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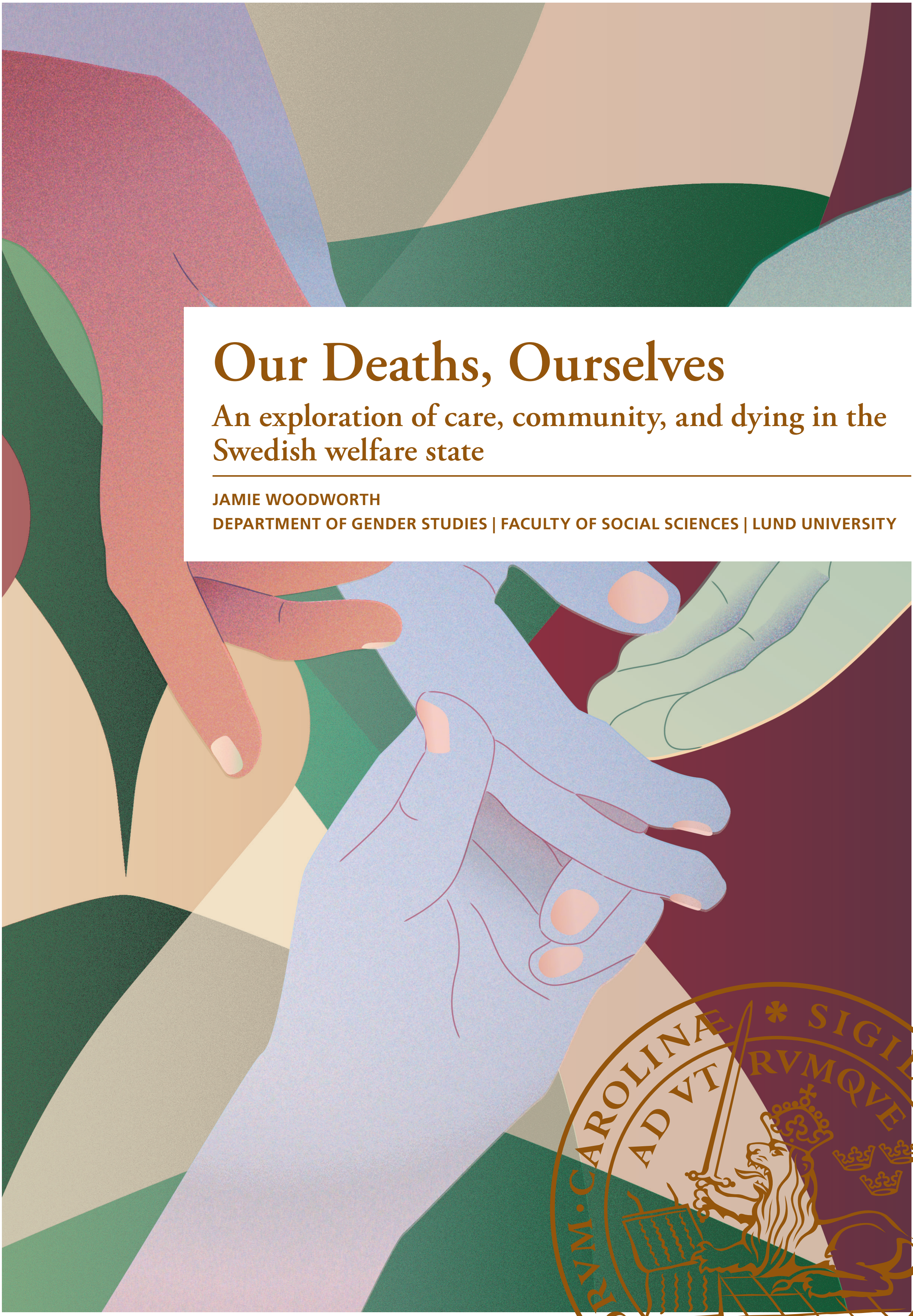

Our Deaths, Ourselves

An exploration of care, community, and dying in the Swedish welfare state

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Jamie Woodworth

LUND
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DOCTORAL DISSERTATION

Doctoral dissertation for the degree of Doctor of Philosophy (PhD) in Gender Studies at the Faculty of Social Science at Lund University to be publicly defended on the 5th of June at 13:00 in G:a Kökets Hörsal, Department of Social Work, Allhelgona kyrkogata 8.

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Abstract:

The way that we die and care for the dying today is changing, related to extended life expectancy, neoliberalization, as well as shifting caring roles in relation to gender. In a time of "care crisis", both formal and informal care resources are under duress, making the question of how to provide "a good death" complex and contested in new ways. Scholars in public health have posited a health promotion approach to palliative care where communities are uplifted as a source of social capital and support for the dying and their significant others. This model invokes the responsibility of civil society to provide support – through volunteerism, cultural engagement, or everyday compassion – during a period of time that will inevitably affect us all. However, this approach lacks a critical perspective which accounts for how gender and welfare shape possibilities for caring and living well until the end. Sweden is an interesting case for examining community perspectives on the end-of-life because of the welfare state context which has enabled a high degree of individual autonomy and independence from family and community throughout the life course. This dissertation fills this gap in research by exploring the relational networks of care which surround dying patients, their significant others, and communities in the unique Swedish context. It examines individual experiences of giving and receiving support in the end-of-life, while relating data back to the socio-political context of care in the welfare state via three empirical studies. Action research, feminist visual methods, and interviewing are employed to understand people's agency to provide support in the end-of-life context; the different supportive roles played by family, community, and care professionals; and the lived experience of receiving social support in old age. To address the cross-border nature of this research, the dissertation ends with an empirical study examining hindrances and possibilities to interdisciplinary study of the topics of dying, death, and grief. This thesis, which also exemplifies the inquiry of this study, employs a transdisciplinary approach by bringing critical feminist theory into conversation with the literature on public health palliative care. It contributes to both fields by invigorating conversation on a topic seldom discussed in feminist scholarship, and uplifting gender and welfare as critical areas of interrogation in public health research and development.

Key words: Care, Gender, Welfare, Palliative care, Dying, End-of-life care, Community

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For Fred and friends

Table of Contents

Abstract

The way that we die and care for the dying today is changing, related to extended life expectancy, neoliberalization, as well as shifting caring roles in relation to gender. In a time of "care crisis", both formal and informal care resources are under duress, making the question of how to provide "a good death" complex and contested in new ways.

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This dissertation fills this gap in research by exploring the relational networks of care which surround dying patients, their significant others, and communities in the unique Swedish context. It examines individual experiences of giving and receiving support in the end-of-life, while relating data back to the socio-political context of care in the welfare state via three empirical studies. Action research, feminist visual methods, and interviewing are employed to understand people's agency to provide support in the end-of-life context; the different supportive roles played by family, community, and care professionals; and the lived experience of receiving social support in old age.

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Populärvetenskaplig sammanfattning

Alla dör, men våra upplevelser av livets slut ser olika ut beroende på hur vårt liv och våra relationer sett ut. Denna avhandling undersöker hur genus, ålder och relationer påverkar människors erfarenheter och möjligheter under livets slutskede. I en tid då såväl hälso- och sjukvårdssystemen som informellt vård- och omsorgsgivande är satta under press är det extra viktigt att utveckla kunskap om hur åldrande och döende ter sig för människor. Det pågår en omfattande debatt i samhället om hur de offentliga hälso- och sjukvårdsresurserna ska prioriteras och fördelas, samtidigt många familjer kämpar med att hitta sätt att ta hand om sina nära och kära. I allt större utsträckning lyfts civilsamhället fram som en potentiell resurs för att balansera omsorgstrycket på såväl offentliga institutioner som närstående, och stötta de människor som kämpar med allvarlig sjukdom och förlust.

Genusforskare har länge studerat hur vi tar hand om varandra i hemmet och inom institutioner, i olika faser av livet: från förlossning till nära relationer och i arbetslivet. Livets slutskede är en särskild fas i livet som på ett unikt sätt påverkar hur vi relaterar till varandra. Omhändertagande vid denna tid i livet involverar en rad olika roller och aktörer: samhällsinstitutioner, professioner, familjemedlemmar, vänner och kamrater. Dessa relationer påverkas inte bara av mellanmänskliga faktorer, alltså av hur människor förhåller sig till varandra och agerar mot varandra, utan också av samhälleliga strukturer som både möjliggör och begränsar våra möjligheter att få och ge omsorg. Ett feministiskt perspektiv bidrar till att belysa hur både självförståelse och maktrelationer präglar omsorgen både på den mellanmänskliga nivån och på den strukturella nivån. Exempelvis har tidigare forskning kunnat illustrera hur historiskt, politiskt, ekonomiskt och kulturellt formade genusrelationer får betydelse för hur olika grupper betraktar sig själva och betraktas av andra i förhållande till förväntningar och krav på omsorgsgivande och –tagande. Av det skälet lyfts genus fram i avhandlingen som en primär analyskategori. Genus är en viktig faktor i hur arbetsfördelningen inom informellt (alltså obetalt) vårdande snedfördelas. Men genus framträder också i termer av praktiker, värderingar och ideal för hur omsorg och vård skapas. Ålderdom är en annan analyskategori som undersöks i denna avhandling eftersom majoriteten av de som dör idag i Sverige är över 65 år. Ålder, precis som genus, har betydelse för hur vi uppfattar oss själva och vad som är viktigt i vårt liv och våra relationer.

De personliga erfarenheterna av livets slutskede påverkas av övergripande politiska processer. I den svenska välfärdsstaten sker idag ett skifte mot att allt mer ansvar för vård och omsorg läggs på närstående. Civilsamhället lyfts återigen fram som en omsorgsresurs, också i livets slutskede – ibland under rubriken "hälsofrämjande palliativ vård", alltså ett folkhälsoperspektiv på palliativ vård. Samtidigt ökar trycket på vårdinrättningar som sjukhus och äldreboenden. Många av dessa vårdformer byggdes ut under välfärdssamhällets framväxt i mitten av 1900-talet, och uppfattades i allmänhet av de feministiska rörelserna som verkade vid den tiden som möjligheter för skapandet av ett mera jämlikt samhälle. Den offentliga sektorns vård- och omsorgsinstitutioner avlastade kvinnor genom att minska bördan på obetalt arbete i hemmet, samtidigt som de erbjöd möjligheter till karriärvägar och ökad ekonomisk självständighet genom att erbjuda kvinnor anställningsmöjligheter. Detta ledde till att allt fler individer kunde leva mer självständighet från familjen i stort. Sverige, liksom många andra länder, befinner sig i en brytningstid då människor, institutioner och beslutsfattare omformulerar och omförhandlar frågan "vems ansvar är det att bry sig?" Sättet som den frågan besvaras på har förändrats genom historien och får konsekvenser för alla människor i samhället. Vems ansvar det är och vart gränserna går för ansvaret att ta hand om de äldre, de svårt sjuka och döende är också en känslig fråga att ställa till enskilda, om en period i livet som ofta präglas av turbulens och sorg.

Avhandlingen frågar: hur kan en ökad betydelse av civilsamhälleliga insatser i palliativ vård och vård i livets slutskede te sig i en svensk välfärdskontext? Hur präglas upplevelser av att ge och ta emot vård och omsorg i livets slutskede av genus, ålder och andra interpersonella och strukturella relationer? Vilka styrkor och svagheter kan identifieras med ett transdisciplinärt angreppssätt för att studera de sociala och samhälleliga dimensionerna av palliativ vård?

I den **första studien** undersöks en hälsofrämjande intervention för att förstärka kunskapen om livets slutskede och öka kompetensen om hur människor kan stödja den som är svårt sjuk eller sörjer, kallad Last Aid (Sista Hjälpen). Studien diskuterar hur vårt handlingsutrymme att ge vård och omsorg ser ut i olika delar av livet: i privatlivet, i våra möten med hälsosjukvårdssystemet, och ute i civilsamhället – samt hur genus får betydelse för detta handlingsutrymme.

Den **andra studien** undersöker hur vården utformas på olika sätt mellan familjemedlemmar, samhället, och vårdpersonal. Studien diskuterar hur genus påverkar ansvarsantagandet i hemmet, relationen till de professionella vårdgivarna, liksom vår benägenhet att ta emot omsorg från olika aktörer.

Den **tredje studien** diskuterar socialt stöd i livets slutskede, med fokus på äldre personer. Den utforskar socialt stöd utifrån ett feministiskt fenomenologiskt perspektiv och fördjupar sig hur begreppet socialt stöd bör förstås som en relationell och intersubjektiv process som upplevs olika i olika faser av livet

I den **fjärde studien** undersöks möjligheterna till tvärvetenskaplig forskning om döende, död och sorg . Den diskuterar nyttan av transdisciplinär forskning vid universitetet, samtidigt som den också belyser de hinder som finns för att bedriva ett sådant arbete.

Avhandlingen pekar genomgående på behovet av ett kritiskt fokus på genus och välfärd inom utvecklandet av ett folkhälsoperspektiv på vård och omsorg i livets slutskede. När närstående förväntas ta ett större ansvar för att ge vård och omsorg, innebär det oftast mer obetalt arbete för kvinnor. Sverige är ett relativt sett jämställt land, men normer kring genus formar fortfarande arbetsdelningen mellan män och kvinnor och våra förväntningar på vem som ska ta ansvar för att ge vård och omsorg - särskilt när det gäller obetalt omsorgsarbete. Föreställningar om ålder påverkar också vilken status och kvalitet som omsorgen anses ha. En utveckling där mängden obetalt arbete kring personer i livets slutskede ökar leder inte nödvändigtvis till förbättringar. Strategier för att öka frivilligarbetet skulle kunna utgöra en trojansk häst i den pågående nedmonteringen av välfärdsstatens institutioner. Motiven för att införa mer frivilligbaserade insatser bör studeras vidare, eftersom de ofta rymmer outtalade föreställningar om genus, ålder, och om vem som bör ta ansvar för vad i samhället.

List of Papers

Paper I

Woodworth, J (2023) Building death literacy at the end-of-life through Last Aid: A case of gendered informal caregiving within the Swedish welfare state, NORA – Nordic Journal of Feminist and Gender Research

Paper II

Woodworth, J (2024) Exploring networks of care in the end-of-life context through eco maps: Feminist perspectives on caregiving in between family, community, and professionals in Sweden. Community, Work & Family

Paper III

Woodworth, J., B.H. Rasmussen, R. Selberg (*submitted to Medical Humanities*) Locating social support in time: A Beauvoirian exploration of relationships of care amongst older people near the end-of-life

Paper IV

Woodworth, J., J. Kristensson, B. H. Rasmussen & R. Selberg (2022). 'Exploring Narratives of Death' (END): A case study of researcher experiences in studying dying, death and grief in an interdisciplinary setting. Mortality: 1-16.

Author’s contribution to the papers

Paper I

The single author wrote the manuscript and performed the fieldwork.

Paper II

The single author wrote the manuscript and performed the fieldwork.

Paper III

The first author wrote the manuscript and performed the fieldwork. Author two assisted in the fieldwork. Authors two and three supported in constructing the theoretical framework of the text.

Paper IV

The first author wrote the manuscript and performed the fieldwork. Authors two, three and four supported in constructing the theoretical framework of the text.

Abbreviations

PHPC	Public Health Palliative Care
CSO	Civil Society Organization
WHO	World Health Organization
HPPC	Health Promoting Palliative Care
PAR	Participatory Action Research
AR	Action Research
NPM	New Public Management
LCP	Liverpool Care Pathway
S-PCG	Swedish Palliative Care Guide
DNR	Do Not Resuscitate

Acknowledgements

A dissertation, though formally attributed to a single author, is in fact a collective work. It is built through supervision, collaboration, and peer-support. I therefore would like to acknowledge the community of people around me who have contributed to making this thesis possible. This community is so large. Although I would like to fully enumerate each person to the degree that they each deserve, I hope these few pages I am limited to will suffice.

First, I would like to express my thankfulness to Birgit Rasmussen (my co-supervisor) and Carl Johan Fürst who, in 2018, gave me a job to develop a community engagement project on the issues of death and dying here in Lund. I hardly spoke Swedish and barely knew what palliative care was. They are strange, wonderful individuals that have made a significant impact on my life, both academically and personally. Birgit, in particular, I hope that the conclusion of this project leads not to less time together, but more. It is clear to me that there is much more I have to learn from you. In extension, I would like to express my gratitude to all of my colleagues at the Institute for Palliative Care. First, Christel Wihlborg, who has been my close colleague and confidante for these last years. She has embraced all my effervescence and welcomed me with open arms into her world as a palliative care physician. We have spent many hours discussing the problems of the world and how we will fix them, while also taking the time to forget those problems and get stupidly drunk together. My doctoral student colleagues (three of which have already finished their dissertations), Dröfn Birgísdóttir, Mattias Tranberg, Karin Dalhammar, and Sofia Persson, have also been steadfast and cherished supports. I would like to similarly thank Rose-Marie Stiller, Felicia Matz-Wennerhed, Ann-Louise Tidell, Maria Schelin, Anette Duarte, Marlene Malmström, and Juliet Jacobsen. You all have not only been wonderful colleagues, but teachers – I don't think I could have learned Swedish without you. To Jimmie Kristensson (also my co-supervisor), I also extend gratitude, for taking me on as a PhD student, supporting my creative interests, and helping to grow by leading me to gender studies.

To which I point out that I have had the luck to have two workplaces and intellectual communities. It has been an honor to be a part of one of the oldest, and most celebrated, centers for gender studies in Europe. First, I want to thank Rebecca Selberg, my main supervisor, who welcomed me into this department. I could not have asked for a better mentor throughout this journey. She has accompanied me with kindness, patience, and confidence, from the first day to last. Rebecca is a fearsome writer, skilled speaker, and dedicated feminist. While, without a doubt, I can say that I admire her and feel privileged to have learned from her, I can also say that I am equally grateful to have gotten to know the lovely, singular person that she is. I would also like to thank Terese Anving, who has also been a valued intellectual mentor for me during my time at the department. To all my colleagues at gender studies, I want to extend my thanks: Jens Rydström, Diana Mulinari, Marta Kolankiewicz, Maja Sager, Andrés Brink Pinto, Sara Goodman, Lena Karlsson, Mia Liinason, Josefin Larsson, Maria Persson, Helle Rydström, Irinia Schmitt, Orly Siow, Cristian Norocel, Ulrika Dahl, Nanna Dahler, Mathilda Ernberg, Birke Friedländer, Onur Kilic, Sunny Gurumayum, Elin Lundell, esethu monakali, Ellen Sunesson, Kat Kehl, Amaranta Thompson, and Hansalbin Sältenberg. Your support in my seminars, the lunchroom, and encounters inside and outside the third floor of Gamla Polikliniken have been of great benefit to me and my work.

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Of course, my largest thanks must be extended to the individuals who participated in my studies and shared their vulnerabilities, joys, and hardships. I hope this dissertation does justice to your experiences, to what degree it can, and brings to light the important struggles and tensions that we as scholars, healthcare practitioners, and policy makers can work towards improving for those in similar situations. I would also like to express my particular gratitude to all of my colleagues who were involved in the Österlen project and who have made my fieldwork possible, to name a few: Ibe Lager, Monika Olin Wikman, Dag Lundberg, Christer Neleryd, Bo Olsson, Gunilla Hepp, Sofia Spetz, Christina Eriksson, Åsa Persson, Charlotte Nordén, Maria-Clara Videla, Bertil Jönsson, & Annika Hallin. I would also like to acknowledge the Kamprad Family Foundation and Vinnova for providing financial support for my research and development work.

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Preface

Nothing has ever excited me more than the idea of doing feminist research. However, when I first acquired a PhD position and began to organize my fieldwork, my specific feminist approach to understanding death, dying, and care was misty. As a starting point, I considered the gendered division of labor in care work around the end-of-life to be the natural locus of my attention. A substantial part of this thesis is dedicated to this matter. As time went on though, I realized that gender plays into our experiences in the end-of-life in ways beyond materialist notions of care as work. Care is a relationship of social reproduction, and it is also an intersubjective category. It relationally informs how we understand ourselves as gendered subjects, how we relate to our bodies, and how some subjects are cast as "other". Age is one social category, like gender, that can also be read in the care relationship in these ways. Re-visiting Beauvoir's work, in particular, pushed me towards taking a more transdisciplinary reading of how power and subjectivity can be understood in the end-of-life context. In doing so, my particular feminist approach to this topic became clearer. She spared no tools in writing *The Second Sex*, as well as *The Coming of Age,* drawing on biology, psychoanalysis, historical materialism, existential philosophy, and phenomenology together to explain the situation of becoming woman and becoming old. This thesis also draws on several disciplinary perspectives to understand and explore this unique period in life and the circumstances in which we come to live and die together. Using an approach informed by feminist theories of care, relationality, and phenomenology, I hope that greater light is cast on how dying and caregiving are inflected by social structures and power, but how they are also intimately matters of selfhood, relationships, and what it means to live a life in time.

There are certain times in life that are more celebrated and investigated than others: youth and working life, for example, are points in the life course which are venerated in post-industrial, capitalist cultures. The patients and significant others that get admitted to palliative care are going through a very specific and often veiled period in life. What happens after a serious diagnosis is not often discussed around the dinner table, much less in public fora or in media. This is not necessarily to affirm the death-denial thesis of modern times, but rather to point out that dying and caregiving are in many ways shaped by alterity. Dying is the "other" end of life. Caregiving is the realm of the feminine "other". These two periods in the life course are drawn together then not only by circumstance but also by their shared marginalizations. Studying end-of-life issues makes for a unique and sensitive fieldwork environment because of the veiled nature of the topic and the associated vulnerability of research participants. As a PhD student, I felt nervous going into the field – how could I treat dying and care as objects of study while also being attentive to the sensitivities of the subjects at the center of these experiences? These feelings and tensions are classic to feminist research, which has always dealt with how the "private" realm of personal life is in fact a source of important scientific and political knowledge. Working through how I approached this research empirically, in addition to how I studied and framed the data, were important components to how this PhD project has made me a better gender studies scholar. At first, I tried to disarm the interview setting by showing up sweaty and windswept, cycling to each interviewee's house across the region. But I came to see that these encounters didn't require the overthinking or pretense I ensconced myself in. Despite being what could be described as a contrived setting, the conversations I had felt so natural – one stranger talking to another, honestly.

When I first met – let's call her 'Pia' – she had a stiff exterior. She spoke first in short sentences, recounting what had happened in her life over the last year, caregiving for her husband who was dying of brain cancer. I had never met someone who could talk so factually about what were clearly still immediate and heavy emotions. She started to speak in longer sentences and I spoke less, our roles seamlessly reversing. Typically, these sorts of conversations take place within a therapeutic or intimate social agreement. What's interesting was that our meeting was one of instrumentality. Even though I approached her with care and kindness, my role was simply to hear what she had to say, not to palliate. I got the sense that Pia appreciated that inert quality to my presence in the room. She expressed that she hadn't told anyone about how tough the last year with her husband was, how she felt she had begun to entirely disappear in a demanding and socially isolating routine of caregiving. Her utility eclipsed other aspects of herself which slipped into a state of dormancy. She was like an oak in perpetual wintertime – resolute and weightbearing, but never in bloom. Speaking was a catalyst for thaw. At the end of a two-hour long conversation, much longer than I had intended, she repeated several times, "I hope whatever I said can be useful to you". Many encounters in the field were characterized by this kind of generosity and ease. Many also expressed how the interview setting allowed them to reflect upon things that they had never given space to before. In each interview, a unique aspect of each person's personal experience came through. While so many others had described to me the supportive relationships they had with their siblings or neighbors in the difficult process of becoming a caregiver, Pia gave a very singular answer. The one time her countenance broke, and she smiled, was when she looked out the window and said, "would it be ok to say that my garden has been my most important support?" In the many maps I drew together with patients and significant others throughout my interviews depicting networks of social support, Pia's was the only one that had a non-human (and non-animal) entity. I made sure to take an extra look at her garden before I cycled off.

The ease of these interviews was occasionally bracketed by uncomfortable moments too. When I first met – let's call him Bo – he warmly shook my hand, offered me a Fanta, and then told me stalwartly that he was not dying. Just because he was in palliative care didn't mean he was dying; he was very much still living. I understood what he meant, of course dying is a matter of biological fact but also subjective interpretation. The question of when we start dying is a topic of age-old philosophical and medical debate – are we always dying from day one or are we always living up until the point when we suddenly die? That is up to each person to decide when and how they want to take on that mantle. Anyways, I was most interested in hearing about experiences of social support in the last year or so of life, it did not actually matter whether the person was, in a manner of speaking, "dying". After we had come to an agreement about the pretext of our meeting, Bo and I proceeded to have a friendly conversation. He described how his social support was tied up in the day-to-day machinations of working life, and uplifted small interactions with his co-workers that left a lasting impression. Like a group of young, male employees asking how he was feeling. He didn't expect "young people" to show an interest in his life. In the end, he said he wanted to think more deeply about a few of the matters we discussed and would be eager to talk again if I needed any help.

Alongside my research activities, I also organized many "death cafes" – pop up event spaces where people could come and talk about death with strangers over free tea and cake. During one such occasion in the attic of a local museum, I sat down with a group of four pensioners who were enjoying their cake amid avid discussion on memorials, last testaments, and things to get done before one is dead. A pair of crutches were leaning on one man's chair. He hunched and his hands shook as he gripped the lip of the table and leaned in towards us. He grinned emphatically and said that if he was alive next month he was certainly coming back for more. All of this is to say that the way that people encounter this phase of life is variegated and individual. Although there are similarities to be noted between people's experiences in the generalized categories of illness and caregiving, it is also important to look at the differential subjectivities that arise during this time. This is what fascinated Beauvoir, the "absolutely unique individual". The fact that every unique individual must die is also a point that strongly compelled her to write and capture what meaning there is before the extinction of this singular sum of experiences.

At the same time, Beauvoir also pointed out that while there is absolute uniqueness, there is also collective struggle. In the midst of all the individual narratives I heard throughout my fieldwork, shared conflict was a perennial undercurrent. This was visible in the interlocking experiences of mostly female caregivers who were overwhelmed by responsibility and uncertainty, as well as a collective fight to be heard in healthcare. Throughout our work together in the Österlen Project (an inter-professional collective which worked together to improve living while dying for everyone in Österlen, the South-east corner of Skåne) my colleague, Christel, always intoned the importance of helping patients and their significant others demand good palliative care. Christel is a palliative care physician who, during our educational courses, public seminars, death cafes and other various meetings with the general public, impressed upon her listeners the imperative to demand the care they needed after a serious diagnosis. She is a person intensely committed to educating people about what happens in the approach towards life's end (physically and emotionally) and supporting them in self-advocacy as they come into contact with institutional services. During our last seminar with a group of 100 members of the general public, regional politicians, nurses, and other municipal employees, I can lucidly recall her waving her fists in the air, professing everyone's right to good care and knowledge about the end-of-life.

She reminded me of a group of second-wave feminists working in 1970s America, raising awareness of women's health and celebrating female sexuality – the *Boston Women's Health Book Collective*, today known as the *Our Bodies, Ourselves* organization, which was also the title of their first landmark publication. The purpose of this book was to first, uplift first-person accounts of women's bodily experiences; and furthermore, use this knowledge as a basis for evaluating institutional care provision and its ability to meet women's healthcare needs. Like this collective in the early women's health movement in the United States, Christel – and many physicians, nurses, social workers, and community activists like her – are attempting to do the same with end-of-life issues. They want to talk about a veiled topic, death, like the way that second wave feminists wanted to talk about female bodily and sexual experience. They both want to revolutionize dinner conversation and improve our wellbeing and access to good care in doing so. The new public health palliative care movement, similarly, is trying to unearth and activate knowledges about the end-of-life that can help individuals, families, and communities approach dying and caregiving with more agency and confidence. Moreover, they are trying to push healthcare to not only be more "patient-centered" but more "community" and even "citizen" centered. In between the fields of medicine and social science, this dissertation offers a commentary and critical inspection of this public health palliative care movement and reflects upon how we as individuals and communities come to meet death, and how we are able to give and receive care from one another as well as institutions in this time. That is why the title of this book is *Our Deaths, Ourselves*. It is a unique, transdisciplinary conversation between feminist scholarship and palliative care. Like the original publication, it uplifts our individual experiences and how those experiences are part of a collective struggle to care well and die well.

Introduction

Rationale

Death and dying have become topical issues. On the global stage, this was thrown into relief during the start of the COVID-19 pandemic in 2020. However, end-of-life is also an inveterately important topic as it is a universal stage in the life-course. For some it comes late and takes a long time, for others it comes early and goes quickly, but regardless of when and how long it is, dying is something that will happen to all of us first-hand, and we will most likely experience second-hand several times along the way. Most of us will also experience some form of care in the end-of-life or be involved as carers ourselves. These are constants throughout human history. What makes studying end-of-life issues particularly relevant for social scientists today, even outside the context of the pandemic, is the changing social context in which dying and caring take place. A century of medicalization in the West has made dying institutionalized and caring more and more professionalized (Kellehear, 2007). Some have argued that this has led to a form of "death denialism" or even death "illiteracy" in families and communities (Becker, 1997; Noonan et al., 2016; Tradii & Robert, 2019). On the other side of the coin, in healthcare institutions, there is increasing pressure to care for more people today with palliative care needs with an overburdened supply of carers. In both the private and public spheres, there is a form of "care deficit" around the end-of-life, where institutional resources are under duress, and families and communities are not always equipped to care for their significant others or have little time to do so in the day-to-day trenches of modern working life (Hansen, 2022).

These pressures are all intertwined in a much more difficult question: Whose responsibility is it to care for the dying? Previously in history, gender and class norms generally dictated the answer in no uncertain terms. Those with the most money could afford the most professional care, otherwise, a lot of dying happened at home, under the management of wives, daughters, and sisters (Illich, 1975; Kellehear, 2007; Lewis, 2022). What's interesting is that – even in the so-called "women friendly" Nordic states – these norms still hold true in many senses. In Sweden, working class daughters represent most informal caregivers in long-term care, through to the end-of-life, performing the most time-consuming, physically taxing work (Ulmanen, 2013; Vicente et al., 2022). Women seem to also bear the mantle of the emotional, cognitive, and practical care in the home – from childbirth to the death of parents – as well as out in communities in the volunteer sector (Finch, 1983; von Saenger et al., 2023). The difference is, today, we question more about what our roles are. It is specified in Swedish law that the state has first responsibility to care, and informal care should always be a choice (Prop., 2008). With the prevalence of policy promoting gender equality across sectors in Swedish society, this has led to a kind of catch-22 for women (Bartlett et al., 2018; Hansen & Jansson, 2022; Lotherington et al., 2018). The law says I am free, but are my choices totally free when these norms yet endure? The end-of-life is a particularly poignant period to ask these questions, when relating to others is not only textured by gender, but also by the immanence of loss.

At the same time, end-of-life issues and challenges cannot merely be boiled down to a matter of women's changing domestic roles. It is clear that care in the end-of-life is gendered in more ways than just "who does what" (Doucet, 2023). Gender also appears in how we respond to dependency, vulnerability, and in how we relationally make sense of our lives and situations through our interactions with family, community, and institutions (Koggel et al., 2022). Furthermore, end-of-life struggles today are not only defined in the private sphere of life. Care struggles are also deeply imbricated in structural shifts related to neoliberalism and marketization/market waves (Hansen, 2022). Sweden has opened more of its healthcare system to privatization than any other Nordic country, especially in the long-term care sector (Dahl, 2017, Hansen, 2022). Nursing homes, which are an increasingly common place of death, are also more commonly run by private businesses, raising questions about how to maintain quality and accessibility of care (Stranz, 2022; Ulmanen & Szebehely, 2015). The nature of for-profit managerialism also changes the way that care is organized and made accessible to dying patients (ibid). These shifts are complemented by policies which support and subsidize more informal care at home by significant others, indicating a trend towards re-familialization. An interlocking trend, self-responsibilization, is also play, where individuals are made more accountable for their health and encouraged to cultivate more "self-care" practices (Dahl et al., 2015; Fink & Lundqvist, 2010). As families and individuals become more beholden to their well-being, formal services are in turn made less and less available, with class and gender-related consequences.

The shift towards the re-familialization of care around the end-of-life would seem to be an amiable change of course for those who have raised the flag against our "death denying" society. This form of argumentation can ally itself with a conservative strain of thinking that poses the family as the only good location of care and the family home as the best place to die (Cooper, 2017; Tradii & Robert, 2019). Choosing a different point of reference, those in the field of public health palliative care (PHPC) have lifted up a different platform for "compassionate" care in the end of life, the community (Abel, Kellehear, et al., 2018; Kellehear, 2005). Though the literature doesn't seem to consistently define what a "community" is, it is generally understood in this field as those people in your geographical area, ranging from friends and neighbors to local business owners, teachers, and employers. In this new health promotion paradigm, communities are uplifted as important reservoirs of support which also have a "responsibility" to care (Kellehear, 1999, 2015). This care is often articulated in terms of social support – such as catching those who are struggling in an understanding and empathetic social environment (Horsfall et al., 2012; Mills et al., 2015; Noonan et al., 2016). Sometimes care also comes in the form of policy – supporting workers with extra leave after bereavement or implementing a school-wide education on end-of-life issues for students (Clark et al., 2017). While the growing expanse of literature on this paradigm is inspiring and at times promising, there is some detail and criticality left to be desired. For instance, what does it mean to promote more community responsibility in this time of intensifying neoliberalism? What gender-related consequences could more community responsibility imply? Relatedly, how is gender something that is created through relationships of care in the end-of-life context? And, finally, what kind of support is meaningful for people in the end-of-life, and from whom? These are some of the themes that this dissertation seeks to explore. In doing so, I additionally hope to provide some insight and guidance for future theorizing and empirical work in the field of public health palliative care.

I argue here that building more knowledge about how we care for our dying is a topical pursuit for healthcare, and it is also a topical pursuit for feminist scholars. While death is a topic par-for-the-course in health sciences, dying is a period in life which is less theorized by feminist scholars. However, as I have laid out, it is a time as imbricated in issues of gender, relationality, and power as other, more broadly discussed phases in life such as parenthood, partnership, reproduction, and work life. It is a unique time worth examination, not only because it is a terrain characterized by new struggles in the welfare state, as well as gendered relations of care, but also because those who are in the end-of-life are most typically the oldest old. Interestingly, old age is also an underexplored category in gender studies. Simone de Beauvoir was one of the first feminist scholars to write about old age in the 1970s in *The Coming of Age*, using *the same tools* to unpack the experience of being old that she used to unpack the experience of being a woman in *The Second Sex*. The perspectives and methods of feminist scholarship which have been used throughout the last century to dissect subjectivity, relationality, and care are incredibly germane for understanding how to care for the dying in a time of immense and complex challenges. For these reasons, I take a unique, transdisciplinary approach in this dissertation, uniting perspectives from health sciences, public health, feminist care scholarship, and feminist philosophy.

Research aims and questions

The **overall aim** of this dissertation is to explore, from a transdisciplinary and feminist perspective, community, family, and professional relations of care in the end-of-life and in the context of the Swedish welfare state.

The **research questions** this thesis addresses are:

(1) How do community perspectives on palliative and end-of-life care map onto the Swedish welfare state context?

(2) How are experiences of caregiving and care-receiving in the end-of-life gendered, relational, and inter-subjective?

  a. What are the different roles and caring functions adopted by community, family, and professionals in the end-of-life?

  b. How is agency to care delimited and empowered in the end-of-life context?

  c. How does age factor into relationships of care?

(3) What are the prerequisites, strengths, and weaknesses of a transdisciplinary approach to studying the social and community dimensions of palliative care?

  a. How can a feminist theoretical lens inform a public health perspective on palliative care?

The contribution of each specific study to the research questions is addressed below:

Study 1 (Building death literacy at the end-of-life through Last Aid: A case of gendered informal caregiving within the Swedish welfare state) addresses question 1 and question 2b. It discusses how a health promotion intervention fits into the social contract of care imbricated in the Swedish welfare state model. It additionally elaborates on how education in end-of-life issues impacts individual agency to care and respond to the needs of others in different spheres of life. Question 3a is addressed by studies 1-3 as all three of these studies use some form of feminist theory to unpack and/or inform the PHPC framework.

Study 2 (Exploring networks of care in the end-of-life context through eco maps: Feminist perspectives on caregiving in between family, community, and professionals in Sweden) addresses questions 1, 2, 2a, and 3a. It elaborates on the different caring roles and functions of family, community, and professional actors in the latter stages of life. It discusses how these roles are built intersubjectively and informed by gender. The text is framed around the political context of the Swedish welfare state and the negotiation of caring responsibility between formal and informal actors.

Study 3 (Locating Social Support in Time: A Beauvoirian exploration of meaning-making in relationships of care amongst older people near the end-of-life) addresses questions 2, 2c, and 3a. It illustrates how age and time impact relationships of care in the latter stages of life using a feminist phenomenological approach. It elaborates on the intersubjective nature of care and discusses how social support can confer diverse meanings for different subjects.

Study 4 ('Exploring Narratives of Death' (END): A case study of researcher experiences in studying dying, death and grief in an interdisciplinary setting) addresses questions 3 and 3a. It explores a case study of interdisciplinary research and discusses the prerequisites, strengths, and weaknesses of working across disciplinary borders, specifically in relationship to research on end-of-life issues.

Transdisciplinarity in this dissertation

Inter- and transdisciplinary approaches to research have often been posed as working methods well suited to building real-world solutions to complex phenomena and have therefore become more central in research agendas within modern universities (Graff, 2015; Lyall & Fletcher, 2013). The global pandemic, climate change, and the "care crisis" all represent real world problems which makes death a topical issue. It is also apparent that there are many different ways to study the end-of-life. Dying is a medical event, but it is also a social event, in that it is curated by diverse cultural rituals and represents a significant narrative topic in major works of literature. It is a phenomenon which can be looked at as a philosophical problem, but also something to be organized and improved on through policy and organizational development. Dying is both an existential phenomenon and a concrete event and as such, it spans not only research fields but also different spheres of society, from polity to family, from university to care facility, from literature to unique individual. This dissertation draws on transdisciplinarity as a mode of inquiry spanning research fields as well as the scholarly and practical fields. It also explores the end-of-life in relation to gender, which is a transdisciplinary concept in itself (Sandford, 2015). Gender *studies* is a field broadly defined by transdisciplinary theories and methods oriented within a critical and political praxis dedicated to equality (Sandford, 2015; Taylor et al., 2020).

Within gender studies, transdisciplinarity has been defined in terms of the usage of concepts and theories “which are not necessarily identifiable with any specific disciplinary field, either in their origin or application” (Sanford, 2015 p. 166). In other words, transdisciplinarity is a matter of moving and employing travelling concepts – ideas which shift from one field and social sphere to another and change in meaning in the process. Here are some of the transdisciplinary concepts used in this dissertation and how they are used:

(1) Gender: as a relational construction and as a political category characterized by structural inequality, which is made visible in social relationships including in the relationship between the state and individual human beings.
(2) Care: in terms of practices and values relating to reproductive work in the contexts of individual life as well as institutions and structures.
(3) Subject: as a social and relational construction but also a phenomenological term which manifests via the body.

In the various studies in this dissertation, I put these concepts into communication with the field of public health palliative care. In the process, I produce new knowledge which is more than “gender studies” plus “public health palliative care”. The transdisciplinary application of these concepts works prismatically, showing new colors and dimensions to a complex issue, end-of-life, which were not visible before. This is because travelling concepts are more than transdisciplinary in themselves, they challenge existing ways of thinking within the disciplinary contexts they are applied to (Sandford, 2015). Here is a simplified outline of how these concepts are used to challenge existing knowledges in PHPC:

(1) To challenge the gender neutrality in the theoretical and methodological framework of PHPC.
(2) To challenge the idea that care is a pre-existing, atomized practice with stable corresponding values. Likewise, to nuance the idea of “social support” as it is used in the PHPC literature, and how it is conditioned by dependency.
(3) To nuance the premise that there are “subjects” which need “care”. Rather, to explicate how subjectivity and care are intertwined, changing, and imbricated in categories such as age and physical disability.

Hornscheidt and Baer (2011) frame transdisciplinarity as an approach which is fundamentally reflexive, and critically reflects upon “all disciplines, their agendas, methodology and established findings” (p. 171). Travelling concepts, by virtue of their vagrancy, can be used therefore to lodge a “practical criticism” of established knowledges (Sandford, 2015, p. 171). Likewise, this dissertation sets out to critique the agendas, methods, and findings within the field of public health palliative care and generate some practical critique which can help scholars and practitioners re-conceptualize future theory as well as interventions. These new knowledges are placed within a critical framework which questions not only what we can come to know about community and care in the end-of-life context, but also placing public health strategies within a political praxis.

I hope that this text is legible to a broad audience and contributes to both the fields of gender studies and public health palliative care. On the side of gender studies, I believe this dissertation contributes in both theoretical and substantive terms. While there is a wealth of feminist writing about the beginning of life, from sex to gestation to child-rearing, there is comparatively little work (especially empirical work) pertaining to the very end-of-life (*cf* Gunaratnam, 2014; Lykke, 2022), and none on public health perspectives on dying and grief. In 1970, Beauvoir wrote one of the first feminist treatises on the trespasses and struggles of old age and dying using a feminist phenomenological lens (de Beauvoir, 1996). And since the 1990s, there has been a push for more critical feminism in gerontology (Ray, 1999). Even so, old age and death have been marginally explored in feminist intersectional scholarship, though this is changing (Stoller, 2014). Extending the feminist lens also into the domain of end-of-life, for those who are old and those who are young, is prescient as neoliberal transformations in long-term care have brought new struggles to the fore (Dahl, 2017; Hamington & Flower, 2021).

In addition to contributing to feminist scholarship on care, I hope that this research can function as a critical compass to other public health researchers, practitioners in healthcare, and policy makers. These studies are framed by a collaborative project including healthcare providers, municipal leaders, policymakers, and civil society organizations which aimed to improve living while dying for all residents in Österlen (detailed in the next section). The claims brought forth in this text are therefore not formulated "from the outside" but brewed within a working context that incorporated ideas from PHPC. The disposition of this text has followed the work in the Österlen Project and has been informed by a long period in the field. This research has already been used as a basis for discussion in Simrishamn municipality, and future public health planning. I hope that our experiences in the Österlen Project, and the related findings of these studies, can shed further light on future development of PHPC especially in the Nordic countries, but also in other contexts around the world.

The final study in this dissertation is itself a study of barriers and possibilities to working across disciplinary borders. Compared to studies 1-3, this text may appear out of place. However, it contributes to this work as a whole by demonstrating the importance of inter-disciplinary perspectives. As study 4 points out, institutions limit our agency to work inter- and trans-disciplinarily. Such institutions include universities themselves, individual departments, funding bodies, and government bodies which build policy guiding work life and research (Berg & Seeber, 2017; Lyall & Fletcher, 2013). However, the advantages of cross-border research and collaboration are multiple: from providing "playful" intellectual environments to promoting critical and more holistic insight into complex issues. Moreover, thinking across disciplines can be invaluable in developing knowledges that can address complex real-world problems (Callard & Fitzgerald, 2015; Graff, 2015). This dissertation, then, is object to this hypothesis. Working across disciplines, these texts attempt to address the intertwining structural and interpersonal factors which constitute the real-world problem of how to care for people in the last phase of life.

Background

This section will provide contextual information about the Swedish welfare model, how care and specifically palliative care are organized in the Swedish state, and lastly how Swedish civil society can be conceptualized. Afterwards, I will provide some background on public health palliative care, and the implications of importing the "compassionate communities" concept into the Swedish cultural and political context. I will then conclude this section by describing the Österlen Project, which foregrounded the research done in this dissertation.

Setting the Scene

The welfare state and the Swedish model

In a global perspective, Sweden is considered to be one of the strongest welfare states in the world. The Nordic countries tend to be grouped together in this respect, having comparable welfare models of "social democratic type", as conceptualized by Esping-Andersen (1990). The "Swedish model" carries a certain specificity, both in terms of history as well as policy and ideology. This moniker has been used in a few different ways. An early example is in the American publication from 1937, *Sweden: The Middle Way*, where the "Swedish model" refers broadly to a unique compromise between socialism and capitalism or market liberalism with social welfare (Qvarsell, 2017). It is still widely used to refer to the specific industrial relations model characterized by negotiations between unions and employer organizations striving for consensus rather than conflict (ibid p. 56). Yet another way that the Swedish model has been described has been in terms of a welfare system, developed from the 1960s and onward, with a relatively high investment in the public sector (ibid). On an ideological level, Trägårdh (2007) defined it as "a particular form of statism built on a vision of a social contract between a strong and good state on the one hand and emancipated and autonomous individual on the other" (p. 27-28). Still, to understand the real specificity of the Swedish model, one has to refer to its history.

Up until the late 1930s, Sweden was largely an agrarian country characterized by great income inequality. Welfare provision was offered by charity organizations, like the church among other secular associations, if one was not cared for already by family (Meeuwisse & Scaramuzzino, 2018). In the post-war period, the construction of the welfare state came underway after intense labor movement mobilization with an ideological outset to liberate the individual from dependency on institutions in civil society such as the family, the church and charitable organizations (ibid). This vision was rooted in the idea of "folkhemmet" or "the people's home" where ensuring the security of every citizen would be made the prerogative of the state, which would be resourced by a society modelled on social solidarity and unity (Swärd, 2017). Esping-Andersen & Korpi's (1986) description of the difference between a marginal welfare model and an institutional model captures the significant shift between Sweden pre-"folkhem" and during the height of the social democratic welfare regime (p. 40):

> The marginal model is premised on a commitment to market sovereignty. It stipulates that governments play only a limited role in the distribution of welfare. A marginal social policy assumes that the vast majority of the population can contract its own welfare, and that the state need only step in when the normal channels of distribution fail. Marginal welfare systems therefore tend to be targeted towards that human residual that is incapable of self-help. Hence, the boundaries for public commitments are narrow and the classical liberal emphasis on market solutions and self-reliant individualism is favored. In contrast, the institutional model does not recognize any fixed boundaries for public welfare commitments. The underlying view is that the welfare of the individual is the responsibility of the social collective: the family's or the market's capacity to secure an optimal distribution of welfare is seriously questioned. Moreover, the institutional model promotes the principle that all citizens should be equally entitled to a decent standard of living, and that full citizenship rights and status should be guaranteed unconditionally. ...The institutional welfare state presumably will tend to limit and partially supplant the market as the distributive nexus of welfare.

According to Esping-Andersen and Korpi (1986, p. 42), the Swedish welfare state developed from the 1960s and onwards in a distinctively institutional direction characterized by its comprehensive social policy; an institutionalized social entitlement principle; and a solidaristic and universalist nature of social legislation. The Swedish Model of welfare has since been characterized by four fundamental principles (Swärd, 2017, p. 22):

(1) Generality above selectivity wherein services are made available based on general criteria rather than means-based criteria. In other words, universality of services, where welfare is provided on the basis of need rather than ability to pay.

(2) Public trust in the system.

(3) A social contract between the state and the individual where both sides have obligations to one another.

(4) Compromise between different interests concerning employers and workers.

The mid-century welfare state built out a wide infrastructure of social services that eradicated some central class barriers, such as educational attainment, and decreased income inequality and gender inequality. The premises for this welfare expansion rested on a rather homogenous idea of the public and civil unity that would later come into strong critique in the following decades. The speed and veracity at which the welfare state was built at this time has been attributed to the relative wealth of the Swedish state following the end of World War II in comparison to other European countries and accumulated wealth from arms sales during the duration of the war (Swärd, 2017, pp. 40-41).

In the onset of the 1960s, some key sectors in the welfare status were further expanded. Public childcare was made more widely available, effecting a strong increase in women's participation in the formal labor market. While public childcare was politically framed around an intention to expand women's possibilities outside the domestic sphere, the successive institutionalization of care for older adults in 1964 was introduced as an initiative to give older persons "economic independence", "housing" and "personal care" (Ulmanen, 2013, p. 73). Still, the introduction of publicly financed long-term care also contributed to women's freedom from the home. Women's participation in the labor market increased 47% between 1960 and 1996 (Peterson, 2017, p. 5). The strengthening of social care for children and older adults was, in addition to being framed around women's liberation, oriented more broadly towards an ambition of the de-familialization of care (Lundqvist & Roman, 2008). Wherein, the individual was afforded more autonomy to live without necessary assistance from family or, on the other side of the coin, obligation to provide care for significant others. The enshrinement of the autonomous individual in the welfare policy can be seen to reflect also cultural changes at the time related to the feminist movement and a resistance to following "traditional" lifestyles (Qvarsell, 2017).

This movement towards individualization in the 1960s posed a challenge to the previously homogenous and collectivist vision of "folkhemmet". In addition to the feminist movement, the '68 movement lodged a critique of the existing welfare regime from a different angle. In the years before the end of the decade there arose increasing skepticism of the "totalitarianism" of institutional care, such as practices of forced sterilization and forced adoption (Qvarsell, 2017). It was here that a discourse of "individual rights" percolated to the surface, posing a new challenge to the conceptualization of the Swedish Model going forward. Indeed, the individualist values of the 1960s ensconced within the collectivist history of the welfare regime formed a kind of paradox where the state was held responsible for guaranteeing individual rights at the same time that it must ensure collective wellbeing (ibid p.60).

In the aftermath of the oil crisis of the 1970s, and influenced by the rising wave of market liberalism in the West following globalization and other changes in the structuration of the global markets of labor and finance, the political landscape of Sweden changed and public policy transformed from de-commodification (the deliberate withdrawal of services from the market to the public sphere) to re-commodification (meaning the deliberate marketization and privatization of services) (Ryner, 2004, p. 99). By mid-1980s, the growth of the welfare state stemmed, and governments adopted policies of cost saving and inflation control, with the stated intent of imposing market discipline on socio-economic actors, especially, according to Ryner (1999), trade unions and social service ministries in budget bargaining. Further economic crises in the 1990s and early 2000s deepened the entrenchment of private actors into the public sector. Especially the free choice reform of 2009 ("valfrireformen") which opened the gate to widespread privatization in health and social care (Qvarsell, 2017). Civil society was also prodded into a more active role in provision of support to vulnerable groups (Kings, 2018). Today, there are increases in nursing homes and home care services also in the non-profit sector (Blomqvist & Winblad, 2019).

Some forty years after what Ryner has called the neoliberalization of the Swedish welfare state, it is not uncommon that discussion of the welfare state is framed around "crisis" or deterioration. In particular, the gaps of the welfare system have come into more critical recognition. Inghe and Inghe (1970) wrote already in the 60s of "The Incomplete Welfare State" ("Den Ofärdiga Välfärden") where many lay bare, outside the warming blanket of welfare services, such as the homeless and migrant populations. Now, especially with the onset of Europeanization, globalization, and neoliberalization, the matter of who is actually entitled to care from the welfare state, and how that support should be organized, is unclear (Meeuwisse & Scaramuzzino, 2018; Swärd, 2017). What can be said is that the Swedish Model of the welfare state is in a time of transition, where the relationships between the individual, civil society and the state are becoming renegotiated on economic as well as ideological grounds.

The following paragraphs will attempt to address some key dimensions of the welfare state in "crisis" and transformation today, drawing primarily on feminist scholarship on care (Dahl, 2017; Hansen, 2022; Ulmanen, 2013). The coming sections will elaborate specifically on care in the latter stages of life, including palliative care, and the gender dimensions of care in the informal sphere. Furthermore, I will flesh out the role of civil society in care and how community-oriented palliative care can be framed in the Swedish context.

Long-term care for older adults

Early in the formation of the Swedish welfare state the precarity and loneliness of older adults was a matter of public concern and political debate. In *Den Ofärdiga Välfärden* the situation of older adults was described in a despondent tone, where life was characterized by poverty, poor or unhygienic living conditions, as well as social isolation (Inghe & Inghe, 1970). In the 1960s, 27% of those aged 65+ did not live in what was at that time considered modern housing and 25% of the 80+ population lived in what were considered the worst housing conditions (ibid p.96). Many of those who did not live in cramped housing with family were described as isolated and unable to manage daily tasks alone (ibid).

Since then, the standards of living for the old and oldest old have changed, and substantively improved. First, in discussing how this change has played out, one needs to acknowledge that *how* we age has changed in the last 60 years. With advances in medicine and access to better housing and nutrition, the life expectancy of the average Swede has increased almost ten years since the '60s (Trydegård, 2017). This means that there is not only an increasing population of older people, but that we have more healthy years as well as more sick years, where many of us have multiple life-limiting illnesses that are managed over longer periods of time (ibid). This means that our care needs have changed: older people, who increasingly live in single person housing (Sweden Statistics, 2020), require more intensive help at home or residential care. In the 1950s senior housing and home-care services were introduced. Originally, this care was the prerogative of the regional healthcare authorities, but this was reformed in the 1990s. Residential and homecare has been provided by municipalities since the Community Care Reform in 1992 (ädelreformen) and framed as a form of social care rather than healthcare (in Swedish this difference is distinguished as *vård* versus *omsorg*)[1] (Peterson, 2017; Trydegård, 2017). The number of people receiving these services increased, then plateaued in the 1980s, and began to decline in the 2000s (Ulmanen & Szebehely, 2015). In 1992 this sector was also opened to private actors (who received public financing). In this decade the number of carers employed by a private entity increased 400% (Trydegård, 2017, p. 215). Today, private care providers take up a fifth of the long-term care market (Broms et al., 2018) (more details relating to these changes will be discussed in the "care struggles" section). Nationally compiled data on income shows that a higher percentage of people over the age of 65 live at the "risk of poverty" threshold in comparison with people in lower age brackets (Sweden Statistics, 2017), indicating that although progress has been made in lessening the precarious living conditions of older adults through state-offered care services, vulnerability endures.

The loneliness of older adults in residential care or in single person households is also still a matter of public concern in Sweden (Ågren, 2020). However, contemporary research on the topic employs a more nuanced understanding of loneliness, where it is understood to incorporate not only the amount of social

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[1] While I use the language of long-term care in this text, the Swedish term for this sector is "äldreomsorg", or eldercare. I have chosen, however, to use the term long-term care as it is an internationally established term by the World Health Organization and wish to frame this text within an international context of debate.

contact one has, but also dimensions of existential loneliness (Dahlberg et al., 2022; Sjöberg et al., 2018). Overall, contemporary studies indicate that older people don't feel significantly lonelier than younger adults in Sweden (The Nordic Welfare Center, 2019). This is not to say, however, that loneliness amongst older adults is not a problem. Evidence from the National Board of Health and Welfare (2016) indicates that while the 65-80 aged population doesn't report significantly higher levels of loneliness, the 80+ population in residential care or receiving home care does: 43% of which report loneliness sometimes and 15% often.

As formal services have become retrenched in the last 20 years, informal care for dependent adults at home, through to the end-of-life, has been on the rise, indicating a trend towards re-familialization of care (Ulmanen & Szebehely, 2015; Vicente et al., 2022). According to the National Board of Health and Welfare (2020), informal care is defined in Sweden as unpaid care, help or support, provided by a significant other (a relative, friend, or neighbor). In total, 20% of all Swedes provide informal care for a significant other, most of the time to an older person (National Board of Health and Welfare, 2021), and the prevalence of informal care is estimated to be up to four times greater than formal care (Cahill et al., 2022). Informal care work in the latter stages of life can involve diverse tasks. For example: driving, cooking, nursing, shopping, and assisting with finances – as well as diverse forms of emotional and/or spiritual support (Wolff et al., 2007). In the last two decades, care from significant others has become more supported by policies providing a system of public care subsidies for up to 100 days, most often for care receivers in the final stages of life (in Swedish, "närståendepenning") (Dedering & Henning, 2013). There is also a care allowance ("omvårdnadsbidrag"), however access to this form of support varies across municipalities (Cahill et al., 2022). The subsidization of informal caregiving in Sweden makes the category of informal care distinct from other national contexts. Although the National Board of Health and Welfare defines informal care as unpaid, the care provided by significant others receiving subsidies cannot conversely be defined as formal care. Cahill et al. (2022) have used Twigg's (1989) model of care to characterize informal care in Sweden therefore as a relation of "co-working" with the state in some instances. However, this is not to say that informal care (paid and unpaid) is de-classed in Sweden. Access to state care subsidies is varied (sometimes depending on municipality) (Cahill et al., 2022); moreover, duration of these forms of support are often inadequate, as many adults with debility and serious illness live with care needs for longer than 100 days. On the whole, caring for a significant other at home is generally associated with lower income and lower education (Trydegård, 2017). Those in higher income brackets are also more likely to purchase privately run services, which are becoming more common in Sweden (Ulmanen, 2022; Ulmanen & Szebehely, 2015). Informal care is also textured by gender inequalities, which will be described below.

Gender inequality in informal caregiving

Sweden's history of universal and state-offered care, where services are guaranteed by need rather than ability to pay, as well as the dedication to women's employment, has afforded the Nordic welfare states the monikers of "care friendly" or even "woman friendly" (Hansen, 2022, p. 3). However, even in these so-called "feminist paradises", struggles in care, also relating to gender, persist. It is specified in Swedish law that informal caregiving should be voluntary, and the state has the prerogative for providing care (Prop., 2008), and this stance is generally supported by both older adults and family members as well as the general public (von Saenger et al., 2023). However, despite formal support for gender equality and autonomy in the policy landscape, gender inequalities are still visible in the normative distribution of unpaid care labor (also in paid care labor, where women are also overrepresented). For example, although women's employment dramatically increased with the increased public provision of long-term care in the 1960s, daughters have and still represent the majority of informal carers in Sweden today (Ulmanen, 2013, 2017, 2022; Vicente et al., 2022). On average, 72% of people who take out an informal care subsidy are also female (Social Insurance Agency, 2018). Although informal care work is formally understood as a voluntary practice in Swedish law, it is clear that women are still beholden to normative prescriptions of gendered behavior regarding care, calling into question the real degree of freedom or agency that women can exercise in making care-related choices. This has consequences for women's health and economic possibilities. Informal caregiving can incur moderate to severe emotional and psychological distress (United Nations, 2009), as well as long-term economic difficulties in maintaining work during or after the fact (Vicente et al., 2022).

One population-based study in Sweden (Stratmann et al., 2021) found that those who reported negative impacts on their personal life in relationship to caregiving also reported higher degrees of depressive symptoms (OR 1.85) and anxiety (OR 1.91) equaling a two-fold increased risk compared to those who were not caregivers (ibid pp. 3-4). Importantly, those who experienced informal caregiving as the most life-limiting also had the least amount of social support during their time caregiving (ibid p. 4), demonstrating the relationship between social and community factors and negative health outcomes for informal carers. Other research demonstrates that older women also often take on the role of informal caregivers for dependent adults, and this has specific age-related consequences for working life. Krekula et al. (2017), for example, have pointed out that extended working life policy in Sweden neglects to consider the extra responsibilities of caregiving women who consequently have less opportunity to work late in their careers. Even when families decide to pursue housing and supportive care in a nursing home, a high degree of unpaid work is required in terms of "navigation" and "advocacy" in order to gain access to this care, amounting to an additional "structural burden" on top of typical caregiving responsibilities in the home (Ulmanen et al., 2023, p. 19). The psychological, social, and economic consequences faced by informal caregivers are afforded little public scrutiny and structural redress despite the fact that this care represents immense value to society. Alwin et al.'s (2021) study of informal care work in Sweden demonstrated that the combined economic value of informal care labor provided to community-dwelling older adults was estimated to equal approximately 72,000 SEK (7,477 euros) per annum per dependent adult. The yearly cost of caring for dependent community-dwelling adults in Sweden is approximately 11,000 million SEK (1150 million euros), meaning that that the support of these informal caregivers is an economic necessity.

Swedish civil society and care

The concept of civil society as we know it today came into being around the turn of the 20th century. It broadly refers to a "specific social sphere that is separate from the state, the market, and the family" (Meeuwisse & Scaramuzzino, 2018, p. 2). As stated previously, the welfare state was seeded in 1930s Sweden in part to liberate individuals from dependence on civil society (including charitable organizations and the church) and the family. In the development of the welfare state since the 60s, civil society has functioned as a locus for popular movements ("folkrörelser") and played an important function in the social democracy (Kings, 2018; Meeuwisse & Scaramuzzino, 2018). Even though the Swedish model stresses the responsibility of the state in ensuring collective wellbeing, today's Swedish civil society can still be described as "vibrant" in terms of the number of organizations and dedicated engagement of citizens (referred to in Swedish as "föreningslivet") (Meeuwisse & Scaramuzzino, 2018, p. 10). Popular movements in Sweden via civil society organizations (CSOs) have been characterized by formal membership; divided representation on a local, regional, and national level; democratic decision-making processes; and a consensus-based relationship to the state (Kings, 2018, p. 82). While for the past half century, the role of civil society has largely been to form and push political agendas, ideas, and policies, in the last decade the role of civil society has come to be more muddled with the roles of the market and state. Since the turn of the millennium, CSOs have become increasingly professionalized, and it is not uncommon for these organizations to be acquisitioned with formalized social duties (ibid). This has happened in step with welfare retrenchment and increased privatization (Linde et al., 2017). The role of civil society in Sweden, while once considered to be unique in the world, is coming to resemble more closely that of more liberal welfare states today.

This has certain consequences in the long-term care sector. Interestingly, the original formation of home-care services for older adults in the mid 20th century were started by CSOs, and later handed off to the state. The first home-care service was developed by the Red Cross in Uppsala in 1950 where the idea was initially to provide meal delivery, social visits, and contact bridges between nurses and the church on an entirely voluntary basis. However, the demand for these services became so high that the organization began to recruit formal employees starting in

1952 (called “hemsamariter” in Swedish) (Linde et al., 2017). Similar models arose in Stockholm with different CSOs leading the way like The Women’s Guild (“Kvinnogillet”). Since 1964 the responsibility for long term care has lied entirely within the sphere of the state (Prop, 1964:85), although the Red Cross still offers volunteer-run social visits to older people. A similar process occurred in relationship to the church, which also provided some forms of home-based care to older adults, whose services became eclipsed by district nurses (Linde et al., 2017). Today, the role of civil society in relation to care is moving back towards providing some forms of support that have been the exclusive province of the state for the last half century. On the whole, long-term care for older adults is a sector with vibrant volunteer networks and CSOs in Europe with the exception of the Scandinavian countries (Blomqvist & Winblad, 2019). However, this is changing. As the care sector began to open up to private actors in the ‘90s there also arose more enlivened discussion about renegotiating the relationship between civil society and the state, reconsidering how civil society could contribute in new ways to service provision (ibid). Namely, CSOs were thought to be able to contribute to care in ways that the public or private sector couldn’t – such as conferring “genuineness” and “trust” (Linde et al., 2017, pp. 290-291). The relevance of civil society in providing care to older people is also often linked to discussions of loneliness in later life, which institutions are perceived as unable to alleviate (Ågren, 2020; Linde et al., 2017). At the same time, the growth of the non-profit sector has been marginal in comparison to the private sector. Between 1993 and 2015 the nonprofit share of the nursing home sector grew from 1.2% to 2.4% while the private share expanded from 0.5% to 15.9% (Blomqvist & Winblad, 2019, p. 519). A large part of this can be explained by the fact that CSOs are not well resourced enough to compete with for-profit companies, nor do they necessarily have the desire to do so (ibid).

Care struggles: A breakdown

Today’s care landscape in the Swedish welfare state is characterized by diverse “struggles”. Dahl (2017) has framed care struggles as a matter of how power affects ideals of care, and how care in turn becomes fragmented in specific and often unequal ways (p.62). The aggregation of different care struggles has been referred to as emblematic of a larger “care crisis”. Fraser’s (2016) definition of the care crisis has come to be one of the most broadly used: “linked to ideas of ‘time poverty’, ‘family-work balance’, and ‘social depletion’, it refers to the pressures from several directions that are currently squeezing a key set of social capacities: those available for birthing and raising children, caring for friends and family members, maintaining households and broader communities, and sustaining connections more generally” (p. 1). The unique conditions of care in the Nordic countries merits a re-approximation of the local meaning of “care crisis”, which has hitherto been dominantly theorized in the United States (Dahl, 2022). This is because the care crisis takes on specific cultural characteristics in the Nordic states, but also because the process of neoliberalism is a relatively late comer to these welfare regimes. Neoliberalism broadly refers to "a political-economic governance that extends the logic of the market, individualization, and responsibility into all areas of social life" (Hansen, 2022, p. 6). Care scholars have referred to neoliberalism as one of the central fulcrums in the breakdown of strong and accessible welfare services (ibid). In order to bring some clarity to the many different facets of these care struggles, I will break down my discussion into discrete sections that are related to the context of this dissertation:

Disavowal of the value of care – Fraser (2013, 2016) has theorized the "care crisis" as a process of *separation cum dependence cum disavowal*, meaning that the division and devaluation of care work is necessary for capitalism to legitimate its cannibalism of such labor. The long-term care sector in the Nordic states has been described as not adequately "attractive" to laborers for several reasons. This kind of work is generally offered part-time, on hourly employment contracts, and work is often needed on weekends and holidays (Myndigheten för Vård- och Omsorgsanalys, 2021). Work related stress and dissatisfaction are prevalent amongst nursing home staff (Stranz, 2022), which can be partly attributed to increasing workplace managerialism and outsourcing to private companies, detailed below.

Privatization and managerialism – Approximately 20% of residential care is outsourced to the private market in Sweden (Broms et al., 2018). Since increased privatization in the early 2000s, access to residential care has become more delimited. This lack in accessibility is strongly correlated with geographical location, as private care providers are clustered in urban centers (Kullberg et al., 2018). There is mixed evidence concerning the quality of care in public versus privately run nursing homes in Sweden (Broms et al., 2018). But as Jönson (2016) points out, the dilemma of privatization is now framed as less of an ideological issue in Sweden as an administrative one, as nursing home facilities have become more regulated, though they are still allowed to operate as profit-making entities. Regulation can also introduce its own problems related to strict quality control and managerialism inspired by new public management (NPM). A high burden of documentation, time pressure, and Tayloristic working methods have had negative impacts in the working lives of nursing home staff, as well as for residents (Hoppania et al., 2022; Peterson, 2017; Stranz, 2022).

Self-responsibilization and enablement – These two terms refer to the individualization of care and a reassignment of responsibility for health to the individual and the family (Dahl, 2012; Gilbert, 2002). They are therefore interlocking with the process of *re-familialization,* where families are encouraged to take on more responsibility for the care of children and dependent adults (Fink & Lundqvist, 2010). This is exemplified in the increased subsidies available to and reliance on caregiving significant others (Cahill et al., 2022; Ulmanen & Szebehely, 2015). Some policies in long-term care which exemplify self-responsibilization are healthy ageing, ageing-in-place, self-care for older adults, and re-ablement (Dahl, 2017, 2022). Although some of these policies and framings have existed since the 1950s (ageing-in-place for example) and have focused less on promoting familialism in care than on helping people age and die where they want (Jönson, 2016), today's usage of these policies has taken a distinct form. In a time of neoliberal reform, these policies' focus on informal responsibility can be interpreted as a strategy to compensate for diminished or beleaguered formal services, discussed below.

Retrenchment – Although there is an image of Sweden as one of the largest investors into the public sector, it actually commits only 11% of its national GDP to healthcare, ranking below the United States, which tallies in at 18% (World Bank, 2023). Public healthcare coverage across sectors in Sweden has been significantly decreasing since the 1990s. Just between 2000 and 2015, a quarter of residential care beds disappeared (Ulmanen & Szebehely, 2015). This has had the effect that nursing homes in Sweden are mostly filled by very frail and old people (Stranz, 2022) and the resulting gap of comparatively younger people with care needs has not been compensated by home care services (Ulmanen et al., 2023). While municipalities used to receive earmarked state grants for eldercare, these allotments were redistributed into lump sums for the larger care sector in the 1990s, including care for children, people with disabilities, and older adults. Municipalities were given thus the freedom to distribute these sums with the least priority afforded to eldercare (Peterson, 2017; Trydegård, 2017).

The palliative care context: Organization and inequalities

Palliative care is a supportive care approach for patients with life-limiting illness(es) and their significant others. It has roots in the nursing philosophy of Florence Nightengale but became mainstream and formalized in medical practice in the late 20th century (Clark, 2016). It is still considered a new field and there are only a few options for specialization in mostly Western countries. Sweden is one country which has a palliative specialization which can be taken post hoc in one's medical and nursing training. Palliative care takes a unique and holistic focus on care which is centered on alleviating symptoms, quality of life, and meeting the needs of the whole family. Palliative professionals use the term "total pain" to refer to the multi-faceted and often hybrid form that pain takes – with physical, emotional, psychological as well as existential components (Gunaratnam, 2014). There are two forms of palliative care which one can receive, generalized palliative care (allmän palliativ vård) and specialized palliative care (specialiserad palliativ vård), of which can be in-patient or at home (advancerad sjukvård i hemmet, ASIH). Generalized palliative care is the form of palliative care one can receive in hospital or primary care in the case of life-limiting illness(es). The success of generalized palliative care depends on the education and awareness of non-specialized physicians and nurses in these settings concerning palliative care. Practitioners and scholars in palliative care broadly consider there to be a dearth of such knowledge outside of specialized settings, and education/consultation are therefore targets for quality improvement (Aldridge et al., 2015). Most patients with palliative care needs will be cared for in hospital, primary care, or in a nursing home (särskilt boende). However not all in these settings who have palliative care needs will be met with a palliative care approach.

The amount of people admitted to nursing homes has significantly decreased in the last decades, with increasing focus placed on ageing-in-place for the 80+ population (Stranz, 2022). The increasing frailty of residents in nursing homes means that there is a higher demand on staff's competence in providing palliative care (Svenska Palliativregistret, 2022). The minority of dying people (11%) will receive specialized palliative care, which includes 24-hour access to a team of nurses and physicians (Svenska Palliativregistret, 2022). Access to specialized palliative care is unequal in Sweden on several axes. The largest inequality in specialized palliative care is on the axis of diagnosis, where those with cancer represent the majority of those receiving specialized care (Svenska Palliativregistret, 2022). Relatedly, older age is correlated with lower admittance to palliative care and most of the oldest old patients have multiple life-threatening conditions (Axelsson, 2022). The amount of palliative care units is also highly variable among regions, even when adjusted for population, indicating geographical inequalities in care provision (ibid). One Danish study also showed that patients in the highest income quartiles and with the highest education were more often admitted to specialized palliative care (Adsersen et al., 2022).

Time to care in the end-of-life

To enable earlier identification of patients with palliative care needs and create smoother care pathways into treatment, programs such as the Liverpool Care Pathway (LCP) or the Swedish Palliative Care Guide (S-PCG) have been rolled out in primary care, nursing homes and home care. LCP is a documentation protocol that advises on symptom management and care measures which can be taken. It involves several layers of assessments, checklists and notetaking concerning patient needs, habits and symptoms that can be completed either on paper or digitally. There is some evidence to show that models like LCP have increased patient satisfaction with their care (Schelin et al., 2023). While there are positive indicators for satisfaction with such programs both on the side of caregivers and patients it is important to consider how they can fit into current evolutions in the welfare state –

especially in regard to neoliberalism and more specifically new public management (NPM) in the long-term care sector. NPM is described in terms of the rationalization of public institutions often involving cutbacks in staff, intensified working schedules, and strict control of service provision (Gustafsson, 2023). Stranz (2022) and Dahl (2012) have made the argument that one manifestation of neoliberal logics in this sector has come in the form of intensified documentation, often framed around the terminology of "patient centered care". This increasing amount of documentation related to quality assurance also runs the risk of escalating work intensification for care providers. This is one example of how market-based logics have been imposed upon the care sector, in the form of maximizing and effectivizing "quality" of service provision via standardized measures (a hallmark of NPM).

Time has a significant impact on the process of caregiving. The patients interviewed in the studies for this dissertation were admitted to specialized palliative care (n=6) or to a nursing home (n=5). It is important to point out the unique positionality of the patients admitted to specialized palliative care. They represent a minority of patients that on average express a very high degree of satisfaction with their care, which is also paralleled by high satisfaction amongst their significant others (Klarare et al., 2017). They receive some of the most holistic care available, having 24-hour access to a multi-professional team that is able to respond quickly to needs as they arise. In contrast to this setting, the structure of care in nursing homes is increasingly characterized by time squeezes and fragmentation amongst nurses (Hoppania et al., 2022). The same is true for other home care services (Katzin, 2020). As an example, a Finnish study showed that between 2005 and 2015, the number of residential care workers that felt they had time to sit down and have a cup of coffee with a client decreased from 25% to 5% (Kröger et al., 2018). This struggle in time interlocks with new management structures in care institutions that promote Taylorist logics of production alongside logics of self-governance. Taylorist logics emphasize "assembly line" style, compartmentalized styles of working. This is reflected in the increased forms of standardization and quality control in care professions, where carers are obliged to "constantly document and report upon their work" (Hoppania et al., 2022, p. 104). This is complemented by a logic of self-governance, which emphasizes flexibility, resiliency, and autonomy. Meaning that struggles that carers encounter in the work environment are often reduced to personal defects or failure to be "flexible enough" or execute wise decision-making skills (ibid). This intensified pressure on carers to produce and be accountable to meeting high standards of quality control has the effect of rationalizing the process of care. However, many scholars are firm in stating that care is a practice and orientation which resists rationalization on an ontological level (Hoppania et al., 2022; Kittay, 1999; Tronto, 2010). The consequence is that the practice of care, which requires meeting others in their time and an ability to respond organically to needs as they arise (as I argue in study 3), is contorted into a form of productive time where clients as well as carers experience higher levels of dissatisfaction.

Public health palliative care: What and why

In the last two decades, a burgeoning public health movement in palliative care has emerged which promotes an agenda of community care in the end-of-life, called by some as "communities of care", "compassionate communities" or "compassionate cities" (Abel et al., 2013). In Kellehear's (2005) book, *Compassionate Cities*, he describes this movement as seeking to affirm end-of-life care as "everyone's responsibility", generate more awareness of end-of-life struggles, and re-center end-of-life care around people as citizens rather than just patients (p. 26). Under this civic program for care and inter-dependency, communities are enlisted as important reservoirs of support in circumstances of serious illness and bereavement. Some have likened this theoretical outset to the concept of "social capital" (Sallnow, 2018) – while Kellehear utilizes the concept of "social ecology" (Kellehear, 2005). Scholars working in the field have posited that community capacity building to care in and around the end-of-life can be accomplished through a variegated set of strategies, such as: the creation of volunteer networks, educational programs, cultural events, and integration of supportive policies in schools, workplaces, and healthcare settings (Clark et al., 2017).

One primary rationale in the field-related literature for strengthening caring capacity in civil society via compassionate communities is framed in terms of risk management. Demographic trends predict that by 2050, the proportion of older adults in the world population over the age of 60 will approximately double from 12% to 22% (World Health Organization, 2021a). Yet today, there are more dying patients which require a palliative care approach than are currently being treated (The Economist Intelligence Unit, 2015). The WHO indicates that more than 50 million people require palliative care and globally only 12% of those individuals actually receive the care they need (Axelsson, 2022). The majority of these patients are in low- and middle-income countries where availability of palliative care is minimal (ibid). Therefore, buttressing healthcare services with informal community caring networks may be important to mitigate the health risks associated with significant demographic change. While this risk management rationale is, on the one hand, uplifting unmet care needs in society, it also often articulates the care needs of older adults as a noxious threat to common welfare. Framing older generations as a "threat" or "financial burden" to healthcare systems is a prevalent and growing discourse globally but especially in mature welfare state contexts (Jönson & Jönsson, 2015). While the validity of unaddressed care needs stands, the reproduction of this reasoning can have an "othering" effect on older adults and reduces their citizenship to its potentially negative impact (Jönson, 2021a).

Another motive for this public health perspective on end-of-life is cultural. Research indicates that dying and bereaved people face specific social challenges, such as social isolation and existential loneliness (Dahlberg et al., 2022; Sjöberg et al., 2018). This is often attributed to modern Western society's "death denialism" and the medical sequestration of end-of-life in media and policy discourse (Ågren, 2020). However, some have argued that the rhetorical popularization of loneliness as a social issue in the end-of-life is primarily deployed to critique modern individualism and is perhaps a weak indicator of real social problems (Tradii & Robert, 2019).

At the same time, some empirical work has shown that engaging communities via volunteerism, education or awareness campaigns can contribute to alleviating the physical, social, and psychological tribulation that often accompanies a serious diagnosis (Abel, Kingston, et al., 2018b; McLoughlin et al., 2015; Sallnow et al., 2016). Studies as well as policy briefs have argued that developing a public health framework for palliative care is essential to building up sustainable systems of support and care around dying and grieving populations (Abel, Kellehear, et al., 2018; Horsfall et al., 2012; World Health Organization, 2021b). The "compassionate community" approach has, for example, evidenced positive results in reducing adverse medical events amongst dying patients. Abel et al.'s (2018a) study in the U.K. on the *Compassionate Frome Project*, the goal of which was to reduce loneliness in elderly and ill populations, demonstrated a reduction of emergency hospital admissions by 17%, with a 21% reduction in costs. They accomplished this through improving community capacity to provide care services through coordination and training of volunteer networks.

Health promotion, neoliberalism, & moralism

The compassionate community movement is undergirded by a philosophy of "health promotion" in palliative care. Health promotion is defined by the World Health Organization (WHO) as "process of enabling people to increase control over, and to improve, their health". Health promotion generally refers to making changes in people's health behaviors and lifestyles. It is one aspect that is typically involved in public health endeavors, although public health is conceptually broader and can also include various forms of disease prevention, health education and policy development. In the Ottowa Charter (1986), end-of-life care was identified as an important area of development for health promotion by the WHO. This was elaborated on by Kellehear (1999), who coined the term "health promoting palliative care" (HPPC). He enumerates (1) improving education about dying and grief, (2) empowering early decision making around end-of-life care, and (3) building community support structures, as foundational to the development of HPPC (ibid). While health promotion strategies acknowledge the important social and subjective dimensions of health and illness, they tend to reflect neoliberal ideologies of risk management and individual responsibility, promoting a certain ideal of "healthfulness" that is beneficial to state interests (Ayo, 2012).

The public health movement in palliative care emerged in the 1990s adjacent to Kellehear's work. The field also encompasses both scholars and activists within the "compassionate communities" as well as "death positive" movements (Van Brussel, 2014). These movements have broadly emphasized the rights of individuals to die at home, surrounded by family and community literate in end-of-life issues – often drawing reference to the "good death" described by Aries (1981). Aries (1981) argued that in our pre-modern past, dying was "tame" or familiar. Moreover, dying had different implications in social life – it was a process of spiritual reckoning that required the practical and moral engagement of family, community, and clergy. Pain was considered to be modus of atonement and dignifying one's kin, and therefore seldom treated (ibid). A "good death," in this context, was one that was embedded in a tight social network which performed practical acts of care around the dying, as well as spiritual support, with little symptom relief. Therein, death was viewed as an accomplishment – both of the individual who had atoned for their sins, and the community which has helped transport them to the afterlife (ibid). In contrast, the medical view of dying in the 20th and 21st centuries views death as a failure of the medical practice, and pain as a target for pharmaceutical management (Clark, 2016; Illich, 1975). Both the compassionate community and death positive movements have broadly mobilized a certain ideology of "good dying" in backlash to the last century of medical dominance over end-of-life. In marked difference to the medieval "good death", however, the modern ideation of dying well within the public health palliative care paradigm emphasizes professional symptom management complemented with the healing tonic of community – colloquially put, "old wine in new bottles".

In striving after a kind of moral ideal of a "good death" or "good health," public health movements attempt to prescribe and control certain forms of social behaviors around illness and care (Ayo, 2012; Metzl & Kirkland, 2010; Sontag, 1990). One could even say that public health measures represent a form of social governance that is interpellated by and enforced through social collectivities or individual subjects, often empowered by feelings of moral righteousness. The "health-conscious citizen" for example, is formed by "inciting the desire within autonomous individuals to choose to follow the imperatives set out by health promoting agencies, and thus, take on the responsibility of changing their own behaviors accordingly" (Ayo, 2012, p. 100). In the case of public health palliative care, the promotion of social engagement, home-based care, and minimal institutional and technological intervention, can align with a growing neo-conservative politics of the family which attributes social problems to the expropriation of care work from the nuclear family unit (Cooper, 2017). Similarly, the public health agenda for community engagement in end-of-life care, in promoting informal caregiving, can also reinforce traditional notions of "the family" and the gender normative roles associated with caregiving in the private sphere of life. Therein, the "good (de-medicalized) death" can become an arena for a moralistic politics appraising the re-familialization of care work and minimizing state-run formal services in an effort to restore lost "family" or "community" values (ibid).

As Sontag (1990) noted, "illnesses have always been used as metaphors to enliven charges that a society was corrupt or unjust" (p. 72). Her work elaborated on how illness becomes conflated with individual moral failings: as punishment or a malaise of unresolved inner conflict (ibid). Today's health-moralism around life-threatening illness is pointed additionally at the moral character of the community at large – dying alone is framed as a modern malady which reflects upon the individualistic and spiritually defunct nature of society and family. Such argumentation easily lends itself to right-wing communitarianism, seeking to reactivate "more caring" communities based around nuclear family units (Held, 2006). Feminist political economists today hold that "neoliberalism and neoconservativism must be thought of together" in order to understand the "political rationality of power" (Cooper, 2017, p. 18). The case of long-term care highlights this tenuous marriage, where conservative rhetorics about family care and the ills of institutional loneliness align with policy transformations in the welfare state supporting re-familialization and welfare retrenchment. This emulates Milton Friedman's rationale for dismantling welfare structures in the U.S. context – that they erode the "natural incentives" of care in families and communities (ibid. p.30).

Care between family and community

But as Sophie Lewis (2022) questions, do such "natural incentives" or values of care "spring from the family" or "survive in spite of it" (p. 30)? Contrary to providing a "compassionate" or even "loving" refuge from life's trespasses, Lewis (2022) as well as hooks (2000a) have argued that the family is often ground zero for abuse. Yet, despite evidence of the family's failure to provide care, it is still regarded as the last and most important stronghold for love and support. Thus, the idiom, "in the end, all you have is family". Is it so, that "in the end", or in life's end, family is the last and primary vestige for care? What role does community play? In the wake of welfare retrenchment, what relationships of care pick up the slack when serious illness comes afield?

For a long time, scholarship on care has focused on family practices, often with a very monolithic, genetic understanding of what family can entail (Nordqvist, 2014). However, field-related understandings of care practices have significantly broadened in recent decades, acknowledging how family is something that we *do* rather than a taken-for-granted construct (Morgon, 2022). Meaning that caring identities and social roles (such as family roles) are built relationally via practices and over time. Care can take place not only in the family but also in diverse and even diffuse webs that straddle relationships composing kin, friends, and acquaintances as well as strangers (Dahl, 2017; Tronto, 1993). However, knowledge about extended networks of care in communities is sparse. Caring networks outside of families and close friend groups are empirically under-researched. Even less so is there empirical investigation of what it *means* to receive care from more peripheral others, such as neighbors or even volunteers.

Policy discourse around long-term as well as palliative care has broadly emphasized the positive role that volunteers can have, especially for those who are living alone or in residential care facilities (Borglin et al., 2006; Noonan et al., 2023;

Sundström et al., 2021). These discourses have emerged often in relation to rising concerns about social isolation and loneliness amongst dying older adults (Ågren, 2020). However, there is little empirical knowledge which elaborates on how communities already do and can factor into alleviating loneliness, and what sort of social support is even desired amongst those older adults who do identify as lonely. It is on these gaps in research that the studies in this dissertation seek to elaborate upon.

Travelling concepts

What happens when a concept travels from one context to another? As I have laid out previously, Sweden has a specific conception of civil society, long considered to be unique in the world, where CSOs functioned primarily as a platform to build political opinion rather than service provision (Kings, 2018). Community-capacity building in strong, secularized welfare states with a history of state responsibility in care, such as Sweden, will be necessarily different to the U.K., for example, which has a steady history of volunteerism and religious roots in palliative and hospice care (Clark, 2016).

Knapp (2005) has pointed out that concepts do not always travel well across international borders, as they necessarily change in meaning depending on the cultural and political landscape which receives them. Based on the last half century of history in the Swedish welfare state, the concept of encouraging civil society's responsibility to care would be a controversial one. Yet in the last decades, private actors as much as CSOs have come to have a stronger presence in long-term care, and discussions of civil society have also become apparent in the specific end-of-life context in media (Ågren, 2020), as well as policy documents (National Board of Health and Welfare, 2007). Region Skåne, the regional healthcare authority for the South part of Sweden where the research for this dissertation took place, has even constructed centers ("anbudsskolor") to help with supporting the startup of small care and service organizations (Linde et al., 2017, p. 295). At the same time, there is a wariness of the growth of CSOs and fear of the civil sector becoming the "trojan horse" in the dismantlement of the welfare state (ibid p. 296). Still, as I discuss in Study 1, there is a desire for the "warm hands" offered by civil society in comparison to the "cold hands" of professional care providers (Dahl, 2017; Hochschild, 1979). The perception then, of communities being able to provide more "compassionate" care then is also legible in the Swedish context. But the matter of leveraging community actors and setting them into motion on the scale achieved in liberal welfare state contexts, such as the U.K., is uncertain. As laid out, CSOs have had trouble gaining ground in the long-term care sector because of the high level of competition posed by the burgeoning private market (Blomqvist & Winblad, 2019).

Compassionate communities are organized differently depending on where they are implemented, and which agents make up the driving force. There is therefore debate in the field about whether a top-down or bottom-up approach to the model is most effective, as well as the different outcomes they confer (Patel & Noonan, 2022). In the Swedish context, where civil society has had a consensus-based relationship to the state (Meeuwisse & Scaramuzzino, 2018), the outcome of compassionate community development could potentially assume a hybrid form, with a lateral form of organization and power between state and civil society. Regardless of what kind of structural form compassionate communities might take in the Swedish context, it is important to meditate upon the ideological usage of the concept. For example, there is a risk that the compassionate communities concept travels from one cultural context with a "progressive" intent to de-medicalize and normalize dying and caregiving, to a context which can employ the same concept in a "regressive" fashion. The adoption of compassionate communities into the Swedish welfare state context which is currently in modus of re-commodification and re-familialization could mean that the project takes the form of reinforcing the expropriation of care responsibility into families and civil society.

The Österlen Project

This dissertation was written in collaboration with the Österlen Project (Österlenprojektet), a cross-border initiative to improve living while dying for everyone in Österlen via education, strengthened care integration, and public outreach. The project was conceived and steered in partnership between specialized palliative care in Southeastern Skåne (ASIH Ystad), the Institute for Palliative Care in Lund (Palliativt Utvecklingscentrum), Simrishamn hospital, primary care, and municipality, and the Österlen Hospice Foundation (Stiftelsen Hospice Österlen). In the beginning, the Österlen Project was framed around improving care integration for patients with a serious illness, and enabling more seamless care across the many different care providers one meets in the end-of-life. This was coupled with the ambition to increase education in palliative care amongst care providers in the hospital, primary care, and municipality. When I met the project manager (Christel Wihlborg) in 2018, we decided to incorporate a community engagement dimension to the Österlen Project with a research component. The initiative then took on a three-pronged approach – to improve living while dying from the side of healthcare via (1) integration, (2) education, and (3) community empowerment. The project, in its original form, was active between 2017 and 2023. In the Autumn of 2023, the project was deconstructed into an interprofessional executive committee which integrated the project goals into already existing work at the hospital, primary care, and municipality.

Contextualizing care in Österlen

Österlen is an area in the Southeast corner of Skåne (the southernmost region in Sweden) distinguished by unique natural landscape features and its cultural heritage and is therefore a popular sightseeing and travel location. It is popularly thought of as an "ideal place to retire" and for that reason many people move from other parts of Sweden to spend their pension there (SVT Nyheter, 2012). It includes the municipalities of Ystad, Tomellilla, and Simrishamn – although the majority of fieldwork in this project took place in Simrishamn. This is because Simrishamn has the oldest population in Skåne, where for every 100 working adults, there are 76 on pension (Region Skåne, 2023, p. 18).

Table 1: Demography of Simrishamn compared with Skåne's total population in 2022 based on data compiled by Sweden Statistics

	Population	Education after high school (%)	Born outside of Sweden (%)	Above the age of 85 (%)
Simrishamn	19,267	34.5%	14.8%	4.4%
Skåne	1,402,425	41.2%	23.5%	2.6%

Recently compiled data within Österlenprojektet has demonstrated that there are noteworthy shortcomings in care around patients in the end-of-life in this municipality. Most significantly, that those who died in nursing homes (which represented the most common place of death) had poor documentation of wishes and priorities, as well as a lower incidence of "break point conversations"[2] with their care providers, meaning that they had comparatively poor care planning in their final months, weeks, and days of life (Wihlborg et al., 2023). This lack of adequate planning is reflected in the high incidence of emergency room visits as well as admission to hospital in the last six months of life for those living in nursing homes. This is in comparison with specialized palliative care (where the minority of patients died), where between 83 to 100% of wishes, priorities, and break-point conversations were documented (ibid).

In-patient specialized palliative care in Southeast Skåne is located in Ystad hospital, which is 50 kilometers away from Simrishamn. The outpatient services though are spread out through the whole Southeast Skåne region. The palliative care team (often including a physician and nurse) often drives for between 20 minutes to an hour to meet patients. One is admitted to specialized palliative care typically after

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[2] Break-point conversations (in Swedish,"brytpunktssamtal") are defined by the social department as the conversation that happens between a physician or other responsible healthcare provider regarding transitioning to palliative care, where the contents of continuing care are discussed in relationship to the patient's condition, needs, and wishes. Socialstyrelsen [National Board of Health and Welfare]. (2018). *Palliativ vård – förtydligande och konkretisering av begrepp*.

a referral from a primary healthcare provider or acute hospital care. Most of these patients have cancer and complex needs that cannot be met by other levels of care. Some patients in nursing homes also receive care from the specialized palliative care team. According to the Swedish Palliative Register, in 2023, specialized palliative care treated 52 patients from Simrishamn, which represented 17% of those that died that year.

Simrishamn hospital, which is semi-privatized, has been involved in discussions about incorporating a stronger palliative approach in primary and geriatric care. All staff based at the hospital received ongoing trainings since 2017 from the palliative team in Ystad in how to incorporate a palliative and holistic care approach in their respective wards. Similar trainings have also been held with nurses from the municipality. According to data from the Swedish Palliative Care Register, in 2023, 23% of all Simrishamn citizens who died that year occurred hospital. From that same year, in Skåne, .8% of people reported that they would wish to die in a hospital (Svenska Palliativregistret, 2023).

The municipality is responsible for other home care ("hemtjänst") services in addition to nursing homes. Receival of home care is determined by a needs assessment wherein municipal social care is integrated with care on the regional level (primary care) (established in the Community Care Reform of 1992) (Peterson, 2017). The most common recipients of home care are women over the age of 65 (National Board of Health and Welfare, 2022a). In Simrishamn, 1,858 people over the age of 65 received some form of home care during 2022 (ibid). The specialized palliative care team works often alongside the home care team.

Framing the research

The research in this dissertation is framed by our collaborative work in the Österlen project. While I was co-organizing public events, I met physicians and community actors which later became important "gatekeepers" for the research field (Eklund, 2010). Our collective decision, for instance, to buy, translate, and freely offer the International Last Aid Course to the public became an opening for an action research approach. Via the Österlen project, I also met physicians and nurses who would later help me get in contact with the patients and relatives who were interviewed in studies 2 and 3. Beyond opening up terrain in the field, the activities in the Österlen project enriched my understanding of care struggles and the cultural context around end-of-life care in Sweden. Being an American who had moved to Sweden in 2015, I still had not only a lot to learn about the healthcare system, but also about the cultural aspects of dying and caregiving. Throughout my time working in the Österlen project, my interpersonal and cultural understanding of the field deepened. So, while I started out as an "outsider", I slowly became more of an "insider", although always partially (Taylor, 2011).

Our outreach strategy was based on public health palliative care initiatives in other cultural contexts, primarily inspired by the “compassionate community” model. As Clark et al. (2017) enumerate, there are several approaches to engaging communities in end-of-life issues, including but not limited to: education, cultural, advocacy, policy, intangible and ethico-legal oriented activities. Being a small team with no prior experience working with public health approaches, we limited our ambitions to a few, small activities that could be managed with little resources. For this reason, we focused our efforts on running Death Cafés (for inspiring cultural change), offering the Last Aid course (for educating the public), and holding public seminars also with local politicians and regional leaders (advocating for more policy attention towards end-of-life issues). What these activities entailed will be explained in more detail below (see headline: “Activities”).

While we took a variegated approach to health promotion in collaboration with local citizens and regional actors, the Österlen project only loosely adhered to some of the functional components of a “compassionate community” project. In Kellehear’s “Compassionate City Charter”, a compassionate city (or community) “publicly recognize[s] people at the end of life and their needs and are aware of the search and involvement of all the main sectors of the city to help through care and accompaniment to reduce the social, psychological and health impact of life’s difficult processes and situations, especially those related to disability, ageing, dependence, end of life, burden of caregivers, pain and loss of a loved one” (Librada-Flores et al., 2020, p. 2). While the Österlen project aligned itself with this theoretical outset, some practices which Kellehear (2015) suggests within this framework were not addressed or planned for, such as (ibid pp. 80-82):

(1) Implementing annually reviewed policies and guidance documents for death, dying and loss in schools, workplaces, religious organizations, unions, hospices, nursing homes, and cultural centers.
(2) Organizing public memorials representing the major sectors of human loss.
(3) Formally celebrating and showcasing various organizations and individuals (as well as policy interventions) that have made a difference in the end-of-life care sector.
(4) Working with local media to raise awareness of end-of-life issues via arts and culture.
(5) Underscoring the role of diversity in experiences of illness and loss and providing support to marginalized groups (such as the homeless and imprisoned).
(6) Establishing a formalized action plan across sectors and professions that is annually reviewed.

While our project group was invested in involving palliative care services in local government policy and planning, only a few actors from specialized palliative care were engaged in communication with regional and municipal leaders. Such cross-border collaborations never took on a formalized character or manifested concrete policy changes/interventions. However, the activities of the Österlen project were included in the municipal care plan (vård och omsorgsplan) in 2021 (Simrishamn Muncipality, 2021). In this document, it states (p. 7):

> Within their work mandate, staff from the social welfare services have participated in the Österlen project… This project has the ambition that death should be considered a natural part of life and that dying individuals, as well as their relatives, need support not only from healthcare but also from the surrounding community. We have introduced the concept of 'compassionate communities' – which can be translated in Swedish to 'ett samhälle där vi hjälps åt'. The social welfare committee includes this concept in the municipality's strategic planning around caring for the increasing population of elderly[3].

While the project did not create any guidance documents around death, dying and loss that could be used in, for example, schools, workplaces, unions – the intention to foreground end-of-life issues in care planning was made explicit in our collaboration with the municipality.

Furthermore, while our team was also engaged in reducing the "taboo" of death and dying via cultural activities (Librada-Flores et al., 2020, p. 2), we did not manifest a strong sustainability plan to motivate community engagement without the executive leadership of the project team, which was necessarily limited by time and funding. Several compassionate community projects in international contexts have emphasized collaboration between healthcare and community in their development strategy. This is generally built around volunteers or healthcare workers which connect patients to relevant community groups and networks (Abel, Kingston, et al., 2018a; McLoughlin et al., 2015; Noonan et al., 2023). While the Österlen project did engage volunteers and community leaders in planning events and in teaching the Last Aid course, there was no formalized or systematic collaboration established between healthcare providers and community networks. Other scholars in public health palliative care point out additional important components to compassionate community development, such as: interprofessional and cross-border collaboration with communities (Sallnow et al., 2010), or

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[3] Original Swedish: ”Inom ramen för arbetet med planen har personal från socialförvaltningen också deltagit i de träffar som Österlenprojektet har anordnat… Österlenprojektet har som ambition att döden ska vara en naturlig del av livet i samhället och att man som döende eller som anhörig till någon döende behöver stöd från samhället runtikring och att det inte enbart ska vara en fråga för sjukvården eller socialtjänsten. Man har introducerat konceptet compassionate communities – som kan översättas till ”ett samhälle där vi hjälps åt”. Socialnämnden vill inkludera det begreppet också i kommunens utmaning med fler äldre”.

education about dying and loss in schools and workplaces (Abel et al., 2011) – both of which the Österlen project focused intensively on. Considering the current scholarship around compassionate communities as a whole, the Österlen project did not meet many of the field-defined norms of a compassionate community initiative. At the same time, it is important to point out that public health palliative care is a relatively new field and there are no broadly agreed upon frameworks for how to create a compassionate community (for example, via top-down or bottom-up approaches) or validated tools for measuring program outcomes (Librada-Flores et al., 2020). From a wide-angle view then, it can be said that the Österlen project did engage in important *groundwork*, inspired by the compassionate community approach*,* which could preface a more well-resourced public health intervention in the future.

Importantly, the goal of this dissertation is *not* to evaluate the progress of the Österlen project as a beta-level compassionate community. Some research has used qualitative methods for evaluating and exploring compassionate community development, such as Sallnow's (2018) mixed methods exploration of the *Compassionate Neighbour Project* in England. In contrast, this dissertation, while partly based on the work done in the Österlen project (study 1), will explore the context and implications for developing a public health approach to palliative care in Sweden, rather than the outcomes and progression of the project itself. This work provides important insight into existing social networks of care around patients and their significant others, and the complexities of relations of care in this phase of life across a diverse range of actors in the context of the Swedish welfare state model. These studies can be used to critically foreground future public health strategies.

Activities

A diversity of cultural events were offered to the general public in order to increase awareness of and agency to respond to end-of-life issues. "Death cafés", for instance, were social meetups organized within the project two times per year. A death café can be described as pop-up café event, lasting approximately two hours, where people are invited to discuss issues related to illness, dying, and grief over free coffee and cake. While they open up for discussion around end-of-life, they are not intended to be settings for grief support. The intention rather is to destigmatize the topic of death and exchange knowledge and experience about a period of life which is not often discussed (Miles & Corr, 2017). Over the project period, we organized eight cafés (with approximately 25 participants each) often in partnership with other community actors such as: the Swedish Church, Österlen's museum, the municipal project group "Together against Loneliness" (Tillsammans mot Ensamhet), and various local artists. Preceding some of the cafés were special exhibitions:

(1) Mixed-media artist Thomas Romlöv presented his film, “What is Death?” (Vad är Döden). Organized in partnership with Österlen’s Museum.
(2) Professor emeritus Anders Palm held a talk, “Love, Illness, Death: The case of Hjalmar Gullberg” (Kärlek, sjukdom, död: Fallet Hjalmar Gullberg). Organized in partnership with Österlen’s Museum.
(3) Filmmaker Paul Jackson and performance artist Börje Lindberg present their film “The Dance of Death” (Dödsdansen). Organized in partnership with the Österlen Hospice Foundation and the Swedish Church.

In addition to bi-annual steering group meetings (including representatives from the hospital, municipality, primary care, nursing homes, the Österlen hospice foundation, and specialized palliative care), several public seminars were held to call other community leaders and organizations into participation, as well as to educate the general public about palliative care and planning for end-of-life. Some of these activities were financed by joint funding received from *Vinnova’s Social Innovation* grant received in 2019. In chronological order:

(1) Kick-off seminar for project collaborators (current and potential) and the general public. The national association for pensioners (Sveriges Pensionärsförbund) as well as the Swedish church joined in to give presentations about finding support after a serious diagnosis.
(2) Public lectures: ”Cultural issues in Palliative Care – prof Birgit Rasmussen” and ”Testaments – Linus Broström” held in partnership with the Swedish Church.
(3) Invited guest Professor John MacArtney holds a public lecture on social issues in the end-of-life, hosted by the Institute for Palliative Care.
(4) Seminar on public health palliative care with the municipal association of pensioners (Kommunala Pensionsrådet).
(5) Seminar on involuntary loneliness amongst the frail elderly hosted by Österlen Hospice Foundation.
(6) Presentation of public health perspective and the Österlen Project to local politicians during a yearly municipal assembly.
(7) Panel debate: ”The last breath is just as important as the first” (Det sista andetaget är lika viktigt som det första) featuring speakers from the Österlen Hospice Foundation.
(8) Public seminar: “Senior in Österlen”, in collaboration between the municipality, specialized palliative care, Simrishamn hospital and primary care.

We also adapted the international education in “Last Aid” to Swedish and offered courses for free across Skåne. Last Aid is a European educational concept which aims to educate non-professionals in basic skills related to caring for seriously ill people and grieving significant others (Bollig et al., 2019). Like First Aid, the course content is framed around improving health literacy—or in this case, “death literacy”, in the general public. Death Literacy is defined as the knowledge and skills which enable one to make and act upon end-of-life decisions. The Last Aid course is a half-day long course broken up into four units: Death as a natural process, planning for the future, relieving suffering, and saying goodbye. In each of these units, participants are given the knowledge and tools necessary to not only plan in the case of their own illness, but support others around them that are in the midst of serious illness or loss. We offered nine courses, three of which were offered online during the COVID-19 pandemic, educating approximately 180 people total. Several collaborators (Simrishamn municipality and the Swedish Church) sponsored the education with venues and catering. In 2022, we held a teacher training course in Last Aid with nurses, doctors, and volunteers from around Sweden so the course could be spread and implemented in other healthcare and community settings. The specialized palliative care unit in Sollentuna became a satellite teaching group and collaborator in quality improvement for the course. According to course evaluations gathered for study 2 (which had a 68% response rate), the education was positively received and 90% of participants expressed that they would recommend it to others.

Several articles were published in Ystads Allehanda, Österlen Magasinet and Dagens Nyheter between 2019 and 2023 covering activities offered by the Österlen Project.

Relating to death

This section provides an outline of the theoretical framework of the dissertation. It will discuss how dying and caregiving can be viewed through a gendered and relational lens. It may seem oxymoronic to call death a relational or even socially constructed phenomenon. After all, from a secular, Western perspective, it is the most absolute, material inevitability of life – or even, “the ultimate biological essentialism” (Van Brussel & Carpentier, 2014, p. 3). However, the phenomenon of death is socially and relationally curated, ritualized, and can even be hastened or slowed by social forces. It is also imbricated in gendered notions and norms surrounding dependency and responsibility to care. This claim is not made to refute death as a real physical phenomenon that happens independently of human thought and human relationships – but to illuminate how society makes meaning of and controls the process of dying.

Theoretical choices

There are many ways to talk about and frame end-of-life issues. Matters relating to autonomy, agency, dignity, suffering, and “the good death” are well theorized, for instance, in the field of the sociology of death and dying (Aries, 1981; Bauman, 1992; Das & Han, 2015; Engelke, 2019; Kleinman et al., 1997; Richardson & Hockey, 2020; Van Brussel & Carpentier, 2014). While I do draw on some of this work for background and theoretical context, the main analytical concepts I use in this dissertation come from feminist scholarship on personal life, care, and lived experience. I will briefly touch upon how I have and will use scholarship from the field of the sociology of death and dying, and then go into what I mean by “feminist scholarship” and why I have chosen to maintain analytical focus there.

In the background section, I have touched upon the work of Ariès, which has been very influential in developing the medicalization and death denialism theses that have undergirded the death positive movement and as well as the field of health promoting palliative care. I have also drawn upon the work of Metzl and Kirkland (2010) to elaborate on the neoliberal aspects of public health and potential implications in the phase of the end-of-life (in the section: “Health Promotion, Neoliberalism, & Moralism”). Going forward in this chapter, I will reference Van Brussel (2014), Armstrong (1987), Lawton (1998), among others, to develop theoretically how autonomy and dependency can be theorized in the end-of-life context. I will explore how these concepts texture the idea of the "good death" as well as how care is performed and valued.

Throughout this dissertation, however, I lay more attention to feminist scholarship on relationality, care, and phenomenology. Feminist scholarship can take many forms and the field is characterized by divisions and disagreement. At the same time, there are some unifying principles in what can be considered feminist scholarship. As laid out in the section on transdisciplinarity in the introduction, feminist research can be considered to be a mixed field where gender is used as a *critical concept* to challenge disciplinary knowledges as well as social oppression (Lykke, 2011; Sandford, 2015). This can be done in a myriad of ways. I will lay out below in which ways I use feminist theories in this dissertation:

Regarding relationality and care – Scholarship on relationality, while broadly falling within the fields of philosophy and sociology, has been prominently theorized by feminist scholars, i.e. scholars who have worked from the standpoint of women's experiences in order to come up with a critical theory of a relational social reality. Ethical scholars such as Gilligan, Tronto, Held, and Kittay, who are keystone figures in care ethics, are case in point. They worked from the standpoint of women's experiences to decenter justice-based ethical theories, and instead formulate moral life as relational. Sociologists like Smart, Morgon, May, and Nordqvist have also explicitly worked from a feminist standpoint by theorizing gender as a constructed and relational category in the public and private spheres of life. By illuminating gender as a relational and social construction, oppression on the basis of gender is made more surmountable (Koggel et al., 2022). I use feminist relational theory in this dissertation (studies 1 and 2) in order to unpack how the practical and affective dimensions of care in the end-of-life are entwined with gender – often with negative consequences for women. I lay this against the backdrop of feminist scholarship on welfare, which employs gender as an analytic in criticizing state organized forms of care (Fraser, 2013; Hansen, 2022).

Regarding phenomenology – Feminist phenomenology is a form of critical phenomenology which seeks to destabilize what are considered to be universal aspects of human experience, using gender as one fulcrum for subversion (Oksala, 2023; Zeiler & Käll, 2014). This form of phenomenology attempts to account for experiences of otherness and difference, rather than grasping after universal "essences" (ibid). In doing so, feminist phenomenologists seek to describe how power moves through society, creating social divisions. In addition to gender, other social categories such as disability and age have been the topic of feminist phenomenological inquiry (Shildrick, 2009). In study 3 in this dissertation, I use Beauvoir's phenomenology of age in order to explore experiences of social support in old age and very old age. In doing so, I decenter the meaning of social support and encourage a more diversified and inter-subjective view of this concept in the end-of-life context. In following with Beauvoir's method, the personal dimension of experience (the view from within) is critically connected with a political and social context (the view from without).

I focus on feminist scholarship throughout this dissertation because: (1) feminist theories of personal life and lived experience are well suited to examine not only gender, which is a salient category in end-of-life experiences; (2) but also old age, as Beauvoir's work demonstrates; (3) as well as the political context for care. Theories and knowledge developed within the sociology of death and dying are used to foreground the feminist theoretical basis of the text. Scholars in this field have well laid out how "life and death are folded together in the lives of individuals and communities" (Das & Han, 2015, p. 1). What I contribute to this field is how life and death are "folded together" along the lines of gender and old age in the welfare state context, and to what consequences.

What is care?

Different disciplines have disparate ways of conceptualizing and analyzing care. In psychology, care is talked about as a practice which changes one's responsiveness and relational way of thinking (Gilligan, 1993). Feminist economists have elaborated on care as experiences of love and responsibility in an economic regime which doesn't recognize these factors of human relationships (Folbre & Nelson, 2000). Feminist philosophers have formulated care in terms of an ethical theory which focuses on how moral life is textured by our inevitable dependency (Held, 2006). Marxist theorists have uplifted care as a form of reproductive labor which makes other forms of productive labor possible (Bhattacharya, 2017). Care is multidimensional: it has cognitive, affectual, ethical, and material components, and each aspect contributes to our understanding of how care works in societies as much as our individual lives.

Research on care is central in gender studies, but it is also defined within this field in different ways. For the purposes of this dissertation, I prefer Duffy's (2011) interpretation: care is "any occupation in which the primary task involves maintaining people both on a daily basis and intergenerationally" (p. 6). Fisher and Tronto (1990) have also offered a widely cited definition: care is "a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible" (p.40). However, Duffy's definition refers more precisely to the meaning and labor of care between humans both in the vicissitudes of daily life and in a larger structural perspective, which is why I choose to center it in this text. In her framework, care can be divided into two forms of practice: nurturant and non-nurturant work. The former denoting the relational, face-to-face care work which is done to improve the well-being of others (for example, nurses, teachers, social workers); and the latter denoting the indirect work which makes the nurturant forms of care possible (for example, house cleaners, kitchen workers, hospital laundry workers) (Duffy, 2011, p. 9). This distinction is very useful for understanding the intersectional and unequal divisions of labor in formal care work. In the informal sphere, nurturant and non-nurturant work are often packaged together, so in this sense, this dissertation deals with both of these dimensions of care. At the same time, I also take a wide-angle view and consider how the welfare state shapes possibilities for care in this phase of life more generally.

To call care relational means to recognize that practices of care are defined in relation to shifting and variegated needs which are in turn shaped by a specific social environment (Smart, 2007; Twamley et al., 2021). Moreover, caring practices are always performed in relation to specific others, and "in carrying out these practices, these sets of others are defined and redefined" (Morgon, 2022, p. 23). Care is therefore understood in this dissertation as relational as well as inter-subjective, meaning that our self-concept is also continually shaped by how we relate to others through the practice of care. This takes place in connection to close significant others, broader community networks, as well as strangers (such as professional carers) (May & Nordqvist, 2022). These relational networks of support are complex and "shaped through layers of meaning, history, biography, and emotionality that reside within and between people" (ibid p. 11). They are furthermore variegated across time and space, sometimes spanning vast geographical distances (Dahl, 2017).

Care is relational and personal, but it also takes place in a structural context. This means that care is shaped by relations of power in society. The ways in which individuals relate to and care for one another are influenced by socio-political factors and institutions such as location of care, working life policies, and availability of care resources, to name a few. Hochschild's (1979, 2012) work on emotional labor seminally demonstrated how structures of power shape care by elaborating on how those in caring professions are expected to manage their emotions in line with organizational codes of conduct as well as social norms. The emotional dimension of care that professionals provide (for example, nurses) are always shaped by structural demands on their productivity (for example, of healthcare authorities or private care institutions). This is also the case for emotions in private life, which are managed according to social norms and expectations, relating to identity categories like gender and age. These tensions complicate the long-held view that care was either a matter of love or labor, and instead posited that these components of care are actually imbricated in one another and molded by how power moves through society as well as individual relationships. At the same time, the power of structures is not totalizing. Bolton (2000), building on Hochschild's theoretical framework, demonstrates how carers construct their own "nurturing rationalit[ies]" in working life (p. 585). In her study on the emotional work of gynecology nurses, she shows how nurses offer "extra emotion work as 'gift' to patients" on top of the demands on their emotional labor made by the healthcare institution (ibid p. 584). Therein, they make choices about how to delegate their emotional resources, attending to the demands of care made by the care institution but also choosing to give extra emotion to patients as they see fit. Likewise, in the studies in this dissertation, the agency of individuals is highlighted in caring relationships and how choices are made amidst constraining structural factors. The exercise of such choices demonstrates how caring is not a static category, but a practice which is continually shaped through micro as well as macro processes.

The influence of social structures in how we practice care can foster contestations between individuals in a caring relationship but also between different professional groups, which may have different ideas about their own identities as carers or the goals of care. The welfare state is one overarching structure which feminist scholars have described as a site of power and struggle in care (Hansen, 2022). Dahl (2017), for instance, has elaborated on how power comes to express itself in the logic of welfare institutions and inflects the way that welfare professionals approach care in their working lives. The influences of neoliberalization, bureaucratization, and globalization, for example, change the way that welfare institutions organize care work and conceptualize the ideals of care (ibid). Neoliberalization, as I explain in other sections of this thesis (see: "care struggles" and "health promotion, neoliberalism, and moralism"), promotes an ethic of competition in care via privatization, encouraging modes of working which are subject to higher division of tasks and rigid performance control (ibid p. 48). In this paradigm of care commodification, efficiency and uniformity become expressed ideals of care. This can lead to struggles between families of patients and carers, carers and managers, and between different institutions responsible for patient care. These struggles in ideals of care are exemplified for example in study 1, where ideals between "warm" and "cold" forms of care are discussed in relationship to community versus professional support. Throughout this dissertation, care is discussed in terms of practices, the ideals and values attributed to those practices, and the ways in which gender inflects care on both of these levels.

The ways in which our agency to care is influenced by social structures, and textured by struggle, will be elaborated on in more detail in the next sub-sections.

Agency in care

One of the most common divisions in sociology is between those who look first at social systems and those who look first at social action. This has been described by Alan Dawe as "the two sociologies" (Dawe, 1970). On the one hand, there is a view of structure as being the determining force in defining social reality – i.e. macro-level phenomena such as: the family, the state, the market. On the other hand, there is a view of agents as the arbiters of creating the social fabric – i.e. that accumulated human practices and choices make up the nature of society. Most social scientists can recognize that both are “true”, but they cannot be simultaneously (Danermark et al., 2019, p. 75). Finding clarity and purpose in how to analyze agency and structure is crucially important for studying care, as I explore in this dissertation. This is because there are analytical consequences for analyzing care using either agency or structure as a primary outset. Many feminist care scholars would argue for first analyzing from the point of structural relations of power. The reason for this is because in the neoliberalization of the care sector, the forces of “self responsibilization” and “enablement strategies” aim to lay the prerogative of care at the feet of the free and choice-making citizen (Hoppania et al., 2022). This has the effect of inflating the role of human agents in the process of care, explaining deficit or abuse as the fault of defunct individuals that made poor choices. In the formal care sector, Gustafsson (2023) has described this tendency in the form of “emotionalization” of inherently ethical and structural problems in care institutions. When healthcare professions encounter problems or make mistakes at work, management structures often try to individualize their experiences, and explain them in terms of emotional distraction, while remaining blind to problems in the working environment (p.263).

In the informal sphere

Also in informal care, the role of the free and willing significant other is increasingly uplifted in policy spheres. However, performing informal care at home is not always a matter of choice, but rather of lack of rules and resources which provide formal state support across different care situations (Stranz, 2022). Miller (2021) has framed this in terms of “moral injury” inflicted upon significant others. While some can provide the ideal care that they want for their significant others at home, not all do. Those who are afforded the least resources and latitude to give the time needed to care are faced not with an emotional crisis but a moral one, where they are unable to give adequate attention to their significant other’s care needs. This focus lays the onus of deficit at the doorstep of the state, rather than the failure of individuals to provide care.

A core theme in this dissertation, particularly study 1, is that the sphere of personal life is not only a matter of “basic individual needs or characteristics” but must also be viewed as “being shaped by wider social and cultural factors”, particularly in reference to the welfare state (Morgon, 2022, p. 19). Agency is not only a matter of individual power, but the internalization and negotiation of social scripts which prescribe certain caring behaviors. Neoliberalism is one force which has induced changes in the dominant social scripts surrounding care, and whose responsibility it is to care in modern welfare states. As Dahl (2017) points out, neoliberalism is enacted through concrete state-level practices that migrate through policy spheres, but it also instantiates a shift in basic relational logics, “changing our ways of arguing and identifying ourselves and others” (p.47). One effect of “self responsibilization” or “enablement” is the interpellation of the belief in oneself as a free and self-determining individual. However, this belief in autonomy is contradicted by systems-level prejudices and barriers delimiting which subjects should and can provide and receive care. The creation and enforcement of these social scripts, or logics, also has a strong gender component.

For example, the self-concept of the “free and gender-equal woman” in the Nordic welfare context can become a “subordinating weakness” as well as functional fallacy when considering that informal care is still overwhelmingly performed by women in these states (Lotherington et al., 2018, p. 129). Appeals to one’s sense of duty and love are not uncommon in women’s interactions with healthcare services, where they become normatively obliged into caregiving roles. Lotherington et al. (2018) have framed this in terms of turning women into resources for the “management of welfare state tasks” via gendered practices of informal caregiving in the Nordic countries (p. 138). In their review article on informal caregivers of people with dementia, Bartlett et al. (2018) also underscore how care is performed at home by gendered next of kin. Importantly, though, they indicate that in unpacking the impact of re-familialized caregiving, attention should be paid not simply to women’s inequality, but rather the relational dimensions of gender, privilege, and oppression more broadly. Doucet (2023) similarly articulates the need for feminist scholarship to go beyond thinking of care as “tally sheet” and start thinking beyond who cares, to how and why gender figures into specific caring practices.

Ambivalence

This dissertation also deals with the theoretical and methodological conflict inherent in the structure/agent binary. Articles 1 and 2 particularly explore the complex interaction between structure and agency. In the case of study 1, this relationship is described in terms of sociological ambivalence. Connidis (2015) defines ambivalence in the context of research on family and personal life as a dynamic of interlocking “sentiments, expectations, and forces” in relationships. The concept of ambivalence encompasses a multi-level understanding that accounts for human actions on both the level of individual experience and macro-level processes (p.77). While, as mentioned previously, analytical focus on either structure or agency has been perceived as mutually exclusive, the concept of ambivalence encourages us to view these two outlooks as “fluid” with “reciprocal influences” (ibid p. 78). Connidis, as well as other scholars of personal life (May & Nordqvist, 2022; Smart, 2007), have underscored the importance of accounting for both of these sides together, in order to capture a more holistic picture of “the mutual influence of individual action and societal processes” in relationships (Connidis, 2015, p. 78).

Using this lens, one can see that contradictions and conflicts in relationships can be described in terms of clashes between, for example, social norms and interpersonal experiences. This is visible in a plurality of ways (pertaining to race, sexuality, class, for example), but gender is foregrounded in this dissertation. One example of such ambivalence is the tension between the perception of being a woman in a "gender equal" society, and the lived experience of inequalities in the home in regard to caring responsibilities, as described above. Lynn Jamieson has discussed this tension in intimate partner relationships and the prevalence of relationship breakdown. In this context, she describes a "gap between cultural ideals and structural inequalities" (Jamieson, 1999, p. 477). To resolve this gap, there are a range of creative identity saving or relationships saving strategies that emerge in order to resolve the tension. Her explanation of intimate and caring practices as a matter of constant negotiation of values also rebukes the widespread discourse of relationships being a matter of pure personal choice amongst free agents, and their breakdown as a matter of personal failure. The negotiation of care in personal life after a serious diagnosis, and the gendered values and traits these care practices take on, is discussed in study 2. Here the discussion focuses not relationship breakdown, but how relationships are managed and sustained against the (often) uncomfortable shift into dependency and dependency work.

Another dimension of this ambivalence that is explored in this dissertation is related to one's normative relationship to (i.e. expectations of) the welfare state. Merton's (1976) original articulation of sociological ambivalence as an alternation between norms and counter-norms is used to understand this dimension of ambivalence in study one. In study 1, there is a vacillation between conceiving the community and the state as alternately responsible for compassionate care in the end-of-life.

The relational self in the end-of-life context

Autonomy and "the good death"

In the West today, "the good death" is broadly articulated through a discourse of autonomy, characterized by public rituals of management involving a variety of professional actors such as physicians, lawyers, undertakers, and therapists, to name a few (Van Brussel, 2014). Likewise, Kellehear (2007) and Armstrong (1987) have described modern constructions of the "good death" as cognate to a "well managed death". Indeed, death is typically accomplished in relationship to some form of medico-legal decision making, such as advance care directives, do not resuscitate (DNR) notices, pharmaceutical prescriptions, and legal exchanges. International policy today also typically frames the ability of individuals to make and manage healthcare choices as a "human right" (Van Brussel, 2014, p. 20). One function of this superstructure of decision-making is to help individuals maintain autonomy (i.e. physical and symbolic independence from the care of family and friends) and preserve dignity (via careful management of bodily functions) (Van Brussel, 2014). The maintenance of autonomy and dignity then, in today's terms, are strongly tied up in embodiment and one's ability to make choices and live as independently as possible through to death.

Scholars such as Lawton (1998) have disrupted this conflation of bodily control and dignity by demonstrating how social norms around bodily maintenance are historically situated. She argues that while bodily taboo and regulation were originally an artifact of the upper classes in pre-modern Europe, such "affect controls" slowly trickled down to lower social classes, eventually instantiating a hegemonic bodily norm which transitioned from "an 'open, 'incomplete body', to a body with clearly defined boundaries, isolated, alone and fenced off from other bodies" (ibid p. 135). Sexuality has taken on a similar code-switch, as Shildrick (2009) delineates: "it is precisely because of the inherent risk of losing self-control and self-definition that the domain of sexuality is so highly disciplined and regulated" (p. 119). The violation of this normative ideal of the disciplined and self-enclosed body – via illness or sexual desire – risks a loss of personhood or self-worth. Dignity is thus discursively juxtaposed with a life conditioned by dependence. Living dependently conflicts with canonical Western ideals of subjectivity, which morally centers life around an *atomized* idea of personhood rather than a *relational* self (Held, 2006). Therefore, dependency is often attributed negative ethical monikers such as weakness, uselessness, and parasitism (Fraser, 2013; Goffman, 1986; Illich, 1975; Kittay, 1999).

Relationships of dependency

Rather than being autonomous units, people are conceptualized in this dissertation as necessarily embedded in a vast and complex social network where we are all dependent upon the care or labor of others at some point in life, drawing on the work of feminist scholars like Smart (2007), Dahl (2017) and Barnes (2012), among others. This theoretical outset considers dependency as an inevitability rather than exception (Fineman, 2005). And from a care *ethics* perspective, acknowledging inter-dependency and building a society which allows for the sustainable care of dependent others is a moral prerogative (Kittay, 1999, 2015). While the majority of this dissertation does not deal with care ethics as a self-contained field, it does address how dependency is attributed certain values and is inter-subjectively constructed via caring practices across a broad range of actors (study 2).

In the end-of-life context, and in cases of intensifying dependency, caregiving can become an even more interpersonally sensitive practice. This is because extreme dependency can negatively impact one's sense of dignity and self-concept. In Chatterji's (2015) study of caring in nursing homes, for example, dignity was managed and maintained through a form of "stranger sociability" (p.698). Caring in nursing homes often involves intimate bodywork that can function to alienate care receivers where they feel a sense of diminishing personhood. In order to preserve dignity amidst this intimate work, nurses would attempt to relate to residents as strangers in any other civic space, "fram[ing] invasive activities carefully so as to make them seem impersonal," conferring a sense of "normality" to the care situation (p.705). Preserving corporeal self-containment becomes less and less possible in the deteriorating effects of serious illness and very old age. However, maintaining a fiction of autonomy and normality can be very important in relationships of care, especially in order to make life feel livable in the face of death (ibid). Receiving care is not always an easy task in home settings either. Sand Andersen et al. (2020) point out that in a serious illness trajectory, accepting help and the changing circumstances of life (bodily, socially, and existentially) can be challenging. Some can also prefer dying in hospital or other institutional settings rather than receive help from significant others at home, to preserve some distance between the physical realities of dying and social life (MacArtney et al., 2016).

The "lived experience" of gender, dying, and old age

This dissertation draws upon the phenomenological tools of Simone de Beauvoir to understand the meaning of social support in old age in study 3. Phenomenological and relational understandings of gender are also employed throughout studies 1 and 2. Beauvoir is understood to be a keystone figure in establishing the field of feminist phenomenology – an approach to understanding subjectivity as necessarily situated, often with specific attention paid often to the role of gender in shaping experience. It is a discipline characterized by "rigorous self-interrogation of its own grounds and pre-suppositions" and thereby challenging any essentialist notions of reality and lived experience (Zeiler & Käll, 2014, p. 9). In phenomenology, "lived experience" refers to the first-hand experience of the person in question, as opposed to the second-hand information of such experience that a mediator or researcher has access to.

Instead of making a claim to generalized human experience, Beauvoir sought out phenomenological "constants", structures which transcend historical and cultural borders, that are made visible in examining a plurality of experiences. As she explains in *The Coming of Age*: "The difficulty is that one can adopt neither a nominalist nor a conceptual view of age. It is just something that happens to people who become old; and this plurality of experiences cannot possibly be confined in a concept or even in a notion. But at least we can compare them with one another; we can try to isolate the constants and to find the reasons for the differences" (de Beauvoir, 1996, p. 279). In contrast with more traditional conceptions of phenomenology, Beauvoir rejected the idea that experience can be understood apart from social context and the interpretation of the analyst. Her basis for understanding experience was rather in unpacking how social categories are imbricated in and imposed upon embodied subjects in different ways. The "constants" that she sought out, therefore, are not equitable to Husserlian "essences", they are contingent structures which express meaning across different experiences. In other words, while traditional phenomenology has focused on distilling similarities, Beauvoir's critical phenomenology focused on illuminating ontological differences (Oksala, 2023).

Conceptualizing gender

Throughout this dissertation gender is used as an analytical concept. In some parts, particularly study 1, gender refers to a political and substantive category in the realm of care work. Gender here is discussed mainly in terms of women's overrepresentation in informal care work, and how women's caring roles can be reinforced by health promotion frameworks which neglect this gendered division of labor. In study 2, the analysis of gender is deepened. Here, gender is unpacked as a relational and inter-subjective category which is legible in and through care practices. Throughout these studies, I draw on Young's (2005) feminist phenomenological definition of gender as: "a particular form of the social positioning of lived bodies in relation to one another within historically and socially specific institutions and processes that have material effects on the environment in which people act and reproduce relations of power and privilege among them" (p. 22). Young's definition is useful because it acknowledges: 1) how gender is something which is enacted through individual, lived bodies, and 2) how gender emerges from how people respond to structural relations of power.

Let's unpack what this means. In reference to point one, Young draws on Beauvoir's existentialist understanding of gender as something which emerges from the "body-in-situation". In *The Second Sex*, Beauvoir explicates gender as a matter of not just becoming through social conditioning, but becoming through the way the body, also in its relation to others, is grasped by the subject: "Woman is defined neither by her hormones nor by mysterious instincts, but by the manner in which she grasps her body and her relation to the world through other consciousnesses" (de Beauvoir, 2011, p. 761). In other words, categories such as female-ness are not simply "a matter of biology or myths, but of the way that the body figures in experience at its most intimate and fundamental level" (McWeeny, 2017, pp. 238-239). Beauvoir called this the "situation" of womanhood. In existentialist philosophy, a "situation" is the combined circumstance of facticity and freedom – facticity being one's social/physical environment and freedom being one's ontological possibility to engage in "projects". A project is a future-oriented activity which is "for-itself" – a commitment which contributes to life's transcendence (de Beauvoir, 1996, p. 451). In other words, the situation (of gender, for instance) is "the way that the facts of embodiment and social and physical environment appear in light of the projects a person has" (Young, 2005, p. 16).

However, Young underlines how gender is not only expressed in lived experience, but that it must also be understood in terms of structures which impose themselves on individual life. Her view expands upon Beauvoir's in this way. Beauvoir wrote before the idea of a sex/gender distinction, so instead of using the concept of gender to explain the condition of the female sex, she wrote instead about how womanhood is lived. While Young finds her existential approach useful for understanding subjectivity, she did not want to dispose of theorizing gender as a structural relation of power as well (point two, above). She clarifies why gender theory must not only account for how gender arises in the particular but also as a general category (Young, 2005, pp. 19-20):

As I understand them, feminist and queer theory consist not only in giving account of the meaning of the lives of women and men in all their relational and sexual diversity. Nor are they only about analyzing how discourses construct subjects and the stereotypical or defamatory aspects of some of these discourses that contribute to the suffering of some men and women who fall on the wrong side of normalizing processes. Feminist and queer theories are also projects of social criticism. These are theoretical efforts to identify certain wrongful harms or injustices, locate and explain their sources in institutions and social relations, and propose directions for institutionally oriented action to change them. This latter set of tasks requires the theorist to have an account not only of individual experience, subjectivity, and identity, but also of social structures.

To do just this, she offers an interpretation of gender in terms of “seriality”. A series is made when individuals are passively grouped into unities, such as women or men, according to structural relations of power which create certain restraints in our lives and possibilities for action: “rules, relations, and their material consequences produce privileges for some people that underlie an interest in their maintenance at the same time that they limit options of others, create relative deprivations in their lives, or render them vulnerable to domination and exploitation” (ibid p. 25). Women and men, from this point of view, are “series” and not defined by some kind of essence, but by “the actions that they undertake together” and those actions are shaped by oppression and privilege (Selberg, 2012, p. 42).

In individual life, gender structures enter our consciousness as facticity or “sociohistorical givens” which we respond to, such as how to dress, act, and engage in public and private life (ibid). Our freedom as subjects is always gendered in the way that we practice and enact our social lives in response to such conditioning. Gender then is “experiential response” *not* a common “set of attributes” (Young, 2005, p. 26). This is importantly different from a pure constructionist approach to gender, which would posit that gender is only discourse. In this phenomenological approach, gender does not merely arise, it is actively made (Leboeuf, 2016; McWeeny, 2017); and this process happens not only via subjects who are socially conditioned, but via lived bodies which are enculturated.

Using Young’s theory of gender then, we can see that gender is something that is visible in *practice* and *in relation* to specific others. Connell (1995), notably, expanded upon this ontological starting point and articulated how masculinities and femininities are configurations of practices which are performed by lived bodies in a given historical context. These configurations are not always locked dichotomously on to female or male bodies, but they generally express what is "typical" of female or male experience (Serano, 2016). They are written in the plural because masculinities and femininities are multiple depending on relational context, position in society, and one's embodied responses to such factors. Some are normative, meaning that they comply with dominant ideologies of how men and women *should* act in order to preserve the hegemony of patriarchy and heterosexuality in society. When talking about "caring masculinities", as I do in study 2, I demonstrate how the particular relational context of old age and dependency affect gendered practices, such as care. Men who articulated a more normative way of being men previous in life, atomized and self-sufficient, expressed that as their bodies became more dependent, they came to value care from their friends to a greater degree. Similar research has articulated how ageing can inflect masculinities in this way (Blake et al., 2018).

In this next section, I will go on to explore another social category, age, from the feminist phenomenological perspective, drawing on Beauvoir and contemporary Beauvoirian scholars.

On temporality and old age

The "body-in-situation" can be used to describe many different kinds of experience, beyond just gender. In *The Coming of Age*, a "methodological twin sister" to *The Second Sex* (Heinämaa, 2014, p. 167), Beauvoir (1996) describes age as a situation which is interpellated through the examination of others and their reactions to one's body, which changes one's own grasp of their objective being. She writes, "within me is the Other – that is to say, the person I am for the outsider – who is old: and that Other is myself" (p. 284). The grasping of oneself as old, she explains, plays out as a dialogue between the internal experience of the body with how that body is met by the outside world. The "view from without", the cultural context, bequeaths the old person with the identity of "old", a "situation," which they relate to within. The point here being that biological age is not perfectly mirrored in internal experience. The inner and outer experience of age work together to form what age is for each individual person. Although she emphasizes how the lived experience of age is unique for each individual, Beauvoir also underscores how culture attributes negative meanings to old age and likewise marginalizes, diminishes, and objectifies older people.

While *The Coming of Age* lodges an important critique of an ageist society, Beauvoir's own theorization of age was not completely edifying. She portrays age as a slow process of an inevitable loss of meaning and makes high demands of people to strive towards transcendence against all social and biological obstacles (Kruks, 2023). Ageing is tied up with a temporal destiny towards meaninglessness in Beauvoir's philosophy. Because transcendence requires futurity, old age's proximity to death necessarily robs life of continued meaning. She writes: "For the young, the world has a boundless wealth of meanings and promises; the slightest incident awakens innumerable harmonics: later, when it has shrunk to the standard of our brief future, the vibrations die away" (de Beauvoir, 1996, p. 451). This is also bound up in physical debility, which limits one's agency to pursue meaningful projects: "The old man's want of curiosity and his lack of interest are aggravated by his biological condition. Paying attention to the world tires him. Often, he no longer has the strength to assert even those values which gave his life a meaning" (ibid p. 453). In order to make meaning in the march towards life's end, she describes how older people take refuge in the past, drawing comfort from company and habits that are threaded together in their life's biography. Those relationships that connect to a past self also function as ontological anchors, and the death of loved ones of many years are experienced as an "unbearable" loss – not only of the person in question, but how that person once knew them (ibid p. 469).

In the conclusion of *The Coming of Age*, she states "it is old age, rather than death, that is to be contrasted with life. Old age is life's parody, whereas death transforms life into a destiny" (ibid p. 539). She does not rebel against the facticity of death, however her position on old age is somber. In her view, growing old will always be a trespass or violation for the individual in question. However, she proclaims one defense against the descent of life into "parody" as one grows old – a commitment to the life of others through love, friendship, and compassion; or devotion to groups or causes, social, political, or creative; despite the dimming light of life's possibilities (ibid pp. 540-541). At the same time, this is the privilege of the few, who have the possibility to keep themselves healthy into old age and have people and interesting work to fill their days up until the end-of-life (Kruks, 2023).

Much of what Beauvoir contributed to the study of ageing is still valuable today, especially concerning her phenomenological method and theorization of alterity in relation to old age. At the same time, it is clear that there are many points in Beauvoir's theory of old age that have become contested or dated, such as the terminal meaninglessness she attributed to it as well as the material conditions of life which have changed for the older population today (discussed in the "long term care for older adults" section). She also does not address the many different intersectional aspects of ageing, beyond gender differences and some discussion of class (although most of her material is sourced upper-class individuals). In the next section I will go into contemporary sociological conceptions of old age, how this literature builds on and diverges from Beauvoir's work, and how I employ these perspectives in this dissertation.

Sociological and feminist perspectives on old age

Many sociologists today conceptualize age as relational. Age is something that is given meaning based on one's social environment (Närvänen, 2009). In other words, age is something that one *does* – it is an accomplished rather than natural category.

It is also a *power relation*, where belonging in a certain age group confers privilege or lack thereof (Krekula et al., 2018). Like other identity categories such as gender, race, and ability, age then is also a social category which is employed to organize society based around certain norms. The concept of ageism is therefore correlate to processes of sexism, racism, ableism, etcetera.

Ageism is cultural but it can also be institutionalized where access to resources or participation are divided along age lines. Some examples include voting and labor market participation (Närvänen, 2009), as well as disability policy (Jönson & Norberg, 2023). For example, Jönson & Norberg (2023) argue that in Sweden, as is the case in many other Western countries, disability policy "others" older people as a separate category of citizens who don't get the same service entitlements as younger people with disabilities. This stems from a needs interpretation that sees people with disabilities and older people as having fundamentally different care and social needs, even if they carry the same diagnosis or functional limitations. In Swedish policy discourse, this is visible in the way that younger people with disabilities are framed as needing support to fulfill their roles as full and active citizens and live free of discrimination, and older people with similar disabilities are described as simply needing more cost-effective functional support (p. 149).

On the whole, ageism in the West rests upon a hierarchy of power in the life course, where youth is venerated, and old age is associated with social problems and decline. This hierarchy informs social norms which dictate how and when one should act, dress, and what relationships are appropriate to have according to age. However, the way that the life course is valued and constructed has been variable throughout history, and the relative low status afforded to old age didn't come into being until the time of the industrial and scientific revolutions in the West. The idea of a productive versus non-productive population which arose during this time generated a new view of the life-course, where working adults acquired higher status and young children and retired, older people sank in status (Närvänen, 2009). The "productive" life of people today is lengthening, related in part to our increased life expectancy but also the policy focus placed on "active" ageing and extended working life (Trydegård, 2017). The emerging notion of the "silver workforce" or "silver economy", reflects how cultural views of old age are shaped around economic values of productivity reaching into later life.

Like with other forms of social analysis, age cannot be viewed in isolation and must be looked at intersectionally (Krekula et al., 2018). Age is a social category that overlaps with other subjectivities, such as race, gender, nationality, etcetera. Ageing women, face specific forms of marginalization that are different to those of ageing men. Extended working life policy in Sweden, for example, has been critiqued by Krekula et al. (2017) for neglecting to consider the caring responsibilities born mostly by older women, limiting their ability to work and earn income later into their careers. Age also intersects with masculinity in specific ways, where, for instance, values such as autonomy and self-reliance can come under contestation as frailty makes one more dependent. This can open up room for more caring masculinities, as I discuss in study 2 (Blake et al., 2018; Hanlon, 2012).

However, what differentiates age from other subjectivities is the fact that it is a social position which all of us (hopefully) will come to occupy, which is not the case for sex, gender, race, etcetera (De los Reyes & Mulinari, 2005). Beauvoir already lodged the question in *The Coming of Age* of how discrimination against the old is like shooting our future selves in the foot, thus begins her text with the invocation "let us recognize ourselves in this old man or that old woman" (p. 5). The self-sabotaging implications of ageism are often explained away as young peoples' inability to imagine themselves as old or think in a longer-term perspective. But Jönson (2021b) makes the interesting point that ageism is not merely a form of myopy but is justified by intricate forms of generational othering. In his review of interviews conducted with professional carers working with older adults, he showcases how staff framed this generation of care-recipients (born in the 1920s) as inherently "passive", and unable to "formulate or know their own needs" (p. 85). This characterization was attributed to the fact that they belonged to a society that no longer exists, and therefore find themselves as outcasts. Jönson demonstrates that despite the shared fact that we all live in time, time alone is not enough to foster solidarity across age groups. Generational divides endure as axes for othering.

Methodology

On studying death and dying: Positionality and ethics

Coming nearer to understanding care struggles via research and outreach activities necessarily meant that I came closer to an issue which is very intimate and often emotionally rife. Throughout my time visiting the specialized palliative care clinic, running events, organizing Last Aid courses, and in focus groups and interviews, I conversed with people about what was, for some, the hardest thing they had ever gone through (or were currently going through). This is the *sine qua non* of researchers working with death, dying, and bereavement – a trenchant exposure to bodily, emotional and existential tribulation, often at its zenith. And as Hockey (2007) has put it, many researchers had to fight for legitimacy in working in a field that was, to the academe of mid 20th century, an area where only "the heart was competent" (p. 437). Like feminist and gender studies scholars, then, death researchers have also rejected the dichotomies of head and heart, public and private, and personal and political, which are so often used to delegitimize scientific engagement with some experiences that are the most common to being human: living and dying in relationship with others (Fraser, 2013).

Doing empirical research on end-of-life issues means engaging with a vulnerable population: people who have life-limiting illness and their significant others. Ethical challenges for research involving a vulnerable population can include research-related distress; consent and capacity issues; and ensuring confidentiality (Koffman & Yorganci, 2021, p. 98). These risks should be mitigated, and potential benefits of the research should also be judged to be worth the risks. In the following section, I will elaborate on these ethical considerations and how they were handled.

Causing no harm, informed consent, and risk versus benefit

The studies included in this dissertation were approved by the Swedish Ethical Review Authority (ref: 2020-02545) and written in accordance with the Declaration of Helsinki. According to the declaration of Helsinki, the researcher has the responsibility to safeguard the health, wellbeing, and rights, as well as ensure respectful treatment of participants (World Medical Association, 2022). Those interviewed in studies 1 through 3 included seriously ill individuals and significant others to someone who was seriously ill. Most of these patients were admitted to specialized palliative care. Interviews included questions pertaining to illness, death, caregiving, and social support, meaning that the data compiled in these texts is ethically sensitive. Risks for participants in such research could include mental or existential distress or disturbance in social relationships. Participants were therefore met with sensitivity and data was collected with their needs and rights in the center of all proceedings. Every step of the research process has been designed to protect participant integrity. All interview participants were informed of the content of the interviews and purpose of the research in a document given to them by their contact nurse, physician, or myself beforehand (studies 2 and 3); or by myself via email during recruitment for focus groups (study 1). Project leaders interviewed in study 1 provided informed consent after receiving verbal and written information about the goals and methods of the research in a meeting. Participants in the Last Aid course were informed that fieldnotes would be taken via email as well as verbally before the start of the course. The interviews took place on participant terms, where they were given latitude to stop or change the course of discussion should they feel that they did not want to go further down a line of inquiry. The interviewers were also sensitive to signals of stress or discomfort and made sure the informant felt comfortable continuing before asking further questions. Participants could withdraw their consent at any point – before, after, or during the interview. All data was handled confidentially, meaning that participant data was anonymized already in the transcription phase and in the studies, where a key with participant names was stored in a separate vault from interview and field data. All materials were stored according to Lund University's guidelines (Dnr V 2019/1904), as well as the State Authority for Research Activities (Statliga Myndighetens Forskningsverksamhet RA-FS 1999:1), concerning safe storage of data, in locked safes at the Institute for Palliative Care in Lund.

Doing more research about end-of-life issues, from illness experiences to caregiving, can enable researchers and practitioners to provoke positive change in society and practice. Cultivating means for social transformation is also one of the central components of feminist research. The research undertaken in this dissertation aims to critically reflect on public health perspectives on the end-of-life to improve social support around dying individuals and their significant others in community and healthcare settings. Qualitative research can also confer potential benefits to participants, such as opportunities for reflection or increased feelings of agency, which will be discussed in the next section. The benefits of this research therefore are judged to outweigh the potential risks.

Care and empowerment in the research environment

It is not uncommon in qualitative and feminist-oriented research environments that researchers can feel uncertain and insecure in relationship to participants and their own capacity to deal with their responses adequately (Barnes & Brannelly, 2022). Participants can also be just as nervous as researchers in these encounters (ibid). A year after the interviews and focus groups were completed, and I was in the final stages of finishing my manuscripts, I would occasionally go back to my audio recordings to make sure that the texts I had written were in harmonious communication with the voices of my participants. By this point in time, nearly all of my participants who were patients in palliative care or in nursing homes were dead. Relating back to data then was always to some degree an emotional process, which required attention to my own wellbeing. Scholars who study issues around death and dying are often faced with challenging field environments where they must confront suffering and loss up close (Lawton, 2002). Self-care is therefore an important facet of engaging in these topics. To treat myself empathically, but also not veer into a purely functionalistic relationship with data, was a fine balance to strike.

Researchers have a voluntary and temporary relationship with the field, and standard research practice advocates for an instrumental relationship to participant experiences (Stacey, 1988). What is for one person a horrific memory is for the researcher a useful piece of data. However, most feminist researchers today consider the role of care in the research process and in field-based relationships as vitally important. While data has an instrumental value in one sense, that doesn't preclude the possibility for empathy in those relationships which bring forth that data. Following with Barnes and Brannelly (2022), I practiced an "ethic of care" within the field, which involved self-care as well as care for the participants. For example, I have not known, from personal experience, what my participants had gone through, or were going through, but I can care about the consequence that has for the research I have performed. I can perform care in the field by caring about how my research is positioned in relation to my participants' lives (ibid).

Barnes and Brannelly (2022) also posit that data collection and analysis can work to promote "improved wellbeing", rather than just avoid incurring harm (p. 38). Evidence from research and our own experiences are that patients, even those close to dying, and their families want to participate in research (Gysels et al., 2012). For instance, many of my participants expressed how they decided to participate in my studies because they wanted to "give back" in whatever way they could. The interview environment is not only characterized by the taking of data, but also participant agency in giving. Participants expressed that participating in the research helped them reflect upon things in their social lives they had not had the opportunity to consider previously, and this was especially the case with the process of creating eco maps (study 2). Rosetto (2014) has described how interviews pertaining to sensitive subjects, while containing the risk of causing harm, also can confer therapeutic effects. Likewise, participants in these studies expressed satisfaction in being able to talk through components of their experiences that were sometimes unspoken or hidden. This is not uncommon in the situation of serious illness or loss, where emotions and experiences are often concealed because of social stigma or discomfort (Frank, 2013). Participant empowerment is also a central component of action research, employed in study 1. Participation in an action research study can strengthen community bonds and engagement in local issues during and beyond the scope of the research period (Aldred, 2011). The Last Aid course, which was topic of study 1, was carried on in collaboration with the local community after the study period, as well as other collaborative activities nested within the Österlen project, focusing on awareness, education, and engagement of the general public.

Sample

The inclusion criteria and recruitment strategy for the different studies are summarized in the table below.

Table 2: Inclusion criteria and recruitment

STUDY 1	STUDY 2	STUDY 3	STUDY 4
Participation in one of the Last Aid courses or being a course leader.	Being either a patient or relative to a patient/resident who is receiving some form of care in the end-of-life.	The same participant base as study 2.	Being a participant in the END advanced study group.
Informational fliers were distributed in print and via email to all course participants, informing them of the study.	Contact nurses and physicians in specialized palliative care and nursing homes distributed fliers with information about the study to current patients and/or their significant others.		Group members were informed of the study, and given written information, during the start-up period.

The studies included in this research project revolve around end-of-life care and the meaning of community support in the context of the Swedish welfare state. This is important as community perspectives on palliative care have been explored almost exclusively in Anglo contexts and in liberal welfare states such as Australia and the UK. While this research effort brings new light to issues around community support in end-of-life care in the Swedish context, the studies included have some limitations. Sweden is an increasingly heterogenous society; however, this project mostly explores experiences of white men and women. The demography of the study sites sampled, as well as the potential reluctance of more vulnerable groups to participate in a study/activity pertaining to dying and grief, could have had an impact on who was able to gain access to and participate in these studies. Gatekeepers can also have an influence on recruitment. In the case of studies 2-3, contact nurses and physicians were responsible for distributing information to participants. Several factors can influence how they choose potential informants, such as: perceived health and perceived willingness to be interviewed. Recruitment, in other words, is filtered through the interpretations of the gatekeepers concerning who would be a "good" interview participant. It was also the case in this fieldwork that certain clinical gatekeepers in more ethnically diverse areas declined to participate in the studies. There is evidence to support that gatekeepers can exacerbate the exclusion of certain social groups, as elaborated on by Renert et al. (2013): "while community gatekeepers can facilitate recruitment of non-dominant ethnic groups into research, they can also hinder it based on their own perceptions of the relevance and importance of particular studies" (p. 3). The relative lack of diversity in these studies means that a partial view of end-of-life issues is represented, which does not encompass the diverse ways in which people can experience illness, caregiving, and loss. Research has illustrated that informal care practices, traditions around death and dying, and community support can take different forms in different cultural contexts (Fink, 2004; Gunaratnam, 2014; Tranberg et al., 2016). Experiences of interacting with public agencies and in mobilizing formal support are also shaped by class, race/ethnicity, and other forms of social capital (Baroudi et al., 2022; Lidbeck et al., 2018).

As Barnes and Brannelly (2022) point out, "research is as political an activity as it is a scholarly one. What gets researched, how, and by whom, reflects and reinforces power structures" (p. 44). At the same time, an investigation of gender norms and social contracts in privileged social classes can broaden scholarly understanding of power, how it operates, and how it permeates into other echelons of society. While feminist scholarship has classically theorized from "margins to center" (hooks, 2000b), it is important to interrogate the subject at the center. Undertheorizing powerful social categories can reaffirm the norm – allowing whiteness to be seen as racially neutral, maleness as gender-neutral, and wealth to be class-neutral (Frankenberg, 1993). Also, in the case of the Nordic welfare states, which are often framed as "care friendly" or even "woman friendly", markers of crisis are legible. Even for those with the social capital to access and benefit from the best resources available in these societies, struggles endure. As Hansen et al. (2022) point out, "even in the best of circumstances in the supposedly feminist nirvana, there is a care crisis" and "if a care crisis is valid for this case, then it applies to all cases" (p. 4).

This is not to forget that dying, ageing and caregiving also mark periods in life characterized by silence and marginalization. As Beauvoir (1996) has written, old age is shaped by social alterity. While feminist scholars have thoroughly explored oppression across categories such as gender, race and sexuality, still relatively little work is done in critically unpacking the experience of old age (Stoller, 2014). Especially in modern western society, the "old" (who, today, also represent the majority of the dying) are often characterized as a "non-active" and "burdensome" population which poses a threat to state care infrastructure. In Beauvoir's time as much as today, getting older also entails more precarious life conditions, as one becomes dependent on paltry pensions, diminishing welfare services, and the care of often already strained significant others (Närvänen, 2009; Segal, 2013; Trydegård, 2017). Illness as well is often attached to negative attributes, such as "failure" to make healthy lifestyle choices, or even moral failure to ward off disease (Berlant, 2010; Sontag, 1990). For these reasons the experiences of the old and ill are often silenced or retold in the marginalizing words of more powerful others, such as physicians or policy makers (Frank, 2013; Zeiler & Käll, 2014). Caregivers are similarly subject to marginalization and silencing, related in part to the fact that most of them are women. Care has long been discursively framed as the place of the "feminine other" – a heterotopy confined to the enclosed sphere of private life (Dahl, 2017, p. 98). As Tronto (1993) has pointed out, "caregiving and care-receiving are left to the less powerful" and "groups that have been traditionally excluded from centers of power in our culture often exhibit a commitment to ideals of connection and mutual support – that is, care" (pp. 116-117).

While this dissertation speaks to the "partial perspective" of a group of relatively privileged caregivers and patients, it still accounts for some experiences which are marginalized and silenced (Haraway, 1988). Still, the absence of more diverse perspectives in data sampling has consequences for the findings of this research, which must be read as contextual and specific. Ageing, for one, is an intersectional category that affects people differentially across the axes of race, sexuality, gender, class, etcetera (Krekula et al., 2018). For example, Torres (2019a, 2019b) has elaborated on how older black and brown migrants use less care services and typically have worse health outcomes, also when controlling for other factors such socio-economic status and geographical location. This means that these diverse experiences of inequalities in the 65+ population are not captured in the various studies within this dissertation. The way one relates to community and care is also influenced by intersectional social factors. In queer communities, for example, non-kin relationships can play a more defining role over the life course in terms of care (Knauer, 2016). The participants in my studies, however, focused comparatively little on non-kin relationships and intoned the importance of family and professional actors in their support networks (study 2). Further research on the intersectional aspects of dying, ageing, and caregiving is merited in order to capture a more holistic view of our social reality which can inform justice-oriented forms of community development in palliative care.

Describing the interview participants

The participants in studies 2 and 3 belong mostly to two age groups: 65-80 and 80+ (see table 5, below). Patients who were younger than 80 were all admitted to specialized palliative care at home, whereas all the 80+ patients were living in nursing homes. All significant others in studies 2 and 3 (n=9) were affiliated with specialized palliative care. It is important to note that care needs, as well as experiences of social life and loneliness, are generally different between these two age groups, respectively between what are called the "third" and the "fourth ages"

(Laslett, 1996). The third and fourth age are differentiated by “healthy” versus relatively “unhealthy” years. In Sweden, the last 5.9 years of life are on average characterized by significant illness, frailty, and dependence, and this is the period marking the fourth age (Trydegård, 2017, p. 197). The third age marks the period between retirement and decline, where one can more or less maintain an autonomous life (Andersson, 2009). I refer to the category of the fourth age here while acknowledging that any attempt at categorization necessarily also presents an oversimplified image of complex social reality (Andersson, 2009; Närvänen, 2009). At the same time, drawing this boundary helps to clarify some important differences, both material and subjective, in the constitution of my participant base.

For one, the nursing home participants and specialized palliative care participants were approaching life’s end in different ways. About 70-80% of patients admitted to specialized palliative care in Sweden have cancer (Svenska Palliativregistret, 2023). A reason being that it is easier to predict the proximity of death for patients with cancer than older people with multimorbidity. Still, nursing home residents typically have multiple life-limiting conditions and extensive palliative care needs. In 2022 the median length of stay in nursing homes decreased significantly supporting the hypothesis that older people in residential care are sicker than before. About 20 % die within six months of admittance, and the median length of stay being 21 months (National Board of Health and Welfare, 2022b). People in the fourth age, and living in a nursing home, can also experience a loss of sense of personhood related to intensifying decline and reliance on the help of others (Harnett & Jönson, 2017). This experience of de-personalization can lead to an existential loneliness that is unique to loneliness experienced earlier in life (Sjöberg et al., 2018). Altogether, this means that the social, relational, and care experiences of these participants were particular. Nursing home residents received routine physical and practical support from professional carers in the nursing home. Significant others provided support via social visits and small tasks like shopping, generally once a week. Many of these participants stated that they felt lonely in a way that was independent of how much social contact they had with others (participants H, I, G), indicating that they experienced a kind of existential loneliness that was not prominent amongst the home-care participants. Part of this loneliness was related to the fact they no longer had the physical ability to engage in meaningful activities like they once could, even with the support of a caregiver.

Participants in specialized palliative at-home care were diagnosed with a life threatening condition that required intensive support from professional carers as well as their co-habiting significant others. Many of them had diagnosis-related disabilities which severely limited their ability to live life autonomously. However, their relative health up until diagnosis and greater ability to maintain daily routines differentiates them from the participant group in the fourth age. One of these participants was also much younger than the others, in the 45-65 age group. Significant others typically play a much more intensive role in caring for patients admitted to specialized palliative at-home care (Linderholm & Friedrichsen, 2010).

This at-home care is typically reliant on an engaged significant other who can supplement the support of professional carers – who most often takes this work upon themselves voluntarily (ibid). This is one reason why specialized palliative care incorporates a family-perspective and support is given also to these caregiving significant others (Klarare et al., 2017). None of these participants expressed that they were lonely, and generally had more regular contact with people such as neighbors, friends, and extended family (both physically and over the phone), multiple times a week. They therefore lived life more broadly than the nursing home participants, with more people, and also taking part of activities outside of home. Some of them were also able to engage in normal activities and hobbies out in their communities with minor assistance in the earlier phase of their illness, such as volunteering at the church (participant R), walking the dog with neighbors (participant L), or playing music (participant E).

The fact that these interview studies describe the experiences of patients and significant others from different life situations means that this research captures the diverse social and physical realities of people nearing, or caring for someone, in the end-of-life. While these experiences do not capture the full diversity of end-of-life experiences in Sweden, these studies do provide insight into one of the most common places of death (nursing homes), and one of the most preferred places of death (the home). The following tables summarize in more detail the participants included in each study.

Table 3: Participants included in study 1

PARTICIPANT OBSERVATION	FOCUS GROUP 1	FOCUS GROUP 2	FOCUS GROUP 3
During Last Aid Courses and during practitioner meetings.	7 course participants from course 1. Two men and five women.	3 course participants from course 2. One man and two women.	3 course practitioners: one female physician, one female nurse, one retired male physician

Table 4: Participants in Last Aid courses included in study 1

	COURSE 1	COURSE 2	COURSE 3
Number of participants	17	25	10
% Female	76%	60%	90%
Response rate to course evaluation (%)	65%	100%	40%
% Retired based on response rate above	64%	80%	25%

Table 5: Participants included in studies 2-3

PARTICIPANT		AGE GROUP	SEX	PLACE OF CARE
A	Daughter	15-30	F	Specialized palliative care
B	Patient	65-80	M	Specialized palliative care
C	Daughter	30-45	F	Specialized palliative care
D	Sister	45-65	F	Specialized palliative care
E	Patient	65-80	M	Specialized palliative care
F	Patient	65-80	M	Specialized palliative care
G	Patient	80+	M	Nursing home
H	Patient	80+	F	Nursing home
I	Patient	80+	F	Nursing home
J	Patient	80+	M	Nursing home
K	Patient	80+	M	Nursing home
L	Patient	45-65	F	Specialized palliative care
M	Patient	65-80	M	Specialized palliative care
N	Wife	45-65	F	Specialized palliative care
O	Husband	65-80	M	Specialized palliative care
P	Wife	65-80	F	Specialized palliative care
Q	Wife	45-65	F	Specialized palliative care
R	Patient	65-80	M	Specialized palliative care
S	Wife	65-80	F	Specialized palliative care
T	Wife	65-80	F	Specialized palliative care

Table 6: Participants included in study 4

PARTICIPANT	
A	Mid-career academic
B	Mid-career academic
C	Doctoral student
D	Doctoral student
E	Senior Professor
F	Mid-career academic
G	Lecturer
H	Senior professor
I	Music pedagogue
J	Senior professor

Study 1: Action research

One goal of this project was to generate knowledge which builds a bridge between the development and research components of the Österlen Project – that is, to foster deeper understanding of how to do something by actually doing it. The “something” which was chosen was the development of the Last Aid course. While this course had been run in several European countries, this was the *first* time the education had been adapted to Sweden. Our team, which translated the curriculum, wanted to understand what it meant to plant this course into the Swedish context, and how education fit into our vision for public health palliative care in Österlen.

Action research (AR) is a methodology which privileges knowledge which is based in action and experience – i.e. “knowing through doing” (Bradbury & Reason, 2003, p. 158). Demand for participatory action research (PAR) and action research methods have increased in these settings because of its ability to address social complexity and the growing need for more democratic dialogue in reference to the development of organizations and communities (Svensson & Nielsen, 2006). Action research has a long and rich tradition, especially in the Nordic countries; and has been often grounded in collaboration between public welfare institutions, civil society and academia (Kemmis et al., 2014; Roos, 1998; Wilkinson & Kleinman, 2016). This methodological tradition builds upon different types of qualitative data collection; in most cases, where the researcher is also playing a coordination role in a development initiative. Study one was therefore centered around my active participation in the development of the Last Aid course. During this time period, I administrated the course, organized each course gathering, taking care of technology, evaluations, food, and answering questions from participants. Collaborators from the municipality, Hospice Foundation, and church helped to disseminate information and advertise the course. The teachers (from this initial phase in the research) included one physician from specialized palliative care, one nurse from the same ward, one representative (a retired physician) from the Hospice Foundation, and one volunteer (training to be a death doulah). Data collection therefore included fieldnotes taken from my time organizing and observing the course, as well as three focus groups (two with participants and one with the course leaders). AR methods have been appraised as well as criticized because of the direct involvement of the researcher in the research process. Being involved in the research process means that the researcher can influence the outcomes of the research in bringing conscious as well as unconscious biases to the action (Ladkin, 2004). However, the strengths of researcher involvement can outweigh the potential risks when done reflexively. Incorporating a “first-person” reflection of the research process can make AR a more robust form of inquiry which accounts for multiple ways of knowing (ibid p. 481). For my part, I can see that my involvement in the Last Aid project had an impact on the research outcomes. For example, while gender was an important topic which came up multiple times in planning meetings and focus groups independent of my input, I observed that practitioners more actively asked questions about gender because of my presence at times. My participation therefore contributed to gender becoming an object of critical focus in the project.

This action research-inspired project loosely followed Lewin's traditional spiral of planning (planning a change, acting and observing the process and consequences of the change, reflecting on these processes and consequences, and then re-planning, acting and observing, reflecting, and so on…) (Kemmis et al., 2014, p. 18). Despite a handful of departures from this ordinal process, the participants and course leaders of Last Aid engaged in ongoing and critical reflection about the progress of the education (via formal meetings, chats during coffee breaks, and course evaluations). Participants and collaborators were invited to identify new problems, interpret the meaning and value of the course, and determine how to move forward via focus groups (Bradbury & Reason, 2003). In line with conventional approaches to analysis within AR, data was critically framed around a larger political context (Ladkin, 2004). This was done with the intention to not only cast light on how a specific intervention impacted the participant base, but how informal care in the end of life is made more or less possible (or desirable) within the welfare state context.

There are methodological challenges to take into account when employing an AR approach. For instance, when planning the Last Aid course it was clear that there were hierarchies and different levels of engagement amongst course leaders, and community, hospital, and municipal partners. Ideally, action research is built upon democratic structures of decision making and consensus oriented collaboration (Kemmis et al., 2014; Ladkin, 2004). This is not to say that decisions were not taken with equal consideration of every collaborator, but that it was clear that some collaborators took a more active role and some a more passive role in making decisions within the overall frame of the Österlen Project. The project members affiliated with the local hospital, for instance, while expressing support for the implementation of Last Aid, seldom participated in planning meetings or actively supported dissemination of information. The members in the municipality, in contrast, took a more active role in planning, advertising, and reflecting communally on the impact of the course. So, while the AR project was based on consensus, the engagement in democratic decision making was unequal. This dynamic is not uncommon in AR more generally. As Ladkin (2004) discusses, collaborators in a given AR project could and often have different vantage points and have diverging purposes for engagement from the point of the project’s initiation. Ideally, AR is an approach which helps discover and work with “the actual concerns” of stakeholders, rather than just evaluate “their reactions to an imposed framework” (p. 485). However, attaining a shared purpose across all stakeholders and motivating completely equal engagement in a highly stratified and large project is not always a feasible task. Nor is it always desirable. The formation of an AR inquiry is also a political task, and reformulating the purpose of a project around a certain stakeholder’s interests can serve to make a given inquiry less critical or even useful to the collaborative as a whole.

Epistemologically, the approach taken in this AR study differs from the following interview studies. Instead of analyzing and developing knowledge primarily about participant experiences, this study also develops "practical" and "presentational knowledge". The former denoting "knowledge gained through the doing of things" and the latter denoting "knowledge gained by ordering our tacit experiential knowledge into patterns" (Ladkin, 2004, p. 480). An inductive approach was therefore employed in the analysis of data where manifest and descriptive codes were first applied to the interview transcripts (Braun & Clarke, 2023; Guest et al., 2012). The analysis was largely "data-driven" meaning that the conclusions made in this study were derived from what was first observable in the data (ibid). However, these conclusions were also later informed by a theoretically informed reading of the data (Chowdhury, 2015), which was necessary also to frame the findings within a social and political context.

Interviewing and analyzing "experience"

Any given research field is textured by power dynamics – researchers are in a more powerful position than participants (especially in non-participatory methods) because they own the means of interpretation. The intentional silencing and direct harm caused by researchers who have chosen to omit certain experiences or even cause direct harm to certain populations (through experimental treatments or degrading behavior) in studies shows the ethical importance of conveying and theorizing through all kinds of experiences (Barnes & Brannelly, 2022; Stacey, 1988). The fieldwork in these studies represents a period in life that is often hidden and obscured – the experiences of the oldest old, the dying, and their caregivers. These texts therefore attempt to bring light to marginalized experiences, in line with a critical, feminist approach to research.

There are however important critiques to acknowledge when approaching "experience" as a taken-for-granted object of study. Scott (1991) has pointed out that the evidence of experience is, in a few meaningful senses, limited. She argues that attempting to understand subjectivity via "experience", while taking categories such as gender, age, race as pre-given identities, can fail to account for the conditions which create these subjectivities in the first place. Most feminist and critical scholarship holds that any given "experience" cannot be bracketed away from the social collectivity. Experiences – analyzed within, for example, interviews – are not evidence of individual narratives alone, but of an intersubjective self, which is shaped by social interactions with family, friends, community and the state (Kleinman et al., 1997).

This dissertation has largely taken a constructionist and phenomenological approach to understanding experience and producing knowledge about society (May & Nordqvist, 2022). Meaning that, in both studies two and three, the analysis of data explores “how a particular way of defining something came about and why it continues to be so” (ibid p. 11). Using this approach and reflecting upon Scott’s (1991) critiques, knowledge has not been treated as transparent in the data. That is to say, experience cannot merely be located in individual narratives, but the meanings of these experiences must be interrogated via these narratives. In study two, gender and caregiving are analyzed through practices which are “carried out in relationship to specific others” (Morgon, 2022, p. 23). These practices are understood to not only emerge from but also constitute and continually reshape gender identity, as well as one’s experience as an ill person, caregiver, neighbor, friend, or kin (ibid). Study three employs the tools of feminist phenomenology, inspired by Beauvoir, to unravel how meaning is intersubjectively and relationally manifested in networks of social support. Beauvoir’s phenomenology incorporates a constructionist perspective by challenging the assumptions and demarcations that surround old age as a social category. But this approach takes also a critical look at how one lives through the body and becomes a subject in relation to norms projected onto certain bodies, developing also more knowledge about how these social categories come to have meaning.

Study 2: A transdisciplinary approach to eco maps

Eco maps were chosen as a method to develop a deeper understanding of existing social networks of care around patients and significant others. Eco maps were first developed in 1975 by Hartman, and have since been demonstrated in research to be effective tools to measure the structure and strength of social relationships (Ray & Street, 2005). They have broadly been used in research to support the work of rehabilitation in social work and in healthcare settings (Miller et al., 2017; Miller et al., 2021). “Eco” refers to “ecology”. The purpose of the map is to therefore to map the ecology (connection between actor and environment) of social relationships and their significance to participants (Ray & Street, 2005).

For study 2, six patients and nine significant others connected to specialized palliative care at home were asked to complete eco maps within a semi-structured interview. A transdisciplinary approach was taken uniting eco maps with feminist cartographic and visual methods to interviewing. This methodological approach incorporated the structure of the eco maps in conjunction with the critical and relational approach of feminist visual methods common to research on family and intimate life (Anving, 2023; Eldén, 2016; Gabb & Singh, 2015). As such, the eco maps were used as a means to stimulate deeper thinking around diverse practices of care, ranging from forms of care which could be understood as “labor”, to the “emotional” and those practices which blurred the boundary between the two (Eldén, 2016). The analysis focuses therefore on the relationship between participant and their social network and how that relationship manifests in practices and values of care, rather than on the map as such. However, some quantitative data was compiled in SPSS to describe the frequency of different forms of relationships (such as, brother, sister, partner, etcetera), as well as who the primary informal caregivers were (also sister, brother, partner, etcetera). This data was used as a descriptive backdrop to the richer interview data which elaborated on the quality of different relations of care between families, professionals, and community members. The interview data was analyzed thematically, beginning with descriptive coding and then categorical sorting according to the kind of relationship described in the interview (such as sister, brother, partner, etcetera) (Braun & Clarke, 2023). Based on an informed reading of data, codes were then subsequently categorized into themes pertaining to experiences and practices of care (Guest et al., 2012)

The majority of interviews were completed by myself and some were completed together with a supervisor. The interviews spanned between one and two hours. Some interviews were completed consecutively (i.e. in the same location, first with the relative and then with the patient). The interviews took place at the interviewee's place of residence, where they generally felt more comfortable talking (with the exception of one relative, who wanted to talk at a café at a distance from her sick partner). Most interviews with significant others were completed before their counterpart's death. Some interviews were completed afterwards, in which case the respondents could discuss their experiences from a different perspective, and could also reflect upon grief. Each participant co-constructed an eco map at the time of the interview. The maps were constructed collaboratively with the patient or significant other through semi-structured interview questions. The map locates the patient at the center. The maps were built progressively through a series of questions such as: who helps you with practical things? Who do you go to when you're feeling sad? Do you feel like you are missing any kind of support? Lines were drawn from the center to each social relationship, visualizing all of the sources of support which surround the participant. Patients who were unable to draw or write were given assistance, and in some cases the whole map was drawn by myself.

It was the case for this participant base that the practice of drawing eco maps was met with interest and generally helped smooth the course of the interviews. Participants expressed curiosity in exploring their social life visually and some of them remarked that they found the exercise valuable – conferring insight to their personal life that they had not reflected on before. Similar research in the palliative care context has shown how using visual tools can help participants explore issues that are not always easy to talk about, for example, serious illness and loss (Tishelman et al., 2016). Visual methods on the whole have a long history in qualitative research as tools to better enable communication, represent data in a novel way, and enhance quality and validity of data (Glegg, 2018). However, one aspect of mapping exercises which should bear scrutiny is how the co-creation of these diagrams can blur the boundary between researcher and participant in the process of interpretation (ibid). This is especially the case for those instances where the researcher takes on more responsibility for drawing when the informant is unable to draw themselves. In order to minimize this risk, the participants were asked in the middle and end of the interview to assess the validity of representativeness of their maps.

Study 3: Feminist phenomenology as a method

This dissertation draws on the tools of feminist phenomenology to understand the experience of social support in relationship to old age via 10 semi-structured interviews with patients (study 3). The interviews examined in this study include five interviews with patients examined also in study two, as well as five additional interviews with patients living in nursing homes. All of these participants were above the age of 65. During these interviews, patients were asked to reflect upon their networks of social support and the meaning that social support brought to their lives. These interviews therefore attempted to not only understand substantive practices of care but how care was attributed different meanings across relationships. While completing the eco maps, participants were further asked to describe how different people helped them make sense of lives after their diagnosis or admittance to a nursing home; or how they felt support from others contributed to making meaning in daily life. The creation and maintenance of meaning within one's social environment is discussed in specific relationship to old age and very old age.

Beauvoir's work is drawn upon heavily in this endeavor because she wrote one of the first and still seminal works regarding a critical phenomenology of old age and dying: *The Coming of Age*, published originally in 1970. Feminist phenomenology can be seen as a strand of critical phenomenology, which is a form of inquiry that is "critical of its own methods, concepts and limitations" (Oksala, 2023, p. 146). In analyzing experience, this approach generally rejects the Husserlian "eidetic reduction" which aims to "distill the essential features or invariable structures of experience" and collapse all differences in experience under generalizable similarities (Oksala, 2023, p. 141). This means that within critical phenomenology, lived experience is always something which must be read through and accounted for in regard to social structures of power as well as the reader's presumptions and biases, in resonance with social constructionism and feminist critical theory. Furthermore, critical phenomenology sees the purpose of viewing the world via first-person accounts as not only to create some sort of description of society but to provide some platform of social critique (Oksala, 2023). This view of experience as necessarily situated and textured by power makes feminist phenomenology a well suited approach for analyzing subjectivity in relationship to oppression and social transformation (ibid). Beyond studying the tribulations in the experience of old age, Beauvoir, for example, pondered "whether recognizing the inevitability of ageing could help us all to reconceptualize our responsibilities towards those we are so often inclined to reject" (Segal, 2013, p. 10). Therein lies a certain normative approach Beauvoir advocated for in critical phenomenology, that analysis should not only seek to illuminate how lived experience figures into a shared social reality, but also how we can critically interpret data within an ethical framework (Heinämaa, 2014; Oksala, 2023).

It is because of Beauvoir's unifying approach to lived experience and social critique that her work is still relevant today. It has a complementarity to more sociological, feminist scholarship on care as necessarily relational, contingent, and informed by broader networks of relationships and social discourses (Doucet, 2023; Fink, 2004; Morgon, 2022). *The Coming of Age* in particular demonstrated a further shift in Beauvoir's thinking which integrated a phenomenological approach with a form of sociological critique (Beeson, 1999). In study 3, her methodological tools are then employed in a transdisciplinary fashion. In the first hand, her phenomenological lens is used to locate overarching "structures" of meaning across participant experiences, and relating those structures back to the situatedness of each participant narrative (Simms & Stawarska, 2013). These structures of meaning are afterwards related to a sociological analysis of how care is made more or less possible interpersonally as well as institutionally. This is transdisciplinary in the sense that the analysis takes tools from two disciplinary traditions (phenomenology and sociology), to not only describe but critique a phenomena (social support) in relationship to first-person experience but also society at large.

Study 4: A case study of interdisciplinary research

In the last article, the "Exploring Narratives of Death" (END) group was explored via a case study methodology including field observation over a year long period and semi-structured interviews. Field observation included taking notes at the bi-weekly meetings and at the final seminar which was the summarized the collaborative work of the END team over the year. The interviews took approximately an hour long each, and during the conversation the participants were asked to deliberate on both how they saw the role of interdisciplinarity in investigating end-of-life topics, but also how they practically fit such collaborations into their work-life. In this way, interdisciplinary was reflected upon in this study both in abstract and substantive terms.

Case studies typically include mixed methods to broadly investigate the phenomenon of a certain life history, event, or institution, and capture the uniqueness of a specific social situation (Gomm, 2009). At the same time that case studies are used to exemplify a specific social situation, they are also used to provide some sort of generalizable reflection back to a larger context. In this particular case study environment, I was an "insider" to the group, and therefore occupied a specific positionality in relationship to the group members as well as to the content of the work (Taylor, 2011). In any given research environment there are dynamics of power and influence at play. Especially in sensitive research environments, this sort of implication in the field can confer difficult ethical questions, such as negotiating tensions between preserving research integrity while also respecting respondents' dignity and/or privacy (Stacey, 1988). Being embedded in the activities at END, however did not confer the same degree of risks, being a less sensitive field environment. Rather, being an insider to END conferred significant benefits in understanding more deeply the epistemological and functional components of conversations during meetings. That being said, this paper offers insight into a unique interdisciplinary study environment from a certain standpoint, from the inside. It thus offers a partial perspective, but one that is enriched by field-specific knowledge and a more intimate view into the inner workings of interdisciplinary collaboration (Haraway, 1988; Taylor, 2011). In contrast to studies two and three, the interviews and field data in this study were analyzed inductively, that is, taking a "data-driven" approach (Braun & Clarke, 2023; Sundler et al., 2019). Analysis followed a process of latent thematization of descriptive codes, where experiences were compared across participants (Graneheim et al., 2017).

Summary of findings

Study 1

Building death literacy at the end-of-life through Last Aid: A case of gendered informal caregiving within the Swedish welfare state

Study 1 is inspired by an action research approach and investigates how an educational intervention to increase knowledge and caring capacity around dying is perceived by participants and practitioners and how this intervention fits into current social relations of care within the Swedish welfare state context. The study additionally examines how the educational intervention, called Last Aid, can be employed in future public health strategizing. The study is thematically analyzed under the groupings: Agency in the domestic sphere, agency in healthcare, and agency in society.

The study describes how the implementation of Last Aid could be seen to reflect a pattern of sociological ambivalence where agency to care and make end-of-life related choices was in tension with norms of caring informed by the changing welfare state context. This tension related to the increasing focus on self-responsibility in care policy as well as the related gendered aspects of informal care at home. **Section one** (agency in the domestic sphere) unpacks how, in the informal caregiving situation, participants expressed many uncertainties in how to provide the right care for a dying significant other. In this uncertain space, women generally take more action to acquire the necessary knowledge and skills to improve these caring situations. This was demonstrated by the strong gender imbalance in the courses, which were 75% female. **Section two** (agency in healthcare) discusses how participants and practitioners articulated the Last Aid course as a tool to help them demand good care and resolve individual needs. However, the widely expressed difficulty in acquiring the right care in the right time, and the uneven level of responsibility for care that was taken upon by women, was not articulated as a collective issue. Healthcare was discussed in terms of individualized service provision, which could be better understood and acquired with the help of the Last Aid course. **Section three** (agency in society) examines how participants and practitioners articulated the Last Aid course as a remedy for inspiring more active community care in a hyper-individualistic society where loneliness is a common issue especially for dying and frail older people. This was also framed as a modern problem in contrast with a more "compassionate past" where family and community were inherently more supportive. On the one hand, while there was a desire for more formal services (as pointed out in section two) there was also a desire for more informal engagement that had roots in communitarian ideals around family and civil society.

This article describes how Last Aid was perceived as a valuable tool to increase one's sense of agency around end-of-life issues on several levels (public and private). At the same time, these findings suggest that the health promotion paradigm it falls into is potentially sympathetic to the re-familialization of long-term and end-of-life care in a diminishing welfare state, which demands more agency to care from private individuals. It was also clear in the data that agency could be interpreted as a gendered category. 75% of the participants of the course were female, reflecting real gender divisions of labor in the private sphere. The choice to better educate and prepare oneself for caregiving is therefore not made by purely free individuals, but by individuals influenced by gendered norms of responsibility. Secondly, the responsibility to care for the seriously ill and dying was also framed in an atomized fashion in reference to the welfare state. Rather than being accountable to a collective, the healthcare system was articulated as a service provider which should meet individual needs. Therein, collective issues such as gender inequality in informal care, as well as disempowerment in healthcare settings, became opaque. Finally, the Last Aid course was also perceived as a tool to reinvigorate "traditional" values around care and social support which have historically been built upon women's labor and gendered caring roles. It was clear then, that the implementation of Last Aid reflected a tension between agency and structure – and ambivalence between one's ability to choose to care and social structures which normalize certain caring behaviors and gender roles.

For these reasons, it is important for future work in public health interventions to consider the social context for their implementation, and the gendered impacts such initiatives can incur. The HPPC paradigm, which frames the end-of-life as "everyone's responsibility," should then take more seriously the commitment to engaging everyone on equal terms. The **implication** here is that public health interventions must then be either meaningfully complemented by cultural change concerning gender roles in caregiving or integrate cultural change into their framework. In the center of this text is a critique of the notion of increased agency concerning end-of-life questions as desirable social outcome. The Last Aid course is not necessarily a co-conspirator to the neoliberal project in the healthcare sector. It could equally as much be argued that in a time of increased re-familialization, significant others, now more than ever require more education and agency in what is often an emotionally and practically turbulent life transition. What matters more, in a political sense, is rather how agency is used to justify certain policies which aim to shift responsibility to care away from formal institutions into the private sphere.

Study 2

Exploring networks of care in the end-of-life context through eco maps: Feminist perspectives on caregiving in between family, community, and professionals in Sweden

This article explores supportive relationships in the end-of-life – in line with contemporary feminist work on care and relationality, in dialogue with the growing field of public health palliative care. It deliberates on: 1) how dying patients and their families are connected to supportive networks of care in the end-of-life; and 2) how care in this context has gendered aspects. The study is therefore broken up into two analytical sections: 1) the role of welfare services in sustaining care and 2) gendered aspects of caregiving and receiving – under the framing theme of "moral boundaries of dependency".

This study points to how increasing dependency following a serious diagnosis can provoke an uncomfortable shift in moral understandings of one's care responsibilities and relational understanding of self. Furthermore, it describes how self-concept and boundaries of comfort in asking for and receiving support are differentially constructed in relation to specific others. The following subsections relate how caring practices matched with certain values around respectability and responsibility in assuming new caring rolls and becoming dependent in relation to professional, family and community actors. In **section one** (the role of welfare services in sustaining care), the text elaborates on how professional support from the palliative care team was valued for mediating and alleviating the discomfort in the boundary shift from being someone's daughter or wife to becoming their caregiver. In other words, professional support was valued for mitigating the harsh shift in one's relational identity around care, both in practical and emotional terms. **Section two** (gendered aspects of caregiving and receiving) first outlines how the (mostly female) informal caregivers expressed how friendships were most valuable for the sense of normalcy they conferred in an otherwise challenging personal life. However, the personal and emotional elements of caregiving were seldom shared with friends and neighbors. These informal caregivers often took on primary responsibility of care for their significant others, with the support of the palliative care team. The community support that they valued most for their own part came in the form of restoring a sense of selfhood congruent with "normal life" before they became absorbed into caregiving. The section goes on further to elaborate how male patients expressed opened up for more caring relationships with friends after their diagnosis. As networks of support shift and change as one ages, and some people die or become more peripheral, these patients described how male friends became more personally important. These participants felt that as they grew older and frailer, they became more comfortable asking for help and challenging previously held values about masculinity. Friends became more valued for providing both practical and emotional support, sometimes even lessening the burden on the "primary" informal caregiver.

This paper has found that professional support was extremely important to participants and was valued for diminishing the discomfort that arises in changing roles and identities related to dependency and caregiving. Specialized palliative care at home represents a special context for examining the role of professional care because it is one of the few services that works inter-professionally and is available on a 24-hour basis. Patients placed a high value and appreciation for this support, but this specialized service is available to a very small proportion of dying patients. Community members (defined as friends, workmates and neighbors in this text) were appreciated by female informal caregivers as refuges for restoring a sense of "normal life" but were not often invited to partake in the practical and emotional work of caregiving. On the other hand, male patients demonstrated new possibilities for developing caring masculinities in the course of ageing and increasing dependency, as male friends took on more practical and emotional significance in life. This text expands knowledge about how networks of care are relationally constructed around dependency, and how caring roles are differentially attributed to professionals, family, and community. Dependency necessarily incurs change in subjectivity and social roles, often in painful ways. Professionals and community both played important but different parts in mitigating the uncomfortable shifts in self-understanding that serious illness brought on. Professionals were the most involved in the highly intimate work of taking on practical and emotional responsibility for care within the family. Community members, on the other side of the coin, helped caregiving significant others reacquaint themselves with a side of themselves they felt they lost in becoming caregivers. And for patients, community became a source of greater meaning and support as one faced the challenges of increased frailty and vulnerability.

The high value placed on professional support from female informal caregivers suggests that welfare services play a key role in mitigating the burden that informal caregivers take on. Caregiver burden is often associated with negative health impacts, such as psychological distress, burnout and even long-term unemployment. Strong professional support can diminish this risk while helping to maintain more sustainable relations of care at home between significant others. This has **implications** for how practitioners can develop public health palliative care agendas. While promoting more community capacity to care, it is important not to forget that sustainable caring in families and communities is often enabled by holistic and accessible professional services. Furthermore, it is important for public health palliative care frameworks to consider the desired and actually existing roles of community in networks of support. Community was not often accepted as a source of intimate support for caregiving significant others, but this was not the case for patients. These different values attributed to community support could be meaningfully integrated into future interventions.

Study 3

Locating social support in time: A Beauvoirian exploration of relationships of care amongst older people near the end-of-life

This article explores Swedish, older persons' experiences of meaning in social support in the end-of-life. Taking inspiration from Simone de Beauvoir's feminist phenomenology and theory of age, the analysis unpacks how social support confers meaning while considering the relational context that these care practices play out in. The text is broken up into two analytical sections discussing the significance of temporality in social support: 1) Projects and habits, and 2) Relationality in the past, present, and future. This text suggests that fostering social support around dying older people is a matter of time of age. Meaningful support is something which is performed in resonance with an individual's specific life patterns and developed biographically over time. These accounts of meaningful support are discussed in light of the structural context of care provision in the Swedish welfare state and implications for developing public health palliative care initiatives.

Using a feminist phenomenological approach, this text unpacks how the experience of meaningful social support is entwined with temporality. Temporality in this sense refers to not only an individual's experience of time, or age, but also how past, present, and future are tied up in self-concept. **Section one** explicates participant experiences in terms of Beauvoir's concepts of projects and habits. Participants living in nursing homes describe how meaningful projects, or future-oriented goals that confer purpose, became out of reach as disability encroached. This is discussed through the case of Helga, who was a lifelong craftswoman. Knitting had been a project which meaningfully tied her to her significant others through gift-giving. As she lost her sight, she was no longer able to engage in this activity which conferred meaning. The section goes on to explore how habits, daily routines which confer ontological security, also became weakened as residents were subjected to the institutional time regimes of the nursing home. In both cases, meaningful habits were maintained relationally, either via the responsiveness of caregivers or the presence of significant others with whom habits were oriented around. For patients receiving specialized palliative care at home, caregivers and significant others were more able to organically respond to the participants' needs and support their projects and habits. These participants also were generally less disabled, and therefore had more latitude to maintain projects and habits. **Section two** elaborates on how relationality changes with age. Beauvoir interprets relationality in old age as tied up in biography. The most meaningful relationships are those which are tied up in one's self-concept throughout the life-course. This was evident in some stories of participants who valued most the support and company of old friends and family who knew a significant part of them. However, some participants did express value in making new connections, though those people became significant by playing a role in the care receiver's life story and life patterns.

This paper elaborates on social support as a relational and temporal category. It suggests that meaningful social support is, first, a matter of relational integration into one's daily life patterns founded in projects and habits. Disability was a serious limiting factor to being able to maintain projects and habits, as well as institutional time schedules which were not sympathetic to participants' personal rhythms. Secondly, meaningful social support is relationally entwined with biography and the most appreciated social interactions were with those people who had an established place in a person's life history and self-concept.

The body is an important factor in relating, and for the oldest old, it often becomes a barrier in the pursuit of maintaining projects. However, habits are more workable routines which caregivers can support. In residential care facilities, where visits from significant others have a clockwork character, and formal caregivers are restricted to rigid time schedules, the ability to organically respond to and help residents maintain habits is limited. In homecare the case was different, participants were more temporally and spatially embedded in networks of care which played active parts in their projects and habits. For many of the oldest old, important significant others had died. This led to a feeling of existential loneliness, as those who contributed to their understanding of self were no longer present. The meaning these significant others conferred is not necessarily replaceable. This has **implications** for the development of public health initiatives which seek to expand and strengthen networks of social support around dying, older people. This study argues that social support is not a stable metric that can be achieved with uniform means. This means that public health interventions could be most effective if they aim to strengthen social support insofar as it is integrated into a recipient's life patterns and as they are developed over time. In today's policy and media discourse around older people's loneliness and need for social support, their needs are often framed as being inherent to ageing. In doing so, the complex and subjective dimensions of loneliness and social support in the end-of-life are often lost. This study contributes to field related literature by elaborating on the relational and shifting character of social support in the particular case of nearing the end-of-life in old age, as well as expanding the theoretical horizon for understanding social support via feminist phenomenology.

Study 4

'Exploring Narratives of Death' (END): A case study of researcher experiences in studying dying, death and grief in an interdisciplinary setting

This article explores an interdisciplinary research group focused on dying, death and grief, and the hindrances and possibilities for future research it preludes. This paper offers a unique glimpse into the creation, gestation, and growth of an interdisciplinary effort to expand and enrich the field of death studies over a year-long period. The text is broken up into three sections: 1) Fitting the group into work life; 2) Being scholarly; and 3) Making meaningful research agendas. The paper underscores how end-of-life issues have become more relevant in context of changing healthcare systems, and global demography, as well as crises such as the COVID-19 pandemic and climate change. Investigating these complex phenomena as well as formulating solutions necessitates more inter- and transdisciplinary approaches to research. The paper therefore makes a contribution to the field by elaborating on hindrances and possibilities in practice for making more interdisciplinary research possible.

This study followed an interdisciplinary research group (END) which explored end-of-life issues. The analysis examines participant experiences both from a perspectival as well as structural standpoint – relating to how we produce knowledge about a particular thing as well as the institutional conditions for engaging in that knowledge production. **Section 1** (Fitting the group into work life) elaborated on two key hindrances to interdisciplinary collaboration. First, the participants expressed that there was a lack of slack time in their schedule to participate in collaborative endeavors outside of their faculty. Additionally, the long-time span that is often required to produce interdisciplinary knowledge is not always accommodated for in researcher schedules or in funding bodies. **Section two** (being scholarly) elaborated on how END enabled participants to have fun and be experimental in a research environment. The participants framed the END group as a fertile intellectual environment which accommodated for crafting a deeper understanding of specific phenomena and topics. **Section 3** (Making meaningful research agendas) described the divisions in how researchers made meaning of END in relationship to their field and research agendas. For some participants, the END group was meaningful because it had some personal resonance, or because it contributed to making them better scholars by building more holism into their intellectual understanding of a topic. For other participants, the group was valuable insofar as it contributed to producing some form of applicable, real-world output that could have an impact on society. This difference in personal meaning versus applicable meaning was also correlated with a division between social science and humanities scholars contra medicine.

These findings reflect upon the rationalization and marketization of university structures and research more broadly. Many participants described a tightly booked working life with little slack time for reading or talking to scholars outside of their field. Funding bodies and university management tend to prioritize disciplinary research because it is quicker and therefore cheaper to produce. At the same time, slack time for reading or collegial encounters with other scholars are important factors in fostering creativity in the research environment. The lack of long-term funding for interdisciplinary collaboration, which many argue as necessarily slower, also poses a significant barrier to cross-border research within death studies.

Interdisciplinary collaboration has several merits which justify greater support and interest from universities. Participants in this study articulated END as a unique scholarly environment which allowed them to be more creative and pursue intellectual endeavors. It not only made work more pleasurable, but it also contributed to making their research and mindset more holistic.

Creating well-functioning, synergistic groups is not always straightforward. Field-related research has indicated that creating positive group processes requires time and deliberative approaches to collaboration. There are also often tensions in interdisciplinary environments between the so-called "hard" and "soft sciences". Because END never pursued formal research activities, such tensions or challenges never rose prominently to the surface. For example, concerning how to orient research objectives around producing research with application value or theoretical value. However, there were some clear power differentials in the group – where those in the medical faculty occupied the most central leadership roles. At the same time, all members indicated that they found the group to be fair and enjoyable. A researcher from the humanities faculty also ended up taking the work of END forward by creating a bachelor's level course based on the group seminars.

This study showcases a group of researchers which strongly advocate for more interdisciplinary collaboration on the topics of death, dying and grief. A central hindrance discussed in this paper concerns how university-level and structural barriers in work life often delimit interdisciplinary collaboration in the long term. The possibilities expressed by the participants center on how interdisciplinary research environments are often well-suited for facilitating "play" and more creative group processes. These collaborations can also help researchers develop more holism around their research topic as well as in their overall academic profiles. One important factor that could represent a hindrance or possibility in future interdisciplinary projects concerns purposiveness. Interdisciplinary groups would benefit from discussing the direction of the collective research agenda and whether or not the group wishes to pursue an output with application or theoretical value. This tension also interlocks with potential power struggles between fields, which poses additional scientific challenges to interdisciplinary knowledge production.

Discussion and conclusions

Public health palliative care: Future directions

This dissertation in gender studies offers a unique and critical view of possibilities for public health palliative care interventions in the Swedish welfare state context. Concisely, these studies suggest, in order of each publication:

(1) Patients and significant others appreciate and desire more education around end-of-life issues, to better help them approach illness as well as caregiving with a sense of confidence and agency. At the same time, future public health interventions should take into account and plan for the gendered ways in which this education can reinforce informal responsibilities in care. This means incorporating some strategies to address cultural change around gendered norms in informal caregiving at home and in community settings.

(2) Furthermore, the changing neoliberal context of mature welfare states makes the framing of health promotion policy acutely relevant. Health promotion policy can reinforce a discourse of self responsibilization and relinquishment of state responsibility. Therefore it could be fruitful to construct such interventions in dialogue with other welfare policy structures to position them as mutually supportive, rather than contradictory. This latter point is important because the comprehensive support of professionals can enable more comfortable and interpersonally sustainable relationships at care at home.

(3) Relationships of care and social support for older adults potentially confer the most meaning when support is integrated into the life patterns and personal biographies of recipients. This is important because strengthening social support cannot be treated like an impersonal intervention which can be carried out by anybody at any time. Likewise, place of care (at home or in a nursing home) can make possibilities for social support different. For instance, nursing home staff may not have the same latitude to provide social support as professional carers and significant others caring for someone at home.

(4) An inter- and transdisciplinary approach can help researchers capture a more holistic picture of end-of-life issues and potential solutions for the complex challenges faced by dying patients and their significant others.

While there are some important limitations to the studies included in this dissertation, chief among them is the relative homogeneity in the study sample. As mentioned previously, these studies capture only a partial perspective of the experiences and struggles relevant to the end-of-life care context in Sweden. Further research is merited which complements this research and deepens our intersectional, cross-cultural, and critical understanding of caring and dying in the Nordic welfare state context.

There are also some important strengths to this dissertation, namely the critical contribution it makes to understanding care in the end-of-life through the lens of gender and welfare struggles, filling an important gap in research. This point will be elaborated on in the following section, where I will take a wide-angle view of the role of communities around end-of-life issues, drawing upon the findings of each article included in the dissertation.

Towards community

I am writing this thesis on the intersection between dying, community, and care at a timely moment, when there is more discussion than ever in the global public health arena about loneliness and social isolation as modern "epidemics" which require the healing tonics of compassion, community, and connection. When dying, these issues take on urgency, as personal relationships are changed definitively. It is within this public health context that older adults, which represent the majority of those who die today, are also framed as a risk group which is particularly vulnerable to loneliness and associated poor health (Kotwal et al., 2021). Concurrently, feminist scholars have been uplifting the new challenges facing care systems globally (Miller, 2021), emerging forms of care deficit around dependent adults (Hansen, 2022; Katzin, 2020), and the changing role of civil society in relationship to welfare in the Nordic countries (Linde et al., 2017; Meeuwisse & Scaramuzzino, 2018).

It is clear that these two scientific communities frame problems around care differently; public health from the standpoint of individual and community behavior and feminist scholarship from the standpoint of an enervated public sector. This thesis has attempted to bring the perspective of the latter to critique the former. Far from being an endeavor to dismantle or dismiss the important knowledges produced from public health scholarship, as Berlant (2004) posits, "a project of critique seeks not to destroy its object but to explain the dynamics of its optimism and conclusions" (p. 5). I will conclude this thesis by drawing together some of these key dynamics and consider where opportunities and pitfalls lie looking towards the role of community in care around the end-of-life. In particular, I point to how the normative deployment of community in public health discourse serves to obscure the important structural components which contribute to loneliness and quality of life while dying. At the same time, I will also attempt to defend the possibilities of "community" and elaborate on the ways in which community can and has already contributed to sustainable conditions of care and possibilities for "a good death".

In public health discourse, disconnection from family and community resources, or "social capital", is framed as a social problem that has biological components (Lewis et al., 2013). Social isolation is a biopolitical category, an issue that is equally as toxic as smoking 15 cigarettes a day, according to the U.S. Surgeon General's 2023 Advisory on Loneliness (2023). In the literature, social isolation in the end-of-life context is linked to negative health events like frequent admission to emergency care (Abel, Kingston, et al., 2018a). Lacking social support is also linked to poor communication about end-of-life wishes and not receiving the right care at the right time (Aoun et al., 2021). For caregivers, the consequences could be burnout, psychological distress or "complicated grief" (Mason et al., 2020). Community is now being spoken about in medicalized terms, and a lack of as potential pathology. This is fairly paradoxical as the PHPC paradigm arose out of a social movement toward the de-medicalization of death and dying, but in doing so the burden of pathology moved to a new target: our "individualistic" societies.

As an example, here is an excerpt from the U.S. Surgeon General's Advisory on Loneliness (2023) published last year:

> If we fail [to build a more connected society], we will pay an ever-increasing price in the form of our individual and collective health and well-being. And we will continue to splinter and divide until we can no longer stand as a community or a country. Instead of coming together to take on the great challenges before us, we will further retreat to our corners—angry, sick, and alone. We are called to build a movement to mend the social fabric of our nation … Each of us can start now, in our own lives, by strengthening our connections and relationships. Our individual relationships are an untapped resource—a source of healing hiding in plain sight. They can help us live healthier, more productive, and more fulfilled lives. Answer that phone call from a friend. Make time to share a meal. Listen without the distraction of your phone. Perform an act of service. Express yourself authentically. The keys to human connection are simple, but extraordinarily powerful (p. 5).

Also, in Sweden this same year, the Ministry of Health and Social Affairs committed 145 million Swedish crowns (approximately 13 million euros) to combat loneliness, with almost singular focus on older adults (Ministry of Health and Social Affairs, 2023). Therein, municipalities will be expected to begin offering individual counseling services ("hälsosamtal") which can help users reflect upon their wellbeing and identify resources for interpersonal and community connection or possibilities for municipal support. Using similar language to the U.S. Surgeon General's advisory, the role of the individual is uplifted, as well as a striving towards an ideal of a "warmer" society:

> At the same time, one must be aware of the limitations of political redress on this matter. We all have a responsibility as human beings to diminish involuntary loneliness. Sometimes, one can make a difference via relatively simple acts, such as taking initiative to call someone or start a conversation which would otherwise happen infrequently. Or asking how someone is doing. These are small steps towards a warmer, more connected society[4] (Ministry of Health and Social Affairs, 2023).

In these two passages, it is understood that: (1) community is something which is lost and must be rediscovered, and (2) this is necessary for the political and biological health of the state. Therein, the individual is placed in the center as the arbiter of these problems as well as the source of their solution.

Also built into this rationale for community is a characterization of modern society as individualistic and reliant upon "cold" forms of care in institutional settings. Social changes inspired by feminist political organizing, such as increased women's employment, critique of the nuclear family, and institutionalization of care work, are often credited with the demise of a warmer, more collectivist past (Herd & Meyer, 2002; Hochschild, 1995; Wilkinson, 2022). Sweden in particular has been described in terms of "welfare state individualism" by Trägårdh (2014) because of the ways in which supportive welfare structures, many built by feminist movements, have enabled individuals to live more autonomously from the obligations of family, religion, and community and pursue their own destinies. However, as Wilkinson (2022) well lays out, laying the onus of loneliness solely on the shoulders of factors such as "individualism" and "personal failure" serves to depoliticize how loneliness is structurally created. Self-responsibilization in care is a proliferating logic which functions to move responsibility from the state into the hands of private individuals and families (Dahl, 2012; Gilbert, 2002; Hansen & Jansson, 2022). In the case of loneliness, individuals are expected to solve the problem of loneliness by both locating and building social capital via their communities.

As I discuss in study 1, the logic of self-responsibilization was also legible in the Last Aid intervention. While this education was appreciated by participants,

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[4] Original Swedish: "Samtidigt måste man vara medveten om att politikens möjligheter på det här området är begränsande. Vi har också alla ett ansvar som människor för att bryta den ofrivilliga ensamheten. Ibland kan man göra stor skillnad genom relativt enkla saker, som att ringa det där samtalet som kanske blir av alldeles för sällan. Eller att man vågar fråga hur någon mår. Små steg på vägen mot ett varmare samhälle med mer gemenskap".

working solely from the standpoint of education, and individual empowerment, fails to account for the structural barriers to securing good care in the end-of-life. Gendered norms around caring responsibility, furthermore, delimit the actual degree of agency and choice individuals have when a significant other becomes ill. In this way, self-responsibilization strategies can have the effect of intensifying women's caring roles by failing to interrogate the social norms and customs which delegate care responsibility along unequal lines. This was intimated by the data, where approximately 75% of the participants in the Last Aid course were female. Valorization of community seems to be a counterstrike against later-modern individualization, where "family" and "community values" are used as moral leverage (Cooper, 2017). However, there is a paradoxical element to this too, that in the battle cry against individualism, the moral power of the individual is called upon to restore the collective. This individual, more often than not, is female.

Although the warmth of community is portrayed by the Swedish Ministry of Health and Social Affairs (2023) and the U.S. Surgeon General (2023) as a kind of biopolitical elixir, as I discuss in study 2, community does not always rank first in importance in the everyday lives of people with serious illness and their significant others. In fact, professionals were appreciated as some of the most significant supports. The role of formal support in healthcare was essential in this case to enabling forms of informal care which felt sustainable. Furthermore, many informal caregivers felt reticent to be vulnerable and accept support from non-kin community members and felt more comfortable leaning on the professional care team. As other scholars have pointed out (Chatterji, 2015; Sand Andersen et al., 2020), dependency is not something that all patients and significant others desire to share with others, in their families or in their communities. These points call into question the normative dichotomy between the "warmth" of community and "coldness" of professional care implicit in these public health discourses. This study elaborates on the ways in which the informal and formal work together to create security and satisfaction in care.

Another normative premise in the public health idealization of community is that social engagement and connection are inherently good social (and biological) goals. Moreover, that they are achievable goals for everyone, given the right commitment and effort. However, as I point out in study 3, there are structural as well as existential barriers to alleviating loneliness for the very old living in nursing homes. In this care setting, formal carers are not always given the latitude to provide the kind of social support desired by residents, in part due to increasing time squeezes and managerialist working models in these care settings (Stranz, 2022). Furthermore, in very old age, meaningful social support often includes attention to life-history and daily rhythms that not all supportive significant others are equally able to give, especially when they no longer cohabitate. Several participants in this study also pointed out that those who could provide the most meaningful social support were partners and siblings whom they had lost. This is not to say that there are not actions and collective organization which could increase quality of life for these people – but, as Beauvoir (1996) would argue, they cannot fill the existential hole left by the loss of people who knew them and their life story. This form of loneliness is not a completely curable wound, but something which must be lived with (Sjöberg et al., 2018).

As Beauvoir (2011) laid out in *The Second Sex*, the desire for happiness, just like this will for connection, is a form of wishful politics, a demand for others to live according to a preconceived notion of the good life, and in this case, the good death. What passes for description is prescription. She writes: "It is not too clear just what the word happy really means and still less what true values it may mask. There is no possibility of measuring the happiness of others, and it is always easy to describe as happy the situation in which one wishes to place them" (p. 16). Beauvoir helps us understand that ability to know the truth of other's experiences as outsiders is limited. But moreover, that happiness, a necessarily normative term, is perhaps not the best metric in any case for theorizing a future where people are most free to live and care to their fullest extent.

Likewise, it is important to remember in this age of idealized community, that community has always been built upon forms of exclusion (Halberstam, 2022). As Ahmed (2010) has argued, the notion of living well always positions itself opposite to the lives of certain others, which become construed as "wretches, strangers, [and] dissenters" (p. 573), those which our community must either position itself against or delegate compassionate resources towards. The alterity of old age is case in point. Old people are and have been cast as "non-human" subjects (de Beauvoir, 1996) – as people on the "outskirts of life" with different needs than other humans (Jönson, 2021b, p. 82), either because of their fundamentally different form of consciousness or state of physical decline. Public health policy posits that the isolated condition of the old must be resisted through healthy habits and the compassion of communities. But is this singular condensation of old age into a state of lonely decline not an objectifying discourse? It totalizes a large section of the population into a risk category, positioning their lives and needs as threats to social welfare (Jönson, 2009), as well as to the biological and political health of the state. Addressing social isolation in old age and the end-of-life is more complicated than helping "individuals with problems". There are also structural factors that disproportionately expose some individuals to loneliness, such as the dwindling of civic spaces, exhausting and/or precarious working conditions (Gustafsson, 2023; Wilkinson, 2022), lack of affordable and collective housing alternatives, or inaccessible care and/or disability support (Torres, 2019b).

I do not wish to deny the fact, however, that struggles in the end-of-life, like loneliness, as much as caregiver burden and other forms of psycho-social distress, are real forms of suffering which can be meaningfully alleviated by local networks of community support, as several studies suggest (Aoun et al., 2020; McLoughlin et al., 2015; Sallnow et al., 2016). There are also feminist arguments strongly in support of community care. Scholars in care ethics, for example, have intoned the importance of inter-dependence and distribution of care-work in broad community networks in order to unburden the often-dyadic caregiver-care receiver relationship (Cawston & Archer, 2020; Kittay, 2015). Other feminist scholars have also pointed out that the de-privatization of care out of the nuclear family and into broader community and state networks could serve to improve the wellbeing and minimize abuse of dependent individuals (Fineman, 2005; Lewis, 2022).

Community has represented the primary site of care throughout history, the localization of care into families and care institutions are both recent phenomena. Therefore, any analysis of care must take into account the historical situatedness of any given care landscape or intervention. As pointed out previously, the engagement of civil society in social welfare in Sweden is not new, in fact, civil society organizations founded many models and institutions for social care in the welfare state today (Linde et al., 2017). Previous to this the care of the dying was largely handled by individual families or religious institutions (Clark, 2016). CSOs, the Swedish church, and informal/familial caregivers, still play important roles in giving social support to dying and bereaved individuals (Grassman & Whitaker, 2007), alongside welfare state services.

The tension between these two loci of care, the state and the informal sphere, has been discussed at length by scholars as a relationship of either complementary or substitution (Jegermalm & Grassman, 2013). The former denoting a necessary hybridity between state and civil society regarding care and the latter denoting care from civil society as symptom of welfare state failure (ibid p.207). Both sides represent different dimensions of truth. In the neoliberal context of the welfare state today, the shift of responsibility from the state to the individual and community sector can represent a “trojan horse” in the dismantlement of the welfare state (Linde et al., 2017, p. 296) – especially when residential care services are retrenched in the process. At the same time, civil society and family constellations of care have always existed as a “hidden abode” of social reproductive work alongside state and private services, to varying degrees (Fraser, 2014). Those who have been excluded from state services, moreover, have been more dependent on such informal networks. Community organizations have been instrumental, especially in Swedish history, in meeting these unmet needs and later inspiring some form of integration of this care work into the formal sector, as was the case for homelessness and HIV/AIDS (Linde et al., 2017). Participation in civil society as a volunteer or informal carer for a non-cohabiting contact can also have a positive dimension (Jegermalm & Grassman, 2013). The benefits of informal caring and volunteering are often lost in the debate on whether or not activity in the private sector is symptomatic of an ailing public sector. Being a carer and/or volunteer has been associated with increased feelings of belonging and even health benefits (Jegermalm & Grassman, 2013; Warburton & McLaughlin, 2006). Most informal care is done voluntarily and is often recounted as a valued experience amongst men and women (Linderholm & Friedrichsen, 2010).

What matters then, in designing a program for community engagement in end-of-life issues, as the studies in this dissertation indicate, is critical focus on gender in the realm of care work and complementarity with welfare services, rather than substitution. This will necessitate inter- and transdisciplinary collaboration in the field of PHPC. Care, in both its material and ethical dimensions, is a complex subject which cannot be condensed to dichotomies such as: state or civil society, warm or cold, compassionate or instrumental. Transdisciplinary approaches, and feminist approaches, as I have demonstrated in this thesis, are crucial to developing communities of care which are premised on equity and our common welfare.

Responding to the research questions

Question 1 – How do community perspectives on palliative and end-of-life care map onto the Swedish welfare state context?

This dissertation has discussed how public health initiatives could be harnessed in a way that serves to substitute welfare state services in long-term and palliative care contexts. While communities are and have historically been engaged in providing different forms of care and social support around frail older people, the dying, and their significant others, the promotion of informal support in the neoliberal context of the care sector today positions this reservoir of care as a potential replacement for formal services. This has gender-related consequences, as the majority of informal carers today are still women. Community engagement initiatives could therefore run the risk of re-entrenching gendered norms around care and responsibility when women represent the majority of engaged participants. At the same time, increasing knowledge and agency around end-of-life issues through PHPC-inspired interventions, like Last Aid, can be strongly appreciated by informal caregivers who feel overwhelmed by their situation. Participants in study 1 expressed a desire for more understanding and support after their own or a significant other's diagnosis. What this study intimates then, is that community engagement could play an important and complementary role to formal services. Similarly, study 2 demonstrated how patients and significant others appreciated the dual support of professionals with family and community. In these participants' experiences, professional support enabled more sustainable relationships amongst family and community.

The main point then, in answer to the research question, is that informal and formal sources of support in the end-of-life context could be mutually beneficial. However, given the context of the Swedish welfare state, where processes of retrenchment and re-familalization have become more common in the care sector, PHPC initiatives could be used in service of further neoliberal reform, with gender-related consequences.

Question 2 – How are experiences of care-giving and care-receiving in the end-of-life gendered, relational, and inter-subjective?

It was clear in study 2 that informal care took on gendered qualities related to responsibility and vulnerability. Female caregivers expressed a sense of moral responsibility to care as well as a reticence to share the burden of care with significant others, preferring instead to lean on the support of the palliative care team. Responding to sub question 2b (how is agency to care delimited and empowered in the end-of-life context?), this case demonstrates how care is not just a matter of "who does what" – rather, that how women assume responsibility in care situations is textured by social norms and values. For instance, the desire to show up and take full responsibility for care, even to the detriment of one's health and wellbeing, was a common experience expressed by these female significant others. Although informal care is a choice, as specified in Swedish law, the real degree of agency in exercising choice is up for question, when gendered norms of behavior around care prescribe responsibility and even self-sacrifice.

Study 2 also informs sub question 2a (what are the different roles and caring functions adopted by community, family, and professionals in the end-of-life?). As described in this text, significant others expressed how the support of the palliative care team was instrumental in ensuring that they were able to keep their heads above water and continue being engaged as carers. Patients also expressed their satisfaction with the support of the palliative care team, expressing how these care providers were able to see them as whole people, as well as provide support for their significant others. This professional support provided a sense of security in an otherwise turbulent home situation, making other forms of care more possible. Male patients in study 2 similarly expressed that they felt more open for calling upon friends for support and showing vulnerability. These findings suggest that the differential functions of formal and informal caring roles can be mutually supportive and complementary. Responding to sub-question 2c (how does age factor into relationships of care?), many of these participants expressed that as their illness progressed, they valued relationships with their friends more, and felt that previous masculine values of autonomy or independence diminished in importance. This study shows, therefore, how ways of relating in the end-of-life are textured not only by gender, but also potentially ageing and debilitation.

Also, in connection to sub-question 2c, study 3 discusses how social support is in inter-subjective process, where the meaning of support was entwined with how the care-giver and care-receiver meet each other in time. Temporality is discussed in this paper in terms of two main components, daily life patterns as well as age. This study demonstrated that social support takes on meaning when that support is provided by others who contribute to the projects and habits of the person in question. This was most possible for those patients living at home, where kin and non-kin caregivers had lives which were more organically intertwined with the patient's and were therefore more able to respond to needs as they arose. Patients living in nursing homes, however, were subject to clockwork and routinized schedules (of both staff and their significant others), and it became harder therefore to maintain habits that had importance to them. These patients were also more hindered by multiple illnesses and disability in advanced age, which impaired their ability to hold on to projects. They additionally described how the loss of close significant others who were part of their life story left them feeling lonely, despite having other sources of social support. Habits, however, were in some cases described as possible areas where meaningful support could still be supplied. Social support then, as described in this study, can be understood as an intersubjective practice where meaning is derived not only from how the lives of care-givers and care-receivers come to overlap in daily life, but also how their lives come to overlap throughout the life-course.

Question 3 – What are the prerequisites, strengths, and weaknesses of a transdisciplinary approach to studying the social and community dimensions of palliative care?

As pointed out in study 4, inter- and transdisciplinary methods have been lauded as approaches which are well suited for tackling complex social problems. However, there is little time in most university settings for researchers to build and do research in cross-border collaborations. This can be due to increased marketization in academic institutions, that stress high productivity and output, which is typically more feasible within disciplinary research. As discussed in this study, researchers in the END group intoned that in contrast to other academic environments characterized by productivity demands, END was a milieu where they felt they could relax, "play" with ideas, and develop a more holistic understanding of end-of-life issues. Related research has demonstrated that having such "slack" time to be creative can be instrumental to producing novel research which as "real-world value". Concisely, this study posits that interdisciplinary research confers important strengths, such as the potential for creativity, more theoretical holism, and highly applicable knowledge for addressing complex social issues. However, marketized university structures pose a significant obstacle for enabling ideal interdisciplinary research environments that can survive in the long-term.

The work included in this dissertation is itself an example of transdisciplinary work concerning end-of-life issues, bridging palliative care and gender studies. Concerning sub-question 3a (how can a feminist theoretical lens inform a public health perspective on palliative care?), then, this dissertation itself demonstrates the potential use and value of analyzing end-of-life issues from a feminist theoretical vantage point. Studies 1-3 apply a critical feminist lens to relationships of care in the end-of-life context. Death, dying, and caregiving are complex issues that are entangled with gender and welfare; however, these concepts are seldom interrogated in the literature in PHPC. This dissertation fills this gap in the literature and exemplifies how a transdisciplinary approach can illuminate important areas of improvement public health planning and address the “real-world” issue of how to improve living while dying for individuals, families, and communities.

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Our Deaths, Ourselves

> "He sat holding the dying man's hand in his own for half an hour, an hour, another hour. Now he was not thinking about death at all. He was thinking about what Kitty was doing, about who was staying in the next room, about whether the doctor had his own house. He was hungry and sleepy. He cautiously freed his hand and felt his brother's feet. His feet were cold, but the sick man was breathing. Levin once again tried to leave on tiptoe, but the sick man stirred once again and said: 'don't go'"
>
> – Leo Tolstoy in Anna Karenina

This dissertation is about how we relate to one another and ourselves in the end-of-life. The context is Sweden and the welfare state model of care. It explores how caregiving and dying are textured by interpersonal as well as political processes and how gender and age are imbricated on both of these levels. The way that we die and care for the dying today is changing, related to extended life expectancy and neoliberalization in the healthcare sector. In a time of "care crisis", both formal and informal care resources are under duress, making the question of how to provide "a good death" complex and contested in new ways. Scholars in public health have posited a health promotion approach to palliative care where communities are uplifted as a source of social capital and support for the dying and their significant others. This model invokes the responsibility of civil society to provide support – through volunteerism, cultural engagement, or everyday "compassion". However, this approach lacks a critical perspective which accounts for how gender and welfare shape possibilities for caring and living well until the end. Throughout, these texts discuss matters of responsibility and meaning in how we become care-givers and care-receivers alike in this unique phase in the life course.

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