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Robots in end-of-life care and the good death? On the relations of discourses

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Abbreviations

AAL	Ambient assisted living
EoL	End-of-life
R&D	Research and development
R&I	Research and innovation
SKAD	Sociology of knowledge approach to discourse
STS	Science and technology studies

1 Introduction

Since the beginning of my dissertation project, I have been puzzled by an observation. Although there have been deliberations on the future of robots in elderly care since the 1980s (Borenstein & Koren, 1985; Engelberger, 1989; Engelhardt, 1988; J. Evans et al., 1989), the inevitable dying of the elderly users of these robots has not been thematised in this area of research and innovation (R&I). Roboticists have presented robots in care as machines providing various types of assistance for elderly care recipients (Abdi et al., 2018; Broekens et al., 2009; Kachouie et al., 2014), but these users or beneficiaries of robots have never entered the ultimate stage of their lives.

In 2017, I could only find one attempt to design a robot focussing on end-of-life (EoL) care: the *Last Moment Robot*. However, this robot was not designed to take care of real patients. Instead, it was created as an 'interactive installation' (Chen, 2012a, p. 32) outside the field of care robotics. As artistic device it should initiate reflection on the possibility of creating emotional intimacy with machines:

> 'The process of dying is probably the most vulnerable moment of a human life – a moment in which one seeks the reassurance of human connection. In this installation, human presence is replaced with a robot, questioning the quality of intimacy without humanity.' (Chen, 2012a, p. 33)

The Last Moment Robot has a clinical and non-human appearance consisting of a padded arm that softly strokes the arm of the 'dying patient', a female participant of the performance lying in a mock-up hospital bed. The robot speaks to her in an artificial voice, reassuring her that she is not alone and that her close one's love and will remember her. After a while, it declares time of death (Chen, 2012a, pp. 32–35, 2012b). Showing the Last Moment Robot to and discussing it with colleagues and friends, I encountered mixed reactions ranging from disbelief, to curiosity, to very emotional reactions or even open hostility. For some people, the mere idea of a robot caring for a dying person was appalling.

Research has shown that acceptance of robots in care varies depending on the robots' designs and applications (Broadbent et al., 2009; Hall et al., 2019; Łukasik et al., 2020; Savela et al., 2018). Have roboticists deemed robots inappropriate or inacceptable for this vulnerable user group and thus removed them from EoL care situations? Have they anticipated negative reactions to such a robot? Relates this neglect of robots for dying users to much broader scepticism against the use of medical technology in EoL care (Clark, 2007; Granda-Cameron & Houldin, 2012; J. E. Seymour, 1999; Timmermans, 1998)? Has a presumed social taboo around dying and death (R. L. M. Lee, 2008; Walter, 1991) led to the omission of dying users in reports on robots in care? How does this phenomenon relate to socio-normative discourses around good dying and death (Bührmann & Schneider, 2008; Carpentier & Van Brussel, 2012; Schneider, 2014; Seale, 1998; Van Brussel & Carpentier, 2012; Walter, 1994)?

1.1 Research interest and approach

My cumulative dissertation emerged from these deliberations. I wanted to understand the conditions of the absence of dying users in care robotics. In concert with insights from science and technology studies (STS) and adjacent fields (Borup et al., 2006; Grunwald, 2014; Jasanoff, 2015), I assumed that the envisioned future of robots in care interacts with broader societal discourses around good care and dying. Robots have been imagined in literature, film, and the arts long before their technical feasibility (Behnke, 2008; Cheng & He, 2018; Decker, 2008; Koistinen, 2016; Nocks, 2017). Robots in care have gained existence through socio-technical future discourses (Lösch, Grunwald, et al., 2019; Roßmann, 2021) that guide research and development (R&D) activities (Lipp, 2019; Rommetveit et al., 2020). At once, societal ideas about a desirable *good dying,* as a value-laden and contingent phenomenon (Kellehear, 2007; Walter, 2003), have been created and transformed through discourses, as well. Discourses constitute dying and death as phenomena and negotiate how dying and death should ideally take place, how to deal with dying and death appropriately, how good EoL care needs to be practiced, and so on (Bührmann & Schneider, 2008; Carpentier & Van Brussel, 2012; Schneider, 2014; Seale, 1998; Van Brussel & Carpentier, 2012; Walter, 1994). Given this importance of discourses for the socio-political issues of EoL care and future technology, I followed my research interest through the lens of discourse analysis. I focussed on the expected but seemingly non-existent relation of the roboticists' discourse on robots in care with other discourses. I traced the relations of the socio-technical future of robots in care (Lösch, Grunwald, et al., 2019; Roßmann, 2021) with wider social stocks of knowledge and discourses to better grasp the absence of dying within the roboticists' discourse. Furthermore, I wanted to trace possible implicit relations of this discourse to wider discourses around good dying. I adopted a sociology of knowledge approach to discourse (SKAD) analysis (Keller, 2011b, 2021) to investigate how the creation, sense-making, and assessment of envisioned futures of robots in care are interrelated with social values, norms, beliefs, and knowledge intertwined and reproduced through discourses. As a consequence, I further conceptualised the relations between 'special discourses' produced by and confined to particular social groups – here, roboticists creating a socio-technical future – and 'public discourses' (Keller, 2021, p. 38) created and reproduced by a wider variety of actors for a more diverse audience.

I required a solid understanding of the multiple discourses of interest to comprehend their relations. I started by studying the social phenomenon of good dying from a discourse analytical perspective (section 2.1). First, I empirically analysed a debate on dignity at the end of life in Austria as a typical case of a contemporary public discourse on good dying. The resulting paper reconstructs the double nature of an institutionalisation of dying as, both, undesired yet necessary condition of good dying (section 5.1). With this work I started to build a basis for my comparative discourse analysis and a stock of 'sensitizing concepts' (Blumer, 1954, p. 7) to make the absence of dying users in robotics better tangible. Second, I presumed that professions dealing with EoL care develop and reproduce definitions of good dying that derive from and inform their caregiving activities. Although specialised palliative and hospice care are regularly recognised as ideal institutional care approaches to promote good dying, most people die receiving non-specialised professional care (Centeno et al., 2016; Clark et al., 2020; Woitha et al., 2016). Two colleagues and I wanted to know how professionals outside the realm of specialised palliative and hospice care conceptualise good dying. We

reviewed empirical studies dealing with these professionals' perspective on this issue. In our paper, besides reconstructing common elements of good dying, we were able to analyse how this type of research promotes a particular view on good dying in line with broader social discourses (section 5.2). As part of my dissertation, this integrative review (Whittemore & Knafl, 2005) added another layer to my understanding of good dying by focussing on a profession dealing with the practical realisation of good dying.

Based upon my astonishment of the lack of dying users in the field of care robotics, an empirical analysis of the socio-technical futures discourse around robots in care then came to the centre of my study. I understood roboticists as actors from policy, research, development, or business contexts developing, working on and promoting robots in care. I attempted to reconstruct the socio-technical future discourse reproduced by these actors. This discourse orients, promotes, and enables particular developments, designs, and applications of robots (Ballo, 2015; Barker & Jewitt, 2022; Borup et al., 2006; Brown & Michael, 2003; Lipp, 2019; Rommetveit et al., 2020; Vallès-Peris & Domènech, 2020; van Lente & Rip, 1998), and therefore is of relevance for this technology's future implementation. I collected and analysed documents from the field of robotics and conducted problem-centred interviews (Witzel & Reiter, 2012) with roboticists. I interpretively explored how visions around robots in care implicitly exclude those dying as users of robots. My paper (section 5.3) originating from this research is based on concepts of user representation in R&I (Hyysalo et al., 2016; Oudshoorn & Pinch, 2003). I added to this field by conceptualising the *absent user of technology* as additional category besides users and non-users.

From the beginning of my project, I aimed to acknowledge the perspective of care workers on robots, too. Although roboticists and the media often present care robots as seemingly autonomous machines, care professionals are necessary to realise their application in practice (Erebak & Turgut, 2019; Pfadenhauer & Dukat, 2015; Wright, 2018). Another empirical study of mine was meant to address how professional caregivers envision robots in EoL care. However, in conjunction with the challenging pandemic conditions unfolding in 2020 and subsequent years, I changed my empirical approach. Instead of directly involving caregivers in my research, I investigated the discourse on digital technologies in palliative care (Clark, 2016; Stolberg, 2017). Understanding robots in care as one type of assistive digital technology, I reconstructed how palliative care actors maintain and adapt their discipline's discourse in envisioning socio-technical futures with a variety of digital technologies such as electronic records, telehealth devices, robots, and virtual reality (section 2.3). In my resulting paper, I distinguish the processes of affirmation, alignment, and adjustment that, at once, conserve and transform the normative foundation of palliative care. Therewith, I provide a heuristic to capture the joint creation of social and technical prognoses in socio-technical futures (section 5.4). Within my dissertation, this subproject enabled an understanding of how socio-technical futures discourses constructively incorporate elements of other discourses and thus build discursive relations. Analysing this discourse was also about dealing with how digital technologies such as robots can be consolidated with norms and values of EoL care. It showed that, in principle, having a robot in EoL care is a 'thinkable alternative' (Schröter & Taylor, 2018, p. 6) and, thus, the absence of dying users in the roboticists' discourse is of significance (section 3.4.3).

Finally, bringing together my different endeavours, I comparatively analysed the discourses around good dying, robots in care, and digital technology in palliative care. I understood discourses as to a certain degree distinct symbolic orders reproduced in various social arenas and around different topics (Keller, 2011b, pp. 228–232, 2018, pp. 25–26). At once, I aimed to conceptualise their relations or lack of relatedness in producing socio-technical futures. As a result, I elaborated a heuristic framework to comprehend relations between socio-technical futures and public discourses (section 5.5).

1.2 Structure of the dissertation and list of publications and manuscripts

The dissertation's structure is as follows. In the next chapter, I explain in detail my research design and subprojects. I delineate key concepts of my study and elaborate on the context of my work, which was partially conducted as part of collaborative projects (chapter 2).

Then, I deal with the theoretical and empirical state of the art related to my research topics and interests. This includes the social and discursive construction of dying in contemporary societies, socio-technical visions around robots and other digital technologies in EoL care, and the relations of discourses (chapter 3). Additional aspects of the state of the art are elaborated within the papers in chapter 5.

In the fourth chapter, I describe my methodological approaches concentrating on my empirical implementation of the SKAD. Furthermore, I outline the methodology of the problem-centred interview and considerations regarding research ethics. Further details of my data collection and analysis can be found in the respective papers.

Chapter five comprises the publications and manuscripts of my cumulative dissertation. Two papers have already been published in a journal listed in the Social Science Citation Index (SSCI) (Clarivate, 2021). They are presented in sections 5.1 and 5.2:

- Lang, A. (2020). The good death and the institutionalisation of dying: An interpretive analysis of the Austrian discourse. *Social Science & Medicine*, 245(112671). https://doi.org/10.1016/j.socscimed.2019.112671
- Lang, A., Frankus, E., & Heimerl, K. (2022). The perspective of professional caregivers working in generalist palliative care on 'good dying': An integrative review. *Social Science & Medicine*, 293(114647). https://doi.org/10.1016/j.socscimed.2021.114647

I submitted the third paper to *Technology Forecasting & Social Change*[1] on 4.11.2022. It underwent peer review. The verdict I received on 18.12.2023 was 'major revisions' needed but the possibility of revision and resubmission was rejected. Nevertheless, I considered the comprehensive feedback given by one reviewer in revising the manuscript, which has not been submitted to another journal, yet (section 5.3):

- Lang, A. (n.d.-a). Absent users of technology: the absent dying users in the development of robots for care. Manuscript.

[1] Published by Elsevier and listed in the SSCI.

The other two papers have neither been submitted to nor published in a journal, yet. The manuscripts are presented in sections 5.4 to 5.5:

- Lang, A. (n.d.-b). Co-producing values and technology in a professional discourse: affirming, aligning, and adjusting digital technology and good palliative care. Manuscript
- Lang, A. (n.d.-c). The relations of discourses: an empirically informed heuristic concept. Manuscript.

The dissertation concludes with a discussion of my conceptual and empirical work (chapter 6).

2 Research design and context

This chapter outlines the research questions, methodological approaches, and contexts of each of the different subprojects forming my overall dissertation. In this overview of the research design, I also sketch central assumptions and introduce definitions of key terms and concepts important for understanding my work.

2.1 The discursive construction of good dying

In my dissertation, I focussed on good dying as a discursive phenomenon assembling social knowledge, values, norms, practices, institutions, artefacts, and so on (Carpentier & Van Brussel, 2012; Granda-Cameron & Houldin, 2012; Kellehear, 2007; Schneider, 2014; Seale, 1998; Van Brussel & Carpentier, 2012; Walter, 1994). The guiding question for the inquiry into the meaning of good dying was: *How is good dying constructed in contemporary public discourses?* This included addressing how dying and good dying are discussed in principle, for example, what causes of death or dying trajectories dominate public deliberations, how are social conditions and practices of EoL care assessed, or how are values and norms invoked in deliberations on good and bad dying.

There are various concepts characterising desirable ways of dying. They include terms such as good death, good enough death, peaceful death, appropriate death, smooth death, dying well, dying with dignity, or dying with panache (Granda-Cameron & Houldin, 2012; Hutter et al., 2015; Mak & Clinton, 1999). The majority of scholarly work in English uses the term *good death*[2]. I adopted this term in my dissertation proposal and first paper (section 5.1) but revised this decision later on. As outlined in the second paper of my dissertation, *good dying* draws better attention to the 'processual nature of the phenomenon' (Lang et al., 2022, p. 2) of dying than *good death* (see also Heimerl et al., 2023). Good dying is about multifaceted and complex situations, relationships, materialities, and practices of dying and death and may comprise the characteristics and circumstances of dying, the quality of care, or experience of physical, psychological, emotional, social, or spiritual aspects related to the end of life. This choice reflects the postmodern discourse on dying (see section 3.1) and is in line with my interest in robots in care, a technology centred on this world rather than the afterlife[3].

[2] In November 2022, searching abstracts, titles, and keywords in the Scopus (Elsevier, 2022) database, I retrieved 1 414 results for 'good death', 579 results for variations of 'dignified death' or 'dying with dignity', 167 for 'dying well', and only 48 for 'good dying'.

[3] Robots have also been used for funeral rites in Japan (Gould et al., 2021). However, this application focusses on the well-being of relatives and a good otherworld journey of the dead and was outside the scope of my study.

Substantial parts of my work in this first subproject were done within the interdisciplinary project *Dying Worlds in Austria: Perspectives of Those Affected on Good Dying*[4]. Between January 2017 and June 2018, this project investigated the social meaning and practices of good dying.[5] Qualitative interviews with terminally ill, very old, or bereaved people formed the core of the project (Heimerl et al., 2023). We assumed that our interlocutors made sense of their situations and assessed what constitutes good dying in relation to societal discourses. Thus, I investigated a public debate related to the parliamentary enquete commission on *Dignity at the End of Life* that took place in Austria between 2014 and 2015. Analysing documents created in the parliamentary process, statements submitted to the enquete commission, and newspaper coverage, I reconstructed a public discourse with diverse audiences and speakers (Keller, 2011b, pp. 228–232). Diverging assumptions about the possibilities and limitations of autonomy at the end of life resulted in 'competitive discourses' (Keller, 2021, p. 37) over the regulation of EoL decision making.

I extended this subproject by an integrative review on the perspective of professional caregivers on good dying. Given the disregard of the professional caregivers' perspective on robots in care because of the COVID-19 pandemic (section 2.3), I decided to add this study to consider this group's perspective on good dying, nevertheless. The review was part of the project *Dying Worlds – the Perspective of Professional Caregivers in Regular Care on 'Good Dying'*[6] carried out from January 2020 to June 2021. In this project, we focussed on professionals who were not specialised in palliative but nonetheless taking care of dying patients. Amongst others, we conducted focus group discussions with caregivers from hospitals, nursing homes, or home care on their experiences and assessments of good dying (Heimerl et al., 2021). Furthermore, we reviewed the state of the art on this topic. As lead author of the integrative review (section 5.2), I was responsible for conceptualising the literature review, collecting data, supervising and implementing the process of screening and selecting papers for full text assessment, analysing the final selection of articles, and writing and revising the manuscript in the submission process. My co-authors supported the design of the literature review, and we conducted the screening of abstracts and full texts together. After I had analysed the final selection of papers, we discussed my preliminary findings before I implemented another cycle of analysis. My co-authors gave feedback on the paper draft and revised version in the peer review process. The resulting paper consolidates findings of empirical studies dealing with how non-specialised palliative care professionals define *good dying.* Additionally, it scrutinises the methodological and analytical approaches of the reviewed studies (section 5.2).

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[4] *Sterbewelten in Österreich: Die Perspektive der Betroffenen auf „gutes Sterben"*. Supported by funds of the Austrian Central Bank, Anniversary Fund, project number: 17075.

[5] The notion of *dying worlds* (*Sterbewelten*) adapts the concept of *lifeworld* (Schütz & Luckmann, 2003) with a focus on the interactive construction of social realities of dying involving different actors, institutions, systems of knowledge, discourses, material artefacts, et cetera (Schneider, 2014).

[6] *Sterbewelten: Die Perspektive der professionell Sorgenden in der Regelversorgung auf „gutes Sterben"*. Supported by funds of the Austrian Central Bank, Anniversary Fund, project number: 18240. This was a follow-up project to the first 'Dying Worlds' project described above.

2.2 Envisioning robots in (end-of-life) care

For over thirty years now, business entrepreneurs, policymakers, researchers, engineers, and others have identified assistive robots amongst other digital technologies as solutions to challenges of care (Abdi et al., 2018; Kachouie et al., 2014; Liu et al., 2016; Steinhubl et al., 2015). These roboticists, individual and collective actors from policy, research, development, business, or marketing, have been involved in promoting the design, development, and marketisation of robots in care. They have produced and reproduced visions of robots in care and in turn, these visions have guided endeavours to realise robots in care. In their *socio-technical futures* (Lösch, Grunwald, et al., 2019; Roßmann, 2021; Urueña, 2022) the envisioned materiality and functionality of *technical* devices are interlinked with a predicted *social* situatedness, for example, their future users and non-users, spatial and institutional embeddings, and so on. Thereby, these visions mobilise broader social values, norms, and knowledge (Ballo, 2015; Borup et al., 2006; Brown & Michael, 2003; Grunwald, 2014; Haas, 1992; Jasanoff & Kim, 2009; van Lente, 2012).

My study was about reconstructing a socio-technical futures discourse reproduced within and connected to this field of R&D: *How are possible futures with robots in EoL care settings envisioned by roboticists?* This included how elderly, relatives, and caregivers as primary or secondary users of robots are represented in terms of their situation, capabilities, needs, and so on. It was also about investigating roboticists' ideas about the future of care systems and the values, norms, and practices of good care. At once, it dealt with how roboticists assess the current state and envisioned the future of robots in care including the design, application, and role of these technical artefacts within care. In my analysis, I focussed on the 'meaningful absence' (Schröter & Taylor, 2018, p. 6) of dying users in this field's discourse. Being sensitised for the different characteristics, needs, and demands of elderly in general care compared to EoL care, I interpretively reconstructed the absence of the dying users in the roboticists' discourse. Empirically, I combined discourse analysis of roboticists' publications and policy documents and problem-centred interviews with roboticists working in European R&D contexts. I limited this study to R&D activities located in Europe. European R&I policy together with other actors have created and reproduced common discursive visions and narratives that legitimate the development of assistive robots (Lipp, 2019; Rommetveit et al., 2020). By focussing on this socio-political context, I could closely trace the relationships between technical developments and R&I policies and funding. I understood R&I policy strategies and funding programmes such as the European Commission's Framework Programmes (FP6, FP7, Horizon 2020) as 'infrastructures' (Keller, 2018, p. 27, 2021, pp. 41–42) (see section 3.4.1) of the roboticists' activities and discourse production. As part of my analysis of the relations of discourses (chapter 5.5), I considered the wider history of care robotics and also included documents from the United States where deliberations on care robotics started earlier than in Europe.

In my dissertation, I focussed on robots as machines with 'mechatronic components, sensors and computer-based control and guidance function' differing from other machines in terms of their 'higher number of degrees of freedom and the variety and scope of […] forms of behaviour' (Christaller et al., 2001, p. 5; cited after Decker, 2008, p. 318). Robots in care differ in their design and functionality. In terms of their application, they can be broadly categorised in robots providing physical support including but not limited to fetch-and-carry tasks, mobility

assistance, or personal care and nutrition, and robots offering non-physical or social assistance including but not limited to social interaction and entertainment, monitoring and surveillance, or information supply and reminders (Bedaf et al., 2015; Broekens et al., 2009; Maalouf et al., 2018). I was neither interested in software bots without a distinct hardware body nor in general domestic robots such as vacuum cleaners. Rather, I considered robots with a physical presence that 'operate partly or fully autonomously' and have the 'aim of supporting potential users, older adults and relatives as well as professional caregivers, in providing physical, cognitive or emotional support' (Johansson-Pajala et al., 2020, p. 1103). At once, though a robot could be capable of some (semi-) autonomous operations, it nevertheless might need support by others (Pfadenhauer & Dukat, 2015; Wright, 2019).

There has been a debate whether or not a robot might be able to truly implement or convincingly simulate care (Coeckelbergh, 2015; Metzler et al., 2016; Sparrow & Sparrow, 2006). Care implies the identification of somebody's needs, the assumption of responsibility to address these needs, the implementation of activities to satisfy the needs, and the consideration of the response to this activity (Tronto, 2015, pp. 5–7). It 'involves moral and value commitments' (Tronto, 2015, p. 7) and comprises a social and emotional dimension in care activities. Assuming this multidimensional definition of care, I used the phrase *robots in care* instead of *care robots* to stress that although robots might operate in care settings this does not necessarily involve their ability to truly care according to this multidimensional definition.

In preparing my results for a journal submission, I concentrated on the *absent user of technology* within the framework of research on user representation in STS (Hyysalo et al., 2016; Oudshoorn & Pinch, 2003; Peine et al., 2021). I used this study as another case for my comparative discourse analysis. Thereby, I explored substantial commonalities of this with other seemingly unrelated discourses as a basis for conceptualising interdiscursive relations.

2.3 Doing research in a pandemic: adjustments and reflections

In early 2020, I was amid my work on the roboticists' discourse, analysing documents and scheduling first interviews with roboticists. In parallel, I conceptualised the planned interviews with professional caregivers in EoL care on robots in their domain. Then, the COVID-19 pandemic unfolded. Despite the pandemic waves and preventive measures including lockdowns, I was able to proceed with the discourse analysis and interviews with roboticists via videoconferences or telephone. The roboticists were accustomed to online meetings and seemed comfortable talking at a distance about their work, robots in care, and even dying and death.

However, over the following one and a half years, I could not implement the foreseen personal interviews with professional caregivers in a responsible and predictable manner. Personal meetings were temporarily legally prohibited given the possibility of infection with COVID-19. They would have been especially unsafe considering the caregivers' close contact with high-risk groups. Even in times of low incidence and relaxed precautionary measures, the organisation and conduct of a series of interviews would have been difficult due to the impossibility of foreseeing the duration of these phases. I felt insecure if I could finish the interviews in time after starting with my fieldwork. I pondered the alternative of conducting

remote interviews but decided against it. First, I did not want to burden these professionals with more work in times of continuous overload of the healthcare system. Second, I assumed that professional caregivers are rather not accustomed to giving interviews. I doubted to establish a personal relationship and trust necessary to delve into a topic such as robots in EoL care remotely. Robots in EoL care do not only concern dying as a sensitive issue but also the caregivers' professional lives, including everyday distressing challenges in care or fears of being replaced by machines (Ivanov et al., 2020; McClure, 2018; van der Plas et al., 2010). In videotelephony, uplifting interventions to alleviate negative reactions of the interviewees would have been difficult. Thus, I decided to replace this part of my research with another discourse analysis to understand the meaning of technology in palliative care (section 2.4).

By skipping the interviews with professional caregivers, some aspects of my initial research design faded. In my research proposal, I argued for the importance of exploring the perspective of professional caregivers on futures with or without robots in EoL care because of the potential to open up a critical perspective on innovation (Groves et al., 2016; Grunwald, 2014). Talking to them could have brought insights into how they negotiate their professional role and identity as well as their concepts of care facing a new technology (Bedaf et al., 2019; van der Plas et al., 2010). At once, adjusting my research design was an opportunity to strengthen the methodological coherence of my analysis. Now, by focussing on a special discourse on digital technologies in the field of palliative care, I closely mirrored the approach and level of abstraction I had chosen in analysing the roboticists discourse. Analysing documents from palliative care published over two decades allowed generalising my findings to a larger degree than it would have been possible analysing interviews with a selection of caregivers. Thus, the reconceptualisation implied a productive turn towards the discursive construction of socio-technical futures and a chance to analytically reconstruct the relations between different discourses more thoroughly.

2.4 Digital technologies in palliative care

The speciality of palliative care wants to improve the quality of life of those with terminal illnesses and dying, as well as their relatives and families.[7] It emphasises the importance of accepting and preparing for death as well as multidisciplinary, holistic, and patient-centred care addressing the *total pain* of patients. Total pain is a concept that draws attention to physical pain and complaints as well as to psychological, social, or spiritual suffering (Hui et al., 2013; Pastrana et al., 2008; Streeck, 2017). The promotion of palliative care is at the centre of debates around the practical organisation of good dying besides matters of euthanasia or assisted suicide. Palliative care as a discipline was an interesting case for studying the relations of technology and good dying, because the emergence of the hospice movement as its predecessor was closely linked to a critique of medical technology (Clark, 2016; Milligan & Potts, 2009; Stolberg, 2017), as outlined in detail below.

[7] In my study, I focussed on the discipline of palliative care but also considered hospice care. Even though these approaches differ to some extent (Bosma et al., 2010), they have multiple commonalities in their concept of good dying and EoL care. These include their patient-centred and holistic approach. However, palliative care may start earlier in the trajectory of a disease than hospice care, which is supposed to be implemented only in the last months before death (Hui et al., 2013).

The third subproject of my dissertation dealt with how the discipline of palliative care envisions socio-technical futures of EoL care with or without digital technologies. I investigated how palliative care as a discipline discursively constitutes digital technologies together with their core professional values and norms, including their concept of good dying. Since assistive robots for care purposes have hardly been a topic in palliative care (Nwosu et al., 2019), I decided on a broader focus on digital technologies, including but not limited to telehealth systems[8], electronic health records, the internet, social media, or virtual reality systems. I understood robots as a specific type of assistive digital technology that often combines technical elements and functionalities of such digital technologies employed to support care. Various robot prototypes (Bajones et al., 2018; B. Graf et al., 2004; Mišeikis et al., 2020) merge monitoring functionalities, for example, surveillance and emergency alarms, and social interaction features, for example, videotelephony systems, also provided by other technical devices that have already been discussed and tested in palliative care (see, for example, Coradeschi et al., 2013, 2014). Looking at digital technologies with functionalities found as components of robots in care, I approximated my initial research topic.

I conducted a discourse analysis of publications from the field of palliative care concerned with digital technologies in EoL care. Care professionals are involved in EoL care but may also inhibit key roles in field trials or the routine application of assistive technologies in care. They may act as primary users of technology and as intermediaries between technologies and care recipients/patients (Erebak & Turgut, 2019; Papadopoulos et al., 2020; Persson et al., 2022; Pfadenhauer & Dukat, 2015). In my analysis, I differentiated the concept of co-production (Jasanoff, 2004) of technology and the social by outlining the discursive processes of *affirmation*, *alignment*, and *adjustment.* In the context of my overall dissertation and as part of my fourth paper, I interpreted these connected discursive mechanisms as ways of establishing interdiscursive relations while maintaining core knowledge, principles, values, and norms of a discourse.

2.5 Analysing the relations of discourses

R&D discourses are produced and reproduced by social actors inhibiting legitimate positions as experts and specialists in their respective fields.[9] These actors have the resources and power necessary to shape socio-technical future discourses in science, applied research, or engineering, in ‘closed arenas for special publics’ (Keller, 2021, p. 38). Roboticists have the ability to inform and raise funding, implement projects, develop and test their machines, and verbalise and spread their knowledge through established but often access restricted channels of communication, such as scientific journals. Similar holds true for the palliative care discourse.

[8] Different concepts describe applications of information and communication technology of ‘care at a distance’ (Pols, 2012). *Telemedicine* is usually understood as the remote delivery or support of healthcare services for the curative treatment of health conditions. Thereby, communication happens between professionals and patients as well as between different professionals. *Telecare* comprises technological devices to monitor and support people independently living with care needs. Telecare and telemedicine can be both categorised as *telehealth* (Carrasqueiro et al., 2017; van Dyk, 2014).

[9] As outlined below, there is a caveat to this statement because science fiction literature and movies have had an impact on socio-technical futures and R&D processes as well.

At once, robots in care do not emerge on a blank drawing board. Roboticists design, develop, and implement them in relation to wider social structures, practices, and meanings of ageing, care, and dying. Reciprocally, technology is inherent to our understanding of ageing, care, and dying too (Peine et al., 2021; Peine & Neven, 2021; Timmermans & Berg, 2003). The final part of my study focussed on the complex discursive relations unfolding between R&D of new digital technologies, professional values and norms of good (palliative) care, and wider social discourses around ageing and good dying. I strived to understand *how socio-technical futures of new technologies interact with the wider societal conditions* by comparatively looking at discourses in different fields and publics. In line with the concept of 'interdiscourse' (Link, 2012, 2018; Parr, 2020, 2022), I assumed that special discourses are not confined to their particular discipline and field. Special discourses diffuse into the wider public by means of interdiscourses popularising particular stocks of knowledge. Interdiscourses make expert knowledge and special discourses available for other audiences, social groups, or society as a whole. These interdiscourses are created and maintained in the media or in literature and condensed in collective symbols. However, in contrast to research on interdiscourses, I was not interested in how special discourses permeate through society. Rather, I investigated how special discourses are interrelated with other special discourses (Foucault, 1972, pp. 157–165), as well as how special discourses creating socio-technical futures draw upon public discourses respectively interdiscourses.

My fourth subproject was occupied with this comparative analysis. Over the course of my dissertation, I collected and developed ideas about the interrelatedness of the various discourses while working on their empirical analysis. As much as these discourses could be demarcated, elements of discourses of other disciplines appeared to play a role in making sense of robots in care or digital technologies in these fields. I explored how societal stocks of knowledge and norms were reproduced, translated, or transformed in the analysed special discourses – or, in contrast, how discourses did not pervade other discourses and thus produced absences.

The comparative analysis was conducted independent of any third-party funding or collaborative project. I elaborated a conceptual framework for interdiscursive relations. This heuristic supports the identification of the different explicit and implicit relations of discourses. These relations can be positive ones, stocks of knowledge can be shared, or negative ones, discourses can contest one another. Finally, and in line with my initial research interest, I identified the 'rear side' of discursive relations, *meaningful unrelatedness* as expectable but not realised relatedness of discourses (section 5.5).

3 State of the art and conceptual basis

In the following, I delineate theoretical considerations and concepts as well as empirical findings and social diagnoses related to my various research subjects. These include the meaning of good dying (section 3.1), the entanglement of the social and care technology (section 3.2), socio-technical futures (section 3.3), and the relations of discourses as well as the discursive absence of topics (section 3.4). I used this knowledge as 'sensitizing concepts' that give 'a general sense of reference and guidance in approaching empirical instances' (Blumer, 1954, p. 7). Thus, I do not only outline the state of the art against which to assess the contribution of my research. Additionally, I make transparent some of the knowledge that made me attentive to various issues and dimensions of the reconstructed discourses.

3.1 Meanings and practices of good dying

Over millennia and centuries, with evolving social structures, living conditions, scientific knowledge, public health, and medical care, the period of dying has become longer, death more predictable, and sudden death rarer (Howarth, 2007; Kellehear, 2007; Seale, 2000). Shifting social, environmental, and technological conditions continue to transform the face of dying. Lately, the COVID-19 pandemic resulted in a decline in life expectancy in several world regions (Chan et al., 2021; Islam et al., 2021) and temporarily changed conditions and practices of EoL care (Jordan et al., 2022; Mercadal-Sánchez et al., 2022).

As dying and death, social practices and meanings of good dying are contingent. Historically, attention has shifted from enabling a good transition to the afterlife to preventing or managing the dying process. Clergy has lost its central role to healthcare professionals whose capabilities to treat illnesses and to control pain and symptoms improved. In the twentieth century, dying increasingly took place in hospitals instead of family homes (*institutionalisation*) and was interpreted as a medical phenomenon, concern, and field of action (*medicalisation*) (Ariès, 2008; Clark, 2016, pp. 1–31; Kellehear, 2007; Seale, 1998, pp. 50–71).[10]

Across social groups, good dying is commonly related to effective pain and symptom management and appropriate care for emotional, social, cultural, spiritual, religious, and other personal needs of the dying patient. Thereby, good dying appears to be based on 'kind, compassionate, accessible, honest, and clear' (Zaman et al., 2021, p. e596) communication. Awareness and acceptance of dying are prerequisites for preparations that enable good dying. Furthermore, good dying comprises respect for autonomous decision-making, for example, concerning medical treatments. Thereby, the latter should be used with caution to prevent futile and potential stress- and painful treatments. The place of dying and death is assessed

[10] The scientific literature on good dying particularly focusses on Europe, North America, Australia, and New Zealand, but does not fully account for global variations (Zaman et al., 2021, p. e599).

as important as well, with private homes as preferred locations. Good dying should be supported by social and emotional support from friends and family, but the death of a person ought not become an excessive burden for them (Zaman et al., 2021).

Contemporary public discourses[11] on good dying reproduce a similar concept of good dying. They revolve around the autonomously controlled dying enabled by open awareness and acceptance of death. Media reporting replicates this notion of good dying in positive stories of heroic individual deaths (Frith et al., 2013; Seale, 1995, 2002; Walter, 2010). Thereby, the emphasis on autonomy, control, and the courageous dying person leaves 'no room for the unaware and the un-heroic, for the reactions of denying, fighting, and fearing death' (Van Brussel & Carpentier, 2012, p. 495). Good dying seems threatened by challenges of predicting death, by diseases impeding patients' capabilities to voice their wishes, by insufficient care resources, or by denial of death (Carpentier & Van Brussel, 2012; Cottrell & Duggleby, 2016). In addition, the media often depicts dying alone as undesirable and as a moral and practical failure of the deceased, the social environment, and society (Nelson-Becker & Victor, 2020; Seale, 2004; N. Turner & Caswell, 2020). One commonplace yet contested ascertainment is that modern societies are in denial of dying and death, that these topics are social taboos. Scholars expressing the ideas of taboo and denial identified a close relationship with the medicalisation and institutionalisation of dying and death in contemporary societies (Ariès, 2008; Kearl, 1989; Moller, 2018). However, others highlighted the vagueness of the terms *taboo* and *denial*, the insufficient empirical evidence for, counter-evidence to, and lack of nuance of this thesis. Some also stated that the taboo had already been overcome in the late twentieth century (Armstrong, 1987; R. L. M. Lee, 2008; Stolberg, 2017, pp. 191–193; Tradii & Robert, 2019; Walter, 1991). Either way, the taboo of death has been at the centre of contemporary public and professional discourses on dying and death (Robert & Tradii, 2019; Zimmermann & Rodin, 2004). The socio-political debate on good dying I analysed in my first paper featured several of these dominant public concepts of good dying. And, as many contemporary ones, it dealt with issues of hasting death through assisted suicide or euthanasia.

3.1.1 Euthanasia and assisted suicide as contemporary controversies

Assisted suicide can be defined as actively ending one's own life by using drugs prescribed and/or supplied by physicians or others. In *euthanasia*, a physician administers a lethal drug with the intention to cause death at the request of the patient.[12] The modern debate[13] around *euthanasia* emerged in the nineteenth century. It can be related to the scientific rationalisation

[11] Here, *contemporary* is about discourses that have emerged from the 1960s on. Albeit regional and cultural differences and changes, this period is characterised by 'revivalist' (Walter, 1994) counter-movements against an assumed medical dominance and taboo of dying and death.

[12] *Medical assistance in dying* or *physician-assisted dying* are sometimes used as umbrella terms for assisted suicide and euthanasia (Mroz et al., 2021). Euthanasia is regularly combined with qualifiers such as *active*/*passive* (Walter, 1994, pp. 152–153). Less frequent terms for euthanasia include *mercy killing* (Cassel & Meier, 1990) or *killing on request* (Materstvedt et al., 2003). I used *killing on request* in my first publication because this mirrored the terminology in the Austrian debate (*Tötung auf Verlangen*) but otherwise use *euthanasia* here.

[13] In ancient Greek, *euthanasia* was understood as an easy, painless, quick, timely, nobel, and dignified dying process. However, it did not include actively causing death (Benzenhöfer, 2009; Van Hooff, 2004).

and secularisation of life and death as well as to new medical knowledge and technologies including diagnostic procedures, analgesics, or anaesthesia (Benzenhöfer, 2009, pp. 62–68 & 133–173; Emanuel, 1994; Fye, 1978; Lavi, 2005, pp. 41–74; Stolberg, 2008). The development of life-sustaining measures in the second half of the twentieth century stimulated discussions on the legitimacy and practicalities of withdrawing or withholding medical treatment and, thus, letting people die (Benzenhöfer, 2009, pp. 122–132; McCormick, 2011); a practice often defined as *passive euthanasia*[14] (Brassington, 2020; Garrard & Wilkinson, 2005; Hopkins, 1997). Today, passive euthanasia is widely legal and socially accepted. From the 1970s on, with growing individualism, liberalism, and secularism, also acceptance of active assisted suicide and euthanasia increased (Cohen, 2016; Cohen et al., 2014). Subsequently, several countries have decriminalised assisted suicide or euthanasia (Mroz et al., 2021).

Discourse studies have identified two common normative positions[15] on assisted suicide and euthanasia competing with each other. On the one side, a discourse represents the pursuit of hastened death positively in line with values of autonomy, individuality, and choice. On the other side, a counter-discourse questions the capability of autonomous choice at the end of life, negates the physician's role in assisting hastened death, and advocates the protection of vulnerable groups and the principal sanctity of life. Legalising assisted suicide or euthanasia is envisioned as a slippery slope to involuntary requests for hastened death because of increased pressure on the old and ill (Booth & Blake, 2022; Burlone & Richmond, 2018; J. N. Clarke, 2006; Hausmann, 2004; McInerney, 2006; Pool, 2000; Van Brussel & Carpentier, 2012; van Wijngaarden & Sanders, 2022). In these debates, actors also negotiate the possibility and limitations of remedies against suffering provided by palliative care.

3.1.2 The emergence and discourse of palliative care: enabling good dying

Over the last century, there has been a shift from care as a family concern to care as a political matter that includes the professionalisation and marketisation of care services (Fine, 2007; León, 2014; Simonazzi, 2009). After the Second World War, hospitals were institutions that represented hope for curing illnesses but also places of an 'impersonal and technological death' (Stolberg, 2017, p. 174). The hospice and later the palliative care movement challenged the medical focus and resulting pain- and stressful but sometimes futile treatments. Death should neither be hastened nor the dying process unnecessarily prolonged. They emphasised the improvement of the quality of life at the end of life (Clark, 2016; Milligan & Potts, 2009; J. Seymour et al., 2005; Stolberg, 2017).

Palliative care focusses on the comprehensive relief of physical, emotional, existential, and social suffering. This concept of *total pain* makes the whole dying patient as well as their families and relatives available for and controllable by professional intervention (Clark, 1999, 2016; Streeck, 2016). Awareness and acceptance of death are essential for palliative care because they allow planning and management of the dying process. In contrast, denial of death is impeding good dying because necessary preparation cannot be made (Borgstrom et

[14] This term is disputed (Brassington, 2020; Materstvedt et al., 2003) but commonly referred to and 'retains a certain intuitive appeal' (Hopkins, 1997, p. 29).
[15] Some studies also distinguish more nuanced 'frames' (Burlone & Richmond, 2018; Van Gorp et al., 2021) or 'interpretative repertoires' (van Wijngaarden & Sanders, 2022) between these two positions.

al., 2013; Zimmermann, 2007). The ‘active and responsible patient’ should make ‘proper choices, in accordance with the authorities’ advice’ (Thoresen & Røberg, 2022, p. 4) in a highly scripted social situation (Parker-Oliver, 2000, p. 501). This normative stance might impede the choice of not accepting death, to protest one’s state, or to refuse communication and cooperation (Borgstrom & Walter, 2015; Floriani & Schramm, 2012; Hart et al., 1998; Livne, 2019; Ohnsorge et al., 2017; Saake et al., 2019; Streeck, 2017). Furthermore, people with other types of terminal illnesses than cancer have been under-represented in palliative care (Luddington et al., 2001; Ostgathe et al., 2011). Gender (Gott et al., 2020), ethnicity (Hussain et al., 2021), and other social aspects (Richards, 2022) have been widely neglected in the palliative care discourse, too.

The ideal palliative caregivers appear as trained specialists working in multi- or interdisciplinary teams that are capable of sensitive, respectful, and compassionate interaction with and holistic care of patients (Borgstrom & Walter, 2015; Pastrana et al., 2008; Soikkeli-Jalonen et al., 2020). In line with its critique of medicalisation of dying, palliative care scrutinises physicians as actors possibly advocating futile treatments but at once as crucial in mitigating suffering (Karsoho et al., 2016). Scholars have also highlighted that norms of palliative care especially benefit professional caregivers and healthcare institutions because they simplify care routines (Hart et al., 1998; Livne, 2019, pp. 161–164; Streeck, 2017).

Public debates, such as the debate in Austria I analysed, often thematise palliative care with relation to euthanasia and assisted suicide. Opponents of assisted suicide and euthanasia propose that the desire to end one’s life vanishes with palliative care. In contrast, speakers advocating the legalisation of euthanasia or assisted suicide question the capability of palliative care to enable good dying as self-determined, dignified, accompanied, and free from total pain in all cases (Carrasco et al., 2019; Durnová, 2018; Frith et al., 2013; Hahnen et al., 2009; Van Brussel & Carpentier, 2012; Van Gorp et al., 2021). At once, palliative care and proponents of legalising euthanasia or assisted suicide share key values and concepts. They focus on reducing multidimensional suffering and emphasise planning and control in dying (Hurst & Mauron, 2006; Streeck, 2017) and are based upon a discourse constructing medicalised dying in high-tech settings as detrimental to good dying (Carpentier & Van Brussel, 2012; Howarth, 2007, pp. 137–154; Seale, 1998, p. 190; Walter, 2003). My empirical study added another layer to these theories about common foundations of palliative care and euthanasia/assisted suicide. Reconstructing a typical contemporary discourse on good dying, I argued that both are critical about institutionalised dying but at once demand further mechanisms of institutionalised EoL care (section 5.1).

3.2 The co-production of technology and good dying

A basic tenet of my dissertation was that as much as robots might affect EoL care and dying, they are themselves influenced by discourses of good (EoL) care. STS have emphasised the contingency of technology and the entanglement of the social and technologies or even questioned the categorial differentiation of the social and technology per se (Hess & Sovacool, 2020; Lynch, 2016; Rohracher, 2015). Such constructivist perspectives have been used to study the relatedness of technology, ageing, and care (Lipp, 2023; Peine et al., 2021; Peine

& Neven, 2021; Timmermans & Berg, 2003). However, research into the interwovenness of non-medical technology and good dying has been scarce. My research addressed this gap.

In the background sections of my respective papers, I outline the theoretical concepts of *user representations* (section 5.3) and *co-production* (section 5.4). Following, I elaborate on research exploring the co-constitution of technologies (robots and telehealth) and care (section 3.2.1). Then, I outline the state of the art on the interdependency of medical and non-medical technologies and good dying (sections 3.2.2).

3.2.1 Technology and care

In the field of robots in care, R&D of robots are often understood as instrumental in solving social problems. Thereby, technological aspects appear as detached from social conditions and practices (Šabanović, 2010; Vandemeulebroucke et al., 2021). In contrast, research has shown how the development and design of technologies such as robots and telehealth systems co-constitute users, care, and the social and material environment (Peine et al., 2021; Peine & Neven, 2021). Scholars have emphasised that users form and realise technologies through practice and that technologies encourage particular practices by their designs as well (May et al., 2001; Pfadenhauer & Dukat, 2015; Pols & Willems, 2011). Introducing telehealth or robots means 'fitting' (Mol et al., 2010; Pols, 2012) or 'interfacing' (Lipp, 2023) the technology, users, and concepts of (good) care (Böhlen & Karppi, 2017; Lipp, 2022, 2023; Sánchez-Criado et al., 2014). Besides adapting the users' homes to the needs of the robots, the roles of elderly care recipients and caregivers need to change.

R&I policies envision particular users that guide R&D activities and the design of these technologies (Lievevrouw et al., 2022; Lipp, 2019, pp. 87–124; Oudshoorn, 2011, pp. 5–16). In organising remote care via telehealth systems or robots, patients become integrated in new ways into care. They need to know how to check, self-assess, and communicate their health status and how to maintain the devices appropriately (López & Domènech, 2008; May et al., 2005; Oudshoorn, 2008, 2011, pp. 145–158). These new responsibilities of an *active* care recipient are not only by-products but integral part of policies promoting these technologies (Finch et al., 2008; Lipp, 2019, pp. 87–124; López & Domènech, 2008; Lupton, 2013; May et al., 2005). Thereby, care technology can be based on negative stereotypes of ageing, too (Bischof & Jarke, 2021; Neven, 2010; Peine & Neven, 2021). Burema (2022) found that in the field of human-robot interaction, robots are often associated with elderly people seeking independence yet at risk of health problems, as digital illiterates, or even as a burden to society. However, users do not necessarily submit to the user representations and goals associated to technological systems (Aceros et al., 2015; H. R. Lee et al., 2016; Neven, 2010).

Given novel technologies, healthcare professionals assume new roles in mediating between patients/clients and other healthcare professionals or relatives (Mort et al., 2003; Oudshoorn, 2008; Roberts et al., 2012; Segar et al., 2013). Robots and telehealth systems divide care into separate domains of monitoring care recipients, physically taking care of needs, and addressing social and emotional aspects of care (Oudshoorn, 2008; Roberts & Mort, 2009). For care professionals, clients may only be present by their data and images and not perceptible with other bodily senses (Lupton & Maslen, 2017; May et al., 2005; Mort et al., 2003). The use of robots to avoid physical care tasks can disturb the social and emotional

relationship between care professionals and care recipients because these physical tasks may ‘constituted an integral part of […] intimate care’ (Wright, 2018, p. 35)..

Analysing the implementation of social care robots in Japanese elderly care, Wright (2019) argued that robots produce additional but less qualified work. Robots may ‘open up new technologically-facilitated global care chains’ by enabling and promoting ‘culturally odorless care’ (Wright, 2019, pp. 349 & 350) which could be more easily realised by migrant workers (Wright, 2019). Similarly, van Wynsberghe (2022) argued that socio-technical futures of robots in care direct resources towards the development and implementation of robots instead of human caregivers, who then have a double burden of caring for humans and robots.

In developing and implementing technologies in care, values and norms are at stake. Robots and telehealth systems maintain particular ideas of personal autonomy and independence (Aceros et al., 2015; Lehoux & Grimard, 2018; López & Domènech, 2008; Mort et al., 2013; Neven, 2015). Furthermore, these technologies allow novel patterns of communication. Thus, the perspectives and possibilities of caregivers shift (Højlund & Villadsen, 2020; Pfadenhauer & Dukat, 2015; Pols, 2012, pp. 59–60). However, especially with regards to robots in care, the values of social interaction, physical contact, and a holistic concept of care (caring *for* and *about*, see section 2.2) seem at risk (Archibald & Barnard, 2018; Coeckelbergh, 2015; Parks, 2010; Sparrow & Sparrow, 2006; van Wynsberghe, 2022).

At once, scholars (Coeckelbergh, 2015; Willems, 2010) have highlighted that there is not a uniform concept but ‘varieties of good care’ (Willems, 2010, p. 258). Although research into technologies in care often focusses on possible negative effects on care, scholars also emphasise the situated, processual, non-linear, and ambiguous appropriation of these technologies. They scrutinise prevalent categorisations of technology as *inhumane* or *unnatural* (Barnard & Sandelowski, 2001; J. Seymour, 2003) or as *cold* (Pols, 2012; Pols & Moser, 2009) and describe how these categorisations may dissolve in applying technologies. For example, monitoring technology provides additional insights into patients’ lives and opens up novel ways to get to know patients. New forms of ‘digital intimacy’ (Piras & Miele, 2019) can emerge when using digital technologies such as telehealth or robots (Hjorth & Lupton, 2021; Pfadenhauer & Dukat, 2015; Piras & Miele, 2019; Pols, 2012, pp. 53–58).

3.2.2 Digital technology, robots, and good dying

Dying and good dying have always been interrelated with technology. The history of dying is filled with technical artefacts such as crucifixes, holy water, coffins, tombstones, or embalmment techniques (Ariès, 2008; Hoy, 2021; Kellehear, 2007). Even before the advent of modern medicine, nurses and physicians cared with the best of intentions for the terminally ill with non-curative means to soothe pain and symptoms such as bloodletting, wound dressing, or natural remedies (Stolberg, 2017, pp. 15–49).

Studies on the role of medical technologies in dying, such as artificial respiration or resuscitation devices, question the assumed negative impacts of these technologies on the dying process and provide a differentiated perspective on the medicalisation of dying (Barnard & Sandelowski, 2001; Carmel, 1999; Connelly, 1998; J. E. Seymour, 2000; Timmermans, 1998; Willems, 2010). Thereby, the distinction between technology as *humanmade* and *artificial* on the one hand and *natural* phenomena such as dying on the other hand is at the core of a dominant understanding of technology but also critically challenged (Carroll, 2017;

Sandelowski, 2000, pp. 21–23; J. E. Seymour, 1999, 2000). In palliative care, there has been applied research on the implementation and effects of different non-medical digital technologies in EoL care (Cameron & Munyan, 2021; Ostherr et al., 2016). Social research has also been conducted on dying and death on the internet, on how terminally ill patients discuss dying and death online, thereby finding social support and creating a legacy (Andersson, 2019; Bassett, 2015; Bovero et al., 2020; Keim-Malpass et al., 2015; Sofka, 2012).

However, the meaning and use of robots and digital technologies in EoL care have rarely been investigated. Böhlen and Karppi (2017, pp. 13–14) argued that robots for care have the potential to 'reconfigure care' in a similar way as the cardiopulmonary bypass changed our perception of the centre of our human existence, shifting its assumed centre from the heart to the brain. Beyond issues of technical capabilities, safety, and control, robots and digital technologies have raised concerns regarding their ethical implications. Issues of privacy and informed consent as well as the associated objectification of care recipients have been identified as problematic. In particular, critics highlight the robots' inability to provide compassionate care. The prospect of replacing human caregivers with robots appears to be interrelated with the risk of reduced human contact and thus a deterioration of the quality of care (Coeckelbergh, 2010; Pedersen et al., 2018; Sparrow & Sparrow, 2006; Vandemeulebroucke et al., 2018; Yew, 2021). Thereby, it is not only the quality of EoL care that is at stake but also the position, responsibility, mode of work, well-being, and satisfaction of caregivers (Fortunati, 2018; Hamblin, 2022; Persson et al., 2022; Wright, 2018, 2019). Analysing prospects and risks of robots in palliative care, Nwosu et al. (2019) identified similar issues. Robots have the potential to affect the practical implementation of key principles of good dying. They may improve or compromise personal autonomy, social embeddedness, emotional compassion, or open communication. However, their effects on care and dying remain speculative for the time being because only a few robots have been regularly used in elderly care (Bardaro et al., 2022; Buhtz et al., 2018). Coeckelbergh (2016) argued that robots may transform care but not necessarily to the worse. Care and EoL care have been suboptimal even without new technologies. They comprise physical abuse (Graß et al., 2007; Schiamberg et al., 2012), loneliness (Greenwood et al., 2018; Jansson et al., 2021), or deception (A. Turner et al., 2017).

Although numerous studies deal with the acceptance of robots in care, there is no evidence on the assessment of robots in EoL care. Studies analysed how sociodemographic factors, technology affinity, digital skills, or experiences with technology/robots affect the attitude towards these machines (Broadbent et al., 2009; Carradore, 2021; Flandorfer, 2012; Heerink et al., 2010; Papadopoulos et al., 2023). Others investigated the acceptance of robots for different tasks or conditions (Hall et al., 2019; Łukasik et al., 2020, 2021; Rebitschek & Wagner, 2020). These studies showed that people hypothetically accept robots conducting routine tasks that relieve but do not to replace human caregivers. Robots to be used for rather intimate activities such as personal hygiene are deemed less useful and/or acceptable (Hall et al., 2019; Rebitschek & Wagner, 2020). One study found that people would want socially assistive robots rather to be used as tools for reminders or activities and training than as means to check and improve the emotional and social state of a person (Łukasik et al., 2021).

My exploration of the palliative care discourse on digital technologies as well as on robots in EoL care both contributed to a better understanding of the mutual relations of these new technologies and concepts and practices of good (EoL) care (see papers in sections 5.3 and 5.4).

3.3 Envisioning socio-technical futures with robots in care

In the following sections, I elaborate on concepts and findings that support an understanding of the emergence and significance of *socio-technical futures* (section 3.3.1) and review existing insights on envisioned futures of robots in care (section 3.3.2).

3.3.1 Conceptualising and investigating socio-technical futures

Scholars have emphasised the importance of envisioned futures for R&D of technologies. Concepts such as 'expectations' (Borup et al., 2006; Brown & Michael, 2003), 'sociotechnical imaginaries' (Jasanoff & Kim, 2009, 2015), or 'visions' (Böhle & Bopp, 2014; Grunwald, 2013) deal with socio-technical futures from (slightly) different angles. Narrower in scope, research on user representation is concerned with futures of technology, too (Davenport et al., 2003; Hyysalo & Johnson, 2016; Wilkie & Michael, 2009). I used the notion of *socio-technical futures* to capture diverse aspects and dimensions highlighted by these concepts.

Socio-technical futures entail visions about the prospective design and functionality of a technology as well as ideas about humans, society, nature, the environment, or other issues (Borup et al., 2006; Grunwald, 2014; Jasanoff, 2015). They draw on social orders and values and reproduce or transform them, and they propose aspirational societal conditions with or without technology or dystopias to be avoided (Ballo, 2015; Jasanoff & Kim, 2009; Longhurst & Chilvers, 2019; Šabanović, 2014; Tutton, 2021). Research on socio-technical futures enables a discussion of assumptions and interests related to dominant socio-technical futures (Groves et al., 2016; Grunwald, 2007, 2013; Urueña, 2022) or gives presence to 'counter-hegemonic visions' (Longhurst & Chilvers, 2019, p. 989). Making transparent guiding vision for R&D can facilitate a 'more informed debate' with 'more robust expectations that take into account the diverging assessments of other actors' (Beumer & Edelenbosch, 2019, p. 238; see also Lösch, Böhle, et al., 2019; Roelofsen et al., 2008).

Ideas about the future may initially be devised by individuals but are processed, negotiated, and reproduced in distributed social practices and materialities. They have an impact when they are socially stabilised and become reference points for collective actions (Berkhout, 2006; Borup et al., 2006; Grunwald, 2014; Jasanoff, 2015; van Lente, 2012). Actors from research, politics, public administration, industry, or other areas contribute to the creation and reproduction of a shared vision (Ballo, 2015; Rommetveit et al., 2020). Socio-technical futures then 'guide activities, provide structure and legitimation, attract interest and foster investment' (Borup et al., 2006, pp. 285–286) by defining a rationale and trajectory for R&D. They legitimise R&I strategies, technology governance, and funding programs (Bareis & Katzenbach, 2022; Davenport et al., 2003; Kim, 2014; Konrad, 2006; Lemay, 2020; Šabanović, 2014; Shove & Rip, 2000; van Lente & Rip, 1998; Wentland, 2016). R&D practices consider, create, and negotiate socio-technical futures. For example, through research into prospective users, their demands, requirements, and attitudes towards a novel technology,

the future users receive a shape and presence (Hyysalo & Johnson, 2016). The design and technical features of a technology are then aligned with future users envisioned in R&I policy and within particular R&D settings (Akrich, 1992; Hyysalo & Johnson, 2016; Wilkie, 2010; Wilkie & Michael, 2009; Woolgar, 1990). Devices become embodiments of the feasibility of expectations and visions, or produce unexpected outcomes or failure and stimulate a renegotiation or transformation of socio-technical futures (Berkhout, 2006; Bischof & Jarke, 2021; Blümel, 2016; Gardner et al., 2015; Hoppmann et al., 2020; Lipp, 2022; Roßmann, 2021; Schulz-Schaeffer & Meister, 2019).

Futures emerge, unfold, and are considered in different social arenas. Literature, movies, or works of art create science-fiction worlds that inspire scientists and engineers to realise imagined technology (Allgaier, 2018; Bell et al., 2013), fuel public expectations, and promote innovation governance (J. H. Evans, 2020; Osawa et al., 2022). Policy discourses produce, negotiate, and implement socio-technical futures in which national endeavours and interests, societal challenges, and technical solutions coincide (Jasanoff & Kim, 2009; Kim, 2014; Šabanović, 2014; Schlogl et al., 2021; Wentland, 2016). Expert communities produce socio-technical futures guiding and legitimising R&D in their fields (Bakker et al., 2011; Ballo, 2015; Fujimura, 2003; Hyysalo, 2006; Selin, 2007; Throndsen, 2017; Wentland, 2016). Organisations and companies strategically promote visions of technological innovations to support their products and business models (Beckert, 2021; Martin, 2015; Meyer, 2019; Pollock & Williams, 2010; Sadowski & Bendor, 2019). Social groups hoping for the realisation of an innovation, for example, patients waiting for a medical cure, promote socio-technical futures beneficial for their cause, too (Langstrup, 2015, p. 2015; Novas, 2006).

Socio-technical futures exhibit different degrees of stability and heterogeneity. National policies or industry networks produce more stable and homogenous futures than single organisations, smaller groups of people, or individuals (Meyer, 2019; Upham et al., 2023). Depending on their role in a situation, people might voice their expectations in different ways. For example, a scientist in a role as a public entrepreneur may make more promising claims about the future of a pursued technological innovation than as a scientist within a scientific community (Borup et al., 2006; Selin, 2007). Through interviewing roboticists, who created and reproduced this professional discourse, I tried to determine if the absence of dying users was an effect of deliberate silence in publishing, if they voiced different socio-technical futures in scholarly articles than in personal interactions.

Different actors and groups envision and promote different socio-technical futures. These diverging and ‘contested futures’ (Brown et al., 2016) are associated with controversies over the appropriate course of technology development, testing, implementation, regulation, etc. (Beumer & Edelenbosch, 2019; Horst, 2007; Jasanoff & Kim, 2009; Longhurst & Chilvers, 2019; Mager & Katzenbach, 2021; Mutter & Rohracher, 2022). Even individual actors within an R&D field may hold different visions about socio-technical futures depending on their professional role (Leonard & Tyers, 2021). In my study, I identified controversial points even within a professional field’s discourse and interpreted argumentative structures to mitigate critical issues as a mode of interdiscursive relation (section 5.5).

Socio-technical futures have a presence in discourses, practices, and structures, as well as material artefacts embodying assumptions about the future of and with a particular technology (Borup et al., 2006; Brown & Michael, 2003; Groves, 2017; Hoppmann et al., 2020;

Jasanoff, 2015). Policy documents, research strategies, scientific publications, newspaper articles, literature, movies, interviews, websites, or other types of media describe and depict socio-technical futures (Ballo, 2015; Bell et al., 2013; Haupt, 2021; Hielscher & Kivimaa, 2019; Jasanoff & Kim, 2009; Sovacool et al., 2020) and create a 'socio-technical futures discourse' (Böhle & Bopp, 2014, p. 158). Scholars have explicitly proposed to adopt discourse research in general and the SKAD in particular as a heuristic to study futures of and with technologies (Böhle & Bopp, 2014; Lösch, 2013). At once, social practices and institutions draw on, create, enable, reproduce, or transform socio-technical futures. In my dissertation, although I focussed on the discursive dimension of socio-technical futures, this always comprised some engagement with the textually conveyed materiality of the technical artefacts, the bodies of the envisioned users, or the spatial circumstances of care and the application of devices. For example, interviewed roboticists were keen to communicate a seemingly realistic assessment of the future of robots in care based upon their practical experiences with (and forecast of) the robots' materiality as well as technical capabilities (section 5.3).

3.3.2 Envisioning robots in care

Over the last decades, different actors have created ideas around the future use of robots in care. Decker (2008, p. 315) stated that 'robots are one of those rare technical systems whose potential in terms of construction and impact were comprehensively described and discussed before they were actually built'. These visions and ideas have oriented activities working towards the practical realisation of robots (Barker & Jewitt, 2022; Lipp, 2019; Rommetveit et al., 2020; Vallès-Peris & Domènech, 2020).

The term *robot* was coined in the 1920s by Karel Čapek (2004) in his play *R.U.R* (*Rossum's Universal Robots*). His story introduced robots as manufactured artificial people that become increasingly self-aware. At some point, the machines revolt against their human masters, leading to the annihilation of almost all humans (Čapek, 2004). As much as this work envisioned a dystopia, it mirrored the socio-economic and -cultural conditions of Čapek's time. Čapek's robots can be interpreted as 'political allegory that alludes to the transformation of the working class into dehumanised force for drudgery' (Bakardjieva, 2015, p. 245). The robots are constructed as replacements for human workers who are less effective and efficient than their technical counterparts.

It is reasonable to assume that public assessments of robots in care are interconnected with science-fiction worlds (Broadbent et al., 2010; Stafford et al., 2014; Vincze, 2017). However, research has shown that the imagined futures with robots in care are less dystopian than those about other types of robots. Movies or television series featuring robots for care purposes do not present them as 'slaves or monsters any more, but [as] helpers and companions' (Cheng & He, 2018, p. 475) who are 'an antithesis' (Cheng & He, 2018, p. 478) to human irrationality in old age (Cheng & He, 2018; Koistinen, 2016; Schreier, 2012). In public deliberations on the internet, robots in care are regularly linked to friendly robots that enable independent living (Eriksson & Salzmann-Erikson, 2018; Eriksson & Salzmann-Erikson, 2017). In German print media, they are imagined as 'assistants, colleagues, and even friends' (Laryionava & Gross, 2012, p. 269) that yield benefits in medical, social, and economic terms. However, in contrast to these findings, a study from Finland reported negative assessment of a pilot test of a concrete humanoid robot in elderly care in comments in online and print media

(Tuisku et al., 2018). Public surveys yielded diverging findings on the desirability of robots in care, too, ranging from rather critical (European Commission, 2012, p. 35) to rather supportive (Eggert et al., 2018).

In professional deliberations on robots in care, robots are regularly identified as technical solution to a societal challenge or as a potential threat to humans and society. A 'solutionist position' envisions robots as instrumental in addressing demographic challenges of present and future societies. Thereby, robots need to be 'humanised' appropriately in order to be deployable (Lipp, 2019, pp. 25–28). This future depicting robots in care as a factual necessity has especially been promoted by R&I policies and roboticists (Bischof, 2020; P. Graf et al., 2020; Lipp, 2019; Maibaum et al., 2022; Neven & Peine, 2017; Roberts & Mort, 2009; Šabanović, 2010; Vallès-Peris & Domènech, 2020; van der Plas et al., 2010). In my analysis of the robotics' discourse, this was a central justification for robots for care purposes, too (section 5.3). In addition, I found this way of reasoning in the reconstruction of the palliative care discourse on digital technologies, as well (section 5.4). In contrast, a 'humanist position' questions the capability of robots to provide adequate care. It envisions a socio-technical future *to be avoided* in which robots replace human caregivers and dehumanise care. Both positions reproduce techno-deterministic assumptions of robots unilaterally affecting care but neglect the reversed impact of social actions on the design and implementation of this technology (Lipp, 2019, pp. 28–32).

Focussing on robots in care, Lipp (2019) analysed the conditions to allow the 'interfacing' of robots and elderly care in the first place. At their core was a shifting perspective on ageing. The robot-promoting discourse presented the 'demographic change not primarily as a threat but as an opportunity for technological and economic development' (Lipp, 2019, p. 89).[16] Lipp (2019) explored the unfolding of this discourse from the late 1990s. However, European research funding programs created key elements of this discourse already in the early 1990s (Commission of the European Communities, 1992, 1993; European Commission, 1995). The *Technology Initiatives for Disabled and Elderly People* (TIDE) aligned their funding with a forecast of an ageing society in which the independence and activity of elderly users should be promoted by technical innovations such as robots. At once, they were about innovations as resources for economical revenue and competitiveness.

In this socio-technical future with robots in care, the transfer of technology from one domain (industry) into another one (healthcare) has been envisioned (Östlund & Frennert, 2021, p. 229). Scholars have highlighted that this transfer implies the segmenting of care into isolated tasks implementable by the robots and differentiating these tasks from others that need to be conducted by human caregivers (Böhlen & Karppi, 2017; Östlund & Frennert, 2021; Vallès-Peris & Domènech, 2020). However, the translation of this vision into practice has proven to be difficult because of numerous technical, social, and other barriers (Lipp, 2023; Neven, 2010; Nickelsen, 2019; Tuisku et al., 2018).

Research on how professional caregivers, care recipients, or other future users envision robots in care found similar visions in these groups as in the wider R&D discourse, for

[16] In my analysis of the roboticists' discourse, I found that the ideas of an ageing society and that of a resulting care crisis were rather central elements of the discourse and legitimised R&D of robots in care in the first place (see papers in section 5.3 and 5.5).

example, images of robots as taking over repetitive tasks, as relief for caregivers, as enablers of independence, or as tools to address a care crisis. At once, these groups also envisioned other socio-technical futures in which robots became competitors for jobs, safety risks, or harmful for the quality of care (Coco et al., 2018; Frennert et al., 2021; Johansson-Pajala & Gustafsson, 2022; Lehoux & Grimard, 2018; van der Plas et al., 2010; Wolbring & Yumakulov, 2014).

Studies have stated that R&D of robots for care purposes are often oriented towards an envisioned homogeneous group of *the* elderly user 'strongly related to illness, frailty, lost competences, and expenses' (Neven, 2010, p. 335). Thus, they do neglect different capabilities, needs, and perspectives amongst the actual prospective users (Burema, 2022; Hsu et al., 2020; Neven, 2010; Righi et al., 2017). At once, empirical investigations showed how user representations are envisioned and at play in R&D processes. Neven (2010, p. 338) described how researchers working on robots in care 'imagined old people as varied' with different characteristics, capabilities, and needs. Another study found that future users were imagined based upon the actual or prospective technical capabilities or overall goals of R&D processes. The user representations emerged 'as a byproduct of routine and everyday activities' that functioned as 'image-evoking activities' (Fischer, Östlund, et al., 2020, p. 236). A similar tendency to create users in field trials and align the users and use cases with the technical capabilities of the robots was found in other empirical research, too (Bischof, 2017). My own study contributed to this field of research on how robots in care are envisioned by drawing attention to one group of prospective users not explicitly considered in this area of R&D (section 5.3).

However, the perspective of the prospective users themselves, those considered and those absent, was outside the scope of my research. Research investigating the perspective of prospective elderly users showed that elderly study participants distanced themselves from assumed representations of robot users. Although they assessed assistive robots as useful in principle, they rejected the stereotypes they thought were related to their application scenarios (H. R. Lee et al., 2016; Neven, 2010). In practice, such a lack of consistency between the envisioned and actual users has led to failure of technical devices and lack of acceptance (Östlund & Frennert, 2021). The involvement of future users in R&D processes should better adapt the technology to the needs and demands of users (Östlund et al., 2015; Righi et al., 2017). At once, even such participatory approaches might reproduce stereotypical user representations because of their design and context (Bischof & Jarke, 2021; Fischer, Peine, et al., 2020; Peine et al., 2015).

3.4 Discursive relations

Socio-technical futures with robots in care can be understood as 'temporarily stable outcomes of heterogeneous activities of scientists and engineers and their entanglement in wider social and political relations' (Rohracher, 2015, p. 200). Given the importance of discourses for futures in fields of innovation in general, and of robots in care in particular, it is valuable to conceptualise the relations of discourses to better understand the emergence of new technologies against the background of existing social orders.

Multiple discourse concepts from linguistics, social psychology, social science, political science, cognitive science, literary studies, or philosophy propose varying theoretical and methodological approaches to discourse research (Fairclough, 2013; Foucault, 1972; Gee, 2010; Gordon, 2021; Jäger, 2012; Keller, 2011b; Potter & Wetherell, 1987; Tenbrink, 2020; van Dijk, 1985; Wodak, 2001). Scholars of discourse have acknowledged this diversity (Johnstone, 2018, p. 60; Potter & Wetherell, 1987, p. 6; van Dijk, 1997, p. 1). It is beyond the scope of my dissertation to unravel and discuss these approaches[17]. Rather, I deliberate upon the suitability of the SKAD for addressing my research interest (section 3.4.1). Then, I conceptualise the relations of discourses (section 3.4.2) before turning to the issue of absence (section 3.4.3).

3.4.1 A sociology of knowledge approach to discourse

The SKAD is a research programme that builds upon the sociology of knowledge (Berger & Luckmann, 1991), social phenomenology (Schütz & Luckmann, 1974), and symbolic interactionism (Blumer, 1986; Mead, 2015), and combines them with Foucaultian discourse theory (Dreyfus & Rabinow, 1983). It seeks to avoid limitations of, both, hermeneutic sociology of knowledge and discourse analysis in the vein of Foucault (Dreyfus & Rabinow, 1983) by outlining 'a perspective on discourse that bridges the gap between agency and structure-oriented traditions' (Keller, 2021, p. 37). The formation rules of expert discourses are of interest as well as the construction, transformation, and institutionalisation of knowledge through public and special discourses as social practices (Keller, 2011b, pp. 228–232). The SKAD focusses on how collective stocks of knowledge and symbolic universes are generated, reproduced, or altered in discourses as 'regulated, structured practices of sign usage in social arenas' (Keller, 2021, p. 36), and how they affect social practices, structures, and materialities. Discourses consolidate and legitimise different types of knowledge, including but not limited to ideas, theories, beliefs, values, and norms, and thus support the interpretation of phenomena. The SKAD can be used to explore discourses in publics, social collectives, fields, or organisations, and to address different research questions (see contributions in Keller et al., 2018; Keller & Truschkat, 2013). The relations of different discourses are of interest in the framework of the SKAD, too (Keller, 2009, 2011b, pp. 228–232). With my dissertation, I propose a concept that further sensitises for the emergence and types of discursive relations (section 5.5).

In my studies, I reconstructed discourses in the fields of robotics and palliative care as '*special discourses* performed in closed arenas for special publics' (Keller, 2021, p. 38). These discourses have created socio-technical futures with robots or digital technologies in care in said expert fields. At once, I looked at a broader 'public discourse[]' (Keller, 2021, p. 38) in analysing the Austrian debate on good dying. Public discourses have a more diverse audience and often unfold in mass media (Keller, 2011b, pp. 228–232). All of these discourses reproduce assessments and forecasts about society in general and care in particular, values and norms of care, the design and capabilities of technologies for support and care, and so

[17] Keller (2013a, pp. 5–67) provided an excellent overview of different disciplinary developments and traditions of discourse analysis.

on. They provide orientation for interpreting phenomena such as dying and EoL care as well as the application of technology therein.

Discourses are conditions and resources of social practices. At once, different actors realise and constitute them through their practices (Keller, 2011a, pp. 53–54). Although discourses reproduce social power relations, actors are not necessarily determined by them. In producing and reproducing a discourse, actors interpret knowledge. In this, they may creatively alter the discourse (Keller, 2011a, pp. 51–56). Thereby, actors occupy different 'speaker positions' which allow more or less legitimate, powerful, or durable contributions to a discourse. Actors are represented in the discourse, too, and have different 'subject positions' with specific meaning and roles attributed (Keller, 2018, pp. 35–36).

The SKAD draws on Foucault's notion of 'dispositif' for conceptualising the material conditions and effects of discourses. A dispositif comprises institutions and organisations, laws and guidelines, social practices and specific actors, the organisation and content of education and training, various material structures and resources, technologies, other artefacts, and so on. Keller (2021, p. 41) defined the dispositif as 'corresponding infrastructure of discourse production and problem solving'. Socio-structural and material conditions are resources for producing discourses and to realise discursively identified goals and practices (Keller, 2018, p. 27, 2021, pp. 41–42). Keller (2011b, pp. 260–262, 2018, pp. 38–39) proposed to examine the relation between discourses and social practices or materialities using ethnographic approaches to investigate how social actors in social situations draw on, reproduce, or transform discourses. Others have conceptualised and implemented ethnographic approaches adopting the SKAD (Elliker, 2017, 2018; Elliker et al., 2017; Hornidge & Feuer, 2018; Wundrak, 2017). A comprehensive discourse ethnography was beyond the scope of my study. However, I considered some outcomes and conditions of the discourses in my investigation of the robotics' discourse. These included, for example, R&I funding programs that enabled the development of robots in care.

The SKAD favours an approach of not assuming particular ideological underpinnings of discourses prior to the analysis. This does not mean that issues of power are not of interest. Rather, 'knowledge politics' as discursive efforts of social actors to impose specific social realities (Keller, 2011b, p. 193) should be scrutinised empirically. Discourse analysis means 'to work against ever ongoing simplification' (Keller, 2017, p. 68) and to question seemingly objective '"evidences" via a precise empirical analysis of its discursive construction, its genealogy, contingency, and effects' (Keller, 2017, p. 66). In my investigation of discourses, I adopted such a stance. I raised awareness of critical absences in technology R&D by working against the simplification of future elderly users of digital innovations. At once, with my analysis of the Austrian public debate on good dying, I identified shared basic assumptions between seemingly incompatible political positions but also discussed their critical implications.

3.4.2 Relations of discourses

Speaking of *discourses* in plural is in contrast to discourse theories that use *discourse* abstractly as a mass noun referring to structures and impacts of language use in communication in general (Johnstone, 2018, pp. 2–3; van Dijk, 1997, pp. 3–4). The SKAD assumes that there is a plurality of discourses. It focusses on 'particular discourses' created

and maintained through practices in concrete socio-historical conditions and not about finding 'THE discourse' (Keller, 2018, p. 26) as generalised symbolic order.

Each discourse is an 'attempt to freeze meanings' in a 'social collective[]' (Keller, 2021, p. 36). This context-dependency is obvious in a scientific discourse that is produced and reproduced by very specific actors using a specialised and technical language within a particular social, institutional, and material infrastructure. At once, there different discourses on the same issue, such as on robots in care, might exist that are created by different speakers for different audiences in medial publics (Laryionava & Gross, 2012), countries (Hsu et al., 2020; Šabanović, 2014), scientific disciplines and R&I fields (Lipp, 2019; Nierling & Domínguez-Rué, 2016; Rommetveit et al., 2020), situated projects (Fischer, Östlund, et al., 2020), or elsewhere. The boundaries of these discourses are not objective but are interpretively formed in the research process. Analysing discourses is as much 'constructive work' assembling a discourse as it is 'reconstructive work' (Keller, 2021, p. 50) identifying established connections or homologies between utterances. Discourse analysis is based upon systematic data collection and analysis that needs to argumentatively justify the correlation of scattered utterances to understand them as typical and interconnected statements forming a discourse (Keller, 2011b, pp. 228–232).

Conceptualising discourses as distinguishable entities opens the possibility to scrutinise their *relations*. Different notions of *interdiscourse* are of interest in this regard. With Foucault, interdiscursive configurations can be understood as interrelations between special discourses (Foucault, 1972, pp. 157–160). Link (1996, 2008, 2012) proposed the concept of *interdiscourses*, drawing attention to non-specialised discourses that partially interrelate and integrate elements of special discourses and their stocks of knowledge. Such interdiscourses reproduce selected elements of special discourses. For example, the media, arts and literature, or politics utilise expert knowledge and special discourses and thereby simplify or popularise their content. Thus, they create interdiscourses that transgress discursive boundaries. Although I was not interested in the diffusion of knowledge from special to public discourses, but rather the other way around, this theory of interdiscourse was important for my understanding. As I show in my comparative analysis, the different special discourses draw upon popular ideas of an ageing society and undesirable nursing homes and therewith establish an indirect relation to one another (see paper in section 5.5).

Initially, attentive to the absence of particular users of robots, I aimed to identify and understand *expectable yet unrealised* intersections of technology and EoL care discourses in my dissertation. Through my comparative analysis, I identified this *absence* as mode of meaningful unrelatedness in comparison to various modes of discursive relations. In light of the concurrent embedding of speakers and practices of discourses in various social arenas, such relations of discourses are not surprising. In producing and reproducing discourses, actors are not trapped inside one discourse. Engineers working in the field of robotics have been recipients and consumers of cultural products comprising visions of (science-fictional) killer and other robots, of public news on the challenges of nursing care and the lives of the elderly (Domingo, 2008; Messerschmidt, 2018) or on the threats of automation (Benanav, 2020), and also get in contact with other disciplines' perspectives such as social sciences (Gallistl & Wanka, 2019). While the compatibility of different bodies of knowledge varies, actors can creatively and interpretively establish connections and incorporate elements of knowledge

into their own reasoning. Individual documents or other pieces of communication are not coherent representatives of a single discourse in the first place. Rather, they can encompass elements of different discourses concurrently (Keller, 2018, pp. 29–31).

Social, political, and environmental conditions can promote the relation of different discourses. These include but are not limited to demographic shifts, technological progress, R&I policy, environmental change, or other societal events. As outlined in one of my papers (section 5.4), the COVID-19 pandemic and its effects increased attention for digital technologies. In the discourse around robots in care, funding policies have promoted interdisciplinary work that supported interdiscursive relations (section 5.5). R&I discourses have to deal with these new conditions, thereby incorporating stocks of knowledge on the design, functioning, and impacts of these new technologies from other fields, including computer sciences, engineering, or further disciplines engaged with new technologies. Otherwise, discourse may lose their persuasive power and appropriateness for orienting practices because they do not consider material conditions and other dominant discourses. It is an empirical question if these relations are durable and lead to a longer-term change of a discourse's form and content.

Although discourses draw on and reproduce common stocks of knowledge or are informed by each other, they do not necessarily completely fuse but preserve some of their distinct characteristics. Discourses are necessarily selective; otherwise, they would be useless. A hypothetical non-selective discourse would offer a multitude, if not a (nearly) infinite number, of perspectives and interpretations for issues of concern. Thus, it would have hardly any use for orienting or informing practices of meaning-making in a social collective. Some knowledge of one discourse may be incorporated by another one, and some knowledge may be omitted. Some elements of a discourse may remain unchanged in this transfer to another one, and some elements may be transformed.

At the heart of Foucaultian discourse theory and approaches building upon his work lies the idea that discourses establish and maintain 'regimes of power/knowledge' (Keller, 2018, p. 18) that enable and reproduce particular symbolic and social orders. Power relations are based upon stocks of knowledge but also enable and reproduce these (Diaz-Bone et al., 2008; Dreyfus & Rabinow, 1983). It is reasonable to assume that processes of interrelating different discourses to one another are associated with particular characteristics of the different discourses (for example, linguistic or conceptual proximity/distances and contact points/barriers), the involved actors (for example, social networks between or isolation of speakers), and societal power relations (for example, dominance of particular scientific disciplines, political and economic interests). Thus, the reconstruction of relations of different discourses can make visible hierarchies and hegemonies of discourses. In turn, I argue that it is vital to study those discursive relations that one could very well expect but that documents and statements do not realise and thus remain absent.

3.4.3 Absence in discourses

Foucault highlighted how discourses create realities and truths but thereby also exclude things that should and could not be said or things that are not considered as proper knowledge:

> '[…] in every society the production of discourse is at once controlled, selected, organised and redistributed according to a certain number of procedures, whose role is to avert its powers and its dangers […]' (Foucault, 1971, p. 8).

As three modes of exclusion he distinguished 1.) the prohibition of particular topics, including critical or taboo issues, 2.) the categorisation of speakers as mad (in contrast to rational) and thus their utterances as invalid, and 3.) the division between true and false knowledge (Foucault, 1971).

Discourses are inherently selective and thus exclusive. They direct attention to specific aspects of the world. An all-encompassing discourse is neither viable nor valuable because dealing with 'anything in its totality is simply not an option, inevitably many considerations are—and are often acknowledged to be—bracketed out' (Rappert, 2014, p. 42). Every issue of concern is surrounded by 'a plethora of absences' (Schröter & Taylor, 2018, p. 2), of topics not mentioned, facets of an issue not addressed, or actors not present. Social research predominantly focusses on what actors have said, written, or done rather than on those things unsaid, those words not written down, or non-actions. This is understandable given the challenge of theoretically and methodologically dealing with things not present.

The absence of a topic can originate from social dynamics, interactions, and choices that do not have the primary goal of hiding a particular issue but nonetheless result in its absence. In drawing on established discourses and being embedded in certain social conditions, speakers together reproduce a discourse that entails the presence of one matter but the absence of other one's without necessarily thinking about or intending this (Murray & Durrheim, 2019a; Rappert, 2015; Schröter & Taylor, 2018). Furthermore, the modes in which utterances reproducing a discourse are usually made can also contribute to the emergence of absences. Different types of communication and formats can limit the range of topics and ways to address them through genre-typical conventions (Huckin, 2009; Zerubavel, 2019). In interactions, assumed common knowledge can also become implicated and thus absent (Huckin, 2009; Murray & Durrheim, 2019a; Schröter & Taylor, 2018; Zerubavel, 2019).[18] In addition, who can speak in a social arena and reproduce or challenge a discourse is interrelated with the social status of an actor and the respective speaker positions opened up by a discourse and its infrastructure. Thus, in line with this social selectivity, some issues might not be raised, some perspectives might not be considered.

Against this background, absence can also be understood as a lack of relatedness of discourses. In general, our society is widely based on the division of labour and specialisation. In particular, science, research, and innovation develop and maintain disciplines and specialities with more or less permeable boundaries and special knowledge. Within their scientific or professional communities, actors produce and reproduce particular perspectives and stocks of knowledge (Ballo, 2015; Haas, 1992). These specialised stocks of knowledge – solidified and reproduced through special discourses – may or may not be accessible to or

[18] There are other conditions and processes on various levels leading to absence, including but not limited to 'lexical silence' through 'paradigmatic word choice[s]' (Huckin, 2009, p. 424) or through 'vague terms, ellipsis […] passive voice or in metaphorical conceptualisations' (Schröter & Taylor, 2018, p. 11). Tenbrink (2020, p. 251) also raises the possibility that an absent topic 'is not or cannot be represented in language, even though it may be present in the mind'.

considered by actors outside the respective discipline and community. Thus, even issues of central concern in one discipline could remain absent in other ones. For example, in their study on the emergence of bioethics as a field on its own, Francis et al. (2005) described how the issue of 'infectious disease was largely absent from the early texts in bioethics that were formative in the development of the field' (Francis et al., 2005, p. 308) between the 1950s and 1970s. At that time, with the exception of patient confidentiality, ethical issues related to infectious disease were hardly addressed in texts of this discipline. Even when bioethics dealt with infectious disease, it was foremost concerned with research ethics discussing historic experiments with involuntary research subjects (Battin et al., 2009, pp. 45–47). Only with the advent of HIV/AIDS, ethical issues related to infectious diseases were considered to a greater extent.

At once, absences can be fostered intentionally too. In cases of purposeful *silence,* 'individual speakers […] make a more conscious and intentional choice about what (not) to say' (Schröter & Taylor, 2018, p. 7). Issues might be avoided because they are assessed as not appropriate, as too sensitive, or as disturbing (Huckin, 2009; Murray & Durrheim, 2019a). Topics, perspectives, or actors may also be silenced because of political or economic interests. Research has focussed on identifying such intentional *silence* as a means and expression of power relations and vested interests (see contributions in Murray & Durrheim, 2019b; Rappert & Balmer, 2015).

There are seamless transitions, overlaps, and relations between intentional silence and unintentional absence. For example, a societal taboo exists within collectives 'beyond decisions of individuals' (Schröter & Taylor, 2018, p. 8) but can also become tangible in instances of 'self-censorship' (Schröter & Taylor, 2018, p. 9) or when actors intentionally decide to break a taboo. In my research on 'absent users of technology' (section 5.3), I considered various reasons for the absence of dying people in the robotics discourse, including discursive dynamics as well as technical artefacts, research processes, or individual or collective decisions that shifted the focus on particular user groups, thus producing the absence of other ones.

Against the fundamental insight that 'absences are abundant' (Rappert, 2014, p. 42), the questions arise what discursive absences are of relevance and how to identify these. Schröter and Taylor (2018, p. 6) argued to focus on '*meaningful* absences' that become visible and comprehensible against a framework of reference:

> 'Only when a thinkable alternative occurs to us will we begin to perceive its absence as meaningful. Wherever this is not the case, absences remain unnoticed because they are meaningless, and meaningless absences are outside of human perception. We would not notice the existence of an absence outside of a perceptive framework that renders them meaningful on the basis of an imaginable alternative of presence.' (Schröter & Taylor, 2018, p. 6)

I understand this 'perceptive framework' as in line with Blumer's (1954, p. 7) 'sensitizing concepts' outlined above. Given the abundance of alternative discursive constructions of social realities and phenomena, it is neither feasible nor useful to arbitrarily identify different topics absent in a discourse. Rather, reconstructing absences means identifying those issues that could in principle make sense within a discursively and practically reproduced social

reality but are not considered. *Absence* most often indicates a 'relative' absence of issues and things that 'were there once, or have become hidden, or are somewhere else' (Frickel, 2014, p. 87). Again, an issue absent in one discourse might be prevalent in other ones. In contrast, the 'absolute absence' (Frickel, 2014, p. 88) of things without a presence anytime and anywhere may be, in principle, hard if not impossible to grasp. If we do not have any knowledge, concept, or perception about something, identifying its absence in a situation seems challenging, to say the least. However, even restricting one's search for absent issues to those present elsewhere leaves a high (if not almost endless) number of possible absences.

Analysing how discourses unfold historically/chronologically, the emergence or disappearance of topics can be identified. Another possibility is to compare communication in different social arenas and thus notice the absence of an issue in one or the other. Social collectives reproduce different discourses that highlight particular issues and abandon others (Schröter & Taylor, 2018; Venkataraman, 2018). This is in line with the concept of the plurality of discourses presented above. A meaningful absence can be identified by comparatively analysing different discourses. My dissertation project arose from an astonishment about the absence of dying within a discourse on robots as assistive technology for elderly care. I could only comprehensibly identify this absence in one discursive arena (care robotics) against instances in which the issues of assistive technology and dying or EoL care were brought together, such as the *Last Moment Robot* (Chen, 2012a) or publications from other fields. At once, my research on good dying from a sociological perspective made me attentive to the changing characteristics and needs of elderly care recipients in approaching their end of lives.

As discourses in general, discursive absences can have critical impacts on practices and materialities. For example, due to the aforementioned absence of infectious diseases as a topic of bioethics, this discipline's debates often focussed on the individual patient affected by biomedical decisions but omitted questions arising from this individual patient being a vector of a disease and thus endangering others (Battin et al., 2009; Francis et al., 2005). One of the most prominent examples of an absence is that of sex and gender in medicine that only in the last decades got addressed by gender medicine. Medical research and development have regularly focussed on males as a model for humans in general and thus neglected sex and gender differences in terms of, for example, typical trajectories and symptoms of illnesses as well as treatment response (Baggio et al., 2013; Legato et al., 2016; Regitz-Zagrosek, 2012).

4 Research methodology

In this chapter, I discuss the methodological approach of my research, foremost the SKAD as the primary foundation of my study (section 4.1). Additionally, I outline the problem-centred interview (PCI) (Witzel & Reiter, 2012), which I used to approach roboticists on the absent topic of dying (section 4.2). The respective papers forming my dissertation describe the concrete implementation of data collection and analysis as well as the characteristics of my data (see papers in chapter 5). In order to avoid excessive duplicate descriptions, the methodology of the integrative review (Whittemore & Knafl, 2005) is only described in the methodology chapter of my paper in section 5.2.

4.1 Discourse analysis

The SKAD does not understand a discourse as ‘an ontological entity per se’ (Keller, 2018, p. 19) but as a research heuristic for making sense of communicative acts. The researcher has an active role in constituting discourses. The process starts with addressing a research question and selecting documents as data for analysis, and continues with identifying and interpreting utterances as statements forming discourses (Keller, 2011b, pp. 269–271; Keller & Clarke, 2018, p. 48). Thereby, discourse analysis is *reconstructive* in relying on concrete data and *constructive* in elaborating interpretations and concepts based upon this data (Keller, 2021, p. 50). Thus, reflecting one’s own position and assumptions as a researcher, being transparent in the data-based empirical work, systematically questioning assumptions and hypotheses, and argumentatively underpinning findings are essential in doing discourse analysis (Keller, 2011b, pp. 269–274). In the processes of data collection and analysis, I constantly strived to review preliminary ideas and findings. To support this reflection, I continuously produced memos and notes, put my preliminary findings up for discussion in research colloquia, research seminars, conferences, summer schools, or bilateral exchanges with fellow researchers. This allowed me to gather external input on the completeness and consistency of my reconstruction.

Demarcating the boundaries of a discourse is part of reconstructing it. In my dissertation, this happened to some extent based upon my research interests and subjects. In the case of the Austrian debate on good dying, I limited my inquiry to communicative acts around a political event in a particular region. Investigating the two R&I discourses, my aim was to reconstruct how particular social collectives reproduced special discourses. This already limited my focus to certain actors as speakers, such as roboticists, or arenas of interaction, such as palliative care journals. At once, I identified thematic focal points to handle the magnitude of potential data produced within these collectives. This included, amongst others, having definitions of *robots in care* (section 2.2) or *digital technology* (section 2.4) and searching for and collecting documents for analysis accordingly.

Continuously demarcating boundaries of different discourses in accordance with my (preliminary) analytical insights was necessary, nevertheless. Thereby, I was inspired by Clarke's approach of situational analysis (A. E. Clarke, 2003, 2005). A discourse can be understood as a 'situation to address' (Keller, 2021, p. 48). Thus, during each empirical investigation, I asked myself questions in the style of Clarke, including but not limited to: 'Who and what are in this situation? Who and what matters in this situation? What elements "make a difference" in this situation?' (A. E. Clarke, 2003, p. 561). I used these abstract questions to reflect if I had considered all relevant social actors, documents, and topics in my data collection and analysis. Progressing with my analyses, my understanding of the relevance of particular topics and actors developed, and thus I could increasingly comprehend the major characteristics of the discourse at hand.

4.1.1 Data collection and processing

The SKAD is based within the interpretive paradigm (Keller & Clarke, 2018). Its proponents suggest using qualitative methods to conduct empirical research. They highlight practices from grounded theory methodology (Charmaz, 2006; A. E. Clarke, 2005) to organise and conduct data collection and analysis (Keller, 2011a, pp. 61–63; Truschkat, 2013).

Before starting data collection, I familiarised myself with the fields and matters of consideration, including their historic conditions and circumstances, relevant speakers, key documents and policies, spaces of interaction, communication channels, and so on. Based upon these overviews and first identified documents, I systematically started to search and collect various types of documents related to the particular field of inquiry. I conducted broader internet searches and used specialised databases to find professional and scientific papers (Elsevier, 2022; Google, n.d.; IEEEXplore, 2020), magazine or newspaper articles (GBI-Genios Deutsche Wirtschaftsdatenbank GmbH, n.d.), or research funding information (European Commission, 2021; European Union, n.d.).

Thereby, data collection alternated with data analysis. Data analysis allowed me to identify common reference points, including publications, incidents, or actors that informed further rounds of data collection. On an analytical level, after doing 'initial sampling' (Charmaz, 2006, p. 100) of a series of documents, I developed a preliminary understanding of the matters at hand as well as first codes, hypotheses, and open questions. These insights then guided further searches and selections of documents as data – a process in line with the principle of 'theoretical sampling' (Charmaz, 2006, pp. 96–121). On the one hand, I reviewed and substantiated preliminary findings by incorporating further documents that reproduced similar elements of the discourse. By adding documents from speakers or on topics similar to other documents in my corpus, I backed my initial codes and hypotheses with additional data. On the other hand, since the ultimate goal of my data search and selection strategy was to 'explore the whole range of the discourse or the discursive field of interest, the positions taken, and the actors who appear (or, surprisingly, do not appear)' (Keller, 2021, pp. 49–50), I continuously tried to identify actors, cases, or documents potentially contradicting, widening, or changing my perspective.

Although I did not fully adopt Clarke's (2005, p. 86) approach to mapping, I created more or less structured maps of relevant and interesting topics, actors, documents, and other entities. Some maps made transparent the manifest relations between different documents

and R&D endeavours (for example, documents explicitly referencing each or relations between documents, research projects, funding programs, and R&I strategies). I used *yEd graph editor* (yworks, 2022), *Microsoft Visio,* or the *Network* feature of *ATLAS.ti 8* (ATLAS.ti Scientific Software Development GmbH, 2019) to create graphical maps but also mapped social and discursive relations in longer text documents, brief research memos, or systematic lists and tables. This approach helped me to keep an overview of and to identify and address possible gaps within my data.

As an example, figure 1 below represents a small excerpt from a large map visualising the conditions of selected robot developments. It identifies the connections between robots (*circles*, here: HOBBIT and GIRAFFPlus), R&D projects (*octagon*, here: projects funded within the European Union's Seventh Framework Programme (*trapezoid)*), related documents (*parallelogram*, including articles or reports presenting the robots as well as R&I policy documents guiding the funding), as well as their location of publication (*arrow-shape*), and selected involved organisations (*squares*, here the coordinators of the project or the partner manufacturing the robot). This particular map helped to keep track of, for example, which R&I policy documents guided funding programs and robotics R&D activities. Other maps and tables, for example, visualised the chronology of publications and cross-references amongst them or presented the phenomenal structures of discursive phenomena.

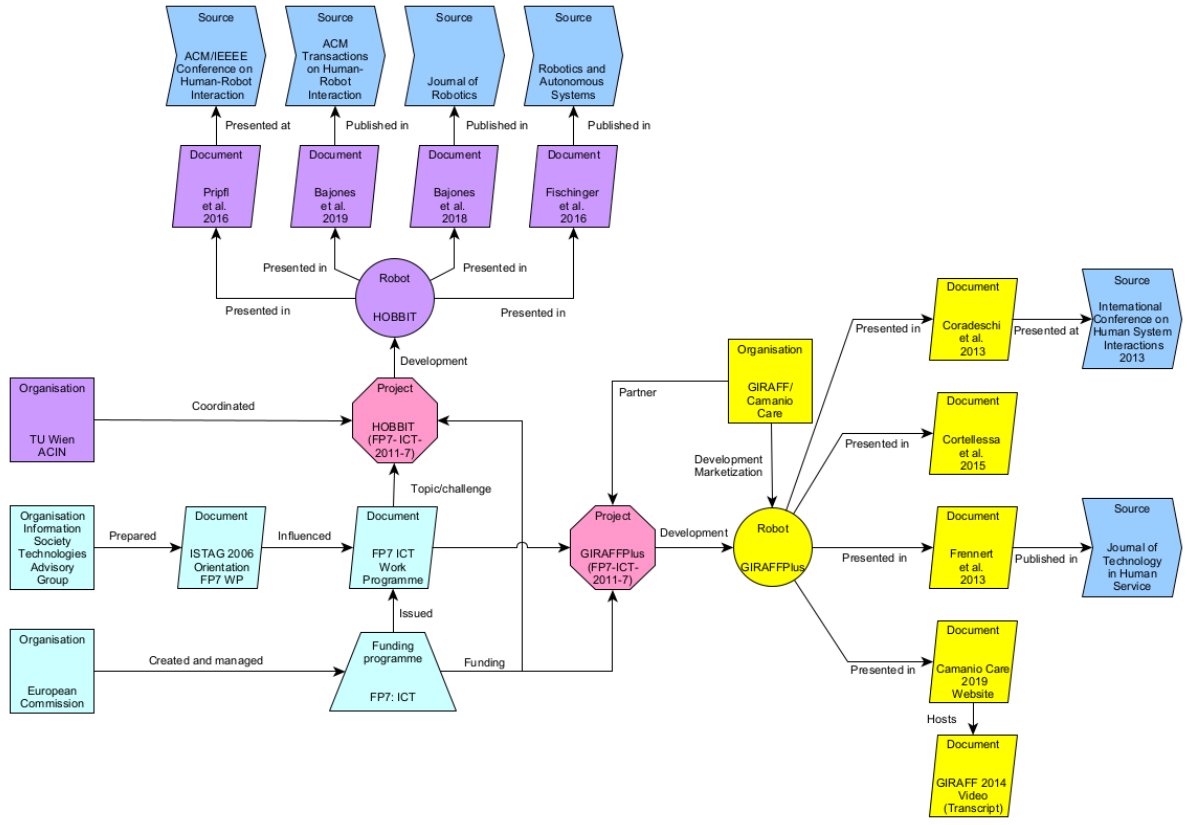

Figure 1 Robots, projects, institutions, and documents (*yEd graph editor)*

In line with the SKAD, the empirical material of my discourse analyses included documents, websites, videos, or images (Keller, 2018, pp. 19–20). The majority of my data was available as text documents directly usable for coding with ATLAS.ti. However, other relevant pieces of

data needed further processing. In the field of care robotics, companies and R&D institutes have produced various illustrative or promotional videos of their robots comprising their envisioned future use. I transcribed these videos scene by scene, sequentially describing their visual content, the appearing human actors as well as robots, courses of action, but also each spoken word and caption text. My transcripts were structured through time stamps, indicators for changes of scenes, but also screenshots of scenes. In coding and interpreting these video transcripts, I often resorted to the original video, closely rewatching short sequences that I was analysing at that moment in order to reassess visual aspects of a scene or the tone of a spoken sentence. In the following, I use *document* as a notion for one piece of data, irrespective if it was an article, a research report, a video transcript, the copy of a website, or another format.

4.1.2 Analysis of data

I conducted the analysis of my data in multiple and recurring steps. Before turning to its content, I considered the context and materiality of each document. This included the social and institutional embedding and position of its author(s), its intended and probable audience, its format and location of publication, and so on (Keller, 2013b, pp. 52–53). This contextual knowledge was important to better understand features of the texts but also to assess its potential reach and impact.

According to the SKAD's concept of discourse, documents comprise 'utterances' as 'the concrete given and ever singular micro-discursive event[s]' that are interpretively analysed as typical 'statements' considering their 'symbolic content' as building blocks of a discourse (Keller, 2018, pp. 31–32). The SKAD provides a heuristic to support the interpretation of statements as elements of discourses. In discourses, 'interpretive schemes' provide a frame for making sense of a situation or phenomenon. They support an understanding of what a situation, an event, or a phenomenon is about (Keller, 2011b, pp. 240–243, 2018, pp. 32–33). 'Classifications' are 'more or less elaborate, formalized, institutionally fixed form of social typification' (Keller, 2021, p. 44) to categorise and qualify situations, events, actors, things, and other entities (Keller, 2011b, pp. 243–248, 2018, p. 33). Furthermore, phenomena created and reproduced in discourses have specific 'phenomenal structures' comprising different dimensions including the cause, related causalities, relevant aspects, social responsibilities, normative evaluations, wider effects, etc. of a phenomenon (Keller, 2011b, pp. 248–251, 2018, pp. 33–34). 'Narrative structures' connect interpretive schemes, classifications, and phenomenal structures through story lines including a plot, protagonists, antagonists, a time structure, episodes, and so on (Keller, 2011b, pp. 251–252, 2018, pp. 34–35).

I analysed documents by reading them closely and sequentially. In this process, I developed and applied 'codes' by interpreting the texts and 'categorizing segments of data with a short name that simultaneously summarizes and accounts for each piece of data' (Charmaz, 2006, p. 43). I did not predefine any codes but developed, adapted, and refined them based on my empirical data. First, I employed 'initial coding'. I created codes that were 'provisional, comparative, and grounded in the data' (Charmaz, 2006, p. 48) and progressed 'line-by-line' as unit of my analysis (Charmaz, 2006, pp. 50–53). Later on, with the further development of my ideas, codes, and hypotheses, I implemented 'focused coding'. Therefore, I used existing 'codes to sift through large amounts of data' (Charmaz, 2006, p. 57). I regularly switched between these approaches to coding depending on insights from my data and

research focus at the time. At later stages, I employed rather 'theoretical coding' (Charmaz, 2006, pp. 63–66) with categories derived from the SKAD's research heuristic to identify segments as particular elements of discourses.

I used ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, 2019) to manage data analysis. This qualitative data analysis allows the organisation of documents, creating and applying codes to text, taking notes, searching and retrieving information, and interrelating codes and memos (Rädiker & Kuckartz, 2019).

4.1.3 Comparative discourse analysis: relations of discourses

Going beyond investigating discourses of various collectives and publics in isolation, one analytical step of my dissertation was to comparatively analyse these disconnected discourses. I analysed the public discourse around dying and death to have a necessary 'thinkable alternative' (Schröter & Taylor, 2018, p. 6) to the absent dying users in the roboticists' discourse (section 3.4.3). Analysing conditions of this absence was only possible by having a framework of what EoL care and good dying mean in discourses. Through the diverse reference points for various facets of dying, such as the characteristics of the dying, the responsibilities of caregivers, the norms of good EoL care, etc., I could identify dynamics in the roboticists' discourse that excluded the dying elderly as users of robots in care. I implemented this type of analysis after I had gained a solid first understanding of the roboticists' discourse on robots in care through initial and focussed coding of large portions of my data. I considered key codes and findings from my discourse analysis of the Austrian debate or the integrative review in reassessing the preliminary codes and categories developed in analysing the roboticists' documents. In an iterative motion, going back and forth between the insights on good dying and reassessing my emerging codes and theory on the absent dying user, I developed a better understanding of discursive elements relevant for this absence.

Second, I was interested in the explicit or implicit relations between different discourses. Social issues of care and EoL care are negotiated in various arenas and discourses. Clarke (2005) argued that while critical discourse analysis in the tradition of Foucault's discourse theory focusses on 'only *one discourse in a situation*–that with the most power in that situation' (A. E. Clarke, 2005, p. 174), her situational analysis aims to consider the various dominant discourses constituting a particular situation (A. E. Clarke, 2005, p. 48). In my dissertation, I considered this argument in a specific way. I did not focus on how in a 'particular social world' or situation various discourses interact. Rather, my comparative analysis was about finding common discursive elements across discourses (see section 5.5).

4.2 Problem-centred interviews

In the beginning of my study, it seemed possible that experiences with dying and death were simply not put in writing or reported in the available documents and publications from robotics (Bormann, 2013, p. 359). To address this issue, I approached roboticists as speakers and subjects of the discourse. I adopted the problem-centred interview (PCI) as a '*qualitative, discursive-dialogic method of reconstructing knowledge about relevant problems*' (Witzel & Reiter, 2012, p. 4). The notion of *problem* emphasises the alignment of the interview with a

specific research *problem* (my research question) as well as with 'an everyday problem in the perspective of *practical knowledge* that the respondent can articulate' (Witzel & Reiter, 2012, p. 5), such as the development of robots in care for roboticists.

The PCI allowed to engage with roboticists in a dialogic way and to bring up the absent topic of dying. Similar to Blumer's (1954) 'sensitizing concept', the PCI assumes that researchers have to use 'prior knowledge' as 'sensitising knowledge' (Witzel & Reiter, 2012, pp. 44–45). Sensitising knowledge provides orientation for the analytical work without predefining the phenomena under investigation (Witzel & Reiter, 2012, pp. 39–51). Therefore, the PCI combines an initial 'general and non-directive' (Witzel & Reiter, 2012, p. 68) question eliciting a broader narration with follow-up questions on issues from the respondent's account or on predefined topics in line with the research interest (Witzel & Reiter, 2012, pp. 68–89).

I approached roboticists working at European universities or companies developing or marketing robots for care settings. I strived for regional diversity and variation with regards to the type and functionality of the robots. Furthermore, I tried to recruit female roboticists for interviews but largely failed doing so. Only two of the nine respondents were women.[19] Between February and October 2020, I conducted nine interviews via videoconference or telephone lasting 40 to 60 minutes. Given the small size of the R&D community developing robots for care settings in some countries, I refrained from characterising my interview partners in my paper too closely to protect their identity.

After a short introduction, I started each interview with an invitation to talk about the interviewee's background and how the R&D of the robot came into being. After their initial accounts, I asked for clarification or further elaboration of aspects that emerged in these initial narrations and touched upon further issues related to the envisioned use and users of the robot. At a later stage of each interview, I raised questions about the possibility to use these robots in EoL care situations and about the roboticists' experiences with these circumstances. In none of the interviews, the roboticists addressed this subject on their own.

I recorded and transcribed all interviews. In the process of transcription, I pseudonymised the interviews by removing personal identifiers such as the roboticist's name, place of residence, company or university, projects, robot developments, and so on. In line with the informed consent (see section 4.3.2), I will delete the audio recordings on completion of my dissertation and the pseudonymised transcripts ten years after I obtained my PhD.

Witzel and Reiter (2012, pp. 100–109) suggested using techniques of grounded theory methodology to analyse interviews. I analysed the interviews together with all other documents as outlined above. I understood the interviews as social situations in which roboticists drew on, reproduced, and/or transformed discourses around robots in care and other social discourses (Talja, 1999). Thus, the interviews enabled 'exploring the discursive landscape people navigate when engaging in the production of narratives' (Van Brussel, 2018, p. 287). Additionally, I gathered information about work experiences, perspectives, and emotions not communicated in their scientific writing.

[19] In Europe, women are under-represented in engineering and computer sciences (Huyer, 2016). From all roboticists that I contacted, one third was female, but I received more rejections from female roboticists, some of which referred me to male colleagues of theirs.

4.3 Research ethics

The analysis of the Austrian discourse on good dying and the integrative review were conducted as parts of the two *Dying Worlds* projects, which both received approval by the *Ethics Committee of the University of Vienna* (reference number: 00255, approved 23 March 2017; reference number: 00540, approved 17 April 2020). For the other sub-projects, I did not seek an ethics review because no vulnerable groups were involved as research participants. Nonetheless, I reflected and adhered to ethical principles of research in my projects.

4.3.1 Discourse analysis: using public data without explicit consent

I only used public documents as data for my discourse analysis. I did not obtain consent from their authors to use them for my discourse analysis. Rather, I implied their knowledge about the possibility of becoming subjected to critical appraisal when making public statements. A large share of documents analysed in my study on the Austrian discourse were newspaper articles and commentary. This kind of document is seeking public attention and wants to contribute to or stimulate a public discussion. The documents either reported on the political and normative opinion voiced by public figures or their authors themselves stated their viewpoints in editorials. I understood my research as 'discourse about discourses' (Keller, 2021, p. 50) and as yet another form of taking up discursive points of reference and interpretively commenting on them, similar – albeit more abstract and systematic – to the customary practice of writing a comment in response to another public statement. Given that journalists or other actors writing these texts are accustomed to and have to anticipate their texts being read, (mis)interpreted, and addressed by others, I assumed their consent of becoming subject to my reception, interpretation, and processing as well. Similar holds true for journal articles, reports, or other types of documents written and published by actors from the scientific or policy community from the fields of robotics or palliative care.

In my study on the discourse on good dying in Austria, I also used statements written by citizens or organisations and submitted to and made public by the enquete commission. The parliamentary enquete commission was a public space in which these actors deliberately chose to voice their opinions to impact the political debate. Those submitting these statements could decide if their statements would be made publicly available or not. Seeking informed consent from each author for using their texts for research was not possible. The statements included the name but lacked other personal information to clearly identify the authors. After deliberating upon this issue with colleagues, I decided to use their statements as data, nonetheless. Excluding their contributions would have meant to devalue their contribution to the discourse, a contribution they desired to make in the first place.

4.3.2 Interviews: seeking informed consent, protecting privacy

I obtained informed consent from all interview partners. They received written information about my project and the interview in advance and had the possibility to raise issues of clarification or concern before or during the interviews. One version of the informed consent document, the one for interviews conducted via Microsoft Teams software, can be found in Annex A. Interviewees themselves could decide about the technical implementation of the interview; they were free to choose between interviews over landline phone or various digital

solutions. I always offered a digital solution in compliance with the European Union's General Data Protection Regulation. In addition, my information document outlined the processing of the interviews. I fully transcribed each interview and thereby pseudonymised all data by removing or modifying personal identifiers such as name, affiliation, or location. At once, I highlighted that given the limited size of the R&D community for robots in care, colleagues or others might nonetheless be able to identify them even based upon pseudonymised yet directly quoted statements. I emphasised that they should feel free to retract information if they felt insecure and that they could withdraw their informed consent even after the interview.

5 Findings

This chapter comprises the five papers of my study. Each paper presents the findings of comprehensive research efforts. Papers one, three, and four concern the reconstructed discourses on good dying, robots in care, and digital technologies in palliative care that were the basis for my subsequent comparative discourse analysis presented in the fifth paper. The second paper comprises the integrative review about the perspective of healthcare and nursing professionals on good dying.

The papers are reproduced here as published or as final versions of manuscripts to be submitted to scientific journals. In line with the requirements for this type of dissertation, the consecutive pagination of the present document continues and was included at the bottom of each page in addition to each paper's own pagination.

5.1 Paper 1: ‘The good death and the institutionalisation of dying: An interpretive analysis of the Austrian discourse’

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The good death and the institutionalisation of dying: An interpretive analysis of the Austrian discourse

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ABSTRACT

The institutionalisation of dying is recurrently assessed as adverse to a good death. However, a majority of people die in institutions such as hospitals or nursing homes and end-of-life care at home is more and more professionally supported. This article analyses how the discursive production of dying, the good death, and the issue of institutionalisation at the end of life are interrelated. The study empirically investigates a parliamentary enquiry on dying with dignity that took place in Austria between 2014 and 2015. It employs the Sociology of Knowledge Approach to Discourse to analyse parliamentary documents and minutes, written statements submitted by individuals and organisations, as well as newspaper articles. Data analysis shows a restrictive and a permissive normative position considering both killing on request and assisted suicide. Apart from their different political demands, they both reproduce a discourse constructing dying as a longer lasting and painful process striking old or ill people. In order to enable a good death, the dying person needs comprehensive support that the informal social environment is incapable to provide. Thereby, institutionalisation is associated with negative characteristics and at the same time identified as requirement for a good death considering its role in pain management and provision of care. The analysis interprets the call for institutionalisation in the context of medicalisation and the central role of physicians to alleviate pain. The article proposes a differentiated view on institutionalisation processes and practices in end-of-life care, also reflecting the potential of institutionalisation to obstruct fundamental societal transformation.

1. Introduction

Since the middle of the 20th century, institutionalisation has been affecting the process and experience of dying. Scholars have related the institutionalisation of dying to broader social change including the rising employment of women, urbanisation, and medicalisation at the end of life (Howarth, 2007; Kellehear, 2007). Institutionalisation can also be understood as part of the "civilizing process" (Elias, 1994) that increases self-constraints of emotions and instincts as well as the control of bodily functions (Seale, 1995a).

In these discussions, institutions are understood as professional organisations featuring specific organisational goals, arrangements, actors, and processes as well as physical structures. Foremost, the hospital is highlighted as end-of-life institution that stands in contrast to an ideal of home that is represented as non-institution and preferred place of death (Gomes et al., 2013). Scholars critically identify institutionalisation as transfer of the old, ill, and dying to care facilities and hospitals, as the displacement of dying and death from everyday life and as connected to the societal taboo of age, illness, dying, and death (Ariès, 2008; Elias, 1985). Institutionalisation in this sense "carries negative connotation" linked to "loneliness, isolation and helplessness" (Thonnes and Jakoby, 2013, 15), while home as place of dying is linked to more positive emotions. However, since dying at home is often professionally organised and supported, it can be seen as institutionalised dying too (Gott et al., 2004; Gronemeyer and Heller, 2014). In practice, this institutionalisation of home might obliterate some of the differences between private homes and other places of death such as hospitals or care facilities. Against this background, the question arises how the institutionalisation of dying is understood and negotiated considering the provision of a good death.

Public debates around the good death (e.g. Karsoho et al., 2016; Van Brussel and Carpentier, 2012) generate a "discursive field", a social arena organised "around contested issues, controversies, problematizations, and truth claims" (Keller, 2011, 52), that co-construct institutionalisation of dying as social phenomenon. The study at hand adapts an interpretive methodology based on the Sociology of Knowledge Approach to Discourse (SKAD) (Keller, 2011; Keller et al., 2018) to analyse how concepts of the good death are interwoven with basic assumptions of dying in contemporary societies and how these translate into strategies to promote and enable a good death. Given the

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significance attributed to the institutionalisation of dying, the examination of its discursive re-/production further advances the understanding of this phenomenon. How does the discourse conceptualise the institutionalisation of dying and death? How is this institutionalisation embedded in the discursive formation of dying and death as social phenomena? How does it relate to the characteristics and strategies of accomplishing a good death?

The empirical case for this inquiry is a public debate initiated by the Austrian Parliament's Enquete-Commission *Dignity at the End of Life* that took place between 2014 and 2015. This parliamentary enquiry was an important reference point for politicians, experts, and citizens to share their perspectives on the good death, producing a wealth of newspaper articles, written statements, and minutes of parliamentary discussions. This event constitutes an interesting case for investigation, because it does not initially focus on a specific controversial case but establishes a rather open space for discussion that enables a broad variety of actors to engage and topics to emerge. However, in its progress it becomes a debate on the good death with antagonistic ethical positions regarding killing on request and assisted suicide.

The study reconstructs the knowledge underlying the different normative positions and shows a shared yet ambivalent demand for institutionalisation of end-of-life care. This demand appears closely linked to the discursive construction of dying as a longer lasting process affecting old and ill people in need of comprehensive support – neglecting instances of sudden death. The paper argues that while institutionalisation might be explicitly linked to negatively perceived places of dying such as hospitals or nursing homes, the institutionalisation of dying in any place, including home, is assessed as necessary by the discourse.

First, the paper reviews insights on the discursive construction of the good death considering the role of institutionalisation. Second, patterns of dying in contemporary societies with a focus on Austria are outlined, enabling a better understanding of the empirical case. Third, the paper presents the SKAD as methodological approach and outlines the data collection, selection, and analysis process. Then, the text turns to the results of the empirical analysis, describing how conflicting positions regarding euthanasia reproduce a shared concept of the good death. Finally, the paper discusses the insights as well as the limits of this empirical investigation. In all of this, the paper does not want to criticize or support certain normative demands regarding the end of life and good death, but wants to shift the perspective towards their common ground and to ask about the discursive and practical significance of the knowledge configurations they reproduce.

This paper further develops ideas previously published in a working paper (Lang, 2018).

2. Discursive construction of the good death and institutionalisation of dying

In contemporary societies, the good death appears individualised and with planning and timing death at its centre (Kellehear, 2007). Until the second half of the 20th century, a "medical-rationalist discourse" recognizing dying and death as medical problems dominated. Since then, this view has been incrementally replaced by a "medical-revivalist discourse" that assesses dying as a natural part of life (Van Brussel and Carpentier, 2012).

Hospice and palliative care have their origins in the critique of medicalised dying. They emphasise psychological, emotional, spiritual, and bodily needs of the dying person and their relatives (Clark, 2007; Pastrana et al., 2008). While palliative and hospice care are often linked to the good death, these care concepts might not be appropriate to support a good death in every social and cultural context (Walter, 2003; Zaman et al., 2017). Scholars also critically identify these concepts and practices as controlling and restrictive (Hart et al., 1998) and discuss the negatively assessed potential of (re-)medicalisation of dying as a challenge (Clark, 2002; Floriani and Schramm, 2012). However, medicalisation does not necessarily contradict a good or natural death, depending on the individual case and overall conditions (Seymour, 1999). And as Timmermans (2005, 1008) argues, there have been decades of criticism of institutionalisation, but yet further "entrenchment of medical authority" in end-of-life situations.

Physicians construct the well-timed, well-organised, and peaceful dying process as good death (Good et al., 2004). However, expert discourses assess control in dying as ambivalent, positive if oriented towards pain and symptoms management, negative if restricting the autonomy of the patient (Cottrell and Duggleby, 2016; Demjén et al., 2016). Professional literature definitions of the good death include the fulfilment of the dying's preferences concerning the conditions of the dying process, freedom from pain, emotional wellbeing, biographical closure, implementation of preferences regarding treatment, dignity, and support for the dying's family (Meier et al., 2016). In contrast to the aware and accepted death as good death, professional and media discourses construct denial as adverse to a good death (Seale, 1995b; Zimmermann, 2004, 2012). The aware death seems positive because it is a practical prerequisite for comprehensive support (Seale, 1995b).

The construction of home as preferred place of death involves positive connotations such as love, comfort, familiarity, memories, and family, while hospitals or care facilities are assumed to lack these characteristics. If professional support at home is necessary to enable appropriate end-of-life care, the presence of professional caregivers might impair these qualities of dying at home (Gott et al., 2004). At the same time, professional support is able to provide social meaning and routines to end-of-life situations (Timmermans, 2005). A positive assessment of institutionalised dying can also be based on practical reasons and the wish to reduce the burden on relatives (MacArtney et al., 2016). In contrast to dying in social contexts (home, hospital, care facility, etc.), dying alone is constructed as bad death because of the absence of social support (Seale, 2004; 1995a).

Institutionalisation can be found at the core of the professional discourse (timing, organisation, control of death) and to a lesser degree also in other discourses that emphasise the necessity of social embedding. However, good death discourses identify institutionalisation predominantly as hospitalisation and antithetical to a good death. This might disregard the diversity of end-of-life situations, peoples' needs and cultures, as well as the variety in the organisation and embodiment of the various end-of-life settings – not every hospital, care facility, or home is the same and equally adequate for every individual case. This paper adds to existing research by analysing the manifold and complex discursive interconnections that bring forth an ambivalent status of institutions considering good death. It shows how the discursive construction of dying and the good death implicitly and explicitly argues for institutionalisation of the end of life.

3. Dying in contemporary societies and the case of Austria

Austria corresponds to broader patterns of contemporary dying in developed countries: most people die at a high age and of diseases of the circulatory system or cancer (OECD, 2017). Dying primarily occurs in hospitals (49%), at home (26%), or in care facilities (19%) (data for 2016, retrieved from Statistik Austria, 2017). In general, the place of death correlates with factors including personal living circumstances, type of illness, or care setting, but also structural conditions such as degree of urbanisation or number of hospital beds available (Cohen et al., 2006; Gomes and Higginson, 2006). Broader societal circumstances (e.g. culture or employment patterns) are supposed to play a role too (Broad et al., 2013).

Austria has statutory social and health insurance providing nearly total coverage of citizens. Public health expenses are higher and the hospital sector is larger than in almost every other EU country (OECD and European Observatory on Health Systems and Policies, 2017). At the same time, it has a "family-based care system" (Haberkern and Szydlik, 2010) – the responsibility for care foremost rests with relatives,

most often women. State allowances are a key enabling factor for this system. Furthermore, various services support home care, including home nursing, household services, or 24-h-care (Österle and Bauer, 2012). While in Austria long-term care predominantly happens at home and in the family, death occurs often in hospitals. Austria has a comparatively advanced palliative care and hospice system (Woitha et al., 2016), but further development of the multilevel system is still seen as necessary (Pelttari et al., 2016).

Rather than palliative and hospice care, the topic of euthanasia often dominates public debates around the good death. The reoccurrence of this kind of debate on euthanasia (see e.g. Van Brussel, 2018) can be linked to advances in medical technology and demographic trends that prolong fatal illnesses and dying processes, as well as to broader social change including secularisation, liberalisation, and individualisation (Howarth, 2007: 149–153; Weyers, 2006). Acceptance of euthanasia has increased in many European countries in the past decades. In some countries, killing on request and/or assisted suicide have been legalised under specific circumstances (Cohen et al., 2014). In Austria, voluntary killing on request and assisted suicide are prohibited (§§77–78 StGB Strafgesetzbuch, 1974). Allowing death by stopping or refraining therapy is permitted (§110 StGB Strafgesetzbuch, 1974) and people can issue advance directives to register their binding decisions regarding medical treatment (Schaden et al., 2010). In contrast to their prohibition, surveys identify a majority acceptance of voluntary assisted suicide or killing on request in the Austrian population (Stronegger, 2016). Civil society initiatives have sought a liberalisation of euthanasia laws (Initiative Religion ist Privatsache n.d.), but none of the larger parties in parliament have made efforts in this direction.

4. Methodology and data

This study follows an interpretive paradigm adapting the SKAD as its methodological basis. The SKAD combines Foucauldian discourse theory with the Sociology of Knowledge in the tradition of Berger and Luckmann (Keller, 2011). It focuses on "the *discursive construction* of symbolic orders which occurs in the form of conflicting social knowledge relationships and competing politics of knowledge" (Keller, 2011, 48). Knowledge is understood not only as "socially recognized and confirmed positive knowledge" (Keller, 2011, 48), but as all types of knowledge forming perceptions of the world. The SKAD conceptualises discourse as "regulated, structured practices of sign usage" (Keller, 2011, 51) that re-/produces power. However, while discourses enable and promote specific symbolic orders and practices, social actors can creatively adopt and modify them. According to the SKAD, discourses materialise as texts, verbal communications, images, artefacts, or else. Researchers can collect, analyse, and interpret these manifestations, thus co-constructing the discourse by comprehending single acts of communication as typical and interrelated statements (Keller, 2011).

Discourses on good death differ between societal arenas (Hausmann, 2004; McInerney, 2006). Thus, it is important to consider diverse sources of material to receive a more complete picture. The documents analysed here originated related to the Enquete-Commission, but encompass different types of communication including newspaper articles, written statements, press releases, and plenary discussions. Data was collected via internet and database research between February and June 2017. Data analysis and selection of documents from this comprehensive dataset alternated ('theoretical sampling', Charmaz, 2006, 96–122) and was conducted by the author of this paper.

- In order to cover the discussion in the formal political arena, this study analyses fifteen documents produced by the Enquete-Commission including reports, press releases and written minutes of the Enquete's public sessions (Republik Österreich – Parlament n.d.). In the result section, quotes from the public sessions are labelled [PS] and a short characterisation of the speakers given.
- The study considers the perspectives of individuals and organisations through analysis of written statements [WS] to the Enquete-Commission. 712 statements were submitted between July 2014 and January 2015, 330 of them were made publicly available with permission of their authors on the Parliament's website. 58 of them were selected considering the similarity and diversity of statements (topics, position with regard to euthanasia, and gender) also balancing the types of authors: statements came from organisations like social welfare organisations, special interest groups, or palliative care providers, as well as from individuals. They contain political opinions, normative assessments, personal experiences, stories, and even statistical data.
- To cover the media debate, 151 newspaper articles [NA] dealing with or mentioning the Enquete-Commission published between 2014 and 2015 in Austrian newspapers were collected through a newspaper database (GBI-Genios Deutsche Wirtschaftsdatenbank GmbH, n.d.). In the end, 40 pieces were analysed in-depth, including articles, features, interviews, editorials, and (guest) opinions.

Analysis and interpretation adapted the Constructivist Grounded Theory methodology (Charmaz, 2006), an approach underpinned by the SKAD (Keller, 2011). Through sequential reading and analysis, codes were developed and applied to the texts. The analysis process included constant comparison of data and modification of codes as well as the targeted search for contrasting cases and contradictions against preliminary hypotheses within the material. Memos contained conceptualisations and initial theories. Four "exploratory concepts" (Keller, 2011) were used as heuristic for codes and memos supporting the systematisation of discursive elements: 1) *Interpretative schemes* are frames that provide meaning to grasp and typify phenomena. Through 2) *classifications*, phenomena are assessed along more fixed categories. 3) *Phenomenal structures* construct issues by identifying their key features, contexts and determinants, causal relationships, and relevant actors. Interpretative schemes, classifications, and phenomenal structures are assembled by 4) *narrative structures* in a "coherent, portrayable, and communicable form" (Keller, 2011, 59) as story lines.

The analysis focused on interpretative schemes as well as phenomenal structures to reconstruct central elements of the discourse. It asked how certain situations or phenomena are problematized (e.g. end-of-life care as deficient or dying as issue concerning the old and ill) and how different phenomena are comprehensively constructed (e.g. the need for professional care through a specific characterisation of the dying person, their social environment, and society).

QDA-software was used for organising the data analysis (ATLAS.ti GmbH, 2010). In regular reflection sessions, the process and interim results were discussed in interdisciplinary settings.

5. Results

In Austria, Enquete-Commissions discuss fundamental and complex societal issues in order to inform political decision making on federal legislation. They consult experts and citizens and hold political meetings. Their findings are then a subject-matter in the National Council of the Austrian Parliament, but their recommendations are not binding in any way. According to its official agenda, the Enquete-Commission on *Dignity at the End of Life* aimed to discuss palliative and hospice care, advance directives, assisted suicide and voluntary killing on demand, as well as dying with dignity as constitutional right. All parties in the Austrian Parliament together appointed the Enquete-Commission (Republik Österreich – Parlament, 2014c).

Combination of different data proved to be useful, because some positions were more absent in certain arenas: The Enquete-Commission's expert presentations and plenary discussions mainly

revolve around the status quo of palliative medicine, hospice care, and advance directives in Austria. In contrast to the Enquete-Commission, most of the written statements by citizens and organisations, as well as many newspaper articles, deal with assisted suicide or killing on request. They often address issues and positions put forward in the Enquete-Commission's debates, e. g., affirming the necessity for development of palliative and hospice care. However, they also open up the discussion about the legitimacy or even demand a liberalisation of assisted suicide or killing on request, thereby criticising the limited debate within the Enquete-Commission. Yet, the Enquete-Commission hardly reacts to this contrasting framing of the issue and the existing polarised normative positions.

5.1. Polarised normative positions

The discourse exhibits two polarised positions regarding assisted suicide and killing on request: a *restrictive position* supporting the ban and a *permissive position* in favour of legalising such practices under certain conditions.

The *restrictive position* understands a person's desire to die as only temporary and depending on the particular conditions. If there was adequate medical and social support, nobody would want to die:

> [NA: member of Enquete-Commission] "The desire to die is very much related to suffering through pain. If the pain is alleviated by palliative medicine, accompaniment takes place, and appropriate conditions are created, then the will to live and the courage to face life awake once again" (Neues Volksblatt, 2014).

This narrative is based on the idea that pain and suffering are treatable by palliative care and medicine. The desire to die becomes a failure of the social and healthcare system. The restrictive position constructs a mutually exclusive dichotomy between intimate and emotional care on the one side, and the support of people in actively ending one's life on the other side. Thereby, liberalisation of euthanasia laws becomes a threat to palliative care and hospice:

> [NA: chairperson of Enquete-Commission] "If killing on request would be permitted, this would be the end to all hospice and palliative care efforts" (Baldinger, 2014).

Proponents of the restrictive position bring forth a slippery slope argument predicting social disintegration, pressure on old and ill people to end their lives, or even the murdering of people without their consent. This argument is emphasised by drawing parallels to the [PS: retired member of parliament] "machinery of death" (Republik Österreich – Parlament, 2015, 76) in Nazi Germany by framing the topic with the negatively connoted term *euthanasia* (see Michalsen and Reinhart, 2006). The Enquete-Commission's plenary discussions reproduce this restrictive position, which also manifests in a share of written statements and newspaper articles.

In contrast, the *permissive position* is especially present in newspaper articles and written statements. It is not part of the Enquete-Commission's agenda and is widely omitted in the official political discussion. The permissive position identifies voluntary euthanasia as widening the opportunities for action, not as contradiction to palliative and hospice care:

> [NA: professor of philosophy] "Palliative medicine and the hospice system are excellent approaches […] however, they are no alternative to self-determined dying" (Kampits, 2014).

The permissive position identifies limitations of care and medicine to control or minimise pain and suffering: there are cases in which pain management and comprehensive support are not capable of providing sufficient relief. It argues that in these cases death is the last resort:

> [WS: relative of deceased] "On the last night, the morphine no longer worked at all" (Rocca, 2014).

> [NA: journalist] "[…] there will always be people, whom nothing can help anymore, who just want to die" (Baldinger, 2015).

In line with this argument, the prohibitive laws prolong suffering or have other negative effects on the dying persons and their social environment. For example, if terminally ill people commit violent suicide or need to travel alone to Switzerland, where assisted suicide is legal, to organisations providing physician-assisted suicide, those helping in Austria or accompanying them might be punished:

> [NA: internist] "I see it as a socio-political problem when you criminalise a person who wants to help another in a situation of extreme suffering" (Weiser, 2014).

From this position, the prohibition of active euthanasia contradicts individual autonomy, the liberal social order, as well as the attitude of the majority of the Austrian population, who is ascertained as being in favour of a more liberal regulation. Societal progress seems to be obstructed by conservative forces because of power struggles. While regulation and control of active euthanasia in the case of its permission are seen as necessary, this discursive position does not project horrible outcomes and abuse of a liberal regulation, but positive effects on those in need of this kind of help.

5.2. The tabooed death of the old and ill

While the restrictive and permissive positions appear to be irreconcilable, they reproduce the same discourse about dying and death in contemporary societies and the context of Austria.

The discourse constructs dying as an abstract universal challenge everybody has to face inevitably and concretises it as a matter of old age or terminal illness. Dying individuals are portrayed as old and frail people or as patients suffering from illnesses, especially cancer or dementia. In contrast, sudden deaths as consequences of accidents, acts of violence, or acute illness are marginalised in this discourse. Rather, dying is constructed as a longer lasting and manageable process leading to death, which can be anticipated to some extent:

> [PS: professor emeritus of moral theology] "From a statistical point of view, with almost 75-years-old I will probably be one […] who is next to accomplish this task [dying, A.L.]" (Republik Österreich – Parlament, 2014b, 54).

The characterisation of the dying persons as of old age and/or suffering from an illness is in line with findings from other studies (Carpentier and Van Brussel, 2012). It has an effect on the discursive assessment of their situation and abilities. Dying is linked to frailty, physical and psychological deterioration leading to pain and fear. The discourse constructs dying persons as dependent on comprehensive support. Thus, their social environment and society in general have to take care of them. However, the discourse diagnoses a societal taboo of dying and death that impedes early preparation for this process. The taboo is constructed as a lack of communication and consideration of dying and death in society:

> [WS: cancer patient] "As long as you are fine, you do not deal with the topic [dying]. It is uncomfortable and still not a topic of conversation in the general population" (Herzog, 2014).

> [PS: member of parliament] "Death is one of the last major taboos in our society. We do not like to talk about death, do not like to talk about our own death, about our own dying – nor about that of our relatives" (Republik Österreich – Parlament, 2014a, 4).

The discourse identifies the fear of pain and illness, the discomfort facing the unknown, but also the economically driven and utilitarian contemporary society as causes of this taboo. Dying and death seem to be disregarded because of a general utilitarian and economically driven social system that lacks solidarity with vulnerable and unproductive groups.

5.3. A better death: holistic care

Interwoven with this concept of dying, the discourse creates the good death as realisation of an appropriate social and spatial embedding, the availability and quality of professional support, and the autonomy of the dying individual. Thereby, processes of dying are not described as *good*, but as more desirable (*better*) than their alternatives (see also Carpentier and Van Brussel, 2012). The *good death* functions here analytically as an umbrella term for these *better ways of dying* that are often identified in the discourse through "surrogate terms" (Granda-Cameron and Houldin, 2012), such as dying with dignity:

> [NA: professor of moral theology] "[Dying with dignity] requires good support: medical, psychological, spiritual. We need palliative care units, well-trained palliative care physicians, hospices, avoidance of loneliness of old, frail, seriously ill, or abandoned people" (Beck, 2014).

These surrogate terms are used by different actors to label distinct ways of dying. For example, assisted hastened death can be assessed as *dignified* (permissive position) or *undignified* (restrictive position) death. Thus, the meaning of *dignity* – as well as other surrogate terms – is highly contextual.

Since dying is a discursively constructed process affiliated with frailty, illness, and pain, professional pain and symptom management become requirements for experiencing a good death. The discourse reproduces a holistic perspective of the dying persons' needs that resembles palliative and hospice concepts of good end-of-life care (Clark, 2007; World Health Organization, 2019), identifying physical and medical, psychological, emotional, social, and spiritual support as necessary.

Especially physicians are identified as important professional actors that need to accomplish the balancing act between sufficient therapy and distressing overtreatment. Further professional and informal caregivers and family or relatives are represented as prerequisite for a good death because they do not only provide domestic help and nursing, but especially personal contact and intimacy reducing fear and stress. In sharp contrast, the discourse identifies dying alone as a form of bad and undesired dying:

> [PS: member of parliament] "Decisive for dignity are humanity, mindful attention, and the loving and professional care that every single person experience. No one should feel alone and abandoned when it is about his dying at the end of life" (Republik Österreich – Parlament, 2014b, 14).

The discourse interprets the good death as individual experience that has to be facilitated by collaborating actors. The subjective well-being of the dying person functions as the key criterion for a good death. In contrast, the experience and state of all other related actors does not seem to be directly relevant for the assessment of the dying process as either good or bad. Above all, their well-being appears to be relevant in order for them to be able to provide the necessary holistic care for the dying person.

In the discursive construction, open and timely reflection and communication on dying and death are necessary to enable a good death because they support the realisation of self-determination in a situation of manifold dependency. However, this preparation is impaired by the identified taboo of dying and death that prevents people from determining their wishes for their end of life. It leads to insufficient preparation for the end-of-life on the societal level (e.g. lack of palliative care services) and the individual level (e.g. lack of advance directives). The discourse identifies the breaking of this taboo as an important prerequisite for the good death.

5.4. Institutionalisation as – unwanted – necessity

The discourse spatially locates dying in a variety of places that are not only important because of their physical appearance, but the interlinked social settings they provide for the dying process. It is not only the place that matters regarding a good death, but the concrete social organisation of the support the dying person receives; however, certain places or contexts are strongly interconnected with certain good or bad practices of care and support.

Home is depicted as the ideal social setting for dying because of the familiar environment and intimacy, calmness, and steadiness it provides. Thereby, not only private households are identified as possible homes, but also nursing homes that offer appropriate conditions for their residents. In contrast, accounts link hospitals to burdensome and probably unnecessary therapy as part of high-tech medicine, hastiness, noise, and lack of privacy:

> [NA: jurist, bioethicist and chairperson of the Austrian Bioethics Commission] "We know from surveys, that practically every person would prefer to die at home in the circle of his relatives. Yet just the opposite is the case. Most people die in hospitals, not always in an atmosphere that enables a dignified farewell" (Mauritz, 2014).

Hospitalisation is discursively presented as antithetical to the good death. In the discourse, it combines numerous negative aspects including hospital transfer, environmental noise, impersonality, and possible overtreatment. Repeatedly, it is depicted as an impersonal machine lacking communication capabilities that reduces the self-determination of those dying.

The discourse conveys the hospital as a paramount example for an institutionalised and bad death. However, the discursive constructions of the dying person and of the social conditions lead at the same time to an often implicit call for institutionalised support for the end of life: The societal taboo of dying prevents healthy persons to take precautionary measures, but when they reach the end of life, their self-determination is limited and they need comprehensive help from others. Unfortunately, the immediate social environment is not capable of providing all the necessary support in this situation. Thus, the establishment or further development of adequate and stable institutional care mechanisms become solutions for providing a good death – even though these interfere with the idealised comfort and privacy of home.

This discourse contains a notion of institutionalisation that not only comprises institutionalisation in the shape of hospitals or nursing homes. It also encompasses institutional arrangements that ideally combine the constant availability of professional medical and care support with the emotional experience of the own home. The discourse identifies a deficit in institutionalised support – in the form of palliative and hospice care resources – at the end of life. This insufficiency needs to be remedied by political actors and healthcare organisations:

> [PS: professor of law] "[A dignified death] needs a comprehensive nationwide development of hospice and palliative care, which should grant easy and affordable access, the best possible pain treatment, the guarantee of mobile and stationary hospice care, the enablement of care for close relatives […]" (Republik Österreich – Parlament, 2015, 24).

With dying linked to feared and burdensome pain and bodily symptoms, the professional support by physicians and nursing staff becomes necessary to enable a good death. Professionals have to alleviate suffering and provide holistic care. Even dying at home, often positioned by the discourse in sharp contrast to dying in hospitals, needs professional support in order to evolve into a good death:

> [PS: general practitioner] "[…] let us make it possible for those seriously ill and dying that they can stay in their home environment, with highly professional care" (Republik Österreich – Parlament, 2014b, 54).

The development of this system of palliative and hospice care is discursively not only linked to additional financial resources, but also to a better integration into existing care structures as well as the palliative

care education of professional actors (nurses, doctors, etc.). Furthermore, care providers need to develop a less medical and more death-accepting attitude as part of a new approach to end-of-life care.

Considering patient autonomy in the dying process, advance directives are assessed as an important tool to ensure the proper consideration of the wishes of those dying. Through simplification and promotion of this possibility, more people could prepare earlier and better for their own end of life. The establishment of advance directives involves professional actors (lawyers, notaries) as does their proper implementation (physicians, caregivers). In order to be effective, the institutionalisation of these means and related processes is necessary. At the end of life, advance directives then provide clear guidelines and procedures on how to deal with the wishes and demands of the dying. However, also advanced directives discursively appear to be impaired by the societal taboo.

This demand for institutionalisation is not only voiced considering hospice care and advance directives. Actors reproducing the permissive position identify a need for institutionalisation of euthanasia practices: the legalisation and institutionalisation of these practices constitute a prerequisite for their accurate, appropriate, and rightful implementation. The active termination of life could only constitute a good death if regulated and controlled as well as professionally implemented. In parallel to palliative medicine and hospice care, physicians play an important role in this perspective. They have the expertise and authority to prescribe and prepare or even administer the terminal drugs. While the restrictive position identifies an intra-role conflict for physicians that shall in principle do no harm to or kill patients, the permissive position emphasises their responsibility to help those in pain and suffering. From this perspective, the absence of an institutional framework leads to more suicides due to a lack of psychosocial counselling, to more brutal and violent suicides, or to forsaken and desperate terminally ill people committing suicide alone and without their beloved ones.

Ultimately, both of the diverging normative positions towards euthanasia identify the present conditions for dying as deficient. While the restrictive position only sees a quantitative deficit in terms of palliative care resources, the permissive position identifies a lack of alternative practices at the end of life.

The demand for institutionalisation can also be interpreted as alternative to radical change. Although the call for a new [PS: member of parliament] "culture of dying that really ensures dignity at the end of life" (Republik Österreich – Parlament, 2014a, 48) represents a shared demand for an overarching social transformation, it remains abstract and undefined in terms of concrete measures, apart from its inclusion in the socialisation and education of professional actors. The discourse hardly scrutinises the socio-economical structures including the organisation of employment, reproductive work, and care. In some accounts they appear as underlying causes for the challenge to enable a good death for everyone, but the discourse does not pursue strategies to address these issues systematically. Rather, palliative and hospice care – and from the permissive perspective assisted suicide or killing on request – create in individual cases the alleviation of pain and suffering for the dying person and the immediate social environment. Single accounts identify the realisation of a good life as prerequisite for a good death, but this idea does not affect the discourse on how to promote a good death through concrete measures.

6. Discussion

Studies on the good death and places of death identify the institutionalisation of dying as an important aspect to the end of life. Thereby, dying in hospitals as paradigmatic institution is often represented as an undesired way of dying, while palliative and hospice care settings and especially home are closely linked to a good death.

This paper reveals how the discourse constructs institutionalisation as necessary for a better way of dying irrespective of its negative association with hospitalisation. In the discourse, a good death seems only possible through pain and symptom management, social and emotional support, as well as awareness and openness considering dying and death. Thereby, institutionalisation compensates the inability of the informal social environment to provide necessary medical and care support measures to realise this holistic concept. Even proponents of a liberalisation of euthanasia regulation reproduce this assessment by demanding the creation of an institutionalised framework including appropriate regulation and professional services that support those wishing to die.

This overarching yet often implicit demand for institutionalisation can be linked to the broader phenomenon of medicalisation. In their analysis of a right-to-die debate, Karsoho et al. (2016) show how proponents of physician-assisted dying reproduce a frame of medicalisation while they have been historically positioned against medicalisation of dying. In parallel, this study delineates how the institutionalisation of dying is, on the one hand, discussed as unwelcome social condition that interferes with desired concepts of home or family, and, on the other hand, as necessary due to the dying person's physical deterioration. The discursive demand for institutionalisation mirrors and expands this medicalisation frame because of the central role of the physician in pain and symptom management, but also for euthanasia support.

A discourse element that informs this key role of institutions and medicine is the focus on a certain type of dying: dying as old or ill person in a longer lasting process. Seale (1998, 49) identifies this focus on longer dying trajectories in discussions on good death as related to the medical ability to "predict death early in the disease process" (Seale (1998)). Only this timely identification of an individual's condition as *dying* makes interventions possible. In contrast, in cases of sudden death, recognition of dying cannot be achieved or just achieved briefly before onset of death. Also, the strategies for a good death identified in the discourse here (e.g. palliative care) are bound to fail in such cases. The discursive and political dynamic might thus lead to the prioritisation of fields of actions in which political and social measures are actually able to improve the situation.

The assumption is reasonable that the social discourse and practices towards sudden death also follow an intervention logic, but one that is aimed to prevention of death or life-saving rather than a good death. Another explanation might be a higher degree of taboo regarding sudden death (Pitman et al., 2018). However, additional research on the discursive construction of the sudden death and its relationship with concepts of the good death seems required to develop a better understanding of this issue.

The analysed discourse reproduces rather stereotypical and sometimes vague images of different end-of-life settings that hardly ever differentiate between different variations of one setting. However, the open deliberation on how institutionalisation has to be designed in order to be desirable at the end of life might be more expedient than (deadlock) discussions about seemingly fixed alternatives between an idealised home and a catastrophised hospital. Thereby, the inability of either an institutional setting or the social environment alone to provide multidimensional holistic care is perhaps inevitable. And even under perfect conditions, the concurrent attainment of different inherently contradictive dimensions of a good death might be impossible (Sandman, 2005, 158).

The examined discourse focuses on the dying process and its more immediate framework conditions (e.g. availability of care services). Strategies to enable a good death remain on a social meso-level, aiming at strengthening existing institutions such as palliative care or developing new ones such as physician-assisted suicide services. However, the discourse rarely challenges the social structures and systems that lead to the social environment's inability to provide adequate and intimate care for everyone dying. As phenomena embedded in a broader societal context, the good death and necessary related practices of social attention, companionship, and holistic care are bound to a functional social life and environment. In consequence, the social

environment has to be capable and needs the capacities to provide such support. Structural changes e.g. regarding the organisation of employment, reproductive work, and care might be necessary to create free time and open spaces that could be used for this purpose.

While expectations and practices of end-of-life care are intertwined with gender norms and roles and formal and informal care are foremost provided by women (Fine, 2007; Williams et al., 2017), gender aspects regarding end-of-life care are surprisingly absent in the analysed material. Only in single instances, the division of labour in formal and informal care is addressed and problematized. However, gender then does not become an issue e.g. regarding strategies to improve the situation of the dying or the caregivers. This omission is in line with the discursive disregard of measures addressing wider societal issues such as the "social division of care" (Fine, 2007). Further investigations have to shed light on how responsibilities in care are negotiated focusing on the positioning and image of female professional and informal caregivers. Thereby, data triangulation (e.g. using interviews, participant observation or policy analysis) could be expedient to examine the dynamics that cause the discursive exclusion of this important topic.

In the discourse, medical and care professionals as well as relatives appear as important prerequisites of a good death. However, the impact of the various end-of-life care situation and associated demands on their emotional and physical wellbeing is hardly reflected in the assessment of a good death. Empirical inquiries in the construction of the good death need to address this issue and focus on how ideas of the good death conceptualise and support the wellbeing of formal and informal caregivers and how institutionalisation might affect their status. In addition to discourse analysis, interviews or focus groups and participant observations of this group might be helpful to deal with this issue.

At last, while the Enquete-Commission in principal provided an open space for different societal actors to voice their opinion, the wider public debate appears to be dominated by political actors, experts, and journalists. On closer examination of the available material, a plethora of different social actors and perspectives emerge that are not equally represented in the formal political arena. Nevertheless, their positions are part of the media discussion via the representation of experts or as illustrative cases in the news coverage. This article could not provide a thorough analysis of the social position, characteristics, and resources of the different actors engaged in the debate. Additional investigations could make visible the social power structures and imbalances that influence the discourse. This study also remains within the boundaries of discourse and does not analyse the mutual relationship amongst the discursive construction of the good death and institutionalisation with healthcare policy, care practices, or the situations of those affected. Also in this regard, approaches beyond discourse analysis could be valuable.

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5.2 Paper 2: ‘The perspective of professional caregivers working in generalist palliative care on “good dying”: An integrative review’

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The perspective of professional caregivers working in generalist palliative care on 'good dying': An integrative review

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ABSTRACT

In today's industrial societies, many people die receiving professional care. Although specialist palliative and hospice care have often been identified as ideal care approaches to promote good dying, more people die receiving generalist palliative care. This integrative review examines how professional caregivers providing generalist palliative care in hospitals, nursing or private homes define good dying. Furthermore, through comparative analysis of existing empirical studies, it explores conceptual aspects in researching good dying that better reflect the social complexity of this phenomenon. Three databases (Scopus, MEDLINE, and CINAHL) were searched for peer-reviewed studies published between January 2000 and April 2020. Studies were selected if they presented original empirical findings from qualitative or quantitative studies on the perspective of professional caregivers in generalist palliative care (nurses, physicians, surgeons, clergy, and other staff) on good dying or related concepts (e.g., good death, dignity in dying, or quality of life at the end of life). 42 studies were included in the review. They identified good dying as expected, accepted and prepared dying, as free from pain and suffering, as socially embedded, as being at peace with one's life and situation, as supported with individualised and holistic care, as based upon professional cooperation and communication, and as in a peaceful and private environment. The paper concludes that the perspective of professional caregivers in generalist palliative care shares many elements of good dying with societal and specialist palliative care discourses around good dying. Through comparing the different studies, the review found that studies that explicated who benefitted from ideals and practices of good dying, questioned the dichotomous categorisation of good/bad dying, or discussed the compatibility of elements of good dying, provided more nuanced perspectives on this topic. Thus, the review calls for a more systematic analysis of these aspects in research of good dying.

1. Introduction

Social meaning and practices of dying and good dying are socially contingent (Kellehear, 2007). Good dying can be understood as 'complex set of relations and preparations' and as 'a series of social events' (McNamara et al., 1994, p. 1501). As a social phenomenon, it is constructed through discourses (Lang, 2020; Van Brussel and Carpentier, 2012) but also co-created and negotiated in social situations (Munday et al., 2009; Seymour, 2000). Research on good dying has not only been conducted to improve our understanding of society, but also to inform care policy and practices by identifying needs and values of those involved in and affected by end-of-life care situations (Asano et al., 2019; Meier et al., 2016).

In industrial countries, dying regularly happens in institutional contexts under the care of professionals (Broad et al., 2013). Even dying in private homes often involves the presence of professional caregivers in addition to family and relatives (Emanuel et al., 1999; Gott et al., 2004). Thereby, contemporary societal debates have often discussed hospice and palliative care as paramount professional care approaches to promote good dying (Lang, 2020). The concept of good death is identified as fundamental for the hospice movement (Hart et al., 1998; McNamara et al., 1994), but in palliative care it has also transformed towards a 'good enough death' (Masson, 2002; McNamara, 2004). Yet, many people do not have access to specialised palliative and hospice care (Woitha et al., 2016) and die receiving 'generalist palliative care' (Ryan and Johnston, 2019) in hospitals, nursing homes, or at home. Generalist palliative care can be defined as care provided to people with life-threatening diseases and dying as part of standard care and clinical

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practice outside of specialised palliative care organisations, departments, or teams. As in specialised hospice and palliative care, professionals working in generalist palliative care – together with families, relatives, or community members – strive for accomplishing good care, the well-being of the patient, and ultimately, good dying. Their values and beliefs, as well as their work experiences and practices, are important aspects in creating the conditions, social interactions, and meanings related to good dying.

Against this background, our integrative review (Whittemore and Knafl, 2005) had two aims: First, we wanted to examine empirical insights into the perspectives of professional caregivers who do not work in specialised palliative or hospice care but nonetheless experience end-of-life care situations. Existing reviews on the perspective of professional caregivers on good dying focus on specific care contexts, e.g., the emergency department (McCallum et al., 2018) or intensive care units (Mu et al., 2019), particular causes of death, e.g., heart failure (Asano et al., 2019), or certain concepts related to good dying such as dignity (Guo and Jacelon, 2014). Others have reviewed studies on the perspective of different groups of social actors concurrently, including professional caregivers but also relatives or patients (Meier et al., 2016). However, the present review focused on professional caregivers working in different healthcare contexts — but not in specialised palliative care — and considered various concepts to grasp good dying. We identified key elements of good dying as analysed by a diversity of quantitative and qualitative studies empirically investigating the perspectives of these professional caregivers in non-specialised/generalist palliative care (see 3.2).

Second, we aimed to explore differences in how empirical studies have approached good dying. Scholars have already discussed research approaches to investigate dying and good dying, often focusing on practical challenges regarding the study design and methodology, ethical aspects of doing research on sensitive topics, and emotional challenges on behalf of researchers (Kendall et al., 2007; Koenig et al., 2003). There is also a considerable body of work on operationalising and measuring 'good dying' (Hales et al., 2010). We wanted to detect ways to better capture the social complexity of good dying in empirical research by comparing the different approaches and findings of existing studies. Through comparing the different studies, we identified a number of broader conceptual issues concerning research on good dying that can inform future scientific endeavours in this field (see 3.3). The integrative review method allowed us to scrutinise a large number of empirical studies, thus increasing the chance of finding these uncommon ways of researching and framing good dying.

2. Methods and data

The integrative review is a method of compiling, summarising, and analysing existing insights of studies 'to provide a more comprehensive understanding of a particular phenomenon' (Whittemore and Knafl, 2005, p. 546). It can serve different purposes including 'to define concepts, to review theories, to review evidence, and to analyse methodological issues of a particular topic' (Whittemore and Knafl, 2005, p. 547). Thereby it 'looks more broadly at a phenomenon of interest than a systematic review' (Toronto, 2020, p. 2), but is more systematic in its design and implementation than a narrative review (for a comparison see Toronto, 2020, p. 2–3).

2.1. Inclusion and exclusion criteria

The integrative review allows the inclusion of scientific studies with different designs (experimental, non-experimental) and types of data (quantitative, qualitative) and can be aligned with different research interests and questions (Whittemore and Knafl, 2005). In our review we included empirical qualitative and quantitative studies collecting and analysing primary data (original research), but we excluded purely theoretical papers, reviews, opinions, research letters, notes, and editorials.

We considered 'surrogate terms' (Granda-Cameron and Houldin, 2012, p. 634) for good dying, including but not limited to the 'good' or the 'peaceful' death, 'dying well', 'dying with dignity', or 'quality of life at the end of life'. In presenting our results here, we used the term 'good dying' as an inclusive term for these different notions to emphasise the processual nature of the phenomenon.

We were interested in studies that empirically investigated good dying as a multifaceted social phenomenon. Thus, we included studies that dealt with various conditions and elements of good dying concurrently but excluded studies that only dealt with the positive or negative impact of isolated, single aspects of dying, such as place of death, advance directives, or physician-assisted suicide. In line with this, we excluded studies that aimed at evaluating or testing processes, therapies, or interventions to improve care at the end of life, because these only considered particular elements or conditions of good dying. Furthermore, we included studies that described the professional caregivers' assessment of dying processes (e.g., as good or bad), but excluded studies that only dealt descriptively with care practices, without an explicit assessment of their positive or negative influences on dying.

With regards to the participants of the studies, we defined professional caregivers broadly by including medical and non-medical professionals: nurses, physicians, paramedics, social and community workers, clergy members, undertaker, morticians, and other staff conducting care activities in end-of-life situations. We only considered articles dealing with professional caregivers not working in specialised palliative or hospice care; thus, we excluded articles on the perspective of specialised palliative care providers and informal caregivers. Several papers concurrently described the perspective of different actor groups on good dying within and outside the scope of this review, for example the perspective of professional caregivers (inside our scope) as well as family members of dying persons (outside our scope). We included them if they distinguished the different groups' perspectives but excluded studies that conflated them.

2.2. Search and retrieval strategy

We used the databases Scopus, MEDLINE, and CINAHL for our literature search; we searched MEDLINE and CINAHL via EBSCOHOST service. In combination, these databases covered a wide range of peer-reviewed journals from different disciplines potentially concerned with our research topic including, but not limited to, medical and nursing sciences (especially MEDLINE and CINAHL), as well as sociology, psychology, or anthropology (especially Scopus).

In line with our research focus and inclusion criteria, the search string combined different terms for professional caregivers (nurse, provider, staff, professional, physician, doctor, paramedic, chaplain, pastor, social worker, community worker, undertaker, mortician, aide, practitioner) and their perspective (perception, attitude, perspective, opinion, experience, view, meaning, image, concept) towards good dying (good, better, quality, or dignity combined with dying, death, or end-of-life). Wildcards accounted for minor variations (e.g., 'nurs*' for 'nurses' or 'nursing') and proximity operators narrowed searches ('W/15' defining a maximum of 15 words in between the search terms for 'good' and 'dying').

Table 1 shows our search strings including filters; we modified the search string in accordance with the requirements of the different databases. Results were exported and duplicates removed. The publications' metadata, including titles and abstracts, were further processed with Microsoft Excel (see Table 2).

2.3. Selection and analysis

[Author 1] and [Author 2] screened titles and abstracts independently and in line with the predefined criteria; there was a 97,4% agreement between [Author 1] and [Author 2]. In cases of

Table 1
Search strategy and string.

Search in	Title, abstract, keywords
Search string	(nurs* OR care* OR provider OR staff* OR professional OR physician OR doctor OR paramedic* OR chaplain OR pastor OR "social worker" OR "community worker" OR undertaker OR mortician OR aide OR practitioner) AND (perception OR attitude OR perspective OR opinion OR experience OR view OR meaning OR image OR concept) AND ((good OR better OR quality OR dignity OR dignified) W/15 ("end of life" OR dying OR death))
Filter: limit to	Type: journal articles Date: years 2000–2020 (April) Language: English, German

disagreement, [Author 3] decided on the inclusion or exclusion of articles. Then, the full texts of articles selected were screened again independently by the two reviewers, yielding a high proportion of agreement for inclusion or exclusion in 91% of cases. In cases of disagreement, the third reviewer decided.

We used Microsoft Excel to systematise study characteristics and calculate descriptive statistics. For the analysis of the full texts, we used ATLAS. ti 8.0 (ATLAS.ti Scientific Software Development GmbH, 2019). We did not aim to quantify the occurrence of certain aspects of good dying across our data, but rather aimed to qualitatively identify different aspects of good dying. We searched for similarities and differences across the different publications/studies. We conducted a thematic analysis (Braun and Clarke, 2006). Based upon close reading of the publications, we developed and applied thematic codes inductively, which we then used to code all articles in our sample. In this process, codes could be thematically enhanced, split into separate codes, or merged. Later on, we categorised various codes in overarching themes.

2.4. Quality control

Given the diversity of research approaches in the reviewed papers, we refrained from operationalising and applying a quantitative score to grade the quality of studies. As Whittemore and Knafl (2005) argue, such a rigid approach may not be suitable for a review that includes different types of empirical studies. Nonetheless, we implemented several measures to ensure the quality of the studies included in our review. We only searched for and included peer-reviewed studies published in journals listed in renowned scientific databases. In reviewing papers, we considered the presentation of the methodological approach and data. The reviewed studies used a variety of empirical approaches based upon different methodological concepts. We did not want to assess (and question) these concepts per se or initiate a fundamental discussion about advantages and disadvantages of certain methodologies. However, we excluded articles if they insufficiently described and outlined the studies' methodological approaches because in these cases it would have been difficult to reproduce key aspects of these studies as part of our review.

To prevent error and bias in selecting papers, at least two researchers screened every paper independently. Furthermore, in the process of analysing the selected full texts, a sample of ten papers was analysed independently by two reviewers to monitor and check consistency in retrieving information from the studies.

3. Results

Database searches were conducted on 24 April 2020. This resulted in 4.959 articles after removal of duplicates. Through title and abstract screening, we selected 103 publications for full text examination. Out of these, we evaluated 48 articles as relevant for in-depth review. In analysing them, four articles were removed because of quality issues or because they did not meet our review criteria after all (see Fig. 1). Furthermore, one paper (Adesina et al., 2014) was removed because it reported on the same study and findings with regards to good dying as another one (Adesina et al., 2016), but in less detail. Two other papers were based on the same study (Díaz-Cortés et al., 2018; Fernández-Sola et al., 2017), but focused on different aspects of good dying. We included both papers in the review, but in analysing the study characteristics (see 3.1), we only counted them as one study. In the end, the review included 43 papers dealing with 42 empirical studies.

3.1. Study characteristics: research design, participants, and concepts

33 studies had a qualitative design, eight had a quantitative design, and only one had a mixed-methods approach. Most studies used interviews (n = 18) or surveys (n = 16), others also used focus groups (n = 3) or combined focus groups and individual interviews (n = 5) to investigate the perspective of professional caregivers on good dying. 55% (n = 18) of the qualitative studies used interviews and all quantitative studies used surveys to collect data.

The majority of studies collected data in the USA (n = 11), the UK (n = 8), or Australia (n = 5). Furthermore, two studies each were concerned with Canada, Italy and Sweden, and one study each with China, Ethiopia, Finland, India, Ireland, Israel, Japan, Kenya, The Netherlands, South Africa, South Korea, Spain, Thailand and Turkey. Two studies used and compared empirical evidence from several different national contexts including Ethiopia, India, Kenya, and the USA (Coenen et al., 2007) and England and Israel (Endacott et al., 2016). While we also translated our search string and searched for studies in German, no study in German met our inclusion criteria.

In the qualitative studies, the number of participants ranged from five in an exploratory interview-based study (McCallum and McConigley, 2013) to 707 participants in a survey-based study (Cagle et al., 2017) (median: 25, average: 81). Qualitative survey-based studies used written responses to a limited number of open-ended questions for their analysis and thus could include a higher number of participants than usual in qualitative research (Beckstrand et al., 2006; Cagle et al., 2017; Coenen et al., 2007; Dillon et al., 2018). Quantitative studies had between 76 (Gibson et al., 2008) and 856 participants (Demir et al., 2017) (median: 368, average: 426). Studies investigated professional caregivers working foremost in hospitals (n = 24) (emergency departments, intensive care units, oncology units, progressive care units, surgical units, paediatric (oncology) units), nursing homes (n = 10), and private homes (n = 6); in several cases, caregivers working in different contexts were included (n = 7) or no place of care was indicated (n = 7). Nurses, including registered nurses, nurse practitioners, acute or critical care nurses, were the most prevalent participants and addressed by 35 studies. Nine studies analysed data from physicians, five from managers, four from social workers, two from psychologists, two from clergy, two from other staff, and one from nursing students. One study empirically investigated the perspective of traditional healers (Graham et al., 2013). Studies sometimes focused on different professional groups concurrently. While not all studies indicated their samples' gender distribution, study participants in those who reported it were predominantly female, ranging from 53% female participants (Kim, 2019) to 100% female participants in several studies (Karlsson and Berggren, 2011; Kongsuwan et al., 2010; McCallum and McConigley, 2013; Volker and Limerick, 2007). Some studies had an explicit focus on care for specific groups including children (Bennett and Proudfoot, 2016; Nagoya et al., 2016; Souza et al., 2013), people with advanced dementia (Kupeli et al., 2016), intellectual disabilities (McNamara et al., 2019; Todd, 2013), or a particular illness such as heart-failure (Borbasi et al., 2005).

The studies employed different concepts for 'good dying'. Most studies conceptualised a 'good death' (n = 20) and others used concepts of 'dignity' of dying, death, or end-of-life care (n = 9). A few studies framed their research in terms of 'quality' of dying and death or of life at the end of life (n = 3). In some instances, the phenomenon was labelled in more processual terms such as 'dying well' (n = 3) or 'good dying' (n = 1). Several studies focused on experiences in end-of-life care (n = 4) or

Table 2
Overview of reviewed studies.

Reference	Country	Concept/ terminology	Design	Sample (gender) and participants	Place of care
Adesina et al. (2016)	Australia	Good/bad death	Qualitative: survey	N = 87 (85% female, 13% male, 2% unspecified) Nursing students with clinical experience	No information available
Albers et al. (2013)	The Netherlands	Patient dignity inventory	Quantitative: survey	N = 653 (not available) Support and Consultation on Euthanasia Physicians (n = 427) and trained volunteers (n = 226)	Home, hospice
Becker et al. (2017)	USA	Dying well	Qualitative: survey	N = 49 (86% female, 14% male) Registered nurses	Community hospital
Beckstrand et al. (2006)	USA	Good death	Qualitative: survey	N = 485 (93% female, 7% male): 53% staff nurses, 36% charge nurses, 4% clinical nurse specialists, 6% other	Hospitals: intensive care units (ICU)
Bennett and Proudfoot (2016)	USA	Quality of dying and death	Quantitative: survey	N = 309 (not available): Registered nurses (44,6%), chaplains (13%), social workers (8,8%), respiratory therapists (8,8%), physicians (7,5%), nurse practitioners (3,3%), child life specialists (2,9%), supportive care team members (1,6%), other (9,4%)	Tertiary paediatric hospital
Borbasi et al. (2005)	Australia	Good/bad death	Qualitative: interviews	N = 17 (70,6% female, 29,4% male) Registered nurses	Hospital, home, hospice
Bovero et al. (2019)	Italy	Patient dignity inventory	Quantitative: survey	N = 306 (75,5% female, 24,5% male) Nurses (46,1%), physicians (29,1%), nurse assistants (14,4%), psychologists (10,5%)	Hospital
Bratcher (2010)	USA	Good death	Qualitative: interviews	N = 15 (66,6% female, 33,3% male) Critical care nurses	Hospital: ICU
Cagle et al. (2017)	USA	Positive/negative experiences	Qualitative: survey	N = 707 (93,4% female, 4,7% male, 2% missing) Nursing assistants (39,9%), practical nurses (29,8%), registered nurses (15,1%), social workers (3,8%), other (8,9%), missing (2,7%)	Nursing home
Casey et al. (2011)	Ireland	Dying well	Qualitative: interviews	N = 33 (88% female, 12% male) General nurses (60,6%), health care assistants (27,3%), general practitioners (6,0%), occupational therapist assistant (3,0%), physiotherapist assistant (3,0%)	Hospital, public extended care units, nursing homes, long-stay unit attached to palliative care centre
Cipolletta and Oprandi (2014)	Italy	Good death	Qualitative: focus groups	N = 37 (67,6% female, 32,4% male) Nurses (48,6%), physicians (35,1%), health workers (13,5%), psychologist (2,7%)	General medical organisations, hospitals, home service
Coenen et al. (2007)	Ethiopia, India, Kenya, USA	Dignified dying, Dignity-Conserving Care Model	Qualitative: survey	N = 560 (not available) Nurses	No information available
Costello (2006)	United Kingdom	Dying well	Qualitative: interviews	N = 29 (not available) Registered nurses	Hospital
Decker et al. (2015)	Australia	Good death	Qualitative: focus groups	N = 25 (100% female) Registered nurses	Hospital: emergency department
Demir et al. (2017)	Turkey	Dying with dignity, good death	Quantitative: survey	N = 856 (92,3% female, 7,7% male) Nurses	Hospital: intensive care and oncology
Díaz-Cortés et al. (2018) and Fernández-Sola et al. (2017)	Spain	Dignified end-of-life care	Qualitative: focus groups and interviews	N = 26 (65,38% female, 34,6% male) Nurses (61,5%), physicians (38,5%)	Hospital: emergency department
Dillon et al. (2018)	USA	Good death	Qualitative: survey	N = 117 (not available) Physicians and surgeons	Hospital: colon and rectal surgery
Dwyer et al. (2009)	Sweden	Dignity in end-of-life care	Qualitative: interviews	N = 21 (80,95% female, 19,5% male) Nurse assistants (57,1%), registered nurses (23,8%), managers (19,0%)	Nursing homes
Endacott et al. (2016)	England, Israel	Good death	Qualitative: focus groups and interviews	N = 55 (not available) Registered nurses	Hospital: ICU
Gibson et al. (2008)	Canada	Good death	Quantitative: survey	N = 76 (82,9% female, 9,2% male, 7,9% missing) Nurses	Nursing homes: long-term care programme for war veterans
Graham et al. (2013)	South Africa	Good death	Qualitative: focus groups and interviews	N = 21 (61,9% female, 38.1% male) Traditional healers	No information available
Griggs (2010)	England	Good death	Qualitative: interviews	N = 17 (not available) Community nurses	No information available
Hanson et al. (2002)	USA	Good death	Qualitative: focus groups	N = 77 (not available) Nursing assistants, nurses, physicians	Nursing homes
Hopkinson and Hallett (2002)	United Kingdom	Good death	Qualitative: interviews	N = 28 (not available) Nurses	Hospital: acute hospitals
Karlsson and Berggren (2011)	Sweden	Good end-of-life care	Qualitative: interviews	N = 10 (100% female) Nurses	Home
Kim (2019)	South Korea	Good/bad death	Qualitative: interviews	N = 15 (53% female, 47% male) Social workers	Long-term care: institutional settings, nursing homes, home care
Kongsuwan et al. (2010)	Thailand	Peaceful death		N = 10 (100% female)	Hospital: ICU

(*continued on next page*)

Table 2 (*continued*)

Reference	Country	Concept/ terminology	Design	Sample (gender) and participants	Place of care
			Qualitative: interviews	Nurses	
Kupeli et al. (2016)	United Kingdom	Good qualitative end-of-life care	Qualitative: interviews	N = 14 (78,6% female, 21,4% male) Care home managers, nursing managers, nurses, therapists, other health care professionals	Nursing homes, hospitals, nursing services
LeBaron et al. (2015)	USA	Good/poor death	Qualitative: focus groups and interviews	N = 35 (91,4% male, 8,6% female) Clergy: ministers and pastors	No information available
McCallum and McConigley (2013)	Australia	Experience	Qualitative: interviews	N = 5 (100% female) Critical care nurses	Hospitals: high-dependency units
McNamara et al. (2019)	Australia	Person-centred care, good end-of-life care	Qualitative: focus groups and interviews	N = 26 (not available) Nurses (34,6%), disability residential accommodation managers (23,1%), social workers (15,4%), occupational therapists (11,5%), disability support workers (7,7%), counsellors/psychiatrists (7,7%)	Nursing homes, homes
Nagoya et al. (2016)	Japan	Quality in dying and death	Quantitative: survey	N = 427 (71,4% female, 28,6% male) Nurses (63,2%), paediatricians (36,8%)	Hospital: paediatric oncology
Oliver and O'Connor (2015)	England	Good death	Qualitative: interviews	N = 13 (92% female, 8% male) General nurses	Hospital: acute hospital
Souza et al. (2013)	Brazil	Dignified death	Qualitative: interviews	N = 8 (87,5% female, 12,5% male) Nurses	Hospital: paediatric oncology
Srinonprasert et al. (2019)	Thailand	Good death	Quantitative: survey	N = 656 (96,7% female, 3,3% male) Nurses	Hospital: various departments
Stokes et al. (2019)	Canada	Meaningful experiences	Qualitative: interviews	N = 6 (not available) Nurses	Hospital: ICU
Terkamo-Moisio et al. (2016)	Finland	Good death	Qualitative: survey	N = 81 (93,9% female, 6,1% male) Nurses	No information available
Todd (2013)	United Kingdom	Experiences	Qualitative: interviews	N = 22 (not available) Staff	Care homes for people with disabilities
Volker and Limerick (2007)	USA	Dignified dying	Qualitative: interviews	N = 19 (100% female) Oncology advanced practice nurses	Hospital: oncology
Wilson et al. (2006)	USA	Dignified dying	Mixed-methods: survey	N = 281 (not available) Nurses	No information available
Yang et al. (2019)	China	Good death	Quantitative: survey	N = 122 (98,4% female, 1,6% male) Nurse's aides (50,8%), nurse practitioners (37,7%), nurse-in-charge (10,7%), associate professor of nursing (0,8%)	Hospital: cancer hospital
Young et al. (2017)	United Kingdom	Good dying	Qualitative: interviews	N = 16 (94% female, 6% male)	Nursing homes

on the quality of end-of-life care (n = 2), but thereby analysed normative assessments of these too. In a single instance the focus was on a 'peaceful' death. Sometimes, concepts to frame good dying in general reappeared as single attributes of other notions of good dying, especially dignity as one attribute of good death amongst others (Becker et al., 2017; Beckstrand et al., 2006; Bratcher, 2010; Cagle et al., 2017; Cipolletta and Oprandi, 2014; Costello, 2006; Demir et al., 2017; Griggs, 2010; Hopkinson and Hallett, 2002; LeBaron et al., 2015; Stokes et al., 2019).

The majority of qualitative studies conducted their empirical work in an exploratory and descriptive manner and with no reference to an explicit and detailed theoretical framework. However, two qualitative studies used the Dignity-Conserving Care Model (Chochinov, 2002) as conceptual framework (Coenen et al., 2007; Díaz-Cortés et al., 2018). A few other studies located themselves in a symbolic interactionist (Decker et al., 2015; Todd, 2013) or phenomenological tradition (Hopkinson and Hallett, 2002; Karlsson and Berggren, 2011; Oliver and O'Connor, 2015; Volker and Limerick, 2007); one identified as 'Phenomenographic Study' (Terkamo-Moisio et al., 2016).

Most quantitative studies were based upon existing survey instruments, including two studies adapting the 'Patient Dignity Inventory' by Chochinov et al. (2008) (Albers et al., 2013; Bovero et al., 2019). Other studies developed their instruments based on different concepts and instruments (Srinonprasert et al., 2019; Wilson et al., 2006) or on the basis of their own qualitative studies (Nagoya et al., 2016).

3.2. Good dying from the perspective of professional caregivers

Overall, although in different countries and locations of care, with different patient groups, or by different professional groups, we observed rather similar descriptions of good dying across the studies. The same holds true for conceptual differences; key requirements and characteristics of a positively assessed dying process were similar across studies. However, some studies nonetheless considered different aspects related to good dying that brought forward specific insights not thematised by other studies (see 3.3).

3.2.1. Expected, accepted, and prepared good dying

In several studies, professional caregivers assessed that the dying and death of a person needed to be *expected* in order for good dying to be possible. Death should not occur suddenly, but the actors involved had to predict and know about the approaching death, for example, by having a valid diagnosis of an illness. This was interlinked with the issue of *awareness*. Professional caregivers had to adequately inform the dying, the family, and the relatives (open awareness) about a terminal illness and expected death. These persons needed realistic expectations about the development of an illness and dying processes (Adesina et al., 2016; Becker et al., 2017; Beckstrand et al., 2006; Borbasi et al., 2005; Bratcher, 2010; Cagle et al., 2017; Cipolletta and Oprandi, 2014; Costello, 2006; Dillon et al., 2018; Endacott et al., 2016; Griggs, 2010; Hopkinson and Hallett, 2002; Karlsson and Berggren, 2011; LeBaron et al., 2015; Oliver and O'Connor, 2015; Srinonprasert et al., 2019; Todd, 2013). In turn, several quantitative studies found that professional caregivers associated unexpected deaths with negative impacts on dying

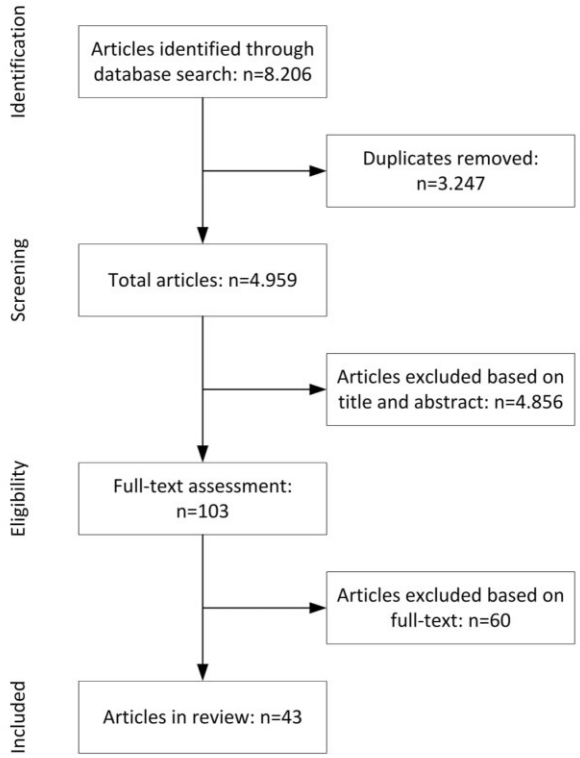

Fig. 1. Systematic screening and selection process (adapted from Moher et al. (2009).

or bad dying (Bennett and Proudfoot, 2016; Gibson et al., 2008), and highly valued full knowledge about one's own illness (Srinonprasert et al., 2019). In contrast, some quantitative studies analysing the prioritisation of elements of good dying showed that professional caregivers prioritised the expectation of death or having awareness lower than other aspects (Albers et al., 2013; Demir et al., 2017; Nagoya et al., 2016). However, even in these studies, expecting death, that is knowing about the terminal nature of a patient's condition, seemed to be essential in order to facilitate a range of other activities prioritised higher as necessary for good dying, for example, 'to have access to hospice care' (Demir et al., 2017, p. 120) or 'dying in the presence of family' (Nagoya et al., 2016, p. 489).

With respect to awareness, single studies described how some professional caregivers favoured closed awareness, i.e., that patients were not (fully) informed about the lethality of their disease (for the concept of 'awareness contexts' see Stacey et al., 2019). For example, in a study on the dying of people with intellectual disabilities, '"being there" involved masking dying from the person with intellectual disability' (Todd, 2013, p. 223). Another study described both staff working in long-term care advocating for open awareness as well as others opting for closed awareness, because they felt that 'discussion of death was unsettling for residents' (Casey et al., 2011, p. 1828). In a study on professionals working in paediatric cancer care, the awareness of the child and family was also rated as less important than other aspects, especially by nurses, while paediatricians rated this aspect significantly higher (Nagoya et al., 2016).

In addition to being aware of death, according to professional caregivers, death also needed to be *accepted* by all actors involved, including patients, family and relatives, as well as caregivers. Acceptance appeared as a prerequisite for further preparation activities, for example, for saying goodbye to family and friends, as well as necessary for good dying (Borbasi et al., 2005; Bratcher, 2010; Hanson et al., 2002; Kongsuwan et al., 2010; LeBaron et al., 2015; McNamara et al., 2019). LeBaron et al. (2015, p. 1002) described how acceptance was a pre-requirement of other elements of good dying, that '[w]ithout acceptance, preparation within any domain was impeded, rendering dying more difficult'.

Thus, expectation, awareness, and the acceptance of death were important for the professional caregivers because it was only then that *preparation* to achieve good dying was possible. One study summarised the relationship between expectation and preparation as follows:

> 'The nurses saw expected deaths as good because everyone had been given an opportunity to prepare for the death and had been afforded the opportunity to say goodbye' (Hopkinson and Hallett, 2002, p. 536).

Preparation encompassed various activities in different domains with regards to the organisation of end-of-life care, social and personal arrangements, and medical interventions including pain and symptom management (Adesina et al., 2016; Borbasi et al., 2005; Cagle et al., 2017; Costello, 2006; Dillon et al., 2018; Griggs, 2010; Hanson et al., 2002; Hopkinson and Hallett, 2002; Kongsuwan et al., 2010; Kupeli et al., 2016; LeBaron et al., 2015; Terkamo-Moisio et al., 2016). For example, Borbasi et al. (2005, p. 106) analysed preparation on the level of the individual and family (saying goodbye), but also on a professional level (palliative measures) and that a.

> '"good" death was one where patients and family had "planned ahead" […] so the individual had "their affairs in order" and "said goodbye" to their relatives and were provided adequate palliative measures.'

On behalf of the professional caregivers, preparation was also connected to the aspect of having control over the situation (Becker et al., 2017; Costello, 2006; Decker et al., 2015). Costello (2006, p. 598) described how professional caregivers perceived absence of preparation as responsible for a bad death because organisational procedures were disturbed:

> 'Bad death was characterised by limited control over the events leading up to and including the "death event". Lack of preparation and time to get to know the family and make an accurate assessment of patients' needs constituted a risk to the smooth running of the ward.'

In line with the issue of preparation and control, one study described how suicides, as well as accidents or other sudden deaths, were assessed as bad deaths by clergy, because they inhibited preparations on different levels (LeBaron et al., 2015).

3.2.2. Free from pain and suffering

In most studies, good dying was related to the absence of pain and symptoms, an issue which appeared in connection to health conditions at the end of life, terminal illnesses, or the dying process. Professional caregivers identified distressing pain and bodily symptoms (especially breathlessness) as problematic, and the management, alleviation, and inhibition of pain and symptoms as key for good dying (Adesina et al., 2016; Albers et al., 2013; Becker et al., 2017; Beckstrand et al., 2006; Bennett and Proudfoot, 2016; Borbasi et al., 2005; Bovero et al., 2019; Bratcher, 2010; Cagle et al., 2017; Casey et al., 2011; Coenen et al., 2007; Costello, 2006; Decker et al., 2015; Demir et al., 2017; Dillon et al., 2018; Endacott et al., 2016; Gibson et al., 2008; Griggs, 2010; Karlsson and Berggren, 2011; Kim, 2019; Kupeli et al., 2016; LeBaron et al., 2015; McCallum and McConigley, 2013; Nagoya et al., 2016; Oliver and O'Connor, 2015; Souza et al., 2013; Srinonprasert et al., 2019; Stokes et al., 2019; Terkamo-Moisio et al., 2016; Volker and Limerick, 2007; Wilson et al., 2006; Young et al., 2017). In quantitative studies which prioritised elements of good dying, absence of or minimal

pain and symptoms, were often rated higher than other aspects. In one study, 99,3% of participants rated 'having no pain and suffering in the body' as important or very important (Nagoya et al., 2016, p. 489) and in another one 100% of participants rated 'that it be painless or largely pain-free' as essential or important (Gibson et al., 2008, p. 377).

Professional caregivers framed pain and symptom management in terms of reducing stress and improving the comfort of patients (Becker et al., 2017; Beckstrand et al., 2006; Bratcher, 2010; Oliver and O'Connor, 2015; Souza et al., 2013). Sometimes, professional caregivers assessed a 'brief' dying process as good dying because it reduced suffering (Dillon et al., 2018; Kim, 2019). In other instances, death was assessed as relieving the dying person from suffering (Costello, 2006; Souza et al., 2013; Todd, 2013), but also for the family (Costello, 2006). Another study found that pain management measures 'allow the family to be close to the patient' (Endacott et al., 2016, p. 13) and thus benefited families too. In one study, reduction of 'distressing signs and symptoms' (Cagle et al., 2017, p. 202) of the dying person was described as also comforting the care staff. Thus, pain and symptom management, while having positive effects on the patients, also had positive impacts on caregivers and families.

A number of studies drew attention to prevention and cessation of futile treatments, for example, artificial nutrition, resuscitation, artificial ventilation, or surgery. From the perspective of professional caregivers, such futile treatments caused more misery than benefits for the patients, and consequently their cessation was found as a means of reducing pain and suffering (Adesina et al., 2016; Becker et al., 2017; Beckstrand et al., 2006; Bennett and Proudfoot, 2016; Bratcher, 2010; Cagle et al., 2017; Cipolletta and Oprandi, 2014; Costello, 2006; Demir et al., 2017; Díaz-Cortés et al., 2018; Dillon et al., 2018; Endacott et al., 2016; Fernández-Sola et al., 2017; Kongsuwan et al., 2010; Kupeli et al., 2016; McCallum and McConigley, 2013; Nagoya et al., 2016; Srinonprasert et al., 2019). However, professional caregivers described how this ideal may be counteracted by strong expectations of physicians or the patients' families in medicine, a lack of acceptance of death (Beckstrand et al., 2006; Cipolletta and Oprandi, 2014; Decker et al., 2015; Demir et al., 2017; Díaz-Cortés et al., 2018), or by the 'logic' of certain care contexts that focus on saving lives (McCallum and McConigley, 2013). These may lead to futile treatments from the perspective of professional caregivers.

3.2.3. Not alone: socially embedded good dying

The reviewed studies found that professional caregivers assessed the presence of family, relatives, or friends of the dying as vital for good dying. In line with this, being alone was most often related to bad dying. The professional caregivers described the presence of others as important for its own sake and because it created a comfortable atmosphere and reduced stress as well as anxiety (Adesina et al., 2016; Becker et al., 2017; Bennett and Proudfoot, 2016; Bovero et al., 2019; Bratcher, 2010; Cagle et al., 2017; Cipolletta and Oprandi, 2014; Endacott et al., 2016; Fernández-Sola et al., 2017; Gibson et al., 2008; Graham et al., 2013; Hopkinson and Hallett, 2002; Karlsson and Berggren, 2011; Kim, 2019; Kongsuwan et al., 2010; LeBaron et al., 2015; McCallum and McConigley, 2013; Nagoya et al., 2016; Srinonprasert et al., 2019; Stokes et al., 2019; Terkamo-Moisio et al., 2016; Todd, 2013). Furthermore, social presence was identified as a prerequisite for saying goodbye or for creating closure (Borbasi et al., 2005; Cagle et al., 2017; Dillon et al., 2018; Fernández-Sola et al., 2017; Graham et al., 2013; Volker and Limerick, 2007). Graham et al. (2013, p. 389) described the various opportunities and benefits social presence entailed in their study:

> 'Their family gathering at the deathbed is not only for the comfort of the dying person but also for the chance to restore relationships, express wishes for the family, and give a verbal will.'

Sometimes, professional caregivers even assessed the involvement of family in care activities positively (Coenen et al., 2007; Wilson et al., 2006). And one study identifies the possibility for people to see their pets as important (Coenen et al., 2007).

Several studies found that from the professionals' perspective, the social accompaniment of the dying person should also involve the professional caregivers, especially in cases where no family or relatives could be present (Becker et al., 2017; Coenen et al., 2007; Hanson et al., 2002; Hopkinson and Hallett, 2002; LeBaron et al., 2015; McCallum and McConigley, 2013; Stokes et al., 2019; Todd, 2013; Wilson et al., 2006). Hanson et al. (2002, p. 121) outlined this finding in long term care as follows:

> 'Nursing staff felt they had to be surrogate family, chaplain, or friend to a dying resident who did not have these sources of support […] They knew when a resident was afraid to die alone, and would work to find extra time or come in after their shift to be with her.'

One study described how the professional caregivers' personal presence was important for their relationship to the patients and for their quest for meaning in their work (Todd, 2013).

In contrast to the above, one study reported on some research participants who 'stated that a good death is faced alone, without the presence of mourning relatives' (Terkamo-Moisio et al., 2016, p. 456, p. 456). In other studies, professional caregivers also described how family presence could have negative impacts on the end of life in cases of conflicts in the family that disturb the dying process (Bennett and Proudfoot, 2016; Cagle et al., 2017; Dillon et al., 2018; LeBaron et al., 2015; Terkamo-Moisio et al., 2016). Professional caregivers brought up the feeling that the dying person had of being a burden for their families. Having this feeling was assessed as adverse to good dying (Albers et al., 2013; Bovero et al., 2019; Díaz-Cortés et al., 2018; Kim, 2019; Srinonprasert et al., 2019). In one study, caregivers related suicides of patients to a lack of social support and assessed these deaths as bad deaths (Kim, 2019).

3.2.4. Being at peace and preserving personhood

Socially embedded dying opens an opportunity to deal with unresolved issues and the necessity to say goodbye to family and friends. This seemed to be connected to a broader biographical aspect of good dying. Professional caregivers in several studies emphasised the importance of being at peace with one's own life and situation. This included settling lingering conflicts (e.g., within the family) and managing unresolved issues and businesses (e.g., burial or legacy) (Adesina et al., 2016; Bennett and Proudfoot, 2016; Borbasi et al., 2005; Bovero et al., 2019; Bratcher, 2010; Dillon et al., 2018; Endacott et al., 2016; Gibson et al., 2008; Graham et al., 2013; Griggs, 2010; Kongsuwan et al., 2010; LeBaron et al., 2015; Srinonprasert et al., 2019; Terkamo-Moisio et al., 2016; Volker and Limerick, 2007). Professional caregivers related this to the issue of acceptance too, which we have already discussed as a precondition for preparing for good dying (see 3.2.1). They associated acceptance with the state of being at peace with the situation and with death, which promoted calmness and reduced stress (Adesina et al., 2016; Cagle et al., 2017; Coenen et al., 2007; Fernández-Sola et al., 2017; Gibson et al., 2008; Kongsuwan et al., 2010; Terkamo-Moisio et al., 2016).

Some studies linked good dying to the broader biographical background: Professional caregivers identified having lived a fulfilled or good life as a factor for good dying (Adesina et al., 2016; Kim, 2019; Terkamo-Moisio et al., 2016). In some studies, this was connected to the prerequisite of dying at old age while dying young was assessed as bad (Adesina et al., 2016; Terkamo-Moisio et al., 2016). However, studies concerned with good dying of children showed that also dying at a young age was rated in a differentiated manner, and also for younger people and children, good dying was deemed possible (Bennett and Proudfoot, 2016; Nagoya et al., 2016; Souza et al., 2013).

With regards to the biographical context of dying, professional caregivers described the preservation of the dying person's identity and

personhood as important for good dying. This aspect was foremost identified with respect to the dignity of the dying person and included the subjective feeling of being oneself despite declining health, illnesses, or impairments (Albers et al., 2013; Bovero et al., 2019; Nagoya et al., 2016), as well as being recognised and treated as an individual with an individual identity (Dwyer et al., 2009; LeBaron et al., 2015; Srinonprasert et al., 2019; Todd, 2013). One study described how professional caregivers evaluated dying processes against the biographical background and personality of the dying person. Thereby, good dying reflected the way of life of the dying person and meant 'dying with integrity' (Borbasi et al., 2005, p. 108).

3.2.5. Individualised and holistic care

Professional caregivers identified the need for care and medical treatment to respect the individual's autonomy, needs, demands, and values. In the reviewed studies, this was often interlinked with the necessity to continuously communicate with the dying persons and their families in order to get to know their wishes (e.g., regarding medical treatments) and needs (Adesina et al., 2016; Albers et al., 2013; Becker et al., 2017; Beckstrand et al., 2006; Bennett and Proudfoot, 2016; Borbasi et al., 2005; Bratcher, 2010; Cagle et al., 2017; Casey et al., 2011; Coenen et al., 2007; Decker et al., 2015; Demir et al., 2017; Dillon et al., 2018; Dwyer et al., 2009; Fernández-Sola et al., 2017; Gibson et al., 2008; Graham et al., 2013; Griggs, 2010; Karlsson and Berggren, 2011; Kongsuwan et al., 2010; LeBaron et al., 2015; McCallum and McConigley, 2013; Nagoya et al., 2016; Souza et al., 2013; Srinonprasert et al., 2019; Stokes et al., 2019; Terkamo-Moisio et al., 2016; Volker and Limerick, 2007; Young et al., 2017). Professional caregivers identified different areas of personal autonomy; LeBaron et al. (2015, p. 1002) described the range as follows:

> 'Autonomy was exercised when the wishes of patients were honored in terms of preferences related to treatment options, location of care, appointment of a health care proxy, and desires regarding interventions such as cardiopulmonary resuscitation or intubation. Autonomy extended not only to medical choices at the end of life, but also to the extent of spiritual support desired by the patient.'

In some studies, professional caregivers identified advance directives as organisational means to better know about the wishes of patients (Beckstrand et al., 2006; Demir et al., 2017). In other cases, challenges related to preserving autonomy and decision making were described, for example, with regards to persons with intellectual disabilities at the end of life, especially in hospital environments (McNamara et al., 2019). Professional caregivers not only saw the necessity to adapt their care to the specific situation and personal needs of people at the end of life, but in some studies they also identified the preservation of a normal daily life as important for good dying (Albers et al., 2013; Bovero et al., 2019; Nagoya et al., 2016; Terkamo-Moisio et al., 2016).

In one study, professional caregivers discussed euthanasia as the 'ability to decide about one's own death' (Terkamo-Moisio et al., 2016, p. 454) and related to good dying, whilst others in the same study indicated that one's autonomy should not be expanded to this kind of decision making. Otherwise, euthanasia or physician-assisted suicide were not discussed by professional caregivers in the reviewed studies.

Studies showed that professional caregivers identified individualised care not only considering medical and physical aspects of the dying persons, but also their social, emotional, spiritual, religious, and cultural needs (Becker et al., 2017; Bennett and Proudfoot, 2016; Bratcher, 2010; Coenen et al., 2007; Costello, 2006; Demir et al., 2017; Gibson et al., 2008; Griggs, 2010; Hanson et al., 2002; Hopkinson and Hallett, 2002; Kongsuwan et al., 2010; Kupeli et al., 2016; LeBaron et al., 2015; McCallum and McConigley, 2013; Souza et al., 2013; Srinonprasert et al., 2019; Terkamo-Moisio et al., 2016; Wilson et al., 2006). Some studies explicitly described how, according to professional caregivers, different goals in different domains of care needed to be achieved concurrently in order to enable good dying (Borbasi et al., 2005; Casey et al., 2011; Coenen et al., 2007). Studies also described the necessity of compassion for the patient and family (Coenen et al., 2007; Díaz-Cortés et al., 2018; Fernández-Sola et al., 2017; Souza et al., 2013; Stokes et al., 2019). One study on traditional healers also showed how rituals and ceremonies after death were deemed important for the spirit of the deceased and the well-being of the family (Graham et al., 2013). Another study emphasised the importance of activities such as cleaning the dead body for the family (Griggs, 2010; Kongsuwan et al., 2010).

In several studies, professional caregivers identified having enough time and resources as necessary for such forms of individualised and comprehensive care (Beckstrand et al., 2006; Borbasi et al., 2005; Casey et al., 2011; Cipolletta and Oprandi, 2014; Decker et al., 2015; Díaz-Cortés et al., 2018; Dwyer et al., 2009; Hopkinson and Hallett, 2002; McCallum and McConigley, 2013; Oliver and O'Connor, 2015).

3.2.6. Good (inter)professional cooperation and communication

Studies found that professional caregivers emphasised good communication and cooperation within care staff and between different disciplines, which included information exchange, requesting professional support from other disciplines, and shared decision making (Adesina et al., 2016; Becker et al., 2017; Beckstrand et al., 2006; Bennett and Proudfoot, 2016; Borbasi et al., 2005; Casey et al., 2011; Cipolletta and Oprandi, 2014; Dillon et al., 2018; Griggs, 2010; Hanson et al., 2002; Karlsson and Berggren, 2011; Kupeli et al., 2016; Souza et al., 2013; Stokes et al., 2019; Young et al., 2017). As an example, Young et al. (2017, p. 856) described the importance of communication as follows:

> 'Communicating with those internally and external to the nursing home was visible across all practice elements and seen as fundamental for the staff to achieve their value of "good dying".'

Several studies highlighted the importance of good cooperation and communication, especially between nurses and physicians (Griggs, 2010; Hanson et al., 2002; McCallum and McConigley, 2013). For example, Hanson et al. (2002, p. 122) outlined:

> 'Physicians and nurses felt a need for shared communication to facilitate treatment decisions when a resident was dying.'

Professional caregivers also emphasised the importance of good communication and cooperation in order to be 'on the same page' (Stokes et al., 2019, p. 4) and to have an agreement within and between different professional groups on the care and treatment of a dying person (Adesina et al., 2016; Dillon et al., 2018; Griggs, 2010).

Furthermore, professional caregivers indicated the need for appropriate (palliative care) education and training to provide care for patients at the end of life in order to be able and confident enough to provide good care in these situations (Casey et al., 2011; Cipolletta and Oprandi, 2014; Díaz-Cortés et al., 2018; Hanson et al., 2002; Kupeli et al., 2016; Oliver and O'Connor, 2015; Souza et al., 2013).

3.2.7. Peaceful and private environments: at home and elsewhere

In several studies, home was identified as a preferred place of dying; however, under specific conditions (e.g., need for specific therapies) hospitals or other places of care were seen as better for the well-being of the dying person and the family (Dillon et al., 2018; LeBaron et al., 2015; McNamara et al., 2019; Terkamo-Moisio et al., 2016; Todd, 2013). The emergency department was assessed as altogether not optimal for good dying in two studies investigating the views of professionals working in emergency departments (Decker et al., 2015; Díaz-Cortés et al., 2018), but also in another study (McNamara et al., 2019).

Palliative and hospice care, both stationary or mobile teams, were most often assessed positively by professional caregivers if they thematised them (Adesina et al., 2016; Borbasi et al., 2005; Cagle et al., 2017; Demir et al., 2017; Oliver and O'Connor, 2015). However, in two

studies, some professional caregivers from nursing homes described their experiences with hospice care rather negatively because they felt excluded by hospice providers from caring for their residents (Cagle et al., 2017) or they identified hospice as not the home of the dying person (Todd, 2013).

Apart from the care context, professional caregivers identified several key requirements regarding the environmental conditions that were important for good dying. These included having, in the best case, a private single room or at least a room situation that allowed for some privacy, sufficient space for the patient and their family to be present, a low noise level and an overall calm environment. Sometimes, professional caregivers described how they created special spatial arrangements (e.g., privacy screens) or moved patients to specific rooms to die (Becker et al., 2017; Beckstrand et al., 2006; Borbasi et al., 2005; Bratcher, 2010; Cagle et al., 2017; Casey et al., 2011; Cipolletta and Oprandi, 2014; Coenen et al., 2007; Díaz-Cortés et al., 2018; Dillon et al., 2018; Dwyer et al., 2009; Endacott et al., 2016; Fernández-Sola et al., 2017; Kim, 2019; McCallum and McConigley, 2013; Stokes et al., 2019; Terkamo-Moisio et al., 2016; Wilson et al., 2006). Several of these studies also highlighted creating a sense and atmosphere of 'home' in institutional contexts as desirable, for example, Cipolletta and Oprandi (2014, p. 22):

> 'Participants pointed out that a good death is comforted by loved ones in a quiet and comfortable environment, which recreated the home atmosphere, where the patient might die away from prying eyes, and where families might express their grief without feeling embarrassed.'

In this, a second sense of 'peaceful' dying is tangible: On the one hand, good dying was related to being at peace (accepting, having closure) with the situation and one's life (see 3.2.4), on the other hand, peaceful as described here is related to characteristics of the care environment as being calm, quiet, private, and not public, hectic, or stressful. The studies described how an appropriate environment benefitted the patients, but also the family and relatives. In contrast, one study described the emergency department as an inappropriate environment because it lacked these characteristics (for another example see McNamara et al., 2019, p. 9):

> 'participants believed that the ED was not an appropriate environment for death to occur because it created an environment that was busy, noisy and lacking in privacy' (Decker et al., 2015, p. 71, p. 71)

In line with the overall emphasis on individualised care, the assessment of a place of death was also interlinked to the preferences of the dying person (see 3.2.5). Given the overall descriptions of good dying in the various studies, the social, emotional, and care aspects seemed to be more important than (but sometimes related to) specific places of death. One study summarised this as follows:

> 'In general, the quality of the microenvironment—access to loving, competent caregivers and feeling secure—and the spiritual status of the dying person, were reported as more important than the location of dying.' (LeBaron et al., 2015, p. 1004, p. 1004)

3.3. Approaching good dying: opening different perspectives

Besides identifying the meaning of good dying from the perspective of professional caregivers, our review aimed to identify differences in the studies' approaches towards good dying through a comparative examination of the included studies. Through this comparison, peculiarities in how different studies analysed good dying became apparent. We detected three issues that single studies in our review addressed, and thus are not in principle out of scope of such empirical investigations, but which were not considered by most other studies. These three perspectives widen and differentiate our view on good dying. First, in making explicit who benefits from certain practices related to good dying, but not only focusing on the patient's well-being, some studies highlighted the wider implications of care and social practices supporting good dying (section 3.3.1). Second, some studies comprehended the dying process beyond a strict dichotomous relationship of good versus bad dying, thus offering the opportunity to account for differentiated views on this matter (section 3.3.2). Third, studies opened up a space for critically reflecting and weighting specific practices and ideals of care against one another by thematising the practical compatibility of different elements of good dying (section 3.3.3). In addition to these issues derived from our comparative analysis, we identified other 'blind spots' in research on good dying by drawing on and discussing further studies that were not part of our review (section 4).

3.3.1. Good dying for whom?

The first issue we identified concerns the analytical focus on, or the omission of, specific social actors involved in the dying process. It is about the question of who benefits from specific requirements and practices that promote good dying as identified by the research participants: Good dying for whom?

In most studies, the beneficiaries of certain practices or norms were often not made explicit. Rather, they had a focus on the well-being of the dying person as a default (and sometimes implicit) assumption. They described the well-being of others parenthetically amongst a bundle of practices targeting the well-being of the dying person, especially considering the acceptance of and preparation for death, the resolution of family issues, as well as saying goodbye. Professional caregivers indicated that families need to be supported in these matters for their own, and ultimately for the patient's well-being (Adesina et al., 2016; Becker et al., 2017; Beckstrand et al., 2006; Bennett and Proudfoot, 2016; Borbasi et al., 2005; Bratcher, 2010; Cagle et al., 2017; Casey et al., 2011; Coenen et al., 2007; Graham et al., 2013; Griggs, 2010; Kim, 2019; Kupeli et al., 2016; McCallum and McConigley, 2013; Souza et al., 2013; Terkamo-Moisio et al., 2016). Studies also described elements of good dying pertaining to families alone, for example, when caregivers supported families in grief after the death of their beloved ones (Adesina et al., 2016; Becker et al., 2017; Cipolletta and Oprandi, 2014; Coenen et al., 2007; Griggs, 2010; McNamara et al., 2019; Terkamo-Moisio et al., 2016). Some studies also discussed the well-being of the professional caregivers. Costello (2006, p. 598) stated that '[g]ood death benefited nurses as much as patients and relatives'. He described how nurses assessed those deaths good that involved minimal stress for the patients and for themselves and had minimal impact on their ward's routine. Furthermore, good end of life care appeared as a source of meaning and satisfaction with their own work (Borbasi et al., 2005; Hopkinson and Hallett, 2002; Stokes et al., 2019; Todd, 2013; Young et al., 2017).

However, there were only some studies explicitly differentiating and systematising the perspectives of the actor involved and affected. Griggs et al. (2010, p. 142) distinguished the 'focus' of 'contributory factors' to a good death for the patients, the nurses, or the professionals' team, and Dwyer et al. (2009) analysed the dignity of patients and staff members separately. Professional caregivers in the study by Borbasi et al. (2005) reflected on the possibility of imposing their own values on the dying person and their families, thus having a negative effect. Similar, McNamara et al. (2019, p. 8) stated that 'it is important that the person's wishes are not conflated with those of the family' but that also their needs and the needs of professional caregivers are considered. And Cagle et al. (2017, p. 200) made explicit that the assessment of good dying always constituted an indirect account of the well-being and desire of someone else. Therefore, they categorised the experiences of the professional caregivers in end-of-life care as 'first-hand', and those experiences of residents and families reported by the professional caregivers as 'observed in others'.

3.3.2. Good or bad dying: beyond a dichotomous relationship?

Our review, and many studies therein, in terms of terminology imply a dichotomous relation of good dying and bad dying on opposite ends of a scale. While some studies only dealt with good dying and just implicitly with bad dying as the absence of specific conditions (e.g., Bratcher, 2010; Casey et al., 2011; Demir et al., 2017; Hopkinson and Hallett, 2002; Terkamo-Moisio et al., 2016; Yang et al., 2019), others identified negatively and positively assessed dying processes explicitly (Adesina et al., 2016; Borbasi et al., 2005; Cagle et al., 2017; Costello, 2006; Kim, 2019; LeBaron et al., 2015).

However, single studies scrutinised the seemingly dichotomous nature of good and bad dying: One study in its results analysed a 'middle death' as 'more nuanced experiences' that 'cannot be easily dichotomized' (LeBaron et al., 2015, p. 1004) from the perspective of their research participants. The authors of this study interpreted this notion of middle deaths as having a 'pervasive sense of conditionality' (LeBaron et al., 2015, p. 1006) considering the subjectivity of dying processes. Another study highlighted the challenge of finding a conclusion on what constitutes good dying; their 'focus groups participants could not identify clear components of a good death' linked to a 'discomfort that many participants expressed when dealing with death and dying' (Cipolletta and Oprandi, 2014, p. 25).

In the topic of care approaches that consider the individual needs, demands, and values of those dying (and their relatives), the subjectivity of good dying is reflected to some extent (see 3.2.5). However, in these cases good dying was also identified as attainable through personalised care approaches, often in contrast to the identification of bad dying as a non-personalised or uniform way of caring for a dying person, and thus a (unproblematic) dichotomous relationship is implied.

3.3.3. Compatibility of elements of good dying

Above, we presented several elements of good dying that were identified by the reviewed studies. In line with their publications and findings, good dying emerged as a comprehensive phenomenon. And, as some studies explicitly conclude, the concurrent realisation of different elements of good dying was deemed important for achieving an ideal good dying.

However, some studies scrutinise the possibility of realising this in practice. Cipolletta and Oprandi (2014, p. 24) outlined how professional caregivers were ambivalent in their assessment of analgesics since 'removing awareness becomes a problem for many because it prevents the dying persons from being present and sharing their last wishes and thoughts with their loved ones'. In some studies, professional caregivers also raised the problematic issue of correct identification and evaluation of pain and suffering from symptoms with regards to patients with 'cognitive impairments' (Hanson et al., 2002, p. 119) or 'intellectual disabilities' (McNamara et al., 2019, p. 6). As described above, some other studies also showed ambivalent views of caregivers with regards to the awareness of patients about their impending death: Caregivers favoured closed awareness of patients in support of a peaceful situation with less suffering and fear (Casey et al., 2011; Todd, 2013). In these studies, these different ideals seem to be (partially) irreconcilable to the professional caregivers.

In total, the compatibility of specific conditions with requirements of good dying (e.g., certain mental capabilities) and the compatibility of elements of good dying amongst each other (such as pain management and awareness) were rarely discussed. Rather, many different elements were listed and described, often without critically discussing their relationship to one another.

4. Discussion

We analysed 43 peer-reviewed articles dealing empirically with the perspectives of professional caregivers not working in specialised palliative or hospice care on good dying. We found common elements of good dying across different countries, locations of care, and professional groups. They were related to the social anticipation of dying, the management and relief of pain and symptoms, the social embedding of dying, the consolidation and completion of one's life, the provision of individualised and comprehensive care, good professional cooperation, as well as environmental conditions.

4.1. Good dying in generalist palliative care: commonalities and non-topics

Comparing the main elements of good dying we identified in our review with that of other reviews on the meaning of good dying, we found many commonalities. With some variation, many of the above outlined elements of good dying were also identified by reviews focusing, for example, on professionals, patients, and families altogether (Meier et al., 2016), on specific patient groups such as patients with dementia (Takahashi et al., 2021) or heart failure (Asano et al., 2019), or only on specific concepts such as dignity (Guo and Jacelon, 2014). Elements of good dying identified in the reviewed studies also largely mirror palliative and hospice care concepts and discourses. Awareness and acceptance of death, pain and symptom management, personalised and holistic care approaches, communication, interdisciplinarity, and so on were not only described by professional caregivers in generalist palliative care, but are at the core of palliative and hospice care concepts and discourses too – as studies analysing the palliative care literature showed (Pastrana et al., 2008; Zimmermann, 2012). Thus, we may hypothesize that principles of palliative care have permeated non-specialised care at the end of life. Furthermore, we found that many studies shared elements with broader societal discourses around good dying. Studies have shown that media frame dying alone as bad death (Nelson-Becker and Victor, 2020; Seale, 2004) or that awareness, control, and autonomy are key elements of the 'subject position of the dying person' in the dominant 'medical-revivalist discourse' (Van Brussel and Carpentier, 2012, p. 491) on death in late modernity.

However, other topics around good dying, often at stake in social or expert discourses, were rarely or not at all raised in the studies. For example, given the often-controversial public debates around good dying that often revolve around the issues of euthanasia and physician-assisted suicide (Lang, 2020; McInerney, 2006; Van Brussel and Carpentier, 2012), it was interesting that this had hardly been an issue in our reviewed studies. Exceptions occurred in one study in which euthanasia was discussed with regards to autonomy (Terkamo-Moisio et al., 2016) and one in which suicide in general was identified as the outcome of a lack of support and inappropriate social conditions (Kim, 2019). In quantitative studies with predefined items and closed questions, this could be attributed to the conceptual omission of these topics; they were simply not part of a questionnaire. However, in qualitative studies the non-thematisation of topics such as physician-assisted suicide was not simply explainable. The reason could have related to the questions posed, conversational dynamics, the perspective and attitude of the professional caregivers, or the analytical focus on specific topics; however, we cannot provide a conclusive finding on this not being a topic of most reviewed studies. Other studies have shown that professional caregivers in countries with legalised medical assistance in dying sometimes relate this option to a good death because it alleviates the patient's pain and suffering and is seen as part of a patient's right to make end-of-life decisions (Beuthin et al., 2018). At the same time, professional caregivers also report ambiguous and negative effects of such practices on their work and well-being (Beuthin et al., 2018; Mathews et al., 2021).

Furthermore, while individualised care respecting the cultural or religious specifics of the dying persons was identified as important, gender, ethnic, or other social differences regarding good dying were not found to be issues from the perspective of the professional caregivers. As studies outside the scope of our review emphasised, there are differences in how women and men spend the evening of their lives when faced with dying due to differences in life expectancy and marriage patterns (Seale,

2000), as well as differences in their expectations, wishes, and patterns of medical treatments at the end of life (Carmel, 2001; Sharma et al., 2015), and in terminal care communication (Skulason et al., 2014). Similarly, the studies did not discuss how gendered roles and expectations in care (Sutherland et al., 2018) and gendered care labour distribution might affect the professional caregivers' perspective on good dying. And although other studies have shown that there are variations in how different social groups understand good death (Cain and McCleskey, 2019; Volker, 2005), ethnicity or social class as factors of social inequality at the end of life were not discussed by the studies or the professional caregivers therein. As broader social determinants of good dying, the reviewed studies foremost identified structural issues in the healthcare organisations, such as scarcity of resources or lack of palliative care education. Beyond that, for future studies, it might be worthwhile to raise issues around social inequity in dying and how socio-structural conditions related to gender, class, or ethnicity are perceived and understood by actors involved in the care of dying, and how they are related to their ideas and practices of good dying.

In our review, most studies dealt with the perspective of health professionals (nurses, physicians), whereas other professions included in our search were less prevalent (e.g., clergy members) or not present at all (e.g., morticians or undertakers). In the reviewed studies, the role of clergy and other actors outside of the medical professions was described to some extent (e.g., regarding the spiritual dimension of good dying) but their own views were explored only in single instances (LeBaron et al., 2015). The same holds true for other non-health professionals, including social workers or personal assistants. Investigating the understanding of good dying of further actors could contribute to a more complete picture of this phenomenon in our societies.

Since the beginning of 2020, the COVID-19 pandemic has posed a major challenge to society and the health care system. In our review, we could not consider its impact on professional perspectives on good dying. However, it appears as if central elements of good dying have been rather consistent. Research and commentaries have repeatedly highlighted that the social embedding of dying patients and also the adequate management of their pain and symptoms are threatened by the pandemic and related preventive measures. Thus, care practices have been adapted in order to fulfil these requirements of good dying including the use of information and communication technologies to enable social connectedness at a distance (Crispo et al., 2021; Wang et al., 2020). Actors from the field of palliative care have also emphasised this discipline's 'key role' in dealing with the pandemic (Radbruch et al., 2020). Further research is needed to determine how new care practices will be maintained and how these practices in particular, and the COVID-19 pandemic in general, may transform ideas around good dying.

4.2. Analytical approaches to good dying: extending the perspective

The second aim of our review was to explore how to better grasp the social complexity of good dying in empirical research based upon our comparative analysis of the included studies.

We found that the studies infrequently identified whose good dying was described by the caregivers, or who benefitted from certain elements of good dying. While studies in passing identified ramifications for family, relatives, and the professionals themselves, the few studies that did raise such issues more systematically, yielded interesting findings related to the dynamics and effects of specific ideals of good dying within care organisations. In line with this, we propose to explore the interwoven nature of the well-being of different relevant social groups in palliative care as well as discuss the well-being of others, apart from the dying person. Dying as process and situation involves the patient, those providing care and social support, and others affected including family, relatives, friends, or workmates. Given the close relationship of the well-being of the different involved actors, good dying could be more adequately understood as an ideal process that concurrently affects and is implemented by various social actors. Researching good dying then means analysing the interrelated state and well-being of those dying, their caregivers, their families and relatives, and others affected, as well as how ideas and practices of good dying emerge in these social contexts. This conclusion is in line with other critical inquiry and discussion around concepts of good dying. Many scholars have highlighted the importance of scrutinising who benefits from specific ideals and ways of good dying (Hart et al., 1998; Zimmermann, 2012) or that good dying means different things depending on the social perspective (Kearl, 1996). Thereby, conflicting definitions and practices related to good dying need to be considered; for example, in a German study, the necessity to reach acceptance before dying is seen critically from the patients' view (Ohnsorge et al., 2017) in contrast to our findings.

Furthermore, the reviewed studies rarely dealt with the interplay and congruence of different elements of good dying. In supporting and implementing specific characteristics of good dying, tensions might arise because of the incompatibility of different aims, as Sandman (2005) argues. In addition, some studies discussed the feasibility of categorising dying processes or certain elements of them as good or bad, and highlighted the possible inadequacy of such dichotomous categories for understanding a highly subjective and contingent matter such as good dying. Research on the assessment of practices and goals could aim for more nuanced data and analysis by considering what one study in our review (LeBaron et al., 2015) coined 'middle deaths'. This is an aspect that other scholars have raised with regards to palliative care and the practical ambivalence of good death through the notion of 'good enough death', both, on behalf of professionals (McNamara, 2004), but also patients and relatives (Masson, 2002). These investigations showed how social actors in practice dealt with tensions between different elements of good death and the inability to reach a good death. In empirical research, such aspects could be addressed more openly, probably without introducing a dichotomous category of good versus bad dying in the first place. Narrative approaches (Mueller, 2019; Thomas et al., 2009) to data collection using broader open-ended questions, for example, eliciting memorable experiences of professional caregivers, could be useful in this regard. Furthermore, research could search for and interpret cases that defy easy categorisation and illustrate the practical tensions between different goals. However, our own strategy of searching papers that deal with 'good dying' and similar concepts might have limited our results in this regard in the first place.

4.3. Limitations

A majority of studies in our review were conducted in anglophone countries (USA, UK, Australia). Amongst others, this could be linked to the language restriction inherent in our search and review strategy focusing on English and German publications. Further studies on this topic may be published in the respective national language of the country of data collection, but it was beyond our language competencies to consider them appropriately.

In addition, we focused on peer-reviewed journal articles, thus excluding study results published in monographs, edited volumes, as reports, or conference papers. Although we covered a wide range of academic journals searching Scopus, MEDLINE, and CINAHL, using additional databases could have expanded our review and findings.

While we used a broad variety of search terms to grasp different concepts related to good dying, we cannot rule out that we have missed studies using different terminology. The same holds true for our definition of professional caregivers. We searched studies on different professional groups, not only considering nurses or physicians, but also social workers or clergy. However, other professional actors might also be relevant for promoting good dying. Furthermore, by searching for papers dealing with 'good', 'dignified', or 'better' dying, our review to some extent remained within a conceptual frame of categorising dying processes and experiences in dichotomous categories. Although we still found papers going beyond these categories, we cannot rule out that we

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5.3 Paper 3: ‘Absent users of technology: the absent dying users in the development of robots for care

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The paper is complemented by comprehensive supplementary material. To improve the readability of the present document, the supplementary material is located in Annex B of the dissertation.

Absent users of technology: the absent dying users in the development of robots for care

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Abstract

In research and development (R&D) of technology, representations of users and non-users are created and orient the design of technical systems. This paper conceptualises a type of users that has received little attention so far, entirely *absent users*. It investigates the case of robots for elderly care purposes and focusses on the absence of dying elderly users in this field of R&D. The interpretive study explores this absence in European robotics by analysing publications and policy documents in line with the sociology of knowledge approach to discourse as well as through problem-centred interviews with roboticists. It shows that the absence is associated with a dominant representation of the elderly as active and independent users of robots. At once, roboticists do not neglect the future use of robots in end-of-life care in principle but justify this application drawing on a common narrative of care crisis. However, they assess robots as technically still too immature to address complex requirements of end-of-life care. Furthermore, the paper examines how the design of robotics' trials may contribute to the absence of dying patients in robotics. Concluding, the paper discusses social implications of user absences in R&D.

Keywords

User representation, non-users, absent users, robots in care, dying, discourse analysis

1. Introduction

Research and development (R&D) processes ‘inscribe’ (Akrich, 1992) envisioned users into technological devices or ‘configure’ (Woolgar, 1990) user-technology relationships. In parallel, scholars have drawn attention to the relevance of non-users of technology (Kline, 2003; Oudshoorn & Pinch, 2003; Wyatt, 2003). Representations of users and non-users have the power to orient R&D policy, funding, practices, and ultimately the design of technological artefacts. Thereby, they can reproduce power relations, inequalities, and stereotypes (Hyysalo & Johnson, 2016). User representations affect the acceptance and adoption of a technology (Neven, 2010) and may have implications for the diffusion of technologies.

This paper draws attention to those users who are neither envisioned as users nor explicitly addressed as non-users but not considered at all: *absent users of technology.* Absent users do not occur in R&D discourses but are, nonetheless, ‘thinkable alternatives’ (Schröter & Taylor, 2018, p. 6) to users and non-users. In 2014, Frickel (2014, p. 87) stated that science and technology studies are ‘characterized by a relative absence of absence-related research’. Since then, there have been several anthologies on absence conceptualising and illustrating the emergence and impacts of absence (Murray & Durrheim, 2019a; Rappert, 2015; Schröter & Taylor, 2018). However, absent users of technology have not been addressed, yet.

In this paper, I empirically investigate the case of R&D on robots in elderly care in Europe to substantiate a conceptualisation of absent users. Over the last decades, robots for elderly care have increasingly been developed and tested. These robots are developed to be used in home or institutional care. They have a physical presence, operate semi- or fully autonomously, and provide physical, cognitive, emotional, or social support directly to elderly users or to relatives and caregivers implementing care activities (Johansson-Pajala et al., 2020). In funding, researching, designing, and implementing robots for care, policymakers and roboticists have envisioned the technology with their prospective users and use cases (Fischer, Östlund, et al., 2020; Lipp, 2019; Neven, 2010) as part of discursively produced

socio-technical futures (Lösch et al., 2019). However, care recipients at the end of their lives and dying have been absent in this field of R&D and its envisioned technology. Since contemporary dying is associated with old age, illness, long dying trajectories, and comprehensive care (Lang, 2020), this absence seems surprising.

To study this absence, I combined a discourse analysis in line with the sociology of knowledge approach to discourses (SKAD) with problem-centred interviews with roboticists. I show how the roboticists' discourse has produced a user representation incompatible with the characteristics and needs of dying elderly patients. At once, although roboticists did not reject the idea of robots in end-of-life care in the future, they refrain from this application for the time being given the robots' technical limitations. Furthermore, I discuss how the design of trials may be associated with the absence of dying elderly in robotics R&D. Concluding, I discuss the social implications of such absent users.

2. Background

2.1. Users and non-users of technology

User representations are assumptions about and images of users and their relation to a technology. Actors form, reproduce, draw on, negotiate, or contest user representations in innovation politics and funding (Lipp, 2019; van Kammen, 1999), R&D processes (Fischer, Östlund, et al., 2020), installing technical devices (Sánchez-Criado et al., 2014), or using them (Pols, 2012). In R&D, user representations are based on research into user characteristics, involvement of users, experiences of the designers, existing products, business considerations, regulatory requirements, cultural conventions, or social narratives (Hyysalo & Johnson, 2016). Studies described how user representations associated with robots in care are interrelated with socio-political discourses of ageing and care. In European research and innovation (R&I) policy, the idea of an ageing society has transformed, from being a threat for society to being a chance for the economy. The focus of R&I shifted from understanding basic questions of ageing to addressing elderly care challenges via technological innovations. Since

this shift, elderly people have been envisioned as living independently at home, supported by assistive robots (Lipp, 2019). This vision of robots for activation, health preservation, and independent living also pervades R&D processes focussing on designing and testing robots for care (Neven, 2010).

Representations of elderly robot users do not emerge in R&D in isolation. Technology and ageing are co-constituted through the interrelatedness of 'images of ageing', the 'design world' of technology developers, the elderly users' 'life worlds', and the form and function of the technological artefact itself (Peine & Neven, 2021). Šabanović (2014) showed how Japan's industry, academia, and government co-produced imaginaries of robots and culture drawing on conservative social values. However, robotic technology may also challenge established values and norms. A study indicated that the visions of Spanish roboticists 'are predominantly sustained by a social process of care fragmentation' (Vallès-Peris & Domènech, 2020, p. 157) that is in conflict with established ideals of holistic care.

R&D processes favour specific users and implicitly or explicitly designate others as non-users concurrently because of material, cultural, and political conditions (van Kammen, 1999; Wilkie, 2010). In parallel, R&D, industry, and politics may evaluate non-use of a technology as undesired and actively focus on non-users who resist or reject using a technology. Dealing with resistance against technology can bring designers and companies to reconfigure a technology (Kline, 2003). However, some people may also be assessed as 'virtuous non-user' (Gabe et al., 2016, p. 640) in line with political norms and lifestyle concepts.

2.2. Absent users of technology

In contrast to users and non-users, *absent users of technology* do not manifest in R&D. Whereas R&D efforts address non-users of technology, absent users of technology are not considered at all. The characteristics and needs of such absent users are not studied in the design of a technology, which may lead to challenges in its deployment.

Analytically, one has to be aware of who is present in a context to identify absent users. In studying European robotics, this was about analysing user representations in this field before turning to those without presence. Given the 'plethora of absence around whatever is given' (Schröter & Taylor, 2018, p. 6), research on absent users cannot map everybody not considered in technology discourses. It is about those whose absence is 'epistemologically salient' or 'meaningful' (Schröter & Taylor, 2018, p. 5). This involves drawing on different stocks of knowledge and thus becoming sensitised for the absence of particular users in particular contexts. Such a comparative approach is possible because absence is rather relative and not 'absolute absence' (Frickel, 2014, pp. 87–88), which may be hard to notice. Potential users absent in specific communities may be present in other disciplines' deliberations or other genres. Even the same actors may remain silent about an issue in one situation (e.g., writing an article) and thematise it in another one (e.g., a team meeting). Absences can change over time and actors can actively bring them to awareness, for example through political campaigns or critical research (Murray & Durrheim, 2019a; Rappert, 2015; Schröter & Taylor, 2018).

In the field of robots in care, dying users do not appear as unthinkable users. Similar disciplines' attempts to integrate digital technologies in end-of-life care (Gordon et al., 2021) indicate that the association of novel technologies with dying users is a thinkable option. Given the social association of dying with old age and longer trajectories of health decline producing complex care needs (Lang, 2020), elderly care and end-of-life care intersect at one point. Dying is often interrelated with 'progressing age-related weakness' accompanied by 'clinical symptoms […] as indicators of imminent or approaching death' (Austrian Bioethics Commission, 2015, p. 40). End-of-life care can be related to the last months and years, or the 'last few hours or days of life' in which a person needs 'comprehensive care' (Radbruch et al., 2009, p. 282). Thus, elderly users of care robots, at some point, enter a process of dying in which they need increased care and support.

The absence of particular users can be interrelated with undifferentiated user representation (Rommes, 2000). In designing and developing technology, elderly users have often been identified as a homogenous group. R&D has represented them as ‘frail, dependent, rigid, reluctant and inept users of technology’ (Peine et al., 2014, p. 205) but neglected their diversity. R&D might lack the knowledge about heterogeneity of users and their needs (Oudshoorn et al., 2004; Peine et al., 2014).

Dealing with absent users of technology, *absence* and *silence* can be differentiated. Absence can be understood as ‘umbrella term’ (Schröter & Taylor, 2018, p. 7) for different types of absences, including silence and, more specifically, absence associated with particular social constructions of reality. The latter does not necessarily include a deliberate act of omitting a topic. Rather, the absence may result from unintentional discursive dynamics. In contrast, *silence* implies an actor’s ‘more conscious and intentional choice about what (not) to say’ (Schröter & Taylor, 2018, p. 7). This distinction between absence and silence is ideal-typical given the entanglement of discourses, social practices, and individual agency (Keller, 2011). Nonetheless, being sensitive to different shades of intentionality behind absences is vital in researching absent users.

The concept of absent users presented here has to be differentiated from other forms of user absence. For example, telemedicine systems produce spatial and temporal distances between different involved actors (patients, nurses, doctors) that result in ‘absent patients’ in the diagnostic process. However, they are nevertheless present as data and images (Mort et al., 2003). The concept of absent users here does not comprise such physically absent but nonetheless considered or represented users. Still, one has to be aware of practices of physical exclusion as origins of absence. In parallel, users physically present in a situation may not be represented in communicating about this situation.

The following empirical investigation illustrates and concretises several aspects of this preliminary conceptualisation of absent users.

3. Methodology and data

This study builds upon the interpretive sociology of knowledge approach to discourse (SKAD). The SKAD is a research program consolidating discourse theory in the tradition of Foucault, social phenomenology, and the sociology of knowledge of Berger and Luckmann (Keller, 2011). Discourses are understood as 'regulated, structured practices of sign usage' that 'institutionalize a binding context of meaning, values and actions/agency' (Keller, 2011, p. 51). At once, social actors are speakers able to challenge and alter discourses. *Roboticists* as actors funding, developing, and marketing robots for care settings reproduce a 'special discourse performed in close arenas for special publics' (Keller, 2011, p. 52) about (future) robots and their users.

I focussed on R&D in Europe, assuming a higher level of 'socio-cultural homogeneity' (Böhle & Bopp, 2014, p. 156) compared to other regions. Although the field of robotics is international, European policy, academia, and industry have together created a common and influential socio-technical imaginary of robots (Rommetveit et al., 2020).

The identification of the *absence* of dying elderly as users in this field of R&D was based upon an analysis of the roboticists' discourse around robots in care. To reconstruct the discourse, I analysed different types of documents produced by roboticists as qualitative data. First, I comprehensively searched for *robots* and *elderly care* using Scopus, IEEE Xplore, Google Scholar, existing systematic reviews (e.g., Maalouf et al., 2018), and Google. Overall, I was able to identify more than 90 robots for elderly care developed in Europe.

I implemented the data collection and analysis in an iterative process, applying principles of theoretical sampling (Charmaz, 2014). From the initial set of identified robots, I selected robots with different functionalities from varying countries and collected roboticists' publications about them. Based upon preliminary findings from the analysis of these documents, I selected further robots and documents for investigation. I repeated this process of alternating selection, data collection, and analysis several times. I aimed to cover a range of R&D efforts considering

different care settings, functionality and design of the robot, institutional contexts, and national embedding.

I analysed 40 documents concerned with 19 different robots published between 1993 and 2020 (supplementary material section 2). Documents included journal articles, conference proceedings, book chapters, transcribed videos, reports, and brochures. To better understand the conditions of these R&D efforts, I additionally collected and analysed eleven related policy documents (supplementary material section 1).

The reconstructed roboticists' discourse on robots in care did not address dying users. Thus, I systematically searched abstracts and full texts in Scopus, IEEE Xplore, and Google Scholar with terms including *palliative*, *hospice*, *end-of-life care*, *dying,* or *death* in conjunction with *robot* and *care*. This resulted in a limited number of relevant results, foremost from outside the field of robotics. Out of these, I analysed five papers and one video.

Additionally, between February and October 2020, I implemented nine problem-centred interviews (Witzel and Reiter, 2012) with roboticists involved in the R&D of robots as managers (IP1, IP5), engineers or computer scientists (IP2, IP4, IP6–9) or marketing (IP3) in European universities, research institutes, or robotics companies. I conducted all interviews via telephone or Voice-Over-IP software after obtaining informed consent. Interviews started with a narrative question about how their robot development came into being. Then, open questions dealt with the envisioned use of the robot. Later, I asked the interview partners (IP) about robots in end-of-life care. I recorded, transcribed, and pseudonymised all interviews. Analysing the interviews, I reconstructed how the interviewees reproduced the discourse around robots in care. At once, interviewees were informants about R&D experiences that may not have been mediated in publications due to social norms or publication practices.

The SKAD provided heuristic concepts that supported the analysis of my data. I used the concepts of *interpretive schemes* to grasp the typical representations of a phenomenon, that of *phenomenal structures* to differentiate the dimensions of a discursively established

phenomenon such as *robots in care* (including the associated cause, causalities, responsibilities, solutions, normative evaluations, impacts, etc.), and that of *narrative structures* that bind these elements in a story line (Keller, 2011, pp. 57–60).

I used ATLAS.ti 8 for organising documents, coding the data, and memo writing. I sequentially and closely read all documents. Thereby, I developed and applied codes to segments of my data. First, I employed line-by-line coding for key passages (e.g. introductory sections) and developed initial codes and hypotheses. Afterwards, I used focussed coding to interpret larger portions of the data (Charmaz, 2014). Following the principle of constant comparison of data, I searched utterances contradicting or backing up preliminary hypotheses.

Outlining the results, I give selected illustrative quotes reproducing aspects of the discourse. Additional quotes (Q[i]) can be found in the supplementary material.

4. Results

The documents and interviews concern R&D activities from over 25 years. In this time, European and national funding agencies promoted specific R&D activities through a variety of programs that roboticists co-created, addressed, interpreted, and put into practice. Despite some variability, the documents and interviews reproduce common representations of the robot and their users, against which the absence of dying users of robots can be reconstructed.

4.1. Robots as answer to a care crisis and social demand

Across the documents and interviews, two interlinked narratives justify the development of assistive robots. The first narrative of a *care crisis* identifies an ageing society in which an increase in life expectancy coincides with low birth rates that both lead to a rising care demand but lack of financial and personal resources for care services (Q1–Q8):

> ‘[…] it is estimated that by 2030, approximately one in five people in developed countries will be aged over 65 years […]. Such demographic changes are putting increasing pressure on health and social care systems […]’ (Papadopoulos et al., 2020, p. 3).

This crisis narrative has been persistent from the 1990s on (Commission of the European Communities, 1993) without losing its message of urgency. The crisis manifests as a shortage of and high workload for caregivers resulting in a risk for inadequate care for the elderly.

Documents and videos present robots as a technological solution to close the gap in trained personnel, relieve caregivers, and thus satisfy care needs (Q9–Q14). They describe robots as co-workers for caregivers or support for the elderly by conducting transport tasks, reminding about appointments, guiding training activities, monitoring care recipients, assisting in personal hygiene, promoting social interaction, etc. (see robot descriptions in supplementary material). Documents published after the outbreak of COVID-19 also identify relieving and protecting caregivers as aims of robots, e.g., by disinfecting areas or taking people’s temperatures.

The second narrative revolves around the prolongation of independent living. Documents identify the desire and demand of most elderly people to live at home as long as possible (Q15–Q19) or present independence and autonomy as goals per se (Q20–Q25):

> ‘Because of the fact that older adults prefer to independently live on their own at home as long as possible [citation], the necessity of developing assistive technology is increasing.’ (Fischinger et al., 2016, p. 60)

Thereby, independence is understood as being (more) self-reliant in everyday life, e.g., implementing personal hygiene or household chores. The dependence on human support mediated through robotic technology does not seem to interfere with this autonomy. Publications envisage professional caregivers as scheduling and controlling the robot, and as co-workers to complete care tasks:

> ‘If an elderly person falls at night, the robot might help by giving support at standing up or by starting a video call with the tele-operator. The remote operator can then use the robot to observe the elderly person and decide to set up an emergency call.’ (Reiser et al., 2013, p. 106)

As soon as the robot’s capabilities reach their technical limits, a human co-worker gets involved to provide an appropriate reaction. Thus, the robot becomes a monitoring device and on-site surrogate for spatially remote care providers necessary to finalise care activities. Thereby, the discourse does not only identify prolonged independent living as a preference of the elderly but as an approach to diminishing the care crisis, too. It appears as less resource intensive than institutional living arrangements (Q26–Q29).

These purposes of robots in care settings are interlinked with a common representation of the elderly users.

4.2. Representing the elderly users: independence and well-being at risk

The discourse represents the elderly users as having on the one hand limited physical capabilities, e.g., as in need of walking aids or wheelchairs, and on the other hand as physically and socially active within their capabilities. Promotional videos and pictures show them walking around, socially interacting, conducting training, playing games, etc. (Camanio Care, 2017; F&P Personal Robotics, 2018; Kompaï Robotics, 2018). Promoting this activeness is identified as socially desired, beneficial, and key for preserving physical and cognitive abilities (Q30–Q36), as, e.g., a European Union funding programme illustrates:

> ‘Elderly people want to perform meaningful activities, to have fun and to experience satisfaction when learning new things. […] Research has shown that when embedded in active social networks people tend to enjoy better physical and mental health.’ (Ambient Assisted Living (AAL) Joint Programme, 2009, p. 6)

The discourse represents users as desiring to remain active members of their communities. It identifies robots as technical means to support this activeness by mitigating some of the users' physical limitations or extending their possibilities by providing support in walking (Reiser et al., 2013), in physical exercise (Stogl et al., 2019), or in personal hygiene (Zlatintsi et al., 2018), but also facilitating social interaction through telepresence (Camanio Care, 2017; Papadopoulos et al., 2020). At once, documents describe the elderly as being at risk of having accidents, declining health, and losing their ability to live independently (Q37–Q40):

> 'Fall detection of older adults is a major health risk […] fall prevention and detection is a crucial functionality that Hobbit is designed to support in order to help elderly users to feel safe in their homes […]' (Fischinger et al., 2016, p. 71).

Documents present robots as technological links to relatives and care/support professionals. Through monitoring functionality, robots open up the private domestic or institutional environments to a positively connoted surveillance. Furthermore, some robots intervene to make the living environment safer, e.g., by collecting obstacles from the floor (Fischinger et al., 2016) or lighting hallways (Kompaï Robotics, 2018).

The elderly's activeness is an essential part of the narrative of prolonged independent living because it is assessed as having a positive effect on the elderly people's health and capabilities to live on their own. On the one hand, elderly people are still active and healthy enough to live on their own and use a supportive robot appropriately. On the other hand, the robots enable this situation by being a safety net and a means for preserving the capabilities of the elderly that are necessary for their independence. Even in cases of R&D in which potential users are described as being increasingly restricted, e.g., as 'severely', 'chronically sick persons', or shown as lying in bed, the robot's purpose is described in terms of activation of the individual, for 'support and instructional help […] and to promote self-initiative' (Graf et al., 2004, p. 194). In their publications, roboticists even envision the elderly users of robots with dementia as activated by robots providing social interaction, entertainment, cognitive

stimulation, or reminders (e.g., Naroska et al., 2018). Thereby, the scope of activation is different but yet elucidates the persisting theme of the elderly at risk, in need of protection and activation (Q41–Q45). This common representation of the elderly users is closely related to the absence of dying users.

4.3. Absent users in care robotics: the dying elderly user

The search for and analysis of documents showed that, with one exception (Mackey et al., 2020), there is an almost complete absence of dying users in roboticists' publications. Furthermore, in my interviews with roboticists, these issues only emerged in response to my explicit inquiry into these matters.

4.3.1. The discursive absence of users in robotics

This absence does not mean these topics have not been discussed at all in wider academia. I identified a small number of publications on robots in care related to the end of life from nursing sciences, bioethics, law, and design studies (Q46–Q50). One paper in a palliative care journal explores the potentials and impacts of robots in this field. It links the robots to similar tasks as the roboticists' discourse, such as interacting with patients, transporting things, or monitoring patients (Nwosu et al., 2019). Other articles discuss personal autonomy considering robot-supported assisted suicide (Beck, 2018; Tonkens, 2015). The design installation 'Last Moment Robot' reflects the possibility of creating intimacy by a robot patting the arm of and talking to a dying patient (Chen, 2012, p. 33):

> 'The process of dying is probably the most vulnerable moment of a human life – a moment in which one seeks the reassurance of human connection. In this installation, human presence is replaced with a robot, questioning the quality of intimacy without humanity.'

The designer put forward the idea of robots as imperfect but nonetheless valuable means given the worse alternative of entirely missing personal care (TEDx Talks, 2016).

These deliberations show that connecting robots with dying users is nothing unthinkable in principle. The absence of the dying users is meaningful because there is an ‘arguable alternative of presence’ (Schröter & Taylor, 2018, p. 6) beyond the boundaries of the field of care robotics. The roboticists’ documents, in contrast, hardly touch upon dying and end-of-life care, let alone highly controversial topics such as assisted suicide. They do not refer to the publications described above, neither in an affirmative nor in a critical manner. This absence of elderly users in the process of dying is in line with the dominant user representation in robotics. In focussing on active and healthy elderly living independently, the end of this phase of life only appears as an implicit negative reference point. In the robotics discourse, the robot pushes the undesired future, the onset of dying, further away. The robots support activation, monitor the health status, or provide further means to ensure the safety and health of the elderly. The dominance of this narrative of activation and independence appears as one reason for dying elderly as absent users of robots in care. The discourse does not consider the biographical turning point, after which activeness dwindles and the need for external support, beyond the means of the robots (see section 4.2), increases.

The incompatibility of the dominant user representation with a potential dying user becomes tangible by looking at the sole publication from robotics dealing with palliative care. It describes a telepresence robot prototype that should enable the dying elderly to virtually leave their homes. The envisioned function of this robot shifts compared to other telepresence robots. Instead of monitoring people at home, telepresence here is a means to virtually leave home. The publication aligns the robot with a core goal of palliative care, improving quality of life through not only addressing physical but also psychosocial and emotional needs (Radbruch et al., 2009). It links its ‘robot surrogate’ to psychological issues identified in end-of-life care patients:

> ‘Patients in palliative (end-of-life) care are likely to be at risk of mental health issues, with some experiencing helplessness, depression, demoralisation syndrome, and even suicidal thoughts.’ (Mackey et al., 2020, p. 585)

The contrast of this user representation to that of the active elderly is apparent. The study identifies the users as ‘patients’ with specific health conditions, and not as active or independent elderly members of society. The user representation differs markedly from the healthy and independent users of robots in care in the robotics discourse: it is not about preserving health and independence anymore but about mitigating the negative emotional and psychological repercussions of dying.

Does this isolated deliberation on robots in palliative care contradict the determination of the absence of dying users in care robotics? I argue that this is not the case: although this publication considers dying users, it has not found an echo in this field’s wider deliberations.

4.3.2. Negotiating the absent users of robots in care

The interviews with roboticists were an opportunity to address the absent dying users of robots in care. Questions about the envisioned elderly users and the absent dying users stimulated deliberation on the roboticists’ experiences with users and provoked reasoning for/against the consideration of people dying as users. Roboticists reflected upon and negotiated these absent users and thereby also provided traces on how this absence came into being.

Before conducting interviews with roboticists, I considered the possibilities of dying and death being a societal taboo affecting this professional field’s discourse. Yet, the interviews showed hardly any traces indicating that they were reluctant to engage with or deliberately silenced this topic. The roboticists elaborated on dying and end-of-life care although they acknowledged the social sensitivity of these issues (Q51–Q55).

Except for one roboticist (IP4-R&D), the roboticists did not neglect the possibility to apply a robot in end-of-life or palliative care. Although they distinguished regular and end-of-life care, describing the latter as special (‘enormously sensitive area’, IP4-R&D, translated; ‘It is a very hard situation, very, very tough situation’, IP8-R&D), most of them emphasised the usefulness of technical support in end-of-life care. They expressed a need for technological support or reflected on specific tasks the robot could fulfil in end-of-life care situations but linked this to

an abstract deliberation about the desirability of robots in these situations: ‘It’s an ethical discussion’ (IP5-Management-R&D). Even one researcher who ruled out developing or testing their robots in end-of-life care settings on personal grounds did not reject this possibility in principle:

> ‘In general, I think it needs to be done. Practically, I don't think that I am the right person to do it. […] I am personally feeling very uncomfortable to do these kinds of studies. I don't want to be disturbing […] in this particular situation with my robotic studies.’ (IP8-R&D)

Without conveying a full concept of good end-of-life care, the ideals of peaceful and socially embedded dying were present in the roboticists’ accounts. They reproduced the narratives of a care crisis and possible lack of caregivers in a slightly different shape when deliberating on the use of robots in end-of-life care. They presented the robot as a better alternative to a lack of support at the end of life:

> ‘You are just happy to speak with something [a robot], if there is nobody who has time to speak with you.’ (IP3-Marketing)

> ‘When you are at the end of life yourself, and you have a choice, you can be petted by a robot or be left alone completely, what would you prefer?’ (IP5-Management-R&D)

From this perspective, the robot, though not an adequate substitute for human presence, could mitigate some repercussions of the care crisis that would strike end-of-life care and lead to undesired situations, such as patients being left alone. The roboticists made sense of robots in end-of-life care by drawing on the common narrative of a care crisis that justifies the development of robots for elderly care in general. The care crisis and the technical solution are inescapably linked together, even considering the (hitherto) absent users. In the interviews, the roboticists aligned the otherwise absent users with the field’s overall rationale

for building robots. Against this background, their absence in the wider discourse seems even more surprising.

4.3.3. Robotic capabilities and requirements of end-of-life care

Asked about dying people as users of their robots, roboticists negotiated the absence by focussing on the connection between the robots' technical capabilities and their representation of the dying users. In general, roboticists' publications and other documents present a positive vision of robots to address the challenges and demands of elderly care. Concurrently, and sometimes in contrast to such optimistic assessments, several interviewed roboticists evaluated their own and other robotic developments as immature technology for the time being (Q56–Q63):

> 'We are very, very, very far from long-term independent deployments of robots in peoples' homes.' (IP8-R&D)

> 'The robustness in the operation is still missing. […] The real world is changing all the time. We don't think we can achieve full automation for the next twenty years. The robot simply does not have enough real-world knowledge.' (IP5-Management)

Roboticists identified technical limitations and issues impeding the use of robots for regular care tasks, including insufficient orientation, manipulation, recognition, or social interaction in unstructured environments such as private homes. They also referred to the necessary approval as a medical product as a reason delimiting the use of the robot in close interaction with a care recipient's body (e.g., drawing blood). The robots' technical inability to provide certain care activities becomes apparent in the roboticists' emphasis of the non-replacement of human caregivers:

‘Everybody will start to say: “Oh, you want to steal jobs from caregivers. You want to put robots in place of caregivers – and what is about the human touch?” […] Luckily, my answer is: Our robot cannot do that.’ (IP7-R&D)

Thereby, the documents and the interviewed roboticists vaguely identified genuinely human aspects of care a machine cannot substitute, such as ‘the unique presence of human assistance’ (Kompaï Robotics, 2019) and the ‘human way’ (IP1-Management, translated) of care. However, even these imprecisely defined boundaries may be transgressed in cases of a lack of human alternatives; a stance similar to that of the designer of the Last Moment Robot described above (Chen, 2012; TEDx Talks, 2016).

Evaluating their robots as technically too immature, the roboticists assessed their robots’ implementation in a sensitive and demanding setting such as end-of-life care as especially out of scope for the time being:

‘I think we are all aware of the technical limitations that are still there in the interaction with the robots somehow. Well, I think there is the feeling that you would use a very immature tool in an enormously sensitive area. […] You do not operate with a sword. You need other tools, you need to have another maturity in order to start thinking about probably using it in the first place.‘ (IP4-R&D, translated)

The roboticist frames the robot as a coarse tool (‘sword’) that does not fit the requirements of sensitive care in end-of-life situations. Rather, a refined tool to ‘operate’, a *scalpel* to complete this surgical metaphor, is needed. Most interviewed roboticists did not deny the possibility to use a robot in end-of-life care per se, but they saw the realisation of this in a distant future and dependent on further technical improvements.

The roboticists’ reasoning on not using robots in end-of-life care voiced in the interviews does not necessarily reflect the cause of the discursive absence of the users in the first place. However, their negotiations nonetheless provide insight into one factor that could be related

to the absence of users: that of a perceived mismatch between technological capabilities and the dying users' demands and needs. They retrospectively justified the absence based on the technological state of the robots. Thereby, they aligned the technological capabilities with the dominant user representation of the active elderly.

4.3.4. Absence by research design

The dying users have not only disappeared in the process of presenting robots in publications. Their absence does not seem to be linked to deliberate silence on behalf of the roboticists. Rather, the roboticists reported a lack of work experience with robots in end-of-life care settings or with dying users in the first place. The discursive absence mirrors a physical absence of research participants at the end of their lives:

> 'This is […] something we do not have any experience with.' (IP1-Management, translated)

> 'We didn't have any test sites or any experiences in these settings.' (IP8-R&D)

Questioned about dying users, the roboticists did not report that they intentionally avoided end-of-life situations in their studies. Rather, their non-experience can be interpreted as connected to the design of experiments and field trials. Experimental trials with robots often only involved participants over a short period of time and in closely controlled and monitored tests (e.g., Fischinger et al., 2016; Papadopoulos et al., 2020; Stogl et al., 2019; Zlatintsi et al., 2018). These research designs made dealing with dying users unlikely because terminally ill or moribund elderly would not have been selected for this kind of trial. Furthermore, it seems unlikely that the health of the elderly participants would have deteriorated in the short timeframe of an experimental trial. Thus, dying users appear to be absent because of the design of research and testing processes. Even the first experimental trial with a robot for palliative care comprised healthy young research participants (Mackey et al., 2020).

In other cases, roboticists conducted longer-lasting field trials with elderly participants in private homes (e.g., Cortellessa et al., 2015) or care facilities (e.g., Mannion et al., 2019). In related publications, dying users are absent too, although declining health in principle could have occurred over the course of the weeks-long participation of elderly people. In most of these field trials, people with specific needs and capabilities were selected, e.g., with minor or moderate impairments but still living relatively independently and thus in line with the dominant user representation (Q64–Q67). Or, people with declining health were excluded from ongoing trials. One study reported the case of a female participant with 'deterioration in her health status and frailty' (Cortellessa et al., 2015, p. 7) and the subsequent removal of the telepresence robot because of an increasing need for assistance that led to her relocation to a nursing home (Q68).

Although articles rarely outline such exclusion criteria, it is reasonable to assume that the selection of elderly participants in other field trials happened in line with the idea of excluding specific vulnerable (or unsuitable) groups too, e.g., those with declining or already poor health. Since participation in experiments and trials was voluntary, elderly people in overall good shape and health may had been more prone to participate in research than those with poor health. Thus, the probability to encounter end-of-life care or a dying process in these field trials despite their longer timeframe seems relatively low. Thereby, the roboticists' own ideas and norms of appropriate trial participants, the assessment of gatekeepers such as professional care staff pre-selecting participants (Papadopoulos et al., 2020), or requirements from ethics committees could have been reasons for the exclusion of people closer to the end of life. Further investigation of participant recruitment seems necessary to examine these hypotheses in depth.

5. Discussion

Research on user representations has focussed on those users and non-users considered in R&D practices and discourses (Hyysalo & Johnson, 2016; Oudshoorn & Pinch, 2003). Going

beyond these users of concern, this paper has drawn attention, conceptualised, and empirically explored *absent users* in R&D as a previously unaccounted third category of users besides users and non-users of technology. The study illustrated the concept of absent users and identified concrete conditions of user absence in R&D by empirically investigating the field of care robotics, drawing attention to the absence of dying elderly users therein.

Studying and making visible absent users can contribute to confronting social inequalities and power structures. Absence can be based upon and/or reproduce and reinforce societal stereotypes and inequalities (Murray & Lambert, 2019). Furthermore, it may lead to technological designs and functionalities unsuitable or unacceptable for certain user groups. Researching absent users of technology may help to anticipate challenges in the (future) application of a technology. For example, an implementation of robots in care settings that is unreflective of the heterogeneity of elderly robot users and unaware of the absent dying elderly may provoke social problems and inappropriate care situations. Although the technological capabilities of the robots may not suit the needs of dying users, it is reasonable to assume that robots will be used in end-of-life care situations nevertheless, at least by accident, given the interweaving of ageing and dying. By focussing on activating users, care robotics may reproduce a (historic) stance of medicine that activists, researchers, and professionals have scrutinised since the 1960s: the focus on treating and curing patients but partially neglecting or not accepting the inevitable process of dying (Clark, 2002). Technical products may negatively affect people not envisioned as users by the designers and engineers. An incident with a robot in a healthcare setting illustrates this. In a California hospital, a doctor communicated a terminal prognosis to a patient and his family using a telepresence robot. However, the patient could not hear the message mediated through the robot, so his granddaughter needed to repeat all information to her grandfather. The patient's family received this procedure negatively, and it provoked critical media responses (BBC News, 2019). The telepresence robot, though used to enable doctor-patient communication in line

with its design, was not in line with social norms at the end of life (e.g., compassion in communicating with patients and relatives).

The study illustrated how comparative analysis is vital for making absent users of technology tangible. An absent user of one technology might be of central concern in other areas of society and technology. Comparative approaches using several types of data and knowledge from different fields sensitise for user absences in a particular context. Only through comparison it is possible to identify user absences with respect to particular technologies and to substantiate the claim of it being meaningful, i.e., a really thinkable alternative. Triangulation of various data types and sources with regard to one subject or comparatively analysing different cases of absence helps to 'build a persuasive case for an absence' (Murray & Lambert, 2019, p. 101). Entering in a conversation with relevant actors involved in reproducing user absence, e.g., through interviews with speakers within a discourse, can be a means to approach the conditions and reasoning of user absence.

Thereby, researching absent users is not necessarily about finding distinct 'other' groups of users. In robotics, it was not the elderly in general that were absent as users but elderly people in a specific phase of life. It was the dominant representation of robot users as active and independent elderly that obscured potential elderly users with greater and more complex care needs. In line with this, users need to be understood as subjected to change over time in parallel with or even through using a technology.

In R&D processes, the participation of a wider range of social actors in envisioning new technologies could add reflexivity (Fischer, Peine, et al., 2020) and draw attention to the absence of users. At once, Peine et al. (2015, p. 3) argued that participatory processes themselves need critical examination because they are shaped by 'context, premises, methodological choices, stereotypes and discourses'. Participatory research and development processes could reproduce user absences by their own concept of adequate participants or participatory design, too (Bischof & Jarke, 2021; Herriott, 2012). Thus, critical investigation

going beyond dominant discourses and representations of users in a field is necessary to become aware of possible blind spots re-/producing the absence of user groups.

In addition, user absence in R&D discourses may mirror a physical absence of particular users due to practices and structures in research institutions, teams, and projects. My empirical investigation suggests that the organisation of technical trials of prototypes with elderly participants contributed to the roboticists' lack of experience and subsequent discursive absence of dying users. Other studies on technological developments in care/healthcare indicated that anticipated requirements from ethics committees may impede more inclusive design processes (Hsu et al., 2020). Furthermore, users who do not have the necessary capabilities to participate in experimental trials of technological devices may be substituted by proxies (Herriott, 2012). Thus, user groups may remain physically and subsequently discursively absent. And, although intentional silence on behalf of the roboticists did not appear to play a significant role in the absence of dying users, strategic and intentional actions to conceal or exclude particular users of other technologies need consideration nonetheless (Murray & Durrheim, 2019b).

The present study has several limitations. The identified processes related to absence do not represent the full scope of factors involved in the emergence of user absence. Although the combination of discourse analysis and problem-centred interviews was productive to understand the absent dying users, additional interviews, participant observations in R&D, interviews with elderly participants of trials or those involved in selecting participants could provide insights into further practices promoting absences. Comparative analysis of R&D policies and activities in different socio-cultural and -political contexts (e.g., Europe and Japan) could be expedient to identify and better understand societal and cultural factors contributing to user absence. Finally, the active role of users and other actors in co-constructing the technology and its absent users was beyond the scope of this empirical investigation but needs to be addressed.

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5.4 Paper 4: ‘Co-producing values and technology in a professional discourse: affirming, aligning, and adjusting digital technology and good palliative care’

Lang, A. (n.d.-b). Co-producing values and technology in a professional discourse: affirming, aligning, and adjusting digital technology and good palliative care. Manuscript.

The paper is complemented by comprehensive supplementary material. To improve the readability of the present document, the supplementary material is located in Annex C at the end of the dissertation.

Co-producing values and technology in a professional discourse: affirming, aligning, and adjusting digital technology and good palliative care

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Abstract

Values and norms are integral in envisioning, researching, developing, and using digital technologies for care purposes. They influence the design and implementation of technologies, and in turn, technologies affect values and norms. This interpretive study investigates this co-production of digital technologies and values and norms in palliative care. It analyses how digital technologies are discursively interrelated with professional values and norms. Analysing publications from palliative care, it reconstructs three discursive processes of co-production. First, the discourse on digital technologies *affirms* the relevance of palliative care as essential for end-of-life care. Second, deliberations *align* digital technologies with dominant values and norms of palliative care and thereby legitimising its use. Third, given the emergence of new socio-technical circumstances, the discourse determines the need for *adjustment* of palliative care to preserve its core values by reinterpreting its professional responsibilities. The study suggests considering the concurrent conservative and transformative processes in the co-production of technology and values/norms. Therefore, it proposes the tripartite concept of affirmation, alignment, and adjustment as heuristic for research in this domain.

Keywords: digital technology, discourse analysis, norms, palliative care, sociology of knowledge approach to discourse, values

1. Introduction

Innovation discourses have identified digital technologies such as telehealth as answers to the challenges of ageing societies and elderly care. However, these technologies are not only instrumental to support care activities. Rather, social practices and processes establish technologies, ageing, and care reciprocally (Peine & Neven, 2021; Roberts & Mort, 2009). Values and norms pervade these processes. They shape the vision, design, implementation, and assessment of technologies and are also transformed in these processes (Swierstra, 2013; van de Poel, 2021). Drawing on the case of digital technologies in palliative care, this paper further conceptualises the multi-layered relationship of values/norms and technology in care. Thereby, it draws attention to the interrelatedness of change and conservation in the co-production of technology and values/norms.

Multiple ethnographic inquiries have examined how actors involved in designing, testing, and using new technologies for elderly care create desirable technology, old age, and care at once. Amongst others, they demonstrated how telecare explicates and shapes what good care means (Pols, 2012), how installing telecare promotes the notion of 'good ageing' as secured 'ageing in place' (Aceros et al., 2015), how utilising telecare disassembles care into the different domains of physical care, socio-emotional care, and monitoring (Roberts & Mort, 2009), how telecare creates and shifts responsibilities in care (Mort et al., 2003; Oudshoorn, 2011), or how sensor-floor alarms create tensions between security and privacy as values of care (Grosen & Hansen, 2021). Another branch of studies explored how innovation policy discourses promoted specific representations of elderly people and concepts of good ageing (Greubel et al., 2021) or interconnected new technology with health and elderly care (Lievevrouw et al., 2022; Lipp, 2019). The present study adds to this body of research by focussing on a level between ethnographic research and analyses of innovation policy discourses. It empirically explores and conceptualises how discursive practices 'co-produce' (Jasanoff, 2004) digital technologies together with norms and values of care within a particular professional field.

In this paper, I investigate the palliative care discourse on digital technologies, which include electronic health records (EHR), telehealth systems, care robots, artificial intelligent (AI) systems, or the internet, as a '*special discourse*[] performed in closed arenas for special publics' (Keller, 2021, p. 38). Therefore, I analyse publications from this field through the lens of the Sociology of Knowledge Approach to Discourse (SKAD) (Keller, 2021).

I show how the call for digital technologies in palliative care is discursively intertwined with the reinforcement of palliative care as necessary for people at the end of life (*reciprocal affirmation*). Then, I trace how technologies are aligned with elements of good palliative care (*technology-value alignment*). Finally, I outline how the profession adjusts itself to adequately consider seemingly inevitable technological developments while securing its core values and norms (*socio-technical adjustment*). Concluding, I discuss the significance and limitations of this tripartite conceptualisation of the co-production of technology and social values/norms. I emphasise the need to consider and analyse the co-occurrence of conservation and transformation of values/norms with regards to the introduction of new technologies.

2. Background

Values can be defined as 'lasting convictions or matters that people feel should be strived for in general and not just for themselves to be able to lead a good life or to realize a just society' (van de Poel & Royakkers, 2011, p. 72). Norms are more concrete directives to realise values and related objectives (Swierstra, 2013; van de Poel & Royakkers, 2011). For example, quality of life (at the end of life) is a key value of palliative care and is realised through the norm of holistic care, which means addressing not only physical pain and symptoms but also psychological, emotional, spiritual, or existential suffering (Clark, 2007).

2.1. Co-producing values, norms, and technology

In order to 'avoid both social and technoscientific determinism' (Jasanoff, 2004, p. 20) in researching science and technology, the interrelations between technology and values/norms

needs to be understood as mutual. Technology and social orders are concurrently 'co-produced' in envisioning, developing, and using technologies (Jasanoff, 2004).

Studies on expectations in science and technology (Borup et al., 2006; Sovacool & Ramana, 2015) or sociotechnical imaginaries (Jasanoff, 2015; Mutter & Rohracher, 2022) have shown how envisioned futures with technologies are value-laden and normative. Others have outlined, how in R&D processes values and norms are 'inscribed' into the design of technological devices, which suggest a certain use. At once, these inscribed values and norms may also be transformed through practice (Akrich, 1992; see also Woolgar, 1990).

Social actors assess technologies against values and norms. At the same time, technologies have the power to change values and norms, create new responsibilities, and raise ethical questions (Jasanoff, 2004; Miller, 2021; Swierstra, 2013; van de Poel & Taebi, 2022). There are different types of technology-related value change. New values can emerge, existing ones can be applied for the first time to a technology, values can be re-prioritised, re-conceptualised, or re-operationalised (van de Poel, 2021). Thereby, values may not radically change but be transformed in a 'gradual process' (Melnyk, 2022, p. 424).

The present study traces this reciprocal relation between technology and professional values/norms. It suggests a tripartite conceptualisation to draw attention to discursive dynamics in the co-production of technology and values/norms (affirmation, alignment, adjustment) that are based on common stocks of knowledge in social arenas such as professions.

2.2. Good palliative care and digital technology

Professions identify and prioritise values and norms and institutionalise them through, e.g., standards, organisational structures, or education (Moyo et al., 2016). Adapting Pols (2012, p. 45) concept of *good care*, I understand *good palliative care* as values of what is important in end-of-life care combined with norms of how to accomplish associated goals.

Over time, professional values and norms may change. For example, disclosing a terminal prognosis to patients was not as common in the 1960s, before the advent of hospice and palliative care, as it is today, where this is 'generally considered standard practice' (Stacey et al., 2019, p. 212) in healthcare.

Although palliative care professionals are most often not primarily concerned with technology development, they support R&D, adopt, refine, and implement new technologies. In installing technical devices in care settings, particular care arrangements and practices are created (Sánchez-Criado et al., 2014). As intermediaries between technologies and patients/relatives, professionals inhibit an important role in this co-production of good palliative care and technology (Saborowski & Kollak, 2015). In discursive and 'practical tinkering' (Mol et al., 2010, p. 13), different ways of good palliative care with/out technology are negotiated.

The case of digital technologies in palliative care is particularly interesting for studying the co-production of technologies, values, and norms. The hospice movement and palliative care grew out of discontent with medicalised dying in hospitals. Instead of potentially pain- and stressful yet probably futile medical treatment at the end of life using medical technology (*high-tech*), hospice and palliative care aim to increase the quality of life patients (Clark, 2007) (*low-tech)*. Therefore, open communication about and acceptance of death on behalf of patients, caregivers, and relatives is deemed a precondition for adequate care (Zimmermann, 2012). Ideally, palliative care should be patient-centred, holistic, and interdisciplinary. Professionals are expected to understand the patients as individuals, respect their autonomy, and cater to their multidimensional needs on a physical, psychological, emotional, spiritual, and social level (Clark, 2007). Although low-tech dying at home and high-tech dying in hospitals are often juxtaposed and related to either good or bad dying (Lang, 2020), this dichotomy dissolves in practice (Timmermans, 1998).

Compared to medical technologies, digital technologies in palliative care have not received much attention from science and technology studies (Sas et al., 2019). Pols' (2012, Chapter 2) ethnographic study is a notable exception. She analysed the use of a telecare device to

report symptoms and needs in home care for terminally ill people. She showed how palliative care patients and professionals 'fitted' telecare technology, care, and the involved humans. Dealing with new technologies, actors explicated values and practices of palliative care and renegotiated them. In practice, technology was entangled with 'cold' (rationale/instrumental) and 'warm' (personal/emphatic) care at the same time (Pols, 2012; Pols & Moser, 2009). Furthering these insights, my study employs a broader focus on how this field's professional discourse co-produces digital technologies and norms and values.

2.3. The discursive co-production of values, norms, and technology

This study draws on the interpretive Sociology of Knowledge Approach to Discourse (SKAD) as research heuristic (Keller, 2021). The SKAD brings together Foucauldian discourse theory (Dreyfus & Rabinow, 1983) with the sociology of knowledge in the tradition of Berger and Luckmann (1991). It focusses on the 'discursive construction of reality' (Keller, 2021, p. 50) and defines discourses as 'regulated, structured practices of sign usage in social arenas' that 'institutionalize a binding context of meaning, values, and actions/agency within social collectives' (Keller, 2021, p. 36). Thereby, the SKAD assumes that discourses are instructing social practices and are results of social practices. Actors are themselves '(co-)constituted' (Keller, 2021, p. 38) through discourses ('subject positions') but nevertheless have agency to shape and transform discourses depending on their 'speaker positions' (Keller, 2021, p. 39).

The study is concerned with deliberations on digital technologies in the field of palliative care as '*special discourse*[] performed in closed arenas for special publics' (Keller, 2021, p. 38) – professional caregivers and academics in palliative care – in contrast to broader 'public discourses' open to more diverse speakers and audiences. Discourses constitute phenomena such as digital technologies in palliative care through an arrangement of different elements (Keller, 2021, pp. 43–47). They entail and provide 'interpretive schemes' as typical representations or problematisations of a situation or phenomenon. Phenomena of concern are then discursively structured by linking such problematisations to particular causes, identifying and characterising relevant causalities, impacts, actions, actors, values, and norms

(‘phenomenal structure’). Narratives consolidate and mediate the various discursive elements by linking them into a ‘coherent, portrayable, and communicable form’ (Keller, 2021, p. 47).

In the special discourse around digital technology in palliative care, technological devices and their use are envisioned, presented, and legitimised or criticised. Thereby, technology and palliative care are rendered meaningful by combining stocks of knowledge relevant to the situation (e.g., about the state of palliative care, roles of professionals, patients and relatives, technological developments) with values and norms. In empirically investigating this entanglement, it is possible to reconstruct interrelated processes of a discursive co-production of values/norms and technology.

3. Methodology and data

For this study, I analysed articles from journals dedicated to palliative care as an academic and practical topic. These journals represent a relevant segment of this profession’s discourse. For example, several are official journals of palliative care associations (list in supplementary materials, section 1). Additionally, I explored palliative care guidelines to understand how digital technologies have been considered in more general discussions as well as selected widely-cited papers from *The Lancet* and *The New England Journal of Medicine* on digital technologies in palliative care during the COVID-19 pandemic.

I used abstract databases (MEDLINE, CINAHL, Scopus) and the journals’ tables of content to identify articles on concrete digital technologies or digitalisation in general. I searched for publications negotiating and (de-)legitimising digital technologies and palliative care in presenting empirical studies, trials, and devices, or in discussing the (digital) state and future of this profession. I strived for some variation considering the type of technology, regional context, year of publication, and type of paper. The process of searching, selecting, and analysing documents was iterative. Based upon preliminary findings, I determined relevant

themes and searched for further publications. I also identified key publications quoted by multiple analysed documents.

Overall, I analysed 99 documents (list in supplementary materials, section 2). These included original research articles (n=32), editorials or commentary (n=31), reviews (n=12), guidelines (n=10), case reports or brief notes (n=8), or descriptions of technical systems (n=6). The documents present their own development or testing of digital technologies, review, discuss, or comment upon others' R&D or digitalisation in general. They deal with telehealth (n=40), EHR (n=16), social media (n=10), or internet websites (n=7) (I subsume inconsistently used concepts such as 'telemedicine' (Saysell & Routley, 2003), 'telehospice' (Whitten et al., 1998), or 'telecare' (McCall et al., 2008) as 'telehealth' (Carrasqueiro et al., 2017). Several articles address digital technologies or digitalisation in general (n=16), but only few deal with virtual reality (VR) (n=3), robots (n=4), artificial intelligence (AI) systems (n=3), or ambient assisted living (n=2). Most papers are from authors affiliated to organisations in Europe (n=46), North America (n=41), or Australia/New Zealand (n=11), fewer from Asia (n=7), Africa (n=3), or South America (n=2). Articles are primarily by professionals from palliative care organisations and services, related areas of healthcare, and/or in research institutes dealing with palliative care. Authors sometimes inhibit(ed) key positions in palliative care professional associations (e.g., board members), publishing (e.g., editors), or research and education (e.g., university professors).

I read and re-read the documents sequentially and developed and applied codes to text segments. Initially, I employed line-by-line coding, especially for the opening parts of documents that outline rationales for discussing, developing, or applying digital technologies. Later, I used focussed coding for larger text segments (Charmaz, 2006, pp. 45–60). I actively co-constructed the discourse by identifying commonalities in and between different texts (Keller, 2021). In particular, I reconstructed the 'phenomenal structure' of digital technologies in palliative care. The analysis benefitted from this 'sensitizing concept' (Keller, 2021, p. 43)

by being continuously stimulated to reflect the interwovenness of professional values/norms with stocks of knowledge about technologies and palliative care.

I used ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH, 2019) for organising data analysis. In presenting my results, I only cited a selection of papers and quotes. However, I included additional illustrative quotes (referred to as Q[i]) in section three of the supplementary materials.

4. Co-producing digital technologies and good palliative care

Articles in palliative care journals have been dealing with digital technologies since the 1990s. In the early 1990s, publications have started to address EHR and databases to collect, store, and share patient data (Higginson et al., 1992; Mercadante & Lanza, 1994). A few years later, telehealth for monitoring and supporting patients, professional communication, or virtual visits of relatives became a topic (De Conno & Martini, 1997; Whitten et al., 1998). With increasing internet use in the late 1990s, authors turned towards the world wide web for palliative care information, communication, or online support-communities (Pereira & Bruera, 1998; VandeKieft et al., 2001). Later, publications started dealing with the application and impacts of social media platforms for information sharing, collaboration, or advocacy (Granger, 2014; International Association for Hospice & Palliative Care, 2019; Taubert et al., 2014). Other technologies such as VR (Lloyd & Haraldsdottir, 2021; Niki et al., 2019), robots (Nwosu et al., 2019), or AI (Chan et al., 2019) in palliative care have been less and rather recently thematised. Lately, the COVID-19 pandemic stimulated debates on and use of digital technologies in palliative care (Chua et al., 2020; Ritchey et al., 2020).

Apart from journal publications, some palliative care associations issued guidelines and strategy papers that also dealt with telehealth or the internet for supporting palliative care (Bishop et al., 2015; Hospice UK, 2021; International Association for Hospice & Palliative Care, 2019).

Although technological possibilities and social conditions have changed, common discursive elements across documents and over time can be reconstructed. The publications do not merely present digital technologies, their functionalities, use, effects, and acceptance in palliative care. Rather, they elaborate on the state and future of palliative care, its challenges and requirements, and the embedding as well as effects of digital technologies in care. Thereby, they draw on and negotiate its professional values and norms.

4.1. Reciprocal affirmation: digital technologies enabling palliative care

A key rationale for the use of digital technologies in the documents is based on the projection of a care crisis. An ageing society leads to an increase demand for palliative care but also to a shortage of professional caregivers. Documents problematise the state and future of palliative care and identify digital technologies as solutions to mitigate the repercussions of the care crisis (Q1–Q18):

> *By adopting new technology we will be able to provide needed hospice services in today's projected decades of nursing shortages. These services will be sorely needed to attend to the mushrooming elderly populations who are now coming to hospice with multiple and more challenging needs. (Kinsella, 2005, p. 721)*

> *Telecare and other developments in information technology are increasingly being sought as a means of addressing shifting population demographics and rising demands on stretched health services […] (McCall et al., 2008, p. 426)*

Digital technologies should bring palliative care to homes and patient groups otherwise insufficiently covered by palliative care services by providing direct contact between palliative caregivers and patients (Q19–Q24). Furthermore, they are intended to connect caregivers with and without palliative care skills. Videoconferences for expert consultations and

information retrieval and support over the internet should enable every caregiver to provide some level of palliative care (Q25–Q30). Thus, technology directly and indirectly widens and improves access to this kind of care. The COVID-19 crisis appears as an additional load on strained palliative care systems. According to several documents, this acute crisis should be mitigated by rapid implementation of digital technologies in palliative care (Q31–Q37).

Thus, on the one hand, social conditions affirm and legitimise the introduction of digital technologies in palliative care. Digital technologies are described as solutions to ostensibly widely recognised problems. On the other hand, this whole rationale of widening palliative care access hinges on the assumption that palliative care and associated ways of support are, in fact, 'essential' for people at the end of life. Palliative care appears as a necessity and state of the art, and thus needs to be promoted by technological means (Q38–Q42):

> *The COVID-19 pandemic posed a threat to essential palliative care services, including building connections between patients, families, and healthcare teams; mitigating isolation, loneliness, and fear; managing symptoms; determining care priorities in the face of life threatening illness; and promoting comfort, connectedness and dignity during the dying process. (Ritchey et al., 2020, pp. 992–993)*

> *Palliative care has developed rapidly during the last 60 years and is an essential part of modern health care. […] Given that the field of palliative care is expected to expand, it might be beneficial to think in terms of new and innovative ways to provide care, such as the implementation of telehealth (Jess et al., 2019, p. 943)*

Introducing technologies is about enabling 'essential' palliative care without which the well-being of patients at the end of their lives and of their patients seems at risk. The description of digital technologies as necessary to provide palliative care *at all* is central to this discourse. Without digital technologies, widely available palliative care seems to be difficult or impossible

to realise (under the given circumstances). By identifying these technical solutions (digital technologies) to problems (palliative care crises), the discourse reinforces the fundamental assumption of palliative care as a necessary approach to end-of-life care. The importance of palliative care is co-produced with the requirement of developing and implementing digital technologies. In this discourse, *digital technologies in palliative care are essential because palliative care is essential.* It is not only about seeking a technological solution to a particular problem; the technological solution itself refers back to the assumption on which the problematisation of the situation rests. I understand this process of co-producing technology and good palliative care as *reciprocal affirmation*. The discourse *reciprocally affirms* the value of palliative care per se in thematising the need for a technological fix in the given situation.

4.2. Technology-value alignment: good palliative care and digital technologies

Based upon this call for palliative care/digital technologies, documents elaborate upon the technical realisation of good palliative care. For example, they present virtual reality as a tool to better manage pain and symptoms and thus increase quality of life (Q43–Q45), telehealth solutions (Q46–Q49) or EHR (Q50–Q53) to improve interdisciplinary care, and virtual visits to prevent dying without family presence in times of COVID-19 (Q54–Q57). In the following, I will draw on *communication* as an example to show how the discourse *aligns* digital technologies and elements of good palliative care.

Communication represents one key element of good palliative care, and documents explicate this repeatedly. Articles identify continuity, openness, and compassion as desired qualities of communication and, furthermore, frame successful communication as a prerequisite of other aspects of good palliative care, such as patient-centredness and ultimately patient autonomy (Q58–Q64):

> *Palliative care prides itself on its patient-centred focus, where clear and open communication with the patient is a cornerstone of good practice (Smyth, 2017, p. 523)*

The texts invoke the significance of communication for good palliative care and reconcile it with the purpose of the digital technologies. Digital technologies do not only appear as indispensable tools to enable palliative care access but also as *aligned with* particular forms of communication as key elements of good palliative care. They mirror and support the realisation of communication. Thereby, their use is about increasing the quantity, reactivity, and quality of communication. Documents envision more frequent and immediate communication between professionals and patients/relatives by using telehealth systems (Q65–Q68), which furthermore add a crucial visual component (Q69–Q70). Documents describe how telehealth supports professionals to detect problems at an earlier stage than with personal visits and enables more immediate relief of suffering:

> *Telepalliative care holds promise for […] reducing patient and family caregiver illness-related burden, offering real-time monitoring and management of symptoms, and proactively identifying new or unexpected functional decline. (Calton et al., 2019, pp. 981–982)*

According to the documents, telehealth monitoring systems would allow patients to transmit their status, needs, and requests to professional caregivers via structured self-reporting tools, text-message functionality, or automatic monitoring of health parameters at any time. Thus, palliative caregivers could *be there* for their patients more immediately. Using digital solutions, professionals could 'as-needed, when-needed' (Kinsella, 2005, p. 711) respond to the various and complex needs of patients and their family caregivers. Furthermore, it is about diversifying and widening the circle of contacts. Online support communities could provide additional information as well as social and emotional backing. Patients and relatives have the opportunity to engage with a broader variety of physically distant but nonetheless relatable social groups (e.g., other patients affected by a disease) than without technology (Q71–Q73).

In this and other instances, the documents *align technology with values/norms* of palliative care. *Value-technology alignment* means positively interrelating technologies with existing and institutionalised values/norms through discursive practices, and thereby justifying the adoption

of new technologies, but also to reproduce these values/norms in addressing and argumentatively mitigating technological threats to them. The documents do not only facilitate this alignment in highlighting the technologies' adherence to and support of professional values and norms (technology supporting pain and symptom management, accompaniment, interdisciplinarity, communication, etc.). They also reinforce the importance of key elements of good palliative care in addressing the risks digital technology poses to them. In the case of communication, documents invoke a common opposition between using technology ('high-tech') and providing personal palliative care ('high-touch') as well as the risk of depersonalised care through quantifying and standardising patient information (Q74–Q76):

> *[…] concerns remain regarding whether the intimacy and communication that is central to high-quality palliative care will be compromised by the use of this technology. (Ritchey et al., 2020, p. 992)*

In this and other instances, digital technologies risk corrupting the ethos and best practices of palliative care, in which compassion, intimacy, or trust are built and maintained through the direct interaction between caregivers and patients. However, the documents identify such concerns as rather unfounded. They repeatedly determine a 'false dichotomy' (Mills, 2019, p. 146) and reject 'the trap of "either/or thinking"' (Lynch, 1998, p. 157), thereby alluding to the possibility to adequately adopt and control digital technologies in palliative care. They deflect criticisms towards appropriate technological innovation by highlighting conditions and strategies to manage the different risks of digital technologies while at the same time benefitting from their implementation. In line with engrained values and norms of palliative care, an active stance and response of the profession facing challenges is demanded. The discourse conveys the necessity of *adjusting* technology and palliative care. This aspect of *socio-technical adjustment* becomes apparent when looking at another rationale for palliative care professionals to deal with digital technologies.

4.3. Socio-technical adjustment: widening good palliative care

A common diagnosis in palliative care publications identifies an ongoing societal diffusion of digital technologies. Articles describe how digital innovations permeate all spheres of life and predict or report the inevitable confrontation of palliative care with new technologies. Palliative care should be prepared to deal with the impacts of new technologies by facilitating their appropriate application (Q77–Q82), by 'make it happen' instead of 'let it happen':

> *It seems it is no longer a question of whether palliative care will be affected by IT, rather, the real uncertainty is the magnitude of these effects and whether palliative care will choose a 'let it happen' or 'make it happen' approach. (Lynch, 1998, p. 161)*

Documents identify digital needs of patients and their families arising from their online presence in social media or from seeking information on the internet. They describe how palliative care professionals need to guide their clients in using new digital tools, such as the internet, for gathering information or leaving a digital legacy:

> *As online interactions become a norm in society, we need to engage and support a patient's digital legacy as part of our holistic assessment. (Coop & Marlow, 2019, p. 115)*

> *[…] Facebook may be our business in the same sense that preparing families for visitors, for funeral homes, and for the process of grief is our business. (Smith, 2011, p. 429)*

Discursively, palliative care adjusts to the changing conditions and needs of the patients by widening its own realm of responsibilities. The documents imply and determine the necessity to reflect the professions' stance towards technologies, to develop digital skills and knowledge, to facilitate technology uptake, and to actively mitigate possible risks. Otherwise, fast-paced innovation may catch palliative care professionals off guard (Q83–Q88). This adjustment transforms the role of professional caregivers and at the same time *reaffirms* holistic care and

patient-centredness as key elements of good palliative care; alignment and adjustment occur as interlinked and simultaneous processes.

The documents highlight the profession's responsibility to proactively facilitate the uptake and implementation of digital technologies. Only then it seems possible to benefit from their advantages and to preserve good palliative care concurrently. On a more general level, articles present the implementation of digital technologies as a process of evaluating their merits and negative impacts through trials and research. They call for or conduct further research in order to be able to better understand the digital technologies' use in and impact on palliative care. On a more practical level, they outline the implementation of digital technologies as a process of carefully preparing organisations, staff, and patients and adapting the technology to the requirements in a given setting (Q89–Q93). Documents present lessons learnt from implementing digital technologies (Q94–Q96) or detailed guidelines for 'humanizing technology' (Ritchey et al., 2020, p. 994), 'top ten tips about telepalliative care' (Calton et al., 2019, p. 981), 'best practices for using telehealth' (Bishop et al., 2015), or instructions for 'webside manner' (Chua et al., 2020). These lessons and guidelines address systemic (e.g., reimbursement models), organisational (e.g., technical infrastructure or staff training), as well as micromanagement issues in implementing digital technologies (e.g., spatial conditions, webcam positioning, manner of conversation).

Overall, the discourse conveys the necessity of *socio-technical adjustment*. Technology needs to be adapted and used in ways to comply with and minimise risks for good palliative care. In turn, palliative care has to adapt to the socio-technical circumstances and technical devices, to adequately realise core values such as patient-centredness and holistic care. Palliative care as a profession and digital technologies as instruments need to be actively adjusted. This *socio-technical adjustment* is about the mutual transformation of professional practices and technological approaches and devices. It is about widening norms of good palliative care to incorporate digital technologies, but also about putting the latter to good practice. This is complementary to the processes of *technology-value alignment,* the argumentative equation

of available technology with dominant values/norms, and *reciprocal affirmation,* the reinforcement of basic values and assumptions, which can be understood as rather conservative.

5. Discussion

Analysing the empirical case of digital technologies in palliative care, this study reconstructed three interrelated discursive processes of co-producing technologies and values/norms. It drew attention to the concurrent conservative and transformative processes of a profession encountering and adopting new technologies.

Reproducing a rationale to address looming and acute care crises with digital technologies, the analysed documents *reciprocally affirm* the importance and necessity of palliative care in itself. To adopt an expression of Jasanoff (2004, p. 17) describing the co-production of society and science in general, palliative care and digital technologies are 'each underwriting the other's existence' in this discourse. Digital technologies not only enable palliative care but also affirm its status as a basic necessity at the end of life. Given the common notion of technological innovation as a means or driver of transformation (Klecun, 2016), it is important to consider such conservative effects that consolidate social structures and practices as well as values and norms. Affirmation may be judged positively, as in the present case of palliative care, which has societally been assessed as a promoter of good dying (Lang, 2020). However, similar affirmative dynamics can be identified in other areas of technological development, too. For example, electric vehicles have been marketed as means for decreasing carbon emissions and thus addressing the climate crisis threatening our societies and ways of living. Thereby, electric vehicles affirm the value of the current system of private automobility and may perpetuate car dependency and associated negative impacts (Braun & Randell, 2022; Henderson, 2020). Others have highlighted the possible conservative impacts of artificial

intelligence systems which reproduce social inequalities, stereotypes, and power structures (Zajko, 2021).

Furthermore, the analysis has shown how technologies are justified by argumentatively *aligning* them with dominant professional values and norms. This process can be understood as an element of 'human-machine interfacing', which happens through practices 'by which elements in various forms are rendered available for one other' (Lipp, 2019, p. 12), such as technology and its users. Speaking of *technology-value alignment*, I foreground the discursive interfacing of technology and values/norms as a requirement of establishing an ostensibly successful implementation of technology in a professional field. In presenting and discussing digital technologies against the background of professional values and norms of palliative care, the various technologies are rendered acceptable for the seemingly low-tech/high-touch specialty of care. Drawing on Pols (2012) 'metaphor of fitting' to 'understand the goodness and badness of care' in relation to technology, the *alignment* can also be interpreted as a process of questioning or even overcoming the low-tech/high-touch divide. The discourse here assigns professional caregivers an active role in 'fitting' technology and the profession of palliative care. Their 'human touch', instructed by guidelines and rules, fits the technology to the normative requirements of good palliative care.

Across documents, the successful alignment depends on a reciprocal transformation of the technology and the profession. Consistent with an assumed societal technology-push affecting palliative care practices, the discourse engages in a *socio-technical adjustment* of the profession. Thereby, the stabilisation of good palliative care is interrelated to a widening of its norms. It is about adapting to and incorporating changing socio-technical circumstances. Along with Melnyk (2022, p. 422), this process can be understood as 'reinterpretation' of good palliative care 'due to new realities' rather than radical value change. The reinterpretation in the case at hand is as much about widening as it is about preserving key elements of good palliative care, such as patient-centred and holistic care. The discourse is not only about adjusting the profession. Technology is not only described to be used according to an

assumed ‘script’ (Akrich, 1992), e.g., following technical application guidelines. Rather, documents promote an approach on technology use in accordance with an engrained professional perspective towards patient-centredness and a deep-rooted (or even foundational) scepticism considering technology.

The notions of affirmation, alignment, and adjustment presented here could support the investigation of the co-production of values/norms and technology. Thereby, it is important to understand these notions as part of an integrated heuristic that goes beyond the analysis of either value change or the perpetuation of social values and norms through technology development and use. Rather, analysing the co-production of values/norms and technology means identifying the dynamics interrelating the consolidation and transformation of values/norms and technology.

The present study has several limitations. Although there have been efforts to establish a global consensus definition of palliative care (Radbruch et al., 2020), its values and norms differ depending on the sociocultural context (al-Awamer & Downar, 2014). However, publications were mainly from authors located in Europe, North America, or Oceania. Thus, it is reasonable to assume that the study reconstructed particular perspectives on good palliative care and digital technology.

Furthermore, articles published in palliative care journals only represent one segment of deliberations in the field of palliative care. Although I analysed some associations’ guidelines, it was beyond the scope of this study to collect and analyse documents from the wider field of palliative care (e.g., in education or advocacy). Several key documents presenting general standards for palliative care do not thematise digital technologies at all (Radbruch et al., 2009, 2010) or only marginally (WHO, 2018). Thus, the reconstructed discourse here should not be understood as a formative element of palliative care debates in general, but rather as a special sub-discourse within this profession.

Finally, the discursive dynamics of affirming, aligning, and adjusting values/norms and digital technologies do not necessarily have to be reflected in actual palliative care practice. Empirical

studies combining discourse analysis with ethnographic approaches investigating the conditions and effects (*dispositifs*) of discourses (Keller, 2021, pp. 41–42) could promote a more thorough understanding of the coincidence of conservative and transformative processes in R&D and implementation of technology in care.

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5.5 Paper 5: ‘The relations of discourses: an empirically informed heuristic concept’

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The relations of discourses: an empirically informed heuristic concept

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Abstract

This article proposes a heuristic concept of discursive relations based upon the comparative interpretive analysis of three discourses in line with the Sociology of Knowledge Approach to Discourse. Tracing the history of a discourse around robots in care, the study illustrates how discourses emerge and transform because speakers incorporate elements of external discourses into their own reasoning, thus building discursive relations. It identifies three primary modes of relations and important aspects in analysing these relations. First, the *sharing* of knowledge and discursive elements between seemingly unrelated discourses. Second, *contestation* as a form of negative relation between opposing discourses. Third, the *meaningful unrelatedness* between discourses leading to a significant absence of issues within a discourse. Analysing the relations of discourses can further our understanding of how discourses emerge and transform.

Keywords: Sociology of knowledge approach to discourse analysis, discursive relations, interdiscourse, robots in care, good dying

1. Introduction

Discourses are ‘regulated, structured practices of sign usages in social arenas’ (Keller, 2021, p. 36) that revolve around varying issues. Discourse analysis building upon the work of Michel Foucault (Dreyfus & Rabinow, 1983) has often focussed on ‘special discourses […] performed in closed arenas for special publics’ (Keller, 2021, p. 38) reproduced by experts and professionals who have the capability to shape symbolic realities and power relations in and beyond their fields such as medicine and public health (Schübel, 2016; Scott et al., 2017). Other research has investigated public discourses around particular issues of concern with a wider array of speakers and audiences (Cantoni et al., 2018; Keller, 2018; Lang, 2020). In reconstructing the shape, content, and effect of a discourse, discourse analyses demarcate the respective discourse’s boundary and distinguish them from other ones.

Social actors, including those producing and reproducing discourses as speakers, are constantly affected by multiple discourses (Keller, 2021, p. 39). In social situations and arenas, they ‘are all routinely both producing and awash in seas of discourses’ (Clarke, 2005, p. 145) and as speakers ‘are involved in an *interdiscursive process* of creatively drawing on the potential range of established discourses’ (Fairclough, 2013, p. 421). Research has to consider the multiplicity of influential discourses to understand a social situation (Clarke, 2005, pp. 145–179) and also has to pay attention to discourses less powerful or even absent (Schröter & Taylor, 2018). Given this multiplicity, distinctiveness, and co-occurrence of discourses, the question arises if and how discourses relate to one another. Focussing on particular texts and events, the Critical Discourse Analysis (CDA) has drawn attention to the ‘interdiscursivity’ as the incorporation and combination of different ‘discourses, genres and styles’ (Fairclough, 2013, p. 7). Thereby, the CDA assumes that speakers/texts selectively recontextualise external elements and change their meaning (‘appropriation’). At once, powerful discourses and actors may impose particular meanings and practices onto other social arenas (‘colonisation’) (Fairclough, 2013, p. 76).

Research has already dealt with the diffusion of discourses beyond the social arenas in which they emerge. Link (1996, 2012) devoted his attention to ‘interdiscourses’ defined as non-specialised discourses that interrelate and integrate elements of special discourses. These interdiscourses do not reproduce special discourses in their entirety but rather selective and have the power to interrelate different fields. An important element of interdiscourses are collective symbols such as metaphors or allegories. Examples of interdiscourses are popular variants of history, religion, philosophy, science, and other specialities that can be found across mass media, literature, film, or politics (Link, 1996, 2012).

Furthermore, Foucault (1972, pp. 157–160) identified ‘interdiscursive configurations’ as relations between different special discourses that could be reconstructed through comparative analysis. In this vein, Link (2013) identified interdisciplinary fields of science and research in which knowledge from other fields is integrated as arenas of ‘inter-special discourse[s]’.

Besides the relations of discourses emerging from the flow and transformation of knowledge from special to public discourses (*interdiscourses*) or between special discourses (*inter-special discourse* or *interdiscursive configuration*), other modes of how discourses relate to one another are possible. For example, science and technology studies and adjacent fields have established that discursively created socio-technical futures of novel technologies reinforce or transform public and policy discourses. Socio-technical futures draw on broader discursively reproduced societal norms, values, or narratives, including aspirational goals or expectations, and interlink them with technical innovation envisioned and developed in special fields (Lösch et al., 2019; Roßmann, 2021; Urueña, 2022).

In this paper, I want to further explore and systematise the various types of relations of discourses resulting from processes of incorporation of discursive elements and stocks of knowledge. Relations of discourses emerge when speakers introduce (and possibly adapt) components of a previously external discourse into discourses produced and reproduced by them. Thereby, it is not about a singular engagement of an individual speaker with other

discourses but the durable integration of these stocks of knowledge into a discourse's structure. Thus, discourses maintain an explicit or implicit relation to other ones. I propose a heuristic concept that sensitises for different forms of discursive relations. This heuristic is the result of a comparative analysis of special discourses in the field of robotics on robots in care, in palliative care on the use of digital technology in end-of-life (EoL) care, as well as of a public discourse on the characteristics, conditions, and requirements of good dying.

I draw on and extend concepts of the Sociology of Knowledge Approach to Discourse (SKAD) (Keller, 2011, 2021). The SKAD provides a theoretical and methodological framework to understand the 'discursive construction of symbolic orders' realised in social practices (Keller, 2021, p. 37). For analysing discourses, the SKAD proposes several sensitising concepts to grasp different elements of discourses. Although it focusses on the relation between discourses in 'discursive fields […] in which discourses are in reciprocal competition with one another' (Keller, 2021, p. 38) and acknowledges other relations between discourses (Keller, 2011, p. 324), these relations have received little attention so far.

I first outline the methodology and data for my conceptualisation of relations of discourses by sketching a series of discourse studies that formed the basis of my work (chapter 2). Then, drawing on the case of robots in care, I illustrate how a special discourse emerged through interrelating different discourses and stocks of knowledge (chapter 3). Comparatively analysing the three distinct discourses, I elaborate upon implicit relations between discourses that occur through *sharing* particular stocks of knowledge or discursive elements without having manifest documented interconnections (chapter 4). In chapter 5, I deal with relations emerging through explicit contestations between discourses or the anticipatory evasion of controversies. Besides these (more or less) tangible relations, I conceive expectable but unrealised relations between discourses, the discursive absence of issues (Rappert & Bauchspies, 2014; Schröter & Taylor, 2018), as *meaningful unrelatedness* (chapter 6). Finally, I discuss the concept of discursive relations, including its limitations and research desiderata (chapter 7).

2. Approach, methodology and data

This study is based upon three discourse analyses presented in detail elsewhere. The discourses neither had explicit relations in terms of common key documents or speakers nor dealt with the same issues of concern. They were about good dying from a sociopolitical perspective (Lang, 2020), robots in care from a research and innovation (R&I) perspective (Lang, n.d.-a), and digital technology in palliative care from the perspective of professionals of that field (Lang, n.d.-b).

First, I investigated a public debate that emerged around the parliamentary enquete commission on *Dignity at the End of Life* conducted between 2014 and 2015 in Austria. I reconstructed competing discourses on good dying by analysing a variety of documents, including parliamentary minutes, opinion statements from individuals and organisations, as well as news coverage (113 documents) (Lang, 2020). Second, I analysed a socio-technical futures discourse on robots in elderly care produced and reproduced by actors developing and promoting robots (*roboticists*) working in European research and development (R&D) contexts. My data consisted of 56 documents, including journal articles, research and technical reports, websites, videos, or brochures, as well as 9 problem-centred interviews with roboticists. Thereby, I focussed on how users at the end of their lives and dying remained absent in this special discourse (Lang, n.d.-a). Third, I traced how the discipline of palliative care discursively introduced digital technologies (such as telehealth systems, electronic health records, social media, the internet, virtual reality, or robots) considering their professional values and norms of good palliative care. I analysed a total of 99 articles foremost from palliative care journals, including original research, editorials, commentary, reviews, guidelines, case reports, notes, or technical reports (Lang, n.d.-b).

I chose these cases because of my interest in the absence of dying and death as issues in the discourse around robots in elderly care. I aimed to better understand the conditions of this absence (Lang, n.d.-a). Studying the palliative care discourse, I analysed the (possible) discursive consolidation of digital technologies (including robots) with palliative care (Lang,

n.d.-b). I used the discourse on good dying as a sensitising reference point for how dying and death are typically discussed in contemporary societies.

All studies were based upon the Sociology of Knowledge Approach to Discourse (SKAD). I used the SKAD's concepts of 'interpretive schemes', 'classifications', 'phenomenal structures', and 'narrative structures' as heuristics to support my systematic reconstructions of these discourses (Keller, 2021). Furthermore, I utilised methodological approaches from constructivist grounded theory (Charmaz, 2006) including theoretical sampling of documents as well as different approaches to sequentially coding the data (initial, focussed, and theoretical coding). The research design and data are presented in detail in the respective papers.

To analyse the relations of the discourses, I conducted a comparative analysis. For this purpose, I used the SKAD's heuristic concept of 'phenomenal structure'. This concept provides a 'point of access to the levels of content-related structuring of discourses' (Keller, 2021, p. 45) and highlights different dimensions of how discourses create the phenomena of concern, including causes, causalities, problem solutions, artefacts, actors, responsibilities, as well as norms and values. My comparative analysis started from my reconstructions of the phenomenal structures of each discourse and identified commonalities and differences between the discourses in line with these dimensions. After identifying intersecting issues, I revisited my original data and conducted additional fine-grained analysis of selected segments.

Before turning to the results of this comparative analysis, I illustrate how discourses can emerge by building relations between different discourses. I trace the emergence of the robots in care discourse beyond the European context and invoke insights from other relevant studies. Thereby, I reinterpret and apply my concepts of *reciprocal affirmation* and *socio-technical adjustment* that I have developed in the analysis of the palliative care discourse around digital technology. As outlined in my paper, the discourse around digital technology in palliative care interlinked the adoption of new technology with the *reciprocal affirmation* of the

importance of palliative care as such and the concurrent *adjustment* and modification of practices of good palliative care (Lang, n.d.-b). Here, these concepts support the understanding of how the interlinking of the roboticists' discourse with other discourses solidifies and modifies elements of this field's discourse.

3. Building relations: the case of robots in care

The emergence of the special discourse of care robotics can be interpreted as linking the industrial robotics discourse with wider societal discourses. Joseph Engelberger was among the first roboticists (see also Borenstein & Koren, 1985; Engelhardt, 1988) to propose the application of service robots in general and robots in care in particular. Engelberger had been co-founder of the robot manufacturer producing the first industrial robot in the 1950s (Gasparetto & Scalera, 2019) and in 1984 established the *Transitions Research Corporation*, which developed a transport robot for hospitals (G. Engelberger, 1998; Evans et al., 1989). In early deliberations on this topic, he set key arguments for the implementation of robots in care that have been discursively reproduced subsequently.

Engelberger (1989) predicted an ageing society and market demand for assistive technology and envisioned robots living in homes of elderly people, preparing meals and medicine, supporting mobility, offering fetch and carry services, or providing companionship within their technical capabilities (similar see Engelhardt, 1988). In problematising the demographic change, he and his successors have drawn on a discourse that linked an ageing society to critical challenges regarding care resources and the distribution of financial means. In the robots in care discourse, Lipp (2019, p. 55) identified a 'shift in discursive register from an "alarmist demography" (Katz 1992) to an opportunist economy, where demographic change and the elderly population are not primarily seen as a threat to society but rather an opportunity for technological innovation and economic growth'. From my perspective, this economic perspective is more upfront in R&I policy documents than in scientific and engineering publications. The dominant starting point of deliberations amongst roboticists is an alleged

care crisis. The alarmist statements have not been mere 'undertones' (Lipp, 2019, p. 60 footnote 24) but central to the discourse's structure (Lang, n.d.-a).

The roboticists' reasoning has been presenting robots as necessary to support care for people with disabilities or elderly people to aid caregivers and enable independent living and, thus, to mitigate these problems. Engelberger imagined robots in care comparatively to human workers, as machines discarded of human 'ballast'. As he claimed, '[…] a robot requires no personal time, not even for sleeping' (J. F. Engelberger, 1989, p. 215). In the emerging discourse, robots appeared as available around the clock, without the need for rest or sleep (except loading the battery), and never complaining. And, as industrial robots, robots could address 'some of the more stultifying, demeaning, and downright dangerous, human activities' (J. F. Engelberger, 1989, p. 129) or 'odious, routine, demeaning, and boring tasks' (Engelhardt, 1988, p. 820) in care.

At once, Engelberger's vision did not only entail possibilities opened up by a robot but also reproduced a vivid negative image of institutional care with human caregivers:

> *'No, the robot will not be a practical nurse; but a robotized private abode will be so much more desirable than being in a $25,000 to $40,000 per year nursing home, doomed to an elephant's burial ground, smelling urine unto death, and contemplating penury before blessed surcease.' (J. F. Engelberger, 1989, p. 217)*

The application of robots in care got legitimised by sketching worse and seemingly inevitable alternatives. This legitimisation strategy can be found later on in statements on robots in care (Lang, n.d.-a). Engelberger and his successors have envisioned the robot not only based upon an alarmist discourse of an ageing population but also vis-à-vis dominant social assumptions expensive yet undesirable institutionalised elderly care. They could draw on and therewith reproduced a persistent negative stereotype of nursing homes as institutions providing impersonal care that is rather sedating than activating and rather restricting than empowering

the elderly residents (Oldman & Quilgars, 1999; Rozanova et al., 2016; Schwind & Jahn, 2021). In envisioning and legitimising care robots, the robotics discourse has been reproducing this broader societal discourse of institutionalised elderly care in variation ever since. In some cases of robots designed for nursing homes (F&P Personal Robotics, 2018; Kompaï Robotics, 2019), these do not appear as dire as presented by Engelberger. However, the robots, nonetheless, improve the situation of institutional care found there.

Roboticists have incorporated this social knowledge (and stereotypes) into their reasoning, and it has become one central assumption about the benefits of implementing robots to foster independent living in private homes or at least maintain a higher degree of personal independence in institutional care settings. Only against this background of a supposedly dire alternative, the development and application of this *insufficient* technology ('will not be a practical nurse') became desirable. As I argued in my reconstruction of the roboticists' discourse, the assessment of a technical immaturity of robots for care purposes persists and is one reason for the absence of care-intensive (dying) users of these robots (Lang, n.d.-a).

By incorporating new knowledge into its structure, a discourse not only changes the symbolic reality produced therein but also maintains or reinforces elements of the existing discursive structure and content. In the case of the robots in care discourse, building interdiscursive relations comprised dynamics of 'reciprocal affirmation' (Lang, n.d.-b) of the industrial robotics discourse. The early deliberations of robots in care depicted care as an area of application because the robotic technology had advanced to a point that made it possible to explore this technology's capabilities (following first quote) in environments that hold new challenging demands (following second quote) (see also Borenstein & Koren, 1985, p. 158):

'Today, robots can be mobile, sensate and artificially intelligent.' (J. F. Engelberger, 1989, p. 14)

'[…] the more interactively a robot works with a physically limited human, the more demand will be placed on its technological capabilities' (Engelhardt, 1988, p. 815)

In deliberating on this new area of application, the roboticists positively attributed the field of industrial robotics at once as established but also as ambitious and capable of further development. The unfolding discourse described elderly care as a particularly challenging application. It contrasted the unstructured environment and unpredictable interactions with human lay users with the controlled and predictable environment of industrial production. Dedicating efforts on elderly care appeared as critical to further the development and push boundaries of this field as such. Moving to the field of care was societally necessary and also reciprocally confirmed the status of robotics as a vital and prosperous area of R&D.

'Stand-alone robots that could […] aid the handicapped and elderly are real prospects. They will bring the magic back to robotics. Once again engineers will come to the exhibits with their kids on their shoulders. Who knows, even the disenchanted venture capital community may begin to salivate again!' (J. F. Engelberger, 1989, p. 14)

Robotics engaged with discourses of an ageing society and care crisis in a process of legitimising the development of robots in care and, through this, *affirmed* the status of robotics as a socially and economically relevant industrial branch. By addressing this major challenge, robotics gained societal importance and affirmed its own significance for the greater good.

The robotics discourse in adopting elderly care as a field of application also exhibited dynamics of *socio-technical adjustment,* which I understand as 'mutual transformation of professional practices and technological approaches and devices' (Lang, n.d.-b). In extending towards new areas of application, the discourse changed incumbent ways of *doing robotics* and invoked novel ways of implementing R&D activities. Especially, the consideration of user

requirements came into focus early. In 1988, Engelhard (1988, p. 815) identified the needs of potential users as viable starting points for R&D on service robots, including robots in care:

> *'Our fundamental hypothesis is that human, not technology driven applications have a better probability of becoming appropriate systems that can be successfully used and diffused. […] Sensitivity to human dignity and independence are also critical considerations in conducting this type of research.'*

Later on, user involvement in various stages of R&D processes has become a norm of care robotics, e.g., through focus groups with elderly patients and caregivers (Kompaï Robotics, 2019), user-centred design (Fischinger et al., 2016), experimental trials (Chivarov et al., 2019) or field trials with users (Coradeschi et al., 2013; Früh & Gasser, 2018; Reiser et al., 2013). Funding programs required the involvement of different stakeholders and users in R&D projects (Ambient Assisted Living (AAL) Joint Programme, 2009; European Commission, 2015). The discourse has identified research involving the elderly or caregivers as users as important for the successful diffusion of such innovation by increasing the acceptance, usefulness, usability, as well as technical functionality and safety of robots. New speaker positions have opened, allowing professionals from other disciplines to engage in deliberations around the design and application of robots in care. At once, this has created new responsibilities for the future prospective users and the field of care. Now, they need to participate in R&D processes through interviews, focus groups, experimental settings, or field trials to further develop and refine the robots. Furthermore, they have to acquire knowledge and skills to properly handle the new machines.

4. Sharing knowledge and discursive elements

Comparatively analysing the different discourses under investigation, I found that each discourse exhibited specific actors as speakers, spaces of deliberation, and core reference points. Despite this distinctiveness, they *shared* certain content and discursive elements.

Sharing means that these discourses produce and reproduce stocks of knowledge or discursive elements without necessarily explicitly responding to or addressing other discourses. In the following, I illustrate what and how knowledge and discursive elements can be shared by the different distinct discourses by looking at the causal starting point (problematisation) as well as normative reference points of the different discourses.

4.1. The (end-of-life) care crisis and their instrumental solutions

The phenomenal structures of the three discourses I investigated were based on the determination of a crisis of elderly (palliative) care as reason for deliberation, adaptation, and activities such as R&D of innovative technologies or policy change. Society in general and professionals in particular were assessed as becoming incapable of meeting their own practical goals and normative aspirations.

The special discourses in robotics and palliative care reproduced a diagnosis of society as demographically transforming, as being an ageing society. They determined that members of the baby boomer generation are getting older, but fewer young people follow, leading to a lack of professional caregivers to meet the ever-increasing demand for care and support. This discourse has persisted over several decades, forming a particular vision of the users of the assistive technologies. The following illustrative quotes are from my data on the palliative care (first quote) as well as the roboticists' (second quote) discourse:

> *'As demand for palliative care increases as a result of an ageing population and progressive chronic illnesses, mechanisms [telehealth; the author] that support home-based care need to be explored.' (Tieman et al., 2016, p. 2).*

> *'As the European population ages, spiralling health-related costs will place an immense burden on European economies. We envision the development of flexible home-care service robots, which will help people to care for themselves, improve their comfort of living and likely entertain them.' (ISTAG, 2004, p. 4)*

These utterances interlinked a supposedly objective social development (‘ageing population’) as cause for deliberation with a subjectivation of elderly people (at risk to frailty and illness) forming a societal problem (the care crisis) that needs to be tackled with a particular social strategy (‘home-based care’ or ‘care for themselves’) enabled by technical solutions (robots or telehealth).

The documents reproducing the two separate discourses that include this diagnosis are not explicitly and directly interrelated, for example, by referring to documents, actors, or debates from the other discipline. Rather, they draw on a more general discourse on demographic changes towards an ageing society. Sometimes, documents refer to official statistics, sometimes to other scientific or policy papers. Regularly, documents present this shift and its implications as self-evident without giving further reference. This idea of a problematic demographic transition towards an ageing society appears to be created and maintained by a ubiquitous discourse that identifies the ageing of the population as a problematic issue to be addressed by social policy to mitigate negative outcomes for welfare and healthcare systems or the economy, as described by various scholars (Christensen et al., 2009; Katz, 1992; Lundgren & Ljuslinder, 2011; Messerschmidt, 2018).

In the Austrian debate on good dying, the demographic transition was not a prominent topic. Nevertheless, it shared the diagnosis of a systemic insufficiency and crisis-ridden care system. Different actors, irrespective of their political stance, interpreted EoL care as in crisis because of the societal and institutional framework conditions being incapable of providing sufficient holistic care for all dying people and protection from social isolation, pressure, neglect, or abuse (Lang, 2020).

All analysed discourses reproduced the societally dominant interpretation that a ‘crisis is a problem’ (De Rycker & Don, 2013, p. 3) that needs to be actively addressed or preemptively avoided. They were interconnected content-wise in terms of their determination of elderly/EoL care as in crisis, but also in how they used the crisis as point of departure for deliberations and practices. These solutions were localised on a political level, for example, in R&I policy

making providing funding and support for technology development, on an institutional level by identifying particular R&D efforts or concepts of care to be implemented, and even on an individual level by activating and supporting the elderly to live independently. The discourses focussed on individual measures to tackle the challenges but disregarded more systemic approaches that question or change the underlying problematic social and economic structures. As Michalec et al. (2021, p. 2) expressed pointedly, robots as seemingly unpolitical solution function 'as a palliative for economic and societal ills'. As the Austrian discourse, neither the roboticists' discourse nor the palliative care discourse addressed broader systemic approaches to tackle underlying issues and causes of insufficient care, such as supporting immigration or higher birth rates to reverse or bolster the ageing of the domestic population, making nursing professions more attractive, or improving the integration of migrants into the labour market.

4.2. Equality, individuality, and independent living as key values

Across the analysed discourses, shared values and norms were reproduced that impart significance to strategies and actions to prevent or at least diminish the worst outcomes of the care crisis. They orient the situational implementation of care practices and are inherent to concepts of good (EoL) care proposed by the discourses.

In the discourses, the societal approaches to address the care crisis should enable the equal provision of adequate care for all. The care crisis appeared as a situation in which care is insufficient and not available for some. For example, the palliative care discourse described digital technologies as necessary to provide palliative care services not solely to 'a minority of those in need' (Mills, 2019, p. 145) but to whole populations including people in less developed or remote areas:

> *'Globally, access to palliative care is limited in that only a minority of those in need of palliative care receive it. This is true of populations not only in developing countries, but also those in regional, rural and remote areas of developed countries.' (Mills, 2019, p. 145)*

Similarly, the Austrian discourses on good dying categorised those already receiving optimal (palliative) care and those who do not. Based upon the idea of equality, speakers demanded sufficient palliative care services regardless of individual circumstances:

'It must not be a matter of money or where people live that they receive the care and support they need at the end of their lives' (Republik Österreich – Parlament, 2014, p. 33; translated from German).

Thereby, the discourses argued against the provision of uniform care for all. They reproduced the norm that care needs to be adapted according to the needs and demands of care recipients. All three discourses affirmed the value of individuality intricately connected to personal autonomy. They described the elderly or dying as similar in their desires and needs yet ultimately different subjects that have their own wishes and requirements. Documents identified patient-oriented professional practices, new technologies, or legal means, such as advance directives, as ways to promote an individualistic approach to care:

'For me, it is important that this freedom remains, that one can decide for oneself until the end. I believe that a self-determined end of life is possible, especially through hospice care' (Republik Österreich – Parlament, 2015, p. 55; translated from German).

'The ultimate aim of the robot is to enable people to do what they want to do' (ISTAG, 2004, p. 21).

'We have a responsibility to ensure that our dementia patients document their wishes and preferences before they lose capacity. The digital revolutions can enable this to happen. Patients can sit in their homes, go online and make their decisions – decisions that may be difficult for their family and friends to make when they lose capacity' (Riley, 2017, p. 151).

The care recipients should make the decision about their care and be able ‘to do what they want to do’, to have a ‘self-determined end of life’, or at least to have their ‘wishes and preferences’ documented before losing the ability to decide for themselves. Caregivers need to foster this decision making and respect the desires of the care recipients.

These values and norms were interwoven with the own (private) home as the ideal place to experience care and/or the end of one’s life. All discourses reproduced this value of home, which was strongly interlinked with positive and idealised ideas of family, comfort, intimacy, privacy, and peace. Robots were identified as technical solutions enabling the elderly to remain in their own homes and/or live (semi-) independent also in nursing homes (Lang, n.d.-a). At once, the high evaluation of the own (private) home guided the assessment of palliative and EoL care practices and the good dying too (Lang, n.d.-b, 2020). Different means should support people in remaining at home until the end or as long as possible.

5. Contesting interpretations

Discourses regularly emerge ‘around contested issues, controversies, problematisations, and truth claims’ (Keller, 2021, p. 38). In constructing particular social realities, they may also question other discourses. Such contestations can be understood as discursive relations, too. As outlined below, these relations can be realised in different forms, either as direct contestation of opposing discourses or indirect as an attempt to prevent upcoming contestation.

5.1. Challenging social realities

The genesis of the hospice and palliative care movements is an example of discourses arising in reaction to societally and professionally dominant discourses and related practices that become assessed as problematic at some point. They emerged in opposition to dominant medical and nursing discourses focussing on dying and death as medical issues (Clark, 2016; Stolberg, 2017).

In social arenas, such opposing discourses can recur and directly contest each other in an attempt to gain the prerogative of interpretation and influence political decisions or social practices. This was the case in the Austrian debate around good dying. In this debate, a restrictive and permissive position on assisted suicide both *shared* particular assumptions about dying and death (at old age and with illnesses) and means to deal with challenges of enabling good dying. At once, they also exhibited different perspectives and assumptions about processes of dying and critically addressed and adopted each other's line of argument. Actors *contested* their opponent's interpretive scheme and stock of knowledge or verbally attacked them as a group and individuals with problematic morals. A *restrictive discourse* rejected the legalisation of assisted suicide and euthanasia and called for further development of palliative and hospice care. In contrast, a *permissive discourse* identified the legal option of assisted suicide or euthanasia as desirable. Both discourses contested each other on two main issues: 1.) whether or not palliative and hospice care are able to sufficiently alleviate pain and suffering of dying persons, and 2.) whether or not dying individuals are able to autonomously decide about ending their lives through assisted suicide or euthanasia (Lang, 2020). Speakers of both positions related to each other in a temporally and spatially relatively restricted socio-political and medial debate around a controversial topic. They became interrelated by questioning the others' assumptions, drawing opposing conclusions from presented facts, reinterpreting the core values and norms brought forward by their opponents, speculating about vested interests, or simply condemning the others position as morally wrong. The opposing social realities therein were relatively transparent and tangible in public deliberations. This contestation became engrained in the structure of these discourses: Although, both, the restrictive and the permissive discourse have been appealing to their own moral principles and practices, their reasoning has been relating to the other, the opposing discourse.

5.2. Anticipating contestation

Contestation can also occur indirectly within a discourse. The roboticists' as well as the palliative care discourse anticipated a counter-discourse against technology in (EoL) care without directly contesting manifest opponents of their endeavours. Rather, speakers preemptively addressed fears and critique that digital technologies such as robots will not only support caregivers and care recipients but also replace human care or degrade the quality of care:

> *'The goal was to bring both cognitive and physical support, in a way that is friendly, empathetic, and reassuring, though without the intension of replacing the unique presence of human assistance' (Kompaï Robotics, 2019).*

> *'However, the use of computers should not replace the richness of verbal communication and interpersonal relationships' (Bouteiller-Descas & Salamagne, 1999, p. 18).*

Speakers continuously corroborated that technologies will not substitute human caregivers but that technologies are only supportive tools used by care recipients and caregivers. They outlined that technologies should enable professional caregivers to better care for more people, for example, by making care more responsive to the changing needs of care recipients. In these discourses, technologies heighten the productivity of caregivers and thus enabling them to care for more people and to have more time to focus on personal interaction. Already in early deliberations on robots, this aspect was addressed. For example, Karen G. Engelhardt, founding director of the Health and Human Service Robotics Laboratory at Carnegie Mellon University, determined that caregivers 'could be relieved of the less desirable caregiving responsibilities, and could be freed to deliver care that humans can uniquely provide' (Engelhardt, 1988, p. 817).

The palliative care discourse and the roboticists' discourse have not comprehensively addressed or attacked such a counter-discourse. Rather, they have accommodated these

counter-discourses. Roboticists preemptively identified considerations of risks and fears as invalid or highlighted the noble motives of actors involved or procedural requirements to mitigate risks, such as thorough R&D (Lang, n.d.-a). The palliative care professionals closely interrelated their own professional values and practices with the new digital technologies and thereby prepared and adjusted the professional discourse to circumvent contestation from within this discipline (Lang, n.d.-b).

6. Absence as meaningful unrelatedness

In my paper on the roboticists' discourse, I reconstructed how roboticists reproduced a dominant user representation of an active and independent elderly user who was in line with the immature technological foundation of the robots. At once, dying users of these robots were not an issue in the analysed documents (Lang, n.d.-a). Revisiting this insight against the notion of interdiscursive relations, a complementary interpretation of the absence of dying users can be outlined. The *absence* can be understood as a lack of discursive interrelatedness or as *meaningful* unrelatedness.

So far, I have sketched a concept of discursive interrelatedness based upon the insight that discourses can consolidate knowledge from different societal domains and other discourses. Speakers can incorporate stocks of knowledge or discursive elements into their own structure and reasoning and, thus, transform or create a discourse. In addition, I have argued, discourses can not only be interrelated by direct reference to each other but also by sharing common knowledge or discursive elements. Discursive relations can also be negative ones in cases of explicit *contestation* or an anticipatory stance to avoid open contestation. In the following, I elaborate upon the *lack of relations*. Thereby, I want to highlight and illustrate two aspects, drawing on existing social research on absence and silence as well as my own case studies. It is necessary to deal with the *relative* absence of relations and to determine how an unrelatedness is, indeed, *meaningful*.

In principle, the distinction between *absence* and *silence* is important. Absence can be understood as a result of discursive and practical dynamics that do not intentionally aim at excluding a subject. In contrast, *silence* is the outcome of an intentional neglect or suppression of topics because of social, political, economic, or other reasons (Schröter & Taylor, 2018). However, since I could not find any indicators for intentional omission of dying in the roboticists' discourse (Lang, n.d.-a), I will only deal with absence in the following.

6.1. Relative unrelatedness

Studying an absolute absence of an issue or topic, 'things that are not there or anywhere else and probably never were' (Frickel, 2014, p. 88), would be challenging since no references or indicators for such topics could be found. Rather, researching relative absence seems more promising. Relative absence pertains to issues that 'were there once, or have become hidden, or are somewhere else' (Frickel, 2014, p. 87). Considering only relative absences appears straightforward in dealing with interdiscursive relations. In order to identify an absence of relations, it always requires the presence and identification of discourses that, in principle, could become related. I have dealt with discourses that could not only be reconstructed as distinct entities but as discourses that entail stocks of knowledge previously foreign to the field from which they emerged. Roboticists engaged with other discourses and adopted central elements into their own discourse and, therewith, created a discourse on robots in care. At once, dying and EoL care are regular issues across different domains of society. Given the capability and willingness of roboticists to engage with external discourses to form a novel discourse around robots in care, and the availability of respective public and special discourses on good dying or palliative care, the absence of dying can be assessed as *relative* in two senses. First, while dying and good dying have not been topics within the discourse around robots in care within robotics, they have been at the core of other public and special discourses. In contemporary societies, they have a presence in different groups and publics, with the notable exception of care robotics. They are not absolutely absent, although different actors and media have not been getting tired of presenting dying as societal taboo (Robert &

Tradii, 2019; Walter, 1991). Second, the absence is relative because this connection between robots and the dying users has been made in other instances. Documents from outside the field of robotics established this relation. Thus, a relation appears as meaningful in principle (Lang, n.d.-a).

6.2. Meaningful unrelatedness

The latter aspect points towards the feasibility of an relation between different discourses and is closely connected to the categorisation of an unrelatedness as *meaningful*. Schröter and Taylor (2018, p. 6) convincingly argued for dealing with 'meaningful absences' that are characterised by the existence of a 'thinkable alternative' that we are able to identify. Given the reasonable assumption that speakers and discourses cannot deal with an infinite number of topics and incorporate the boundless knowledge of society, absences could be dismissed as a simple side effect of a necessary and inevitable focus on particular topics and issues that leads to the exclusion of others (Rappert & Bauchspies, 2014; Schröter & Taylor, 2018). Interpreting the absence of a relation in this way could be *meaningless* and negligible. Approaching absence as *meaningful unrelatedness* always comprises the need to analytically reconstruct why the alternative, a relation between discourses, is thinkable and expectable as well as significant for the form and impact of a discourse.

In the robots in care discourse, the absence of dying users appears as meaningful considering dominant social discourses and practices of dying in our society. Dying represents not only the logical progression and end point of living but is strongly connected to old age and elderly care, as the discourse around good dying in Austria shows. Dying at an old age, after a phase in which the elderly person needs care, appears as the normal and expected way of dying in contemporary societies. Thereby, dying exacerbates the challenge of care by increasing its intensity and significance for the care recipients and their relatives.

Going beyond a perspective of a seemingly logical relation between old age, care, and dying, the absence of the dying user is striking when looking at how the discourses share discursive elements regardless of this absence in the robotics discourse. The comparative analysis has

shown that even though dying was a non-topics in the roboticists' discourse, this discourse nonetheless *shared* key knowledge and elements with discourses on good dying and palliative care. The social reality of elderly and EoL care reproduced within the roboticists' discourse, despite some difference, had substantial aspects in common with discourses around good dying and palliative care. Robots and EoL or palliative care were not incompatible in principle. Roboticists described robots as appropriate means to address care challenges that are closely intertwined with dying and the end of life. The discourse around robots in care formed a phenomenal structure integrating a societal view of elderly care as in crisis, but also as ideally oriented towards individualised care promoting personal independence as other discourses concerned with palliative care and good dying, as described above.

Thus, the *absence* of the topic of dying as well as the relation of dying with robots in care is not only a *relative* one manifesting in the discourse on robots in care. In addition, it is *meaningful* because the issue of elderly care is societally entwined with dying regularly. In its phenomenal structure, the roboticists' discourse itself closely corresponded with discourses on good dying. Nonetheless, only a specific excerpt of discourses around the elderly and elderly care has become incorporated into the dominant discourse in this field, their relation has been a selective on. In my study, I have linked this selectiveness to the alignment of the prospective user with the limited functionality and effectiveness of the robots but also to R&D practices leading to the exclusion of dying users in trials (Lang, n.d.-a).

7. Discussion

In this paper, I have explored the relations between discourses. So far, social scientific discourse studies have determined particular types of discourses that interlink social arenas and discursive fields (interdiscourses, interdiscursive configurations, inter-special discourses). Here I have proposed an empirically informed conceptualisation of a variety of modes of discursive relations. This concept is not exhaustive but should be understood as a preliminary

approach to grasping cross-discursive relations. It is reasonable to assume that discourses unfolding in other social arenas, with other types of speakers, or around other types of issues might exhibit different and further ways of establishing discursive relations.

7.1. Building relations as stimulus for transformation

By tracing the emergence of the discourse around robots in care within robotics, I have highlighted how roboticists incorporated elements of a discourse around demography to rationalise their R&D endeavours, and, thus, laid the foundation of this (sub-) discourse. Such processes establishing discursive relations can be understood as a driving force of transformations of discourse (Fairclough, 2013; Keller, 2010). They include the uptake of knowledge, the expansion of the group of legitim speakers, or the creation of discursive infrastructures. Analysing relations of discourses thus can provide a better understanding of the conditions and dynamics of the emergence and transformation of discourses.

In my analysis, I could only begin to identify the conditions under which interdiscursive relations emerge. For example, the impact of literature, film, and art should not be underestimated. Engelberger (1983, p. xv) himself identified the work of science fiction author Isaac Asimov as a major influence on his career as a roboticist. His rationale for building a robot for the elderly closely resembled Asimov's ideas of robots, including his *Three Laws of Robotics* as guiding principles for their design (J. F. Engelberger, 1989, pp. 224–225). Although these laws were coined as part of a science fiction story, they have remained popular references in media and science as ethical guidelines for robot development (Murphy & Woods, 2009).

Research needs to consider the conditions under which relations emerge and are maintained. For example, for several years now, R&D funding programs have set requirements for interdisciplinary exchange. Funding calls for robots in care identified 'multi-disciplinary' approaches that also considered '[g]ender and ethical issues' (European Commission, 2015, p. 29) or have to address wider 'ethical, legal, and social aspects' (Bundesministerium für Bildung und Forschung, 2016; own translation) as prerequisites for funding. Ideally, this leads

to the integration of concepts and ideas of different disciplines and fields and thus changes a discipline's discourse in the medium- or long-term. Established discursive constructions in one field, for example, of relevant user characteristics, then may be adopted in another one and transform the overall discourse.

An important aspect that requires further attention is the dynamics of the relations between discourses. On the one hand, speakers might continuously ingest novelties from external discourses into their own discourse. Thus, the relations between discourses may remain vital with a continuous flow of knowledge and discursive elements. For example, in R&D this could be the case when inter- or transdisciplinary cooperations become institutionalised and ensure the transfer of ever new knowledge between the different fields. At once, transferred stocks of knowledge might 'freeze' in a discourse and with time become 'outdated' but nonetheless remain influential. Besides, cutting the relations to another discourse might be possible, for example, by eliminating certain issues and topics or removing speaker positions.

7.2. Modes of interdiscursive relations

Relations between discourses then can be realised and appear in different forms. As a first mode of discursive relation, I outlined how seemingly unrelated discourses can exhibit an inner connection by resorting to shared incorporated discursive elements or stocks of knowledge. It is reasonable to assume that sharing discursive elements without explicitly relating to each other is the most common form of a discursive relation. I only elaborated on a few shared discursive elements, which were by no means exhaustive. For example, commonalities between discourses I could not address concerned the allocation of responsibilities for care to professional actors instead of families or the emphasis on social inclusion of care recipients. However, the identification of such interdiscursive relations between discourses can hardly be complete in principle. Research on the relations of discourses needs to be selective in line with one's research interest in order not to drown in the endless 'seas of discourses' (Clarke, 2005, p. 145). As outlined considering discursive absence, the range of relations as well as absent topics is wide. Research has to make well-founded decisions about which relations or

missing links it follows. Thereby, a combination of following one's research interest and preliminary data-analysis-driven empirical insights, for example on key discursive elements, seems expedient.

Although it is often not possible to recognise manifest indicators of relations between different discourses, for example, as networks of references between documents across fields, it is possible to approximate relations. The SKAD's concept of phenomenal structure proved to be a suitable starting point for this comparative analysis. The analysis of such shared discursive elements and stocks of knowledge could inform and empirically strengthen the identification of 'interdiscourses' (1996, 2012) and provide an understanding of how they unfold and manifest across different fields and social arenas.

In reconstructing discursive relations, it is important to differentiate how knowledge gets incorporated across discourses. Discourses can be interrelated because they share discursive elements, that is, pieces of knowledge with a particular position within a discourse's structure. Beyond reproducing the mere knowledge about a matter, such as the demographic transition towards an ageing society, this knowledge was located in the discursive structure in parallel to other discourse in the reconstructed cases. The demographic knowledge operated as a problematic *cause* for deliberations and actions to solve the resulting societal challenge in a phenomenal structure. Similarly, individuality and independence as core values were integrated in similar ways in the discursive structures. The knowledge was adopted as a building block with a fixed meaning and function, as a particular discursive element. However, in principle, their relation could be different because they interpret an external discourse in varying ways. In the examples at hand, discourses had in common pieces of knowledge as discursive elements with a particular location and function within the discourse. In other discourses, an ageing society could be the outcome of positive development towards increased longevity that itself can yield societal benefits. A larger population of elderly might become a common resource ('social capital') for society, for example, by providing childcare or other volunteer activities, rather than a societal care burden (Calvo-Sotomayor & Atutxa,

2022; Healy, 2004). Although in such cases, the content is the same, its position and assessment may be different. In tracing the diffusion of knowledge within and across discourses, this differentiation is important. Whereas the reproduction of knowledge as a particular discursive element reinforces an associated social reality, a reinterpretation of a stock of knowledge can indicate contestation or incremental changes of discursive realities. This insight resonates with Foucault's conceptualisation of statements. He posits that actors can 'produce, manipulate, use, transform, exchange, combine, decompose and recompose, and possibly destroy' (Foucault, 1972, p. 105) statements. The same holds true for elements composed of interwoven statements forming discursive elements such as parts of phenomenal structures, interpretive schemes, narratives, or else (Keller, 2021). Similarly, interdiscourse theory supposes that a collective symbol can be reinterpreted and gain a different meaning depending on its related discursive position (Link, 2012; Parr, 2020). A collective symbol can even manifest in antagonistic discursive positions (Link, 1996, 2013).

Second, I identified *contestation as another form of discursive relations*. Discourses are often related because they emerge and revolve around controversial and contested issues. In my analysis, I highlighted two modes of such contestation. Discourse research usually has its focus on explicit mutual contestations of opposing discourses. In these, speakers scrutinise the competing position and try to enforce dominance of their own symbolic reality. In addition, I have drawn attention to the more subtle form of anticipated contestation, which means addressing potentially controversial aspects in advance. Although in the latter case, no open controversy emerges, a discourse nevertheless implicitly relates to another competing discourse. Considering socio-technical futures discourses (Lösch et al., 2019; Roßmann, 2021; Urueña, 2022), identifying such implicit negative reciprocal interdependencies can sensitise for possible upcoming controversies, for example, in cases of ongoing but little noticed R&D on technologies that might lead to marketable products in the future. Furthermore, such anticipatory considerations can be indicators for powerful social values and norms as well as dominant discourses.

Third, I drew attention to the non-realisation of expectable interdiscursive relations as meaningful unrelatedness. Thereby, a discourse does not incorporate stocks of knowledge or discursive elements from another discourse, even though building up such a relation would be meaningful within a given context. I interpreted the absence of issues of dying and the dying users in the roboticists' discourse on robots in care as a case of meaningful unrelatedness. Although actors forming and maintaining a discourse cannot consider neither the scientific nor the human knowledge in its entirety, a selective incorporation of other discourses can be connected to particular conditions. In principle, the absence could exist because dying has no substantial relevance in robots in care. It could be absent in a way that other unessential topics and users are absent as well. However, relations might not be created or maintained because of structural conditions and power relations. Speakers could know little to nothing about other fields because of their high degree of specialisation. Limitations considering their financial and personal resources, or their institutional and societal embedding could also elicit a restricted view on the issues of concern. However, the matter of actively avoiding or hindering possible interdiscursive relations, the *silencing* of issues, deserves attention, too. Relations might not be established intentionally because of vested interests of relevant speakers and actors or structural conditions (Murray & Durrheim, 2019). Although deliberate omission (*silence*) was not an issue in my analysis of the roboticists' discourse, it deserves attention.

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6 Discussion

The dissertation stemmed from a sense of wonder about the unexpected absence of dying care recipient in the field of robots in care. This especially vulnerable group of potential users has not occurred in the deliberations of roboticists so far, not even in dissociating robots from this application. My research traced the contours and conditions of this absence. Given the discursive nature of socio-technical futures related to robots in care, it investigated the relations, and lack thereof, between different special and public discourses. Therefore, I employed a research design in line with the sociology of knowledge approach to discourse. As a result, I have proposed a heuristic concept of discursive relations.

The first sub-project of this dissertation reconstructed a contemporary public discourse around good dying. My published study identified and illustrated dominant public concepts of good dying. It was based upon a broader data basis than other studies that reconstructed good dying from debates around extraordinary incidents of death (McInerney, 2006; Seale, 1995, 2002), euthanasia and assisted suicide (Bettin et al., 2018; Cassel & Meier, 1990; Hausmann, 2004; Pool, 2000; Van Gorp et al., 2021), or particularly bad ways of dying such as dying alone (Nelson-Becker & Victor, 2020; Seale, 2004, 2004; N. Turner & Caswell, 2020). The resulting paper has contributed to the sociology of (good) death and dying by showing that the institutionalisation of dying represents a shared but highly ambivalent basis of good dying in otherwise opposing discourses on assisted suicide or euthanasia. In my dissertation project, this study provided a thorough understanding of good dying as a social phenomenon and served as a reference point for the comparative discourse analysis. It offered a differentiated view on the discursive formation and assessment of the institutionalisation of dying and EoL care that is interwoven with a particular understanding of dying in our society. The analysed discourse presented dying as a phenomenon of the old and ill who are in dire need of professional support to cope with their situation. At once, it identified the societal conditions as insufficient to provide adequate care and proposed means to address the symptoms but not the deeper causes of a supposed care crisis. In conducting my further analyses, I assumed that this kind of discourse formed a background for more focussed and socially confined special discourses. Professionals as speakers, including roboticists or palliative care specialists, are not only confined within their particular discipline and area of expertise but are also affected by such broader societal stocks of knowledge and socio-political contestations.

Responding to the challenging circumstances at the time of the COVID-19 pandemic, I could consider the important perspective of professional caregivers only indirectly. Together with colleagues, I implemented and published an integrative review of empirical studies on this group's view on good dying. This second paper of my dissertation has added to existing empirical studies in death studies, the sociology of medicine, and palliative care by synthesising and discussing the approaches and findings of a broader range of existing empirical studies than similar reviews before. Our review highlighted the dominance of a

palliative care understanding of good dying in the broader field of care. Furthermore, it identified a neglect of the heterogeneity of the dying patients, of the interwovenness of the well-being of those dying, their relatives, as well as caregivers, or of the contradictory nature of some elements of good dying. In my dissertation project, these insights strengthened my understanding of the meaning and practices of good dying by opening up a particular professional take on this phenomenon.

In my third paper, I addressed the absent dying users of care robots in the roboticists' discourse on robots in care. Böhle et al. (2014) noted that dying as a longer lasting process was not part of the vision around ambient assisted living (AAL) systems, including robots. Their assessment from 2014 was still true when I started and when I finished my dissertation's empirical research. Although the role of medical technologies in dying has been studied and discussed extensively, the meaning of nonmedical technologies in and for the dying process had not been investigated in depth before. With my research, I provided insights into the (lack of) interrelatedness of digital technologies and dying in this field of R&D. I have added to research on the emergence and characteristics of users and non-users of technological devices (Hyysalo et al., 2016; Oudshoorn & Pinch, 2003; Peine et al., 2021) by going beyond the dichotomous categories of users and non-users of technologies. My paper identified and conceptualised the 'absent user of technology' as a further category and type of user. It proposed to pay attention to very well thinkable yet not discussed users of technology, and to investigate the discursive and practical dynamics connected to their absence. At once, the discourse on robots in care is an example of a special discourse around the role of a new technology in a particular social environment. In this and similar discourses[20], social practices and values are at stake because of technological innovation. Therefore, this discourse proved to be a suitable subject to analytically trace possible discursive intersections between such a special discourse and public discourses, and to pursue my interest in discursive relations.

My fourth paper drew attention to another important group in the development and implementation of care technologies such as robots: professional caregivers. I did not investigate an absent relation, as between robotics and EoL care, but focussed on how a special discourse co-produced new digital technologies and professional practices, values, and norms. My analysis of the discourse on digital technologies in palliative care has contributed to science and technology studies by tracing and conceptualising how professional values and norms and new technologies are discursively interrelated. I highlighted the simultaneous conservative and transformative processes unfolding in introducing and deliberating upon new digital technologies in palliative care. I proposed a tripartite concept – reciprocal affirmation, technology-value alignment, and socio-technical adjustment – to better grasp this concurrent transformation and conservation of professional discourses facing changing socio-technical conditions. In the context of my overall dissertation, this research offered insights into how technologies as discursive phenomena are discussed, taken up, and integrated into an already consolidated disciplinary discourse. In my concluding analysis, I adapted the tripartite concept to identify discursive mechanisms that incorporate novel knowledge (or technologies) into a value-laden professional discourse.

[20] Another example is the discourse on artificial intelligence in higher education, in which the teacher's role and authority are called into question (Bearman et al., 2023).

Finally, I investigated commonalities of the special and public discourses to conceptualise their relations. Concepts of discourses have highlighted the entanglement of different discourses by focussing on particular ways of how discourses relate to one another, become entwined, or diffuse into other societal arenas (Foucault, 1972; Jäger, 2001; Link, 1996, 2008, 2012; Parr, 2022). Through a comparative discourse analysis, I was able to differentiate processes and modes of how discourses relate to one another. My fifth paper explored how speakers incorporated elements and knowledge from other discourses and thereby transformed and/or established the novel discourse of robots in care. Then, by comparatively analysing the discourse on good dying and the discourses on robots in care as well as digital technologies in palliative care, I identified *shared stocks of knowledge and discursive elements*. In the examined discourses, an alleged crisis was the common cause for demanding and seeking instrumental solutions to systemic problems. Equality, individuality, and independence were shared values guiding the evaluation of measures to address this crisis. Looking at the polarised socio-political discourse around assisted suicide or euthanasia, I illustrated how these discourses were interwoven by *mutual or one-sided contestation*. I interpreted the opposing discourses on good dying as typical for a reciprocal (negative) relation. At once, I highlighted more subtle forms of anticipated contestation that led to preventive steps to mitigate controversy, as the palliative care discourse exhibited in discussing digital technologies. Finally, I returned to the issue that stimulated my research interest by interpreting the relative *absence as meaningful unrelatedness*. I highlighted how relative absence of issues in one discourse can be identified because they have a presence in other discourses or social arenas. An absence, such as that of the dying user in care robotics, can be considered meaningful and not arbitrary when discourses on these different issues are interrelated in other regards. The relation then can be understood as a selective one, and the reasons and dynamics leading to this selectivity can be analysed. In the following, I discuss the applicability, usefulness, and limitations of this concept as a heuristic for future research in line with discourse analysis in general and the SKAD in particular.

6.1 Conceptualising the relations of discourses: a heuristic

The concept of discursive relations presented in this dissertation draws attention to the various types of discursive relations and the absence of expectable relatedness (meaningful unrelatedness). It emerged from my occupation with socio-technical futures discourses within professional domains in conjunction with their comparative analysis to a public social discourse on a value-laden and controversial topic. It can be used as a heuristic to explore how discourses are interrelated and what implications and effects these relations have. The notion of ‘sensitizing concepts’ proposed by Blumer (1954) and adopted, for example, in grounded theory methodology (Bowen, 2006; Charmaz, 2006, p. 16) is appropriate to characterise this heuristic. A sensitising concept ‘gives the user a general sense of reference and guidance in approaching empirical instances’ (Blumer, 1954, p. 7). Such a concept does not predict how a phenomenon considered is realised in every instance but ‘suggest[s] directions along which to look’ (Blumer, 1954, p. 7).

What orientation does the concept of the relations of discourses provide? In which directions does it direct the gaze of research? I have adopted the SKAD’s understanding of

discourses as societally embedded and influential (discursive infrastructure, dispositif) social practices by concrete actors (speakers) that in their interplay create and institutionalise social meaning, realities, and orders of knowledge. Reconstructing discourses requires to analytically demarcate the boundaries of discourses to make their distinct structure and content as well as their infrastructures and effects tangible. At once, social actors do not only blindly follow but interpret and modify discourses. They are 'standing in the crossfire of multiple, heterogeneous, perhaps even contradictory discourses' (Keller, 2021, p. 39) and deal with these. Although discourses need some degree of stability to unfold a binding effect in social collectives, they appear nonetheless as permeable for external factors, including other discourses. Especially with regards to the creation of socio-technical futures, a perspective that draws attention to the interdiscursive assembly and composite nature of these discourses could promote a better understanding of their shape and the expectations and fears associated with future and novel technologies.

As my analysis of the history of the roboticists' discourse illustrated, actors incorporate elements and knowledge from other discourses. Thus, over time, they establish new discourses that have an inner connection to other societal realms even though they are (more or less) confined to particular social arenas. Searching for and analysing such incorporation processes can make transparent probably long-standing but later on implicit references to other discourses and support an understanding of the genesis and content-structure of discourses.

The identification of later on solidified discursive relations is rather straightforward in cases in which speakers or documents concretely and explicitly refer to and label external knowledge. It is about searching for those key discursive events, for example, seminal reference publications, that incorporated elements and knowledge of other discourses. Especially in social arenas that highly value novelty and innovation, such as science and research, it is probable that speakers highlight and thus make explicit the introduction of new knowledge into a particular social realm such as a profession or discipline. In subsequent instances of discursive reproduction, these origins may not be tangible or explicit anymore because they have become integral and unquestioned parts of the discourse. Such a transformation of a discourse by incorporating knowledge or elements of other discourses, as well as the purpose of this incorporation might be obvious to those present and acting at that point in time. Later on, with its stabilisation, it starts to appear as 'given, unalterable and self-evident' (Berger & Luckmann, 1991, p. 77). Thus, tracing discursive relations needs solid knowledge of the genesis as well as the conditions of a discourse. However, it is reasonable to assume that even during the process of establishing such relations to other discourses, the introduction of new knowledge might not be recognised and identified as such. Some matters might appear as self-evident or even natural and not as a result of active incorporation of foreign stocks of knowledge. Drawing on Link's (1996, 2012, 2013) concept of interdiscourse, one can assume that popularised (elements from) special discourses are regularly incorporated without recognition of their provenance.

The analysis of interdiscursive relations should also deal with traces of other fields or discourses within a discourse under investigation. When a discourse has already incorporated and stabilised these foreign elements in its discursive structure, their origin might not be easily identifiable. Research on interdiscursive relations has to be aware and knowledgeable of the

wider (discursive) conditions to be able to sense correspondences. However, since it is unmanageable to know and be attentive to the myriads of special and public discourses, it is at least about having a solid knowledge of the different fields and discourses dealing with core issues at stake in a discourse under investigation. In the case of the roboticists' discourse around robots in care, the initial cause (ageing society, elderly care needs) and its effects provided sufficient clues to expect the interconnection to other social arenas concerned with similar issues of demography, ageing, or care. As outlined above, I became aware of the selective incorporation of the elderly care discourse leading to an absence of the dying users only through my concurrent occupation with good dying as a research topic. In general, inter- or transdisciplinary approaches and research teams might assemble a broad set of knowledge and expertise necessary to notice discursive resemblances and possible relations that then can be further investigated. Based upon the awareness of a probable relation, more systematic and targeted comparative analysis can then be conducted.

Going beyond solely detecting discursive relations, such research is about analysing how discursive elements and knowledge are integrated into the preexisting discourse. Thereby, the tripartite concept of *affirmation*, *alignment*, and *adjustment* is not only a suitable heuristic to empirically identify and grasp how values/norms and technology are reconciled with each other. It also sensitises for the diversity of processes involved in building discursive relations leading to a transformation of discourses while preserving core characteristics. Engaging with other discourses can *affirm* the original discourse by strengthening its existing assumptions and narratives, for example, about the importance and relevance of particular consolidated strategies. Thus, this engagement can be conservative in perpetuating a discourse into the future. However, this perpetuation might only become possible by processes of *adapting* the newly incorporated knowledge in a way to *fit* it to basic conditions and requirements of the discourse and, at the same time, by *adjusting* other (less formative or defining) elements of the discourse. Dealing with relations of discourses and the incorporation of external elements is not only about the transformation of discourses. One needs to be attentive to how change is made possible, how it unfolds, and what effects it has, as well as to how discursive continuity and stability are maintained in this process. Researching these issues can further our understanding of the development and transformation of discourses. Discourse research is usually heavily concerned with delineating the integrity and cohesiveness as well as the conditions and forms of discourses. However, for a long time it has neglected 'shifts, transformations, processes that affect discourses or discourse formations and their change across topics'[21] (Keller, 2010, p. 72). Analysing the relations of discourses supports the SKAD's goal 'to engage with the complexities of constellations inherent in discursive constructions of reality, to work against ever ongoing simplification' (Keller, 2017, p. 65) by highlighting the transient and porous boundaries of discourses. Given the constant flow of knowledge between different societal and discursive arenas, understanding how discourses build up and maintain relations seems crucial. Comparative discourse analysis can further our understanding of the translation of discourses and knowledge in these processes and thus

[21] Own translation from German: '[…] Verschiebungen, Transformationen, Prozesse, die themenübergreifend Diskurse oder Diskursformationen und ihren Wandel betreffen.'

promote a better understanding of societal challenges and controversies arising from these processes.

By identifying *shared* knowledge or elements of discourses, it is possible to approach the reproduction of knowledge across different publics and social arenas. In many cases, it might be difficult to trace the origin and direction of how this knowledge travels by means of clearly identifiable communicative acts. Nevertheless, comparative studies investigating the distribution of discursive elements across dispersed social arenas can provide a solid empirical basis for identifying societally dominant interpretive schemes, classifications, phenomenal structures, or narrative schemes. Going beyond the focus of interdiscourse research on the propagation of knowledge from special discourses into public discourses, research on discursive relations needs to be open towards dispersed 'flow' of knowledge in different directions. Searching for *shared* discursive elements or knowledge might have practical benefits. Identifying some common ground between contesting discourses could function as a starting point for constructive deliberation, consensus-building, or even decision-making processes. In times of high polarisation around myriads of issues that might yield negative effects on the democratic makeup of societies (Arbatli & Rosenberg, 2021; Detjen, 2023), finding and highlighting integrating elements could be of high value. In this regard, the SKAD does not only provide concepts to reconstruct discursive structures but also to facilitate the comparative analysis necessary to identify discursive commonalities and relations. Methodologically, it supports comparative discourse analyses by offering rather open and flexible heuristic concepts, including interpretive schemes, classifications, phenomenal structures, and narrative structures. For the purpose of my study, especially the concept of phenomenal structure as part of the '*interpretive repertoire* of a discourse' (Keller, 2021, p. 43) proved to be valuable for a systematic comparison of multiple discourses.

Discourse research often revolves around controversies and contested issues. Keller (2021, p. 38) defined 'discursive fields as social arenas, constituting themselves around contested issues, controversies, problematizations, and truth claims'. My own study also focussed on a contestation between different actors and discourses on good dying. However, beyond these manifest controversies, the concept at hand also directs attention towards more subtle forms of contestation. Doing discourse analysis does not only mean to reconstruct the openly conflicting and opposing positions as I have done in my first paper (section 5.1). In addition, as I outlined with respect to the discourses around robots in care as well as digital technologies in palliative care, discourses incorporate opposing positions to their advocated perspective on and solution to a problem under consideration. Discourses can accommodate counterarguments into their overall discursive structure and thus deprive some of the basis for criticism without openly challenging critical discourses or actors. Thereby, they establish relations with counter-discourses. Searching for lines of arguments dissociating the discourse's proposed problem solution (or other elements of the discourse's structure) from effects marked as undesired can be one analytical strategy to identify such anticipated contestation. These discursive elements can then be used as starting points for tracing and reconstructing the referred discourses, how they are translated into the initial discursive structure, and what the shape of this relation looks like.

The concept of the relations of discourses does not only deal with those explicit and implicit relations between discourses. It draws attention to meaningful unrelatedness, too. Research

on discursive relations needs to consider that relations are established in a selective manner and that some expectable relations are not established at all. Thus, first, analysing interdiscursive relations means to continuously reflect which (probable) relations are established and which are not. Second, analysing the content and form of a relations and the incorporation of knowledge is about continuously reflecting which discursive elements and stocks of knowledge provided by a discourse are considered and which are not. This has the potential to reconstruct intentional (*silence*) and unintentional (*absence*) dynamics of selectiveness. Bringing together insights from various of such studies could give empirically well-funded insights into the societal dominance of particular discourses as key reference points and resources for different other discourses. Identifying patterns of selective interrelations or absent relations between discourse opens up the possibility to voice critique and identify societally neglected issues. As 'studies of the unsaid', also those of meaningful unrelatedness are 'not only about what is verifiable, trustworthy, credible, defensible, or convincing; they are also about politics, ethics, and morality; about what is right and wrong, good and bad, virtuous and evil; and all of the grey areas in between' (Murray & Durrheim, 2019a, p. 13).

6.2 Limitations and research desiderata

Considering my various research endeavours as well as my overall dissertation, different limitations and desiderata can be identified. Those of my individual empirical studies are outlined in the respective sections of each of the four papers. Here, I describe and discuss three main limitations of my overall dissertation project and sketch related future research approaches and topics.

First, from the onset of my dissertation, I have been aware of one blind spot in my research design. In my studies, I focussed on the perspective and discourse of roboticists, palliative care professionals, as well as actors contributing to public political discourses. However, I neglected the point of view of those immediately and personally affected by matters of ageing, care, dying, and death: the people dying, their relatives, and close ones. Although colleagues and I have researched this group's perspective on good dying in another project (Heimerl et al., 2023), I decided to focus my efforts here on socio-technical futures of robots and other digital technologies in care reproduced by societal groups closely related to R&D of these technologies. As others have shown, users can create and voice their visions of robots in care, too, for example, through vision assessment exercises (van der Plas et al., 2010). However, most often it is the vision of particular influential social groups that orients the development of technologies. And, for the time being, these powerful visions have mainly been created, reproduced, and implemented by roboticists. The elderly care recipients, their relatives, and especially the dying users have not taken up a role as active and independent speakers contributing to or creating a discourse around robots in (EoL) care. As part of R&D efforts, they have been foremost invited to share their perspective and assessments that have then been recorded, processed, and presented by others. Notwithstanding this decision, considering the perspective of those directly affected by robots in care and even EoL care seems crucial. Investigating the visions of users or stakeholders opens up a critical perspective on innovation by comparing their visions with the ones of those promoting certain

innovations (Groves et al., 2016). Through R&I or political processes, new speaker positions for the elderly users and their relatives could be opened up so that they can actively make an impact on the debates on robots in care. Thereby, the particularly vulnerable state of those dying should not be regarded as a reason for their exclusion as research participants. In their review, Bloomer et al. (2018) showed that those dying positively assess the opportunity to participate in research and contribute to the improvement of (future) patient care.

Second, my study focussed on how socio-technical futures emerge in discourses and how these discourses are (not) interrelated with other discourses. Through the analysis of documents and interviews with roboticists, I could gain some indirect insights into practical aspects of R&D of robots. However, overall, my study gave little attention to the role of social practices as well as their material infrastructure and artefacts for the creation and adjustment of the socio-technical futures discourses. At some point in the development process, socio-technical futures and the derived technical devices need to prove themselves in their material and practical realisation (Bischof & Jarke, 2021; Blümel, 2016; Gardner et al., 2015; Hoppmann et al., 2020; Lipp, 2022; Roßmann, 2021; Schulz-Schaeffer & Meister, 2019). Their design and functionality get tested in situated experimental or field trials, within spatial structures, and with prospective users having particular capabilities and bodies to be cared for. Within these settings, the socio-technical futures might get revised and transformed. Discourse-ethnographic approaches (Elliker, 2017, 2018; Elliker et al., 2017; Hornidge & Feuer, 2018; Wundrak, 2017) could provide insights into these processes and their impacts on discourses. They could more comprehensively consider the social and spatial situatedness of speakers. Further reasons for discursive absences but also for the establishment of interdiscursive relations could be identified. Thereby, issues of power to speak and thus to establish relations, as well as the power to be heard and thus to be noticed as a source of new knowledge, should be considered. Combining discourse analytical methods with other empirical methods of qualitative or quantitative social research that shed light on the social conditions of discourse production appears suitable for this matter.

Third, I have proposed an empirically grounded concept of the relations of discourses that needs further theoretical and empirical work. Although the suggested types of relations could be starting points for comparative analysis, further (theoretical and empirical) differentiation of their characteristics and dimensions seems necessary. Furthermore, this concept brings into focus the permeability of discourses for external discourses and stocks of knowledge and underlines the transformability of discourses. At once, I could not definitively pin down the processual movement of discursive elements and stocks of knowledge across different social communities and discursive arenas. I identified analogies but was not fully able to trace the processes of knowledge or discursive elements ‘travel’ from one discourse to another over time. More comprehensive studies focussing on a discourse’s historic emergence and development are indicated. They have to even closer follow the different branches, speakers, discursive arenas, and so on while closely examining those points in time, conditions, documents, and discursive events that establish novel interdiscursive connections.

Finally, ‘absence’ is always an ‘exceptionally slippery subject’ (Frickel, 2014, p. 89). In particular, pinning down one particular topic or issue as absent is difficult because there is an abundance (Rappert, 2014, p. 42) or ‘plethora’ (Schröter & Taylor, 2018, p. 2) of absences around those things that have a presence in discourses. Considering this abundance of absent

or silenced topics, recognising and analysing one absence, such as that of dying users in the roboticists' discourse, always 'produces' other absences as a byproduct (Murray & Durrheim, 2019b, pp. 9–10). The same holds true for identifying discursive relations and/or meaningful unrelatedness. Although I have presented several arguments for the meaningfulness of the particular absence of dying users in the roboticists' discourse, other relevant absences could and should be considered as well.

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Annex A Informed consent sheet

On the following three pages, one version of the informed consent sheet used for the interviews with roboticists is replicated. There are different versions of the sheet because I adapted some parts of the data protection provisions depending on the communication channel and tool employed for the interview (for example, landline, Microsoft Skype, Microsoft Teams, Jitsi Meet). Contact details such as email address and phone numbers have been removed from the document.

Project information and informed consent

Version: 17 June 2020

This document informs you about the project "Robots in end of life care" and your participation as interviewee. The document outlines what data is collected from and about you, how it is collected, and how this data will be processed, analysed, and stored. The second part of the document is an informed consent form: If you agree to the conditions described, I ask you to indicate this by filling in your name, by ticking the respective boxes, and by signing the form. **Please sign, scan, and send the last page to Alexander Lang** ([removed]).

Please read the document carefully and **do not hesitate to ask any question** via Email ([removed]), phone [removed]) or during the interview.

Thank you for your good cooperation and willingness to give me an interview! Your participation is important for the success of my study and dissertation!

Project information

This project is conducted by Alexander Lang at the Institut für Höhere Studien – Institute for Advanced Studies (IHS) in Vienna (https://www.ihs.ac.at/). In this, Alexander Lang receives mentoring by Dr. Anna Durnová (IHS). At the same time, the research on this project is used for his doctoral dissertation at the University of Vienna, Faculty of Social Sciences, under the supervision of Prof. Michaela Pfadenhauer.

What is the project about?

The project "Robots in end of life care" investigates how roboticists as well as professional care workers envision and assess the future use of caregiving robots. The project examines expert discourses about the development and design of robots for elderly care by collecting and analysing various kinds of publicly available data (e.g. journal or newspaper articles) as well as data produced through interviews with roboticists and professional care workers as part of this project. The project focusses on research, development, and use of robots in care in Europe.

What kind of data will be collected through the interview?

The interview will collect personal data such as your personal assessments, opinions, knowledge, education, or professional background. The interview consists of open-ended questions that leave room for all different kinds of answers. Thus, the scope and nature of information provided by the interviewee cannot be entirely predicted. The interview focusses on the topics of robots and care. The interview might or might not touch upon biographical, personal, or business matters depending on the succession of the conversation. You are free to share whatever you want and decline to answer any given question.

The interview will be conducted via Skype or Microsoft Teams (Microsoft Corporation). The call will be encrypted according to the company's standards; however, the company might collect data in line with the company's data protection policy[1].

[1] https://privacy.microsoft.com/en-us/privacystatement

How will the data be processed?

The interview will be audio recorded. The audio file will be fully transcribed. In this process conducted by Alexander Lang, the interview data will be pseudonymised by removing or altering personal identifiers such as names, affiliations, or locations. The pseudonymised transcripts will be analysed and interpreted using software for qualitative data analysis. Pseudonymised transcripts might be printed for analysis purposes.

How will the data be used and who has access to the data?

Data will be used for social scientific analysis. Extracts of the pseudonymised transcript might be cited verbatim; some of your statements might be paraphrased, interpreted, and included in the project's results. You will never be identified by name, affiliation, or other personal information as interviewee. However, due to the limited range of the field of care robotics in Europe, it might be possible for people who know you and your work, such as people from your field or colleagues, to identify you because of single statements.

Only Alexander Lang will have access to the audio file and the full pseudonymised transcript. The data analysis will be done by Alexander Lang, but might be supported and discussed by peers such as colleagues from the IHS, fellow students, doctoral supervisors and mentors, or other colleagues from the research community. For this purpose, portions of the pseudonymised transcript might be shared with these peers. However, your identity will never be disclosed. If you explicitly agree in the informed consent form, extracts of the pseudonymised transcript will also be used beyond the research project for educational purposes such as university courses.

How will the data be stored?

The audio file will be stored in a safe place at the investigators facilities and will be deleted by the end of the dissertation project. The pseudonymised transcript will be stored in a safe place. Only Alexander Lang will have direct access to the files. The pseudonymised transcript will be deleted ten years after the end of the dissertation project the latest. Processed data and extracts of the pseudonymised transcripts might survive the project as they may become part of publications, presentations, and other dissemination activities. In case the pseudonymised transcript or parts of the transcript are digitally transferred or transported, for example to discuss it with scientific-peers, the file will be encrypted.

Your rights

During the interview you are free to not answer questions or leave the interview without any consequences. If you would like to address a question or an issue, please feel free to do so. Furthermore, you have the right to access and erase data, to restrict the processing of data, and the right to data portability and the right to object, as granted in General Data Protection Regulation (GDPR) Article 15–22. You can also withdraw the consent given by signing this form according to GDPR Article 6(1) and Article 9(2) without any consequences. Upon request your local supervisory authority will provide you information on exercising your right according to Article 57(e) GDPR.

Supervision and Data Breach

The IHS has a Data Protection Officer (DPO) who can be contacted via Email ([removed]). In case of a data breach, Alexander Lang will inform the DPO. Together they will undertake all steps necessary to minimize negative consequences. You will receive a notification about the nature of the data breach, the information lost, and the actions taken as soon as possible.

Informed consent form

Project title: “Robots in end of life care”

Principal investigator: Alexander Lang

Thank you for participating in this interview. Please read the preceding information sheet carefully and do not hesitate to ask any question. Then, please confirm the boxes below, write in your name in the designated field, and sign the document. Send a scan of the document to [email address removed]. You will get a signed copy back.

Please tick those boxes beside each statement you want to confirm:	**Yes**	**No**
I have received, read, and understood the project information dated 17 June 2020 and have had the opportunity to ask questions. I give consent to collect, process, use, and store data provided by me in the course of the interview as stated in this project information. I understand that I am free to withdraw the consent given here any time without giving any reason and without any negative consequences. I understand that I am free to request the deletion of any data at any time, but that parts of the data that have already become part of presentations or publications cannot be withdrawn.	☐	☐
I agree that parts of the pseudonymised transcripts are used for educational purposes such as university courses.	☐	☐

First and last name in block capitals:

Signature, Date

Alexander Lang’s signature, Date

Annex B Supplementary material paper 3

The following pages (pp. 230–269) contain the supplementary material to my fourth paper presented in section 5.4 of this dissertation.

Supplementary material for ‘Absent users of technology: the absent dying users in the development of robots for care’

1. List and description of robots

Table 1 Robots analysed: purpose, capabilities, funding

Abbreviations: AAL=Ambient Assisted Living, BMBF=Bundesministerium für Bildung und Forschung (Federal Ministry of Education and Research), FP=Framework Programme, H2020=Horizon 2020

Robot	**References**	**Purpose and (envisioned) capabilities**	**Related funding**
Care-O-Bot I	Hans et al. (2002)	Mobile assistive robot for elderly and disabled people to prolong independent living at home as walking aid, guide, or by conducting fetch-and-carry tasks.	Germany: BMBF – project: MORPHA
Care-O-Bot II	Graf et al. (2004)	Mobile assistive robot for elderly and disabled people to promote independent living as a walking aid, guide, or by conducting fetch-and carry tasks	Germany: BMBF – project: MORPHA
Care-O-Bot III	Reiser et al. (2013)	Mobile assistive robot for elderly to promote independent living and support care workers by providing fetch-and-carry functionality, emergency assistance, monitoring, entertainment, and being a walking aid.	EU: FP7-ICT-2009-4 – project: SRS; EU: FP7-ICT-2011-7 – project: ACCOMPANY; Germany: BMBF – project: WiMi Care
Care-O-Bot IV	Kittmann et al. (2015)	Mobile assistive robot for a variety of purposes not necessarily focused on care environments: fetch-and-carry tasks, guidance, information, security, etc.	Germany: BMBF (2016) – projects: RoPHa, ASARob
CARESSES	Papadopoulos et al. (2020)	Mobile assistive robot for elderly to increase their health and well-being through providing social interaction (making conversation), reminders (e.g.,	EU: H2020-SC1-2016-CNECT.EUJ –

		for medicine), entertainment, smart home control, telepresence, and broader social support.	project: CARESSES
EDAN	Vogel et al. (2015), Deutsches Zentrum für Luft und Raumfahrt (2017)	A wheelchair with manipulator, for people with physical disabilities to increase their independence and quality of life by grasping and picking up objects, handing them things, or support drinking.	EU: FP7-ICT-2009-4 – project: THE Hand Embodied EU: FP7-ICT-2011-7 – project: SAPHARI
GIRAFF	Camanio Care (2017, 2019)	Mobile telepresence robot for elderly living at home to promote their independent living by enabling virtual visits of and interaction with others (caregivers, relatives).	EU: AAL-2009-2 – project: GIRAFF
GIRAFFPlus	Coradeschi et al. (2013), Cortellessa et al. (2015)	Mobile telepresence robot and home system to promote independent living of elderly in their private homes by enabling virtual visits of and interaction with others (caregivers, relatives) and implementing a system support he safety of the elderly (e.g., fall detection, activity detection, etc.).	EU: FP7-ICT-2011.5.4 – project: GIRAFFPlus
HOBBIT PT1	Fischinger et al. (2016)	Mobile assistive robot for elderly living at home to prolong their independent living through improving the safety of their homes by supporting fall prevention (picking up things/obstacles from the floor) and emergency response to accidents (fall detection and emergency call).	EU: FP7-ICT-2011-7 – project: HOBBIT
HOBBIT PT2	Bajones et al. (2018, 2019), Pripfl et al. (2016)	Mobile assistive robot for elderly living at home to prolong their independent living through improving the safety of their homes and their fitness by supporting fall prevention (picking up things/obstacles from the floor), emergency response to accidents (fall detection and emergency call), and promoting training. Further developed version of the HOBBIT PT1.	EU: FP7-ICT-2011-7 – project: HOBBIT

Isupport	Zlatintsi et al. (2018)	Stationary robotic shower system for legs and back that is guided by the gestures of the users to support elderly in bathing to increase their independence and quality of life.	EU: H2020
Kompaï	Kompaï Robotics (2018, 2019), Zsiga et al. (2013, 2018)	Mobile assistive robot for elderly, weak, and dependent people in institutional care settings to promote health and safety, social interaction, quality of life, and independence by supporting walking (walking aid), information and reminder, monitoring the status of the elderly, providing entertainment, or transporting things.	EU: Ambient Assisted Living (AAL) Joint Programme (AAL-2008-1-159) – project: DOMEO
LIO	F&P Personal Robotics (2017, 2018, 2019), Früh and Gasser (2018), Mišeikis et al. (2020)	Mobile assistive robot to relief caregivers and to improve the quality of life of care recipients through support in everyday life including handling objects, entertainment and information, transport of goods, activation and training, offering beverages and snacks, etc.	/
MARIO	Casey et al. (2016), Mannion et al. (2019), Kouroupetroglou et al. (2017)	Mobile assistive robot as companion for elderly people with dementia for promoting social interaction and reducing loneliness and isolation by enabling telepresence, providing information and entertainment, facilitating training, or monitoring the status of the users.	EU: H2020-PHC.2014
OurPuppet	Naroska et al. (2018), Schramek et al. (2018)	Interactive puppet as companion robot for people with dementia and their relatives supporting social interaction, facilitating daily routines, monitoring certain parameters, and soothing the patients.	Germany: BMBF (2014) – project: OurPuppet
PAM-AID	Lacey and Dawson-Howe (1998)	Mobility aid for elderly blind to improve their safety, promote independent exercise, and increase their autonomy.	EU: Telematics Applications Program for the Integration of Elderly and Disabled People (TIDE)

Robco	Chivarov et al. (2018, 2019)	Mobile assistive robot for elderly and disabled people living at home to increase their quality of life through promoting activation, giving reminders, serving food and drinks, switching devices on or off, providing fall detection and emergency alarms.	Bulgaria: Bulgarian National Science Fund – project: Tele-controlled Service Robots for Increasing the Quality of Life of Elderly and Disabled
Robot Surrogate	Mackey et al. (2020)	Mobile assistive telepresence robot for people in palliative care to improve their quality of life by enabling social interaction between patients and relatives as well as visiting important places or social events outside of the own care environment.	/
RoboTrainer	Stogl et al. (2019), Stogl, Hein, and Mende (2019)	Robot, similar to a smart walker, to promote neuromuscular training for persons with or without assistive needs.	Germany: BMBF (2016) – project: RoSylerNT

2. Documents analysed

Table 2 Documents and media analysed as part of the discourse analysis

Abbreviations: AAL=Ambient Assisted Living (also: Active and Assisted Living), ICT=Information and Communication Technology, IEEE=Institute of Electrical and Electronics Engineers, ISTAG= Information Society Technologies Advisory Group, TIDE=Technology for the Socioeconomic Integration of Disabled and Elderly People

Related robots	**Reference**	**Title [Translation]**	**Short description**
Care-O-bot	Hans et al. (2002)	Robotic home assistant Care-O-bot: past-present-future	Conference proceeding from an IEEE Workshop on 'Robot and Human Interactive Communication'. It presents a vision for robots in care linked to the first model of the Care-O-bot and outlines further iterations.
Care-O-bot	Schraft et al. (1998)	Care-O-bot: the concept of a system for assisting elderly or disabled persons in home environments	Proceeding from an annual IEEE conference. It outlines general requirements for a robotic system for home care, identifies necessary technical aspects, and presents the construction design of the first Care-O-bot system.
Care-O-bot II	Graf et al. (2004)	Care-O-bot II—development of a next generation robotic home assistant	Journal article presenting the development of the second version of the Car-O-bot including application scenarios, hardware details, and results from user experiments. One of the highest cited journal articles on this robot (232 citations).
Care-O-bot III	Reiser et al. (2013)	Care-O-bot® 3 – vision of a robot butler	Book chapter from an edited volume on robots as butlers. It presents a vision linked to the third model of the Care-O-bot series. The chapter especially deals with design considerations in the robot

Related robots	Reference	Title [Translation]	Short description
			development, but also with its use scenarios.
Care-O-bot III, EDAN	European Commission (2009)	Updated work programme 2009 and work programme 2010: cooperation theme 3: ICT – information and communications technologies	Document by the European Commission outlining the details for the FP7 work programme for 2009 and 2010 in the area of information and communication technologies. Under this funding programme, several projects were funded which are interlinked with the development of robots which are part of this study: SRS (Care-O-bot III) and THE Hand Embodied (EDAN). Furthermore, the Coordination Action euRobotics was funded which subsequently has led to the establishment of the euRobotics association (closely connected to the public-private-partnership SPARC).
Care-O-bot III, EDAN, GIRAFFPlus, HOBBIT	European Commission (2011)	Updated work programme 2011 and work programme 2012: cooperation theme 3: ICT – information and communication technologies	Document by the European Commission outlining the details for the FP7 work programme for 2011 and 2012 in the area of information and communication technologies. Under this funding programme, amongst others, several projects were funded which are interlinked with the development of robots which are part of this study: HOBBIT, GIRAFFPlus, SAPHARI (EDAN), and ACCOMPANY (Care-O-bot III).
Care-O-bot IV	Kittmann et al. (2015)	Let me introduce myself: I am Care-o-bot 4, a gentleman robot	Conference proceeding presenting the R&D vision linked to the fourth model of the Care-O-bot series.

Related robots	Reference	Title [Translation]	Short description
Care-O-Bot IV, RoboTrainer	Bundesministerium für Bildung und Forschung (2016)	Bekanntmachung: Richtlinien zur Förderung von Forschung und Entwicklung auf dem Gebiet 'Autonome Roboter für Assistenzfunktionen: Interaktive Grundfertigkeiten' [Announcement: guidelines for funding research and development in the field of 'autonomous robots for assistance functions: basic interactive skills]	Document by the German Federal Ministry of Education and Research outlining their call for proposals for projects on autonomous assistive robots. While the focus is not entirely on care, healthcare is identified as one area of application and the aging society as a frame and rationale for this call. Under this call, amongst others, the projects ASARob (Care-O-Bot IV), RoPHa (Care-O-Bot IV), and RoSylerNT (RoboTrainer) were funded.
CARESSES	Papadopoulos et al. (2020)	The CARESSES study protocol: testing and evaluating culturally competent socially assistive robots among older adults residing in long term care homes through a controlled experimental trial	Paper presenting a study protocol for the evaluation of a social robot in an intervention study in-depth including the design of the study and the selection of participants.
EDAN	Vogel et al. (2015)	An assistive decision-and-control architecture for force-sensitive hand–arm systems driven by human–machine interfaces	Article presenting EDAN as physically assistive robot for people with disabilities in a high ranked journal in the field of robotics. Focus on technical approach and field test results with one participant.
EDAN	Deutsches Zentrum für Luft- und Raumfahrt (2017)	Project EDAN: towards an EMG-controlled daily assistant	Video presented on the EDAN project page as part of the German Aerospace Center (DLR) website. The video, which is around one and half minutes long and comprises of real live actions and graphical

Related robots	Reference	Title [Translation]	Short description
			presentations, shows EDAN in various experimental/field trial setting handing things to patients and explains some of its technical details.
GIRAFF	Camanio Care (2017)	Cecilia visits Aina	Short live action video clip featured as central element on the company's website. It shows the robot in a private home environment of an elderly woman first virtually (telepresence robot) and then personally visited by a professional caregiver.
GIRAFF	Camanio Care (2019)	Giraff: provides safety from a distance	Website of a company presenting the robot to a wider audience describing its features and use.
GIRAFF	Ambient Assisted Living (AAL) Joint Programme (2009)	Call for proposals AAL-2009-2: 'ICT based solutions for advancement of social interaction of elderly people'	Document by the Ambient Assisted Living (AAL) Joint Programme considering their 2009 call for project proposal. Similar as the AAL-2018-1 call, this document outlines the rationale and implementation of their funding programme. Under this scheme, amongst others, the GIRAFF project was funded.
GIRAFFPlus	Coradeschi et al. (2013)	GiraffPlus: combining social interaction and long-term monitoring for promoting independent living	Article in the proceedings of a conference on human-system-interaction describing the purpose and technical details of the GIRAFFPlus robotic system. One of the highest cited papers on this robot (81 citations)
GIRAFFPlus	Cortellessa et al. (2015)	GiraffPlus: D5.5 system integration: final system and live demonstration	Deliverable from a research project funded by the European Commission (FP7) describing the sites for field trials including the participants

Related robots	Reference	Title [Translation]	Short description
			and their use of the GIRAFFPlus system. The second part of the paper describes the final GIRAFFPlus system including technical details.
GIRAFFPlus	Frennert et al. (2013)	Elderly people's perceptions of a telehealthcare system: relative advantage, compatibility, complexity and observability	Journal article presenting the GIRAFFPlus system and results of a usability test and assessment of the GIRAFFPlus system in a laboratory setting.
HOBBIT	Fischinger et al. (2016)	Hobbit, a care robot supporting independent living at home: first prototype and lessons learned	Article in a robotics journal giving a detailed overview of the robot's development and first field trials. One of the highest cited papers on this robot (128 citations).
HOBBIT PT2	Bajones et al. (2018)	Hobbit: providing fall detection and prevention for the elderly in the real world	Article in a robotics journal outlining field trials in three different countries over several weeks with the second, further developed version of the HOBBIT robot in private homes of elderly care recipients.
HOBBIT PT2	Bajones et al. (2019)	Results of field trials with a mobile service robot for older adults in 16 private households	Journal article presenting findings from field trials with the second version of HOBBIT in private households over several weeks. Amongst others, it describes, how these field trials compare to and exceed field trials with other robots, presents the robot functionality, and the evaluation of the HOBBIT field trials.
HOBBIT PT2	Pripfl et al. (2016)	Results of a real world trial with a mobile	Short paper describing the second version of the HOBBIT robot and its use and results in

Related robots	Reference	Title [Translation]	Short description
		social service robot for older adults	field trials in three European countries.
I-Support	Zlatintsi et al. (2018)	Multimodal signal processing and learning aspects of human-robot interaction for an assistive bathing robot	Proceeding from an international IEEE conference. It presents the design and technical details of I-Support, but also a validation of the recognition system through field trials.
Kompaï	Kompaï Robotics (2019)	Kompaï robots	Promotional website for this robot providing a general overview of the robot including its envisioned use and benefits.
Kompaï	Kompaï Robotics (2018)	Kompaï robotics: the robot to help frail people and their caregivers	Animated video clip presenting the robot's intended use case and setting (care facility) including a depiction of care recipients and caregivers. Featured on the company's website and hosted on YouTube.
Kompaï	Zsiga et al. (2013)	Home care robot for socially supporting the elderly: focus group studies in three European countries to screen user attitudes and requirements	Journal article describing a focus group study to evaluate the participants assessment of the Kompaï robot's functionality and their willingness/acceptance/motivation to use such a robot.
Kompaï	Zsiga et al. (2018)	Evaluation of a companion robot based on field tests with single older adults in their homes	Article in a journal on technological solutions for assistance. The paper presents field trials with elderly participants using Kompaï in their own home environment for several months. The article describes the users' assessment of the robot as well as the frequency of use of certain functions.
Kompaï	Ambient Assisted Living	Call for proposals 2008 AAL-2008-1:	Document by the Ambient Assisted Living (AAL) Joint

Related robots	Reference	Title [Translation]	Short description
	(AAL) Joint Programme (2008)	'ICT based solutions for prevention and management of chronic conditions of elderly people'	Programme considering their 2008 call for project proposal. The document outlines the rationale of funding technological means to prevent and manage chronic conditions by highlighting the European ageing societies and related challenges. Under this scheme, amongst others, the DOMEO project was funded which is related to the Kompaï robot.
Last Moment Robot	Chen (2012)	File > Save As > Intimacy: What is intimacy without humanity?	Master's thesis (Media/Design) presenting several designs of robots that relate to the topic of creating intimacy (touching, listening, interacting, etc.) with machines. Amongst others, it present a last moment robot as 'interactive installation' (Chen, 2012, p. 32) that touches and speaks with a patient (actor in a performance) at the end of life. This machine received wider (internet) media reception but is not intended as prototype for any further development.
Last Moment Robot	TEDx Talks (2016)	File, Save As, Intimacy: What is Intimacy without Humanity? | Dan Chen	Recorded presentation by Dan Chen on his Last Moment Robot.
LIO	F&P Personal Robotics (2019)	F&P Personal Robotics	Promotional website providing an overview and presenting the envisioned use and benefits of the robot (German).
LIO	F&P Personal Robotics (2018)	Care robots Lio and Guido	Short live action video clip accessible as main element of the company's website and hosted on YouTube. It shows

Related robots	Reference	Title [Translation]	Short description
			the use of LIO in multiple scenes including elderly users, the actual robot, as well as professional caregivers in a care institution.
LIO	BFT (2018)	Der Menschenfreund [The philanthropist]	Industry magazine article presenting F&P Personal Robotics and LIO. The article was featured on the company's website.
LIO	F&P Personal Robotics (2017)	Lio – Der persönliche Assistenzroboter: Gezielte Entlastung von Betreuungspersonal und mehr Lebensqualität für Menschen mit Unterstützungsbedarf [Lio – the personal assistance robot: targeted relief of caregivers and more quality of life for people with support needs]	Marketing brochure on LIO that conveys information both textually as well as visually. At the time of data collection, the brochure was prominently featured on the company website.
LIO	Früh & Gasser (2018)	Erfahrungen aus dem Einsatz von Pflegerobotern für Menschen im Alter [Experiences from the use of care robots for people in old age]	Book chapter describing the rational of designing and developing the robot as well as field trials with elderly users in a care facility.
LIO	Mišeikis et al. (2020)	Lio – a personal robot assistant for human-robot interaction and care applications	Article in a robotics and automation journal. It gives an overview on the design and technical details of LIO and presents some insights from the evaluation of experimental and field trials.
MARIO	Casey et al. (2016)	What people with dementia want:	Conference proceeding outlining insights on the needs

Related robots	Reference	Title [Translation]	Short description
		designing MARIO an acceptable robot companion	and demands of people with dementia in relation to companion robots. Furthermore, the proceeding presents the robot MARIO as companion for dementia patient. One of the highest cited papers related to the MARIO project (14 citations).
MARIO	Mannion et al. (2019)	Introducing the social robot MARIO to people living with dementia in long term residential care: reflections	Article in a journal on social robotics reflecting the researchers' experiences with field trials with their robot and identifying strategies to improve the patients' interaction with the robot
MARIO	Kouroupetroglou et al. (2017)	Interacting with dementia: the MARIO approach	Paper from a conference on assistive technology outlining the approach of the MARIO project and first insights from trials with people with dementia using the robot.
MARIO, I-Support	European Commission (2015)	Horizon 2020 work programme 2014–2015: 8. health, demographic change and wellbeing.	Document by the European Commission outlining the H2020 work programme for 2014 to 2015 for the area of 'health, demographic change and wellbeing'. One call for proposals considers the topic of service robotics for assisted living by highlighting the challenge of an ageing society and as one solution service robotics for independent living (PHC-19-2014). Under this funding programme, amongst others, the projects MARIO and I-Support were funded.
OurPuppet	Naroska et al. (2018)	Project OurPuppet: a system to support people with dementia	Paper from an IEEE conference on consumer electronics presenting the OurPuppet project, the aim of

Related robots	Reference	Title [Translation]	Short description
		and their caregiving relatives at home	the robot development, as well as the design and technical aspects of the robotic puppet.
OurPuppet	Schramek et al. (2018)	'OurPuppet'– Nutzerakzeptanz und ethisch-soziale Aspekte einer M-T-I Entwicklung ['OurPuppet' – user acceptance and ethical-social aspects of a human-technology-interaction development]	Paper from a conference on technological innovations in care presenting the OurPuppet project (aims and implementation) including the OurPuppet system as well as insights from tests with patients with dementia and their informal caregivers.
OurPuppet	Bundesministerium für Bildung und Forschung (2014)	Bekanntmachung des Bundesministeriums für Bildung und Forschung von Richtlinien zur Förderung von Forschung und Entwicklung auf dem Gebiet 'Pflegeinnovationen zur Unterstützung informell und professionell Pflegender' [Announcement by the Federal Ministry of Education and Research of guidelines for funding research and development in the field of 'care innovations to support informal and professional caregivers']	Document by the German Federal Ministry of Education and Research outlining their call for proposals for projects on technological innovations in care. The funding programme explicitly addresses innovation for care settings that should support informal and formal caregivers. It identifies the demographic trends and care crisis as rationales for this R&D funding approach. Under this call, the project OurPuppet was funded.

Related robots	Reference	Title [Translation]	Short description
PAM-AID	Lacey & Dawson-Howe (1998)	The application of robotics to a mobility aid for the elderly blind	Article on a smart walker/therapeutic robot describing the requirements of users, the design of the robot, and an experimental evaluation. Highly cited paper in this area (114 citations).
Robco	Chivarov et al. (2018)	Cost oriented tele-controlled service robot for increasing the quality of life of elderly and disabled – ROBCO 18	Paper from a conference on automation presenting the prototype of a service robot including its purpose, interface and control, software, and other technical details and components. It also presents a few findings from a field trial.
Robco	Chivarov et al. (2019)	Usability study of tele-controlled service robot for increasing the quality of life of elderly and disabled – 'ROBCO 17'	Paper from a regional robotics conference describing an evaluation of the usability of robots by elderly participants in a laboratory trial using the robot.
Robot Surrogate	Mackey et al. (2020)	Immersive control of a robot surrogate for users in palliative care	Conference proceeding outlining the development and testing of a telepresence robot. One of a very few explicit references to palliative care as a use setting for robots.
RoboTrainer	Stogl, Hein, & Mende (2019)	Overview of a robot for a neuromuscular training – RoboTrainer	Proceeding from a conference on mobile robots. It mainly describes the technical aspects of the robotic system as training device for elderly or disabled people.
RoboTrainer	Stogl et al. (2019)	Robot-based training for people with mild cognitive impairment	Paper in a robotics journal presenting the design and laboratory trial with elderly test users.
(Kompaï)	Semerano (1997)	New promising applications for service robotics: collective	Early publication on robot applications in care settings describing the field of healthcare as new field of

Related robots	Reference	Title [Translation]	Short description
		organizations services	application and business for robotics. The author worked for RoboSoft, a company that later on developed Kompaï.
/	Tonkens (2015)	Ethics of robotic assisted dying	Contribution to a book on the ethics of using various machines in medical settings. The paper deals with ethics and morals of using robots in assisted dying. It got rarely cited and never in the field of robotics.
/	Beck (2018)	Zum Einsatz von Robotern im Palliativ- und Hospizbereich [On the use of robots in the palliative and hospice sector]	Article published in a journal on medical law. It deals with the potential use of robots in general in palliative and hospice care from a law perspective. It has rarely been cited so far and never by any publication from the field of robotics.
/	Nwosu et al. (2019)	Robotic technology for palliative and supportive care: strengths, weaknesses, opportunities and threats	Article published in a journal on palliative medicine. It presents the findings of a 'strengths, weaknesses, opportunities and threats (SWOT)' analysis of robotic technology in palliative care. So far, it has been cited by three other papers from the field of robotics, including Mackey et al. (2020).
/	Sturgeon et al. (2017)	O-7 robotic technology and palliative care education: the development of a 'nao robot' computer program	Abstract on the development of a software for a NAO robot to enable the robot to support trainings in palliative care education. Published in a journal from the field of palliative care. So far, it has been cited by three other papers from the field of palliative care and medicine, but not from robotics.

Related robots	Reference	Title [Translation]	Short description
/	euRobotics aisbl (2014)	SPARC: the partnership for robotics in Europe: strategic research agenda for robotics in Europe 2014–2020.	Document outlining a research agenda for robotics in Europe produced by the public-private-partnership SPARC, the 'largest civilian-funded robotics innovation programme in the world' (SPARC, 2020). The document includes assessment with regards to the purpose and market of robots as well as deliberation on ethical, legal, and social issues and the European funding programme H2020. It then also provides scenarios and visions of robotic development in different areas, such as healthcare, and societal challenges that could be addressed by robotics, such as the ageing society.
/	Information Society Technologies Advisory Group (2004)	ISTAG report on grand challenges in the evolution of the information society	Document by the Information Society Technologies Advisory Group (ISTAG), an advisory group set up to counsel the European Commission with regards to their research and innovation policy and funding. The ISTAG is explicitly mentioned as one basis of work programmes in FP7. This document outlines the so-called grand challenges for society and policy related to the information society, but also related technological and scientific challenges. Amongst others, this report outlines the challenge of an ageing society and service and companion robotics as one possible solution to this.

Related robots	Reference	Title [Translation]	Short description
/	Information Society Technologies Advisory Group (2006)	ISTAG report on orientations for work programme in FP7	Document by the Information Society Technologies Advisory Group, an advisory group set up to counsel the European Commission with regards to their research and innovation policy and funding. This document explicitly aims to provide orientation for ICT work programmes in FP7. It outlines key challenges (including ageing, but also competitiveness) and presents digital care services as one important area of research and development.
/	Commission of the European Communities (1993)	TIDE technology initiative for disabled and elderly people: TIDE 1993–1994 workplan	Document by the Commission of the European Communities outlining the TIDE funding programme's workplan for 1993 and 1994. It outlines the background and rationale of TIDE as well as the various areas of funding. Assistive robots are identified in several streams of funding (e.g., 'robotic aids with wheelchairs', 'robot systems for assistance with common household and workplace tasks').

3. Further illustrative quotes

Table 3 Illustrative quotes

No.	Reference	Quote
Q1	Bundesministerium für Bildung und Forschung (2014, p. 1)	Translated: 'The care sector is facing particular challenges in view of demographic change. According to projections by the Federal Statistical Office, the number of people in need of care in Germany will rise from around 2.5 million at present to up to 3.4 million in 2030.' Original: 'Die Pflegebranche steht angesichts des demografischen Wandels vor besonderen Herausforderungen. Vorausberechnungen des Statistischen Bundesamtes zufolge steigt die Zahl der Pflegebedürftigen in Deutschland von derzeit rund 2,5 Millionen auf bis zu 3,4 Millionen im Jahr 2030.'
Q2	euRobotics (2014, p. 61)	'The demographic shift to a European population with a far higher proportion of elderly people is well understood. The percentage of elderly people in many European societies will exceed 30% by 2050. [line break] Caring for this older population will place a significant burden on a generation of younger people and on the state. Finding effective technical solutions to providing care for elderly people is one of a range of measures required to reduce the social and economic impact of this future change.'
Q3	Graf et al. (2004, p. 203)	'Due to the given demographic trends and developments within the industrial societies all over the world, practical solutions are required that help to dam exploding medical costs.'
Q4	IP1-Management (min. 13:05 ff.)	Translated: 'We have the same challenges as [other country 1], as [other country 2], namely that everybody is getting older, that there is a shortage of skilled workers, um, that is the case everywhere in Western Europe' [Country names removed for pseudonymisation] Original: 'Wir haben die gleichen Herausforderungen wie [anderes Land 1], wie [anderes Land 2], nämlich, dass alle älter werden, dass die Fachkräfte fehlen, ähm, das ist überall in ganz Westeuropa der Fall.'
Q5	IP6-R&D (min. 14:00 ff.)	Translated: 'Because many have the feeling of being overwhelmed when they are responsible for thirty residents and, yes, that they are actually in emergency mode all the time.'

No.	Reference	Quote
		Original: ‘Weil, viele haben das Gefühl der Überforderung, wenn sie dann für dreißig Bewohner zuständig sind und ja, dass sie da eigentlich im Notfallmodus ständig sind.’
Q6	Kompaï Robotics (2018, min. 00:00–00:14)	‘As our population grows older, it’s beginning to outpace the number of caregivers free to help. […] And when these caregivers’ abilities are spread thin, frail people may lack the support they need.’
Q7	Mannion et al. (2019, p. 1)	‘This is a significant problem given that the number of [people living with dementia] is expected to double in the next 20 years and dementia is expected to affect 66 million people worldwide by 2030 [1]. The ability of social robots to help [people living with dementia] to stay socially connected may help address the significant and progressive problems of loneliness and isolation enhanced by dementia’
Q8	Naroska et al. (2018, p. 1)	‘In 2015 a report published by a large German health insurance fund has pointed out [1] that in 2060 in Germany more than 4 million people in need of care are expected. Due to the higher average life expectancy of the population, the number of dependent people, especially people with Alzheimer's disease, will increase. These transitions result in very high demands for better home and hospital care.’
Q9	Fischinger et al. (2016, p. 60)	‘One option to address the challenge of demographic transition is to build robots that enable aging in place.’
Q10	Information Society Technologies Advisory Group ISTAG (2004, p. 4)	‘The Service Robot Companion: As the European population ages, spiralling health-related costs will place an immense burden on European economies. We envision the development of flexible home-care service robots, which will help people to care for themselves, improve their comfort of living and likely entertain them.’
Q11	IP3-Marketing (min. 20:31 ff.)	‘I think minds are really changing and the people are aware that we need the help of the technology because of the fact that we are too many/ that we have too many frail people and we are not enough people to take care of them.’
Q12	Miseikis et al. (2020, p. 1)	‘Given the issue of ageing population and shortage of medical and nursing staff in many countries, this naturally leads to attempts to use robotics and automation addressing this problem [1] [2].’
Q13	Semerano (1997, p. 6)	‘The emergency in charge is in the phenomenon of rapidly increase of the ageing people in Europe. A phenomen [sic!] which is putting health care national budget agendas, of all member states, at an extreme end. An emergency, which makes public and private health authorities open to any type of

No.	Reference	Quote
		technical solutions, which can contribute to slow this trend down.'
Q14	Stogl et al. (2019, p. 1)	'The shortage on caregivers in the aging western societies has motivated many research groups to develop smart assistive devices for rehabilitation and gait assistance.'
Q15	Coradeschi et al. (2013, p. 578)	'Most elderly people wish to remain in their homes as long as possible as this is in general conducive of a richer social life and paramount to maintaining established habits. To adhere to this wish is also positive from an economic perspective as the cost of care at home is almost always much less than the cost of residential care.'
Q16	Fischinger et al. (2016)	'Because of the fact that older adults prefer to independently live on their own at home as long as possible [1], the necessity of developing assistive technology is increasing'
Q17	Frennert et al. (2013, pp. 219 & 220)	'The healthcare sector has a compelling need to find new ways to address elderly people's preferences for prolonged independent living in combination with the monitoring of long-term medical conditions and social care needs.' 'The GiraffPlus is a telehealthcare system that combines social interaction and long-term monitoring to prolong independent living.'
Q18	Graf et al. (2004)	'Technical aids enable people in need of support and care to live independently in their accustomed home environments for a longer time. This not only fulfils their desire for independence and autonomy, it also helps avoid the high costs for the individual treatment in nursing homes that might otherwise be necessary. This, in turn, results in immense savings for the government as well as for each individual.'
Q19	Schraft et al. (1998, p. 2476)	'Technical aids are required allowing people to live independent and supported in their private home as long as they wish. As a contribution to these required technological solutions ad demonstrator platform for a Mobile Home Care System […] was designed and implemented […]'
Q20	Camanio Care (2019)	'With regular visits a patient that lives at home can experience a new kind of independence with the support of care staff using the Giraff.'
Q21	European Commission (2011, p. 72)	'The services should focus on enabling extended independent living of elderly people and support for higher efficiency and quality of care work based on robotics solutions. Examples of

No.	Reference	Quote
		services include support to daily tasks, mediated social interaction with carers and relatives as well as support to mobility.'
Q22	F&P Personal Robotics (2017, p. 6)	Translated: 'Independence: Lio gives people back autonomy and independence.' Original: 'Selbständigkeit: Lio gibt Menschen Selbständigkeit und Unabhängigkeit zurück.'
Q23	IP2-R&D (min. 01:20 ff.)	Translated: '"What do we do with old people, at home, alone? How can we, how could we help them with a robot?" And so we more or less already had, in hand, a concept and then it developed pretty quickly.' Original: '"Was machen wir mit alten Leuten, zuhause, alleine? Wie kann man die, wie könnte man denen mit einem Roboter helfen?" Und so hatten wir mehr oder minder schon, in der Hand, ein Konzept und dann hat sich das ziemlich schnell entwickelt.'
Q24	IP6–R&D (min 10:45 ff.)	Translated: 'That was actually the/ not only necessarily here in the nursing home, but also at home, that we have the possibility to live self-determined in our own four walls for a longer time. That the robot can help us with small household tasks or, and/ that was actually a bit of the/ the basic intention.' Original: 'Das war eigentlich so der/ nicht nur unbedingt jetzt hier im Pflegeheim, sondern schon auch zuhause, dass wir die Möglichkeit haben irgendwann länger selbstbestimmt in den eigenen vier Wänden zu leben. Dass der Roboter eben uns bei kleinen Haushaltsaufgaben oder, und / das war eigentlich so ein bisschen der/ die grundsätzliche Intention.'
Q25	Reiser et al. (2013, p. 105)	'The main idea behind the recently started European research project SRS (Multi-Role Shadow Robot for Independent Living) [13] is to allow elderly persons to live longer in their own homes instead of moving into an elderly care facility and therefore enable a more independent life. The prominent aspect of the project is to use a tele-operated robot to assist elderly persons at fulfilling household tasks.'
Q26	Ambient Assisted Living (AAL) Joint Programme (2008, p. 5)	'Innovations in prevention and management of chronic conditions of the elderly can have significant impact not only on the individual level, but also on the care organizations and European societies. New innovative solutions can have a major effect on cost effectiveness thus easing the pressure of increasing costs in European social and healthcare systems.

No.	Reference	Quote
		Operational efficiency and innovative processes will allow sustainable operation and business opportunities. Increased self-management and independence will also allow more effective use of limited resources and especially that of an increasingly scarce workforce.'
Q27	ISTAG (2004, p. 21)	'The development of such robots, and their effective integration into a helpful environment, may go a long way to improving the quality of life for elderly and disabled, reducing European health care costs, as well as stimulating the emergence of new industries.'
Q28	Schraft (1998, p. 2476)	'Significant savings occur when individuals that need support in daily-life-activities can continue to live at home, because the high costs incurred for individual treatment in Senior Citizen Centres and in Nursing Homes are eliminated. According to an economical study performed in the USA more than 3 billion US dollar could be saved per year, if all elderly US-citizen would stay just three more months at home before joining a senior citizen home. Beside new decentralised services supporting elderly people at home, accompanying technological solutions are required helping people to facilitate life at home. Thus, after the successful performances of automated solutions in industrial production, it is now expected that the technological concepts of these solutions will be available also for application in common households in the near future.'
Q29	Zsiga et al. (2013, p. 376)	'Remaining longer at home can generate savings for the family and for society compared with having an individual in a nursing centre […] the Domeo-project clearly aims at reducing long-term care costs.'
Q30	Coradeschi et al. (2013, p. 583)	'This project involves elderly as active and mature users of technology that are experts on their own needs and demands. […] In this project, we allow older users to express their problems and life-long habits as users of technology. They are given the opportunity to express their obvious and visible needs as well as the latent needs that can be awakened in the context of playfulness as a tool in the design process'.
Q31	Cortellessa et al. (2015, p. 7)	'Testsite IT-2 (dropped out) Brief [primary user] description: She is a widow 93 years old. She lives alone and is still active. She is a housewife, and does house works. She is still very autonomous in housework, such as cleaning and preparing food. She is not afraid to go out of her home even if she has some walking problem. She has some problems with a

No.	Reference	Quote
		fluctuating blood pressure. She wears hearing aid. She suffers from emphysema with asthma crisis and arthrosis.'
Q32	Cortellessa et al. (2015, p. 9)	'Testsite IT-3 Brief [primary user] description: She is an 80 years old widower. She lives alone and she is a self-sufficient person for her activity of daily living but she needs help for grocery shopping and some housekeeping tasks, so she receives a home-help support for a few hours a week. She suffers from neuropathic pain, renal insufficiency and she had suffered an ictus episode in the past. Her health conditions adversely affect her mobility. The user moves into the house with the help of a walker and she is unable to go out except with the assistance of a family member.'
Q33	F&P Personal Robotics (2017, p. 6)	Translated: 'Interaction: Lio motivates and interacts with people, contributing to fitness and well-being.' Original: 'Interaktion: Lio motiviert und interagiert mit Menschen und trägt dadurch zur Fitness und zum Wohlbefinden bei.'
Q34	Fischinger et al. (2016, p. 70)	'Therefore, the idea of Hobbit is that the robot performs meaningful tasks for the user and cooperatively performs them together with the user where it needs help (e.g. learning a new object). In this way, older adults can remain active and the robot only compensates their limitations by assisting the task, such as picking up something from the floor.'
Q35	Information Society Technologies Advisory Board ISTAG (2004, p. 20)	'We encourage a challenging project that aims to provide flexible service robots for the elderly, robots that would not necessarily do things for people, but would extend and enhance the individuals own ability to perform crucial tasks.'
Q36	IP2-R&D (min 18:20 ff.)	Translated: 'It turned out that the robot was a very good motivator in this nursing home. There were typical walking round, daily walking round, where the staff always had difficulties motivating the people to go on tour. Since the robot went along, it was really cool. It even sang a song and the people sang along, so it was a really exciting thing.' Original: 'Was sich dann dort herausgestellt hat, in diesem Pflegeheim, dass der Roboter als Motivator einen sehr sehr guten Einsatz hatte. Da gab es typische Gehrunden, tägliche Gehrunden, wo das Personal immer wieder Schwierigkeiten hatte, die Leute zu motivieren, dass sie jetzt da einen Rundgang machen und seitdem der Roboter mitgegangen ist, war das voll cool. Der hat sogar ein Lied angestimmt und die Leute haben mitgesungen und das war also eine voll spannende Sache.'

No.	Reference	Quote
Q37	Ambient Assisted Living (AAL) Joint Programme (2009, p. 7)	‘Elderly persons have a higher risk of suffering from loneliness than other age groups. There is evidence that loneliness decreases the quality of life and may cause illness, depression, self-neglect especially amongst elderly men.’
Q38	Cortellessa et al. (2015, p. 9)	‘Testsite IT-3 Brief [primary user] description: She is an 80 years old widower. She lives alone and she is a self-sufficient person for her activity of daily living but she needs help for grocery shopping and some housekeeping tasks, so she receives a home-help support for a few hours a week. She suffers from neuropathic pain, renal insufficiency and she had suffered an ictus episode in the past. Her health conditions adversely affect her mobility. The user moves into the house with the help of a walker and she is unable to go out except with the assistance of a family member.’
Q39	European Commission (2015, p. 29)	‘Citizens in an ageing European population are at greater risk of cognitive impairment, frailty and social exclusion with considerable negative consequences for their independence, quality of life, that of those who care for them, and for the sustainability of health and care systems. The challenge is to develop new breakthroughs for active and assisted living based on advanced ICT solutions.’
Q40	Kompai Robotics (2019)	‘Falling is a constant risk that can have serious consequences. KOMPAÏ provides verifications, alerts key individuals, and can even call for emergency help.’
Q41	Casey et al. (2016, p. 318)	‘The number of people with dementia is expected to double every 20 years to 66 million by 2030 and 115 million by 2050 [1]. More than a third of people with dementia have reported loneliness [2]. Robots have the potential to combat the devastating impact of loneliness in people with dementia by improving mood, quality of life [3] and reduce social isolation by facilitating people with dementia (PWD) to maintain social contacts.
Q42	IP2-R&D (min. 42:15 ff.)	Translated: ‘Or especially in the area of dementia, where people have far too little time to look after people or to listen to a story two or three times or to speak out the memory five times. And I can imagine that robots can still have a positive effect.’ Original: ‘Oder insbesondere im Bereich Demenz, wo die Leute viel zu wenig Zeit haben, um die Leute zu betreuen oder auch einer Geschichte zwei oder dreimal zuzuhören oder fünfmal die Erinnerung auszusprechen. Und da kann ich mir schon vorstellen, dass Roboter noch, ja (.) etwas Schönes bewirken können.’

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Q43	IP3-Marketing (min 06:45 ff.)	‘The objective is to/ we are working on a chatbot to have a dialogue with the robot, but just for specific diseases like Alzheimer, to make some exercise every day, to ask the same question every day to see if the people are progressing or not.’
Q44	Kouroupetroglou et al. (2017, p. 38)	‘MARIO is a companion robot that aims to help people with dementia (PWD) to battle isolation and loneliness by enabling them to stay socially active by providing a number of applications focused on hobbies (music, movies, etc.), staying engaged with communities (reading headlines, reading local twitter feeds, etc.) and staying connected with family and friends (telephoning them, reading their news from twitter, etc.).’
Q45	Naroska et al. (2018, p. 2)	‘People with dementia tend to become inactive e.g. sitting for hours in a chair. To address this inactivity, OurPuppet shall come up with suggestions for activities and perform them together with the elderly.’
Q46	Beck (2018, p. 773)	Translated: ‘Machines that could be used in the context of assisted suicide do not fit easily into the scheme. Such machines would assist patients who can no longer take the drugs themselves.’ Original: ‘Nicht ohne Weiteres in das Schema lassen sich Maschinen einfügen, die im Kontext des assistierten Suizids eingesetzt werden könnten. Derartige Maschinen würden Patienten unterstützen, die die Medikamente nicht mehr selbst einnehmen können.’
Q47	Chen (2012, p. 32)	‘The robot is constructed as a medical device with a padded caressing arm, and a customized mechanical voice device designed to guide and comfort the dying patient. The whole event is carefully scripted.’ ‘The process of dying is probably the most vulnerable moment of a human life – a moment in which one seeks the reassurance of human connection. In this installation, human presence is replaced with a robot, questioning the quality of intimacy without humanity.’
Q48	Nwosu et al. (2019, pp. 1110–1111)	‘Robotics may have a number of potential applications in palliative, supportive and end-of-life care. It is imperative that future work evaluates the health-related, economic, societal and ethical implications of using this technology. There is a need for collaborative research to establish use-cases and inform policy to ensure appropriate use of robotics for people with serious illness.’
Q49	Tonkens (2015, p. 207)	‘The purpose of this chapter is to introduce and critically assess the prospect of “robotic assisted dying”, i.e., the use of (semi-)

No.	Reference	Quote
		autonomous robots for the purpose of assisting willing terminally ill patients in dying, in the medical context.'
Q50	Tonkens (2015, p. 208)	'No one has yet seriously considered the prospect of developing and using (semi-) autonomous robots for the purpose of replacing or supplementing human physicians in the context of physician-assisted dying. At the same time, within the contemporary literature on machine ethics, there have already been a number of intersections drawn between robotics and suicide […]'
Q51	IP3-Marketing (min. 24:48 ff.)	'I think at the end of your life if you have some cognitive problems, you do not ask yourself that kind of questions. You are just happy to speak with something, if there is nobody who has time to speak with you.'
Q52	IP4-R&D (min. 30:59 ff.)	Translated: 'So, you have to be enormously careful, so there was the case in America where/ that was a very tragic case. There was an elderly man with his granddaughter, I don't know if you heard, in the hospital room, a robot came in and the doctor told the elderly man by tele/ what is it called (I: presence?) / yes, telepresence, so to speak, that he was going to die. But the robot moved to the side where the man was deaf. That is, he didn't understand and then his granddaughter had to explain to him that he was going to die. Um, and that went through the whole world, this thing and, no, so in such situations you should really leave the technology completely out of it. I would say/ I wouldn't even want to think about it, as a scientist.' Original: 'Also da muss man enorm vorsichtig sein, also es gab da den Fall in Amerika, wo/ das war ein ganz tragischer Fall. Da war ein älterer Mann mit seiner Enkelin, ich weiß nicht, ob Sie das mitbekommen haben, im Krankenzimmer, da kam so ein Roboter rein und der Arzt hat so per Tele/ wie nennt sich das (I: Präsenz?) / ja, Telepräsenz sozusagen dem älteren Mann gesagt, dass er Sterben wird. Der Roboter hat sich aber auf die Seite bewegt, wo der Mann taub war. Das heißt, er hat das nicht verstanden und seine Enkelin musste ihm dann erklären, dass er sterben wird. Ähm, und das ging durch die ganze Welt, diese Sache und, nein, also in solchen Situationen sollte man die Technik wirklich völlig rauslassen. Da würde ich sagen/ also da würde ich gar nicht drüber nachdenken wollen, als Wissenschaftler.'
Q53	IP5-Management-R&D (min. 38:40 ff.)	'I think, there is a use case there. And I think, Japan is a little way ahead compared to the rest of the world, because their, say, aging problem is more advanced than other parts. But it is an

No.	Reference	Quote
		ethical discussion, but when you are at the end of life, yourself, and you have a choice, you can be petted by a robot or be left alone completely, what would you prefer?'
Q54	IP8-R&D (min. 28:48 ff.)	'In general, I think it [developing robots for end-of-life care; the author] needs to be done. In general, I think, I mean, (...) It is a very hard situation, very, very tough situation [inaudible]. (..) You know, these last moments of life. Sometimes it comes unexpectedly, sometimes it comes expectedly. And there are situations when it's/ As COVID, you know, you know you're not going to meet this person, you're not going to talk to this person again and there is nothing you can do. So, we need some sort of solution. I don't know if it's (..) if it's a topic for an academic study or for scientific study. In general, I think it needs to be done. Practically I don't think that I am the right person to do it.'
Q55	IP8-R&D (min. 32:04 ff.)	'In my case, I can only say about myself. It is very personal experiences, it is very personal, ehm (..) sort of. It is hard for me psychologically. I guess for most people, it is very, very hard to do this kind of studies. You know, I / I know people who work, nurses, who work in this, like, terminal cancer care facilities. It is psychologically hard, I know, I am not the person who can handle that easy. At the same time, I don't want to be, I mean (...) I think majority/ Probably I just don't know, but from my perspective, the technological questions you can study in many different situations and then sort of extrapolate the results of your study. You don't need to disturb people doing the experiments. [inaudible] So, you can do it anywhere else. I don't think/ I mean, I don't have perception that the field is sort of neglected on purpose. If it is, then I would, just intuitively, I would just think it is personal, some personal concerns.'
Q56	IP1-Management (min. 50:30 ff.)	Translated: 'The technology is not yet matured, and one does not want to cause great damage, presumably, or limit that which one could trigger emotionally at least. And where there is still little research in [unintelligible]. That's why I think that it's only natural that there is a bit of restraint.' Original: 'Die Technik ist noch nicht ausgereift und man will vermutlich auch jetzt noch nicht großen Schaden anrichten oder das zumindest limitieren, was man auch jetzt emotional noch, ja, auslösen könnte. Und wo noch wenig erforscht ist, in (unverständlich). Deswegen denke ich, dass das nur natürlich ist, dass da ein bisschen Zurückhaltung auch noch gibt.'
Q57	IP2-R&D (min. 30:57 ff.)	Translated: 'Well, from my point of view, we are still so far away with the technology from the preliminary stages that we don't

No.	Reference	Quote
		even think that far ahead [about palliative care]. […] To be honest, I've never thought about it before.' Original: 'Also, aus meiner Sicht sind wir so weit weg mit der Technologie von den Vorstufen noch, dass wir so weit gar nicht denken [an Palliative Care] […] Um ehrlich zu sein, habe ich noch nie daran gedacht.'
Q58	IP3-Marketing (min. 09:30 ff.)	'And we start to have good results, but it is really recent and it is really hard to have something like that, I can tell you because I am really often going to events about robotics and there, I can see many robots and autonomous navigation is not something casual. And the only robots we can see, most of the time, is for animation and doing only some games and things like that. It is not really useful or is not useful for the healthcare. So, we wanted to develop something useful for their healthcare. So, I can't say, there is something you don't have to do, because you will be limited by the technology anyway.'
Q59	IP4-R&D (min. 32:50 ff.)	Translated: 'I think we are all aware of the technical limitations that are still there in the interaction with the robots somehow. Well, I think there is the feeling that you would use a very immature tool in an enormously sensitive area. And I think, the responsible researchers have this as well, that one says/ (.) Well, you do not operate with a sword. You need other tools, you need to have another maturity in order to start thinking about probably using it in the first place. Well, I think, it is this realisation of technical limitations, which are there, that these scientists have, so that they would not even come up with the idea of doing something in this regard.' Original: 'Ich denke, wir sind uns alle der technischen Limitationen bewusst, die auch in Interaktionen mit Robotern irgendwie noch da sind. Also, da denke ich, hat man einfach das Gefühl, man würde mit sehr unreifen Werkzeugen in einen enorm sensitiven Bereich gehen. Und ich glaube, das haben die verantwortlichen Wissenschaftler da auch, dass man sagt/ (.) also man operiert auch nicht mit dem Schwert. Da braucht man andere Tools, da muss man eine andere Reife haben, um überhaupt irgendwie nachzudenken, dass man da eventuell was machen könnte. Also, da denke ich, da ist einfach diese Realisation von den technischen Limitationen, die da sind, die ist einfach bei den Wissenschaftlern da, dass die auch gar nicht auf die Idee kommen würden, da was zu machen.'

No.	Reference	Quote
Q60	IP5-Management-R&D (min. 14:00 ff.)	‘At the same time, there were some technical results from the experiments that told us that the robot was not fit for use yet completely. [pseudonymised information: description of not properly working function of the robot] It was not autonomous enough, even that (inaudible) use case assumed some eight percent autonomy. So, by now, and we are three years down the line, we are confident that we have achieved fifty percent autonomy.’
Q61	IP7-R&D (min. 09:50 ff.)	‘I think about what the robot can do now, but it can do these things as a prototype, and we would lie that it is able to do it as a real product. There is a lot of work to come to this.’
Q62	IP8-R&D (min. 07:25 ff.)	‘Well, there are many technology limitations. There are technological factors that, ehm, we are yet/ I don't know what other people say, but that is my opinion: We are very, very, very far from long-term independent deployments of robots in peoples' homes.’
Q63	IP9-R&D (min. 21:45 ff.)	‘If there is a need, a strong need, and/ I mean, business need. If there is big money, tomorrow, there will be companies as big as Google as big as Microsoft with good batteries with good access to technology, which will make robot, it is possible to do it now. I don't think there is something (..) you know, with good amount of development effort, would stop it. Pretty much everything is known. For research, we don't need it to be super mega deployable and reliable. And it is not our key thing, to develop things for the market, right? So, as soon as there is interest, as soon as there is a need for which there is (..) Well, as soon as there is big need, in fact, it will come.’
Q64	Fischinger et al. (2016, p. 72)	‘[…] we decided to conduct our studies with participants aged 70 plus, as these will be the users who will have a Hobbit at home. Additionally, we tried to have a representative sample in relation to the typical age impairments [54]. In order to identify impairments we used self-reporting via telephone in the recruitment phase to assess the grade of impairments in the field of vision, hearing, and mobility. Many of our participants experienced impairments in more than one of the three categories. In total, 44 (89.8%) had some form of multiple impairment (e.g. moderate vision and minor mobility problems) and 78% of the sample fulfilled the impairment requirement of having at least one impairment graded as “moderate”.’
Q65	Früh and Gasser (2018, p. 49)	Translated: ‘The leaders used their discretion in selecting whom they asked to participate in the study. Elderly persons with dementia were excluded due to ethical considerations. Interest was so great that a total of 18 test runs were scheduled instead

No.	Reference	Quote
		of the planned 12. Ultimately, 12 female residents and 5 male residents, ranging in age from 70 to 96 (average 85) years, participated in the study. In 15 cases, they had age-related mobility impairments (seven with a walker, eight with a wheelchair). Two participants were physically completely independent.' Original: 'Die Leitenden wählten nach eigenem Gutdünken aus, wen sie für die Teilnahme an der Studie anfragten. Ältere Personen mit Demenz wurden aufgrund ethischer Überlegungen ausgeschlossen. Das Interesse war so groß, dass statt den geplanten 12 Testdurchläufen insgesamt 18 eingeplant wurden. Schlussendlich nahmen 12 Bewohnerinnen und 5 Bewohner im Alter von 70 bis 96 (durchschnittlich 85) Jahren an der Studie teil. In 15 Fällen hatten sie altersbedingte Mobilitätsbeeinträchtigungen (sieben mit Rollator, acht mit Rollstuhl). Zwei Teilnehmende waren körperlich völlig unabhängig.'
Q66	Zsiga et al. (2018, p. 261)	'Recruitment was based partly on the project employees' suggestions and partly on volunteering after the project had been demonstrated in two pensioners' clubs. Inclusion criteria were established toward the users and also their homes. As for the users: at least 70 years old, living alone, able to move indoors without assistance, able to communicate with the robot by voice and touch, signed informed consent.'
Q67	Zsiga et al. (2018, p. 261)	'One male and seven female users were included—their mean age was 77.125 years (70–83). Four graduated from college, two from polytechnic, and two from secondary school. All were pensioners. All users lived alone in an apartment and were self-supporting.
Q68	Cortellessa et al. (2015, p. 7)	'The robot and the complete system were removed at the end of October 2014. In fact, a need of a more continuous type of assistance mainly due to deterioration in her health status and frailty emerged. Then, the user has decided to move to a nursing home near the home of one of her relatives. Overall, the lady appreciated the ability of the system to make feel her safer at home.'

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Annex C Supplementary material paper 4

The following pages (pp. 271–312) contain the supplementary material to my fourth paper presented in section 5.4.

Supplementary material for ‘Co-producing values and technology in a professional discourse: affirming, aligning, and adjusting digital technologies and good palliative care’

1. Journals considered in data collection

Table 1 List of journals considered in data collection

Journal	Publisher	Official Journal of	Publication period
American Journal of Hospice and Palliative Medicine (until 1990: The American Journal of Hospice Care)	SAGE		1984–present
Annals of Palliative Medicine	AME Publishing Company	Society for Palliative Radiation Oncology	2012–present
BMC Palliative Care	Springer Nature/BioMed Central		2002–present
BMJ Supportive and Palliative Care	BMJ		2011–present
Current Opinion in Supportive and Palliative Care	Wolters Kluwer		2007–present
European Journal of Palliative Care	Hayward Medical Publishing	European Association for Palliative Care	1994–2018
hospiz zeitschrift	der hospiz verlag	German Hospice and Palliative Association	1999–present
Indian Journal of Palliative Care	Scientific Scholar	Indian Association of Palliative Care	1994–present
International Journal of Palliative Nursing	Mark Allen Group		1995–present
Journal of Hospice & Palliative Nursing	Wolters Kluwer	Hospice & Palliative Nurses Association	1999–present
Journal of Pain & Palliative Care Pharmacotherapy (until 2001: The Hospice Journal)	Taylor & Francis	Society of Pain & Palliative Care Pharmacists	2002–present

Journal of Pain and Symptom Management	Elsevier	National Hospice and Palliative Care Organization; American Academy of Hospice and Palliative Medicine	1986–present
Journal of Palliative Care	SAGE		1985–present
Journal of Palliative Medicine	Mary Ann Liebert	Center to Advance Palliative Care; Australian & New Zealand Society of Palliative Medicine; Canadian Society of Palliative Care; Asia Pacific Hospice Palliative Care Network; Taiwan Academy of Hospice Palliative Medicine; Hospice & Palliative Nurses Association; Japanese Society for Palliative Medicine; European Association for Palliative Care	1998–present
Journal of Social Work in End-of-Life & Palliative Care (until 2004: Loss, Grief & Care)	Taylor & Francis		1987–present
Palliative and Supportive Care	Cambridge University Press		2003–present
palliative ch		Swiss Association for Palliative Medicine, Care and Support	2003–present
Palliative Medicine	SAGE	European Association for Palliative Care	1987–present
Praxis PalliativeCare	Brinkmann Meyhöfer		2008–present
Progress in Palliative Care	Taylor & Francis		1993–present
Zeitschrift für Palliativmedizin	Thieme	German Association for Palliative Medicine; Austrian Palliative Association	2000–present

2. List and description of documents

Table 2 List and classification of documents

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
Abel and Taubert (2020)	Coronavirus pandemic: compassionate communities and information technology	BMJ Supportive & Palliative Care	Editorial	Diverse	United Kingdom
Abernethy and Currow (2011)	Patient self-reporting in palliative care using information technology: Yes, there is hope!	Palliative Medicine	Editorial	Telehealth	Australia, Unite States of America
André et al. (2009)	Implementation of computerized technology in a palliative care unit	Palliative and Supportive Care	Original research	Electronic health record	Norway
Arrer and Fringer (2020)	Entwicklung eines Monitoringsystems in der häuslichen Palliative Care zur Krisenvermeidung (Development of a monitoring system in home-based palliative care for crisis prevention)	palliative ch	Original research	Telehealth	Switzerland
Australia New Zealand Society of Palliative Care ANZSPM (2021)	Strategic Plan 2022/2025	Australia New Zealand Society of Palliative Care ANZSPM	Guidelines	Diverse	Australia
Baitar et al. (2012)	Falls prevention in a palliative care unit: evaluation of an infrared sensor device	European Journal of Palliative Care	Original research	Telehealth	Belgium

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
Besch (2020)	Künstliche Intelligenz (KI) im Gesundheitswesen (Artificial Intelligence (AI) in healthcare)	Zeitschrift für Palliativmedizin	Comment	Artificial intelligence	Germany
Bharadwaj et al. (2007)	Los Angeles to Mumbai: Providing Palliation Using Technology	Journal of Palliative Medicine	Case report	Telehealth	United States of America, India
Bishop et al. (2015)	Best Practices for Using Telehealth in Palliative Care	National Hospice and Palliative Care Organization	Guidelines	Telehealth	United States of America
Blum et al. (2020)	Digitalisierung und Palliative Care: Die Digitalisierung geht in der Coronakrise viral (Digitalization and palliative care: digitalization goes viral in the Corona crisis)	palliative ch	Review	Diverse	Switzerland
Bonsignore et al. (2018)	Evaluating the Feasibility and Acceptability of a Telehealth Program in a Rural Palliative Care Population: TapCloud for Palliative Care	Journal of Pain and Symptom Management	Original research	Telehealth	Australia
Boston and Bruce (2014)	Palliative Care Nursing, Technology, and Therapeutic Presence: Are they reconcilable?	Journal of Palliative Care	Comment	Diverse	Canada
Bouteiller-Descas and	Information technology in practice	European Journal of Palliative Care	Review	Electronic health record	France

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
Salamagne (1999)					
Bradford et al. (2013)	The case for home based Telehealth in pediatric palliative care: a systematic review	BMC Palliative Care	Review	Telehealth	Australia
Brecher (2020)	Use of a Robotic Cat to Treat Terminal Restlessness: A Case Study	Journal of Palliative Medicine	Original research	Robot	United States of America
Bricker et al. (2003)	Enhancing Communication for End-of-Life Care: An Electronic Advance Directive Process	Journal of Palliative Medicine	Original research	Electronic health record	United States of America
Calton et al. (2019)	Top Ten Tips Palliative Care Clinicians Should Know About Telepalliative Care	Journal of Palliative Medicine	Guidelines	Telehealth	United States of America
Calton et al. (2020)	Telemedicine in the Time of Coronavirus	Journal of Pain and Symptom Management	Guidelines	Telehealth	United States of America
Carter and Schatman (2014)	What is the Evidence Based for Electronic Medical Records Improving Quality in Hospice and Palliative Medicine?	American Journal of Hospice & Palliative Medicine	Editorial	Electronic health record	United States of America
Chan et al.(2019)	Deep learning algorithms to identify documentation of serious illness conversations during intensive	Palliative Medicine	Original research	Artificial intelligence, electronic health record	United States of America

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
	care unit admissions				
Chochinov and Stern (2004)	The Canadian Virtual Hospice	Journal of Palliative Care	Description of technical system	Internet websites	Canada
Chochinov et al. (2020)	Death, Dying, and Dignity in the Time of the COVID-19 Pandemic	Journal of Palliative Medicine	Editorial	None	Canada
Chua et al. (2020)	Webside Manner during the COVID-19 Pandemic: Maintaining Human Connection during Virtual Visits	Journal of Palliative Medicine	Brief report	Telehealth	United States of America
Cleary (2011)	Jumping into the world of social media with Palliative Medicine	Palliative Medicine	Editorial	Social media	United States of America
Collier et al. (2016)	Implementation of a pilot Telehealth programme in community palliative care: A qualitative study of clinicians' perspectives	Palliative Medicine	Original research	Telehealth	Australia
Collins et al. (2016)	Virtual communities of practice such as Palliverse can increase palliative care engagement	European Journal of Palliative Care	Description of technical system	Internet website, social media	Australia, New Zealand
Coop and Marlow (2019)	Do we prepare patients for their digital legacy? A survey of palliative care professionals	Palliative Medicine	Original research	Social media	United Kingdom
Cox et al. (2011)	The acceptability of e-technology to	Palliative Medicine	Original research	Telehealth	United Kingdom

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
	monitor and assess patient symptoms following palliative radiotherapy for lung cancer				
Coyle et al. (2002)	Audio-Visual Communication and Its Use in Palliative Care	Journal of Pain and Symptom Management	Original research	Telehealth	United States of America
De Conno and Martini (1997)	Video communication and palliative care at home	European Journal of Palliative Care	Original research	Telehealth	Italy
Demiris et al. (2004)	Hospice staff attitudes towards telehospice	American Journal of Hospice & Palliative Medicine	Original research	Telehealth	United States of America
Demiris et al. (2005)	Use of Technology as a Support Mechanism for Caregivers of Hospice Patients	Journal of Palliative Care	Comment	Diverse	United States of America
Dorman et al. (2010)	The use of an electronic patient record to facilitate a specialist palliative care multidisciplinary team meeting	Palliative Medicine	Case report	Electronic health record	United Kingdom
Engelke (2018)	Kritische Impulse – smart sterben: Sind End-of-Life-Center unsere Zukunft? (Critical impulses – smart dying: Are end-of-life centres our future?)	hospiz zeitschrift	Comment	Robot	Germany

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
García-Baquero Merino et al. (2014)	infoPAL – electronic records for palliative care patients in the Madrid region	European Journal of Palliative Care	Original research	Electronic health record	Spain
Granger (2014)	Death by social networking: the rising prominence of social media in the palliative care setting	BMJ Supportive & Palliative Care	Editorial	Social media	United Kingdom
Gronemeyer (2018)	Vom Tanz mit dem Sorgeroboter (Of dancing with a care robot)	hospiz zeitschrift	Comment	Robot	Germany
Hanson (2020)	We Will All Be Changed: Palliative Care Transformation in the Time of COVID-19	Journal of Palliative Medicine	Editorial	Telehealth	United States of America
Henneman-Krause et al. (2015)	The assessment of telemedicine to support outpatient palliative care in advanced cancer	Palliative and Supportive Care	Original research	Telehealth	Brazil
Higginson et al. (1992)	Computer database for palliative care	Lancet	Description of technical system	Electronic health record	United Kingdom
Hollander and Carr (2020)	Virtually Perfect? Telemedicine for Covid-19	The New England Journal of Medicine	Comment	Telehealth	United States of America
Hospice UK (2021)	The Future of Hospice Care in Scotland	Hospice UK	Guidelines	Diverse	United Kingdom
International Association for Hospice and Palliative Care (2019)	IAHPC 2020–2024 Strategic Plan	International Association for Hospice and Palliative Care	Guidelines	Diverse	International

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
Jamwal and Kumar (2016)	Maintaining the Social Flow of Evidence-Informed Palliative Care: Use and Misuse of YouTube	Indian Journal of Palliative Care	Review	Social media	India
Jaspers (2019)	Changes are Taking the Pace we're Going Through – Palliative Care international	Zeitschrift für Palliativmedizin	Editorial	Diverse	Germany
Jess et al. (2019)	Video consultation in palliative care: A systematic integrative review	Palliative Medicine	Review	Telehealth	Denmark
Johnston et al. (2011)	An evaluation of the use of Telehealth within palliative care settings across Scotland	Palliative Medicine	Original research	Telehealth	United Kingdom
Jüptner et al. (2009)	Verbesserung der häuslichen Versorgung am Lebensende (Improving home care at the end of life)	Zeitschrift für Palliativmedizin	Case report	Ambient Assisted Living	Germany
Kinsella (2005)	Telehealth in Hospice Care, or Telehospice: A New Frontier of Telehealth Service Delivery	Journal of Palliative Medicine	Editorial	Telehealth	United States of America
Lamas et al. (2018)	Advance Care Planning Documentation in Electronic Health Records: Current Challenges and	Journal of Palliative Medicine	Original research	Electronic health record	United States of America

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
	Recommendations for Change				
Leniz et al. (2020)	Electronic palliative care coordination systems (EPaCCS): a systematic review	BMJ Supportive & Palliative Care	Review	Electronic health record	United States of America
Lloyd and Haraldsdottir (2021)	Virtual reality in hospice: Improved patient well-being	BMJ Supportive & Palliative Care	Original research	Virtual reality	United Kingdom
Lowe et al. (2021)	Communication in palliative care during the COVID-19 pandemic: Lessons from rapidly changing, uncertain, complex, and high-stake interventions	Palliative Medicine	Editorial	Telehealth	Canada, Portugal, United Kingdom
Lowney and Brien (2012)	The landscape of blogging in palliative care	Palliative Medicine	Case report	Social media	Ireland
Lynch (1998)	Navigating new information technologies	European Journal of Palliative Care	Review	Internet websites, social media, electronic health record, telehealth	Canada
Maudlin et al. (2006)	A Road Map for the Last Journey: Home Telehealth for Holistic End-of-Life Care	American Journal of Hospice & Palliative Medicine	Original research	Telehealth	United States of America
McCall et al. (2008)	Perceptions of the use of a remote monitoring system in patients receiving palliative care at home	International Journal of Palliative Nursing	Original research	Telehealth	United Kingdom

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
Mercadante and Lanza (1994)	Informatics in Palliative Care	Journal of Pain and Symptom Management	Description of technical system	Electronic health record	Italy
Mills (2019)	Digital health technology in palliative care: Friend or foe?	Progress in Palliative Care	Editorial	Diverse	Australia
Monteverde (2020)	Editorial	palliative ch	Editorial	Diverse	Switzerland
National Consensus Project for Quality Palliative Care (2018)	Clinical Practice Guidelines for Quality Palliative Care. 4th edition	National Consensus Project for Quality Palliative Care	Guidelines	Telehealth, electronic health record	United States of America
Niki et al. (2019)	A Novel Palliative Care Approach Using Virtual Reality for Improving Various Symptoms of Terminal Cancer Patients: A Preliminary Prospective, Multicenter Study	Journal of Palliative Medicine	Original research	Virtual reality	Japan
Nkhoma et al. (2021)	Stakeholder perspectives and requirements to guide the development of digital technology for palliative cancer services: a multi-country, cross-sectional, qualitative study in Nigeria, Uganda and Zimbabwe	BMC Palliative Care	Original research	Diverse	United Kingdom, Nigeria, Zimbabwe, Uganda

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
Nolan & Crowe (2017)	How we say goodbye: social media, death and the Paediatric Intensive Care Unit	European Journal of Palliative Care	Comment	Social media	Ireland
Nwosu et al. (2019)	Robotic technology for palliative and supportive care: Strengths, weaknesses, opportunities and threats	Palliative Medicine	Original research	Robot	United Kingdom
Payne (2020)	Digitisation and the patient–professional relationship in palliative care	Palliative Medicine	Editorial	Diverse	United Kingdom
Pereira and Bruera (1998)	The Internet as a Resource for Palliative Care and Hospice: A Review and Proposal	Journal of Pain and Symptom Management	Review	Internet websites	Canada
Pereira et al. (1997)	Launching a palliative care homepage: the Edmonton experience	Palliative Medicine	Description of technical system	Internet website	Canada
Pereira et al. (2000)	Palliative Cancer Patients and Their Families on the Internet: Motivation and Impacts	Journal of Palliative Care	Original research	Internet websites	Canada
Phongtankuel et al. (2018)	Mobile health technology and home hospice care: promises and pitfalls	Progress in Palliative Care	Comment	Telehealth, electronic health record	United States of America
Portz et al. (2018)	Potential Technology	Journal of Palliative Medicine	Original research	Diverse	United States of America

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
	Development for Palliative Care				
Radbruch et al. (2009)	White Paper on standards and norms for hospice and palliative care in Europe: part 1	European Journal of Palliative Care	Guidelines	None	Germany, United Kingdom
Radbruch et al. (2010)	White Paper on standards and norms for hospice and palliative care in Europe: part 2	European Journal of Palliative Care	Guidelines	None	Germany, United Kingdom
Radbruch et al. (2020)	The key role of palliative care in response to the COVID-19 tsunami of suffering	The Lancet	Comment	Telehealth	Germany, United States of America, Mexico, Austria
Rana and Fadel (2020)	Telemedicine during the COVID-19 Pandemic: Experience at Bahrain Oncology Centre, Bahrain	Indian Journal of Palliative Care	Comment	Telehealth	India
Regnard (2000)	Using videoconferencing in palliative care	Palliative Medicine	Original research	Telehealth	United Kingdom
Riley (2017)	Visions of the future of palliative care	European Journal of Palliative Care	Editorial	Diverse	United Kingdom
Ritchey et al. (2020)	Reinventing Palliative Care Delivery in the Era of COVID-19: How Telemedicine Can Support End of Life Care	American Journal of Hospice & Palliative Medicine	Original research	Telehealth	United States of America
Saysell and Routley (2003)	Telemedicine in community-based palliative care: evaluation of a videolink	International Journal of Palliative Nursing	Original research	Telehealth	United Kingdom

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
	teleconference project				
Scheve (2013)	Ambient Assisted Living (AAL) für Schwerstkranke? Den Sorgealltag technisch unterstützen (Ambient Assited Living (AAL) for severly ill? Technical support for everyday care)	Praxis PalliativeCare	Brief Report	Ambient Assisted Living	Germany
Schnell (2020)	Palliative Care im Lichte der Digitalisierung (Palliative care in the light of digitalization)	palliative ch	Review	Diverse	Germany
Smith (2011)	Dying in the social media: When palliative care meets Facebook	Palliative and Supportive Care	Brief report	Social media	Canada
Smyth (2017)	Social technology: helping or hindering communication in care?	International Journal of Palliative Nursing	Editorial	Digital devices	United States of America
Sultana et al. (2021)	Psychosocial Challenges in Palliative Care: Bridging the Gaps Using Digital Health	Indian Journal of Palliative Care	Comment	Diverse	Bangladesh, United States of America, India
Tanuseputro (2017)	Delivering care to those in need: Improving palliative care using linked data	Palliative Medicine	Editorial	Digital decision-making system, artificial intelligence	Canada

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
Taubert et al. (2014)	Palliative social media	BMJ Supportive & Palliative Care	Review	Social media	United Kingdom, Germany
The Lancet (2020)	Palliative care and the COVID-19 pandemic	The Lancet	Editorial	Telehealth	Not available
Thorne (1999)	Adding Technology to Care – is this Progress?	Progress in Palliative Care	Editorial	Telehealth, diverse	Australia
Tieman et al. (2016)	Using Telehealth to support end of life care in the community: a feasibility study	BMC Palliative Care	Original research	Telehealth	Australia
Twycross et al. (1994)	Monitoring drug use in palliative care	Palliative Medicine	Original research	Electronic health record	United Kingdom
VandeKieft et al. (2001)	Internet resources for end-of-life care	American Journal of Hospice & Palliative Medicine	Review	Internet websites	United States of America
Vitetta et al. (1999)	The Design and Implementation of a Computerised Inpatient Database for the Efficient Delivery of Palliative Care: with a Brief Review of the Literature	Progress in Palliative Care	Review	Electronic health record	Australia
von Gunten (2005)	Innovations in Palliative Care	Journal of Palliative Medicine	Editorial	Telehealth	United States of America
Wakam et al. (2020)	Not Dying Alone – Modern Compassionate Care in the Covid-19 Pandemic	The New England Journal of Medicine	Case report	Telehealth	United States of America

Reference	Title (Translation)	Source	Type	Technology (focus)	Country
Wang et al. (2020)	Virtual Reality as a Bridge in Palliative Care during COVID-19	Journal of Palliative Medicine	Comment	Virtual reality	Singapore
Ward (2014)	ehospice: revolutionising access to hospice and palliative care news and intelligence	European Journal of Palliative Care	Description of technical system	Internet website	United Kingdom
Whitten et al. (1998)	An analysis of provider perceptions for telehospice	American Journal of Hospice & Palliative Medicine	Original research	Telehealth	United States of America
Whitten et al. (2005)	Providers' Acceptance of Telehospice	Journal of Palliative Medicine	Original research	Telehealth	United States of America
World Health Organisation (2018)	Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises: A WHO guide	World Health Organisation	Guidelines	Telehealth	International

3. Additional illustrative quotes and references

In the following, there are references and illustrative quotes for several elements of the discourse identified as part of the analysis and result presentation. They are not a full list of all relevant passages found across all different documents but represent an excerpt of the data.

Table 3 Illustrative quotes for section 4.1 on 'reciprocal affirmation'

No.	Reference	Quote
Q1	Bonsignore et al. (2018, p. 8)	'There is a national shortage of palliative care providers, and recruitment and retention of providers in rural areas are difficult due to compensation limitations, professional isolation, lack of resources, and burnout due to long travel time and hours. As a result, there is an increase in patient response times, reduced patient/family satisfaction, inferior clinical outcomes, increased use of emergency departments, and reduced hospice transition rates in rural areas compared to more urban service areas.'
Q2	Collier et al. (2016, p. 410)	'An ageing population and increasing rates of chronic illness require identification and evaluation of more effective methods of delivering clinical care including community specialist palliative care services (SPCSs).'
Q3	Demiris et al. (2004, p. 343)	'Over the last 10 years, the demand for hospice care has grown rapidly. In spite of this rapid diffusion, less than 25 percent of dying patients in the United States use hospice services. Many elderly patients approach the end of life in pain and isolation. Several barriers have been identified that impact hospice use, especially in rural areas. These barriers include difficulty recruiting nurses and other essential health professionals, insufficient reimbursement, restrictive regulatory definitions of service areas based on mileage and driving time, and physician hesitation and knowledge deficits. […] Telemedicine, defined as the use of advanced telecommunication technologies to bridge geographic gaps and improve healthcare delivery and education, is considered to have the potential to reduce identified barriers to hospice care.'
Q4	Engelke (2018, p. 26)	Original: 'Die Zahl sterbenskranker und pflegebedürftiger alter Menschen wächst stark. Viele von ihnen werden auf fremde Hilfe angewiesen sein. Wer wird für sie da sein? Nach allem, was wir heute wissen, werden die benötigten Pflegekräfte fehlen. Sie fehlen heute schon. Experten erwarten eine Pflegekatastrophe.' Translated: 'The number of terminally-ill and elderly people in need of care is growing rapidly. Many of them will be dependent on external help. Who will be there for them? According to everything that we know today, there will be a shortage of the necessary

No.	Reference	Quote
		caregivers. They are already lacking today. Experts expect a nursing catastrophe.'
Q5	Jess et al. (2019, p. 943)	'[…] aging populations are contributing to the increasing demand for palliative care. Despite the extensive need for palliative care worldwide, access to care remains inadequate. Given that the field of palliative care is expected to expand, it might be beneficial to think in terms of new and innovative ways to provide care, such as the implementation of telehealth, which is increasingly being used to provide home-based health care.'
Q6	Kinsella (2005, p. 721)	'By adopting new technology we will be able to provide needed hospice services in today's projected decades of nursing shortages. These services will be sorely needed to attend to the mushrooming elderly populations who are now coming to hospice with multiple and more challenging needs.'
Q7	Lynch (1998, p. 157)	'As we struggle to cope with the political, social and financial forces acting upon us, we may have to rely on IT more extensively – just as other professional groups have done.'
Q8	McCall et al. (2008, p. 426)	'Telecare and other developments in information technology are increasingly being sought as a means of addressing shifting population demographics and rising demands on stretched health services, and may help in providing a system which allows patients to report their symptoms as they are happening. This may be one way of enhancing symptom management and improving quality of care at the end of life.'
Q9	Mills (2019, p. 145)	'Globally, access to palliative care is limited in that only a minority of those in need of palliative care receive it. This is true of populations not only in developing countries, but also those in regional, rural and remote areas of developed countries.'
Q10	Nkhoma et al. (2021, p. 1)	'Coverage of palliative care in low and middle-income countries is very limited, and global projections suggest large increases in need. Novel approaches are needed to achieve the palliative care goals of Universal Health Coverage.'
Q11	Nwosu et al. (2019, p. 1107)	'The global need for palliative care is increasing,[19] more purposeful use of healthcare robots has been proposed as solution for health services to meet the needs of an increasingly frail population.'
Q12	Phongtankuel et al. (2018, p. 137)	'Delivering effective home-based hospice care relies on visits from hospice providers to reduce patient suffering by addressing medical, psychosocial, and spiritual issues which are not uncommon in both patients and caregivers. Yet, home hospice visits may not occur as often as needed or in a timely manner that meets patient and caregiver needs. This is especially challenging for patients living in remote areas or whenever an acute change requires immediate attention.'

No.	Reference	Quote
Q13	Saysell and Routley (2003, p. 489)	'A national shortage of consultants in palliative medicine in the UK has led St David's Foundation Hospice Care to begin an innovative telemedicine project. This enabled the foundation's clinical nurse specialists (CNSs) in palliative care to access consultant advice and support.'
Q14	Scheve (2013, p. 23)	Original: 'Vor dem Hintergrund der demografischen Entwicklung, die uns laut Statistischem Bundesamt eine Zunahme der Pflegebedürftigen bis 2020 um 50 Prozent auf 2,7 Millionen Menschen und bis 2050 auf 4,7 Millionen Menschen prophezeit, dürfte den Leserinnen und Lesern vielleicht etwas mulmig werden. Wir wissen, dass sich die Anzahl der Angehörigen und die der professionell Pflegenden im gegenläufigen Trend zu den oben genannten Zahlen bewegt.' Translated: 'Against the background of the demographic trend, which according to the German Federal Statistical Office predicts that we will see a 50 percent increase in the number of people in need of care to 2,7 million by 2020 and to 4.7 million by 2050, readers may feel a little uneasy. We know that the number of relatives and professional caregivers is moving in the opposite direction to the above figure'
Q15	Tieman et al. (2016, p. 2)	'As demand for palliative care increases as a result of an ageing population and progressive chronic illnesses, mechanisms that support home-based care need to be explored.'
Q16	von Gunten (2005, p. 694)	'[…] and perhaps most worrisome, the number of people needing palliative care is projected to grow dramatically over the next few years while the number of people who will provide care is expected to decrease.'
Q17	Ward (2014, p. 309)	'Globally, more than 40 million people need palliative care each year, including 20 million at the end of life. Despite this huge demand, less than one in ten people actually receive the care they need, and millions die every year without access to adequate pain relief (18 million in 2012). There is overwhelming pressure on hospice and palliative care providers worldwide to meet the growing need for care, and this is set to increase as populations age and more people die with multiple conditions and complex needs. Many of those providing palliative care around the world work in isolation: only 20 countries worldwide having palliative care well integrated into their healthcare systems.'
Q18	Whitten et al. (1998, p. 273)	'Although the hospice field has grown and developed since its inception in the 1970s, it continues to fight for its place alongside mainstream medicine. Two major concerns of the field are the challenges of access and cost for the patient and provider. This study

No.	Reference	Quote
		outlined one innovative approach using telemedicine to overcome such barriers.'
Q19	Calton et al. (2020, p. e12)	'Even before the arrival of COVID-19, telemedicine was increasingly being adopted to bring specialty-palliative care into the homes of seriously ill patients and their families.'
Q20	Coyle et al. (2002, p. 175)	'Palliative care may benefit from this technology, as an additional tool bringing a different level of palliative care to the patient's home. This may be helpful in providing state of the art palliative care for the most complex palliative care patients, isolated in their homes by their medical conditions.'
Q21	Hennemann-Krause et al. (2015, p. 1026)	'Patients and their family members often wish to stay at home during the final moments of a patient's life, but the fragility of the situation and feelings of helplessness can lead them to seek hospital support. At this point, telemedicine may play an important role'
Q22	McCall et al. (2008, p. 431)	'The ability to monitor patients' symptoms and intervene appropriately will ensure patients are able to remain in their own homes for as long as possible while receiving optimal supportive care.'
Q23	Schnell (2020, p. 18)	Translated: 'Through the use of communication and information technologies, spatial distances can be overcome and palliative patients can be cared for longer in their own homes.' Original: 'Durch den Einsatz von Kommunikations- und Informationstechnologien können zum einen räumliche Distanzen überwunden und palliative Patientinnen und Patienten länger in der eignen Häuslichkeit versorgt werden.'
Q24	Whitten et al. (2005, p. 731)	'Particularly in rural settings, the introduction of telemedicine technologies to supplement or replace traditional hospice care can help improve patient access to hospice personnel (nurses, social workers and chaplains), reduce travel costs for providers, and provide more timely care in urgent situations.'
Q25	Bricker et al. (2003, p. 512)	'The electronic medical record, therefore, eases access to important patient information. Important discussions about advance care planning, however, are often lost in a long list of clinic notes, discharge summaries, or emergency room notes. A distinct electronic advance directive note is an effective way to improve access to the necessary advance directive information.'
Q26	Chochinov and Stern (2004, p. 6)	'[…] health care professionals will be able to congregate within these virtual spaces and engage in clinical discussions or continuing medical education activities, plan future initiatives, or simply visit.'
Q27	Collins et al. (2016, p. 81)	'vCoPs give professionals opportunities to participate in shared educational activities and problem-solving around common workforce issues. While traditional networks are discipline-specific or confined to a geographic area, vCoPs can help to overcome 'silos' of

No.	Reference	Quote
		collaboration and knowledge.' [vCoP=virtual communities of practice]
Q28	Coyle et al. (2002, p. 174)	'Allowing isolated practitioners to consult specialists and communicate with colleagues, as well as participate in research and clinical projects, and advance their clinical skills, are the areas of telemedicine research focus.'
Q29	Pereira et al. (1997, p. 441)	'Furthermore, individuals in these same developing countries who would like to receive further training, find the lack of funds a barrier to the access of continuing medical education and palliative care training. Electronic journal publishing on the WWW may therefore provide the opportunity to reach a larger readership. The lower costs and potential savings related to this form of publishing may be relayed to potential readers, perhaps in the form of lower subscription fees. The Internet may also provide various groups with a relatively inexpensive opportunity to provide some elements of the palliative care education, in some cases even utilizing this medium's multimedia capabilities.'
Q30	Ward (2014, p. 309)	'The aim of ehospice is ultimately to improve patient care at the end of life and help to extend that care to anyone who needs it. It does this by facilitating the sharing of knowledge and good practice, and by challenging the many misconceptions that still exist about hospice and palliative care'
Q31	Abel and Taubert (2020, p. 369)	'There is a need for public and community coordination to help those in greatest need (particularly in the home), the seriously ill and the dying. We examine the challenges and potential solutions to the crisis, including how caring networks may help and how modern technology may promote safer care.'
Q32	Blum et al. (2020, p. 23)	Translated: 'The corona crisis significantly accelerates digitalisation in palliative care. It is to be hoped that the useful experiences will continue to be lived and developed – even after the crisis situation.' Original: 'Die Coronakrise beschleunigt die Digitalisierung in der Palliative Care massgeblich. Zu hoffen ist, dass die nützlichen Erfahrungen weitergelebt und -entwickelt werden – auch nach der Krisensituation.'
Q33	Calton, Abedini, and Fratkin (2020, p. e12)	'With the emergence of COVID-19, telemedicine has been catapulted into the role of a critically essential service for patients to help mitigate the spread of COVID- 19 and preserve valuable personal protective equipment. For example, the University of California, San Francisco (UCSF) has mandated telemedicine be used to care for palliative care and nonpalliative care patients in ambulatory settings, whenever possible. Similarly, many hospice agencies are currently offering most, if not all, social work and chaplaincy support by telemedicine. For hospitals, strict limitations

No.	Reference	Quote
		on visitors have meant that some inpatient palliative care consult programs are performing family meetings and consults virtually.'
Q34	Chua, Jackson, and Kamdar (2020, p. 1509)	'The COVID-19 pandemic presents a clear need and opportunity for clinicians to engage in virtual serious illness conversations with patients and families.'
Q35	Hanson (2020, p. 1145)	'Virtual visits have allowed us to console and support families shut out by visitation policy, and to bring them to the bedside through video visits with patients. These new skills remind us that before COVID-19, many families were unable to visit due to lack of transportation or ill health—and we will continue virtual visits even when COVID-19 runs its course.'
Q36	Hollander and Carr (2020, p. 1679)	'Previous work has specifically described the potential for using telemedicine in disasters and public health emergencies. No telemedicine program can be created overnight, but U.S. health systems that have already implemented telemedical innovations can leverage them for the response to Covid-19. '
Q37	Hospice UK (2021, p. 38)	'The pandemic has resulted in unexpected positive developments, such as the shift to more virtual services meaning that hospices have a wider reach and can support people they wouldn't normally have been able to, for example those who live too far from the hospice or were too sick to travel.'
Q38	Collins et al. (2016, p. 80)	'Existing primarily online, [virtual communities of practice] cross geographical, cultural and socioeconomic boundaries to enable a new level of shared engagement needed to meet the significant palliative care needs of our aging populations.'
Q39	Jess, Timm, and Dieperink (2019, p. 943)	'Palliative care has developed rapidly during the last 60 years and is an essential part of modern health care. […] Given that the field of palliative care is expected to expand, it might be beneficial to think in terms of new and innovative ways to provide care, such as the implementation of telehealth'
Q40	Nkhoma et al. (2021, p. 2)	'Palliative care is a critical and essential component of care which requires further development to support increasing numbers of people with cancer in sub-Saharan Africa'
Q41	Ritchey et al. (2020, p. 992)	'Palliative care has been highlighted as an essential part of the pandemic response. Among the key roles served by palliative care teams (PCT) are developing system-level pandemic response plans; serving on scarce resource allocation teams; identifying and addressing goals of care; supporting effective symptom management; providing psychosocial support and bereavement care for family members; and supporting other healthcare workers who

No.	Reference	Quote
		are overwhelmed, stressed and traumatized by exposure to traumatic events they have witnessed.'
Q42	The Lancet (2020, p. 1168)	'WHO has issued guidance on how to maintain essential health services during the pandemic, highlighting immunisation, maternal care, emergency care, and chronic diseases among others, but there was no mention of palliative care. This was an oversight. Indeed, palliative care ought to be an explicit part of national and international response plans for COVID-19. Practical steps can be taken: ensure access to drugs (such as opioids) and protective equipment, consider a greater use of telemedicine and video, discuss advance care plans, provide better training and preparation across the health workforce, and embrace the role of lay carers and the wider community.'

Table 4 Illustrative quotes for section 4.2 on 'technology-value alignment'

No.	Reference	Quote
Q43	Niki et al. (2019, p. 706)	'This preliminary study suggests that VR travel can be efficacious and safe for improving symptom burden of terminal cancer patients. Further investigations on the mechanisms and sustainability of symptomatic improvement are needed to verify the possibility of palliative care using VR.'
Q44	Lloyd and Haraldsdottir (2021)	'Virtual Reality (VR) technology as a therapeutic intervention has been gaining attention in health care settings in recent years. Studies suggest that using the technology can help alleviate symptoms such as pain and anxiety and induce positive emotions for people in hospital. Managing symptoms and promoting emotional and psychological well-being are core palliative care goals of relieving suffering of people with life-limiting illness. Accordingly, VR may be highly beneficial for use in hospice care yet remains underdeveloped in such settings.'
Q45	Schnell (2020, p. 16)	Translated: 'Different studies have shown that the use of VR can have a positive effect on the well-being of patients.' Original: 'Verschiedenen Studien haben gezeigt, dass der Einsatz von VR einen positiven Effekt auf das Wohlbefinden von Patientinnen und Patienten haben kann'
Q46	Bharadwaj et al. (2007, p. 1038)	'The Bhaktivedanta Hospital in Mumbai (formerly Bombay), India, was interested in starting a palliative care program. They had a physician who received some theoretical training in the field and had observed the palliative care of patients but had no direct care experience. Long-distance educational support between a fellowship-trained hospice and palliative care physician in Los Angeles, California, and the new multidisciplinary palliative care team in Mumbai comprising interactive sessions over the Internet

No.	Reference	Quote
		three times per week for 2 months was initiated. The Mumbai team included the physician, nurses, and spiritual care staff members. Physical, social, psychological, and emotional aspects of each case were discussed, initially as a history and physical.'
Q47	Maudlin et al. (2006, p. 401)	'The holistic nature of the program is demonstrated in the staffing of the AIPC team and in the role of team members. The team has 3 care coordinators: an advanced registered nurse practitioner (ARNP), a chaplain, and a licensed clinical social worker. A program support assistant provides clerical services for the program. Care coordination is accomplished through a strong interdisciplinary team that delivers patient-centered care.'
Q48	Phongtankuel et al. (2018)	'Because caregivers and hospice providers serve as critical and complimentary components of the care delivery process – both groups are needed to help deliver quality care to hospice patients. An effective partnership can help relieve troubling symptoms and caregiving concerns that often arise during the course of [end-of-life] care, thus avoiding poor patient/caregiver outcomes and inappropriate care transitions. Given the promise of [mobile Health] technology to shape how care is delivered and facilitate connections between patients/caregivers and providers, its implementation in the home hospice setting has the potential to measurably improve care.'
Q49	Schnell (2020, p. 17)	Translated: 'Palliative care requires in a special way a structured interprofessional cooperation of all parties involved, in the outpatient as well as in the inpatient area. Through telemedical care concepts, such as virtual home visits, spatial distances can be overcome in emergencies through video communication and initial fears can be taken away' Original: 'Die palliativmedizinische Versorgung erfordert in besonderer Weise eine strukturierte interprofessionelle Zusammenarbeit aller Beteiligten, sowohl im ambulanten als auch im stationären Bereich. Durch telemedizinische Versorgungskonzepte, wie virtuelle Hausbesuche, können in Notfällen durch Videokommunikation räumliche Distanzen überwunden und erste Ängste genommen werden'
Q50	Dorman, Smith, and Kirkham (2010, p. 198)	'**The use of an electronic patient record to facilitate a specialist palliative care multidisciplinary team meeting** Regular multidisciplinary team (MDT) meetings are core to the delivery of cancer care, enabling the timely and appropriate management of patients with cancer.'
Q51	García-Baquero	'infoPAL contains information on the physical, psychological, emotional, social and spiritual aspects of all patients identified as having palliative care needs. It allows multidisciplinary access,

No.	Reference	Quote
	Merino et al. (2014, p. 42)	continuous updating of the patients' clinical records, and access to up-to-date information regarding resources (for example, the number of beds available). infoPAL is key to the region's round-the-clock, central palliative care service and helps it to respond in a timely, effective and flexible manner to changing clinical needs. It is a fundamental tool to co-ordinate different care levels, settings and specialties.'
Q52	Vitetta et al. (1999, p. 61)	'We have attempted to design a palliative care database which is detailed enough from a medical perspective, but bas potential to enable all interdisciplinary team members to track clinical events, professional contacts and outcomes'
Q53	Bouteiller-Descas and Salamagne (1999, p. 17)	'Teamwork, a fundamental principle of palliative care, is also enhanced since every member of the team has access to comprehensive information about a patient. Staff have to input any data considered to be important during their contact with patients. The computerised record therefore reflects true multidisciplinary management, where communication is facilitated by computers.
Q54	Abel and Taubert (2020, p. 370)	'The old and vulnerable are at risk of dying alone. Minimising harm by attention to how we can all support each other is even more important now than in prepandemic times. […] let us try to maintain physical separation while still maintaining emotional closeness through use of compassion in our communities, using the incredible technologies we have today.'
Q55	Hanson (2020, p. 1145)	'Virtual visits have allowed us to console and support families shut out by visitation policy, and to bring them to the bedside through video visits with patients. These new skills remind us that before COVID-19, many families were unable to visit due to lack of transportation or ill health—and we will continue virtual visits even when COVID-19 runs its course.'
Q56	Radbruch et al. (2020, p. 1467)	'Enable families to virtually visit and partake in health decisions with loved ones, especially at the end of life to address the almost universal fear of dying alone.'
Q57	Wakam et al. (2020, p. e88 (1))	'The fear of dying alone is nearly universal — a fact of which anyone who's taken care of a critically ill patient is acutely aware. So we sometimes go to great lengths to give patients just a little more time for family members to arrive and say their goodbyes. One aspect of the Covid-19 pandemic that has been particularly difficult […] we find ourselves telling families, 'Because of hospital policy, we cannot allow visitors at this time.' This conversation sometimes takes place at the doors to the ICU, over the phone, or in front of the hospital, as families beg to see their loved ones before they die. […]

No.	Reference	Quote
Q58	Abernethy and Currow (2011, p. 673)	‘In palliative care, our conversations with the patient are a key venue to learn about the patient’s problems and to build therapeutic rapport. During such conversations, we learn important dimensions of the patient’s experience in how information is presented, identify corollary problems, evaluate the patient’s quality of life and cognition, and consider caregiver well-being. It follows that the patient report should be paramount. Solutions are needed to rapidly and efficiently incorporate the patient report into routine palliative care. Real time [health information technology] offers many advantages that facilitate timely recognition of patient needs and key changes.’
Q59	Bradford et al. (2013, pp. 1–2)	‘Families rely on the information, advice and support provided by clinicians […]; effective communication is therefore crucial. Telehealth has been proposed as a solution for increasing access to health care services when separated by geography, circumstances, or time by facilitating real time synchronous communication’
Q60	Collins et al. (2016, p. 81)	‘The Palliverse team considers improved communication and engagement as imperative in meeting the growing demand for high-quality palliative care. We also share the view that social media and [virtual communities of practice] offer novel means to promote such engagement.’
Q61	Calton et al. (2020, p. e14)	‘Do not shy away from having these conversations over telemedicine. Key communication principles like asking for permission and attending to emotion should be relied upon when discussing sensitive topics by telemedicine.’
Q62	De Conno and Martini (1997, p. 175)	‘Communication is an essential part of patient care; the physical presence of the physician and the nurse is requested by the patient and his family more than any other therapy. It is also true that the ability to reply promptly to family requests is fundamental in preventing emotional distress. It seems obvious therefore that technical innovations able to improve communication will have an impact on the quality of care. ‘
Q63	Lowe, Martins Pereira, and Yardley (2021, p. 1223)	‘While person-centered communication may have been previously characterized by taking ‘more’ time and an accepted norm that face-to-face contact was essential, the imposed public health requirements of COVID-19 have forced health care providers, patients and families to adapt not only to public health requirements, but also to uncertainty and unpredictability. Much has been learned about rapid advance care planning and end-of-life decision-making. Virtual platforms for communication have presented challenges to providing holistic, interdisciplinary support to patients and their families, yet offer opportunities to strengthen pre-existing relationships.’

No.	Reference	Quote
Q64	Payne, Tanner, and Hughes (2020, p. 443)	'What is clear is that digital technologies will be playing an increasingly important role in palliative care and in healthcare more generally, as well as shifting cultural assumptions and beliefs about how patient–professional relationships are conducted. Sensitive compassionate communication is central to relationships within palliative care contexts, and that patients and families may have variable levels of digital literacy. We argue that robust research into both the efficacy and the implementation of digital health technologies is essential'
Q65	Demiris et al. (2004, p. 345)	'Telehospice was also perceived as a benefit to social workers as they could better prioritize visits, reach timely decisions, and provide faster and more efficient follow-up on different concerns and monitor patients.'
Q66	Kinsella (2005, p. 771)	'From these programs, we can learn about the range of services that can be provided to track patients on a more timely basis. Hands-down, these programs report, telehospice helps providers deliver as-needed, when-needed care—a must in focused hospice care and quite a welcome benefit of using the technology both for the patients and the service providers.'
Q67	Whitten et al. (2005, p. 731)	'Particularly in rural settings, the introduction of telemedicine technologies to supplement or re-place traditional hospice care can help improve patient access to hospice personnel (nurses, social workers and chaplains), reduce travel costs for providers, and provide more timely care in urgent situations.'
Q68	Bishop, Flick, and Wildman (2015, p. 9)	'The ability to monitor patients' biometrics remotely increased timely response to changes in their conditions and provides efficient use of nursing visits.'
Q69	Coyle et al. (2002, p. 174)	'At the end of the 3-month trial period the Pain and Palliative Care team could identify the following medical and social benefits to this patient: 1) an immediate impromptu limited general physical exam became possible, 2) 'curb side' evaluation with an attending or consultants became possible, 3) the patient's obvious pleasure at visual contact with clinicians, 4) the opportunity for visual clues for this patient with profound hearing loss improved communication by maintaining and expanding the conversation.'
Q70	Calton et al. (2019, p. 982)	'Video visits may also supplement in-person visits, by providing continuity and follow-up between in-person visits and addressing some urgent concerns. In all these situations, video visits may add value by allowing clinicians to see into patients' home environments and meet loved ones, such as children and pets, who may not normally appear at an office visit. Video visits allow the clinician to assess the patients' social situation to provide broader insights into

No.	Reference	Quote
		the positive and potentially burdensome factors in the home environment that can impact serious illness and end-of-life care.'
Q71	Granger (2014, p. 2)	'I personally find writing an extremely therapeutic exercise, with my tweeting and blogging helping me to rationalise the difficulties and decision making I face every single day with regard to my health. Being a member of the Twitter community is also like belonging to a huge support group, which you can access any time of day or night.'
Q72	Nolan and Crowe (2017, p. 250)	'There is some evidence that patients seek and obtain particular information, and have their psychological and emotional needs fulfilled, using social media to relate their personal experiences and engage in the experiences of others in similar situations. […] It may not be possible to fulfill this need with patients or hospital staff in the same hospital, as online forums allow a degree of anonymity.'
Q73	Pereira et al. (2000, p. 16)	'Some Internet-based applications, such as online discussion groups and listservs, enable patients and families to find support online […]. These investigators identified some advantages of these online communities over traditional face-to-face support groups, including 24-hour availability and the absence of a perceived pressure to participate in the discussions.'
Q74	Payne, Tanner, Hughes (2020, p. 442)	'There is clearly the risk of having more information about the patient, but less knowledge of them as people and less time interacting with them. This would be particularly detrimental in a palliative care context in which relationship is key.'
Q75	Bouteiller-Descas and Salamagne (1999, pp. 17–18)	'The use of impersonal computers must not depersonalise patients. Sociocultural facts can be recorded, but they lack individuality. The danger is to limit knowledge of the patients to this quantitative aspect, thereby obscuring the richness and diversity of interpersonal relationships'
Q76	Monteverde (2020, p. 5)	Translated: 'One opportunity may be to give patients and family members more control, knowledge, and understanding of health status and disease progression – a risk that of reducing experience and quality of life to numbers, apps, and algorithms.' Original: 'Eine Chance kann sein, Patienten und Angehörigen mehr Kontrolle, Wissen und Verständnis über den Gesundheitszustand und Krankheitsverlauf zu ermöglichen – ein Risiko, das Erleben und die Lebensqualität auf Zahlen, Apps und Algorithmen zu reduzieren.'

Table 5 Illustrative quotes for section 4.3 'Socio-technical adjustment'

No.	Reference	Quote
Q77	Boston and Bruce (2014, p. 293)	'We need to be mindful that we are embedded in a technology (and will be for all time) that, although strong and progressive, poses one of the greatest challenges to the way we define ourselves as nurses in our quest to care for the patient as a whole person.'

No.	Reference	Quote
Q78	Pereira and Bruera (1998)	'With all its advantages and limitations, it appears that the Internet, in different formats, is here to stay. The Internet's potential positive contribution to palliative care and hospice-related education and information dissemination cannot be ignored. […] Measures to counteract the weaknesses should be implemented.'
Q79	Seely and Mount (1999, p. 1121)	'Palliative medicine highlights both the strengths and potential pitfalls of modern technology in modern practice. Human needs, fears, hopes and strengths are never more openly displayed than at the bedside of the dying. The issue is not whether, but how, to apply modern technology in palliative care.'
Q80	Smith (2011, p. 429)	'The palliative team members could argue that it is none of our business how a wider social circle responds to the news of a dying patient online. But Facebook may be our business in the same sense that preparing families for visitors, for funeral homes, and for the process of grief is our business. Our social worker prepares families for financial issues such as insurance, payment of funeral bills, and compassionate care funding programs. The team guides families through grief work and its attendant pitfalls and processes. Therefore, it is understandable that warnings about possible sensitivities over social media may become the norm in a palliative setting that aims to give holistic care. Giving families knowledge about hyperlinks that could exist on the World Wide Web years after a patient's death may become yet another piece of knowledge to impart when patients are introduced to palliative care.'
Q81	Taubert (2014, p. 17)	'Social media are agents of change and have transformed our society and the way we interact with each other. This is most evident in the private sphere, but patients may not want to exclude the end of their life from these activities, and will want to carry this on in their social activities.'
Q82	VandeKieft et al. (2001, p. 319)	'The Internet is moving ahead at rapid speed—efforts to facilitate access to reliable, high-quality information about end-of-life care on the Internet must keep pace.'
Q83	Coop and Marlow (2019, p. 115)	'This survey demonstrates that palliative care professionals do not routinely ask patients about their digital legacy. […] online interactions become a norm in society, we need to engage and support a patient's digital legacy as part of our holistic assessment.'
Q84	Nolan and Crowe (2017, p. 250)	'Can we incorporate social media into our traditional death practices in a critical care environment to benefit the child and their family, and to protect and support staff? The influence of social media is here to stay, so we need to learn how to say goodbye in a new way'
Q85	Payne, Tanner, and	'Among the mass of data generated, checkboxes and pre-defined answers that patients are invited to respond to, we can easily lose sense of the patient as an individual with their own life story, values,

No.	Reference	Quote
	Hughes (2020, p. 441)	beliefs and relationships. As the digital revolution in healthcare progresses, ensuring that the focus remains on the whole person, rather than their quantifiable parts, will probably be the greatest challenge of all. There is also a need to recognize that the impact digitalization may have differential impacts across generations and social groups, with older people and those with lower literacy skills being at greater disadvantage.'
Q86	Saysell and Routley (2003, p. 495)	'The paradox, of course is that just because we have the technology, does not mean we have the knowledge, skills and confidence to use it effectively. We need to hear much about what is happening out there in the virtual world and to encourage the use of thorough and systematic means of assessing, not only the cost effectiveness of such projects, but also the less quantifiable, but equally important element of how this contributed to the patient's quality of life.'
Q87	Smith (2011, p. 429)	'Our social worker prepares families for financial issues such as insurance, payment of funeral bills, and compassionate care funding programs. The team guides families through grief work and its attendant pitfalls and processes. Therefore, it is understandable that warnings about possible sensitivities over social media may become the norm in a palliative setting that aims to give holistic care. Giving families knowledge about hyperlinks that could exist on the World Wide Web years after a patient's death may become yet another piece of knowledge to impart when patients are introduced to palliative care.'
Q88	Taubert et al. (2014, p. 16)	'While it is tempting to not open the potential Pandora's box that the questions raised above bring with them, it is worth staying abreast of ongoing social media developments as much as possible. We simply cannot feign ignorance about all matters to do with the internet, as many patients and their friends and families will see this as important legacy building, and will also expect us to be able to communicate with them appropriately. In the same way that years ago we would not have turned anyone away asking to create a memory box for their family and children once they are gone, we now cannot ignore the fact that end-of-life matters have taken a significant shift into the online world, and that increasingly we will be set difficult, sometimes ethically dubious challenges.'
Q89	Bradford et al. (2013, p. 10)	'Four key elements were proposed: the project coordinator must be fully engaged with participants (clinicians and patients); a seamless delivery process should be defined by the coordinator; a patient centred approach is required, and champion clinicians who support the project must be identified.'
Q90	Calton et al. (2019, p. 983)	'There is no ''one-size-fits-all'' model of telepalliative care, so the first major task to start a telepalliative care program is a needs

No.	Reference	Quote
		assessment. […] One should be prepared to invest time investigating their institution's current use of telehealth, and consulting with the existing institutional resources for hardware, software, connectivity, billing, and scheduling processes.'
Q91	Collier et al. (2016, p. 410)	'Processes involved in developing clinically meaningful telehealth resources that enhance work practices are complex, involving a large number of diverse stakeholders. These resources must meet patient and carer needs, clinicians' utility and usability criteria, health systems' requirements and policy requirements of funders.'
Q92	Hollander and Carr (2020, p. 1681)	'Payment and regulatory structures, state licensing, credentialing across hospitals, and program implementation all take time to work through, but health systems that have already invested in telemedicine are well positioned to ensure that patients with Covid-19 receive the care they need.'
Q93	Whitten et al. (1998, p. 273)	'When implementing a telemedicine project, great care should be taken in ensuring that all providers are very comfortable with hooking up the equipment; educating patients and facilitating their comfort with the technology, using the equipment for routine and emergency consults, and having a basic knowledge of the technology when technical problems occur. Furthermore, necessary knowledge of the technology must be passed on to families and patients early on. Then, telehospice™ will be viewed as a routine element of care rather than something added to the service package.'
Q94	Lamas et al. (2018, p. 527)	'In conclusion, we offer a set of recommendations based on expert opinion that aim to standardize ACP in the EHR. These recommendations cannot all be implemented at once, but could be phased in with an incremental approach—first targeting fairly standardized documents and orders regarding life-sustaining treatment and then moving to goals like building in quality metrics and ensuring access across the health system.'
Q95	Lowe (2021, p. 1222)	'We need to understand both how to achieve this effectively and what is the best way to evaluate new models of communication and palliative care provision in this dynamic context. In this issue, two papers help address the timing and urgency questions which arose during the COVID-19 pandemic.'
Q96	Nkhoma et al. (2021, p. 15)	'This work presents a foundation to guide the development of digital health interventions for the delivery of palliative care for cancer patients in SSA. Through stakeholder engagement we identified the design, practical, and contextual challenges to optimise potential for success.'

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Abstract

Envisioned socio-technical futures guide the development of new technologies. They are discursively created and draw upon broader societal discourses. This dissertation explores the relations between socio-technical futures and other discourses. Its empirical starting point is the observation that those elderly users of robots in care who are dying and receiving palliative care have been widely absent in research and development in this field. Investigating this seemingly absent relation of the care robotics' discourse with discourses of good dying and end-of-life care, it strives to further conceptualise discursive relations. Methodologically, it adopts the sociology of knowledge approach to discourse to reconstruct and comparatively analyse three distinct discourses. First, a study of a sociopolitical public debate around dignity at the end of life in Austria as well as an integrative review of empirical work on good dying in non-specialised palliative care provide an understanding of typical contemporary discourses on good dying. Against this background, second, an investigation of the European roboticists' discourse on robots in care examines the absence of dying elderly as users of these robots. Analysing publications from this field as well as problem-centred interviews with roboticists, this work calls attention to discursive and practical dynamics leading to the absence of users who are not in line with dominant user representations, technical capabilities of the robots, and common testing practices. Third, an analysis of publications on digital technologies from the field of palliative care shows how this discipline discursively incorporates assistive technologies into end-of-life care. It outlines the three processes of discursive affirmation, alignment, and adjustment, and identifies an alternative to the discursive absence of dying users in robotics. Fourth, a comparative analysis interprets the robots in care discourse as the result of incorporating external stocks of knowledge and discursive elements into the established industrial robotics discourse. It discusses how distinct discourses can be positively interrelated by sharing common stocks of knowledge or particular discursive elements, even without explicitly relating to one another. Negative relations can be realised by contesting or preemptively addressing other discourses' assumptions and arguments. Furthermore, the relative absence of issues in one discourse is identified as meaningful unrelatedness between discourses. Concluding, the dissertation proposes to use the concept of relations of discourses as a sensitising concept to study the emergence and transformation of discourses in general and socio-technical future discourses in particular.

Zusammenfassung

Soziotechnische Zukunftsvisionen prägen die Entwicklung neuer Technologien. Sie werden diskursiv erzeugt und greifen auf breitere gesellschaftliche Diskurse zurück. Die vorliegende Dissertation untersucht die Relationen zwischen soziotechnischen Zukünften und anderen Diskursen. Empirischer Ausgangspunkt ist die Beobachtung, dass Nutzerinnen und Nutzer von Robotern in der Pflege, die sich im Sterbeprozess befinden und palliative Versorgung erhalten, in diesem Feld von Forschung und Entwicklung weitgehend abwesend sind. Die Studie untersucht die Gründe für diese scheinbar fehlende Verbindung des Robotik-Diskurses zu Diskursen des guten Sterbens und der Pflege am Lebensende und konzeptualisiert darauf aufbauend verschiedene Typen diskursiver Relationen. Dazu werden drei Diskurse in Anlehnung an die wissenssoziologische Diskursanalyse rekonstruiert und vergleichend analysiert. Erstens liefern eine Studie über eine öffentliche sozialpolitische Debatte über Würde am Lebensende in Österreich sowie ergänzend ein integratives Review empirischer Arbeiten zu gutem Sterben in der nichtspezialisierten Palliativpflege ein Verständnis typischer zeitgenössischer Diskurse über das gute Sterben. Vor diesem Hintergrund wird, zweitens, in einer Rekonstruktion des europäischen Robotik-Diskurses über Roboter in der Pflege die Abwesenheit von Menschen, die sich in einem längeren Sterbeprozess befinden, als deren Nutzerinnen und Nutzer untersucht. Die Analyse von Publikationen sowie problemzentrierter Interviews mit Robotikern lenkt die Aufmerksamkeit auf diskursive und praktische Dynamiken, die zu einer Abwesenheit von Nutzerinnen und Nutzern führen, die nicht mit den vorherrschenden Repräsentationen von Nutzerinnen und Nutzern, den technischen Möglichkeiten der Roboter und üblichen Testpraktiken übereinstimmen. Drittens zeigt eine Analyse von Publikationen zu digitalen Technologien aus dem Bereich Palliative Care, wie diese Disziplin digitale Technologien diskursiv in die Pflege am Lebensende eingegliedert. Anhand von drei Prozessen der diskursiven Affirmation, Angleichung und Anpassung wird eine Alternative zur diskursiven Abwesenheit sterbender Nutzerinnen und Nutzer in der Robotik aufgezeigt. Viertens wird in einer vergleichenden Analyse der Diskurs über Roboter in der Pflege als Ergebnis der Einbeziehung externer Wissensbestände und diskursiver Elemente in den etablierten Industrierobotik-Diskurs interpretiert. Es wird erörtert, wie unterschiedliche Diskurse positiv aufeinander bezogen werden können, indem sie gemeinsame Wissensbestände oder bestimmte diskursive Elemente teilen, auch ohne sich explizit aufeinander zu beziehen. Negative Verbindungen können realisiert werden, indem die Annahmen und Argumente der anderen Diskurse angefochten oder präventiv berücksichtigt werden. Darüber hinaus wird die relative Abwesenheit von Themen in einem Diskurs als bedeutungsvolle Nicht-Relation zwischen Diskursen identifiziert. Die Dissertation regt an, das Konzept diskursiver Relationen als sensibilisierendes Konzept zur Untersuchung der Entstehung und des Wandels von Diskursen im Allgemeinen und von soziotechnischen Zukunftsdiskursen im Besonderen zu verwenden.