developed an understanding that death is a definite and inevitable fact (Paul, 2015; Vázquez-Sánchez et al., 2018). This means that Studio DöBra does not introduce a new concept to children. The choice to conceptualize older adults as being 65 years and older, corresponds with Krekula and Johansson’s (2017) description of “age as an organizing principle” in society, meaning that age is used to organize people, organizations, resources, education, employment, etc. In Sweden, 65 is a common retirement age (Granseth et al., 2021), based on laws and regulations. From this age, people are often referred to as pensioners, seniors, or older adults, even though this age-group includes several generations. Older adults are a growing group in Sweden for whom dying, death, and loss may be increasingly relevant. This age delineation was chosen to include a potentially large group of people.

## **2.2 USING ARTS ACTIVITIES TO SUPPORT COMMUNITY ENGAGEMENT IN EOL-ISSUES**

### **2.2.1 What are “arts activities” in the context of this thesis?**

Arts are notoriously hard to define (Fancourt & Finn, 2019). Scholars in the field of arts and health are therefore making efforts to develop a common terminology to use as a basis for research in this area (All-Party Parliamentary Group on Arts Health and Wellbeing, 2017; Davies et al., 2012; Fancourt & Finn, 2019). In their scoping review of over 900 studies investigating the role of arts in improving health, Fancourt and Finn (2019) followed a conceptualization of “engagement with the arts”, as proposed by Davies et al. (2012). Here, I use Davies et al.’s (2012) conceptualization to frame what is meant with arts activities in this thesis.

Davies et al. (2012) conceptualize arts engagement based on five intersecting categories:

1. Performing arts (e.g. music, dance, theatre, singing, film)
2. Visual arts, design and craft (e.g. drawing, fashion, woodwork, ceramics, painting, photography, sculpture, textiles)
3. Literature (e.g. writing and reading)
4. Online, digital, and electronic arts (e.g. digital animation and graphics, blogs)
5. Community and cultural festivals, fairs and events (e.g. cultural performances, community arts projects such as creating murals)

They propose that arts engagement can be divided into “active” engagement, e.g. through making, creating, writing, and teaching, and “passive” engagement, e.g. through visiting, watching, listening, and discussing (Davies et al., 2012). While arts activities from all five categories may be relevant to this thesis, the focus is on activities that support active rather than passive engagement (Davies et al., 2012); are collaborative rather than individual; and are based on physical rather than virtual interaction. In the following section, I focus on these types of arts activities, while also including other relevant practices.

### **2.2.2 Arts activities in EoL care and health promotion**

In this doctoral project I collaborate with organizations outside the healthcare system, and with children and older adults who are not necessarily at the end of their lives. However, I include literature from the EoL-care field here, as it exemplifies why and how arts activities may be used to support engagement with EoL-issues.

Arts activities are used in various EoL care settings, e.g., elder- and hospice care, as well as in relation to bereaved people. They are generally applied for therapeutic purposes, to enhance the well-being of patients, their families, and care givers (Bertman, 2015), or for occupational purposes, to provide a positive activity with possible therapeutic effects (la Cour et al., 2007). The activities are usually facilitated by professional artists or art therapists (Bertman, 2015; Hartley & Payne, 2008; Walter, 2012).

There appears to be two overall applications of arts in EoL care contexts. The first one is about contact with professional and/or commercial art products, e.g., palliative care patients listening to music (Walter, 2012), or bereaved children reading children's literature to help in dealing with their EoL-related experiences (Corr, 2004; Walter, 2012). The second approach, more in line with ideas about arts activities in Studio DöBra, is about self-expression with a focus on the process of art-making rather than its products, and includes activities e.g., painting, sculpting, and creative writing. This approach is used as a means for expressing feelings and experiences related to dying, death and loss that may otherwise be difficult to put into words (Hartley & Payne, 2008; Walter, 2012).

Along with offering alternative modes of expression, arts activities have been found to support patients, families and caregivers in coping with change, self-realization, meaning-making, and for motivation and growth at the EoL (Beaumont, 2013; Hartley & Payne, 2008; la Cour et al., 2007; Nan, Lau, et al., 2018; Neimeyer & Thompson, 2014). Collective arts activities offer possibilities for creating relationships and supportive communities (Bertman, 2015; Nan, Lau, et al., 2018). Additionally, arts activities in palliative care settings provide an opportunity for patients to leave something behind for those they care about (Hartley & Payne, 2008).

The research literature about arts activities used therapeutically with children who are dying or bereaved, underlines the contribution these activities can make to the wellbeing of the whole family (Clark et al., 2014; Sourkes, 2018). An approach specific to this context is play as a means to facilitate communication between the child, their family, and healthcare staff (van Breemen, 2009). Play is considered integral in children's development and therefore important to stimulate at the EoL and in bereavement (Buser et al., 2005; Finn, 2003; Hill & Lineweaver, 2016; Jasem et al., 2018; van Breemen, 2009).

Arts activities have also been used in health promotion initiatives to engage communities in EoL-issues, but there appears to be little research investigating such initiatives. In her review of literature studying the effectiveness of public health campaigns aiming to improve the awareness and quality of palliative care, Seymour (2018) found that the arts play an important role in "supporting individual and community expression of experiences of illness, death, and grief and to encourage conversation and thoughtful reflection". An example from an early phase of the DöBra research program is the "Room for Death" project (Lindqvist & Tishelman, 2015b). This was an interactive arts-based research project which took place at a palliative care facility, which led to an exhibition held at the Architecture and Design Center in Stockholm in 2012. The Stockholm County Council commissioned artists and crafts people to create prototypes to support conversations in EoL care environments, which were then exhibited. In collaboration with the artists, palliative care researchers formulated a question for visitors to stimulate reflection and allow for feedback: "How would you like it to be around you when you are dying?" Visitors placed their written responses into a box which was incorporated in the exhibition. This material, consisting of 512 responses from visitors

from 46 countries, was later analyzed to allow insight into preferences for surroundings in which dying takes place (Lindqvist & Tishelman, 2015b).

The arts have been used in various forms of death education. For example, Turton et al. (2017) reviewed 138 studies investigating arts-based palliative care education and staff development. Art forms in these educational settings included role play (the most common), visual arts, narratives and stories, film, poetry, drama performance, music, and puppetry (Turton et al., 2017). Below I describe two arts-based death education initiatives because of their relevance to this thesis, i.e., the Schools Project at St. Christopher's Hospice (Tsiris et al., 2011) and a "life-death education program" for older adults in Hong Kong (Nan, Pang, et al., 2018).

The Schools Project in London, in which school children met with hospice patients through arts projects as described above, has applied a variety of art forms e.g., mosaic, music, storytelling, tissue paper sculpting, collage, and pottery (Tsiris et al., 2011). The rationale for using arts activities was that "artistic engagement would be a meaningful way of developing relationships between students and hospice patients, and enable meaning to be explored in metaphorical, symbolic, verbal and non-verbal ways" (Tsiris et al., 2011). Even though Tsiris and colleagues state that participants reacted positively to this approach, this is based on an informal evaluation. I have found no research investigating the use and impact of arts activities in death education involving children.

Nan, Pang, et al. (2018) report on an ethnographic study of an arts-based "life-death education program" for older adults (60+ y/o) in Hong Kong. The application of arts activities was seen as a creative alternative to addressing the difficulties of talking about death with older adults in this context, as discussing the subject directly can be seen as "bringing a bad omen" and may stir up emotions that might be experienced as negative or unnecessary (Nan, Pang, et al., 2018). The aim of the life-death program was to help participants reflect on their own mortality and prepare for the EoL through ten sessions during which the older adults worked with movement, singing, games, creative writing, and visual arts to express and document important memories of their lives, and wishes for the end of their lives (Nan, Pang, et al., 2018). Through analysis of focus group discussions held after the program, researchers found that participants described that art making helped them to recollect memories; enhanced emotional expression; enhanced interpersonal and intrapersonal communication; and inspired insight into issues of life and death (Nan, Pang, et al., 2018). According to Nan, Pang, et al. (2018) further research is needed to investigate which arts practices work best for older adults in relation to specific EoL-topics.

### **2.2.3 Positioning Studio DöBra in this field**

The literature reviewed above illustrates that a wide variety of arts activities have been used to engage individuals of all ages, families, and communities in EoL-issues. The literature describes initiatives in public spaces, healthcare settings and educational contexts. A major motivation for using arts activities noted in the literature, is that they offer alternative modes

of engaging with EoL-related experiences and emotions that may be difficult to talk about. Furthermore, arts activities may provide a context for collective art-making that can foster and build relationships. These ideas informed the use of arts activities in Studio DöBra to support community engagement with EoL-issues and intergenerational interaction.

The process, rather than the product of arts activities, is argued to be important in the engagement of EoL-issues. However, there appears to be a lack of research on ways in which arts processes support this engagement. Additionally, the literature predominantly describes arts activities located in healthcare settings or developed and facilitated by healthcare organizations. There was thus an opportunity to contribute to this field with research into community-based initiatives that use arts activities to support engagement in EoL-issues. Furthermore, as Walter (2012) pointed out, research in this field is often done through “the lens of professional ideology”, and lacks the perspectives of non-professionals, often excluding the general public. This thesis attempts to contribute to this field by addressing these knowledge gaps.

### **2.3 SUPPORTING INTERGENERATIONAL INTERACTION**

As noted above, the goals of Studio DöBra were to support community engagement with EoL-issues and create opportunities for intergenerational interaction. Particularly in relation to the latter goal, Studio DöBra was informed by research literature in relation to initiatives supporting intergenerational interaction.

Age segregation may lead to negative age-related stereotypes, ageism, and loneliness among older adults (Ayalon & Tesch-Römer, 2018; Dahlberg et al., 2018). Internationally, intergenerational initiatives have been developed to address these issues by integrating people of different ages in common activities (Lou & Dai, 2017; Martins et al., 2019). Martins et al. (2019) conceptualize intergenerational programs as “tools that allow for the exchange of resources and learning among older and younger generations for the sake of social and individual benefits”.

In their systematic literature reviews Lou and Dai (2017) and Martins et al. (2019) investigate the effectiveness of intergenerational programs in changing negative age-stereotypes and attitudes, and/or promote wellbeing and active aging among older adults, with Lou & Dai focusing on the East Asian context where “intergenerational interactions follow hierarchy and non-equality” (Lou & Dai, 2017). Both reviews defined younger people as  $\leq 30$  y/o, while older adults were defined by Lou & Dai as  $\geq 55$  y/o and by Martins et al. as  $\geq 50$  y/o. Lou & Dai included 14 East Asian publications, Martins et al. included 16 publications without geographic restrictions, and no article was included in both reviews. Common intergenerational activities were arts, educational, and cultural heritage activities during which, for example, older participants shared stories about their lives with the younger participants (Lou & Dai, 2017; Martins et al., 2019). In describing this field, I complement these systematic reviews with studies particularly relevant for this thesis, i.e., research on

intergenerational initiatives with children ( $\leq 18$  y/o) and older adults ( $\geq 65$  y/o), using arts activities to integrate these two age-groups.

This seems to be a relatively new field of study as most research was reported during the past 20 years. However, the recent publication of literature reviews (Lou & Dai, 2017; Martins et al., 2019) suggests that this field is becoming more established with increasing international interest. This increase in interest may be a response to social challenges such as aging populations, loneliness, and isolation among older adults (Lou & Dai, 2017; Martins et al., 2019). Additionally, demographic changes and a decline of extended family networks may have contributed to age segregation and an increase of prejudices and stereotypes about both older and younger people (Alfano, 2008; Belgrave, 2009; Bishop & Moxley, 2012; Heydon, 2007; Jones et al., 2004; La Porte, 1998). Studies from the USA and Wales point to government policies that promote arts-based intergenerational initiatives (Becker & Saville, 2011; Lawton, 2004; Whiteland, 2013).

One theory that has been used extensively in research investigating intergenerational initiatives is contact theory, first described by Allport in 1954 (Pettigrew & Tropp, 2006). It states four conditions for contact between diverse groups that help reduce intergroup prejudice: Equal status between the groups; common goals; intergroup cooperation; and institutional support (Pettigrew & Tropp, 2006). This theory was originally developed with a focus on ethnic discrimination but has since been applied in a wide variety of contexts including intergenerational initiatives (Kuehne & Melville, 2014; Pettigrew & Tropp, 2006).

Not all publications studied both age-groups. Research focusing on older participants investigated both their subjective experience of participation, and also benefits to health and well-being (Alfano, 2008; de Vries, 2012; Morita & Kobayashi, 2013; Teater, 2016). Studies focusing on children examined ways in which the children's perception of older adults changed and what they learned from older adults (Heydon, 2007; Kulik, 2004; Whiteland, 2016).

In general, positive outcomes were noted for both age-groups after participating in intergenerational initiatives. Younger people were found to have improved social skills and motivation to learn (Jones et al., 2004; Kulik, 2004; Lou & Dai, 2017; Martins et al., 2019), and older adults were found to have greater satisfaction with life and improved mental and physical health (Alfano, 2008; de Vries, 2012; Douse et al., 2020; Lou & Dai, 2017; Martins et al., 2019; Teater, 2016). Both age-groups reported improved self-esteem and a more positive attitude towards the other age-group (Jones et al., 2004; La Porte, 1998; Lawton, 2004; Lou & Dai, 2017; Martins et al., 2019). Intergenerational initiatives were also reported to contribute to the building of relationships across generations and an increased sense of community, and that arts activities supported this (Bishop & Moxley, 2012; de Vries, 2012; Douse et al., 2020; Heydon et al., 2017; Kulik, 2004; La Porte, 1998; McLaren, 2008; St John, 2009; Teater, 2016; Tsisir et al., 2011; Whiteland, 2013). However, in their review, Martins et al. (2019) discuss how the effectiveness of intergenerational programs in challenging age-stereotypes and promoting wellbeing and active aging is difficult to assess



due to the large variation in study designs, settings, and intervention content. Additionally, there is no consensus about which tools and scales would best assess effectiveness (Martins et al., 2019). Martins et al. (2019) point to knowledge gaps related to “evaluation, implications, and knowledge of participant’s motivations”.

### **2.3.1 Arts activities in intergenerational initiatives**

Both systematic reviews reported that in several of the included publications, arts activities played an important role in intergenerational initiatives (Lou & Dai, 2017; Martins et al., 2019). Lou & Dai (2017) suggest that arts activities may be popular in intergenerational initiatives as they are socially accepted activities for both age-groups, which may facilitate recruitment of participants. They conclude that arts activities “provide a relaxed and unthreatening medium for all ages, and they allow participants to work together and self-determine using their unique styles” (Lou & Dai, 2017).

A variety of arts expressions have been used in intergenerational programs: Music (including e.g., music therapy, playing in a band, music education), performing arts (including e.g., dance, storytelling, theatre), visual arts (including e.g., painting, drawing), and crafts (including e.g., jewelry making, sewing, knitting, weaving). Arts activities seemed to be either recreational, in which the activities were used to support intergenerational interaction; or educational, in which the activities were used to support intergenerational learning e.g., about a topic or a skill. Generally, participants from both age-groups were perceived as equals with their distinct qualities contributing to a common goal, both groups were active in contributing to that goal, and both groups benefited from working together. This is a preferred type of intergenerational interaction in line with contact theory (Bishop & Moxley, 2012; Lou & Dai, 2017).

The success of an intergenerational program did not seem to depend on the type of arts expression, but rather on the conditions in which the arts activity took place and how it was facilitated. The role the arts played in intergenerational interaction was not the focus of research, but several publications described criteria for good practice in intergenerational arts activities, based on the experiences of the authors or those facilitating the initiatives. In line with contact theory, authors reported that the arts activity should support mutual participation and collaboration (Bishop & Moxley, 2012; Heydon, 2007; Lou & Dai, 2017), and Teater (2016) pointed out that participation should be voluntary and based on an active decision to support active engagement. Additionally, it is suggested that facilitators should offer good quality artistic media and materials to work with and that the activity should offer challenges that participants can address (Bishop & Moxley, 2012; Heydon, 2007; Rossberg-Gempton & Poole, 1999). It was also argued that facilitators should adjust the physical space, tools, and pace of activities to fit the social context and needs of both older and younger participants (Heydon, 2007; Rossberg-Gempton & Poole, 1999; Teater, 2016). Heydon (2007) also argued that facilitators need to be comfortable working with people of different ages and abilities. A longer or more extended initiative seems to be more effective as it gives participants the opportunity to get to know each other (Martins et al., 2019). The

intergenerational relationships were said to be more sustainable when the program draws on the resources in the participating groups and when participants live in close proximity to each other (Becker & Saville, 2011; Bishop & Moxley, 2012).

### **2.3.2 Positioning Studio DöBra in this field**

The above-described research literature primarily investigated intergenerational initiatives that aimed to change negative age-stereotypes and attitudes, and/or promote wellbeing and active aging among older adults. However, these were not the primary aims of Studio DöBra, which sought to support community engagement with EoL-issues and create opportunities for intergenerational interaction, as noted above. Thus, one difference is that Studio DöBra focuses on intergenerational interaction based on a particular topic (EoL-issues), while the topic was often secondary in the reviewed literature. Therefore, Studio DöBra contributes to this field with studies on a particular topic for intergenerational interaction.

Based on the literature on contact theory, children and older adults in Studio DöBra were intended to have equal roles, and arts activities were intended to support their interaction and development of a sense of community. The criteria for good practices in intergenerational arts activities, summarized above, informed the arts activities in Studio DöBra. These criteria were however not research-based. Thus, there was a need for investigation of the role of arts activities in intergenerational initiatives. Additionally, the research in this field focuses predominantly on investigating predetermined outcomes, with a lack of inductive studies investigating perspectives of children and older participants about their own motivations, experiences, and implications of participating, as Martins et al. (2019) points out. Furthermore, there was a lack of literature investigating the role of the facilitators of intergenerational initiatives. This thesis seeks to address these knowledge gaps.

## **2.4 SUMMARY**

Studio DöBra was a community-based arts initiative about EoL-issues involving children and older adults. Its goals were to support community engagement with EoL-issues and to create opportunities for intergenerational interaction. Studio DöBra was motivated by the Swedish context with an aging and age-segregated society and a lack of community-engagement in EoL-issues (Krekula & Johansson, 2017; Lindqvist & Tishelman, 2016; Line, 2015; Walter, 2017; Westerlund et al., 2018). It used a community-based health promotion approach based on the Ottawa Charter for Health Promotion (Abel et al., 2013; Kellehear, 2019; Sallnow et al., 2016; World Health Organization, 1986). Studio DöBra was inspired by ideas about informal death education which is based on the sharing of experiences (Corr & Corr, 2003; Kellehear, 2014; Paul, 2015; Tsiris et al., 2011). In Studio DöBra, arts activities were applied to support intergenerational interaction and engagement with EoL-issues, based on research indicating that arts activities offer alternative modes of expression for topics that may be difficult to speak about, rather than relying on verbal communication alone (Hartley & Payne, 2008; Tsiris et al., 2011; Walter, 2012). Additionally, arts activities can support

intergenerational interaction and foster a sense of community across generations (Lou & Dai, 2017; Martins et al., 2019).

By focusing on the *processes* of developing, facilitating, and participating in Studio DöBra, in this thesis I make an effort to address knowledge gaps related to the role of those developing and facilitating health promotion efforts addressing EoL-issues and intergenerational initiatives; perspectives of participants in such initiatives; and the role of arts activities in intergenerational community engagement with EoL-issues. Additionally, by also focusing on the *impact* of developing, facilitating, and participating in Studio DöBra, knowledge gaps related to the impact of community-based health promotion initiatives about EoL-issues, as well as intergenerational initiatives are addressed, from the perspectives of both partners and participants.

### 3 SITUATING THIS THESIS METHODOLOGICALLY

#### 3.1 A TRANSDISCIPLINARY INQUIRY

Aging, dying, death, and loss affect everyone. As these are central issues in this thesis, partners, participants, supervisors, co-authors, and I, all contributed with experiential knowledge, as well as disciplinary expertise. The research underlying this thesis is a transdisciplinary inquiry, as it goes beyond disciplinary boundaries, integrating different ways of knowing to address a shared issue (Leavy, 2011).

By integrating different epistemologies, transdisciplinary research can address issues that are entangled in different disciplines and practices, and involve a wide variety of stakeholders (Groth et al., 2020; Hughes, 2021). In Studio DöBra, academic methodologies are integrated with community ways of knowing through partnership with community-organizations to together develop Studio DöBra and together learn about it, as I will describe throughout this thesis. However, integrating different ways of knowing poses challenges, not in the least in terms of what is perceived as valid knowledge by whom and in which context (Hughes, 2021; Leavy, 2011). In writing the research plan, I therefore sought an overall methodological framework that would embrace a multiplicity of knowing (Coleman, 2015), facilitate the sharing of power and ownership among partners, and support partners to use their disciplinary and personal backgrounds, interests, agenda's and curiosities. This led me to research approaches in the participatory action research (PAR) paradigm, particularly CBPAR.

#### 3.2 A COMMUNITY-BASED PARTICIPATORY ACTION RESEARCH PROCESS

In this section, I outline how Studio DöBra is positioned in the PAR paradigm. Action research is often used as an umbrella term for a wide variety of action-based and participatory research approaches (Kemmis & McTaggart, 2005; Kemmis et al., 2014). Bradbury (2015) defined action research as:

... a democratic and participative orientation to knowledge creation. It brings together action and reflection, theory and practice, in the pursuit of practical solutions to issues of pressing concern. Action research is a pragmatic co-creation of knowing *with*, not *on* [or] *about* people.<sup>3</sup>  
(Bradbury, 2015, p.1)

Banks et al. (2017) point out however, that not all action research involves participation, and not all participatory research is based on action. Thus, it can be argued that Bradbury's definition of action research is closer to PAR. Studio DöBra is action-oriented as it aims to create change and develop knowledge through practice. Additionally, Studio DöBra takes a participatory approach through partnering with community-organizations to develop and

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<sup>3</sup> The original definition ends with "not on *about*, people", which appears to be an error as a more common phrase used in action research literature is: research *with*, not *on* or *about* people.

facilitate Studio DöBra, and together learn from it, and is therefore situated in a PAR paradigm (Kemmis et al., 2014; McIntyre, 2008).

PAR initiatives may take place in diverse settings (Kemmis et al., 2014), e.g., education, healthcare, indigenous communities. The context of and issue central to the inquiry determine ways in which PAR is applied (Kemmis et al., 2014; McIntyre, 2008). This has led to a diversification of PAR approaches, often with their own names and relying on numerous theoretical frameworks (Kemmis et al., 2014; McIntyre, 2008). As noted above, Studio DöBra was conceptualized as a health promotion approach to engage communities in EoL-issues. Furthermore, while the initiative for Studio DöBra came from the university-based DöBra research program, my ambition was for it to become a community-based inquiry. The community-based context and focus on health promotion are in line with a type of PAR commonly referred to as *community-based participatory research* (Israel et al., 2017), which Wallerstein et al. (2017) describe as “collaborative efforts among community, academic, and other stakeholders who gather and use research and data to build on the strengths and priorities of the community for multilevel strategies to improve health and social equity.”

Community-based participatory research is within a PAR paradigm as it stems from the same historical and theoretical roots. While inevitably oversimplifying, these roots are often described in terms of a northern and southern tradition (Wallerstein & Duran, 2017). The northern tradition represents an approach of creating change and developing knowledge through cycles of action and reflection, with the German social psychologist Kurt Lewin often being accredited with coining the term action research in the 1940s (Kemmis et al., 2014; Wallerstein & Duran, 2017). The southern tradition represents the approach of creating change by doing research *with* rather than *on* people, with the work of Brazilian philosopher and educator Paulo Freire referred to as catalyzing this research approach (Wallerstein & Duran, 2017). This participatory approach often intends to benefit marginalized communities by striving to address power imbalances and democratize knowledge development (Israel et al., 2017; Wallerstein & Duran, 2017). Community-based participatory research positions itself closer to this southern tradition (Wallerstein & Duran, 2017). In Studio DöBra, developing knowledge through practice plays an important role. To emphasize this, I use the term community-based participatory *action* research to describe the overall Studio DöBra methodology, as other scholars have done (Maiter et al., 2008; McKay, 2011).

Israel et al. (2017) put forward community-based participatory research principles, stating that this type of research:

1. Recognizes community as a unit of identity.
2. Builds on strengths and resources within the community.
3. Facilitates collaborative, equitable partnership in all research phases and involves an empowering and power-sharing process that attends to social inequalities.
4. Promotes co-learning and capacity building among all partners.
5. Integrates and achieves a balance between research and action for the mutual benefit of all partners.

6. Emphasizes public health problems of local relevance and ecological perspectives that attend to the multiple determinants of health and disease.
7. Involves systems development through a cyclical and iterative process.
8. Disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process.
9. Requires a long-term process and commitment to sustainability.
10. Addresses issues of race, ethnicity, racism, and social class and embraces “cultural humility”.

Rather than a set of principles to strictly adhere to, the above principles are situated on a continuum and meant to function as a compass in academic-community partnerships as they evolve over time (Israel et al., 2017). Furthermore, it is recognized that in applying these principles, they need to be adapted to the local context and purpose of the research, and negotiated with all partners (Israel et al., 2017). In this manner these principles informed Studio DöBra.

### **3.2.1 Ideas about community in Studio DöBra**

As stated in the first principle, in CBPAR, *community* is characterized by a shared identity, e.g., based on cultural background, ethnicity, institutional connection, or a geographical connection (Duran et al., 2013; Israel et al., 2017). However, one goal of Studio DöBra was to bring together children and older adults, who may lack a joint sense of community due to age-segregation. To facilitate community development and increase potential for its sustainability (Israel et al., 2017), it was important that prospective participants would live in close geographical proximity to each other, as this could be a basis for a shared identity, a factor also noted as important in the research investigating intergenerational initiatives reviewed in the background (Becker & Saville, 2011; Bishop & Moxley, 2012). Furthermore, I planned to partner with community-based organizations and their representatives to involve children and older adults already in contact with these organizations. Even though children and older adults tend to be part of separate organizations in an age-segregated society, within each age-group, their contact with these organizations might contribute to a shared identity. Shared geographical connection could also be a basis for a shared identity among community-organizations. Duran et al. (2013) point out that in partnering with geographic communities, it is important not to rely on “outside-defined boundaries” such as zip codes, but to get to know how residents define their own community. This was an important part of establishing partnerships with community organizations and inviting children and older adults through these organizations. Even though Studio DöBra aimed to bring together various groups and organizations that may not have had pre-existing relationships, the EoL-issues central to this initiative could be another basis for a shared identity, as they can be of concern to everyone regardless of age.

### 3.2.2 Action and participation in Studio DöBra

As noted above, action research approaches are commonly described as creating change and developing knowledge in various forms through cycles of action and reflection (Bradbury, 2015; Coleman, 2015; Israel et al., 2017). It is argued that all research methods can contribute to this process, as long as they are adapted to the local context, which is a real world context rather than a controlled environment (Bradbury, 2015; Israel et al., 2017).

Action research not only investigates current situations to change them, but also changes situations to investigate them (Kemmis & McTaggart, 2005). This applies to the Studio DöBra CBPAR process as new situations were created, i.e., intergenerational engagement with EoL-issues through arts activities, which were investigated through reflection, which in turn informed further action. This approach also resonates with my design background, as in design practice, new situations (e.g., products, services, and experiences) are designed through a cyclic process of prototyping, trying out, and reflecting.

Kemmis and McTaggart (2005) specify that cycles of action and reflection involve “planning a change, acting and observing the process and consequences of the change, reflecting on these processes and consequences, replanning, acting and observing again, reflecting again, and so on...” It is recognized however that this process is more fluid than that description (Bradbury, 2015; Bradbury, 2016; Kemmis & McTaggart, 2005). Thus, rather than strictly following the different stages, Kemmis and McTaggart (2005) propose that partners focus on ways in which their practices and understandings can evolve through action and reflection. This was the approach in Studio DöBra.

The purpose of community participation in action research is to facilitate a process of self-empowerment by collaboratively developing knowledge that is of use and of value to all partners (Cornwall, 2008; Israel et al., 2017). This is also in line with the Ottawa Charter for Health Promotion, which emphasizes that health promotion efforts should be in participation with citizens and communities (World Health Organization, 1986). CBPAR principles emphasize therefore the importance of equitable partnerships throughout the research process with participation as desired (Israel et al., 2017). What participation means needs to be negotiated among partners and is expected to evolve throughout the CBPAR process (Cornwall, 2008; Israel et al., 2017).

Participation has been conceptualized in various ways to help understand what it may entail in research, health promotion, and community development (Baum, 2016b; Cornwall, 2008). Arnstein’s (1969) well-known ladder of citizen participation, positions forms of participation on a scale from non-participation, through tokenism, to citizen power. White (1996) described the meaning of different forms of participation for the facilitating organization and the participating community on a scale starting with the lowest level of nominal participation, which is a form of legitimation for the facilitating organization and a sense of inclusion for the community. The scale continues through instrumental and representative participation, to transformative participation, said to be a form of empowerment for both the facilitating

organization and the community. Baum (2016b) described participation in health promotion initiatives as a continuum, including: Consultation, initiated and controlled by an outside organization that involves the community by asking for their input; Participation as a means, initiated and controlled by an outside organization that involves the community to achieve a defined end; Substantive participation, initiated by an outside organization that often aims to shift power to the community by involving the community in planning, development, and implementation; and Structural participation, which is driven and controlled by the community, with power shifted to the community. Sallnow and Paul (2015) have described community engagement in health promotion efforts to engage communities in EoL-issues in a similar manner, on a spectrum from informing to empowering.

The models outlined above, all describe participation in terms of there being a facilitator and a beneficiary or receiver, e.g., the academic researcher is the facilitator of the participation of community members in the academic research process. In CBPAR however, in an effort to democratize knowledge development, there should be an exchange and interaction between academic and community partners as they participate in one another's practices. This is metaphorically described by Greenhalgh, Jackson, et al. (2016) as a two-way bridge between academia and community. Furthermore, Cornwall (2008) critiqued models of participation to be "implicitly normative", as they often present forms of participation in a hierarchy from 'bad' to 'better' and more 'genuine' forms. This normativity is also apparent in CBPAR literature describing community's 'full' participation in all research phases as an ideal to strive towards (Israel et al., 2017). I agree with Cornwall's (2008) criticism of this as problematic, as it imposes how participation should be practiced, which may reproduce power dynamics, rather than facilitating social change.

In praxis, participation is more ambiguous and evolves throughout the partnership (Cornwall, 2008). While full participation and control may be ideal in CBPAR initiatives working with marginalized communities, less involved forms of participation may be best in communities that already have a sense of agency (Cornwall, 2008; Stoecker, 1999). Furthermore, academic researchers are often able to work on a CBPAR initiative as part of their academic jobs, whereas community members may already be overburdened by their usual commitments and are often not financially compensated for their participation in CBPAR (Stoecker, 1999). Thus, rather than uncritically striving for full participation, scholars argue for the importance of jointly negotiating sensible forms of participation throughout the partnership, considering questions such as who participates, in what, and for whose benefit (Baum, 2016b; Cornwall, 2008; Duran et al., 2013; McIntyre, 2008). I intended to apply this approach in Studio DöBra.

As initiator of Studio DöBra, I initially framed who would participate. As noted above, my decision to partner with community-organizations was partly based on the assumption that representatives may be supported to participate in CBPAR through a professional mandate which could increase potential sustainability (Duran et al., 2013; Israel et al., 2017).

Organizational representatives might be able to participate as part of their jobs. I anticipated that older adults, children, and their parents would participate in research activities on what



Baum (2016b) refers to as a consultation basis. While Studio DöBra was researcher initiated, my hope has been for it to become a community-based initiative, thus moving from substantive to structural participation to use Baum's (2016b) terms. The concept of participation in CBPAR being two-directional informed my efforts. In practice this meant that, while I approached potential community-partners with an idea and a research plan, these were flexible and could be adapted to their needs and wishes. However, as a doctoral student, I needed to keep a level of control over the academic aspects of the research process (Stoecker, 1999). Throughout this thesis I discuss ways in which participation was practiced and negotiated in Studio DöBra, as well as what action and reflection entailed.

### **3.2.3 Ethical considerations in Studio DöBra**

Ethical approval for this research was obtained from the Swedish ethical review board (dnr. 2016/983-31/1; 2016/1517-31/5; 2018/825-32; 2020-00907). Prior to participation, partners, older adults, children, and parents received information about this research project and signed informed consent forms. Their participation was voluntary, and they could terminate their participation at any time without needing to provide an explanation. Community-partners participated based on their own interests and within the mandates of their job descriptions. Older adults and children participated based on their own active choice.

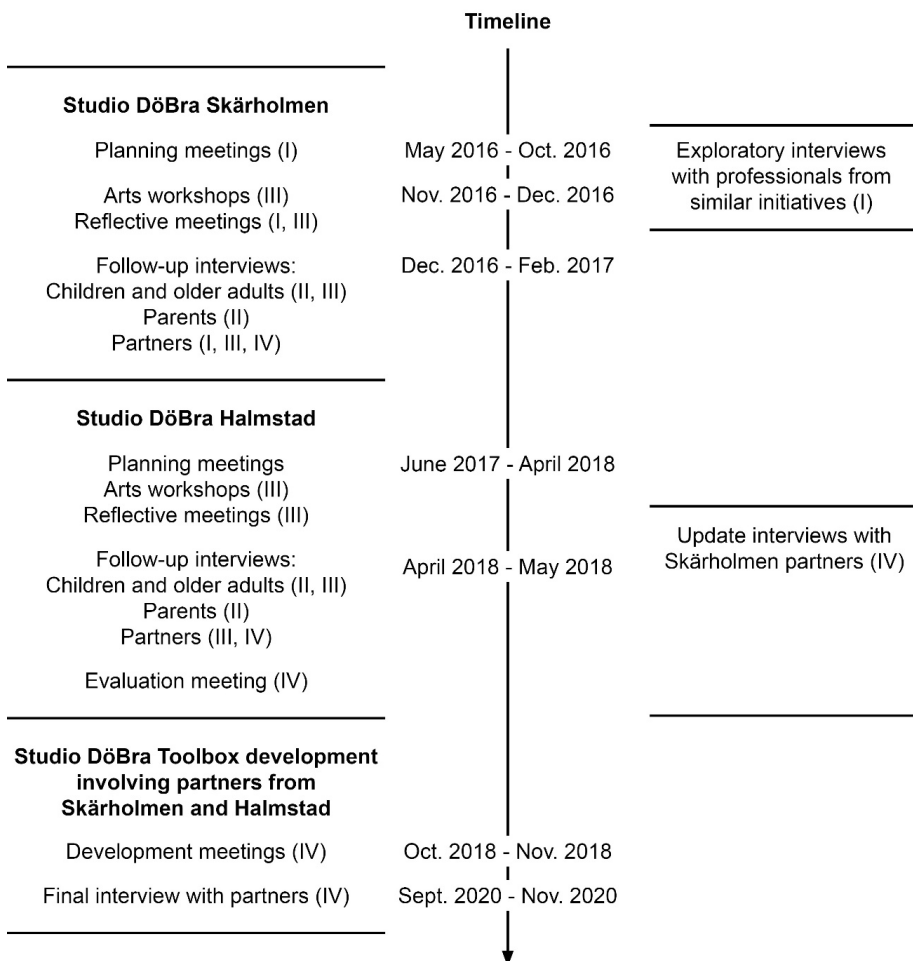
Certain ethical considerations pertain to engaging with EoL-issues in Studio DöBra. Studio DöBra involved children and older adults who to our knowledge did not receive palliative care. As noted above, the children's age was chosen partly based on research suggesting that from age eight/nine, children have developed an understanding that death is a definite and inevitable fact. Thus, while the reality of death may be relatively new for 9-year-olds, it is not expected to be a foreign concept. Efforts were made to ensure that participants, parents, community partners, and myself, could be supported if anyone would be affected negatively by participation. Within the DöBra research group there is long experience in EoL research and knowledge of and connections with sources for support if needed. I also took contact with clinical and research experts in EoL-issues in relation to children and families, to assure that there was support if needed and to receive advice in the initial phases of Studio DöBra development. Furthermore, collaboration with community organizations to which participants were connected, ensured an already established network of support. Throughout the CBPAR process, community-partners and I supported each other through regular reflective meetings.

Other ethical considerations relate to the CBPAR approach in Studio DöBra. Participatory approaches to research are intended to be ethical through efforts to do research *with* rather than *on* people (Bradbury, 2015; Israel et al., 2017). However, as discussed above, participation can take many forms and requires navigating power dynamics (Groot & Abma, 2019). Ways in which participation developed throughout the CBPAR process is discussed throughout this thesis. Another issue concerns confidentiality, which is not always possible, or even desirable to obtain in participatory projects, as partners may want to be acknowledged and/or participate in dissemination of research findings (Kalsem, 2019). I detail how this was dealt with in Studio DöBra in the discussion of this thesis.

## 4 A REFLECTIVE ACCOUNT OF THE STUDIO DÖBRA CBPAR PROCESS AND SUMMARY OF ARTICLES

The articles in this thesis cover four areas of interest, i.e., the collaborative Studio DöBra development process (I); older adults' and children's experiences of participating in Studio DöBra, and how they were affected by participation (II); the arts activities used to support intergenerational engagement with EoL-issues (III); and the impact of Studio DöBra for partners (IV). Data was generated in relation to these four interest areas throughout the CBPAR process which evolved to entail two Studio DöBra iterations and the development of Studio DöBra Toolbox, as illustrated in Figure 2. Specific research aims for the articles were developed iteratively throughout this process.

Figure 2. Timeline of the Studio DöBra CBPAR process and data underlying each article



While the articles illuminate different areas of the CBPAR process, in this chapter, I aim to compliment the articles by providing a more comprehensive overview of the process to illustrate how action and reflection informed each other and how participation was practiced and negotiated. I tell the story of the Studio DöBra CBPAR process from my own perspective, drawing from my reflective practice. I focus on those moments and events that I found pivotal in the CBPAR process and important for my own development as a researcher.

## **4.1 STUDIO DÖBRA SKÄRHOLMEN AND EXPLORATORY INTERVIEWS**

### **4.1.1 Forming partnerships in Skärholmen and a change of plans**

As I found little research literature on intergenerational arts initiatives supporting community engagement in EoL-issues that could inform Studio DöBra development, I intended to begin my doctoral research by conducting an exploratory interview study to learn from professionals with experience of developing initiatives that shared characteristics with my visions for Studio DöBra. My intention was to start to contact community organizations and develop partnerships with them while I conducted this interview study. One reason for this planning was that I assumed that it would take time to establish partnerships, in part due to the potential sensitivity of EoL-issues. Additionally, CBPAR processes ideally start with a need identified by the community (Israel et al., 2017; Minkler, 2004). Here however, I, an academic, had instead identified the research topic, which might be a hinder in forming partnerships.

However, as I began approaching potential partners during the spring of 2016, I was surprised by their immediate positive responses. Moreover, they indicated that they wanted to start in the fall, as this fit with their schedules, a timepoint earlier than I had expected. It seemed only fitting that as I invited community-organizations to participate in my academic practices and processes, I had to be prepared to adapt to and participate in community practices and processes (Greenhalgh, Jackson, et al., 2016). I therefore changed my plans to be able to conduct the exploratory interviews at the same time as I worked with community partners to develop Studio DöBra.

My starting point for finding potential partners was Stockholm City Elder Care Bureau, with which the DöBra research program had an already established collaboration. A representative suggested that I contact the activity center for older adults in Skärholmen, a neighborhood on the outskirts of Stockholm, as the activity manager there was known for community engagement and interest in developing new activities. The Elder Care Bureau representative also suggested involving the local library as they might be interested and could provide an age-neutral place for intergenerational workshops.

At that time, I lived in Skärholmen, which facilitated contacting potential partners. I first contacted the local library, which was in the process of converting to a library for children only. Although they could no longer provide an age-neutral space, they were interested in partnering. A children's librarian facilitated my contact with an arts organization in Skärholmen, with which they had a working relationship; both the artistic director and the

manager of this organization immediately agreed to partner. I thereafter met with the activity manager at the activity center for older adults, who also agreed to partner. The artistic organization for children later engaged a freelance artist during the planning process, and established partnership with an after-school center. Together we formed a project group of seven individuals, five women and two men, aged 28-65 (median age 37). Table 1 lists the project group partners, their organizations, and participation in the Studio DöBra process.

Table 1. Studio DöBra Skärholmen partners and their participation in planning meetings, arts workshops, and reflective meetings

Partnering organization	Partners	Planning meetings					Studio DöBra Skärholmen workshops including related reflective meetings				
		P1	P2	P3	P4	P5	W1	W2	W3	W4	W5
Artistic organization for children	Artist, artistic director	x	x	x	x	x	x	x	x	x	x
	Artist, manager	x	x	x	x	x	x	x	x	x	x
	Artist, freelance	n/a	n/a	n/a	n/a	x	x	x	x	x	x
Children's library	Librarian	x		x	x	x	x				x
Activity center for older adults	Activity manager		x	x		x	x	x	x	x	x
After-school center	Teacher <sup>a</sup>	n/a	n/a	n/a	n/a	n/a	x	x	x	x	x
DöBra research program	MK	x	x	x	x	x	x	x	x	x	x

<sup>a</sup> The teacher participated in the workshops, not in the related reflective meetings

The Skärholmen city district is characterized by a relatively low socioeconomic status and high percentage of inhabitants with a “foreign background”, i.e., born outside Sweden, or with both parents born outside Sweden (SCB, 2021). In 2015 this percentage was 69.4% of the population of 31,562, compared to 31.5% in the Stockholm municipality overall and 22.2% in Sweden (SCB, 2021). Five of the seven Studio DöBra partners were either born outside Sweden or have parents who are both born outside Sweden, myself included. As I contacted potential partners, some said they were wary of outsiders coming to Skärholmen to start time-limited community development projects that have little community support. When I told them that I lived in the neighborhood and am not Swedish-born, I felt they saw me as part of the community, which gave me credibility and a basis for our partnership. However, within this community, I was also an outsider with privileges derived from my education, being a white man, and originating from a country within the European Union.

As I encountered the community-partners' wariness towards outsiders, I saw parallels with the colonizing nature of some research, in which it is clear how the external researcher benefits (e.g., publications, grants) while it is less clear in which ways communities benefit (Minkler, 2004). As noted above, one ambition with CBPAR is to make efforts to

democratize knowledge development through a participatory research approach (Wallerstein & Duran, 2017). However, my being both an insider and outsider, as well as the initiator of the project and partnership, led to power dynamics between academic and community-partners which we needed to recognize and deal with, as discussed below (Duran et al., 2013; Minkler, 2004).

#### **4.1.2 Exploratory interviews to learn from others with experience of developing similar initiatives**

Professionals with experience from seven different initiatives were included in the exploratory interview study, some initiatives were still ongoing. These initiatives were included because they shared characteristics with the plans for Studio DöBra, i.e., arts-based, intergenerational, and/or explicitly dealt with EoL-related topics. Through the DöBra research program's network, I was aware of one initiative in Sweden and two in the UK. An advertisement in a Swedish palliative care newsletter did not generate new information about other potentially relevant initiatives, but through snowball recruitment (Heckathorn, 2011) four additional Swedish initiatives were identified.

Six of the seven initiatives shared at least two of the three characteristics mentioned above. The remaining initiative only shared the characteristic of explicitly dealing with EoL-related topics, but was included as a PAR approach was applied. From each initiative, one to four involved professionals participated in an exploratory interview, a total of 15 individuals, with backgrounds as artists, teachers, researchers, a business developer, and a healthcare professional. The artists had backgrounds in visual arts, sculpture, theater, and/or music, and applied these in the initiatives.

All interviews in this thesis were in conversational form. I conducted exploratory interviews in person or by telephone. In one interview, two professionals from the same initiative participated based on their own suggestion. I began each interview by explaining that the purpose was to inform the ongoing Studio DöBra development process. I had formulated topics to guide me in the interview, focusing on the development of the initiative, its content, facilitation, and implications. All interviews were audio-recorded and transcribed verbatim by a professional, who transcribed all data in this thesis unless otherwise specified. As I conducted these exploratory interviews parallel to developing Studio DöBra Skärholmen with community-partners, I noticed that these processes informed each other. What I learned from the exploratory interviews, I brought with me to the Skärholmen project group, and when questions arose in the project group, I asked about this in upcoming interviews. Exploratory interview data was therefore included in the dataset underlying analysis for Article I, focusing on the collaborative Studio DöBra development process (Figure 2).

### 4.1.3 Studio DöBra Skärholmen planning meetings

Studio DöBra Skärholmen was developed by partners through five planning meetings (Figure 2, Table 1), held at the different community organizations. These meetings were led by me, as I initiated Studio DöBra and our partnership. Each meeting was audio recorded and transcribed, and were part of the dataset underlying analysis of Article I, focusing on the collaborative Studio DöBra development process (Figure 2). Portions of the findings from Article I are incorporated in the description of the planning meetings below.

#### 4.1.3.1 Roles and responsibilities

Planning meetings entailed a process of negotiating roles and responsibilities among partners, which began with getting to know each other and identifying organizational and personal motivations, interests, resources, expertise, and networks that could inform and support Studio DöBra, to facilitate building on community strengths and resources (Israel et al., 2017). I clarified my learning objectives and interest areas, and that I hoped to conduct PhD research that could develop something with potential for sustainability. Interests and motivations varied among community-partners, both on individual and organizational levels. While all were interested in exploring how they could contribute to supporting engagement with EoL-issues and intergenerational interaction, some had more interest in the intergenerational aspect than EoL-issues and vice versa.

Roles and responsibilities were negotiated based on partners' professions and mandates. The representatives of the artistic organization (together referred to as *artists* in this thesis) took responsibility for inviting children via their network of neighborhood schools, and led development of the arts workshops including provision of arts materials. The activity manager took responsibility for inviting older adults, and for providing home-made cake during each arts workshop. The librarian helped to invite older adults via the library. We agreed that I would be responsible for research-related activities, as an academic partner. I explained that the CBPAR approach is to negotiate the initiative to fit with the motivations, interests, and objectives of all partners involved (Duran et al., 2013), and together develop new knowledge through action and reflection (Bradbury, 2015). While we were all experienced in developing new ideas and practices in our own varied professions, it became my role as academic partner to make sure we took time to reflect and learn together.

Based on these conversations we made decisions about the concept and organization of Studio DöBra Skärholmen. Based on the artists' experience and ways of working, we decided to hold a series of five weekly arts workshops of two hours each, ending with an exhibition for the general public at the library. Based on partners' knowledge of the daily routines of potential participants, we decided that workshops would be held on Friday afternoons between 2-4 pm. As each community-organization focused on a particular age-group, we decided to rotate the arts workshops among the organizations' different venues, so that participants could visit spaces designed for other age-groups. We decided to invite eight children and eight older adults as we did not want to favor one age-group over the other,

something which was also supported by experiential data from the exploratory interviews. Based on the artists' experiences, we determined that workshops should not include more than 16 participants, to allow them to get to know each other and become a group. This was also assumed to be a manageable number of participants in relation to the available spaces.

#### 4.1.3.2 *Inviting children and older adults*

In articles I and II, I have used the term *recruiting* to refer to the process of inviting children and older adults to participate in Studio DöBra. In retrospect, however, I do not think this term does justice to the agency children and older adults had in deciding over their own participation. I therefore use the term *inviting* here.

Based on artists' experience, we intended for Studio DöBra to be offered as an activity to 9-year-olds who attended an after-school center. In Sweden, after-school centers are typically connected to a primary school and offer activities based on national guidelines which focus on personal development and providing children with a "meaningful leisure time" (Skolverket, 2019). The artists were responsible for liaising with after-school centers. They followed their standard praxis when inviting children to a project: First contacting an after-school center with a project proposal, then connecting with a teacher who helps invite children. However, as Studio DöBra was a research project, informed consent was needed from the teacher, parents, and children. The artists and I met with a teacher responsible for 9-year-olds at an after-school center who agreed to partner, noting that she would be retiring two weeks after the final arts workshop. We agreed that her role would be to support the children in their participation and communicate with their parents.

To invite children, the artists and I presented Studio DöBra to a group of approximately 35 9-year-olds at the after-school center. We introduced ourselves, explained that we wanted to invite eight children to together with eight older adults engage in arts activities about EoL-issues, and discussed what it would mean to participate in this research project. Almost all children raised their hands when I asked who wanted to participate. A lottery then determined which four girls and four boys were formally invited to participate; the invitation was given through contact with the parents. Both parents and the children themselves were given information about Studio DöBra and signed informed consent documents. Parents of one child did not want their child to participate, saying that EoL-topics were sensitive in their family. In exploratory interviews, artists working with other initiatives said that in similar situations, they would explain to the parents that participation might be beneficial for the child. However, rather than trying to convince the parents, we invited the next child on the list.

In reflecting on the presentation, the artists and I noted that, while children had questions about the intergenerational aspect of Studio DöBra, e.g., who the older participants would be and where they lived, they had no comments or questions regarding EoL-topics. This triggered our interest in the children's motivation to participate. We also discussed that children seemed curious about our backgrounds, as they tried to guess where we were from

and asked where we were living. As most children were either born outside Sweden or had parents born outside Sweden, we speculated that this may be a way for children to determine if we were insiders or outsiders to their community. Of the eight participating children, at least four and maximum six were either born outside Sweden or had parents who were both born outside Sweden.

When discussing this in retrospect, the artists talked about avoiding EoL-topics in their communication with after-school centers, in fear of not being able to involve children. They left me to broach EoL-topics with both the after-school center and with the children. Similarly, the activity manager found it hard to raise the potentially sensitive topic of dying, death, and loss in her efforts to invite older adults to Studio DöBra. Initially she used the research information letter as a means to raise the topic with older adults attending the activity center. However, this approach was not successful as no older adults had agreed to participate by the fourth planning meeting. Older adults said they were either too busy or had health and mobility issues prohibiting them from participation.

One Friday afternoon, after a planning meeting, the artists and I spontaneously went to a local senior housing facility (*trygghetsboende* in Swedish) for older adults where we hoped to meet potential participants. There we entered into a social event called “*Fredagsmys*” (translates to “Friday coziness”, a term referring to a common ritual among families to start the weekend together), where a self-organized group of about 20 older adults were eating snacks and were holding a wine lottery. We introduced ourselves and explained that we wanted to invite eight older adults to, together with eight children, engage in arts activities about EoL-issues. This informal approach resulted in five older adults agreeing to participate. The other three older participants were contacted through the activity center and the library. Thus, eight older adults participated, five women and three men, ranging from 65-85 in age (median 82). At least one and maximum two older adults were born outside Sweden or had parents who were both born outside Sweden.

#### *4.1.3.3 Developing the arts workshops*

As noted above, the artistic organization for children led the development of the arts workshops. In their own practice they use design as artistic expression, often with play as a pedagogical tool, based on the artistic director’s own childhood experiences of playing to explore alternative situations and future scenarios. A challenge some partners encountered in developing Studio DöBra arts workshops, was their own difficulties in approaching EoL-topics. One strategy was to apply metaphors for dying, death, and loss. In exploratory interviews, using metaphors was also mentioned as a way to approach EoL-topics, along with focusing on doing instead of talking, and prioritizing the arts process over the product. Advice repeatedly given in the exploratory interviews was to be “brave” in engaging children and older adults in these issues. During planning meetings discussing ideas for arts workshops, I was initially critical of using metaphors, questioning whether it was a way for us to avoid the topic rather than dealing with it explicitly. These discussions led us to share



personal EoL-related experiences, questions, and beliefs, which facilitated development of workshops.

#### **4.1.4 Arts workshops and reflective meetings**

In conjunction with each of the five Studio DöBra Skärholmen arts workshops, on Friday-afternoons, partners held reflective meetings to discuss the workshops, our own roles, and feedback from participants. Based on the reflective meetings, plans for the next workshop were adjusted. Workshops were documented through my participant observations (Reeves et al., 2013) and reflective meetings were audio recorded and transcribed. Figure 2 shows that data from reflective meetings are part of the dataset used for Article I to investigate the process of developing Studio DöBra, and that participant observations as well as reflective meetings are part of the dataset underlying Article III to investigate ways in which arts activities support intergenerational engagement with EoL-issues.

##### *4.1.4.1 Participant observation*

Israel et al. (2017) recommend that in community-based research, methods for data generation should be adapted to the local context in collaboration with partners, rather than adapting the context to the methods, as is often the case in research reliant on more control. Thus, I tried to adapt observation methods to the way the arts workshops were planned and facilitated, while trying to assure that the data generated had the quality needed to investigate the areas of interest. To this end, I triangulated documentation techniques that could be adopted to different contexts, i.e., writing field notes, taking pictures, and audio recording conversations where possible.

Prior to the start of my doctoral project, I had practiced writing field notes during four intergenerational arts activities in Sweden. This practice helped me develop a way of taking field notes that incorporates both observational and reflective notes (Reeves et al., 2013). I became aware of the limitations in what I could see and document, as many interactions occurred simultaneously and in different places. In an effort to include perspectives from community partners and involve them in data generation, I asked them to also write field notes, and all agreed. However, this did not work as I had envisioned. Most community-partners did not have time to make field notes while facilitating the arts workshops and assisting participants. Additionally, some partners reflected on not being comfortable using writing as a mode to document their reflections. Thus, for some, writing field notes hindered rather than facilitated reflection. We therefore jointly decided that the reflective meetings directly after each workshop provided a better means for generating data regarding our observations.

At the start of each workshop, I explained to all present that I would take notes and photographs and might ask permission to record a conversation. Directly after each workshop, I transcribed my fieldnotes, adding photographs and reflections from the reflective meetings. My role throughout the arts workshops shifted between what was first described by Gold (1958) as a participant-as-observer role and an observer-as-participant role. In the

participant-as-observer role, I focused on supporting the facilitation of the arts activities, engaging in conversations with participants and assisting them in their arts activities where needed, while also writing field notes. In the observer-as-participant role, I interacted less with partners and participants as I stepped back to gain an overview and focus on writing field notes. The duality in these roles was frustrating at times as I found myself unable to document everything I thought was interesting, and unable to support participants and partners in the way I would have liked.

Below I summarize each workshop, focusing on those observations and reflections that informed subsequent workshops to illustrate cycles of action and reflection (Kemmis & McTaggart, 2005).

#### *4.1.4.2 Workshop 1: Bingo-death*

The first workshop took place in the children's library. This workshop's activities aimed for partners and participants to get acquainted with each other and to introduce the topic of dying, death, and loss. The workshop began with partners and participants making nametags including a symbol which partners and participants drew to represent them, and which they used to introduce themselves. The children's librarian read from a well-known Swedish children's book (Ronja Rövardotter) to introduce three themes: That which is important, fun, and sad in life. The passage introducing something sad, described the death of a character in the book.

The artists then introduced the idea of re-designing the standard Bingo game, into "Bingo-death" (Bingodöden in Swedish). The artists had created new Bingo items, i.e., a metal ball spinner, balls decorated with abstract symbols instead of numbers, and large Bingo cards with these symbols. In three smaller intergenerational groups, participants talked about which things in life they find important, fun, and sad, and then discussed these together in the whole group. Important things included e.g., to trust people, to be healthy, to eat, to listen, and to learn. Fun things included e.g., to play, to travel, to be successful, to talk, and to have children. Sad things included e.g., to die, to forget, to be lonely, to move away, and to hear poorly. Each of these were then given one of the symbols on the balls.

We then played Bingo-death. After each randomly chosen ball, participants had time to talk in their small groups about the important/fun/sad thing which the symbol on the ball represented (Illustration 1). For example, when the ball representing "to die" was drawn, participants shared stories about the deaths of people they knew. Some children talked about the death of a grandparent who they had never met, but felt sad about, nonetheless. The workshop ended with an evaluation of the game and how it could be improved.

During the reflective meeting directly after the workshop, we were positive about the workshop as we thought that we fulfilled our aims, even though EoL-topics were only brought up briefly. We agreed that there should be an increased focus on making and doing in the next workshop, rather than relying mostly on talking as was the case in this first

workshop. The artists were particularly interested in testing different creative processes. Additionally, we adapted plans for the next workshop to increase focus on EoL-issues.

Illustration 1



#### 4.1.4.3 Workshop 2: *Where do we end up after we die?*

The second workshop took place at the venue of the artistic organization. An artist began the workshop by asking participants “What’s the topic of this project?” Children responded saying: “Feelings – bereavement – death – Bingo – to play, have fun – something important – life”. The artist then introduced the topic of this workshop by saying:

*Artist: You’re all here to find answers to questions we have [...] And our way to find answers is to say things, with words, like you did now, but you can also answer by building things. And today we are going to try both. [...] Today we are curious about [...] what happens after life, when life ends...*

*Child: You die, obviously.*

*Artist: And what happens then, where do you end up?*

In this workshop, in three smaller intergenerational groups (different constellations of participants than the first workshop), participants created a travel guide to the afterlife. To guide this process, the artists had prepared a form with questions based on a vision of the afterlife as a place, e.g., what language is spoken and what sights are worth seeing? It also included a space for a drawing of how participants envisioned this “afterlife destination”. After this, participants built a vehicle together with sticks, ropes, fabric, and furniture, to play-travel to their afterlife destinations. Participants from each group took turns playing pilots transporting the other participants, who played passengers, to their afterlife destination (Illustration 2).

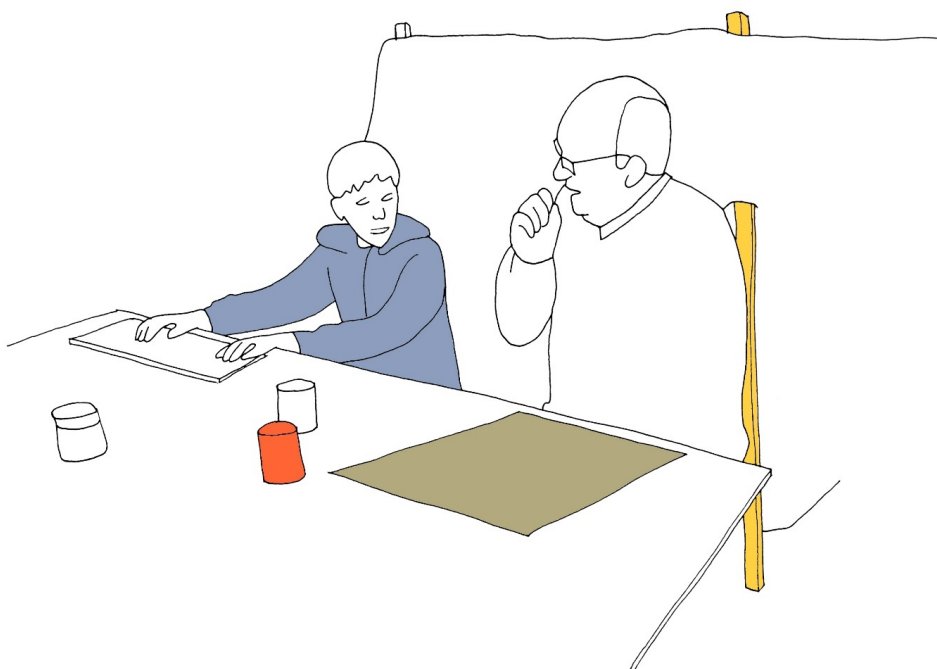
In the reflective meeting following this workshop, the activity manager said she was particularly concerned that the pace of the past two workshops was too fast for the older adults. We agreed that the first two workshops had too many planned components, which led us to hurry through the latter part of the second workshop. We therefore decided to slow down the pace by minimizing the planned components for the next workshops.

Additionally, an ongoing conversation throughout all the reflective meetings was about our role in facilitating arts activities about potentially sensitive topics. The artist who introduced the arts activity during the workshop, for example, talked about struggling with the abstract nature of death, saying:

*It feels like I'm talking about something without knowing what it is.*

I responded saying that I was impressed by the way the artist had introduced the topic, by posing a question without implying that there is a right or wrong answer.

Illustration 2



#### 4.1.4.4 Workshop 3: How does grief feel?

In response to the above-described reflections, in following exploratory interviews, I asked more about the role facilitators had in supporting conversations about EoL-issues. One artist working with an intergenerational arts project involving children and hospice patients, talked about the death of a hospice patient during the project, and spoke of the power facilitators have to either open or avoid conversations about it, and the importance of giving space and value to the expression of feelings.

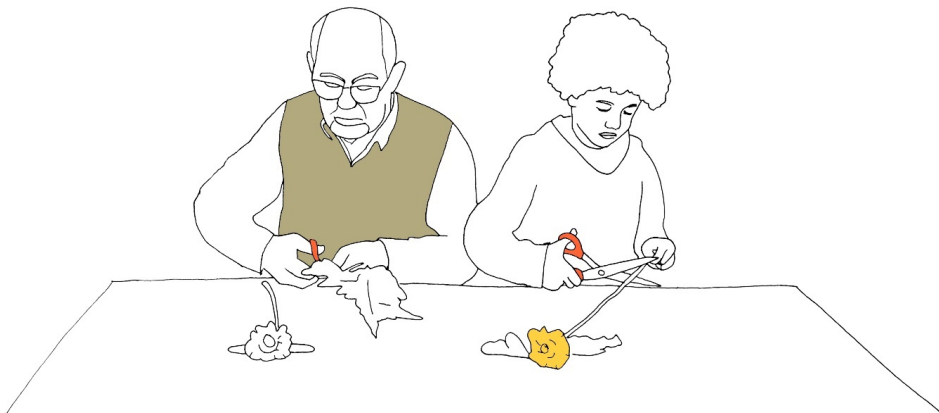
On the morning of the third workshop, which was planned to be on the theme of loss and sorrow, the teacher called me to say that one of the child participants had unexpectedly moved abroad. The teacher pointed out that “to move away” had been raised in the first workshop as something sad in life, and can also be seen as a form of loss. Because of this, and supported by experiences described in the exploratory interviews, we decided to begin

the workshop by asking the children about what had happened. This conversation was facilitated by one of the artists. Children, older adults, and partners talked about feeling sad about this loss, with some children saying they hoped the child would return.

In the continuation of this workshop, the participants worked in four intergenerational groups to make an abstract composition of flowers that expressed the feeling of sorrow. Participants could choose from a table filled with fresh flowers. They deconstructed those to make a composition on a piece of paper. After the workshop, these compositions were dried and framed.

As they worked on this, conversations among participants shifted from talking about the process of making the composition, to sharing personal experiences about loss, and talking about everyday topics, like football. However, in the following reflective meeting, partners talked about having noticed that this workshop was much quieter than both previous workshops, describing that there was a calm and concentrated atmosphere. It also seemed that the older adults took as much space as did the children. We wondered if this had to do with there being an equal number of children and older adults attending, while more children than older adults participated in the previous workshops. Another potential explanation we discussed was that this workshop had fewer planned components.

Illustration 3



We also discussed our impression that things happened “inside” participants that were not shared. In my written reflections, I wrote about feeling frustrated with the limitations of the participant observation techniques, as they relied on what I could see or hear, but lacked ways of recording thoughts, feelings, and atmospheres. I drew Illustration 3 to reflect what I was unable to capture with my other documentation methods. It shows a child and an older participant working together in silence, but what are they thinking, and how are they feeling? What I do know, is that the child had just lost her classmate, and the older adult had just spoken about his sadness remaining after the death of a close family member. I found myself hoping that follow-up interviews would provide more insight into participants’ perspectives.

Prior to this workshop, I described one goal of Studio DöBra as to support *conversations* about EoL-issues. However, it became clear that conversation only covers one mode of engagement with EoL-issues in the arts workshops. I therefore began to describe Studio DöBra as aiming to support *engagement* with EoL-issues.

#### 4.1.4.5 *Workshop 4: An alternative way to measure the passing of time*

The fourth workshop took place at the activity center for older adults. Participants worked in new constellations of intergenerational groups, using old bicycle parts to create an object or sculpture that would measure the passing of time. While travel was used in the second workshop as a metaphor for dying, and flowers as a symbol for sorrow in the third workshop, in the fourth workshop the concept of the passing of time was thought to be a metaphor for aging and approaching death. However, this theme did not trigger the discussions partners had intended. In the reflective meeting, we wondered if time as a topic was too abstract, or if we as facilitators should have been more explicit in introducing EoL-issues. Or perhaps participants did link the passing of time to the EoL but chose to talk about something else? This led to us to question how much talk about death is enough in Studio DöBra?

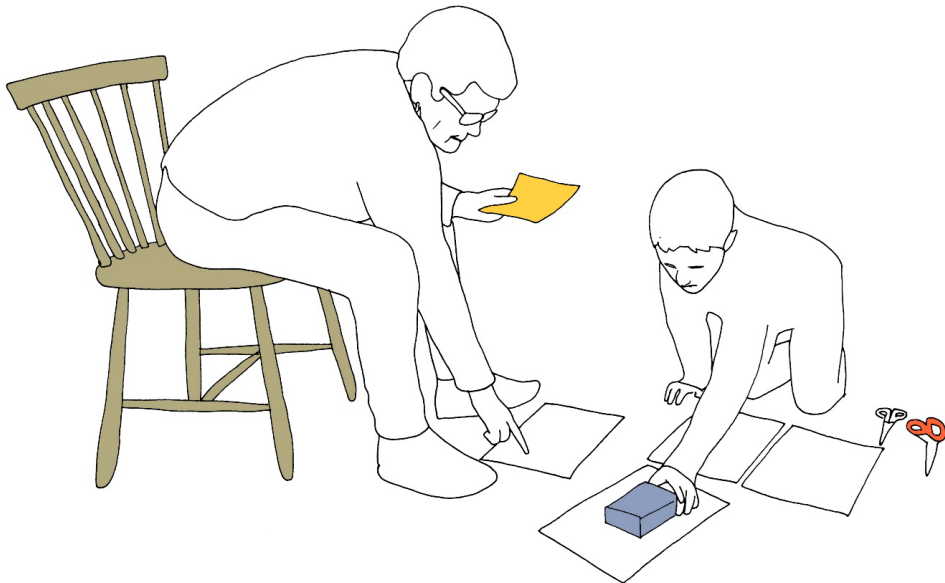
#### 4.1.4.6 *Workshop 5: Making an exhibition*

The final workshop took place in the children's library. Participants themselves told the story of Studio DöBra through an exhibition they created. The partners provided the objects from each workshop and participants curated the exhibition themselves, including explanatory texts. I had printed photographs from each workshop for participants to use in the exhibition. To my surprise participants began cutting in the photographs to make collages for the exhibition (Illustration 4). Some collages seemed to show what participants had done during a workshop, while others focused on who was part of the workshop through an assembly of cut out faces.

One of the children noticed that I was not in any of the photographs as I had taken them. She drew a portrait of me so she could include me in the exhibition. Even though everything in the exhibition was placed at child's height, she climbed on furniture to hang my portrait higher than everything else, which made it look like I had an overview of the exhibition. I interpreted this as symbolizing how she perceived me; an observer who is not an outsider, but not really an insider either. The exhibition was planned to open the following day. We ended this final workshop by playing the opening of the exhibition. Participants and partners took the roles of journalists, art critics, artists, visitors, and a manager, after which we played the opening together. A toast with bubbly soda marked the end of Studio DöBra Skärholmen.

In the following reflective meeting, partners talked about participants saying that they wanted to continue to meet each other. We therefore decided to organize a reunion. This took place about a month later in the activity center for older adults. As the exhibition had then moved to this location, participants and partners looked at this and talked about what they had made. We also played a game of Bingo-death. Data generated during the reunion was not used in any of the articles in this thesis.

Illustration 4



#### 4.1.5 Follow-up interviews Studio DöBra Skärholmen

##### 4.1.5.1 Older adults and children

As illustrated in Figure 2, interviews with older adults and children following Studio DöBra Skärholmen, were part of the analyses focusing on experiences of participating in Studio DöBra (II) and on the arts activities used to support intergenerational engagement with EoL-issues (III).

I interviewed seven of the eight older adults within ten weeks after concluding the workshop series. Interviews were held in person at locations decided by the participants, e.g., the activity center for older adults or their home, with some inviting me over for coffee and biscuits. Interviews ranged from 31-74 minutes (median 63) and were audio recorded and transcribed. A topic guide supported interviews, focusing on motivation for participation, experiences of participating, and ways in which participants might have been affected by their participation. I began by explaining that their critical reflections were important to inform development of potential future iterations of Studio DöBra. I used a set of workshop photographs to support the conversation and reflection on each arts workshop.

It occurred to me, that in general, older adults talked about more than what I asked about, often drawing from previous life experiences. In some instances, I wondered if this was a way of dealing with a sense of loneliness which some older adults talked about. However, I also noticed that participants seemed to tell stories from their lives to help me understand how they had experienced Studio DöBra and how participation affected them. One older adult for example said:

*... so I missed my own [kid's] childhood, so I see this as compensation.*

Later in this interview, this participant cried when he talked about the death of one of his parents, something he had not brought up during the arts workshops. I felt unsure about how to act in this situation. On the one hand, the follow-up interviews can be seen as an extension of Studio DöBra, as both are spaces in which we discuss EoL-issues together, among other things. In this “Studio DöBra space”, I wanted to comfort the older adult, and share my story of the death of my mother, as he had so generously shared his story. On the other hand, however, as this conversation was framed as an interview, my role was to be curious, listen, and support participants when needed. In this “interview space”, sharing my story did not seem fitting, so I focused on supporting the older participant. We took a break in the interview after which he said he wanted to continue. Later, my supervisors and I reflected on this moment, discussing the importance of making sure that participants feel supported, while it is also important that there is support for the researcher in dealing with the stories of others. Throughout this doctoral project, I have had this support from supervisors, colleagues and in my social network.

A week after the final arts workshop, I interviewed the participating children in a group. Six of the eight children participated, with the teacher present. This time was agreed upon together with the teacher, as she would soon retire. My decision to hold a group interview was based on an exploratory interview with another action researcher working with children, who suggested that in a group, children may be less shy and able to build on each other's answers. This researcher also suggested creating short exercises, rather than relying on conversation alone. Thus, while the interview topics were the same for children and older adults, the setup differed. This group interview took place in a small room at the after-school center, where we arranged the tables so we could all sit in a circle. The interview was audio recorded, which I later transcribed.

As with older adults, I began by explaining that their feedback was important to inform development of potential future iterations of Studio DöBra. With the help of workshop photographs, and inspired by the Bingo-death game, children wrote and/or drew what they thought was fun, important, and sad/boring with each workshop, after which we had a conversation about that in the group. As they all used different colors, I knew who wrote/drew what, which was planned to facilitate analysis. In another exercise, the children mapped out whom they had talked with about Studio DöBra. On a piece of paper, one child had written “mother” about ten times, saying that she had talked a lot with her mother. Another child wrote “myself”, to which I asked what she had talked with herself about. Another child answered for her saying:

*Do we have to tell you everything?!*

Thus, although interviews provided insights into participants' perspectives, participants decided themselves what to share, how to share it, and with whom, a characteristic of this data generation method. This informed my curiosity about the agency children and older



adults seemed to have in engaging with EoL-issues, both in the arts workshops and in the interview.

Rather than building on each other's ideas, some children seemed rather cautious in expressing themselves in this group setting. Additionally, I reconsidered my decision to treat children differently from older adults, as the interview topics were the same for both age-groups. These reflections led me to interview children individually after the second iteration.

#### *4.1.5.2 Children's parents*

As illustrated in Figure 2, interviews with the children's parents were part of the analysis focusing on their perspective of their child's participation in Studio DöBra (II). I interviewed one parent each for five participating children within three months after concluding the workshops series; parents from three participants did not participate as one participant had moved abroad and parents from the remaining two participants did not respond to invitations. Interviews were held in person at locations decided by the parents, e.g., in their home, or in a café. Interviews ranged from 10-41 minutes (median 24) and were supported by a topic guide focusing on their perspective of their child's participation and ways they might have been affected by Studio DöBra themselves. As with other interviews, these were audio-recorded and transcribed. Even here, I began by explaining that feedback was important to inform development of potential future iterations of Studio DöBra.

One initial take-away from these interviews, was that parents generally found it positive that their child met older adults outside the family to interact and engage with EoL-issues. However, one parent suggested that future iterations should consider inviting parents to a voluntary meeting with partners to involve parents more, which might facilitate conversations about Studio DöBra at home. These ideas informed the way partners communicated with parents in the second Studio DöBra iteration.

#### *4.1.5.3 Partners*

As illustrated in Figure 2, interviews with partners were part of the analysis focusing on the collaborative Studio DöBra development process (I), the arts activities used to support intergenerational engagement with EoL-issues (III), and the impact of Studio DöBra for partners (IV). All six community-partners were interviewed within two months after concluding the workshop series. I interviewed the teacher, while two of my supervisors (Carol Tishelman and Olav Lindqvist) interviewed the other partners, using a guide of topics focusing on motivation, development process, arts workshops, and implications. Interviews were held in person at locations decided by the partner, i.e., their work environment or a café. Interviews ranged from 40-112 minutes (median 73) and were audio recorded and transcribed.

## **4.2 ARTICLE I**

### **4.2.1 Aim, data, and analysis**

My initial area of interest for Article I was the collaborative process of developing Studio DöBra. In consultation with co-authors, I decided to combine the data from exploratory interviews about other initiatives, with Studio DöBra Skärholmen data from planning and reflective meetings with partners, as well as the follow-up interview with partners as a basis for this article (Figure 2). Our intention was that the findings from analysis of these data could inform other initiatives aiming to engage communities in EoL-issues, including a potential second iteration of Studio DöBra. Thus, the aim of Article I became 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.

Analysis was guided by interpretive description, an inductive non-prescriptive methodology that encourages a critical and creative application of existing social science methods to develop knowledge for practice (Thorne, 2016). This was in line with our CBPAR approach suggesting that methods are adapted to match local relevance (Israel et al., 2017), as well as with our aim of developing knowledge to inform potential future initiatives. I led the analysis, with regular meetings with co-authors to discuss the analytic process and interpretations. I organized and analyzed data chronologically, through an inductive coding process to construct main categories, formulated as issues central to the development process, and subcategories, formulated as challenges and approaches in dealing with them.

Community-partners participated in analysis based on their own interest and possibilities within the limitations of their job descriptions. I held two project group meetings (with my supervisors Carol Tishelman and Olav Lindqvist) participating in the second meeting), to discuss the analytic process and preliminary findings. This led to conversations among partners about when particular challenges arose throughout the development process, and how they were navigated differently over time. These meetings facilitated a process of learning together, informed further analysis, and led to insights into themes running throughout the categories which relate to power dynamics.

### **4.2.2 Summary of findings**

Portions of the findings for Article I were incorporated into the above process descriptions of planning meetings and workshops. Findings focus on central issues in developing community-based intergenerational arts initiatives to engage communities in EoL-issues. We found that these issues were navigated in relation to power dynamics among those developing them, as well as among people of different ages. We conceptualized those developing the initiatives as the “adults-in-between” the children and older adults in age, as we found that they had power over and felt responsible for these two age-groups.

One central issue involved *negotiating roles and responsibilities among partners*. All investigated initiatives were developed by the adults-in-between who were supported by professional mandates, neither children nor older adults were involved. Roles and responsibilities were determined by professional mandates and degrees of self-determination within the job. In Studio DöBra, when partners encountered difficulties, I sometimes felt that it was expected of me to take a leading role in addressing these, which seemed to skew power relations among academic and community partners.

Another central issue focused on *inviting children and older adults* to the initiatives. Challenges related to the adults-in-between feeling responsible for these two age-groups, which could lead to gatekeeping. Another challenge related to finding it difficult to broach EoL-related conversations with these age-groups. These challenges are illustrated by the following quote from an exploratory interview with an artist who contacted healthcare staff to invite older adults to an intergenerational arts project about the EoL:

*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.*

One way of dealing with these challenges was to direct efforts towards the adults-in-between who are responsible for these age-groups, e.g., engaging them in conversations about their own EoL-related experiences in an effort to demonstrate the value of the initiative.

*Developing approaches for engaging children and older adults in EoL-issues* was another central issue. As described above, in Studio DöBra planning meetings, partners talked about EoL-issues potentially being sensitive for children and older adults, while also talking about finding it difficult to talk about these issues themselves. Conversations about personal experiences, questions, and beliefs regarding EoL-issues facilitated development of the arts workshops to engage children and older adults in these topics. In exploratory interviews, partners talked about arts activities offering ways to involve all senses rather than relying on talking alone. Furthermore, approaches in arts activities included the use of metaphors, as also discussed in Studio DöBra, and focusing on the arts process rather than its product. “Be brave” was advice repeatedly given in exploratory interviews, as exemplified by an artist working with an intergenerational arts project about EoL-issues:

*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.*

As described above, throughout the Studio DöBra Skärholmen arts workshops, partners were *adapting approaches for engaging children and older adults in EoL-issues*. The content of

the arts projects was adapted to provide more space for participants to discuss. The abstract nature of death was dealt with by asking questions without implying that there are right or wrong answers. Furthermore, based on advice from exploratory interviews, an experience of loss (a child participant unexpectedly moving abroad) was dealt with by opening up for conversation.

Studio DöBra partners' work time was compensated, as we all participated within the scope of our jobs. While I was seen as having most ownership as the initiator, *investing resources* was a way for Studio DöBra partners to gain a sense of ownership over the initiative, as illustrated by one of the artists in a follow-up interview:

*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.*

In discussing these findings, we describe power dynamics among people of different ages as a “power over” relationship (Gaventa & Cornwall, 2015). Findings from Studio DöBra indicated that collective reflective practice supported awareness of this power dynamic. This reflective practice involved discussing roles and responsibilities in relation to children and older adults, and sharing personal EoL-related experiences. Through this reflective practice, partners began to consciously use this power to enable rather than avoid, block, or silence intergenerational engagement with EoL-issues. We therefore suggest that potential future similar initiatives develop such collective reflective practice. Additionally, we suggest involving children and older adults in developing the initiative, which might compensate for inequalities between age-groups.

## 4.3 STUDIO DÖBRA HALMSTAD

### 4.3.1 Forming partnerships in Halmstad

A producer of cultural activities, employed at the municipal organization for culture in Halmstad, had heard about the Studio DöBra Skärholmen initiative through word of mouth. In the spring of 2017, she contacted me, to ask if I was interested in collaborating with the organization to develop an iteration of Studio DöBra in Halmstad. She had anchored the idea with people on a managerial level, who wanted to further develop an already existing collaboration with the municipal organization for elder care through this initiative. Furthermore, there was an interest in expanding on previous experiences with intergenerational arts initiatives. Participating in research was seen as a means to support these efforts. Halmstad is a mid-sized city on the south-west coast of Sweden. In 2017, Halmstad had a population of 99,533, with 24.6% either born outside Sweden or with both parents born outside Sweden, which is quite similar to the proportion in Sweden as a whole (24.1%) (SCB, 2021).

I readily agreed as this invitation provided an opportunity to continue cycles of action and reflection with new partners in a new context, a form of impact from Studio DöBra Skärholmen. Additionally, lessons learned from Skärholmen could be applied in Halmstad. With the municipal organization for culture leading the initiative, I anticipated that I would have a different role as an invited partner rather than initiator as was the case in Skärholmen.

The producer of cultural activities involved the cultural organization's strategist, and producer of cultural activities for older adults. They in turn involved an activity manager employed at the municipal organization for elder care. The municipal organization for culture employed a freelance artist to work part-time with this initiative. A culture consultant at the municipal organization for children and youth in Halmstad helped find an after-school center interested in joining. As in Skärholmen, the teacher could not participate in planning meetings due to time constraints, but helped in the process of inviting children, and supported children in their participation. Table 2 presents Studio DöBra Halmstad partners and their participation in development and facilitation. Ages of partners ranged from 29-64 (median 33), all community-partners were women, and only I was born abroad.

Table 2. Studio DöBra Halmstad partners and their participation in planning meetings, arts workshops, and reflective meetings

Partnering organization	Partners	Studio DöBra Halmstad planning meetings (P#), workshops including related reflective meetings (W#), evaluation meeting (E)													
		P1	P2	W0	P3	W1	P4	P5	W2	P6	W3	W4	P7	W5	E
Municipal organization for culture	Producer of cultural activities <sup>a</sup>	x	n/a	n/a	x	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	x
	Producer of cultural activities for older adults (artist)	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Freelance artist (artist)	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Strategist <sup>a</sup>	x	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	x	x
Municipal organization for elder care	Activity manager	x	x	x	x	x	x	x		x	x	x	x	x	x
After-school center	Teacher <sup>b</sup>	n/a	n/a	x	n/a	x	n/a	n/a	x	n/a	x	x	n/a	x	n/a
DöBra research program	MK	x	x	x	x	x	x	x	x	x	x	x	x	x	x

<sup>a</sup> The producer of cultural activities and the strategist had a supporting role.

<sup>b</sup> The teacher only participated in the workshops, not in the related reflective meetings.

### **4.3.2 Studio DöBra Halmstad, planning meetings, arts workshops, and reflective meetings**

Planning and reflective meetings were audio recorded, but only recordings from reflective meetings were transcribed, as these were used in analysis of Article III, focusing on arts activities used to support intergenerational engagement with EoL-issues (Figure 2). Additionally, as in Skärholmen, I generated data during the arts workshops through participant observations documented by field notes, photographs, and audio recording of conversations when possible. These data were also included in the dataset for Article III (Figure 2).

#### *4.3.2.1 Learning from Skärholmen and developing a collective reflective practice*

The Halmstad community-partners said they were eager to apply lessons learned from Skärholmen. In the first planning meeting, the decisions about roles, responsibilities, development process, organization, and the concept of Studio DöBra were therefore based on Article I findings and other lessons learned from Skärholmen.

The producer of cultural activities for older adults, the freelance artist, the activity manager, and I together developed and facilitated Studio DöBra Halmstad. These community partners all had arts backgrounds, varying from visual and/or performing arts, as well as primary school arts education. They had not previously worked together in this constellation. The producer of cultural activities for older adults was the project groups' contact person, who also was responsible for contact with the after-school center, the children, and their parents. The activity manager was responsible for inviting older adults. The producer of cultural activities and the strategist (Table 2) had supporting roles and kept management informed. As in Skärholmen, I was responsible for research-related activities.

On an organizational level, community engagement with EoL-issues did not seem to be a motivation to develop Studio DöBra Halmstad; however, on personal and professional levels, community-partners said this was a motivating factor. Both the producer of cultural activities for older adults and the freelance artist had previously worked with death as themes in their own art works; they are hereafter referred to as artists.

Based on the positive experience of the number and length of workshops in Skärholmen, we decided to also hold a series of five weekly 2-hour arts workshops in Halmstad. We planned to invite eight children and about ten older adults, to compensate for potential sick leave among older adults. The development processes however, differed from that in Skärholmen. Based on findings from Article I, the intention was for participants to have more influence in steering the content of the arts workshops. Therefore, rather than planning the arts workshops beforehand, we planned to let participants' processes in the first workshop and informal feedback, inform the next workshop, and so on. Thus, planning meetings were scheduled in between the workshops as shown in Table 2. Additionally, as in Skärholmen, we planned reflective meetings directly after each workshop.

During the first planning meeting with partners, I facilitated exercises to start developing a collective reflective practice about issues related to Studio DöBra, also based on findings from Article I. One exercise was inspired by a creative writing technique to support collective reflective practice, called metaphorical micro poems. I was introduced to this technique at a workshop held by Kyra Harris, during the 2017 Canadian Hospice Palliative Care Conference. These micro poems are based on a theme or experience and can be written by a group and have the following structure:

Theme or experience (e.g., death)

- Color...
- Looked like...
- Sounded like...
- Tasted like...
- Felt like:
- Smelled like:

I had translated the structure to Swedish and chosen the following themes as the basis for the poems: Grief, Sense of community (gemenskap in Swedish), Aging, Support, Childhood, and Death. Each partner contributed sentences to each poem based on the structure, after which one partner edited the poem for readability. We then read the poems to each other. The following are the poems about Aging and Childhood:

#### *Aging*

*Aging has the color grey and it sounds like a squeaking wheel  
It tastes like cupboard-dry bread  
It feels horribly sad  
It smells musty like cemeteries  
Aging makes lines in your face*

#### *Childhood*

*Childhood has the colors beige, brown, and grey  
It sounds like chirping birds  
It tastes like ice cream and it feels like soda pop  
It smells like school hallways  
It looks like dirty pastel colors*

In these poems, aging was described in terms of “tasting like cupboard-dry bread” and feeling “horribly sad”, while we described childhood as sounding “like chirping birds” and tasting “like ice cream”. Based on these poems we discussed how our own views of aging, childhood, and EoL-issues, might influence Studio DöBra.

#### *4.3.2.2 Inviting older adults and children*

Based on experiences from Skärholmen and findings in Article I regarding challenges in inviting older adults, we decided to hold the arts workshop at one place, already familiar to older adults, with the intention to lower the threshold for participation. Additionally, we aimed to invite older adults as a group, rather than as individuals. The activity manager met



with a self-organized arts group, attended by 10 older adults (all women) every Thursday afternoon at a meeting place for older adults. She asked if they were interested in participating as a group in Studio DöBra Halmstad, devoting five of their already planned meetings to this project. The group was positive about this.

I then met with the group together with the activity manager and the artists, to further explain Studio DöBra, providing examples from Skärholmen and information about what it would mean to participate in this research project. The older adults shared personal EoL-related experiences and talked about being interested in trying out new kinds of arts techniques. Eight women agreed to participate and signed informed consent forms. The remaining two were not able to participate due to cognitive problems. The arts activities were planned to take place in the room where the group usually met. The two women who would not attend were able to use an adjacent room which their arts group prepared with materials to accommodate them.

An after-school center was involved through the municipal organization for children and youth. This particular after-school center was chosen as it was within five-minutes walking distance from the meeting place for older adults. The schools' rector had agreed to participate and arranged for me to meet a teacher who was responsible for 9-year-olds. As I presented Studio DöBra to her, she pointed out ways in which it was in line with the national curriculum for after-school centers, particularly with learning objectives about "developing the ability to create and express yourself through different esthetic forms of expression", and "developing the ability to create and maintain good relationships and working together with a democratic and empathic approach" (translated from Swedish) (Skolverket, 2019).

The artists first presented Studio DöBra for about 20 9-year-olds to invite them to participate. As in Skärholmen, almost all children wanted to participate. Four girls and four boys were chosen through a lottery. Parents and children were given information letters. Based on feedback from parents in Skärholmen about wishing to be more involved, we invited parents in Halmstad to a meeting at the school. One parent of seven of the children attended this meeting, held by the producer of cultural activities for older adults, the teacher, and me. I presented Studio DöBra, with examples and lessons learned from Skärholmen, and the planned organization of Studio DöBra Halmstad. Parents seemed generally interested and curious about the research. One parent said she had been doubtful about whether her child should participate due to the potentially sensitive topic but was positive after seeing the examples from Studio DöBra Skärholmen.

Eight children and eight older adults (ranging from 66-93 years in age, median 84) participated in the arts workshops in Halmstad. One child was born outside Sweden. Table 3 summarizes the contexts and characteristics of both Studio DöBra iterations. Below I give a summary of each workshop, particularly focusing on those observations and reflections and lessons learned that informed subsequent workshops, thereby illustrating cycles of action and reflection (Kemmis & McTaggart, 2005).

Table 3. Context and characteristics of both Studio DöBra iterations

<b>Context</b>	<b>Studio DöBra Skärholmen, 2016</b>	<b>Studio DöBra Halmstad, 2017-2018</b>
Setting	Urban multi-ethnic area in a large city in Sweden	Suburban area in a mid-sized city in Sweden
Partnering community organizations	<ul style="list-style-type: none"> <li>- Children's library</li> <li>- Artistic organization for children</li> <li>- Activity center for older adults</li> <li>- After-school center</li> </ul>	<ul style="list-style-type: none"> <li>- Municipal organization for culture</li> <li>- Municipal organization for elder care</li> <li>- After-school center</li> </ul>
Partnership initiated by	Researcher MK	Municipal organization for culture
Inviting children	In both settings, through the partnering after-school centers	
Inviting older adults	Individually, through the collaborating community organizations.	As a group, through a self-organized arts group for older adults.
<b>Characteristics</b>		
Concept	Each iteration involved five arts workshops about topics related to dying, death, and loss, involving 8 children and 8 older adults.	
Arts workshop activities	Design, collage with flowers, sculpture, drawing, play	Collage in paper, collage in fabric, sewing, drawing, funeral for a dead bird
Program ended with	The opening of an exhibition at the children's library, created by the participants themselves.	At the end of the final arts workshop, participants showed what they had created to invited friends, family, colleagues, and journalists.

### 4.3.2.3 *Workshop 0*

To involve children and older adults in developing the content of the arts workshops, partners first met each age-group separately to ask them about their expectations of meeting participants from the other age-group, their thoughts about EoL-topics, and which arts techniques they would be interested in working with. The artists, the teacher, and I met with the children first, after which the artists, the activity manager, and I met with the older adults. While partners talked about these meetings as a part of the planning process, in follow-up interviews, children and older adults talked about these meetings as the start of Studio DöBra Halmstad. I therefore term these meetings W0 here. Thus two W0 meetings were held, one with each age-group.

Participants from both groups were curious about the participants from the other age group and talked about looking forward to getting to know them. One exercise in W0 was based on a deck of cards with illustrations on them. Participants and partners picked an illustration which they related to death, after which everyone explained their choice. Some children seemed to be concerned with choosing the ‘right’ picture, which they thought would be dark and eerie looking. This led to a conversation about there not being a right or wrong answer as people can have different views of death. It was notable that older participants generally chose illustrations they interpreted with a positive view of death, e.g., death as a release or a relief. There was one older participant however, who talked about death in terms of anxiety and loneliness, reminiscing about traumatic experiences from her childhood.

The artists showed some of their own works related to the theme of death to initiate a conversation about different arts techniques that could be used. This work included collages, paintings, and small sculptures incorporating bird skulls. One artist had also brought the ashes of her cremated dog. Whereas in Skärholmen artists talked about having difficulties broaching EoL-topics with participants, the artists in Halmstad seemed intrepid in the way they engaged children and older adults in EoL-issues. While in Skärholmen I encouraged partners to approach the topic more directly, during these W0 meetings, I found myself reconsidering the question: How much talk about death is enough? Can there also be too much? And who decides?

In another exercise, participants were asked to create a mind map of their associations with dying, death, and loss on a large sheet of paper. To trigger ideas, the artists wrote down questions such as “how does it smell” or “how does it sound”, inspired by the micro-poem exercise described above. As the older participants worked on their collective mind map, some mentioned being concerned that the participating children might be put off by what they had written down. However, in the following planning meeting, partners compared the mind maps and were struck by the similarities. Both groups wrote for example about feelings of grief, what a funeral might be like, and related death and grief to love. This inspired us to use these mind maps in the first intergenerational arts workshop.

#### 4.3.2.4 Workshop 1: A collage about a topic related to dying, death, and loss

As noted above, all arts workshops in Halmstad took place in the room that was already used by the older adults for their arts group. This led to some older adults acting like hosts, as they showed us around and helped us set up the furniture and materials before the children arrived. As in Skärholmen, participants and partners made nametags, this included a symbol they drew of something they liked. These nametags were then used to get to know each other. In three intergenerational groups, participants compared the two mind maps made by the different age groups during W0, discussing similarities and differences. Each group chose words or phrases from the mind maps to use as a theme for creating a collage with material provided by partners, e.g., paper, magazines, postcards (Illustration 5).

One group created a collage about the feeling of grief, another group chose memories as a theme, and the third group chose the afterlife as a theme. I overheard one of the children in the third group, telling the others about his idea that when you die, a flying pig will come to bring you to the afterlife, something he had also written on the mind map during W0. The group incorporated this idea in the collage. At the end of the workshop, each group presented their collages. The participants seemed proud of their work, one of the older adults suggested to hang them up in the meeting place, so that everyone can see them.

Illustration 5



The positive tone of the reflective meeting following this workshop can be summarized by one partner saying:

*I feel nervous for next week's workshop, because this was so spot on.*

We discussed the assignment, which seemed clear and allowed for participants to choose a topic of interest themselves. We spent two planning meetings working on ideas for the next workshop. Our aim was to build further on what participants themselves had discussed during the first workshop, without repeating what they had already discussed.

#### 4.3.2.5 Workshop 2: A modern symbol of grief

One of the children suggested we would start each workshop with an introduction round responding to a different question, so we would get to know each other better each time. This time the question was: What year were you born? After this, one of the artists pointed out that grief had come up in the mind maps as well as in the collages, and that this would therefore be the theme of this workshop. She then talked about people sometimes expressing grief through the clothes they wear. This triggered a conversation in which older adults talked about traditional funeral clothing and grief ribbons which were worn when they were younger. They also talked about how they dress for funerals. Some children talked about having seen football players wearing grief ribbons.

One of the artists then introduced the idea of making modern symbols for grief that could be worn, using fabrics provided in various colors and patterns. Participants worked in groups as in Illustration 6, or could create their own grief symbols. As participants were working on their projects, I overheard one child talking about a friend of hers who knew a girl who had died in a fire in Halmstad. She knew that people left teddy bears at this girl's house, so she chose to make a teddy bear as a symbol for grief. Other examples of participants' grief symbols were grief-bandana's, brooches, a clock without arrows, and one group created a hat with a large red flower that had two black beads in it that represented grief. Everyone presented their symbols at the end of the workshop.

Illustration 6



Conversations in the following reflective meeting led to insights into insider-outsider tensions in partners' facilitator role. As we noticed that participants were independently executing the arts activities and engaging with EoL-issues on their own terms, we did not need to steer or support, nor did we want to interfere. This had led to partners remaining outsiders in relation to participants, reaffirming the hierarchy I described as a power-over relationship in Article I. However, during this arts workshop, the artists joined participants in making their own grief

symbols, interacting not as facilitators, but more like co-participants. This seemed to decrease our sense of hierarchy.

In the following planning meeting the community-partners discussed ways to increase a focus on process rather than on short projects. They therefore suggested devoting the last three workshops to one arts project and working with the full participant group rather than dividing them into smaller groups.

The day after this meeting, Olav Lindqvist, my co-supervisor, suddenly and unexpectedly died from an undiagnosed heart problem. We had just talked on the phone. The days following his death, I created my own symbol for grief, maybe to express what I could not say. In preparation for the following workshop, I wondered whether I should wear my grief symbol. Should I mention Olav's death? Do I even *want* to talk about it? How much talk about death is enough? Could I just be quiet and listen?

#### 4.3.2.6 Workshops 3 and 4: A dead bird

Going into the third workshop, I felt supported by the community-partners whom I had told about Olav's death. Rather than wearing my grief symbol, or talking about Olav's death, I decided to take a more observer-as-participant role in this workshop (Gold, 1958), taking a step back to focus on writing field notes and taking photographs. It felt good to *do* something. In retrospect, I can see parallels to ways in which participants modulated their engagement with EoL-issues in arts activities and interviews, as they also curated what they shared, how they shared, and with whom, as discussed in findings in Article II.

At the start of the third workshop, one of the artists brought a dead bird with her, in a box with a transparent lid so everyone could see it. Participants were asked to use sewing tools and fabrics to create images that symbolized the bird's life journey, including its' death and after death experiences. Participants then used these symbols to decorate a large sheet of fabric, which the artists had prepared beforehand (Illustration 7). For this project, the artists had been inspired by embroidered cloths that sometimes cover a coffin (*bårtäcke* in Swedish). The artists explained that we would devote two workshops to this and use the fifth and final workshop to hold a funeral ceremony for the dead bird.

Participants discussed how the bird might have died, wondering if it perhaps fell as it tried to fly? Some children began to talk among themselves, saying that the bird might have been killed by a meteor and turned into a giant kiwi. In the following reflective meeting, some partners discussed being worried that the older participants took offense in these children's fantasies. They preferred not to interfere so participants could engage with EoL-issues on their own terms, but wondered how we as facilitators should best act in these situations. Thus, an unresolved question was to what extent we could or should steer participants' engagement with EoL-issues. In the planning meeting following the fourth workshop, we therefore discussed ways in which we should steer EoL-engagement.



#### 4.3.2.7 Workshop 5: A funeral for the dead bird

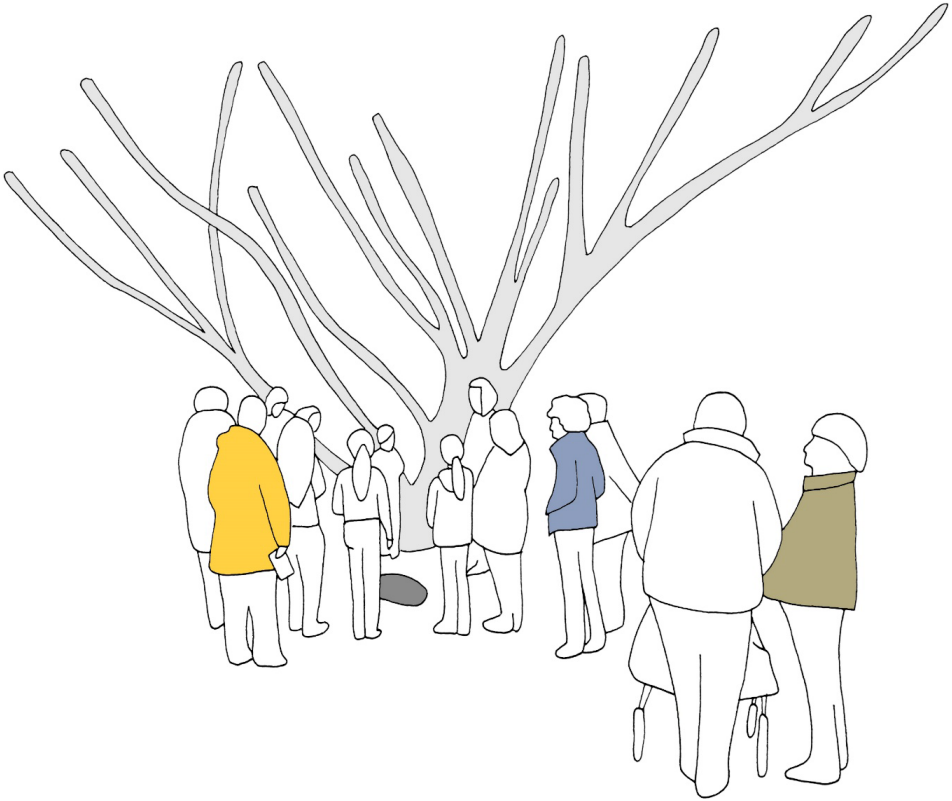
The initial idea for the final workshop was that participants themselves would design a funeral ceremony for the dead bird. Instead, we used this as an opportunity to explore how we could steer engagement with EoL-issues by the way we designed the ceremony. We had changed elements in the room to create a solemn atmosphere. The lights were dimmed, a table showcased a little box as a coffin for the dead bird together with roses and candles, and the fabric with symbols of the bird's life, death, and afterlife, covered the other tables. Participants wore the symbols for grief they had made in the second workshop and wrote farewell notes for the dead bird. We then held a ceremony during which we buried the bird under a tree (Illustration 8), with participants reading from their farewell notes. After the ceremony, one of the children said:

*This was my first funeral.*

Initially I thought the ceremony was like *playing* a funeral, but this comment led me to reconsider my own interpretation, and question how partners and participants viewed the ceremony.

Partners had previously asked participants to invite their friends and family to the second half of the fifth workshop, so they could see the art works and meet the other participants and partners. However, none of the older adults had invited anyone, with some saying that they did not have anyone to invite. Children's parents, siblings, and friends attended, as well as partners' colleagues. Journalists from the local newspaper attended and wrote an article about the initiative. This event marked the end of Studio DöBra Halmstad.

Illustration 8



### **4.3.3 Follow-up interviews Studio DöBra Halmstad**

#### *4.3.3.1 Older adults and children*

As illustrated in Figure 2, interviews with older adults and children following Studio DöBra Halmstad, were part of the analyses focusing on experiences of participating (II), and the arts activities used to support intergenerational engagement with EoL-issues (III).

I interviewed older adults and children within a month after concluding the workshop series in Halmstad. Older adults chose the location of the interviews themselves, generally their home or at the meeting place. Interviews with older adults ranged from 60-118 minutes (median 86). Based on reflections after the group interview with children in Skärholmen described above, I decided to invite the children in Halmstad to individual interviews instead. As I interviewed the children during their time at the after-school center, the teacher made a schedule allowing 20 minutes for each interview, not expecting that the interviews would take longer than that. However, already during the first interview I noticed that they could take much longer than 20 minutes. As I did not want to cut the interviews short, some children had to wait longer, and the teachers' schedule was not kept. This situation illustrates the lack of agency children have, compared to the older adults who could determine the time



and length of their interview themselves. Interviews with children generally lasted about half an hour (15-37 minutes).

All interviews were supported by a topic guide like that used in Skärholmen, focusing on motivation to participate, experiences of participating, and ways in which participants might have been affected by participation; they were also audio recorded and transcribed. I began the interviews by explaining that their feedback was important to inform development of potential future iterations of Studio DöBra. I used a set of workshop photographs to support the conversation.

The older adults commonly invited me for coffee and biscuits, and some showed me art works they had made throughout their lives. As in Skärholmen, they shared stories from their lives which helped me to understand how they experienced Studio DöBra and how participation affected them.

The children's teacher had arranged for me to hold the interviews in a classroom. I found a round table and rearranged the classroom so the child and I could sit next to each other rather than in front of each other, which I hoped would make the children feel more comfortable. Two children had said to the teacher that they were nervous prior to the interview. As I was setting up, these two children came to the classroom together with the teacher to ask me what questions I would ask. I explained that I hoped we could have a conversation about the topics I had prepared on a piece of paper, showing them the list and photographs. As I had not interviewed children individually yet, I was also nervous, which I shared with them. This seemed to reassure these two children.

I noticed that some children shared life stories with me that were not directly related to what I asked about but helped me understand their motivation to participate and ways they were affected by participation, as the older adults had done, although children used fewer words and drew on fewer life experiences. Looking at the photographs together and talking about them seemed to facilitate the conversation by helping them recalling details, something I also experienced with older participants.

#### *4.3.3.2 Children's parents*

As illustrated in Figure 2, interviews with the children's parents were part of the analysis focusing on their perspective of their child's participation in Studio DöBra (II). I interviewed one parent for each of the eight participating children within two months after concluding the workshop series. These were conducted via telephone due to distance which also allowed for more flexibility in scheduling. I had met all the interviewed parents either at the initial meeting or at the final arts workshop, which facilitated the telephone conversations. Interviews ranged from 18-42 minutes (median 24). I used the same topical guide as in Skärholmen. Interviews were audio recorded and transcribed. As with participants, I began by explaining that their feedback was important to inform development of potential future iterations of Studio DöBra.

#### *4.3.3.3 Partners*

As illustrated in Figure 2, interviews with Halmstad partners were also part of the analyses focusing on the arts activities used to support intergenerational engagement with EoL-issues (III), and the impact of Studio DöBra for partners (IV). All community partners were interviewed within one month after concluding the workshop series. I interviewed the teacher, and supervisor/co-author Carol Tishelman and Malin Eneslätt, a doctoral student in the DöBra research program, interviewed the other partners. Interviews were supported by a list of topics ranging from motivation, development process, arts workshops, and implications. Interviews were held in person at locations decided by the partner, which were their work environments. Interviews ranged from 48-111 minutes (median 67). They were audio recorded and transcribed.

## 4.4 ARTICLE II

### 4.4.1 Aim, data, and analysis

As noted in the background section of this thesis, intergenerational initiatives often aim to change age stereotypes and improve well-being among older participants (Lou & Dai, 2017), with positive results generally found in regard to both (Gualano et al., 2018; Lou & Dai, 2017; Martins et al., 2019). However, there appears to be little research that focuses on the perspective of participants in such initiatives, inductively investigating their experiences of participation. The perspectives of the participating children and older adults are therefore central in this article. Additionally, analysis of data from both iterations is intended to inform potential future initiatives. The aim of this article was therefore to investigate how children and older adults motivate their participation, their experiences of participating, and ways in which they were affected by participation. Additionally, we investigated how parents reflect on their child's participation in Studio DöBra.

The data used for analysis are shown in Figure 2. As in Article I, interpretive description guided analysis to focus on developing knowledge for practice in line with our CBPAR approach (Thorne, 2016). I led the analysis, with regular meetings with co-authors to reflect on the analysis process and discuss interpretations. I began by listening to interviews and reading transcripts, while documenting my reflections and ideas for analysis. Rather than comparing data from different age-groups, I treated data from each participant individually to find patterns and themes regardless of age.

As noted above, during the interview process, I had noticed that both older adults and children told me stories about their lives that helped me understand their motivation to participate, their experiences of participation, and ways in which participation affected them. Additionally, interviews with parents also provided this kind of background information. Inspired by the methodological work of Nasheeda et al. (2019), I decided to “re-story” the transcripts by reordering the data to form a chronological story in four parts: Previous experiences that informed participation; Motivations for participation; Process of participation; What mattered and changed in relation to participation.

In relation to each of the four parts, I formulated questions to ask of the data (Coffey & Atkinson, 1996) to help me identify and code relevant data for each story part. I formulated answers to each question, incorporating participant's quotes, while maintaining connections with the data through NVivo software. This process helped me to interpret data while also staying close to participants' own voices, in line with our aim.

#### 4.4.2 Summary of findings

I summarize findings based on the three elements of the research aim: Motivation for participation; experiences of participating; and ways in which participants were affected by participation. Three recurring themes were found: Creating spaces for engaging with EoL-issues; Connecting across generations; and Changing sense of community. Pseudonyms are used in quotes from the data.

*Motivation for participation:* We found that some participants were motivated to participate because of the topic of Studio DöBra, with some older adults referring to lacking spaces for talking about these issues, and children generally indicating a curiosity about the topic. Specific personal EoL-related experiences were also talked about as motivating participation. Some older adults spoke of wanting to help make death discussable as a normal part of life, as illustrated by Karin saying:

[I wanted to participate] *because I thought it was very interesting, the topic, what it would be about. [...] Because I think it's important to make death less dramatic. Or to make it as good as possible for children anyway. That it's a natural occurrence in life, that it happens, that [people] die. [...] [Otherwise] I think they will get lots of questions [...] People can die in horrible ways, like [children] see on television.*

Some older adults said they participated for social connection and activities, in an effort to deal with feeling increasingly lonely. A lack of intergenerational contact was said to be a motivating factor for both children and older adults. Some parents related personal or societal lack of intergenerational interaction to their positive view of their child's participation in Studio DöBra. Some children related a lack of intergenerational contact to a fear for older adults as illustrated by Stella, who said:

*I'm always a little scared of, like, old people. It's weird, but I think it was good [to meet them], but a little scary also. [...] Because they are old and that's scary I think. I don't know why. Yes, because their skin's wrinkly, and I think that's scary (laughs) [...] I wanted to participate because I wanted to know more about dying and stuff, but... I also wanted to participate so I'll learn to be with old people, with old people I don't know. [...] I'm not as scared anymore.*

*Experiences of participating:* We found that Studio DöBra seemed to be a space in which participants modulated their engagement with EoL-issues through the arts activities, as participants curated what they shared, how, and with whom. Some older adults spoke about feeling responsible for the children and therefore taking on a facilitating role. Participants talked about bonding across generations through reciprocal interaction. Some parents talked about their child feeling proud to have been given the opportunity to participate. Some older adults talked about their participation as a privilege, reflecting on feeling excluded from other social activities due to their age, as illustrated by Sigrid, saying:

*It's fun to be allowed to participate, to count, even though you're old.*

*Ways in which participants were affected by participation:* Participants talked about learning how participants from the other age-group reflect about EoL-issues. Some parents from Halmstad had met the older participants during the final arts workshop, and talked about learning about their perspective on the EoL. Other parents talked about having learned that they can talk with their child about EoL-issues. Both children and older adults described creating spaces for conversations about EoL-topics in their social networks. Parents spoke positively about this, as illustrated by Hugo's mother, saying:

*I think it was when [they] did some kind of collage about death and he said that he and his friends had cut out pretty dark images with skulls and skeletons and black and dark and so on, and then one of the older persons in his [group], had cut out bright images, birds and butterflies and so on, and then they talked about how [the older participant] saw it as something positive anyway, death, that it was light somehow... that it wasn't so horrible. And [Hugo] talked a lot about that at the dinner table, I remember that [he] fastened for that [idea] that you could see death as something light.*

In intergenerational interaction, some older adults seemed to reassume their past identities, e.g., as teachers. Some children seemed to have connected with older adults as individuals rather than as part of an age-group. Participants also indicated a changing sense of community from new social connections and continuing to meet in the neighborhood. Older participants also talked positively about continued contact with partners, with some older adults in Skärholmen having become part of the artistic organization. This organization was originally only open to children, but since Studio DöBra Skärholmen, they also welcome also older adults. Participants generally talked about wanting to maintain these new relationships. However, they seemed to lack the agency to do so. Furthermore, a few older adults indicated feeling unsure about whether the children would want to continue to meet with them as exemplified by Edith, saying:

*But I'm not so sure they'd like to meet me. I look like a witch and that's not so easy.*

## **4.5 EVALUATION MEETING WITH HALMSTAD PARTNERS AND UPDATE INTERVIEWS WITH SKÄRHOLMEN PARTNERS**

### **4.5.1 Evaluation meeting Halmstad**

The municipal organization for culture in Halmstad held an evaluation meeting a month after concluding Studio DöBra Halmstad, which was audio recorded and transcribed. As seen in Figure 2, this became part of the analysis focusing on the impact of Studio DöBra for partners (IV). The meeting took place after I had interviewed all the participating children and about half of the older participants. I presented a preliminary analysis of participants' reflections, discussing for example my surprise at finding children themselves reflected on lacking intergenerational contact and relating this to being scared of older adults, while some older adults seemed to have a negative self-image. I also brought up that participants from both age-groups wanted to continue to meet each other. We also discussed lessons learned about developing and facilitating arts activities to engage children and older adults in EoL-issues. The producer of cultural activities noted:

*An important result is that the project contributes to social sustainability—that you create trust and empathy among different groups and create a sense of security in the community.*

Stimulated by feedback from participants and lessons learned, community partners discussed ways they could continue to learn, develop similar projects, anchor these efforts at a managerial level, and share lessons learned with those who might be interested. A funding opportunity at Karolinska Institutet (Engagement Grant 2018) for projects that engaged stakeholders in disseminating research-based knowledge, was in line with these ideas. We decided that I would apply for this funding with a project proposal to develop a “Studio DöBra Toolbox” together, to document and disseminate lessons learned in a manner that would appeal to a broad audience.

### **4.5.2 Update interviews with Studio DöBra Skärholmen partners**

After Studio DöBra Skärholmen ended, I stayed in contact with community-partners, especially with the artistic organization for children and the activity center for older adults. Their professional situation allowed them to remain involved in the CBPAR process, which was in line with findings indicating that a professional mandate was a basis for participation (I). Through this contact, I kept them updated about developments in Halmstad, while they kept me updated about developments in Skärholmen and in their own organizations. Through Studio DöBra Skärholmen, the artistic organization for children had begun to include older adults in their practice, becoming an intergenerational meeting place. However, they had difficulties securing funding to maintain their organization. The activity manager had told me about changes in her job situation as she became responsible for additional activity centers for older adults in the neighborhood. As both organizations were going through a phase of changes while Studio DöBra Halmstad came to an end, I invited these partners to an update-interview to discuss what had happened since Studio DöBra Skärholmen.

I held one interview with the activity manager, and another interview in which both artists participated. These interviews, both about an hour long, were held in person, at locations decided by the partners i.e., the activity center for older adults, and a café. They were audio recorded and transcribed. As indicated in Figure 2, these data were part of the analysis focusing on the impact of Studio DöBra for partners (IV).

During the interview, the artistic director raised the challenge of integrating various epistemologies, saying:

Artist, artistic director: *What I find interesting now, is that you are writing (referring to MK's doctoral thesis) about what we've done, while we (referring to the artists) talk about that knowledge and... what we're going to do tomorrow. We're already into a future vision, and that's a kind of... a quickness. That's quite interesting [that] new knowledge emerges through an interaction and how this knowledge is used in different ways. In your case, you go through all the documentation very carefully...*

MK: *Exactly, yes.*

Artist, artistic director: *And you come with [results], while we've already taken it and applied it several times and developed it further... it's a part of our concept for the future.*

Thus, while I continued with academic analysis, community-partners had already begun to apply experiential and practical knowledge into their practices. Our continued interaction supported an ongoing interactive process of learning together.

During the interviews, community-partners and I also discussed lessons learned from Halmstad as well as possibilities for knowledge exchange between the two iterations. The artists and the activity manager were positive about continuing our collaboration, with the activity manager saying:

*We've had a really good collaboration, I think, and it's fun to—for the first time—be part of a project that you get to continue. [...] It's not just a project here and now and then it ends, and then you don't know anything. Here we've really been able to follow up [...] and we still have this contact [...] so it stays alive in a way. [...] so it feels more rewarding as well.*

After these interviews and the evaluation meeting in Halmstad, I maintained contact with partners, through which ideas for Studio DöBra Toolbox were further shaped. There was an interest among partners to exchange knowledge between Skärholmen and Halmstad, reflect on and document lessons learned, and be able to share this with other stakeholders and decisionmakers, e.g., management, politicians, as well as inspire and inform others to develop similar initiatives. I applied for the Karolinska Institutet Engagement Grant and was granted funding in the summer of 2018.

## 4.6 DEVELOPING STUDIO DÖBRA TOOLBOX

The Studio DöBra Toolbox initiative was an effort to produce community-based knowledge products for societal groups and stakeholders determined relevant by and for community-partners. This is an addition to the university-based knowledge products, e.g., articles, thesis, and research conference presentations, which are generally meant for more academic audiences. The Toolbox initiative is in line with the overall goal of this CBPAR process to develop knowledge that is of use and of value to all partners. It is also in line with the university's mandate for public outreach. The Karolinska Institutet Engagement Grant 2018 provided necessary support for the Studio DöBra Toolbox initiative, illustrating the importance of this type of funding for researchers engaging in PAR processes.

Table 4. Developing Studio DöBra Toolbox

Partnering organization	Partners	Toolbox development meetings	
		In Halmstad Oct. '18	In Skärholmen Nov. '18
DöBra research program	MK	x	x
<b>Skärholmen</b>			
Artistic organization	Artist, artistic director	x	x
	Artist, manager	x	x
Activity centers for older adults	Activity manager	x	x
<b>Halmstad</b>			
Municipal organization for culture	Producer of cultural activities	x	x
	Producer of cultural activities for older adults		x
	Freelance artist	x	x
Municipal organization for elder care	Activity manager	x	x

Table 4 shows the partners who were able to participate in the Studio DöBra Toolbox initiative, participation which was based on their professional mandate. Skärholmen artists ran their own non-profit artistic organization and thus had agency to decide over the resources they would invest in participation. The Skärholmen activity manager and Halmstad partners were all supported by their management. The municipal organization for culture in Halmstad paid the freelance artist on an hourly basis to work on this initiative. Based on the limited resources available, we planned the development process to take place over two full day working meetings as shown in Table 4. My role was to facilitate these meetings as I was the initial link between both groups. Both meetings were audio recorded and I transcribed parts of the recordings for analysis. As seen in Figure 2, data from these two meetings were



used for analysis of the impact of Studio DöBra for partners (IV). The following description of this process also contains portions of the findings from Article IV.

I structured the meeting using a design process known as the Double Diamond (Design Council, 2021). This is a four phases process: A diverging discover phase, a converging define phase, a diverging develop phase, and a converging deliver phase.

*The first meeting*, hosted in Halmstad by partners from Halmstad, began with the diverging discover phase, during which we exchanged knowledge between partners from Skärholmen and Halmstad and shared our goals and wishes for developing the Toolbox. This entailed a participatory analysis process focusing on lessons learned, based on the questions: What are three things you learned through Studio DöBra? What are three things you found important, difficult, and fun in Studio DöBra? These questions were formulated broadly to allow for open interpretation by partners. Each partner shared their answer to each question through conversation as well as on written post-its, which were compiled into a map of lessons learned.

During the converging define phase, we used this map to make decisions about what we wanted the Toolbox to be. As I assumed that partners would have limited resources to work on this initiative, I proposed that the Toolbox should be a draft of a written document, that we could publish online and work on whenever there was time. However, community-partners made clear that they had more ambitious expectations and intended to acquire the resources necessary to make these feasible. We agreed that Studio DöBra Toolbox would be made available both online and in printed form, aimed at anyone interested in supporting intergenerational engagement with EoL-issues through arts activities, or similar initiatives. Community-partners would also be able to use this material to communicate and anchor lessons learned at a managerial level and with local politicians. We agreed that the design of the toolbox should be “playful with seriousness”, and that it should contain practical tips, and examples of arts activities.

The Skärholmen activity manager, talked about having ideas for spinoff projects to create spaces for engagement with EoL-issues in different contexts, e.g., with staff working with people with dementia. She said that she needed physical material to help her in these efforts. The Skärholmen artists said that they wanted to create a physical toolbox, as this is more in line with how they communicate their knowledge, experiences, and skills as artists. They therefore proposed that they would create a prototype of a physical toolbox for the spinoff projects of the Skärholmen activity manager, in addition to the online/printed Toolbox.

This first Toolbox meeting indicates a shift in academic and community-partners’ roles in the Studio DöBra CBPAR process. As academic partner, I had initiated and felt an obligation of leadership in Studio DöBra Skärholmen (I), whereas in Halmstad I was an invited partner with community-partners initiating and leading development, and community-partners were driving the Studio DöBra Toolbox process while I acted as facilitator. During this first development meeting, I realized that Studio DöBra had begun to outgrow what I could

investigate within the framework of my doctoral project, as community-partners were starting to develop their own spinoff projects. I interpreted this as increasing the potential for sustainability and transformation.

*The second meeting*, hosted in Skärholmen by partners from Skärholmen, began with the divergent development phase of the double diamond process, during which we used the mapped-out lessons learned, to develop the content of the digital/printed toolbox. We then developed a plan for the convergent deliver phase, to finalize the Toolbox and begin to distribute it.

After the second meeting, continued collaboration took place virtually with the freelance artist from Halmstad creating illustrations and the Toolbox layout. In May 2019, the Toolbox was released at an event in Halmstad. An English translation was released in September 2019. The Toolbox is protected through Creative Commons (CC BY-NC 4.0), which allows anyone to copy, transform, build on, and redistribute the material, as long as appropriate credit is given. The Toolbox is available online on [www.dobra.se](http://www.dobra.se). Before given access to the downloadable pdf file, people are asked whether we may contact them for research purposes. While this is not a part of this doctoral project, it does enable continued research on the distribution and impact of the Toolbox.

The Skärholmen artists developed a prototype of the physical toolbox, in collaboration with the activity manager. The artists intend for this custom-designed toolbox to stimulate play, exploration, and conversation related to EoL-issues. Its' content and design draw from Studio DöBra arts activities in the first iteration, e.g., Bingo-death, and travel to the afterlife.

## 4.7 ARTICLE III

### 4.7.1 Aim, data, and analysis

The aim of this article is to explore mechanisms in arts activities that support community engagement with EoL-issues. Data underlying analysis is illustrated in Figure 2.

One insight gained through the participatory analysis process of lessons learned during Toolbox development meetings, was that we found elements of play in arts activities from both Studio DöBra iterations. In Skärholmen the artists had consciously used play as a pedagogical tool in the arts activities, e.g., in the game Bingo-death, in the workshop about traveling to the afterlife, and in playing the opening of the exhibition. Through exchanging experiences between Skärholmen and Halmstad, partners could also identify play elements in Halmstad arts activities, although they were not consciously used. We wondered for example if the funeral for the bird could be seen as a form of play. Furthermore, the content of both the online/printed and physical toolboxes were designed to lead to playful engagement with EoL-issues. These insights led to my curiosity about whether play theory could help us better understand ways in which the Studio DöBra arts activities supported engagement with EoL-issues.

I led the following analysis phase, which I repeatedly discussed and reflected on with co-authors, while also staying in contact with community-partners. I was inspired by Tavory and Timmermans' (2014) description of abductive analysis, which aims to develop new theoretical ideas through an iterative process of moving between empirical data and theoretical literature. Tavory and Timmermans (2014) draw from Peirce's pragmatism, defining theory as "any form of generalization about observations that provides a potentially useful insight about the world. *Useful* means that the theory extends its potential to future actions and understandings" (p.42). I saw this approach as in line with the overall CBPAR goal of developing knowledge useful to all partners.

This analysis is based on both Huizinga's (1949) now classic definition of the characteristics of play, and Frissen et al.'s (2015) critique and further development of this theory. Through a coding process I began investigating if and how play elements described in this literature were represented in Studio DöBra empirical data, while writing memos to document and reflect on surprising observations in relation to the theory. A central play element is described by Huizinga (1949) as the "magic circle"—a temporal and spatial boundary that separates play from "ordinary life", and within which different rules and norms apply. While Huizinga (1949) claims that play and ordinary life happen separately, Frissen et al. (2015) assert that players can be both in and outside playful modes simultaneously. Based on Studio DöBra data, we identified the Studio DöBra magic circle as the temporal and spatial boundaries within which the arts workshops took place. However, the Studio DöBra magic circle seemed to function differently than what might be expected based on theory alone. By moving iteratively between data and theory we described the functionality of the Studio DöBra magic circle in supporting engagement with EoL-issues.

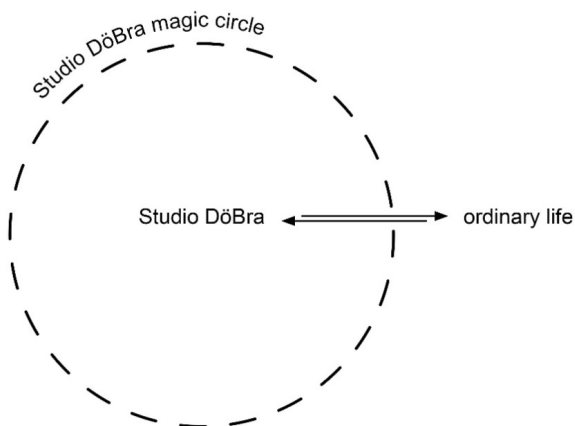
Other play elements we investigated are that play includes both “freedom and force”, involves both “reality and appearance”, and is both an “individual and collective” activity (Frissen et al., 2015) that often leads to “the formation of social groupings” (Huizinga, 1949). As we noted friction between our empirical data and theory, continued analysis focused on further developing play elements to describe ways in which they supported engagement with EoL-issues in Studio DöBra arts activities. In doing so, we searched for variations throughout the data, as the use and functionality of play elements changed across and within workshops. Specific events were analyzed in depth as they were particularly illustrative of these changes. I met with partners to discuss tentatively formulated findings. Their feedback confirmed that findings made sense to them from their perspectives, while also adding nuance to the final formulation.

#### 4.7.2 Summary of findings

Modified play elements are used to explain four mechanisms in Studio DöBra arts activities supporting engagement with EoL-issues.

We call the first mechanism *creating permeable magic circles*. The Studio DöBra magic circle provided the context for intergenerational interaction and engagement with EoL-issues. We conceptualized this as a permeable boundary through which partners and participants could introduce experiences from ordinary life into Studio DöBra, e.g., personal EoL-related experiences, as well as introduce elements from Studio DöBra into their ordinary lives, e.g., using experiences from Studio DöBra to broach EoL-related conversations in different social networks, as illustrated in Figure 3. Groups of participants sometimes created magic sub-circles in which they separated from the whole group. One example, noted above, is when a small group of children in Halmstad began talking among themselves about the bird being killed by a meteor and turned into a giant kiwi. While a magic sub-circle may allow participants to engage with EoL-issues in their own way, it could also create tensions with outsiders to this magic sub-circle. As noted above, an unresolved challenge for partners was the degree to which they should steer participants’ engagement with EoL-issues.

Figure 3. Studio DöBra magic circle



The second mechanism revolves around partners *balancing restrictions and freedoms* in facilitating arts activities. Restrictions in arts activities, such as in relation to topics, processes, and envisioned products, increased partners' sense of control and enabled participants to explore EoL-issues, but also risked diminishing participants' agency and artistic freedom. For example, in Halmstad, Alva (child) did not agree with partners' instructions to create large images to symbolize the bird's life, death, and afterlife, saying:

*But we need to have respect for the bird, it cannot become ugly.*

Too much freedom, on the other hand, could leave participants uncertain about their roles and thus risked failing to initiate engagement with EoL-issues, as for example in the fourth workshop in Skärholmen which dealt with the topic of time, but did not initiate the conversations partners intended about EoL-related topics. When restrictions and freedoms were well-balanced, partners reflected on participants being independent in their execution of the arts activity and engagement with EoL-issues.

To deal with the potential sensitivity of EoL-issues and create a space that could contain and foster diverse perspectives on these issues, partners and participants *approached dying, death, and loss through imagination and real-life experiences*, i.e., a third mechanism. Partners in Skärholmen used metaphors to call on participants' imaginations to explore EoL-issues, e.g., travel as a metaphor for dying and death in the second workshop. Participants in turn used metaphors to talk about personal EoL-experiences implicitly, or explicitly as in the following conversation from the second workshop:

Alex (child): *My mother says that my grandmother has gone on a trip, but she's dead. [...] She still says that she's gone on a trip [...] and I don't believe her.*

Sasha (partner): *How long has she been gone?*

Alex: [...] *since I was three.*

[...]

Bengt (older adult): *It's hard on kids, they ask, where did they go [...] it can be sensitive too... She's not around anymore.*

MK: *It's strange.*

Bengt (older adult): *It's strange. You grow up with your family, you can think that they'll be there forever and then they're gone, that's the way of life, the same with flowers in the field, during the summer there are beautiful flowers and then they die, after that there'll be new ones, those can be their children and grandchildren, the same with trees, everything.*

(Addressing Alex) *Your mother gave birth to you, when you grow up you'll have children, that's how we are.*

In contrast, partners in Halmstad chose to approach the topic head-on through the dead bird, and holding a ceremony mimicking a traditional funeral as described above. Here, the line between imagination and real-life experiences became blurred. During the ceremony, nearby birds began chirping and a partner wondered whether they understood that a bird was being buried, to which both children and older adults earnestly responded yes. Ida (child) commented on this in a follow-up interview, saying:

[The birds] *maybe didn't even know who it was, so I just thought, "but hello, all birds will chirp whenever", that's what I thought.*

Thus, Ida seemed to perceive the group as using imagination. Berit (older adult) talked about the ceremony as a real funeral, saying:

[The funeral] *was beautiful and it was good, but [...] it's just because I am the way that I am when it comes to funerals [...] it's not my melody, I would say. But I... I feel so odd in my opinion, so I didn't want to say that it was wrong. No... and for the children it was clearly a natural part. They are free to take a stand on things later [in life], that's how it is for all people... I stood far in the back here (points at photo).*

While different perspectives about the ceremony co-existed, it seemed that participants self-censored when they anticipated that their perspective might be deviant, as illustrated by Berit and Ida.

The fourth mechanism that supported EoL-engagement through Studio DöBra arts activities is based on *continuing a sense of community after ending the arts workshops*. Shared experiences and tangible products of the arts activities bonded participants. Both iterations ended with a final collective activity (creating an exhibition and the funeral for the dead bird), after which the Studio DöBra magic circle was opened to outsiders, e.g., exhibition visitors, friends, family, journalists. While the temporal and spatial structures of the magic circle ended, we found indications of a sense of community continuing as partners and participants continued to meet informally, visited the exhibition and participated in a reunion (Skärholmen), and visited the bird's grave (Halmstad).

#### **4.8 FINAL INTERVIEWS**

After the release of Studio DöBra Toolbox, community-partners and I stayed in contact to keep each other updated about developments in the community and the academic-side of the research. In 2019 we held workshops and presentations both together and separately to disseminate the Toolbox in various contexts. Upon request from the Skärholmen activity manager, I gave a background presentation to kick off a spinoff project she was facilitating with elder care staff, using both the online/printed and physical toolboxes. Due to the COVID-19 pandemic, which started in the beginning of 2020, community-partners' professional situations changed drastically, and the spinoff project was put on hold. In the fall of 2020, I invited community-partners to a final interview to discuss what had happened since we released Studio DöBra Toolbox, as well as share and discuss preliminary findings from the third article which was then in progress. Figure 2 illustrates that these interviews were part of the dataset for analysis of the impact of Studio DöBra for partners (IV). I held telephone interviews with all partners who participated in developing Studio DöBra Toolbox (Table 4), due to pandemic-related restrictions. Interviews ranged from 30-100 minutes (median 62), they were audio recorded and transcribed, and contained a mutual update of what had happened since the release of the Toolbox, ways in which partnering in this CBPAR process had impacted partners and their organizations, and future plans.

## 4.9 ARTICLE IV

### 4.9.1 Aim, data, and analysis

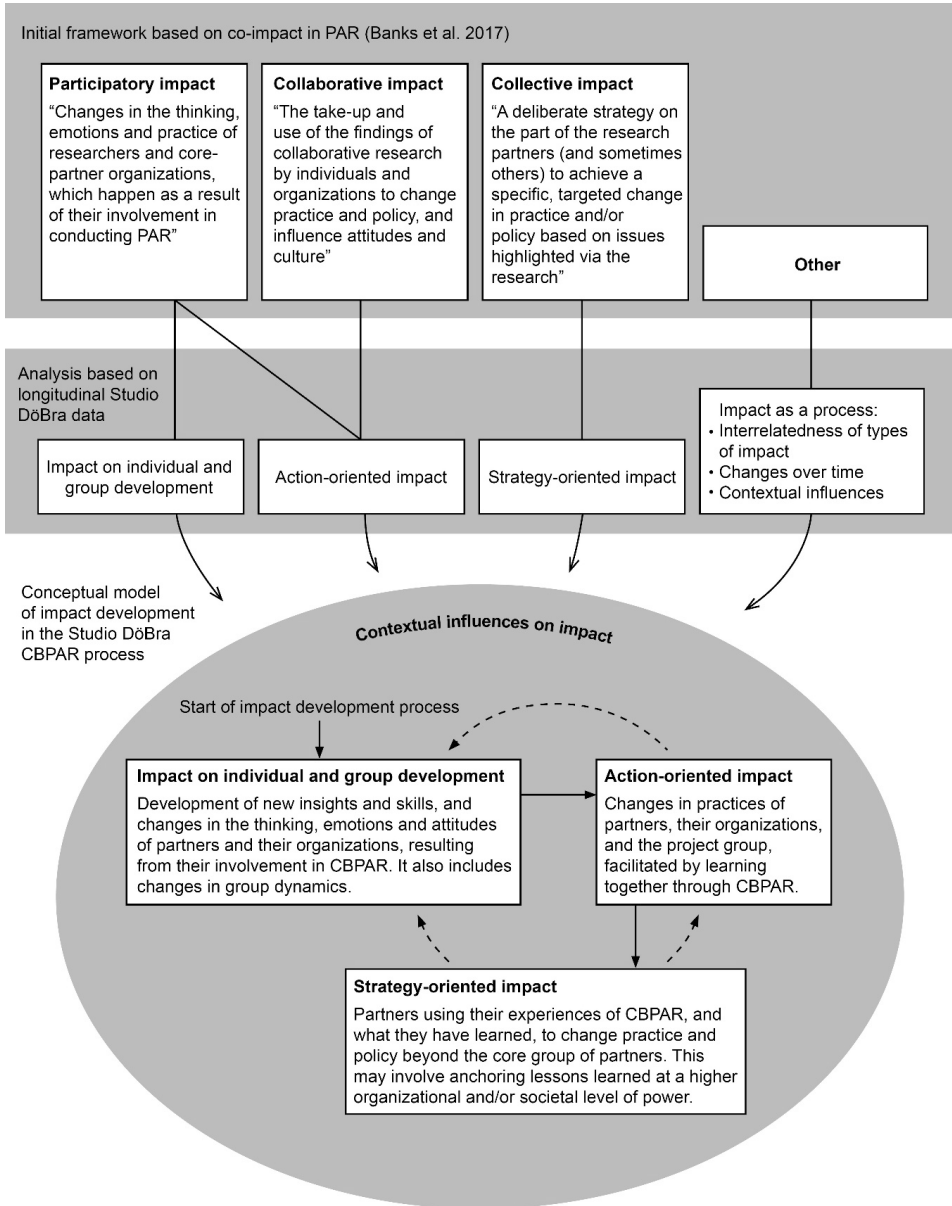
One aim of PAR is to bring about meaningful change for those involved (Israel et al., 2017; Kemmis & McTaggart, 2005). Conceptualizations of impact in PAR contribute to an understanding of how such changes occur (Abma et al., 2017; Banks et al., 2017; Cook et al., 2017; Greenhalgh, Jackson, et al., 2016; Trickett & Beehler, 2017). Banks et al.'s (2017) conceptualization of “co-impact” was the initial basis of the analysis presented in this article. This conceptualization describes three types of co-impact, i.e., participatory impact, collaborative impact, and collective impact, as illustrated with definitions in Figure 4. Throughout the Studio DöBra CBPAR process I had generated data, with which to investigate the impact of Studio DöBra for partners, both on personal and organizational level. The longitudinal nature of this dataset, which had been generated over 4.5 years (Figure 2) allowed investigation of impact development through time (Saldaña, 2003).

The aim of this article is therefore to investigate impact as both process and product in the Studio DöBra CBPAR process. In doing so we seek to contribute to conceptualizations of impact in PAR. Furthermore, we address a need for research investigating impact of health promoting initiatives to increase community engagement with EoL-issues (Collins et al., 2020; Sallnow et al., 2016).

I led analysis in a process inspired by a framework analysis approach as described by Ritchie and Spencer (1994), with repeated discussions with co-authors. Community-partners provided feedback at the end. After familiarization with the data, this approach involves the conceptualization of a thematic framework based on a priori issues from e.g., literature and early ideas about the data (Ritchie & Spencer, 1994). This framework is then further developed through a process of coding and interpretation (Ritchie & Spencer, 1994). This provided guidance for our use of existing theories to support empirical investigation and further development of these theories.

With help of NVivo software, I structured the data chronologically and created a coding framework based on Banks et al.'s theory of co-impact, as illustrated in Figure 4. I added an additional code (“other”) for relevant data which did not fit into the existing codes. As I coded data, I wrote memos, focusing on connections between codes and changes over time. Through this process I found that Banks et al.'s different types of impact could overlap, and their development was interrelated in our data. Furthermore, contextual influences affected impact development in Studio DöBra. We therefore further developed Banks et al.'s conceptualization iteratively, adjusting and clarifying definitions of different types of impact, as well as identifying how the processes of their development related to each other. In doing so we conceptualized a model of impact development in Studio DöBra, based on impact as both process and product, as illustrated in Figure 4.

Figure 4. Schematic visualization of the analysis process and conceptual model of impact development in the Studio DöBra CBPAR process



*Note.* In the conceptual model, arrows represent impact as a process. Solid arrows show the order in which types of impact were developed over time. Dotted lines show the feedback loop which made interrelatedness reciprocal.



## 4.9.2 Summary of findings

The conceptual model describes impact both as process and product. It distinguishes three types of impact, i.e., impact on individual and group development, action-oriented impact, and strategy-oriented impact, as illustrated with the definitions in Figure 4. Table 5 summarizes findings in relation to impact as product for Studio DöBra community-partners.

Table 5. Summary of impacts for Studio DöBra community-partners

Impact on individual and group development	Action-oriented impact	Strategy-oriented impact
<ul style="list-style-type: none"> <li>- Meaningful connections and interactions among partners and participants</li> <li>- Developing interest, confidence, and skills in relation to issues raised in Studio DöBra:               <ul style="list-style-type: none"> <li>o Supporting intergenerational interactions</li> <li>o Supporting engagement with EoL-issues</li> <li>o Using arts activities to facilitate this</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>- Changes in practice within Studio DöBra:               <ul style="list-style-type: none"> <li>o Partners continuously applying lessons learned in following arts workshops</li> <li>o MK transferring lessons learned from Skärholmen to Halmstad</li> <li>o Partners applying lessons learned in developing the Toolbox</li> <li>o Shift from academic partner MK as initiator to initiatives driven by community-partners</li> </ul> </li> <li>- Changes in practice outside Studio DöBra:               <ul style="list-style-type: none"> <li>o Partners creating spaces for intergenerational interaction and engagement with EoL-issues in their own professional practices and social networks</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>- Studio DöBra Halmstad, as it involved new partners</li> <li>- Studio DöBra Toolbox               <ul style="list-style-type: none"> <li>o Anchoring lessons learned with management and local politicians</li> <li>o Disseminating knowledge</li> <li>o Spinoff projects</li> </ul> </li> <li>- Partners facilitating knowledge exchange sessions beyond the partner group (e.g., workshops and presentations)</li> </ul>

Impact as a process relates to the ways in which impact was developed in Studio DöBra. We found that the impact development process began with impact on individual and group development which in turn informed action-oriented impact, as illustrated by the producer of cultural activities who commented in the follow-up interview:

*Something I found very interesting and important in the project, in the first phase, was that we quickly began to talk about... or ransacked ourselves a bit, and tried to think about our own personal experiences of the issues that the project deals with, so death and loss, and people living close to death [...] So we talked quite a lot about that, and that was something which we tried to bring with us into the project.*

The relationship between the processes of developing impact on individual and group development and action-oriented impact is reciprocal, as they are inextricably related, a result from the iterative and interactive action and reflection in the Studio DöBra CBPAR process, as described throughout this chapter. Contextual influences that facilitated or hindered this reciprocal relationship related to organizations' structure and partners' professional mandate.

Partners began developing strategy-oriented impact after they had established action-oriented impact, meaning that partners changed their own practice after which they began to change practice and policy beyond the core partner group and anchor lessons learned at a higher power level. There was a reciprocal relationship between strategy-oriented impact and the other two types of impact. Support from a higher level of power was found to be a contextual factor supporting strategy-oriented impact. However, the prevailing societal notion that valid knowledge is developed in academic institutions, limited community-partners in anchoring lessons learned on higher power levels as illustrated by the Halmstad activity manager:

*I've thought a lot about what [decision makers] rely on when they make decisions, and what type of research results [...] It's like that in society in general [...] that people want to see statistics and percentages [...] And that people don't consider quality more. [...] That's why it's very good to be able to rely on... well that I have a researcher who backs this up [...] [I] notice that when [I] mention [names the academic medical faculty] people take it more seriously.*

The illustration of our model implies that, in theory, once impact development starts, it continues indefinitely. However, in practice this appears to depend on contextual factors, e.g., support from decision makers, (dis)continuity of management, possibilities within job descriptions, resources, dependency on personal engagement, and limitations posed by the COVID-19 pandemic. One facilitating factor for continued impact development was found to be ongoing academic-community partnerships.

## 5 DISCUSSION

In the previous chapter I gave a reflective account of the CBPAR process, weaving together methods and findings. In this chapter, I begin with a summary of findings for clarity.

### 5.1 SUMMARY OF FINDINGS IN RELATION TO RESEARCH QUESTIONS

#### 1. How can community and academic partners develop Studio DöBra or similar initiatives to support engagement with EoL-issues and/or intergenerational interaction? (I, IV)

Partners negotiated various power dynamics to develop Studio DöBra and similar initiatives (I):

##### *Power dynamics among people of different ages*

Neither children nor older adults were involved in developing any of the initiatives investigated in the exploratory interviews, nor in Studio DöBra Skärholmen. Those developing and facilitating the initiatives—the “adults-in-between” the children and older adults—have power over and felt responsibility for people in these age-groups (I). This could lead adults-in-between to deliberately or unwittingly facilitate or hinder participants’ engagement with EoL-issues (I). Based on these findings, partners in Halmstad made efforts to include participants in developing Studio DöBra Halmstad. Studio DöBra partners developed a collective reflective practice through which they dealt with age-related power dynamics and discussed personal EoL-related experiences, questions, and beliefs (I, IV). This practice informed development and facilitation of Studio DöBra, i.e., reflective practice led to individual and group development, which in turn led to action-oriented impact (I, IV).

##### *Power dynamics among partners*

While those who developed and facilitated the investigated initiatives were supported by their jobs to do so, they had different mandates and degrees of self-determination (I, IV). This could lead to frictions in relation to roles, responsibilities, and investment of resources, which could affect sense of ownership (I). Among Studio DöBra partners, roles were largely based on professional mandates, and investing resources appeared to increase sense of ownership (I). Power dynamics among partners shifted throughout the CBPAR process: I had a leading role as initiator in the first iteration (I, IV), community-partners took a leading role in the second iteration with me as invited partner, and the development of the Studio DöBra Toolbox and spinoff projects were community-partner driven (IV). These shifts indicated individual and group development and action-oriented impact, as partners increased their interest, confidence, and skills through cycles of action and reflection during the 4.5 years following the initiation of the first partnerships in Skärholmen (IV).

**2. How do children and older adults motivate their participation in Studio DöBra? How do they reflect on their experiences of participation and ways in which they were affected by their participation? How do children's parents reflect on their child's participation? (II)**

*Motivation to participate*

Some participants talked about EoL-topics as motivating participation, also relating this to personal EoL-related experiences. Children were generally curious about the topic, whereas some older adults referred to lacking spaces for talking about these issues and/or wanting to help make speaking about death a normal part of life. Lack of intergenerational contact was described by both children and older adults, as well as parents, as a motivating factor. Some older adults were motivated by a desire for social connections and activities, to counteract an increasing feeling of loneliness.

*Experiences of participation*

Studio DöBra appeared to be a space in which participants were able to modulate their own engagement with EoL-issues through arts activities. Some older participants talked about feeling responsible for the participating children and taking a facilitating role. Participants seemed to bond across generations through reciprocal interaction. Parents of some children talked about the pride their child felt in participating, while some older adults talked about participation as a privilege. Participants seemed to appreciate learning about how the participants from the other age-group as well as their peers reflected on EoL-issues. Some parents reflected on the benefits of learning about older participants' perspectives on the EoL, either directly or through their child, and having learned that they can talk with their child about EoL-issues. Participants seemed to also create spaces for EoL-conversations in their social networks.

*Ways in which participants were affected by participation*

Participants seemed to bond as individuals across age-groups. Some older adults appeared to reassume past identities in intergenerational interaction. Some participants continued to meet in the neighborhood after Studio DöBra. Some older participants had continued contact with partners, with some in Skärholmen talking about having gotten involved in new social activities as they participated in other projects hosted by the artistic organization. These findings may indicate a changing sense of community. Both children and older adults wanted to maintain these new connections but indicated lacking agency to do so. Furthermore, some older adults were unsure as to whether the children would want to continue to meet with them, while similar doubts were not expressed by children.

**3. How can arts activities support community engagement with EoL-issues? What role can facilitation have in these arts activities? (I, II, III)**

While not all partners had arts backgrounds, those who did in Studio DöBra and in initiatives that shared characteristics with Studio DöBra, had backgrounds in visual arts, sculpture, theatre, music, design, and arts education, and applied these in their initiative's arts activities

(I, III). Partners denoted challenges in developing and facilitating arts activities to engage children and older adults in EoL-issues, i.e., EoL-issues are potentially sensitive, abstract, personal, and difficult to broach (I, III). The Studio DöBra arts activities seemed to be a space in which children and older adults engaged with EoL-issues on their own terms as they curated what they shared, how they shared, and with whom they shared (II, III). Modified play theory was used to explain four mechanisms in arts activities that support this engagement (III):

1) *Creating permeable magic circles.* The creation of a ‘Studio DöBra magic circle’, i.e., the spatial and temporal boundary separating the Studio DöBra arts workshops from ‘ordinary life’, created a space for intergenerational engagement with EoL-issues (III). This is conceptualized as a permeable boundary through which partners and participants could introduce elements from their ordinary lives into Studio DöBra and vice versa (II, III). Smaller groups of participants seemed to sometimes create magic sub-circles in which they separated from the group and engaged with EoL-issues in their own way (III). However, this could lead to tensions with outsiders to this magic sub-circle. An unresolved challenge for partners was the degree to which they should steer participants’ engagement with EoL-issues (III).

2) *Balancing restrictions and freedoms.* When facilitating, partners balanced restrictions and freedoms in the topics, processes, and products of the arts activities. Imposing restrictions increased partners’ sense of control and enabled participants to explore EoL-issues but risked diminishing their agency and artistic freedom. Too much freedom could leave participants uncertain about their roles and risked failing to initiate engagement with EoL-issues. When restrictions and freedoms seemed well-balanced, participants were independent in the arts activity and engaging with EoL-issues. (III)

3) *Approaching dying, death, and loss through imagination and real-life experiences.* Partners and participants approached EoL-issues through imagination and real-life experiences to deal with the potentially sensitive, abstract, and personal nature of EoL-issues (III). In Skärholmen, partners applied metaphors to call on participants’ imagination to explore EoL-issues, something also used by those facilitating initiatives that shared characteristics with Studio DöBra (I, III). In Halmstad partners approached the EoL-topic head-on by focusing on the life and death of a bird (III). The line between imagination and real-life experience appeared to be blurred in some arts activities (III). Even though the Studio DöBra magic circle could foster various perspectives on EoL-issues, some participants seemed to self-censor when they anticipated that their perspective might be deviant (III).

4) *Continuing a sense of community after ending the arts workshops.* While the temporal and spatial aspects of the Studio DöBra magic circle ended when Studio DöBra iterations ended, there appeared to be indication of a continuing sense of community, as shared experiences and tangible products seemed to bond participants (III). Additionally, some participants continued to meet informally in their neighborhoods (II, III).

#### **4. How can impact in a CBPAR project be conceptualized? What is the impact for community and academic partners of participating in this CBPAR process? (IV)**

##### *A conceptual model of impact development in Studio DöBra*

A conceptual model of impact development in Studio DöBra was developed that distinguishes three types of impact, i.e., impact on individual and group development, action-oriented impact, and strategy-oriented impact. The model describes impact as a process by indicating that these three types of impact evolve from each other, starting with individual and group development. Furthermore, the three types of impact are reciprocally interrelated as one seems to inform the others. The process of impact development seems to be facilitated or hindered by contextual influences, which in the case of Studio DöBra involved organizational structures, partners' professional mandates, support from decision makers, resources, and limitations posed by the COVID-19 pandemic.

##### *Impact for Studio DöBra partners*

- Impact on individual and group development included meaningful connections and interactions among partners and participants and developing interest, confidence, and skills in relation to intergenerational interactions and engagement with EoL-issues through arts activities.
- Action-oriented impact included continuous application of lessons learned throughout the CBPAR process, and partners creating spaces for intergenerational interaction and engagement with EoL-issues in their own professional practices and social networks. It also includes changes in partners' roles, e.g., a shift from me as initiator to initiatives driven by community-partners.
- Strategy-oriented impact included the initiation of Studio DöBra Halmstad, the development and dissemination of the Studio DöBra Toolbox, anchoring lessons learned with management and local politicians, spinoff projects, and knowledge exchange sessions beyond the partner group.

## **5.2 DISCUSSION OF METHODOLOGY, FINDINGS, AND IMPLICATIONS**

In this section I integrate discussion of methodology, findings, and implications of this thesis, as these components have been intrinsically related in this CBPAR process (Bradbury, 2015; Israel et al., 2017; Reason, 2006). This section is structured around key issues and themes in this thesis, i.e., Considerations of relevance beyond Studio DöBra; Participation in the Studio DöBra CBPAR process; Different ways of knowing in Studio DöBra; Creating space for engaging with EoL-issues; Creating space for intergenerational interaction; and Impact and sustainability.

In discussing issues concerning methodology, including strengths and limitations, I draw on Reason's (2006) ideas about quality in action research, and Thorne's (2016) ideas about quality in qualitative research. Reason (2006) delineates four dimensions of action research, which are in line with the CBPAR approach taken in Studio DöBra (Bradbury, 2015; Israel et al., 2017). According to Reason (2006), action research should address worthwhile practical

purposes, be democratic and participative, encompass many ways of knowing, and take place in an emergent process. As these dimensions open a wide range of choices, Reason (2006) argues that quality is achieved through efforts in making choices clear and transparent throughout the research process and in communication with a wider audience. Throughout this thesis I have attempted to be transparent about the choices made throughout the CBPAR process. In this section, I discuss some of these choices in more depth.

Based on the work of various qualitative scholars, Thorne (2016) formulates four general principles for quality in qualitative research, i.e., epistemological integrity, analytic logic, representative credibility, and interpretive authority. Epistemological integrity is about research aims and methodology being consistent with assumptions made about ways of knowing. Analytic logic refers to transparency about decisions made throughout the analytic process. Representative credibility means that a study's theoretical claims are consistent with the manner the phenomenon was sampled. Interpretive authority refers to the trustworthiness of the researchers' interpretations, e.g., in dealing with researcher bias and claims about the generalizability of findings (Thorne, 2016). In the articles, efforts were made to demonstrate these four principles of quality, e.g., through a description of the analytic process and by illustrating findings with examples from the data. In this section I discuss some of these issues in more depth.

Navigating and changing power dynamics are a theme throughout the findings. Particularly power dynamics among people of different ages, among partners, and in impact development, have been identified. In discussing findings related to power, I draw from ideas about power in PAR as described by Gaventa and Cornwall (2015). They view power and knowledge as related, arguing that communities may empower themselves through their involvement in knowledge development. Gaventa and Cornwall (2015) characterize one power dynamic as a "power over" relationship between actors, in those with relatively more power determine what knowledge is valid and which voices are included in knowledge development. Another power dynamic is characterized as "power to act", which develops within oneself without implying a limitation of power in others (Gaventa & Cornwall, 2015). Furthermore, "power to act in concert with others" is gained through interaction and partnership (Gaventa & Cornwall, 2015). Gaventa and Cornwall (2015) further argue that power to act and power to act in concert with others are fundamental for social change.

### **5.2.1 Considerations of relevance beyond Studio DöBra**

In this section I discuss overall methodological strengths and limitations that should be taken into account when considering relevance of findings beyond Studio DöBra. One strength of this thesis is that it is based on data from two Studio DöBra iterations in socioeconomically and culturally different communities in Sweden. Furthermore, Article I is also based on exploratory interviews with professionals involved in seven different initiatives in Sweden and the UK, that share characteristics with Studio DöBra. This broadens the project's relevance and contributes to the relevance of findings for other contexts (Polit & Beck, 2010). However, a characteristic of the CBPAR methodology is that findings are intrinsically

context specific, which may lead to limitations in directly trying to apply processes and findings in other settings. I have therefore tried to provide enough detail for others to be able to draw conclusions about the relevance and applicability of findings to their different contexts (Polit & Beck, 2010). Furthermore, cultural differences should be taken into account when considering the transferability of findings in different contexts, e.g., in relation to engaging with EoL-issues and intergenerational interaction.

Another strength of this CBPAR process is that nearly all participants and parents participated in follow-up interviews, and that all community-partners with a professional mandate to do so, continued to participate throughout the several years of this CBPAR process. However, it should be pointed out that, while participants were generally positive about their participation in Studio DöBra, participation was voluntary with no data allowing investigation of the motivations of those invited children and older adults who chose not to participate. There is also no data about how many children or older adults were invited but did not agree to participate.

The process of inviting children and older adults to Studio DöBra (Table 3) affected who was invited and who was not, which should be considered in interpreting findings. Children and older adults were invited through the community organizations with which they had contact. Thus, children and older adults who were not part of these organizations were not invited. This may have played a relatively minor role for inclusion of children, as they were invited through after-school centers which are attended by a large majority of children. In 2016, 94.7% of 6-9-year-olds in Stockholm attended after-school centers (Skolverket, 2021). However, while this may differ by city district, I was unable to find statistics about Skärholmen. In 2018 81.9% of 6-9-year-olds in Halmstad attended after-school centers (Skolverket, 2021).

However, our strategies for inviting older adults did play an important role for the inclusion of older adults. Community organizations in both Skärholmen and Halmstad spoke about challenges in engaging men and older adults with diverse ethnic backgrounds, which is reflected in the backgrounds of the older adults participating in Studio DöBra. Additionally, partners in both Skärholmen and Halmstad noted that the older participants appeared to be socially relatively well-connected and physically mobile, and discussed that this may be due to the ways we invited older adults, but also due to the nature of Studio DöBra which required a level of mobility to participate. This may have led to an exclusion of older adults who are socially less connected and/or less mobile due to health issues.

Different forms of triangulation increased representative credibility and interpretive authority (Thorne, 2016). Triangulation of forms of qualitative data, e.g., interviews, documentation from planning/reflective meetings, and field notes, and triangulation of perspectives, e.g., from participants, parents and partners, provided a broad range of different insights for analysis. Triangulation of investigators (Reeves et al., 2008) helped in dealing with researcher bias. Although I led the analysis processes underlying all four articles, co-authors are researchers not directly involved in Studio DöBra. Our regular discussions facilitated critical



reflection on my role and biases and also provided a range of complementary perspectives on the data. As discussed throughout the thesis, my reflective practice and the collective reflective practice with partners also facilitated critical discussions about partners' roles. One possible limitation is that community partners were not extensively involved in analysis of research findings. Issues related to participation of community-partners, participants, and parents are discussed in the following section.

### **5.2.2 Participation in the Studio DöBra CBPAR process**

The purpose of participation in CBPAR is to facilitate a process of self-empowerment by collaboratively developing knowledge that is of use and of value to those involved as discussed in Chapter 3 (Cornwall, 2008; Israel et al., 2017). Thus, as pointed out by Stoecker (1999), PAR is not only a research endeavor, "it is a community organizing and/or development project of which the research is only one piece." In this section I therefore discuss who participated in what, and how participation changed throughout the CBPAR process.

When I decided to partner with community organizations, I had anticipated that older adults, children, and their parents would participate in research activities on a consultation basis, to use Baum's (2016b) term as discussed in Chapter 3. In practice this meant that findings from follow-up interviews with participants and parents was used by partners to inform development of Studio DöBra Halmstad and the Toolbox. While children and older adults were not involved in developing Studio DöBra Skärholmen, partners in Halmstad made efforts to involve participants in developing the content of Studio DöBra through a workshop prior to the first arts workshop. However, in follow-up interviews, some participants spoke about this meeting as the start of Studio DöBra Halmstad rather than as a means of contributing to its development. Thus, it is unclear if children and older adults saw themselves as having any role in developing the content of Studio DöBra.

As noted, partners' participation in the CBPAR process was to a large extent found to be determined by their professional mandate and interest (I, IV). Furthermore, as the only academic partner, I was able to participate on a full-time basis through my position as doctoral student, while community-partners participated in parallel with their usual practices. In general terms, the change in the type of participation of those community-partners who continued to be involved throughout the whole CBPAR process can be described as a shift from substantive forms of participation to more structural forms of participation (Baum, 2016b).

In substantive participation, the initiative comes from an outsider and the community is involved in planning, development, and implementation (Baum, 2016b). This was the case in Skärholmen where I initiated partnerships, and it is thus not surprising that community-partners perceived me as having most ownership (I). However, to a large degree, community-partners determined the setup of Studio DöBra, the process of inviting participants, the content of the arts workshops, and also led facilitation of Studio DöBra. In structural

participation the community is the driving force (Baum, 2016b), which was the case in Halmstad where community-partners initiated partnerships. As academic partner I participated in planning, development, and facilitation of Studio DöBra. Community-partners' participation in the Toolbox development can also be considered structural participation as they drove that initiative, particularly in relation to the development of a physical toolbox in addition to the online toolbox and the initiation of spinoff projects (IV).

As community-partners' participation became more structural over the course of the CBPAR process, my participation became more substantive. This partly relates to the agency and constraints of being a doctoral student. During the Toolbox process I realized that Studio DöBra developed in ways that were beyond my doctoral project. Furthermore, although partner's spinoff projects are not part of this thesis, it is worth noting that my participation in these projects has shifted towards consultation (Baum, 2016b; Stoecker, 1999).

Community-partners together with me, as academic partner, developed knowledge through action and reflection, integrating academic and community ways of knowing. I was responsible for the academic side of the research process, with community-partners' participation in this process being based on their own interests, mandates and available resources in terms of time and funding. These factors contributed to community-partners' limited involvement in data analysis. The limited involvement of community-partners in research analysis underlying articles that include data derived from their perspectives (I, III, IV) can be considered a limitation, as this risks favoring an academic perspective. Furthermore, community-partners were not involved in writing the articles in this thesis as writing articles for primarily academic audiences was neither within their interest nor their professional mandates. Instead, community-partners and I together communicated findings to audiences that are relevant to their organizations and in manners more in line with their practices, for example through the Studio DöBra Toolbox and the physical toolbox.

#### 5.2.2.1 *Considering the goals of Studio DöBra*

Reason (2006) argues that partners need to continuously review what worthwhile practical purposes they are pursuing, as they are likely to change over time and might vary among partners. The question of what a worthwhile purpose is, raises issues related to power, as it is necessary to consider who defines what is worthwhile. The purposes of Studio DöBra are articulated in its goals, i.e., engaging communities in EoL-issues and supporting intergenerational interaction. As discussed in the background, the goals of Studio DöBra are based on theories and prior research, rather than on explicitly expressed needs and wishes from communities.

I initially defined goals for Studio DöBra in broad terms and intended for them to be adapted based on lessons learned throughout the CBPAR process. Whereas in the beginning, one of the goals was formulated in terms of supporting *conversations* about EoL-issues, it evolved to focus on *engagement* with EoL-issues, to encompass the variety of ways partners and participants explored EoL-issues in Studio DöBra, e.g., doing, making, and using imagination

and real-life experiences (II, III). Additionally, as noted in the background, EoL-issues in the goals of Studio DöBra were defined broadly to include any topic, question, experience, etc. relating to dying, death, and loss. The value of this broad definition was reconfirmed during Studio DöBra, as I noted that participants modulated their own engagement with EoL-issues and also raised forms of loss not related to death (II, III). Furthermore, initially, the term *intergenerational* in the Studio DöBra goals referred to the interaction between children and older adults. However, we soon found that partners played an important role in facilitating this interaction (I, IV). Moreover, partners also talked about having had meaningful interactions with participants, and vice versa (II, IV). Therefore, the goal to support intergenerational interaction developed to also include partners, referred to as the adults-in-between the children and older adults in Article I.

Rather than investigating predetermined outcomes, the overall research aim and questions steering this thesis are process focused on the perspectives of those involved in Studio DöBra. This facilitated an ongoing investigation of what partners and participants found “worthwhile” in Studio DöBra (Reason, 2006). As noted, partners and participants had diverse motivations to be a part of Studio DöBra (I, II, IV). While motivations to participate were different, they seemed to be able to co-exist in Studio DöBra. Furthermore, as community-partners became driving forces in developing toolboxes, spinoff projects, and their professional practices, they formulated their own varying purposes, e.g., some focused on supporting intergenerational interaction while others focused more on supporting engagement with EoL-issues (IV). This implies that a sense of ownership among community-partners increased throughout the CBPAR process.

#### 5.2.2.2 *Reflective practice*

Partners’ collective reflective practice facilitated learning from our actions and informing further actions, referred to as communicative action (Kemmis & McTaggart, 2005; Reason, 2006; Wicks & Reason, 2009). Communicative action allows partners “to consciously and deliberately reach intersubjective agreement as the basis for mutual understanding about what to do in their particular practical situation” (Ahlberg et al., 2015). Additionally, our reflective practice helped us to develop our roles and negotiate participation (Israel et al., 2017). Furthermore, it supported us in dealing with experiences related to the topics of this thesis, i.e., aging, dying, death, and loss (Thorne, 2016; Visser, 2017).

Thorne (2016) states that reflective practice is commonly referred to in qualitative research as a means to improve its quality. However, what this practice actually entails differs by situation, as researchers need to develop practices that are relevant for them in relation to their research context and topics (Thorne, 2016). Throughout this CBPAR process, my personal reflective practice entailed keeping a research journal in which I documented my reflections after each action/data generation occasion (e.g., planning meetings, arts workshops, interviews), and throughout analysis. In the articles, I referred to this form of reflection throughout analysis as memo writing. I also kept a personal journal in which I documented ways in which engaging with aging, dying, death, and loss affected me more

personally. The collective reflective practice with partners, as well as discussions with supervisors/co-authors informed this CBPAR process and my development as a researcher.

### 5.2.2.3 *Participation and confidentiality*

As participation is central in PAR approaches, confidentiality in presentations of research findings is not always possible and/or desirable and therefore needs to be negotiated per situation (Kalsem, 2019). In this CBPAR endeavor, as community-partners did not co-author articles, I therefore made an initial decision to maintain their confidentiality by omitting names and other personal details after consulting community-partners about this.

Community-partners themselves presented research findings through presentations and workshops for the general public, their colleagues, management, and politicians—sometimes together with me. Furthermore, community-partners co-authored the Studio DöBra Toolbox as well as a poster presentation of the Toolbox development, which was presented at the 6<sup>th</sup> National Palliative Care Conference in Sweden in early 2020. In these presentations, partners determined how they presented themselves and the research findings.

However, this means that full anonymity in Studio DöBra is not possible. Therefore, I tried to avoid revealing potentially sensitive information in the articles, e.g., data from partners' conversations about personal EoL-related experiences. Based on the wishes of community-partners, I acknowledge them by name in this thesis framework. Children, older adults, and parents participated in the CBPAR process on a consultation basis (Baum, 2016b) and thus did not have agency to represent themselves in presentations of research findings. The children's teachers and the after-school centers are not acknowledged by name to maintain participants' confidentiality.

## 5.2.3 **Different ways of knowing in Studio DöBra**

It is argued that in PAR and transdisciplinary inquiries, partners need to be open to a multiplicity of ways of knowing, integrating various epistemologies in the pursuit of democratic knowledge creation (Bradbury, 2015; Coleman, 2015; Reason, 2006; Stoecker, 1999; Wallerstein & Duran, 2017). CBPAR principles express this as co-learning, and point to the importance of building on strengths and resources within the community, which include different forms of community-based knowledge and ways of knowing (Israel et al., 2017).

In an effort to explain and understand this complex interaction of epistemologies, Heron and Reason (2008) proposed an extended epistemology with four ways of knowing. 1)

*Experiential knowing* is “my direct acquaintance with that which I meet in my lifeworld”, a

tacit and pre-verbal form of knowing (Heron & Reason, 2008, p. 367). 2) *Presentational*

*knowing* expresses experiential knowing through e.g., imagery, music, movement, drama, and

storytelling. 3) *Propositional knowing* is “knowing ‘about’ something in intellectual terms of

ideas and theories” and is articulated through language (Heron & Reason, 2008, p. 373). 4)

*Practical knowing* is knowing how-to-do a certain action or practice.

Heron and Reason (2008) propose that these types of knowing occur in a hierarchy, assuming that all knowing is based on interaction and experience, through which presentational knowing emerges, after which propositional knowing provides theoretical insights, and in turn informs action leading to practical knowing. Furthermore, they argue that practical knowing can inform experiential knowing, thereby forming a positive spiral of ways of knowing, building on each other in line with cycles of action and reflection (Bradbury, 2015; Heron & Reason, 2008).

In this thesis I share Heron and Reason's (2008) perspective, which is that knowing "is based in the *experiential presence* of persons in their world" (p. 367). This experiential knowing is expressed in presentational knowing in various ways in Studio DöBra. In the arts workshops, partners and participants seemed to express experiential knowing in relation to EoL-issues through the processes and products of the arts activities. Although arts activities were used in Studio DöBra to offer alternative modes of engaging with EoL-issues rather than relying on words alone, the qualitative research methods I used to investigate Studio DöBra relied predominantly on verbal forms of presentational knowing, e.g., interviews, conversations, meetings, as well as written field notes. As I discussed in the previous chapter, I found that this limited investigation of experiential knowing.

As the academic partner it was my role to facilitate moments of reflection, e.g., in reflective meetings and interviews. These moments of reflection contributed to the development of propositional knowing, which in turn informed action and further reflection in a cyclic manner. Heron and Reason (2008) point out that in this way, propositional knowing is "rooted back in experiential knowing" (p. 374).

Practical knowing in Studio DöBra may be seen e.g., in the confidence and skills partners gained to develop and facilitate intergenerational arts activities to support engagement with EoL-issues (IV). Several attempts were made to communicate this practical knowledge beyond the partner group. In Article III, empirical data, theory, and language were used to communicate practical knowing in a propositional manner. The physical toolbox made by the artists from Skärholmen used design to communicate practical knowledge, which was in line with community-partners' practices. In designing this toolbox, the artists literally gave form to practical knowing with the aim of transferring knowledge to toolbox users. This raises the question as to where the physical toolbox fits in terms of the four ways of knowing. In its form it is perhaps closer to a presentational expression of knowing rather than propositional, as it uses design rather than language to communicate knowledge. However, Heron and Reason (2008) define presentational knowing as a further development from experiential knowing, while the physical toolbox seems to derive from practical knowing. Furthermore, it intends to inform the experience of its users, and thereby their experiential knowing. This illustrates a problem with Heron and Reason's (2008) description of different forms of knowing developing from each other in a hierarchical manner. Perhaps the different forms of knowing were more intertwined in Studio DöBra. However, further research would be needed to investigate the relationships between different forms of knowing in Studio DöBra.

As discussed in Chapter 3, PAR approaches aim to build a two-way bridge between academia and communities to facilitate exchange and interaction as they participate in one another's practices (Greenhalgh, Jackson, et al., 2016). On this metaphorical bridge, the articles and this thesis are knowledge products which stand closer to academia and propositional ways of knowing. The Studio DöBra toolboxes, workshops, and presentations for the general public are, on the other hand, examples of knowledge products which stand closer to the community-partners and ways of knowing that are in line with their practices (IV).

An overall goal of this thesis is to develop knowledge of use and value to both academic and community-partners. I have tried to demonstrate epistemological integrity (Thorne, 2016) by choosing different qualitative research methods in the respective articles which are in line with this overall goal. Methods for data analysis in articles I and II were inspired by interpretive description which aims to develop knowledge for practice (Thorne, 2016). In articles III and IV, theory was used in data analysis to build further on existing theory. Theory here is used in line with Tavory and Timmermans' (2014) definition of theory as "any form of generalization about observations that provides a potentially useful insight about the world. *Useful* means that the theory extends its potential to future actions and understandings" (p. 42).

Heron and Reason (2008) argue that propositional knowing is the kind of knowing that is the most accepted form of knowledge in Western societies today. This is illustrated by the difficulties community-partners had in anchoring lessons learned with managers and politicians, who were described as valuing propositional knowledge developed in academic institutions more than practical knowledge, in contrast with Heron and Reason's (2008) hierarchy (IV). While PAR aims to democratize knowledge development, this finding exemplifies that systemic and cultural changes need to occur at higher levels of power for a combination of ways of knowing to be seen as a strength, rather than a limitation (Askheim, 2020).

#### **5.2.4 Creating spaces for engaging with EoL-issues**

With this thesis, I hope to contribute to the relatively young but growing field of health promotion in relation to EoL-issues. As this field is dominated by initiatives initiated by or linked to healthcare institutions (Collins et al., 2020; Sallnow et al., 2016), one way this thesis contributes is with findings from a community-based initiative without healthcare institutional involvement. The ways in which power dynamics were navigated to involve communities in EoL-issues, based on both Studio DöBra and seven other initiatives in Sweden and the UK, has the potential to inform practice in other health promoting palliative care and compassionate community initiatives (Abel et al., 2013; Horsfall et al., 2020; Kellehear, 2019).

As discussed in the background, research about supporting EoL-conversations through arts activities often derives from healthcare, therapy, or community settings with ill or bereaved individuals (Hartley & Payne, 2008; la Cour et al., 2007; Tsiris et al., 2011). This thesis

contributes with findings from a community-based initiative which deliberately involved participants who were not imminently dying, to support early engagement with EoL-issues. More specifically, this thesis contributes with insights into mechanisms in community-based arts activities supporting intergenerational engagement with EoL-issues. These findings can contribute to theory building that can inform future arts activities to support community engagement with these issues.

Based on partners' observation of play elements in Studio DöBra arts activities, play theory was used to explore these mechanisms. However, participants did not use the term play as they reflected on Studio DöBra in follow-up interviews. It is therefore important to recognize that the Studio DöBra arts activities are not conceptualized *as* play, but that play theory was instead used to explore mechanisms in the arts activities. Furthermore, partners spoke about being surprised about what they referred to as the older participants' "child-like playfulness" in some arts activities. Partners wondered if this may have been catalyzed by their interaction with children. Hamayon (2016) argues that play in Western cultures is commonly seen as restricted to childhood and adult leisure. Thus, partners' interpretation of older participants' play is likely to be influenced by these cultural norms. This also indicates that cultural norms related to play need to be taken into account when considering transferability of findings regarding mechanisms in arts activities to support engagement with EoL-issues.

Further research may consider investigating ways in which these mechanisms function in different contexts, cultures and with different groups. Such research could apply these mechanisms in developing and facilitating arts activities to support community engagement with EoL-issues through a PAR process. Additionally, further research may draw from additional theories, such as contact theory which describes conditions of intergroup interaction (Kuehne & Melville, 2014; Pettigrew & Tropp, 2006) and theory about sense of community (McMillan, 1996). Future research and practice might beneficially also further explore the role of the facilitators of arts activities supporting engagement with EoL-issues. In Studio DöBra for example, one unresolved question was to what extent partners should steer intergenerational engagement with EoL-issues.

Another unresolved question, which was brought up repeatedly among partners and in conversations with supervisors/co-authors throughout the CBPAR process, is how much talk about EoL-issues is enough? However, while talking was part of engaging with EoL-issues in Studio DöBra, partners and participants also engaged through acting, doing, and making, using both imagination and real-life experiences (II, III), to offer alternative modes of expression (Hartley & Payne, 2008; Nan, Pang, et al., 2018; Tsiris et al., 2011; Walter, 2012). Therefore, only focusing on *talking* fails to consider these other ways of engaging.

Furthermore, there may be a problem in the way this question is posed. During Studio DöBra Skärholmen and analysis for Article I, partners, supervisor/co-authors, and I, began to understand ways in which partners' position of power over participants as the adults-in-between (Gaventa & Cornwall, 2015) influenced participants' engagement with EoL-issues. Partners could facilitate participants' engagement with EoL-issues, or hinder it by avoiding,

blocking, or silencing engagement (I). Thus, another way to frame this question is to focus on the agency participants had as individuals to determine what enough EoL-engagement is for them.

Participants were found to modulate their own engagement with EoL-issues and could create spaces within the arts activities to engage with them in their own ways (II, III). This agency can be interpreted as a form of power to act (Gaventa & Cornwall, 2015). However, this was to a large extent influenced by partners who tried to balance restrictions and freedoms in the arts activities to create the opportunity for participants to engage with EoL-issues, while also gaining a sense of control over the way participants engaged with EoL-issues (III). This can be seen as a form of reinforcing a power over relationship between partners and participants (Gaventa & Cornwall, 2015). Thus, although to a certain level, participants had agency in determining what enough EoL-engagement is for them by modulating their engagement, it is important to recognize the power partners had in creating space for this engagement in the first place.

#### *5.2.4.1 The Studio DöBra magic circle, providing time, space, and permission to engage with EoL-issues*

Studio DöBra arts activities seemed to provide a space for partners and participants to engage with EoL-issues (II, III). Conceptualization of a Studio DöBra magic circle helped to further understand how this space was created. The Studio DöBra magic circle is the spatial and temporal boundary separating the arts activities from ordinary life (III). This seemed to be a permeable boundary as partners and participants could introduce elements from their ordinary lives into Studio DöBra and vice versa. Inside this magic circle, different norms seemed to apply as partners and participants interacted across generations and engaged with EoL-issues in ways they would not in their ordinary lives (II, III). This appeared to be made possible by a common understanding that the aim of the arts activities was to support intergenerational engagement with EoL-issues. Thus, by entering the magic circle, partners and participants not only created space for engaging with EoL-issues, but also gained permission to do so.

The notion of a Studio DöBra magic circle can be helpful in understanding ways in which space is created for engagement with EoL-issues in other parts of this CBPAR process as well. Interviews can be seen as taking place within a magic circle which provided partners, participants, and parents with time, space, and permission to engage with EoL-issues. Although I held interviews in conversational form, they differ from conversations in ordinary life as they are e.g., audio recorded, confidential, about pre-determined and agreed upon topics, and with a distinction between interviewer and interviewee roles. Similarly, partners' collective reflective practice also seemed to create a magic circle in which we had time, space, and permission to engage with EoL-issues.

The idea of the Studio DöBra magic circle may also help to understand ways in which other health promoting initiatives provide time, space, and permission to engage with EoL-issues in different contexts. To exemplify this, I consider other projects under the umbrella of the



DöBra research program. Kroik et al. (2020) investigated ways in which Sámi, an indigenous people from Sweden, Norway, Finland, and Russia, deal with EoL-issues. To create space for participants to share stories related to dying, death, and loss, Kroik et al. (2020) conducted walk-and-talk focus groups “outdoors, in settings familiar and with significance to reindeer herding Sámi”. In doing so they created what could be seen as a magic circle providing time, space, and permission to share stories related to EoL-issues. In three other DöBra research projects, a deck of cards, the DöBra cards, has been used as a tool to support and structure conversations about values and preferences for EoL-care, both in interviews with community-dwelling older adults (Eneslätt et al., 2020), with elder-care staff in workshops to promote EoL communication (Johansson, 2021), and with Sámi participants at different cultural events (Kroik et al., 2021). The DöBra cards contain statements about what might be considered important at the EoL, which the person using the cards sorts based on their personal values and preferences (Eneslätt et al., 2020; Johansson, 2021). The process of sorting the cards may be seen as creating a magic circle providing time, space, and permission to engage with EoL-issues. Furthermore, as part of the DöBra research program several so called DöBra cafés have been held, often in conjunction with a larger event and in collaboration with other organizations. These DöBra cafés are time-limited events where participants, often from the general public, are invited to discuss questions related to dying, death, and loss in a world café format (The World Café, 2021). In doing so they create a magic circle in which participants have time, space, and permission to engage with EoL-issues.

#### *5.2.4.2 Informal death education*

Participants spoke about having learned from each other’s perspectives on EoL-issues through arts activities (II). Thus, Studio DöBra can be considered as a form of informal death education in line with its’ definition as based on the sharing of EoL-related experiences (Corr & Corr, 2003; Doka, 2015; Noonan et al., 2016). However, in Studio DöBra, participants not only shared EoL-related experiences, but also explored issues related to dying, death, and loss through their use of imagination in arts activities (III). As discussed above, participants had a certain agency in modulating their engagement with EoL-issues in the arts activities. Thus, one value of this form of informal death education can be that learning is guided by individual backgrounds and motivations, rather than pre-defined learning outcomes. From the perspective of partners, this whole CBPAR process might be considered a form of informal death education as partners were found to have developed interest, confidence, and skills in relation to supporting community engagement with EoL-issues (IV). Here, learning seemed to have taken place through cycles of action and reflection.

Leonard et al. (2020) argue that informal death education can lead to increased “death literacy.” They defined death literacy as “the knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end of life and death care options”, which includes practical knowledge, experiential knowledge, factual knowledge, and community knowledge (Leonard et al., 2020). Leonard et al. (2020) recently

published the Death Literacy Index which is intended to aid in determining levels of death literacy and measuring the impact of health promotion initiatives on death literacy. Future research on potential future iterations of Studio DöBra or similar initiatives, might investigate whether this index is applicable in determining a change in death literacy among participants, partners, and parents. To do so, the Death Literacy Index needs to be adapted and validated to the Swedish context. The index was developed with input from adults only (Leonard et al., 2020), and may thus also need to be adapted for children and potentially also older adults.

As mentioned in the background to this thesis, Studio DöBra was in part inspired by the Schools Project at St. Christopher's Hospice in London, where school children visit the hospice to work on arts projects about dying, death, and loss, together with hospice patients (Tsiris et al., 2011). The Schools Project was developed in line with national teaching objectives related to loss and transition, and motivated by the notion that teachers may find it difficult to raise these issues in education (Hartley, 2012). Such teaching objectives are not standard in the Swedish national curriculum (Skolverket, 2019). Further research might therefore also investigate whether there is interest in and support for providing forms of death education in Swedish primary schools and whether teaching objectives like those in the UK should be included in the Swedish national curriculum. Such research should include the perspectives of school children, teachers, and parents. Furthermore, it should investigate whether teachers find themselves prepared and supported to provide such education, as Studio DöBra findings indicate that adults with responsibility for children, such as teachers, might find it challenging to raise this issue with children. Additionally, the role of facilitators of death education is important as their perspectives influence participants' learning, as also pointed out by Talwar (2011).

### **5.2.5 Creating spaces for intergenerational interaction**

Most studies on intergenerational initiatives focus on outcomes in terms of addressing negative age-related stereotypes and benefits for the wellbeing of older adults (Gualano et al., 2018; Lou & Dai, 2017; Martins et al., 2019). This thesis contributes to this field with a focus on EoL-issues as a topic for intergenerational interaction. Further research is needed however, to investigate whether and how EoL-issues can be a basis for intergenerational initiatives in different contexts and cultures. This thesis also contributes with an investigation of the role of partners as facilitators of the intergenerational interaction. Partners had power over participants (Gaventa & Cornwall, 2015), through their fundamental role in enabling intergenerational interaction, as evidenced here, for example, in the processes of inviting children and older adults. In Studio DöBra and similar initiatives, those with formal responsibility for these age-groups acted as gatekeepers (I). Further research into facilitators' roles in intergenerational initiatives could help to better understand ways in which intergenerational interaction can be stimulated and supported.

As discussed above, Studio DöBra's goal to support intergenerational interaction was based on literature about developing intergenerational initiatives to address age-segregation (Lou & Dai, 2017; Martins et al., 2019), rather than informed directly by perspectives from children

and older adults. While this may be seen as a limitation, it is nonetheless striking that both older participants and children generally explicitly mentioned a lack of intergenerational interaction in their lives as one motivation for their decision to participate (II). Age-stereotype embodiment theory suggests that negative age-related stereotypes can become internalized across the life span (Levy, 2009). This provides further insight into findings related to children finding older adults frightening, with the older participants validating this fear as justified, for example, referring negatively to one's own appearance. Embodied negative age-related stereotypes may negatively affect health and lead to avoidance of social participation (Ayalon & Tesch-Römer, 2018). Comments from older participants about feeling privileged to be included in Studio DöBra despite their age may be additional examples of negative stereotype embodiment, as this seems to refer to a cultural assumption of older adults as societal outsiders (de Jong Gierveld, 1998). However, research suggests that intergenerational interaction can work to counteract these negative effects (Gualano et al., 2018; Lou & Dai, 2017; Martins et al., 2019). Examples of this were found in Studio DöBra, e.g., in relation to participants bonding across generations through reciprocal interaction, as well as a sense of identity appearing to be reinvigorated for some older adults in interaction with children (II). This illustrates some of the value of intergenerational interaction (del Carmen Requena et al., 2018).

As discussed in the background, intergenerational initiatives aiming to address negative age-related stereotypes and agism, are often based on contact theory first described by Allport in 1954, stating that interaction between diverse groups should be based on equal statuses between the groups, common goals, intergroup cooperation, and institutional support (Kuehne & Melville, 2014; Pettigrew & Tropp, 2006). Conceptually, Studio DöBra is in line with these as the collaborative arts activities supported intergroup cooperation, and community organization supported the intergenerational interaction. Additionally, partners made efforts to see both children and older adults as equal participants with the common goal of engaging with EoL-issues. However, findings based on participants' perspectives (II) suggest that children and older adults may have not always seen themselves as equal to the other age-group. While participants from both age-groups valued a reciprocal interaction, some older participants took on a facilitating role informed by prior intergenerational experiences, such as experience in teaching children. Children, on the other hand, spoke about preferring to interact with older participants who gave them space in decision-making. Social norms regarding people fulfilling particular roles in accordance with their age (e.g., older adults teach, children learn), may play a part in such role differences (Hagestad & Uhlenberg, 2005). Another issue not explored further here, is whether gender norms may have influenced older participants to adapt certain roles, particularly given that most older participants were women, often with experience of working with children in education or care. This raises issues about the ways social norms and prior intergenerational experiences may facilitate reciprocal intergenerational interactions. It is also possible that participants may be hindered from exploring other roles as familiar hierarchies are maintained.

### 5.2.5.1 *Sense of community*

Both partners and participants spoke about having developed new social connections through Studio DöBra (II, III, IV). Partners and participants continued to meet in the neighborhood, and some older participants in Skärholmen found new social activities as they became involved in the artistic organization (II, III, IV). These findings point to a changed sense of community related to developing a shared identity through Studio DöBra (Duran et al., 2013; Israel et al., 2017). This is also in line with findings from the exploratory interviews as well as with research literature pointing to the potential of collaborative arts initiatives and intergenerational initiatives to promote a sense of community (Fancourt & Finn, 2019; Gordon-Nesbitt & Howarth, 2020; Gualano et al., 2018).

The experience of being part of Studio DöBra as well as collaborative arts products seemed to contribute to the bonding of partners and participants (II, III, IV). However, the shared arts projects raised new issues in terms of ownership (III). In Skärholmen, arts products were saved in an archive kept by the artistic organization. In Halmstad, the arts products were shown at the after-school center after the final Studio DöBra Halmstad workshop. During the summer vacation, the after-school center discarded the arts products without consulting participants or partners. This may be an illustration of the after-school center being less involved in Studio DöBra than the other partnering community-organizations, and therefore lacking sense of ownership. It also illustrates a power over relationship (Gaventa & Cornwall, 2015) between the after-school center and the children.

It is noteworthy that the Studio DöBra magic circle shares features with McMillan's (1996) description of elements which promote a sense of community. The Studio DöBra magic circle defines spatial and temporal boundaries, which McMillan (1996) points out as being essential for establishing space in which individuals can identify as a group. McMillan (1996) argues that the community should provide a space in which members feel safe to share personal experiences. While this was the ambition of partners, it seemed to be occasionally challenging, as some participants seemed to self-censor when they felt that their EoL-related beliefs or perspectives were outside a self-perceived norm (III). On the other hand, self-censoring also points to participants' power to act (Gaventa & Cornwall, 2015) in modulating their engagement with EoL-issues.

### **5.2.6 Impact and sustainability**

This thesis adds to the limited body of research literature investigating impact of health promotion initiatives to engage communities in EoL-issues (Archibald et al., 2016; Collins et al., 2020; Sallnow et al., 2016). As a result of their participation in the Studio DöBra CBPAR process, community-partners who traditionally did not engage with EoL-issues in their organizations, began to do so as they appeared to develop interest, confidence and skills and subsequently applied these to practices and policies within and beyond their organizations (IV). As this indicates an increased power to act and power to act in concert with others (Gaventa & Cornwall, 2015), this process may be seen as a form of empowerment in relation

to EoL-issues (Sallnow & Paul, 2015). Therefore, the model of impact development throughout the Studio DöBra CBPAR process may be relevant for investigating empowerment in community engagement with EoL-issues.

Efforts towards strategy-oriented impact included upstream endeavors to anchor lessons learned at higher levels of power (IV). This had varying success due to contextual influences, which can often be ascribed to power over dynamics (Gaventa & Cornwall, 2015). This included the power which management and politicians wield over community-partners, either facilitating or hindering anchoring lessons learned. Using a social ecology lens may provide further insight into this issue, as it situates power dynamics within micro (individual values and attitudes), meso (inter-sectorial spaces), and macro (socio-political structures) levels (Roura, 2020). As was the case in Studio DöBra, PAR projects are often situated on grassroots, micro, and meso levels (Wallerstein & Duran, 2017). However, as Roura (2020) notes, support on the macro level is needed to anchor lessons learned and thus achieve sustainable social change. Related to the above discussion about different ways of knowing in Studio DöBra, community-produced knowledge demands cultural and systemic change to be recognized as equally valid as researcher-derived knowledge on macro level.

This thesis contributes with a model of impact development, based on both Studio DöBra iterations, as well as on the work of Banks et al. (2017) on a PAR initiative about debt in low-income households (IV). These are two very different contexts. This suggests that the model may therefore have some relevance in other contexts. In approaching impact as both process and product, the model developed here adds to existing conceptualizations of impact in PAR (Banks et al., 2017; Trickett & Beehler, 2017). Although models are inherently reductionist, it may help to understand the complexity of impact development in the Studio DöBra CBPAR process. Partners in PAR initiatives may be able to build further on this model by adapting and applying it to other PAR initiatives.

Although governments and funding agencies increasingly demand that research leads to social change (Cook & Roche, 2017; Greenhalgh, Raftery, et al., 2016; Reale et al., 2018; Sordé Martí et al., 2020), they are arguably most interested in what is termed as strategy-oriented impact in the model (Figure 4). However, our model illustrates that impact on individual and group development and action-oriented impact are also important to consider and report as they were found to be a basis for strategy-oriented impact. Furthermore, the model illustrates that impact development in the Studio DöBra CBPAR process is not a linear process. Thus, established ways of investigating and reporting research impact based on linear processes from knowledge development to application has limited relevance in PAR approaches (Cook et al., 2017; Greenhalgh, Raftery, et al., 2016). Our model may therefore support endeavors of investigating impact development in PAR projects.

#### *5.2.6.1 Participants' and parents' perspective on impact and sustainability*

A limitation of the model of impact development in Studio DöBra is that it is only based on data from the perspectives of partners and does not include perspectives from higher levels of

organizational and societal power. Perspectives from participants or parents were not included in its development either. Continued research is needed to include these perspectives in further developing this model. However, in a thought experiment, I began to explore whether the model might be able to be applied to findings from Article II based on follow-up interviews with older adults, children, and parents. While I found that some findings can be related to impact as a product (see types of impact in Figure 4), I am limited in making inferences about impact as a process, based on retrospective reflections from follow-up interviews only.

Developments in participants' thinking, emotions, and attitudes may be related to impact on individual and group development. This includes findings indicating that participants learned about how participants from the other age-group reflect about EoL-issues, and that parents learned they can talk with their child about EoL-issues. Participants bonding across generations can also be seen as a form of impact on individual and group development as group dynamics changed. Findings related to changes in participants' actions may be interpreted as action-oriented impact, e.g., participants modulating their own engagement with EoL-issues in Studio DöBra arts activities, older adults talking about taking on a facilitating role in relation to the children and reassuming past identities, and older participants from Skärholmen becoming involved in the artistic organization's activities. Participants creating spaces for EoL-engagement in their social networks, can also be interpreted as a form of action-oriented impact (IV). Furthermore, as participants created these spaces themselves, this suggests that they gained power to act (Gaventa & Cornwall, 2015). Interestingly, I found no examples of strategy-oriented impact based on findings from Article II. This may be related to the lack of power children and older adults have to create such impact.

In follow-up interviews, almost all children and older adults talked about wanting to continue to meet, which indicates a wish to sustain impact. However, the inability they felt in actualizing this relates to a prevalent power over dynamic among people of different ages in today's society where children and older adults often rely on support from adults-in-between to provide intergenerational meeting places (Gaventa & Cornwall, 2015; Hagestad & Uhlenberg, 2005; Krekula & Johansson, 2017). The lack of agency of both children and older adults in Sweden today is an important contextual influence limiting sustainability. This is in line with contact theory, which points to the necessity of external support for intergroup interaction (Kuehne & Melville, 2014).

#### *5.2.6.2 Studio DöBra Toolbox, contributing to impact and sustainability*

Although the distribution and use of the Studio DöBra Toolbox is beyond the scope of this thesis, I want to make a few remarks on ways it may contribute to impact and sustainability of Studio DöBra. The Studio DöBra Toolbox was first developed in Swedish after which it was translated to English. The Toolbox is available for download on [www.dobra.se](http://www.dobra.se), as well as in printed form, both cost-free; however, neither the print nor online versions in either languages have been actively marketed. The Swedish Toolbox was published on the DöBra

website in May 2019. As of April 2021, about 450 printed versions were distributed in Sweden, and 98 people have downloaded the Toolbox. The English Toolbox was published on the DöBra website in September 2019. As of April 2021, about 150 printed versions were distributed internationally (mostly via an international conference in Australia), and 27 people have downloaded this English version. Partners have distributed the Swedish printed version in their own networks, as well as at meetings, workshops, and conferences. Based on the information that people who download the toolbox provide, it seems that many have searched for tools to support them in EoL-conversations for various reasons. Some said to be interested in the Toolbox as part of their job in EoL-care, teaching healthcare staff, or leading discussion groups. Others said to be interested as a private person, e.g., in supporting conversation about EoL-topics within their family. This organic spread of the online Toolbox can be termed as a kind of strategy-oriented impact. It also appears to shed light on an interest in the general public in engaging with EoL-issues, although it is unknown how wide-spread this interest is. Further research is needed to investigate ways in which people have used the Toolbox, and whether it contributes to dissemination and sustainability of lessons learned from Studio DöBra.

#### *5.2.6.3 Reflections on the COVID-19 pandemic in relation to Studio DöBra*

The COVID-19 pandemic was found to be a contextual factor inhibiting sustainability of impact development for community-partners (IV). All community-partners needed to adapt their practices in one way or another due to the pandemic, as it became impossible to meet in groups and across generations (IV). Spinoff projects were cancelled or paused, and some community-partners had to change jobs.

Researchers have argued that societies' responses to the COVID-19 pandemic exacerbate and reinforce the exclusion of older adults, as well as negative stereotypes about them (Fraser et al., 2020; Swift & Chasteen, 2021). Although younger people contribute to the spread of the virus and account for a significant portion of hospitalizations, public discourse continues to be dominated by the view that the virus is predominantly dangerous for older adults (Ayalon, 2020; Fraser et al., 2020). Furthermore, many countries, like Sweden, imposed stricter restrictions on older adults, potentially worsening issues related to isolation (Ayalon, 2020; Fraser et al., 2020). Although older adults are inherently a heterogeneous group, restrictions based on age-groups emphasize the idea of older adults as a homogenous and vulnerable group that needs to be protected, reinforcing patronizing attitudes (Ayalon, 2020; Fraser et al., 2020; Swift & Chasteen, 2021) and increasing the stigmatization related to being an older adult (Swift & Chasteen, 2021). The pandemic has also brought forth positive examples of new forms of intergenerational interactions with younger people supporting older adults in their isolation in various ways (Fraser et al., 2020).

Swift and Chasteen (2021) argue that an understanding of the theories and implications of agism can inform responses to future pandemics. Findings from Studio DöBra indicate that children and older adults bonded as individuals rather than as age-groups, in line with research pointing to the potential of intergenerational initiatives to address negative age-

related stereotypes and support intergenerational community building (Lou & Dai, 2017; Martins et al., 2019). Thus, the pandemic also illustrates the need for intergenerational interactions. Furthermore, engaging with EoL-issues has become increasingly relevant now as the ways we die and grieve are changing due to pandemic-related restrictions (Yardley & Rolph, 2020).

As many of our contacts have moved online, questions about how Studio DöBra could work virtually arise. As outlined in the background, I initially framed Studio DöBra arts activities as based on physical rather than virtual interaction. What kind of virtual arts activities could support intergenerational engagement with EoL-issues? Do the mechanisms found in in-person workshops apply in virtual arts activities? For example, would it be possible to create a virtual Studio DöBra magic circle? In which ways would the role of facilitators change? And in what ways might a sense of community develop through a virtual Studio DöBra? These might be questions worth exploring in potential future virtual iterations of Studio DöBra.

### **5.3 CONCLUDING REMARKS**

This thesis contributes to an understanding of ways in which community-based intergenerational arts initiatives can be developed and facilitated to engage community organizations, older adults, children, and their parents in EoL-issues and stimulate intergenerational interaction. It also adds insight into ways in which impact can be understood as both product and process in CBPAR and particularly in Studio DöBra. To illustrate the contributions of this thesis, I consider ways in which findings might inform a hypothetical continuation of Studio DöBra. Based on previous reflections regarding the COVID-19 pandemic, I speculate on both in-person and virtual scenarios.

Partners' collective reflective practice seemed to support them in dealing with challenges in developing and facilitating Studio DöBra. In this reflective practice partners shared personal EoL experiences, questions, and beliefs, and discussed issues related to age-related power structures and assumptions of responsibility. In both iterations, awareness of these issues seemed to lead to partners' increased power to act, and power to act in concert with others (Gaventa & Cornwall, 2015). A collective reflective practice should therefore be the basis of developing potential future Studio DöBra iterations.

Participants were generally not involved in development of Studio DöBra or the other investigated projects with shared characteristics. This illustrates power-over dynamics (Gaventa & Cornwall, 2015) among partners and participants. In the second Studio DöBra iteration, partners made efforts to include participants, but it is unclear if participants saw themselves as having any role in development. In potential future iterations, partners could consider exploring ways to better involve children and older adults in developing the arts activities as this may address some of the power dynamics among people of different ages. To do this, partners should take in account the individual backgrounds of participants, particularly in relation to EoL-experiences and intergenerational interactions (or lack thereof),



as these factors appeared to inform both motivations to participate as well as how participation was modulated.

In the arts activities in the first two iterations, there was a clear division of roles between partners and participants. Partners were facilitators, determining and balancing restrictions and freedoms in arts activities, while participants modulated their participation within this framework. When restrictions and freedoms were appeared to be in balance, participants appeared independent in the execution of the arts activities. Additionally, some older participants seemed to assume a facilitating role in their interaction with children. In potential future iterations, it might therefore be interesting to explore ways in which facilitator/participant roles could blur so that partners could also act as participants, and both older adults and children might take on facilitating roles. This may serve to address some of the issues noted to date related to power dynamics among partners and participants. Furthermore, a virtual setting may also change power dynamics among those involved e.g., as some may be better at navigating virtual interactions than others.

In potential future iterations of Studio DöBra, both in-person and virtual, partners could consciously and critically apply the mechanisms found in arts activities to support intergenerational engagement with EoL-issues. This might facilitate development and facilitation of arts activities. Furthermore, this may contribute to further development of theory about mechanisms in arts activities that support intergenerational engagement with EoL-issues.

The model of impact development in the Studio DöBra CBPAR process, might be of interest for application, not only retrospectively, but also prospectively. For example, it could be used prospectively in participatory processes mapping out early ideas about different types of impacts that partners and participants may want to achieve, and planning ways to develop these. An additional way to investigate impact might be to more actively use ideas about informal death education and death literacy.

Using the model of impact, partners might be helped to determine a plan for sustainability of their partnership after the iteration. This might involve ways in which they can support sustainability of potential new intergenerational bonds and activities. Sustainability in relation to the first two iterations could be further researched retrospectively by investigating the use of the Studio DöBra Toolbox as well as the physical toolbox.

To investigate the applicability of findings in different contexts and cultures, further Studio DöBra iterations might take place in different settings, e.g., rural and remote areas in Sweden, or adapted for another country. A virtual iteration would in theory be able to connect participants from a variety of settings. The Studio DöBra Toolbox might be of use in applying findings to other contexts. Finally, it is my hope that the lessons learned in Studio DöBra thus far, can contribute to continued action and reflection aimed at creating community-based spaces for collaborative engagement with EoL-issues and meaningful intergenerational interactions.

## EPILOGUE

This doctoral project has been close to my heart as I planned it inspired by personal life experiences and my own curiosities. I remember how proud and joyful I felt during the first Studio DöBra workshop. After many months of thinking, and planning, it was actually happening. I told myself to enjoy the moment, even though I was preoccupied with generating good quality data. I also remember the shock and sorrow I felt when I heard of the death of one of the older participants after Studio DöBra Skärholmen. In dealing with aging, dying, death, and loss, Studio DöBra for me was about the experience of being alive and the meaningful connections I made with community-partners and participants.

In this transdisciplinary project, I have been able to build on and extend my design background as I learned about CBPAR methodology, academic research methods, and from the practices of community-partners. I experienced being free to explore my curiosities without feeling confined to disciplinary norms. Being situated at a medical faculty helped facilitate this sense of transdisciplinarity, although it was challenging at times to find my place within its strong research tradition and culture. On the other hand, I have realized that, by being part of this tradition and culture, I also contribute to it.

Through the intergenerational interaction in Studio DöBra, I was able to reflect on my own childhood, get perspective on my current “adult-in-between” status, and imagine possible futures as I age. Through data analysis, it sometimes felt like time stood still as I repeatedly relived the intergenerational workshops, the meetings with partners, and the interviews with everyone involved. But time obviously did not stand still. I know this, because no one asks me anymore why a *young* person like me would be interested in research about aging, dying, death, and loss. Moreover, I wonder how the children – who are teenagers now – and the older adults, look back on Studio DöBra after the years since they participated.

As I look back on Studio DöBra, the beautiful tapestry art that one of the older participants made throughout her adult life comes to my mind. When I visited her for a follow-up interview, she proudly showed me her works that filled the walls of her apartment. In her tapestry she wove various types and colors of yarn, to form vivid images of landscapes. I think of Studio DöBra as a landscape tapestry, created by the weaving of people, different ways of knowing, ideas, theories, practices, and processes.

Throughout this doctoral project I have come to enjoy the characteristic of research—that it is never really finished. There are always opportunities to see things differently, bring in new theories, and generate more data. I therefore like to imagine the Studio DöBra landscape tapestry as unframed and with many loose ends. Although finishing this thesis feels like a loss in some ways, it also allows me to zoom out of the Studio DöBra landscape. I am beginning to see the loose ends, and I feel an itch to continue to weave.

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