Loneliness and Dying as Issues of Public Concern in Sweden

Axel Ågren

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Axel Ågren

Department of Medical and Health Sciences
Linköping University, Sweden
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*To Marie, Alexander and Benjamin.
Thank you for your love and support!*

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ABSTRACT

Loneliness among older people and how the dying should be cared for are issues that evoke public debate. These issues are often described as universal and existential aspects of the human experience. Societal understandings of loneliness and dying have, however, changed dramatically over the past decades. Loneliness among older people and how we die are surrounded with ideals of how to “age well” and “good deaths”, where failure to meet these expectations is associated with tabus, stigma and personal and societal failures. Consequently, studying loneliness among older people and care of the dying gives rise to the question of to what degree loneliness and dying are personal or public concerns.

The aim of this dissertation is to study how loneliness among older people is constructed in the Swedish news press and how care of the dying is constructed in policies and through the perspectives of experts in palliative care. Specifically, the analysis explores to what extent these issues have become public concerns, and how “old and lonely” and “the dying” are positioned and constructed.

In Paper I, the focus is on identifying overall discourses on loneliness among older people in the Swedish news press. Paper II is an analysis of how the responsibility for reducing loneliness is designated in the Swedish news press. Paper III explores how policies on palliative care have emerged and developed in Sweden over time since the 1970s up until today. Paper IV highlights the perspectives of experts, in palliative care, on the development and current state of palliative care, and the role of policymaking in this context.

The findings of Paper I illustrate that although loneliness among older people have seemingly gained increased attention, much of the news articles are about the deficiencies in the organisation of eldercare and volunteer work with aims of reducing loneliness. In Paper II, the main finding is that the task of reducing loneliness is discussed, defined, and designated by and to those who were “non-old” and “non-lonely”, where ambitions of inclusion result in constructing old people as the “others”. Paper III shows how policies on palliative care have changed, from an emphasis on psychological end-of-life care and an overarching critique of the hospice care philosophy, to claims for care to be instead inspired by the very same philosophy. Furthermore, ideals of dying at home have lost their significance as palliative care should be universal and carried out everywhere. Based on interviews with experts in palliative care, the results of Paper IV highlight the complex development of palliative care in between deficiencies in end-of-

life care of the past and improvements of the present. These improvements resulted, however, in risks of too much bureaucracy.

The overall findings of this dissertation indicate that loneliness among older people and care of the dying serve as symbols for criticising the idea of the development of “modern society”, which is altogether viewed as individualistic, bureaucratised and medicalised. Throughout the studies included in this dissertation, the issues of individual autonomy and activity as well as responsibility have shown to be central. In the context of palliative care, the concept of autonomy has a key position and responsibility is on the dying person to make choices in order to achieve “good palliative care”. Regarding loneliness among older people, emphasis is on how to make older people physically and socially active. Loneliness is constructed as a problem which should be avoided and solved by “society” bearing the responsibility for enabling older people not to be lonely.

SVENSK SAMMANFATTNING

Ensamhet bland äldre och vård av döende personer är frågor som diskuteras i offentliga fora. Dessa frågor beskrivs ofta som universella och en central del av människans existens. Dock har samhälleliga förståelser av ensamhet och döende förändrats dramatiskt under de senaste decennierna. Ensamhet bland äldre människor och hur vi dör är frågor som är omgärdade av ideal om "god död" och om att "äldras väl", där misslyckanden med att uppfylla dessa förväntningar är förknippade med tabun, stigma och personliga och samhälleliga brister. Eftersom äldres ensamhet och vård i livets slut är frågor som till viss del välfärdsstaten i Sverige engagerar sig i aktualiseras frågan om i vilken grad ensamhet och vård av döende personer är individens eller samhällets ansvar. Den ökade samhälleliga uppmärksamheten för dessa frågor i media och genom policyer, motiverar behovet av forskning om hur ensamhet bland äldre konstrueras, vad som ger upphov till att vissa definitioner blir förgivettagna och vilka typer av definitioner som nyhetspressen och policyer lutar sig emot.

Syftet med denna avhandling är att studera hur ensamhet bland äldre konstrueras i svensk nyhetspress och vård av döende konstrueras i policyer samt utifrån experters perspektiv. En central del av detta syfte är att analysera i vilken utsträckning dessa frågor är individens respektive samhällets ansvar. Syftet är vidare att undersöka hur "ensamma äldre" och "döende personer" positioneras och konstrueras.

I Paper fokuserade jag på att identifiera övergripande diskurser om ensamhet bland äldre i den svenska nyhetspressen. Paper II utgjordes av en analys av hur ansvar för att minska ensamheten bland äldre utpekats i den svenska nyhetspressen. Hur policyer kring palliativ vård i Sverige först etablerades och har utvecklats över tid, mellan åren 1974-2018, studerades i Paper III. Experters perspektiv på utvecklingen och det nuvarande tillståndet för palliativ vård och vilken roll policyer haft i denna typ av vård belystes i Paper IV.

Trots att ensamhet bland äldre till synes har fått ökad uppmärksamhet i media, visade resultaten i Paper I att nyhetsartiklarna till stor del handlade om bristerna i organiseringen av äldreomsorg och betydelsen av volontärarbete för att minska ensamheten. I Paper II var den övergripande slutsatsen att uppdraget att minska ensamheten diskuterades, definierades och utpekades av och till dem som var "icke-äldre" och "icke-ensamma", där ambitioner om inkludering resulterade i att konstruera äldre människor som de "andra". I Paper III var ett centralt fynd att policyer kring palliativ vård förändrats från betoning på psykologisk vård i livets slut och en

övergripande kritik av vårdfilosofin från hospicerörelsen till krav på att vården bör utgå från denna filosofi. Dessutom tappade idealen om att dö hemma sin betydelse eftersom policyer med tiden betonade vikten av att palliativ vård ska vara universell och kunna genomföras överallt. Baserat på intervjuer med experter inom palliativ vård var resultaten av Paper IV att den historiska utvecklingen av hospice-rörelsen och samtida internationella händelser inom palliativ vård fungerade som referenspunkter för att förstå utvecklingen och det nuvarande tillståndet för den palliativa vården. Dessa metaberättelser sammanflätades också med personliga erfarenheter från palliativ vård.

De övergripande resultaten i denna doktorsavhandling var att ensamhet bland äldre och vård av döende tjänade som symboler för att kritisera utvecklingen av det "moderna samhället" som betraktades som individualistiskt, byråkratiserat och medikaliserat.

I de studier som ingår i denna doktorsavhandling var frågor om ansvar, individuell autonomi och aktivitet centrala. I policyer för palliativ vård var begreppet autonomi centralt och döende personer framställdes som ansvariga för att göra val för att uppnå "god palliativ vård". Beträffande ensamhet bland äldre låg tonvikten på att göra äldre fysiskt och socialt aktiva. Ensamhet bland äldre människor ansågs mestadels som ett problem som bör undvikas och lösas. Det var också "samhället" som skulle göra det möjligt för äldre att inte uppleva ensamhet.

LIST OF PAPERS

- I. Agren, A. (2017). What are we talking about? Constructions of loneliness among older people in the Swedish news-press. *Journal of Aging Studies*, 41: 18-27.
- II. Agren, A., Cedersund, E. (2020). Reducing loneliness among older people – who is responsible?. *Ageing & Society*, 40(3) : 584-603.
- III. Agren, A., Nedlund, A-C., Cedersund, E., Krevers, B. Policy narratives on palliative care in Sweden 1974–2018. Submitted.
- IV. Agren, A., Nedlund, A-C., Cedersund, E., Krevers, B. Dying as an issue of public concern - Cultural scripts on palliative care in Sweden. Under review.

ABBREVIATIONS

LCP	Liverpool Care Pathway
NBHW	National Board of Health and Welfare
WHO	World Health Organization

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whose support, love and friendship means the world to me and our two sons, Benjamin and Alexander, whose energy, and love for life reminds me of what is truly valuable in life and has helped me to enjoy life outside the academic world.

INTRODUCTION

Loneliness and dying are often described as universal and existential facets of the human experience. The language used to describe loneliness and dying has, however, changed over time (Karnick 2005; Tradii & Robert 2019). Loneliness among older people and how the dying are cared for raise public concern and are associated with stigma, tabus and personal and societal failures (de Jong Gierveld 1998; Schirmer & Michailakis 2015; Seale 2004). Consequently, the issues of loneliness and dying highlight the tension between individual and societal responsibilities. Individual autonomy is premised in contemporary Western societies where individuals are responsible for making choices regarding their own life up until death (Bauman 1988; Giddens 1991; Walter 1994). The goal for professionals within healthcare and end-of-life care is to enable individual choices in order to satisfy the individuals inner needs and improving quality of life (Walter 1994; Borgstrom & Walter 2015). The individual responsibility for ageing well has increasingly been emphasised through policies endorsing the concept of “active ageing”, where maintaining an active lifestyle sets the individuals free from “oldness” and decline (van Dyk 2014; Timonen 2016; Rudman 2006).

It is argued that we understand concepts of care in social policy and in everyday life through the construction of categories, where meanings and connotations change through discursive actions. Furthermore, constructions of imagined identities work as the foundation for social policies (Weicht 2013; Hall 2000; Wilinska & Henning 2011). To what extent an issue is understood as a problem and gain societal attention is dependent on how it is presented, discussed and negotiated by claim-makers in public arenas (Blumer 1971; Hilgartner & Bosk 1988; Loseke 2003). Hilgartner and Bosk (1988) argue that there is an ongoing dynamic process of competition between social problems where there are numerous conditions which potentially cause harm, but only a few reach “celebrity” status and becomes recognised as problems in need of solutions (Hilgartner & Bosk 1988). How an issue is constructed and understood in society has an impact on how the issue at hand is dealt with, regarding how plans for organising actions are formulated and what resources that are allocated for solving the problem (Blumer 1971; Spector & Kitsuse 1973). I share these perspectives, and in this dissertation, I will embark on one of the main tasks of social constructionism, namely, to examine how issues become taken for granted as “reality” through language use in different contexts (Berger & Luckmann 1966, p. 26-27; p. 51).

Public discussions on loneliness among older people is not a new phenomenon. In the late 1940s, the Swedish author Ivar Lo-Johansson carried out reports together with a photographer to document the current situation in Swedish nursing homes. In Lo-Johansson's work, several photographs were used in combination with literary work in which dramatic argumentations and historical metaphors served to illustrate and amplify the alleged dire state of Swedish eldercare at the time (Wersäll 2006, p. 138). In the reports, loneliness was a key issue and Lo Johansson himself defined the reports as a study on "Swedish loneliness", and a continuation of his work on monism, which was an umbrella term for individual loneliness, national loneliness and so on (Wersäll 2006, p. 28). Lo Johansson argued that when older people entered a nursing-home, the two vital parts of life were left behind; working life and love life. The sparse institutional environment of nursing-homes could not replace these and there was no social care focusing on the psychological dimensions of ageing. Deficiencies in the physical environment and lack of meaningful activities resulted in, Lo Johansson claimed, the old person freezing on the inside and outside leading to the decline of the soul which also affected the physical body. Consequently, nursing-homes acted as a barrier to the surrounding world where the thread of life was cut off and life in this context was argued to be a long waiting for death (Wersäll 2006, p. 86). The reports triggered public debates and led to the first governmental report on eldercare, where loneliness was a central theme (SOU 1956:1).

During the 1970s, critiques of the state of end-of-life care in Sweden assumed similar perspectives. Feigenberg (1974) argued that the medical treatment of the terminally ill was satisfactory but dying patients were hidden in unfamiliar environments and left alone with their questions, anxieties and pain. Similar to Lo Johansson's arguments, it was claimed that dying patients in hospitals were deprived of their identity, leading to feelings of dependency and incompetence. Experiences of illness and need of communication were not met, which led to feelings of being lost and alienated in hospital environments, which;

[...] often grow into total loneliness and complete helplessness. (Feigenberg & Fulton 1977, p 217).

Sweden is categorised, by Esping-Andersen (1990), as belonging to the "social democratic welfare regime", which is characterised by aspirations of providing welfare services and benefits to its citizens (Esping-Andersen 1990). Thus, it could be assumed that the responsibility for providing social welfare services and benefits mainly lies with the state. Recent studies indicate, however, that the Swedish welfare state, increasingly is undergoing processes of marketisation, privatisation (Svallfors & Tyllström 2017) and reductions in welfare investments, leading to increased responsibility of

family members, informal caregivers, and neighbours (Warburton & Jeppsson Grassman 2011).

Individualism and autonomy have been central elements in Sweden before, during and after the establishment of the welfare state as Sweden is characterised by what Berggren and Trägårdh (2015) define as “state-individualism”, where a strong welfare state enables its citizens to be autonomous individuals. The fundamental premise of the Swedish welfare state is, Berggren and Trägårdh (2015) argue, that “true love” is based on autonomy and not mutual interdependence, indebtedness, and subordination towards others (ibid: p 22-23). This may seem as idealising the foundations of the Swedish welfare state which have been critically scrutinised by scholars with regard to issues such as gender inequalities, segregation, and connections between the founding ideologies of the welfare state and ideas of racial hygiene (Hirdman 2018; Ristilammi 2003; Nilsson 2003). Categorisations of welfare state regimes are considered to build on a male norm in which women’s citizenship and dependency are made invisible. The concept of defamilisation has been developed as a response to this critique by focusing on the possibilities of independence for women (Littmarck 2017). Nevertheless, the arguments made by Berggren and Trägårdh (2015) highlight how, internationally and within Sweden, understandings of Swedes as lonely and anti-social people who prefer communing with nature to mixing with other people have emerged.

Based on the arguments that individual autonomy, enabled by the far-reaching responsibilities of the Swedish welfare state, in combination with the large share of single households and general views of Swedes as lonely people, it would be tempting to conclude that the experience of loneliness among older people in Sweden is widespread and more prevalent in comparison with other countries. Surveys comparing European countries indicate that rates of feelings of loneliness are lowest in Sweden and Denmark, and that the rates of loneliness have decreased since the first national survey was conducted in 1954 in Sweden (Sundström, Fransson, Malmberg & Davey 2009; Dykstra 2009). In a survey comparing the prevalence of loneliness in 1985 and 2008 in Sweden, it was found that people in the age-group 16-29 experienced loneliness to a higher degree than those in the 65-79 age group. Also, loneliness did not increase over the years when comparing 1985 with 2008 (Tornstam, Rydell, Vik & Öberg 2010). The survey conducted yearly by the National Board of Health and Welfare (NBHW) on how satisfied people are with the eldercare they receive (both in nursing-homes and through homecare services) reveal a different picture, with high degrees of satisfaction and, simultaneously, high levels of experienced loneliness (NBHW 2020). The survey has, however, been criticised for low rates of participation and claims made that staff and relatives help old people fill in the surveys. On the other hand, surveys on a European level often

only include “non-institutionalised” people (Sundström et al. 2009; Dykstra 2009).

Palliative care, as inspired by the hospice movement care philosophy, focusing on a holistic approach when caring for the dying, was introduced and developed in Sweden during the mid-1970s, through the “Motala model”, when the geriatric care of dying patients was relocated from the hospital to the home. The terminology has changed over time from “terminal care” to “palliative care”, where the latter term was adapted in Sweden during the late 1980s (Beck-Friis & Edenbrandt 2014). Through the ÄDEL-reform in 1992, municipalities in Sweden were made responsible for providing care for older persons. Municipalities were obliged to provide housing opportunities, which should be homelike and not resemble a care institution, for older persons who could not live at home due to increased need of care and attention (Edebalk 2020). Through this reform, care at the end of life is often located within the context of eldercare. In a dissertation by Holmberg (2020) focus was on the needs of assisted bodily care of older people at the end of life in Sweden. According to Holmberg (2020) older persons with multi-morbidity is a growing group in Sweden who often have several symptoms and extensive pain, which may be a threat to the individuals identity. Furthermore, the dying trajectories are found to be varying and difficult to predict. A central finding was that assistant nurses who assist older persons to achieve bodily tasks led to experiences, by the older person, of the body as lived. Self-determination was found to be key and continued loss of bodily abilities resulted in feelings of powerlessness and loss of the self.

Today, the WHO (World Health Organization) has categorised Sweden as a country;

[...] where hospice-palliative care services are at a stage of advanced integration into mainstream service provision (WHO 2014, p 39-40).

Every year approximately 90,000 people die in Sweden and it is estimated that 70,000–75,000 of these need palliative care (NBHW 2016). In Sweden, palliative care is primarily the responsibility of the welfare state both in the healthcare sector and in municipalities (primarily in eldercare homecare services and in special housing). NBHW is a government agency with overall responsibility for setting national guidelines, goals and indicators, as well as evaluating health and social care and thereby also palliative care. Over the past decade there has been a rise in these types of documents. A clinical guideline (from 2012) and a “knowledge-based” guide for palliative care (from 2013) have been published in Sweden. In a study on the implementation of these documents, in acute care hospitals, it was found that, in all levels of healthcare in Sweden little is known about these types of documents, and possibilities for integrating palliative care early in

disease trajectories were seldom discussed (Lind, Wallin, Brytting, Fürst & Sandberg 2017). Furthermore, quick decision making in hospitals were obstacles for implementation of these guidelines (Lind *et al.* 2017).

Relevance of the study

Conrad and Barker (2010) call for social constructionist understandings of illness. The authors argue that certain illnesses have acquired cultural meanings which do not necessarily correspond with the “nature” of the illness. Furthermore, illness is socially constructed by those facing a particular illness based on how individuals live with and make sense of their illness. Conrad and Barker (2010) also argue that “medical knowledge” is not so much objective as constructed by claims-makers. This, in turn, raises the question of the definitions of a problem upon which certain policies are based and what gives rise to a specific definition (Conrad & Barker 2010). Although not specifically focusing on illness in this dissertation, I consider these perspectives to be applicable for constructions of loneliness among older people and care of the dying.

Loneliness is commonly viewed as a problem of old age (Victor 2015) and care of the dying is often found to depart from ideals of “good deaths” (McNamara, Waddell & Colvin 1994). This motivates the need for analysis on how these issues are constructed and given meaning, where a key question is what the constructs of these issues actually are about. Is it loneliness among older people and care of the dying or are other issues in focus? Furthermore, how these issues are constructed leads to the question of how “lonely older people” and “the dying” are categorised, treated and positioned in society. This, in turn, gives rise to the matter of whether older people and the dying are viewed as possessing autonomy with abilities to act and deal with personal issues or dependent receivers of care and activities conducted by others.

Research on loneliness among older people and care of the dying is today extensive with new studies continuously being published. However, analysis which critically examine constructs and meanings given to these issues only constitute a minor part of the research body. In the context of ageing research, media representations of ageing and older people are common topics. The specific issue of loneliness among older people have however only been examined in a couple of studies. Regarding palliative care, large focus has been on critically analysing philosophies and concepts in relation to the developments of the hospice movement. Regarding policies, issues of implementation and potential improvements of palliative care through policies have been addressed. Constructions of palliative care, death and dying in public discourse have also been examined. Critical analysis focusing on constructions and narratives in policies have however only been

conducted to a minor degree. In the Swedish context, these types of studies have yet to be performed.

Description of the studies

In this dissertation, constructions of loneliness among older people will be studied in the context of Swedish news press which is a public arena where articles on loneliness among older people are continuously published. There are several contexts within the media where portrayals of ageing and older people occur. I would argue that the news media is of particular interest to examine since this context have an agenda-setting role, influencing what the public considers news-worthy (McCombs & Guo 2014). Care of the dying will be studied in the contexts of policies on palliative care and from the perspectives of experts with experiences of policymaking within palliative care. The emergence and development of palliative care represents how care of dying have become managed by medical experts and care professions (Howarth 2007). Since policies have a significant impact on how issues are understood and dealt with, it is of importance to study how care of the dying is constructed in policies. To further understand palliative care in Sweden, experts, with experiences of policymaking, have been interviewed to give their views on the development and current state of palliative care and the role of policies within this context.

Aim

The overall aim of this dissertation is to explore how loneliness among older people is constructed and given meaning in the news press, and how care of the dying is constructed in policies and by experts. Furthermore, the purpose is to examine whether older people and the dying are positioned as autonomous individuals with responsibilities to deal with their own life circumstances or if the responsibility for conducting care and activities is designated to others in society. Departing from this aim, a key question is what the constructs of these issues essentially are about. Is it loneliness among older people and care of the dying or are other issues in focus? This question will be addressed through deconstructing meanings given to loneliness among older people and care of the dying by disassembling the content of the constructs of these issues and to identify concepts and contexts that are related to these issues. Through this overarching aim, this dissertation will highlight to what extent loneliness among older people and care of the dying are personal or public concerns. Concerning loneliness among older people, analysis will be centred on overall constructions of loneliness among older people (Paper I) and how the responsibility for reducing loneliness is designated and constructed (Paper II). Constructions of care of the

dying will be studied through analysis on how policies on palliative care have been formulated and shifted over time from 1974 up to 2018. (Paper III). Furthermore, how experts, in palliative care, make sense of the historical development and the current state of palliative care and the role of policies within this context will be scrutinised (Paper IV).

Outline

The outline of this dissertation is as follows. First a background section introduces the concept of loneliness and general tendencies in research on this phenomenon. Thereafter, I will briefly present the development of critical gerontology, a field of research with focus on critically examining how ageing, old age and older people are represented, constructed and positioned in society. Subsequently, recurrent findings and directions within research on media representations of ageing, old age and older people will be addressed. Next, research on societal views on death and dying and the historical development of end-of-life care will be highlighted. In the theory section key directions, developments of and debates on social constructionism, which is the overarching theoretical point of departure of this dissertation, will be presented. This section also consists of a presentation of the social constructionist perspectives that I have departed from throughout this dissertation. In the methods section, focus is on presenting how I have analysed the empirical material gathered for each of the four studies included in this dissertation. In the results section I will present the results from each study. The discussion section will bring together and discuss the overall findings of the dissertation. This section also includes conclusions, a discussion on methods and theory and suggestions for future research.

BACKGROUND

Loneliness, older people and the media

In this segment, I will first address and discuss central definitions from research on loneliness. Thereafter, critical perspectives on how ageing and older people are understood in contemporary society will be presented. Subsequently, research on how ageing and older people are constructed and represented in the media will be introduced.

Loneliness – between societal understanding and individual experience

Loneliness has been a persistent topic in literature, poetry and song over the past centuries (Karnick 2005). The language used to describe loneliness in contemporary society focuses on the negative aspects of loneliness (Karnick 2005) and it is found that people are unwilling to admit to feelings of loneliness due to stigma (de Jong Gierveld 1998; Rosendale 2007). Views on loneliness as a problem and the stigma surrounding the issue are, however, of a relatively new date, as the language used to describe loneliness have changed over time. Loneliness was, during the 19th century, mainly defined as a precondition for working within literature and art and a state associated with the isolated and lonely poet (de Jong Gierveld 1998). Increasingly, during this period, however, loneliness altered from a privilege of a cultivated elite to becoming a matter for the public (Westberg 2012, p. 25).

The division between social and emotional loneliness is a key definition in research on loneliness. Social loneliness, according to Weiss (1973), is triggered by lack of social networks and a result of being excluded from social communities, while emotional loneliness is caused by the absence of intimate relationships. Loneliness is defined, by Perlman and Peplau (1981) whose work is also considered ground-breaking, as a negative subjective feeling that arises from discrepancies between desired and actual social relations. Despite not directly addressing older people, these concepts have been applied in studies on loneliness among older people. Although being widely recognised, these definitions have, though to a minor extent, been criticised for being too vague (Rook 1984; Wood 1986, p 189). As an example, discontent with social relations does not necessarily evoke feelings of loneliness but simply dissatisfaction (Stein & Tuval-Mashiach 2015). For example, a marriage that does not meet expectations may lead to feelings of resentment and not loneliness (Rook 1984).

Loneliness has, in research, been associated with several similar and overlapping concepts such as 'feeling lonely', 'being alone', 'aleness' 'living alone', 'solitude' and so on (Jylhä & Saarenheimo 2010). The paradox of loneliness, according to Wood (1986, p 187–188), is that it is simultaneously a non-social and a social experience. Loneliness is a private experience, yet social, since there has to be a consensus in society on expectations of the number of different relationships an individual should have in order to be aware of what is missing. Consequently, individual experiences of loneliness vary depending on societal and cultural understanding of what loneliness is and when it should occur (Perlman & Peplau 1981). An individual can feel lonely despite being surrounded by others. On the other hand, being alone is not equal to experiencing loneliness, nor is it an inevitably negative condition (Jylhä & Saarenheimo 2010; Victor, Scrambler & Bond 2009). Presently, research on loneliness among older people is extensive and has been conducted within several fields of research with varying focus. Studies on loneliness among older people have often been based on quantitative methods where different scales are used to study how often older people experience loneliness (Jylhä & Saarenheimo 2010). When comparing the results of studies, the prevalence of loneliness has varied from 7% to 49%. The research context, method, types of questions used, and time of the day are considered to potentially contribute to these differences, since feelings of loneliness are more severe during evenings, weekends and holidays (Savikko 2008; Victor, Scrambler, Bond & Bowling 2000). Several studies have focused on loneliness and its connection with physical or mental health, where chronic disease, poor self-rated health, poor functional capacity and problems with hearing and vision can all contribute to feelings of loneliness (Jylhä & Saarenheimo 2010). Depression and loneliness are often viewed as correlating. However, the concepts are distinct, and it is still unclear which of the two predicts the other (O'Lunaigh & Lawlor 2008). It is argued that the dominant understanding of loneliness in contemporary society is that of a psychological condition that should be diagnosed, treated, reduced, or alleviated (Mullins 2007; Westberg 2012; Rosendale 2007). The point of departure for studies on loneliness among older people differs depending on the various philosophical traditions that exist within social gerontology, the study of social aspects of ageing and later life. Departing from positivist perspectives enables views on loneliness as existing in 'the real world' which makes it possible to predict risks of loneliness and to suggest interventions (Victor, Scrambler & Bond 2009, p. 35-37). It is claimed that research on loneliness in later life departs from an understanding of 'old age as a social problem' that needs to be solved (Victor 2015, p. 189), in line with the problem-oriented perspectives on ageing that have dominated gerontological research for decades (Victor, Scrambler & Bond 2009, p. 31). Research has highlighted

how loneliness in later life is surrounded by stereotypes. When comparing responses from 1982 with 2005 in a survey on age stereotypes, Tornstam (2007) found that, both in 1982 and in 2005, roughly 90 % of the survey respondents in Sweden agreed with the statement that almost half of retired people often suffer from loneliness. According to Tornstam (2007), this is a stereotype that do not “match” previous research. Dykstra (2009) found, based on reviews of surveys and studies, that loneliness is more prevalent among the age-group 15-24 years compared to the age groups 65-79, is less prevalent in individualistic countries, such as countries in Northern Europe, and that, contrary to common belief, loneliness does not, increase over time (Dykstra 2009).

Critical perspectives on notions of ageing and older people

The stereotypical understandings highlighted in the previous segment illustrate how loneliness and images of ageing and older people are embedded in certain societal and cultural contexts. In this segment I will focus on this issue by presenting how the research field of critical gerontology has emerged and developed over time. During the 1980s social gerontologists began to make use of critical theories, both as a result of economic recession and cutbacks in welfare, and as a response to concerns that social gerontology was increasingly positivist and empiricist, and lacked theories, leading to research questions being based on uncritical use of images of ageing incorporated from popular culture. Furthermore, it was considered that poverty was seen as part of old age, institutionalised ageism was not critically examined, and micro-perspectives dominated, with social changes which in different ways affect experiences of old age not being acknowledged. Altogether it was argued that social gerontology tended to reproduce stereotypes of older people (Doheny & Rees Jones 2020). In critical gerontology, the concept of political economy of ageing was developed as a perspective to highlight how social structures, policies, and socioeconomic factors contribute to affect ageing and understandings of older people in society. These perspectives were largely informed by social constructionism where a founding idea was that those, other than “the old”, with power to enforce their views on reality, construct old age and ageing in certain ways (Estes 1999). Within critical gerontology there has been increased attention to the divide between the third age, often referred to as the period of time of activity and consumption, and the fourth age which is associated with decline and loss of agency (Higgs & Gilleard 2014). It is argued that “old age” is no longer a stable chronological phase of life since changes in society, economy, life expectancies and constructions of later life lifestyles have altered meanings and understandings of ageing. In these new conditions of later life, focus is on the third age, developing a social imaginary of the fourth age as the new “real” old age, related to frailty and

costs. This in turn leads to the othering of aged persons where, according to Higgs and Gilleard (2014), the fourth age represents an “unbecoming” with losses of choice, autonomy and self-determination which are highly premised in contemporary consumer-oriented societies. Entering the fourth age is a sort of “event horizon” making the embodied self of the past difficult to return to. Furthermore, Gilleard and Higgs (2010) argue that research has failed to address what constitutes the condition of old age, what differentiates old age from infirmity and what characterises the divide between the third and the fourth age. Gilleard and Higgs (2010) consider that the fourth age is more than merely the end of the “third age project” or the unsuccessful counterpart of third age. Instead, they suggest that fourth age functions as the negation to third age and as a social and cultural “black hole” of ageing to be avoided, where the irreversible admission to a nursing home represents disappearance of personal exchange and “deprivatization of experiences” (Gubrium & Holstein 1999).

The media and representations of older people

In this section I will briefly present theories and concepts developed in the field of media studies. Research on how ageing and older people are constructed and represented in the media will also be addressed. Furthermore, I will discuss challenges and issues yet to be covered within media studies on ageing and older people.

The news media have a significant agenda-setting role in society where issues covered are based on the assumption that these issues are “newsworthy”. These are issues which, in turn, are accepted by the public as being the most important issues of the day (McCombs & Guo 2014). The choice of what to report on is, however, argued not to be a deliberate attempt to influence the public, but more a condition of the media context (McCombs & Guo 2014). This is in line with the influential concept of *media logics*, developed by Altheide and Snow (1979) who stated that the methods of the media regarding how material is collected, sorted and presented have an impact on how an event is presented in different media contexts. Furthermore, the context within which a media context is located is claimed to have an influence on what is communicated and how. Thus, what is communicated in the media should be understood as distribution of symbols considered meaningful by those who produce and potentially receive them (Thompson 2000). One aspect that is central to mass media representations about health, which can be applicable to the media in general, is the creation and use of opposites, with the aim of creating a drama, where life versus the threat of death or actual death is the most prominent. Producing news using these effects is called “tabloidization”. One criticism of this is that it can lead to “sensationalization”, with unnuanced and incorrect representations as a consequence. Seale (2003) believes, however, that the

mass media would lose popularity if the focus were on more complex descriptions and that criticism of inaccuracies in mass media presentations is based on a lack of understanding of the conditions of the mass media where the entertainment agenda is key to attracting audiences.

It is argued that increased mediation of everyday life is an overlooked source for how individuals shape identities that is consistent with personal interests in an era of flexibility. According to Harrington, Bielby and Bardo (2014), the media play an important role in how individual biographies become institutionalised. It is, however, claimed that gerontological research and media studies have not intersected and exchanged perspectives in order to further understand the media's role in constructing social categories of ageing, older people and age identities (Harrington, Bielby & Bardo 2014; Iversen & Wilinska 2020).

Regarding constructions of ageing and older people in the media, a reoccurring finding is that the presence of older people has increased over time. There have also been shifts from predominantly negative images where older people *have* problems and *are* the problem (Nilsson & Jönson 2009) to positive portrayals of ageing, old age and older people (Rozanova 2010). These shifts are, nevertheless, conditioned since older people appear in the media to promote a lifestyle consisting of activity, productivity, consumption and strivings towards self-fulfilment (Uotila, Lumme-Sandt & Saarenheimo 2010), which requires consumption of “anti-ageing” products (Calasanti, Sorensen & King 2012; Ylänné 2015, p. 369). Furthermore, it is argued that older people are mainly portrayed as healthy, youthful, glamorous and middle-aged (Featherstone & Wernick 1995). Despite the increase in positive images, negative understandings still exist, relating ageing and older people to various problems, such as disease, decline, dependency, and older people as being a burden on society (Rozanova 2006; Robinson, Gustafson & Popovich 2008; Lundgren & Ljuslinder 2011). Furthermore, ageing and older people are often depicted in the mass media and in public discussions from an outsider's perspective, where older people are talked about by the “non old” (Nilsson 2008; Uotila, Lumme-Sandt & Saarenheimo 2010). Nilsson and Jönson (2009) state that it is difficult to conclude whether a portrayal of an active old person is derogatory or an upgrading of images of older people as it is challenging to reach conclusions on what a “good” or “bad” portrayal of ageing and older people actually consists of. The authors argue that “counter-images” of older people who are active *despite* their age may be a type of infantilisation where stereotypes of problems associated with old age may be reinforced (Nilsson & Jönson, 2009). Williams, Wadleigh & Ylänné (2010) state that research tends to focus on analysing images of old age and older people in the media as either “positive” or “negative”. Iversen and Wilinska (2020) argue that studies focusing on under-representations and misrepresentations, depart from a view of

reality as given. Here, incorrect images of and lack of characters representing old age is often argued to contribute to misleading understandings of old age and as an expression of ageism, where increased presence and more portrayals of older people is the claimed solution. Furthermore, Iversen and Wilinska (2020) found that several studies do not have theoretical or conceptual reflections on how they as researchers define “older adults” or “old age”. In some studies, 50-55 years is considered to be the lower bar of an “older adult”, with references to this being the standard definition in the advertising industry. In other studies, principles are more randomly made and based on the focus of the articles, making retirement or somewhere between 60 and 65 or even 50 years to be the age of those belonging to the category “old”. In articles where age was not specified in the articles, concluding who is old was based on activities and appearance, with “factors” such as grey hair, walkers and wheelchairs and being surrounded by grandchildren. These chronological interpretations may seem objective but are based on cultural understandings of what characterises old age and older adults (Iversen and Wilinska, 2020). Hence, they run the risk of reproducing established stereotypes despite the aim being the opposite. Several studies were nevertheless found where understandings of old age, older people and what meanings were ascribed to “old” in the media was critically examined (Iversen and Wilinska, 2020).

Care of the dying in society

In the segments that follow, I will provide a background on research focusing on societal understandings of death and dying and the development and current state of palliative care. It is often argued that Western societies, mainly due to industrialisation, are death-denying. This notion has however been an issue of extensive scientific scrutiny and debate. I will address the disputed concept of “death-denial” and studies focusing on the ongoing renegotiations of what constitutes “good death”, in society in general and in the specific context of palliative care.

Death and dying in society – changes in place and understandings

It is often argued that there is a dominant “death denial” in Western societies, where death and dying have become invisible and a “taboo topic” (Aries 1974; Gorer 1955) due to modernisation, institutionalisation, medicalisation and because dying is treated with methods of medical technology and protocols. From the end of the 19th century onwards, the place for the care of the dying has shifted from the home to hospitals (Aries 1974). The advent of the Industrial era led to notions that death could be eliminated “disease by disease” through the “weapons” of technology and science,

which in turn gave rise to ideas of death as a failure of the “body machine”, altering death and dying into something shameful and forbidden (Zimmermann & Rodin 2004; Aries 1974; Kastenbaum 1995). One recurring argument for the “death denial” and the hiding of death is that moving the care of the dying from the home to institutions, the emergence of the funeral industry and the displacement of cemeteries to outskirts of cities (Röcke & Cherry 2002; Elias 1982), has led to death and dying being physically and psychologically distanced from everyday life. Death and dying became an issue to be managed by “licensed experts” (Kastenbaum & Aisenberg 1976; Howarth 2007). Death was, according to Aries (1974), silenced for the sake of the dying person, the family and society to maintain the pleasant rhythm of social life. Consequently, death and dying have become issues which are associated with failure and something to be ignored and postponed. Despite views on death and dying as frightening in an age of ideals of physical perfection (Fonseca & Testoni 2012), death and dying have over the past decades gradually gained public attention. Death and dying also became issues for scholarly inquiry, through the establishment of the scientific field of thanatology, focusing on rites and meanings of death from an interdisciplinary perspective.

Glaser and Strauss published two seminal works on end-of-life care (1965; 1968), where the focus was on awareness of dying in hospital settings working with the terminally ill and issues of time in relation to care of the dying (1965; 1968). The point of departure of the former study was that neither laymen nor professionals are willing to talk about the process of dying, that life is preferable to death and that death is only something to look forward to when in pain. This had, according to the authors, implications for healthcare professionals who are medically and technically skilled, but not trained in how to talk about death with dying persons and their relatives. In the latter study (1968), attention was on how work with the dying takes time and that the “dying trajectory” may or may not correspond to how the work surrounding dying people is organised (1968). The temporal aspect is central, since care of the terminally ill follows schedules for food, turning in bed and medication, variations of need for observation and staff turnovers (Glaser & Strauss 1968).

The rise of the hospice movement and the emergence of palliative care – a brief historical overview

The hospice movement, established by Dame Cicely Saunders in the UK during the 1960s (Clark 2018), arose through criticism of how the dying were treated in acute hospital settings and as a challenge to orthodox cancer care (James & Field 1992). When examining the concept of “total pain”, developed by Cicely Saunders, which served as one of the cornerstones of the hospice-movement, Clark (1999) states that there exists a paradox, as

the intention was to humanise psychological suffering and take into account mental, spiritual and social problems as part of the general developments within healthcare during the 1960s, with efforts to increasingly acknowledge the individual. Simultaneously, Clark considers that there were elements of disciplinary power as “total pain” and holistic approach went;

[...] from an initial focus on the physical sensation of pain, to a wider and deeper searching for signs of trouble, in the social network, in the psyche, even in the soul itself. From this perspective the unlocking key has become an instrument of power. This is of course not a sovereign power of coercion, but rather a disciplinary power rooted in knowledge and the technologies of care. (Clark 1999, p. 734)

Over time this approach to end-of-life care gained acceptance within the medical field and international public health policy and the term “palliative care” became an internationally accepted term, while “hospice care” was associated with a marginal social movement (McNamara 2004; Llamas, Pickhaver & Piller 2001; Clark 2018). The original ambition of the hospice movement is argued by several scholars to have been gradually challenged by societal developments, such as increased medicalisation, bureaucratisation and routinisation (James & Field 1992; McNamara 2004), transition from a sole focus on cancer to include other terminal illnesses and to cancer having developed, in many cases, into a chronic rather than terminal disease (Zaman, Inbadas, Whitelaw, & Clark 2017). Furthermore, is it considered that the original Christian “calling” has been replaced by a secular spirituality altering palliative care from a calling, to “just a job” and death being a process to manage rather than a truth to be confronted with (Bradshaw 1996). Moreover, it is argued that the palliative care philosophy changes according to delivery since palliative care is carried out both within specialised and mainstream medical units (McNamara 2004; Clark & Seymour 1999; Field & Addington-Hall 1999).

Departing from these arguments, ideologies of the hospice movement which have been influential for the development of palliative care, can be seen as located in the complex intersections between individual autonomy (Walter 1994) and disciplinary power, and between the use of medical technologies and knowledge on the one hand and attending to the mental, physical, social and spiritual needs of the dying person, with roots in a spiritual ethos (Bradshaw 1996), on the other.

It is often claimed that palliative care is subject to on-going negotiations and boundary setting for what constitutes the profession and expertise of palliative care. As noted by Hibbert *et al.* (2003), palliative care expertise, despite being successful as a medical specialty without being clearly

defined and lacking evidence, is accessed in the medical world through technical strategies mainly focusing on symptom relief. This, however, involves risks of compromising the “holistic approach” (Hibbert *et al.* 2003). Ideals of “good death”, often considered to depart from professionals’ perspectives, is seen as unrealistic in today’s society where more emphasis is on autonomy and individual choice of the patient. The concept of a “good enough death”, developed in Australia, indicates a general shift in society, bringing more responsibility to the dying person.

Renegotiations of death and dying in society – between denial and “good deaths”

When elaborating on the “denial of death thesis”, Zimmermann and Rodin (2004) query, from a sociological perspective whether there is or ever has been a death denial in Western societies. The authors present three common themes which are seen as illustrating this denial. First, the idea that there is a taboo is considered to be questionable, as movements, research and the media have over the past decades engaged in talking about death and dying, with a common point of departure that there is a taboo. The authors also state that individuals’ reluctance to discuss death and dying may be rooted in it being a distressing issue on a personal level and thus an obstacle for smooth conduct in social interaction, but this does not mean that its existence is denied. The second argument for death denial is, according to Zimmermann and Rodin (2004), that the increase in medicalisation has led to avoidance of death and the “technological imperative” has led to depersonalised care. Acceptance of the naturalness of dying thus, represents a return to a lost era. This is a perspective which is central within the hospice movement and palliative care. Zimmermann and Rodin (2004) argue that emphasis should be on how technologies can be used to reduce suffering among dying people. The third argument used to state that we live in a death denying society is that the dying are segregated from the rest of society, where it is claimed that sending dying persons to hospitals and nursing homes “shields ourselves” from death. Here the authors claim that the segregation of death and dying can be seen as a result of structural changes and increased organisation of death and dying, rather than rooted in death denial. In sum, Zimmermann and Rodin (2004) state that arguments on death denial are simplistic and that the emphasis on embracing the naturalness of dying can be an ethically precarious stance within the medical professions. Also, within palliative care focus should be on relieving suffering, rather than on ending the denial of death. “Natural deaths” are often associated with a “good death”. However, as Sandman (2005) point out, the focus should be on whether people are given opportunities to reflect upon the quality and length of life rather than solely focusing on issues related to natural or un-natural deaths. Notions of a good death have,

it is argued, altered into managed deaths administered by professionals, which in turn have affected societies views on death (Horsfall, Noonan & Leonard 2012). When analysing consultations for chronically ill, Price and Cheek (2007) found that avoidance of death was common. Focus was on living with chronic disease rather than dying from chronic disease, and how to tame death. How and where we should die are based on normative ideals where notions of a “good death” entail images of dying at home and surrounded by others, and simultaneously dying alone refers to a “bad death” (Seale 2004). In a study by Exley and Allen (2007), focus was on home care at the end of life, where the authors conclude that home care philosophies and policies has led to an “over-romanticised” notion of home care. One conclusion of the study is that home is more about social and emotional relationships than solely the private physical space. When conducting a critical discourse analysis on palliative care literature, focusing on “acceptance” of death, Zimmermann (2012) found that acceptance is seen as a facilitator of a “good death” and a crucial goal within palliative care, since acquiescent patients were seen as easier to manage and provide care for. In an ethnographic study of persons who had attended the death and dying of someone close to them, Seymour (1999) found that the experiences could shift between perceiving medical interventions as enabling a “natural” death, while on other occasions being the obstacle to the very same. It was more the case that the meaning of technology was key to how death was experienced in the technical environments of intensive care units. When technology matched up to the expectations of lay persons this led to perceptions of “natural” deaths. Alternatively, when this linking between technology-use and understandings of “natural” death did not match, the dying process was considered “unnatural”. Thus, “good” and “natural” death and dying was given meanings through personal experiences and representations as these matters were constructed and reconstructed sometimes a long while after the events. When studying perspectives on “good death”, Payne, Langley-Evans and Hiller (1996) found that patient perspectives are heterogeneous, with emphasis on dying free of pain, dying suddenly and in their sleep. Staff within a palliative care unit, on the other hand, accentuated involvement of the family, suitable symptom control and lack of distress. In a study focusing on palliative care managers, the findings of Semino, Demjén and Koller (2014) highlight a strong sense of collective identity, where “good death” narratives focus on effective teamwork, whereas a “bad death” occurs outside their control despite the team’s best efforts. Borgstrom and Walter (2015) argue that “good deaths” in England are constituted by compassion with the concept in end-of-life care being used as a defence against market-oriented reforms and as responses to care scandals when older people are described as not cared for during the last months of their lives (Borgstrom & Walter 2015). Furthermore, notions of lack of

compassion have emerged internationally within the healthcare sector in general and methods for enabling compassion have increasingly been endorsed within end-of-life care to reduce suffering.

Expansions and mainstreaming of palliative care and the role of policies

As highlighted in the segments above, palliative care has expanded to specialised and mainstream medical units over the past decades (Field & Addington-Hall 1999). This development has been endorsed in policies, within countries and on a global scale. In Sweden, there has been an increase in guidelines for palliative care in the past decade (Lind *et al.* 2017). The Liverpool Care Pathway (LCP) is an example of efforts to integrate specialist palliative care into mainstream healthcare through policies with emphasis on evidence-based guidelines with steps to follow for multi-professional teams. However, following strong critique from a review and intense public debate, the LCP was abolished in 2014 (Seymour & Clark 2018). In 2014, the World Health Organization (WHO 2014) advocated that all countries should implement palliative care policies in all relevant contexts (Seymour & Clark 2018). According to Zaman *et al.* (2017), a “common global future” for palliative care has become a policy goal on a global level since hospice and palliative care is often seen as self-evidently beneficial and a human right. In the study, the authors claim that there are risks when transferring “one joint idea” for end-of-life care from developed to developing countries, and that the plurality of local problems within end-of-life care should be in focus, rather than striving towards universality. The concept “evidence-based medicine” (Greenhalgh & Russell 2009) has increasingly been endorsed within palliative care (Visser, Hadley & Wee 2015; Aoun & Nekolaichuk 2014; Higginson 1999; Chan 2018). Several studies highlight, however, that the “evidence” on outcomes of palliative care is scarce and focusing on ensuring evidence-based care is difficult in the context of palliative care. Quality of life is difficult to measure among patients with progressive terminal illness and changing problems occurring in the last year of life among different patient groups should, Higginson (1999) argues, be increasingly addressed in reviews of evidence within palliative care. Aoun and Nekolaichuk (2014) state that there is a need to think of new ways to conduct research within palliative care in order to improve “evidence”, as standard methods for achieving “evidence” through randomised control trials and systematic reviews may not fit palliative care due to heterogeneity in patients, varying settings and fluctuating health states. It is, however, noteworthy that despite these “evidence” issues, claims have increasingly been made for the integration of palliative care into mainstream medicine (Hibbert *et al.* 2003; Seymour & Clark 2018) and policies have been developed using the “language” of evidence-based medicine.

Studies have highlighted public debates, policies and politics on palliative care in different countries. A study analysed parliamentary enquires on dignity at the end of life in Austria, where experts, politicians and citizens gave their perspectives on what constituted a “good death”. A pattern was identified where “good death” was argued to be achieved through a combination of institutionalisation, informal support and awareness of dying (Lang 2020). Karsoho, Fishman, Wright and Macdonald (2016) observed, through interviews and reading of legal documents, how physician-assisted dying (PAD) supporters criticised both mainstream medicine and palliative care for causing suffering. Claims were made about how physicians could reduce suffering. Thus, it was found that end-of-life care was configured by using medicalised dying as a framework, rather than a rejection of the very same.

THEORETICAL FRAMEWORK

In this dissertation the theoretical and methodological standpoints of social constructionism are central, as a main objection is to analyse and understand how issues become taken for granted as “knowledge” (Berger & Luckmann 1966), and how we understand our surrounding world through linguistic, both verbal and written, representations of the world. The world is, from this perspective not “out there” but constructed and represented through social interaction, which is largely dependent on societal, historical and cultural contexts (Burr 2003; Winther Jørgensen & Phillips 2002). According to Best (2008), there were growing disagreements, confusions and critiques on the meaning of social constructionism during the 1980s. By seeking to underline the point of social constructionism, scholars searched for flaws in scientific conduct and by demonstrating how moral panic, on for example sadistic rituals, were exaggerated and uncommon and thus served as cases on how minor issues can be socially constructed as major social problems. This, however, led to implying a disjunction between claims and objective reality with the consequence that these types of studies contributed to confusions and encouraging criticism. This inconsistency was illustrated by the concept of “ontological gerrymandering”, developed by Woolgar and Pawluch (1985), where the argument was that sociologists failed to acknowledge that the concepts and language used by themselves were also social constructions. It was also argued that social constructionist analysts lacked consistency, as it was commonplace to emphasise how everything is socially constructed, but simultaneously references were made to existing phenomena and objects. This led to the divide between strict constructionism, with emphasis on the importance of not involving any objectivist assumptions about reality, and contextual constructionism, focusing on how categories and meanings are given to the empirical world. The strict view was, according to Best (2008, p. 46-49), found impossible as even abstract theorisation relies on some cultural assumptions. Within contextual constructionism, “ontological gerrymandering” was seen as inevitable and instead something to recognise (ibid. p. 48-49). These critical debates may at first hand be seen as devaluing the contribution of social constructionism. I view this, however, as a sign of academic development. Awareness of these critical debates are of importance as they highlight the development of social constructionism and how key issues have contributed to shape this theoretical orientation.

In this dissertation, attention is, on an overarching level, on deconstructing the constructs and meanings given to the issues studied. This resembles

what Laclau and Mouffe (2001) define as hegemony, which is achieved through attempts to dominate discourses through arresting meaning in discursive fields that are characterised by constant flows of elements with instable and undefined meanings. To grasp these complex processes focus have been on deconstructing how the issues studied have been constructed. Deconstruction is argued to focus on the essential assumptions, in for example, a text which are made possible through inner power struggles and by suppressing and excluding of elements (Nilsson 2008, p. 53-55; Laclau 1996). When deconstructing the empirical material, attention has been on disassembling constructs and meanings given to loneliness among older people and care of the dying by identifying concepts used and what contexts that are related to the issues studied. Consequently, I depart from an anti-essentialist perspective where the issues studied are not considered to have an essential meaning (Nilsson 2008, p. 53-55; Laclau 1996).

Different social constructionist approaches

In the following segment, I will present the theoretical point of departures of each study.

Paper I Discourse theory

Laclau and Mouffe's (2001) perspective on discourse theory served as a theoretical foundation for this study.¹ Within this theoretical orientation, attention is on constant efforts to fix meaning which is, however, a complex endeavour since the discursive field that surrounds a discourse is filled with ambiguity which can change and undermine the meanings of the discourse. According to Laclau and Mouffe, elements are signs that do not have a fixed meaning, whereas a moment is an element that has had its meaning reduced and fixed within a discourse. Articulation is described by Laclau and Mouffe as all social practices that establish relations between elements. Laclau and Mouffe define a discourse as a structured totality resulting from an articulatory practice, where an element has had its meaning reduced to a moment within this totality (Laclau & Mouffe 2001, p. 105–106). However, this process is never finished since there is an ongoing flow of meaning and differences. Nevertheless, a certain degree of fixation is necessary for the flow of differences to occur. Laclau and Mouffe developed the concept of nodal point to define a privileged sign that other signs are organised around and given meaning to within a discourse (Laclau & Mouffe 2001, p.

¹ The description of theory in *Paper I* is to a large extent retrieved from the original article Agren, A. (2017). What are we talking about? Constructions of loneliness among older people in the Swedish news-press. *Journal of Aging Studies*. 41: 18-27. This article is also included in the licentiate thesis Ågren, A (2018). *Loneliness among older people in the Swedish media - Constructions, discourses and the designation of responsibility*. Linköping: Linköping University.

112). In this study, discourse theory, as described above, was useful for analysing what signs are present in articles on loneliness among older people. Discourse theory was also used to examine whether loneliness among older people was the nodal point around which other signs were given meaning, or if there were other nodal points around which loneliness among older people was given meaning. Discourse theory, as formulated by Laclau and Mouffe, was viewed as particularly relevant when studying the news press since, within this context, there is an intense on-going process of articulation resulting in a flow of signs and nodal points that can acquire, fixate, change or have their meaning undermined.

Paper II Discourse psychology, subject positions and proto-morality

In this study, the focus was on how responsibility for reducing loneliness was constructed and designated in the Swedish news press.² The concept of subject positions was of relevance since emphasis is on how people position themselves and others within discourses. Furthermore, the concept of proto-morality (Bergmann 1998) was used which focuses on structural aspects of any morality which is generally accepted within a society at a specific time. The essence of this morality is the view of ourselves and others as competent actors with abilities to choose among several alternatives of actions. Ascribing the same capabilities to others as we believe ourselves to possess entails a view of others as fellow humans. The question at hand was if older people were constructed, in the news press, as actors with abilities to act in order to reduce their own loneliness or if this was the responsibility of other actors in society. This study was related to central issues of critical gerontology which in general have shifted from examining social structures as unfavourable to older people to increasingly focus today on individual responsibility for remaining active and “ageing well”.

Paper III Policy-narratives on palliative care

How policies on palliative care in Sweden have been formulated and changed over time was in focus in this study.³ These policies were analysed through the theoretical and methodological lens of policy-narratives, where a point of departure is that policies are constructed as stories with the intention of gaining public acceptance by addressing problems as facts with

² The description of theory in *Paper II* is to a large extent retrieved from the original article Agren, A. and Cedersund, E. (2018). Reducing loneliness among older people – who is responsible?. *Ageing & Society*, 40(3): 584-603. This article is also included in the licentiate thesis Agren, A (2018). *Loneliness among older people in the Swedish media - Constructions, discourses and the designation of responsibility*. Linköping: Linköping University.

³ The description of theory in *Paper III* is to a large extent retrieved from the original study Agren, A., Nedlund, A-C., Cedersund, E., Krevers, B. Policy narratives on palliative care in Sweden 1974–2018. Submitted.

causal explanations regarding the cause and solution (Stone, 1989). According to Stone (1997), policy actors use two archetypes for policy stories, for the first of which is the “story of decline” consisting of “stymied progress”, stating that progress on a problem has stalled and “change is only an illusion” and that actual change has not occurred. This story is used to highlight the need for policies that urgently respond to the “decline”. Secondly, the “story of helplessness and control” is deployed in order to evoke feelings of not being helpless in the face of the situation, thus making the proposed policies perceived as possible to implement (Stone, 1997). In an earlier work, Stone (1989) argued that conditions that are deliberately portrayed by political actors as being attributable to human actions are more likely to be viewed as being open to interventions.

Paper IV Cultural scripts on palliative care

In this study, cultural scripts of dying was the theoretical and conceptual point of departure.⁴ Cultural scripts are meta-level concepts on dying available in certain social and cultural contexts (Long 2004; Seale 1998, p. 68; Hunt 1992). Seale (1998) argues that individuals strategically choose, though sometimes unconsciously, from culturally rooted scripts comprising meta-level concepts to make sense of their individual situations by interpreting and justifying behaviours in relation to dying. What type of scripts that are available to an individual are, nevertheless, dependent on the social structures within which an individual is located. Scripts can be utilised by lay persons, the media, claims-makers, and experts in various contexts. Experts’ scripts can contribute to constructing “normal” ways of dying, with the potential of influencing how those who are terminally ill describe the experiences of dying (Breaden 2003). Furthermore, experts in palliative care have an influence on how palliative care is organised and conducted. This study highlights how meta-level concepts, which largely depend on social constructions on societal level, that are available in certain contexts are used and reconstructed by experts in palliative care. Thus, departing from the theoretical concept of cultural scripts of dying illustrates how social constructions on issues of dying and palliative care are used by experts who in turn reconstructs meta-level concepts and use these in various ways within their field of work. This process is however complex since experts have own experiences from palliative care. Thus, when departing from the concept of cultural scripts and conducting interviews with experts it is necessary to analyse the processes of how experiences of the “self” are intertwined with meta-level concepts.

⁴ The description of theory in *Paper IV* is to a large extent retrieved from the original study Agren, A., Nedlund, A-C., Cedersund, E., Krevers, B. Dying as an issue of public concern - Cultural scripts on palliative care in Sweden. Under review.

METHODS

In this section I will first present an overview (in **Table 1**) of the aim, empirical material, source of data and theoretical concepts of each study. Following this, the process of analysis for each study will be presented.

Table 1. Overview of the aim, theoretical and methodological concepts, material, and source of data in Paper I-IV.

	Aim	Theoretical concepts	Material	Source of data
Paper I	Analyse how loneliness among older people is constructed in the Swedish news press.	Discourse theory. Media logics.	94 articles from the Swedish news press from 2013-2014.	www.retriever.se (through Linköping University Library)
Paper II	Analyse how the responsibility for reducing loneliness among older people in the Swedish news press is constructed and designated.	Subject positions Proto-morality. Aging Enterprise. Media logics.	40 articles from the Swedish news press from October 2016.	www.retriever.se (through Linköping University Library)
Paper III	Analyse how policy narratives on palliative care in Sweden have been formulated and how they have shifted over time from 1974-2018.	Policy-narratives	65 policy-documents from the Swedish state and one organisation. From 1974-2018.	libris.kb.se/ https://www5-infotorg-se.e.bibl.liu.se/rb/premium/ (through Linköping University Library)
Paper IV	Analyse how experts make sense of the historical	Cultural scripts of dying	12 semi-structured qualitative interviews with	Potential study participants were identified, found through

	development and the current state of palliative care and the role of policies within this context.		experts in palliative care. Interviews were conducted February-April 2020.	webpages of organisations and contacted by Axel Ågren.
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Material and method Paper I

The empirical material of this study consisted of 94 articles published in the years 2013–2014 in the Swedish news press.⁵ All types of articles (debate, chronicles, news reportages and so on) and newspapers (local, regional, national) were included in the study. The Swedish words *äldres* AND *ensamhet* were used (older people AND loneliness in English). The term *äldres ensamhet*, in the context of the Swedish news press, is commonly used to describe the phenomenon of loneliness among older people. However, using the words separately, I also found articles that address loneliness among older people. The search terms *äldres* AND *ensamhet* generated 210 hits from the years 2013 to 2014. However, several of the articles found were duplicates and thus excluded. 94 articles constituted the empirical material. The articles were sorted into categories based on the societal contexts that were found to be in focus in each article. In the next step I proceeded to ask: What issues are in the main focus in the articles – is it loneliness, or is it something else? Thereafter, I identified types of articles and types newspapers within which loneliness among older people was addressed. Articles may follow different logics depending on the context, type of article and newspaper and who is the author of an article. This part of the analytical process guided me in acknowledging the differences in media logics and how the contexts of the various types of newspapers have an influence on how loneliness among older people was written about. After these steps, I continued to conduct analysis of how loneliness among older people was constructed in discourses in the Swedish news press. Here, I departed from the view on discourses as a result of the ways in which we talk about and understood issues within different societal domains. When identifying discourses, focus was on the process where signs (words) undergo the process from being an element (not a fixed meaning) to becoming a moment (fixed meaning) and how different signs are related to loneliness among older people. The most crucial part of the analysis was

⁵ The description of the process of analysis in *Paper I* is retrieved from the original article Ågren, A. (2017). What are we talking about? Constructions of loneliness among older people in the Swedish news-press. *Journal of Aging Studies*. 41: 18-27. This article is also included in the licentiate thesis Ågren, A (2018). *Loneliness among older people in the Swedish media - Constructions, discourses and the designation of responsibility*. Linköping: Linköping University.

to identify nodal points, which have a privileged position of giving meaning to other signs within a text. Thus, I searched for concepts that were presented as being of particular importance and thereby given a privileged position.

Material and method Paper II

First, the articles were carefully read to gain an overview and initial understanding of the material.⁶ In the second step, the contexts of the news press articles (Thompson 2000), and the logics of the news press, (Altheide & Snow 1979) were acknowledged. Analytically, this was first done by sorting the articles in a table based on types of newspapers (geographical distribution area) and types of articles. Following this, the focus was on the societal contexts addressed, dominant discourses and how responsibility was designated and constructed in the articles from the Swedish news press. Here, the focus was on identifying societal contexts recurrently addressed in the Swedish news press, which provided insights into what societal contexts the issue of responsibility for reducing loneliness among older people was related to. Subsequently, attention was on the types of individuals, collectives, organisations or institutions that were designated responsibility for reducing loneliness, how they were positioned as responsible actors and by whom. Focus was also on why certain individuals, collectives, institutions or organisations were considered to be suitable for the task of reducing loneliness. In this phase of the analysis process, the critical questions were: **1. Who:** Who is made responsible for reducing loneliness among older people? Is it individuals, collectives, institutions or organisations? Is the responsibility to reduce loneliness a matter for older persons or other instances in society? Is it a collective or individual responsibility? **2. Responsible actor:** Who is considered to be a responsible actor with the ability to choose between and perform actions in order to reduce loneliness? **3. Societal context:** What contexts of society are addressed when the issue of responsibility of reducing loneliness is written about? **4. Blame or trustworthiness:** Is the responsibility connected to blame, implying that individuals, collectives, organisations or institutions have failed in relation to the expectations of a certain position? Or is the responsibility designated to those considered trustworthy? Is the responsibility based on moral or legal assumptions or both simultaneously?

⁶ The description of the process of analysis in *Paper II* is retrieved from the original article Ågren, A. and Cedersund, E. (2018). Reducing loneliness among older people – who is responsible?. *Ageing & Society*, 40(3): 584-603. This article is also included in the licentiate thesis Ågren, A (2018). *Loneliness among older people in the Swedish media - Constructions, discourses and the designation of responsibility*. Linköping: Linköping University.

Material and method Paper III

The empirical material for this study comprised government investigations, steering documents, care programs and “knowledge support documents”, all of which were from Sweden.⁷ The Libris database, which stores all publications from the collections of Swedish university libraries and the Infotorg database, which stores documents from the Swedish state, were used to collect material from the Swedish state and one organisation. The timeframe of the study was 1974–2018. 1974 was the year when the first policy document, according to my readings, on end-of-life care in Sweden was published. Searches in databases were conducted from January to March 2019. The material consisted of 65 documents, all in Swedish: government investigations (14); governmental propositions (7); governmental committee reports (27); governmental directives (2); reports from the National Board of Health and Welfare (12); and reports from the Regional Cancer Centre (2) Swedish Association of Mental Health (1). In the process of analysis, I was open towards the concepts used to construct and give meaning to “palliative care” in the empirical material. The concept “end-of-life care” [in Swedish: *vård i livets slutskede*] has appeared as the most frequently used concept over time. “Palliative care” has been used more extensively since the 1990s, “terminal care” to a lesser extent. The analysis process was performed on the material in the original language. The documents were carefully read to gain an overall understanding of the material. After this initial reading, the analysis was directed towards identifying occurrence of policy narratives, i.e., writings within the policies analysed which could resemble a story (Roe 1994). Recurring phrases, terms, expressions were identified. In this process, focus was on identifying narratives that dominated, were less dominant, to what extent counter-narratives occurred and when shifts and the diminishing of narratives occurred. Following this approach, three episodes were identified with shifting dominant policy narratives, less occurrent narratives and counter-narratives. The dividing into episodes was based on how narratives were formulated regarding contents, contexts and when shifts occurred.

Material and method Paper IV

This study was based on qualitative interviews with experts who in various ways are, or have been, involved in policymaking in the context of palliative

⁷ The description of the process of analysis in *Paper III* is retrieved from the original study Agren, A., Nedlund, A-C., Cedersund, E., Krevers, B. Policy narratives on palliative care in Sweden 1974–2018. Submitted.

care in Sweden.⁸ Persons from diverse organisational contexts were interviewed to highlight experiences of provision of palliative care in different settings, and the role of policies in these varying contexts. Twelve participants were interviewed. Seven were physicians by training and five were nurses. Two of the informants had, to various degrees, coordinating roles within policymaking and knowledge production in different organisations. Four had a background as researchers. Five of the informants were actively involved in research, development, and education. All, except for one, conducted clinical work to varying extents. Participants were recruited through a process where organisations and government agencies that are active in policymaking within palliative care were identified. In the next step, persons listed on the websites for these organisations and agencies were contacted. These persons were asked to participate in interviews for this study. I also asked for the names of other potential study participants, which was provided on some occasions. Participants' informed consent was obtained when they accepted the conditions for participation, which were described in a letter. Prior to conducting the interviews, a semi-structured interview guide was developed to enable study participants to describe their perspectives on the development of palliative care and policymaking in this context in Sweden. As the study participants constituted a diverse group, the interview guide was flexible enough to reflect professional backgrounds as well as organisational affiliation. Moreover, how the interviews proceeded was also flexible since the orientation of the interview was directed towards issues that the participant was seemingly most interested in and had the most insights into. Each interview lasted between 40–80 minutes. The interviews were audio-recorded and transcribed word by word. Regarding the process of analysis, the material was initially read thoroughly. In this phase there was an openness to finding dominant, less prevalent, contradictory and sprawling themes. After having gained in-depth insights into the material, the participants' accounts were analysed through the concept of cultural scripts of dying (Seale 1998; Hunt 1992; Long 2004). This analytical focus enabled identification of the ways in which the study participants used culturally available meta-level concepts on death, dying and palliative care to make sense of the development and current state of palliative care, and the role of policies in this context.

⁸ The description of material and method in *Paper IV* is retrieved from the original study Agren, A., Nedlund, A-C., Cedersund, E., Krevers, B. Dying as an issue of public concern - Cultural scripts on palliative care in Sweden. Under review.

Validity in qualitative and constructionist research

I have departed from a social constructionist perspective in this dissertation, using qualitative methods focusing on how certain issues are constructed and given meaning through textual and verbal language use. Issues of validity in findings derived from qualitative research methods have been a topic of debate over the past decades within scientific communities. One outcome of these have been the development of “standards” for qualitative research to ensure quality where transparency through being able to account for procedural rigour, reflexivity, transferability, justification, representativity and interpretations made are common criteria (Kitto, Chesters & Grbich 2008; O'Brien, Harris, Beckman, Reed & Cook 2014). It is argued that criteria serve as strengthening a scientific discipline and is a means of evaluating research. Meanwhile Devers (1999) state that criteria of these kinds are rooted in positivist traditions mainly associated with quantitative research and methods. Seale (2002) argue, however, that the divide between quantitative and qualitative research is often reinforced by “qualitative creation mythologists”. Criteria in qualitative research are not easily utilised due to the dynamic nature of qualitative research with different issues being studied and that the language used within disciplines varies and develops in different directions because of variances in theoretical and methodological foundations. Furthermore, the concept of “qualitative research” may refer to a paradigm that challenges quantitative research or methods used for conducting a specific study (Devers 1999). With the rise of postmodernist perspectives on the world and the breakthrough of constructionist research within social science, traditional positivist terms for describing “validity” and “reliability” of research do not sufficiently cover much of qualitative and constructionist research. Creating criteria for research would require views on the existence of one truth which contradicts the founding ideas of constructionist perspectives, which have been an issue of debate over long periods of time (Seale 2002). According to Seale (2002) attempts to develop criteria for constructionist research resulted in the criteria of “authenticity”, within which it is stated that a researcher should be able to represent different realities, contribute to “sophisticated understanding” of an issue, contribute to appreciation of varying perspectives and inspire and empower to action of some kind. The conclusion made by Seale (2002) is that research is a “craft skill” which is independent of scientific and philosophical divides, where methodological awareness entails understanding consequences of methodological choices. This awareness can be achieved by reading well formulated discussions of methodology, regardless of tradition. Knowledge on key issues of debate concerning criteria for research can, according to Seale (2002), encourage creativity and rigour in the research process and formulated criteria for qualitative research should be debatable principles which encourage exploratory

approaches not limited by strict rules (Seale 2002). In the segment *Discussion on theories and methods* I will reflect upon issues of validity which I have encountered during the process of writing this dissertation.

Ethical considerations

The Swedish Research Council state that research ethics can be divided into considerations for study participants and the researcher's relation to the task of conducting research. The former can be summarised as the balance between legitimate interests of knowledge production and the integrity of participants in research studies. The latter, which is based on The European Code of Conduct for Research Integrity, is about research conduct and integrity of research where reliability, honesty, respect and responsibility are considered key aspects for good research conduct and maintaining integrity of research (Swedish Research Council 2020). When conducting the studies included in this dissertation, the issue of knowledge versus integrity of study participants was only relevant in Paper IV. Issues of conduct and integrity have been met since I have been transparent throughout the research process in the studies included in this dissertation. Furthermore, issues of reliability relate to validity which is addressed in previous segment and will be further discussed in the Discussion section of this dissertation.

The empirical material analysed in Paper I, Paper II and Paper III consists of news articles from the Swedish news press and policy documents from the Swedish state and organisations which were collected from databases. These documents are public and thus persons mentioned and portrayed were not held anonymous in the studies. In Paper IV, twelve persons were interviewed. Regarding ethics in this study, potential participants received a letter containing information about the conditions for participating which were based on Swedish research ethics (Swedish Research Council 2017). In the letter it was stated that the participants should feel that they had been adequately informed about the study's aim and the conditions for participation in order to decide on participating in the study or not. Furthermore, it was emphasised that that participation was voluntary, they had the right to leave the study without motivating this and that all collected material would be treated confidentially. In the study, fictive names were used to obstruct possibilities of identifying the participants. Moreover, personal information that would increase risk of identifying the participants were left out in the study.

RESULTS

Results Paper I

Three discourses were identified. In *Loneliness – within the discourse of eldercare, policies and the welfare society*, loneliness was used as a concept to motivate the need for political change, provision of resources and to underscore deficiencies within eldercare, politics and the welfare society. The second discourse, *Loneliness – within the discourse of volunteer work*, mainly described volunteers and highlighted the value of volunteer work. Within the third and least common discourse, *Loneliness – within the discourse of research reports on older people's health*, ageing was addressed as a risk, with loneliness as one risk factor. Throughout the empirical material, loneliness was given the meaning of being a problem that needs to be solved. A central and somewhat surprising finding was that the focus in the Swedish news press was not primarily on loneliness but instead on eldercare, policies and the welfare society, volunteer work and health among older people. Consequently, the articles of the Swedish news press focused on deficiencies within eldercare, policy and the welfare society (discourse of eldercare, policies and the welfare society), the importance of volunteer work (discourse of volunteer work) and ageing as a risk (discourse of research perspectives on older people's health). In the Swedish news press, these issues were associated to and given meaning in relation to loneliness.

Results Paper II

Three discourses were found, of which the discourse of *responsibility within politics and the welfare state* was the most prevalent. In this discourse there were discussions on how institutions in the welfare state deal with the issue of how to reduce loneliness. In these discussions, municipalities were designated by a state agency as responsible for talking to older people in order to reduce the alleged widespread loneliness. The municipalities, however, argued that numerous activities were already being performed to this intent. Some municipalities admitted, nevertheless, that they should do more to reduce loneliness among older people. Within the *discourse of responsibility in societal and evolutionary perspectives on loneliness*, the responsibility for reducing loneliness was more complex and even, to some extent, contradictory. On the one hand, societal and evolutionary developments which were beyond the individual's control were

argued to contribute to loneliness. When the entire society was addressed as a collective, individuals within this collective were considered to have the ability to act in ways that could reduce loneliness. Noteworthy was that older people were constructed as recipients of activities conducted by “society” with the aim of reducing loneliness. In this discourse, distinctions were made between involuntary and voluntary loneliness. Involuntary loneliness was the “bad” loneliness, where the individual was not considered to possess agency and was therefore a victim of loneliness, with older people being described as particularly at risk of loneliness. Voluntary loneliness, the “good” loneliness, was associated with peacefulness, pleasure and ascribing agency to the individual. This loneliness was, however, not related to older people. In the *discourse of responsibility within seniors’ organisations*, the responsibility was both a collective and an individual matter, with a focus on active older persons. Thus, it was the only discourse in which the ideals of active and successful ageing were present. One central finding of this study was that the responsibility for reducing loneliness and improving well-being among older people was discussed by professionals, politicians, journalists and persons active in the civil society. The focus was on how to include older people in society. At the same time, older people were not included in these discussions and constructed as recipients of activities with aims of reducing loneliness.

Results Paper III

Episode 1 was characterised by an overarching narrative, where the dire state of institutionalised end-of-life care was criticised. Through this narrative, it became possible to formulate goals with claims for standards and norms, the need for a psychological end-of-life care and an emphasis on dying at home. In *Episode 2* and *Episode 3*, it was, however, not a straightforward task to identify distinct policy narratives. This since the number of policy-documents published steadily increased and policies on palliative care were related to various contexts (for example, reforms of eldercare, prioritisation in healthcare and the fact that palliative care should be part of general healthcare) and were increasingly specialised, through the development of various indicators for “good palliative care”. Consequently, the policy narratives became more diverse, specialised and fragmented over time. Thus, the knowledge governance of palliative care has seen a continual increase in the production of knowledge-steering policy-documents. Also, palliative care was increasingly related to various fields of care and healthcare.

In *Episode 1* (1974-1979), the hospice movements care philosophy was met with critique in Sweden, in contrast to many other countries where these care philosophies were embraced. However, in the subsequent episodes the

understandings of the hospice movement care philosophies went from critiquing to embracing. In *Episode 2* (1980-1999), calls were made for “holistic” approaches originating from the hospice movements care philosophy to be adapted throughout the healthcare sector and during *Episode 3* (2000-2018), a crucial policy goal was that the “palliative care philosophy” should permeate all palliative care regardless of place and care organisation. Simultaneously with processes of institutionalisation of end-of-life care in mainstream medicine under the concept of “palliative care”, there were still longings for the original hospice philosophy with its founding idea of “total care” and a “holistic” approach.

Results Paper IV

Four scripts were identified after analysis of twelve qualitative interviews with experts in palliative care: *script of paths towards working within palliative care*; *script of desirable and deterrent reference points*; *script of tensions between improvement and bureaucracy*; and *script of low status, death denial, and uncertain definitions*.

In the *script of paths towards working within palliative care* the study participants focused on individual experiences through reminiscing about the past. However, this script also contained historical descriptions of the reluctance to deal with death and dying, and deficiencies in providing pain relief. Thus, although the focus was on their personal experiences, this script also reflected how end-of-life care was provided over the past decades, and how death and dying was dealt with in healthcare and long-term care, with dying persons being perceived as time-consuming and left to die. Within the *script of desirable and deterrent reference points* the participants' accounts were mainly located on a meta-level, where the history of the hospice movement and the rise and fall of the LCP were used to make the historical development and current state of healthcare and palliative care comprehensible. Through the *script of tensions between improvement and bureaucracy*, the participants described the need for achieving mainly regional consensus and working with evidence-based knowledge, the focus being on the self. When widening the perspectives to include palliative care and the healthcare sector in general, meta-level concepts were deployed to represent the problems associated with increased bureaucracy. Improvement was thus represented through self-narratives, whilst meta-level concepts were used to make sense of bureaucracy. Throughout the *script of low status, death denial, and uncertain definitions* it was argued that palliative care had improved, but meanwhile attract little attention and have low status in society and healthcare today. The same participants who stated that palliative care had improved would later in the interviews

depart from more critical perspectives where difficulties in gaining acknowledgment and reaching consensus were addressed.

DISCUSSION

In this section I will discuss overall findings of this dissertation. Also, I will reflect upon the choices made regarding theories and methods when writing this dissertation.

Loneliness and dying as symbols for critique of “modern society”

The overarching aim of this dissertation has been to explore constructions of loneliness among older people and care of the dying. The overall finding was that loneliness among older people and care of the dying were given meaning in relation to a “diagnosis” of where society is alleged to be heading. This “diagnosis” was characterised by a critique of the current state of society and the development of “modern society”. The core of these critiques consisted of constructions of the “modern” society as represented by modernisation, rationality and technological development which was unfavourable to older people and the dying. Regarding constructions of loneliness among older people in the Swedish news press, the point of departure was mainly that the society of today was unfavourable for older people in general. Primarily, the focus was on how the organisation of the welfare state did not recognise the needs of older people, where many of the articles wrote about cutbacks in eldercare, lack of housing opportunities, lack of activities and politicians not listening to older people. The critique was also aimed towards societal development in general where individualisation and neglect of older people in combination with life circumstances (mainly loss of spouse and decreased mobility), made older people particularly prone to facing loneliness. The focus was mainly on criticising today’s society. Although longings to “traditional” society, only occurred to a minor extent and were diffuse or implicit, constructs of the “modern society” resemble sociologist Tönnies’ argument where *gesellschaft* represents the modern, impersonal and rational ways of organising society. The notions of *gesellschaft* are contrasted with *gemeinschaft*, which is associated with “traditional” societies characterised by communities, family values, traditions and cohesion (Asplund 1991; Schirmer & Michailakis 2015). Concerning care of the dying, the basis for the first articulated policies in the 1970s was that institutionalisation of death and dying was leading to lonely deaths in unfamiliar environments, where the needs of the dying person were not recognised. Behind this argument lay a critique of the

modernisation of society, where the development of medical technology, medicine and science in combination with industrialisation and urbanisation, increased life expectancy, increased survival of infants and the mobility of families overall led to young people not having close contact with older people, death and dying (SOU: 1979:59). This, it was argued, resulted in death and dying being issues people were not confronted with in everyday life and something that medicine and healthcare care could treat. Furthermore, this gave rise to the emergence of death as a “taboo”, possible to deny and hide, and within medicine and healthcare the focus was on how to save and prolong lives through the latest technologies. Professionals within healthcare were, thus, not educated in how to talk about and care for the dying. It was the environment of hospitals that resulted in dying taking place in unfamiliar settings where the needs of the dying were not acknowledged. Death and dying in hospitals thus served as a spatial symbol for constructs of society and healthcare as “death-denying”.

When interviewing experts, the projection of care of the dying on a critique of societal developments was also present. In the scripts, the constructions of modern society versus “traditional” society and its influence on end-of-life care was, however, multifaceted. When recalling the past while not, however specifying what time-periods they referred to, care of the dying in long-term institutions and hospitals was considered to be characterised by lack of resources, lack of knowledge and a general “death denial”, where the dying was a “time-consuming” burden. However, when references were made to the “history” of the hospice movement and its ideologies, this was given the meaning of being important, although to some extent not realistic to implement due to increased bureaucracy of healthcare and palliative care of today. The critique of the current state of palliative care was, however, ambivalent. On the one hand, palliative care was understood as improved in comparison with the past. On the other hand, the problems of current palliative care were associated with an increase in bureaucracy, medicalisation and routinisation. In the scripts, experiences from the past and present were consequently intertwined.

Autonomy, active ageing and responsibility

The use of the concept autonomy varied when comparing the contexts and issues studied in this dissertation. In news articles on loneliness among older people the concept of autonomy was not present. However, the issue of societal or individual responsibility for reducing loneliness was indeed present, but not through the explicit articulation of autonomy. In the context of policies and expert scripts on palliative care, the concept autonomy was more prominent. In particular in the policy documents studied, the concept of autonomy was recurrently articulated and a large amount of

space was allocated for elaborating on autonomy. Dating back to the 1970s already, calls were being made for a dying person to be able to choose where to die (preferably at home) and that more focus should be on attending to the needs and wishes of the dying person. What changed over time was, however, the emergence of several concepts which were associated with freedom of choice, which increasingly replaced the concept of autonomy. Various concepts such as dignity, ethics, human value, integrity, person-centred care were intertwined and were constructed as synonymous with “good palliative care”. Attention to these matters represents a re-definition of “good palliative care”, focusing on autonomy and dignity, which Van Brussel (2014) argues as representing the will to control dying characteristic of late modern societies’ individualisation, secularisation and de-traditionalisation. Furthermore, focus on autonomy represents a shift in professional perspectives on a “good death”, from focus on open communication to placing more responsibility on the dying to live well and make their own choices up until death (McNamara 2004). Emphasis on the autonomy of the dying is, I argue, a means of responding to the alleged “death denial” which, it was argued in policies and scripts, still exists, to some extent within society and healthcare. Thus, although at first sight autonomy can be seen as focusing on the individual, it encapsulates constructs of large societal developments and efforts to value and upgrade views on death and dying, change attitudes and improve the organisation and provision of end-of-life care. It can also be understood as a general development in postmodern Western societies premiering individualistic and consumerist ways of life (Bauman 1988; Giddens 1991; Walter 1994), where the individual is empowered and obliged to make choices right up to the very end of life (McNamara 2004). Although focus is on individual autonomy and enabling choices as a means of achieving “good” palliative care, I nevertheless found that autonomy of the dying was framed as a professional task, since it was the obligation of professionals to enable the autonomy of the dying. Consequently, it was professionals who defined what autonomy is, made claims for its significance and described how it should be achieved. In line with these findings, Borgstrom and Walter (2015) argue that choice, in the context of end-of-life care in England, is framed as a right at the end of life. Choice was however argued to be offered by those in power, and something that is required where not making a choice is not an option in individualistic societies of today.

In the news press articles on loneliness among older people, the role of the older person was primarily that of a passive and dependent receiver of activities to reduce loneliness. The causes of loneliness were ascribed to social structures and evolution which were out of the control for older people. Weicht (2013) argues that the common positioning of older people as passive and dependent is reinforced through contrasting this with idealised

images of active older people of the “third age”. In the news articles analysed, the construction of loneliness focused to a large extent on passivity and dependency. Loneliness was closely linked to problems of ageing and later life, where passivity, decline and isolation were intertwined with loneliness. However, the responsibility for “getting out” of this situation was only implicitly directed towards older people, as focus was on how “we” in “society” could enable older people to become more included in society and less lonely. In some articles voluntary and involuntary loneliness was addressed, implying focus on individual autonomy. In these articles, voluntary loneliness was associated with positive notions such as peace, creativity, and individual choice. Involuntary loneliness, however, was constructed as the dangerous loneliness where the individual was a victim, and this was the type of loneliness older people were at risk of. Within critical gerontology, the original focus was on how social policy, organisations, industries, providers of care and others ‘that serve the aged’ contribute to socially construct ageing as problems and older people as dependent (Estes 1979; Townsend 1981). During the past decades, concepts of “active ageing” have been highly influential in research, policies and practice and have been a concept for critical scrutiny within critical gerontology, where “active ageing” is understood as an indicator for increased focus on individual responsibility to live up to expectations of the new images of ageing. Following this rationale, individuals are liberated from “oldness” by remaining active (van Dyk 2014; Timonen 2016; Rudman 2006). Discourses in news press articles revolved around the issue of how to make older people socially and physically active in order to reduce loneliness. In contrast to policies and scripts on palliative care, enabling autonomy was not explicitly discussed in news press articles on loneliness among older people. Instead, similar to Gilleard and Higgs’ (2010) theory on the fourth age as a “black hole”, loneliness was a problem that must be avoided and solved. Loneliness was, similar to constructs of the fourth age, associated with low degrees of agency, physical limitations, deteriorating health, dependency and as caused by structures out of the control of older people. When discussing the dichotomies of the third and fourth age, Gilleard and Higgs (2010) argue that the fourth age is detached from the economic, social and cultural collective achievements in societies and instead constructed as a definite and unavoidable end of the individual lifespan. The positive connotations of the third age are made possible by othering the fourth age, today understood as the “real” old age, through associating this period of life with loss of autonomy, decline, disability and death. Although loneliness is constructed as an issue possible to solve and not a definite end of life, constructions of loneliness among older people resemble those of the fourth age where lonely older people represent the negative aspects associated with “real ageing”. In line with constructs of the fourth age, lonely older people

are constructed as not possessing agency and part of the “othering” of old age, which in turn makes understandings of active and successful third age possible (Weicht 2013). Furthermore, Gilleard and Higgs (2010) state that there is a lack of knowledge on, and absence of attempts to understand what characterises the fourth age. This was also found regarding constructions of loneliness in the Swedish news press, where few attempts were made to address and understand what loneliness in old age is and how it is experienced.

The issue of reducing loneliness was discussed by persons and organisations who, in different ways, were engaged in the well-being of older people. Thus, it was the “Aging Enterprise” (Estes 1979) that defined the problem, designated responsibility for reducing loneliness and suggested solutions where loneliness was to be solved by the “non-old” and “non-lonely”. This is in contrast to the findings of the studies on policies and expert scripts on palliative care in Sweden, where it was found, in line with other studies, that emphasis is on the autonomy of the dying person in order to achieve a “good death” (McNamara 2004; Lang 2020; Zimmermann 2012; Payne, Langley-Evans and Hiller 1996). This can in part be seen as efforts to upgrade the status of death and dying and to end “death denials” in society and within healthcare (Zimmermann & Rodin 2004). As such it constitutes a response to the critique of institutionalisation of death and dying where the dying person is considered to face a lonely death in unfamiliar and medicalised settings (Tradii & Robert 2019; Feigenberg & Fulton 1977; Elias 1982).

Discussion on methods and theory

Regarding the studies included in this dissertation, the issue of validity becomes relevant in relation to how I contribute to construct new “truths” through research findings, my views on “reality” and my position as being part of the society which I also study. Since the empirical material in Paper I, Paper II and Paper III consisted of already published news articles and policy documents, it was mainly the selection of these articles and documents and the interpretations made by me which have been of importance to reflect upon. I cannot deny that I am affected by how death, dying and loneliness are represented in public arenas within the society which I am part of. There is no straightforward solution to this. I would, nevertheless, argue that methodological awareness, which focuses on being aware of the consequences of choices made in research (Seale 2002), in this case is about insights on my role as a researcher and being transparent with this.

The empirical material of Paper IV consisted of interviews, where the interview situation can be viewed as contributing to what is said and how it is said, by me and the study participants, depending on the interaction

during the interview. This is unavoidable, and the “answer” to this can be found in methodological awareness and being aware of how I may contribute to shape the path of the interviews. One way of dealing with this during the interviews was to ask open questions and have a reflexive and open approach towards the answers by the participants and allowing space for reflection instead of only asking questions formulated prior to the interview. As argued by Seale (2002) methodological awareness grows with experience and over the years I have continuously gained new insights on methods and theories which have contributed to further insights into how to analyse the material and relate my analysis to previous literature within my fields of research. Thus, I have learned to maintain analytical focus although, simultaneously being aware that I am influenced by the society where I live my everyday life and that I contribute to constructs new “truths”. I consider, however, that my findings are not one single truth but contribute to perspectives on how the issues studied are constructed and given meaning. My findings may nevertheless, hopefully to some extent, within the research community at least, contribute to construct knowledge on loneliness among older people and care of the dying.

The perhaps most challenging endeavour when conducting research from social constructionist perspectives is to draw a line between what is “real” and constructs. The division between something as constructed or an object of “reality” have been central in debates on social constructionism (Woolgar & Pawluch 1985; Best 2008). In my research, I view constructions in the news press, in policies and expert scripts as linguistic representations. I have, nevertheless, recognised that loneliness and dying are part of the empirical world, since I use concepts referring to phenomena that do exist in society.

In the four studies included in this dissertation, different theoretical and methodological approaches have been used. Although the main premise that our social world is socially constructed through language use units the approaches, there are, as I have highlighted, differences between the theories from which I have departed. I argue, however, that mixing a social constructionist “package” of my own have contributed to broader understandings of the issues studied where the main contribution of this dissertation is that it displays how issues often described as universal and existential parts of human life, have been constructed as public concerns. Furthermore, the mixing of different theories and methods have also enabled me to deconstruct the empirical material where the guiding question was whether the material was about loneliness among older people and care of the dying or something else. Through this focus on deconstruction, by using different theoretical and methodological approaches, I was able to disassemble the material and reach the overall conclusion that loneliness among

older people and care of the dying were used as symbols to criticise the development of “modern society” considered to increase loneliness and cause deficiencies in end-of-life care.

CONCLUSIONS

The overall finding of this dissertation is that loneliness among older people and care of the dying increasingly have become issues of public concern in Sweden. Through analysis of how loneliness among older people and care of the dying were constructed, it was found that these issues were used as symbols to criticise the development of “modern society”. These constructs were, however, complex with a mix of concepts, notions and ideals which displayed both continuity and change. In the policies on palliative care, the point of departure of *institutionalised death denial* and its counter-narrative of *dying at home* gradually diminished in significance over time as dying was redomesticated in combination with increased emphasis on “universal” palliative care to be carried out everywhere. In the expert scripts, palliative care was considered to have improved over the past years. This improvement was led by increased use of registers, more documentation, universal concepts and methods. This, in turn was argued to lead to increased bureaucratisation and medicalisation, which was at risk of weakening the original “core” of a holistic approach of palliative care. Furthermore, understandings of what “improved” palliative care consisted of was made possible through drawing on deficiencies in end-of-life care in Sweden of past decades.

An overarching understanding was that care of the dying and loneliness among older people needed solutions. Consequently, the question of who is made responsible for care of the dying and reducing loneliness among older people was significant. Although autonomy was defined as a professional task within policies and scripts on palliative care, emphasis was on the importance of enabling for the dying person to be responsible for making choices up until death. Regarding loneliness among older people, those engaged in the “Aging Enterprise” (Estes, 1979) discussed and defined this issue and formulated solutions. Focus was on how to organise eldercare and provide activities which could enhance physical and social activity and enable inclusion of older people in society in general. The responsibility for reducing loneliness was thus a matter for the “non-old” and “non-lonely”.

I argue that, regardless if the focus was on dignity, integrity, human value, compassion, freedom of choice and autonomy of the dying or inclusion of older people in society, with ambitions of reducing loneliness, these were all responses to critiques of “modern society”, which was found to be overarching in this dissertation. I argue that the emphasis on autonomy of the dying and claims for reducing loneliness among older persons represents efforts of recognising the needs of the individual. Meanwhile, since focus

was on the development of “modern society” with its increased individualisation as leading to lonely deaths and loneliness among older people, individualisation in itself was also criticised. Thus, there was an inherent paradox where solutions and causes were intertwined and contradicted one another.

Future research

Although much research which critically examine constructions of ageing and old age, in the media and in other contexts, is continuously conducted, it is somewhat surprising that studies have only to a minor extent focused on how loneliness is associated with ageing and older people. Not least considering the amount of attention on loneliness among older people in public arenas. The research body on constructs of issues such as institutionalised death and dying, palliative care, notions of good and bad deaths is extensive. According to my readings, only a few studies have, however, analysed constructs and meanings given to concepts in policy documents within palliative care. Also, studies on how care of the dying is constructed in the media is a field with great potential for more research.

As highlighted throughout this dissertation, social constructionism is an umbrella for several directions, perspectives and methods. Although social constructionism has specific points of departure I would, in line with Seale (2002), argue that this should not limit research and set boundaries for type of research questions asked and studies conducted. For example, it is argued that media studies have yet to merge with ageing research and medical sociology (Iversen & Wilinska 2020; Seale 2003).

Though the argument that death and dying is not addressed within gerontology was formulated by Kearl some years ago (Kearl 1996), this is still relevant to reflect upon as the overarching focus within gerontology is considered to still be on “positive”, active and successful ageing (Pack, Hand, Rudman & Huot 2018; Calasanti & King 2020). It is commonly stated that older people are a growing “target group” within palliative care, which motivates the need for further research on views on and constructions of ageing and older people within this context.

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Papers

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Linköping University Medical Dissertations No. 1765, 2020
Department of Health, Medicine and Caring Sciences (HMV)

Linköping University
SE-581 83 Linköping, Sweden

www.liu.se

Loneliness among older people and how the dying should be cared for are issues that evoke public debate. These issues are often described as universal parts of human existence. Understandings of the issues of loneliness and dying have, however, changed dramatically over the past decades on a societal level. In this doctoral thesis, focus has been on how loneliness among older people and care of the dying are constructed and given meaning in public spheres and to what extent these issues are understood as personal responsibilities or public concerns. Analysis has focused on constructions of loneliness among older people in the Swedish news press, how care of the dying is constructed within policies in Sweden, and how experts, in palliative care, make sense of and describe the development and current state of palliative care in Sweden.

Axel Ågren is a researcher at Linköping University.