

Social Movement Organizations in Extreme Contexts: A Care Ethical Perspective

Author: Tuisku Takala, Jyväskylä University School of Business and Economics

Address: Varppaaja 3, Apt. 27, 40100, Jyväskylä, Finland

Email: tuisku.t.takala@jyu.fi / tuisku.takala@gmail.com

Summary: This article examines how social movement organizations (SMOs) (re)institutionalize end-of-life care practices through caring agency and care ethics in extreme contexts. Through longitudinal discourse analysis of Finnish media (1990-2024, n=643 articles), I investigate how SMOs transformed palliative care discourse using abductive reasoning and temporal bracketing. Analysis reveals four distinct eras: Conceptual Definition (1982-2000), Criticism and Awakening (1997-2004), Radicalization and Advocacy (2005-2014), and Systematization and Institutionalization (2015-2024). Each era features specific discourses: From Curing to Caring, Institutional Care Responsibility, Shared Vulnerability Mobilization, and Regulated Care. The study demonstrates how SMOs construct discursive agencies in extreme contexts, mobilizing shared vulnerability as empowering force rather than weakness. Findings show how care ethics functions as both critique and constructive system development force. This research contributes to critical management studies by examining the understudied intersection of SMOs, care ethics, and extreme contexts, focusing on how caring agency can reshape institutional practices.

Keywords

discourse analysis; ethics of care; extreme context; organizing death; social movement organizations

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Introduction

Death has been described as the most important event in human life, a unique and singular experience. Despite the ability to objectively explain, predict and attempt to control death, we are increasingly alienated from understanding it (Jacobsen 2013). Even societies reveal their deepest beliefs and values through their attitudes toward death (Ariés 1981). Death is seen as a natural part of life, but also a cultural and social phenomenon, a social construct, that is constructed in different ways throughout history, across geographical and cultural boundaries. Although death is a universal phenomenon, individual cultures understand and deal with it uniquely and individually in their social, cultural and temporal contexts (Jacobsen 2013).

This article examines the social movement organizations (SMOs) of the hospice movement (Clark 1998; Floriani & Schramm 2010), as they can help us understand how organizations can challenge deeply rooted social structures (see Munro 2014). Interestingly, these SMOs operate in an extreme context where life and death meet, creating conditions through which the meanings of SMOs discursive practices in social change can be examined. In summary, discourses may provide access to a paradigm shift, i.e., how SMOs construct alternative realities through discursive practices as part of the palliative care debate.

In this article, I use the ethics of care (Noddings 1986) as a theoretical framework, which remains unexplored in social movement studies (Santos 2020). The ethics of care pays attention to contextual factors and focuses on the nature of the relationships between the parties involved in the caring process (Katila et al. 2023). I argue that the hospice movement's SMOs are particularly suitable extreme context for studying the meanings of the ethics of care and the discursive changes of end-of-life care. My study is guided by the following research question: *How SMOs shape the discourse of care in the context of palliative care over time?*

In this extreme context, my analysis concentrates on media articles and aims to highlight how SMOs construct and shape hospice care discourses, grounded in an ethics of care using an abductive approach (see Locke et al. 2008). SMOs can strategically shape public perception and discourse over time to catalyze societal change (Hardy et al. 2000; Siltaoja et al. 2020). These discourses serve as vital strategic resources that movements leverage to achieve their goals. Analyzing discourses longitudinally through media representations show how meanings evolve and movements influence on our social reality, such as public opinion and institutional practices and systems.

Through longitudinal discourse analysis, I employed a theory-driven, abductive approach to identify discursive themes in textual material, sorted chronologically using qualitative software and open coding (Locke et al. 2008; Williams & Moser 2019). Analysis revealed four distinct eras as discursive practices evolved: Conceptual Definition (1982-2000), Criticism and Awakening (1997-2004), Radicalization and Advocacy (2005-2014), and Systematization and Institutionalization (2015-2024). From these periods, I identify four key discourses, 1. From Curing to Caring, 2. Institutional Care Responsibility, 3. Shared Vulnerability Mobilization and 4. Regulated Care, that reveal the theoretical underpinnings shaping SMO organizing in this extreme context.

Theoretically, this research addresses the understudied intersection of SMOs and care ethics, where ethical perspectives on care remain underexplored (Santos 2020). I demonstrate how SMOs have not only institutionalized palliative care as a specialized end-of-life service but also transformed societal death discourse towards a more caring direction and enabling dignified, compassionate approaches to dying.

Theoretical Framework

SMOs in Extreme Contexts

Social movement research intersects organizational theory by examining both organizations and organizing processes (de Bakker et al. 2017). Social movement organizations (SMOs) are complex entities promoting ethical change and resistance, distinguished from formal organizations by two criteria: mobilizing participants for collective action and pursuing political objectives (Kriesi 1996). SMOs function as partial organizations with open membership and non-hierarchical structures (Simsa & Totter 2017).

Research on extreme contexts deepens understanding of SMO functioning by illuminating specificities and challenges of these environments. Extreme contexts involve continuous exposure to potential extreme events requiring system reliability and specific routines, processes, and materials in empirically risky environments (Hällgren et al. 2017). SMOs operate across diverse extreme contexts—from urban poverty and social exclusion to unstable institutions, political repression, and humanitarian crises (Zapata Campos et al. 2023).

Existing research examines SMOs across diverse extreme contexts through various analytical lenses. Studies have explored tactical approaches in conflict zones and politically tense environments (Meyer 2004), innovation strategies under extreme scarcity across multiple countries (Zapata Campos et al. 2023), and resource mobilization among homeless populations (Cress & Snow 1996). Labor-focused SMOs have been analyzed regarding shifts from bureaucratic conservatism toward radical change during economic instability (Voss & Sherman 2000), while humanitarian contexts have been examined through Médecins Sans Frontières' discourse strategies in health emergencies (Matte 2019). This literature demonstrates that SMO research in extreme contexts has primarily focused on political conflict, urban poverty, social exclusion, institutional instability, and high-risk humanitarian situations.

Within this framework, death and dying constitute quintessential extreme events demanding sophisticated organizational responses (Hearn & Parkin 2021). End-of-life SMOs, grounded in hospice philosophy, embrace care ethics emphasizing dignity, personal agency, and holistic support throughout dying (Graven & Timm 2021). While SMOs provide crucial mobilization, informal networks and support organizations also contribute to movement infrastructure (Kriesi 1996). Institutional inadequacies in end-of-life care have catalyzed SMO emergence, such as the hospice movement, addressing unmet needs of vulnerable populations underserved by conventional healthcare systems (Tam et al. 2021).

SMOs adapt to extreme contexts through various organizational modes, operating as structured entities within broader social movements (Chesters & Welsh 2010). The hospice movement exemplifies this within the larger "death awareness movement," which strives to normalize mortality and integrate it into societal frameworks, enabling individuals to approach death autonomously while maintaining community connections. These SMOs pursue dual missions: enhancing end-of-life quality through comprehensive pain management and holistic support—social, psychological, and spiritual—while advocating systemic change. Their advocacy encompasses fostering open death dialogue, influencing policy, reforming institutional dying approaches, and strengthening end-of-life rights, including the international human right to palliative care (Brennan 2007; Graven et al. 2013).

SMOs provide meaningful opportunities to explore how actors challenge the status quo. Organizational research has neglected the forms of resistance mobilized within social movements (Böhm et al. 2008; Munro 2014). By examining hospice care SMOs through an extreme context lens, this study illuminates how agency shapes discourse to challenge institutional death norms. This approach allows us to explore how SMOs construct social reality from a care ethical perspective through discourse.

Care in Regulated Contexts

The central concept, care, functions both as action toward others and as a value reflecting universal shared vulnerability (Pettersen 2011). I examine caring as "caring with" encompassing the entire care process where caring aims at broader social and political transformation among participants (Tronto 2020).

In regulated contexts, care links to institutional responsibility, requiring entities to demonstrate active care for those affected by their activities. Care regulation encompasses laws, rules, norms, ethics, values, and systems structuring caregiving activities along a continuum from prescriptive to interpretive approaches. Prescriptive regulation defines precisely what employees do, when, and how, while interpretive regulation defines care broadly but leaves provider roles, timing, and methods undefined, relying instead on standards and ethical principles. (Daly et al. 2016.)

Caring encompasses Tronto's (2013) five phases: caring about (attentiveness), caring for (responsibility), care giving (competence), care receiving (responsiveness), and caring with (reciprocity) (Moriggi et al. 2020). Reciprocity involves mutually beneficial relationships through attentiveness, respect, and solidarity, recognizing care recipients as active agents whose needs and practices align with democratic commitments including justice, equality, and freedom (Moriggi et al. 2020). This framework emphasizes deliberate commitment to caring, highlighting moral dimensions of daily activities and care's complexity, enabling broader analysis of caring's role in human life (Tronto 1998).

"Caring with" emphasizes collective responsibility in caring practices, requiring collective action and political commitment. While caring organizations consider human interactions like compassion and understand network importance (Gössling & Van Liedekerke 2014), they cannot fully realize care ethics as conceptualized by theorists like Noddings (2015). Thus, "caring" organizations must be referenced cautiously to avoid distorting caring concepts.

This limitation reveals opportunities for SMO analysis. SMO scholars seek to understand how social movements create solidarity and motivate participation in causes offering no direct personal benefit. Traditional SMO research emphasizing justice and rational action overlooks care ethics' contributions, interpersonal relationships, empathy, and responsibility for others, offering new analytical perspectives on movement participation and organizing (Santos 2020).

This article explores how care is discursively constructed rather than fixed, forming part of symbolic social reality expressed through media discourse where care's meaning emerges through continuous processes (Adoni & Mane 1984). SMOs shape end-of-life care discourse by producing and participating in media discussions. By positioning "death as a guest of honor at the end of life," SMOs actively construct alternative care understandings emphasizing dignity and acceptance over rejection. From a social constructionist perspective, care is constantly constructed and reconstructed through SMOs' symbolic work as they challenge prevailing paradigms and create new meanings for end-of-life experiences.

A longitudinal qualitative approach enables examination of care's discursive practices through temporal bracketing of key events and achievements, analyzed empirically below.

Methodology

In this section I describe the study context and methodological choices, including data collection and analysis.

Hospice Movement

Ariès (1981) charts three pivotal transformations in Western attitudes toward death over the past millennium. First, the late 19th century witnessed the growing isolation of the dying and

the systematic concealment of death from family members. Second, society began suppressing public expressions of grief, forcing mourning into private spaces. Third, the medicalization of death through its relocation to hospitals transformed it from a communal experience into a clinical event. This evolution reflects society's increasingly ambivalent relationship with mortality, where death has shifted from a shared, communal experience to a stigmatized occurrence often perceived as a medical failure to be denied and avoided (Ariès, 1981). For example, the death awareness movement has been creating new institutions when it comes to hospice and palliative care (Graven et al. 2013).

The hospice movement, pioneered by Cicely Saunders (1918-2005), stands as the most influential death awareness social movement, fundamentally transforming end-of-life care through the development of comprehensive frameworks for treating terminally ill patients (Graven et al. 2013). Saunders' influence was also felt elsewhere in Europe, and for example, the first hospice care home was established in Finland in 1988 (Thodén 2022). Finland had already begun formalizing end-of-life care standards when the Finnish Medical Board issued its inaugural terminal care guidelines in 1982. The subsequent transition from the term "terminal care" to "hospice care" reflected a broader philosophical shift toward the more holistic hospice model (Thodén 2022).

The evolution and expansion of palliative care has heightened focus on holistic patient care, encompassing psychological, spiritual, and emotional dimensions beyond physical needs. While the movement fundamentally aims to facilitate a "good death" for all individuals (Graven et al. 2013), contemporary discourse has evolved to distinguish between multiple conceptual frameworks. The notion of a "good death," centered on individual choice in dying, differs significantly from "dying well," which emphasizes quality of life throughout the terminal process rather than optimizing the final moment (Graven et al. 2013). A third framework, "authentic death," has emerged within hospice philosophy, acknowledging death as an inherently individual journey rather than prescribing an idealized model of dying (Graven & Timm 2021).

The modern hospice movement represents a paradigm shift from medieval *ars moriendi*, prioritizing human autonomy, pain management, social connection, and emotional-spiritual healing through forgiveness, trust, and faith (Thornton & Phillips 2009; Graven et al. 2013). While the medieval *ars moriendi* framed death as a performative spiritual struggle for heavenly admission (Thornton & Phillips 2009), contemporary hospice philosophy embraces an ethics of care that emphasizes dignity, personal agency, and holistic support throughout the dying process. Palliative care itself refers to the active symptomatic treatment of a terminally ill patient when the progression of the disease can no longer be influenced. Palliative care aims to alleviate suffering and maintain quality of life - while remembering that death is a normal event in life. Hospice care is part of palliative care. It is timed closer to the likely time of death, usually in the last days or weeks. (Tarnanen et al. 2019.)

This study employs a qualitative and longitudinal approach to study media discourses related to the death care development and institutionalization in Finland from 1982 to 2024. Death care as in end-of-life care encompasses both palliative and modern hospice services. During this 42-year period, Finland experienced remarkable medical advancements in both the quality and accessibility of end-of-life care across regions, largely driven by SMOs advocating for compassionate care and normalizing death as a part of end-of-life care. The Finnish Medical Board's 1982 guidelines for hospice care (then termed "terminal care") marked a significant milestone, as noted by the Finnish Medical Association (FMA 2021). These guidelines defined hospice care as treatment provided when available medical interventions can no longer improve a patient's prognosis, including care during imminent death.

The previous guidelines on hospice care were repealed in the early 1990s, but their principles, humanity, asymptomaticness, patient wishes, choice of place of care, remained

important. In 2003, the National Ethical Advisory Council for Social and Health Services (ETENE) issued recommendations on hospice care, and the Council of Europe issued recommendations to member states on the organization of palliative and hospice care. In 2010, the Ministry of Social Affairs and Health published a recommendation on hospice care and in 2014, the WHO issued recommendations on palliative care, emphasizing its role as a core health care activity. In 2017, a government decree made university hospitals responsible for advanced palliative and hospice care, while in 2018-2019 the Council of Europe issued a position paper on legislative measures for palliative care the STM published a recommendation on palliative care services, the curative care guideline was updated, and uniform criteria for non-urgent care were published (FMA 2021.)

The aim of the Ministry of Social Affairs and Health's Programme for Providing and Improving the Quality of Palliative Care Services (2021-2023) was to ensure that Finns receive dignified hospice, palliative care and pain management. Everyone in Finland should receive timely and equal access to care, treatment and support at the end of life. Palliative care was recognised as a human right that belongs equally to all (Innokyla 2024; Ministry of Social Affairs and Health 2025.)

Finally, context connects discourse and society, linking personal and social dimensions while shaping social structures (Van Dijk 2008). In this study, extreme context provides an interpretive framework for analyzing how discourse is embedded in social and political life. This context actively determines what matters in communication. SMO participants and society define situations subjectively, influencing how discourse is produced and understood. The analysis examines how context shapes appropriate language use, how participants adapt their communication, and develop new concepts. Rather than being a static background, extreme context functions as a lively element of discourse itself. Understanding how participants define situations, adapt their language, and how context influences meaning is therefore central to the analysis (see Van Dijk 2008).

Data Collection

This article employs a discursive approach to analyze how SMOs shape the discourse of care in the context of palliative care over time. Drawing on social constructionist epistemology, I analyze symbolic and social reality through media data, examining care as constructed reality and discursive practice (see Adoni & Mane 1984). Media data provides unproblematic access to events in natural situations as researcher-independent natural data (Juhila & Suoninen 1999). Discourse analysis examines how meanings are constructed through language (Gibbins 2014), where care gains meaning through SMO-generated discourse.

In discourse analysis, language constitutes action—words, sentences, and conversations perform reality-shaping functions. This discursive approach treats media communications and public discussions as arenas where SMO participants construct reality. According to social constructionism, reality emerges through contextual social interaction and language (Berger & Luckmann 1967; Galbin 2014). SMO participants' speech and writing create consequential effects, interpreting how actors construct institutions through media discourse (see Juhila & Suoninen 1999).

Empirical data consists of media articles (n=643) systematically collected from Finland's main newspaper Helsinki's News (Helsingin Sanomat) from 1.1.1990-31.12.2024 including news articles and opinion pieces on palliative and hospice care quality, availability, and ethics. Authors include healthcare professionals and hospice care family members sharing experiences and perspectives. Central to these debates is ensuring dignified death rights and improving care quality and accessibility. The material encompasses critical and positive hospice care examples, illustrating SMO participants' collective agency under the leadership of their key figures.

Data was collected from Helsinki's News news archive, arranged chronologically from 1990-2024 using temporal bracketing. Initially, all articles mentioning "hospice care" (saattohoi*) and/or "palliative care" (palliatiiv*) were collected (n=1,236). After that data was re-read and duplicates were removed (n=1010). The data was then narrowed down to 643 articles based on the research question to extract the articles that related to the discourses of organizing in extreme contexts from care ethics and SMO perspectives. Data was sorted in qualitative research software (Atlas.ti) chronologically and categorized by document groups: news versus opinion pieces, whether articles promoted or discouraged hospice care development, and whether texts mentioned key SMO participants/leaders.

I applied discourse analysis to examine how death care discourse is produced in media with its meaning structures. Analysis focused on identifying different eras as concepts for institutionalizing hospice care evolved. Conceptual shifts from terminal care to hospice care generated increased palliative care media appearances. Through care ethics and extreme context frameworks, I demonstrate how SMOs institutionalized more compassionate end-of-life approaches by strategically shaping hospice discourse.

Data Analysis

This study employed abductive reasoning to develop theoretical ideas parallel with empirical analysis, moving iteratively between data and theory. Abductive reasoning offers a qualitative analysis method alongside deductive and inductive approaches, producing plausible explanations for surprising or ambiguous phenomena particularly useful for identifying themes, codes, and categories (Lipscomb 2012; Vila-Henninger et al. 2024). This approach enables parallel theory development with empirical analysis (Locke et al. 2008). I used abductive reasoning to understand how SMOs shape the end-of-life discourses from care ethics perspective. The extreme context served as interpretive framework, acknowledging context as actively shaping communication and influencing new concept development (see Van Dijk, 2008).

Data analysis proceeded through three steps: temporal bracketing, theory-driven open coding, and discourse analysis of SMO media discourses for organizing and institutionalizing care. I iteratively engaged with data, reading and analyzing while returning to research literature. After defining key concepts based on research questions (care ethics, extreme context, SMO agency, vulnerability), I extracted key elements from the material into research notes (83 pages, 35,700 words in Finnish) documenting timeline and key phenomena. Open coding followed—a fundamental qualitative organizational research technique involving breaking data into discrete parts, examining similarities and differences, and classifying them (Strauss 1987). This process enabled thematic data assembly, categorization, and sorting, providing an organized platform for meaning construction (Williams & Moser 2019).

Figure 1 illustrates the significant conceptual evolution in care terminology. The term "terminal care" (n = 36) appears minimally in the media data, while "hospice care" (n = 2334) dominates the discourse. The waveform pattern reveals discussion spikes typically initiated by SMO participants. "Palliative care" (n = 500) appears less frequently, represented by the lower curve.

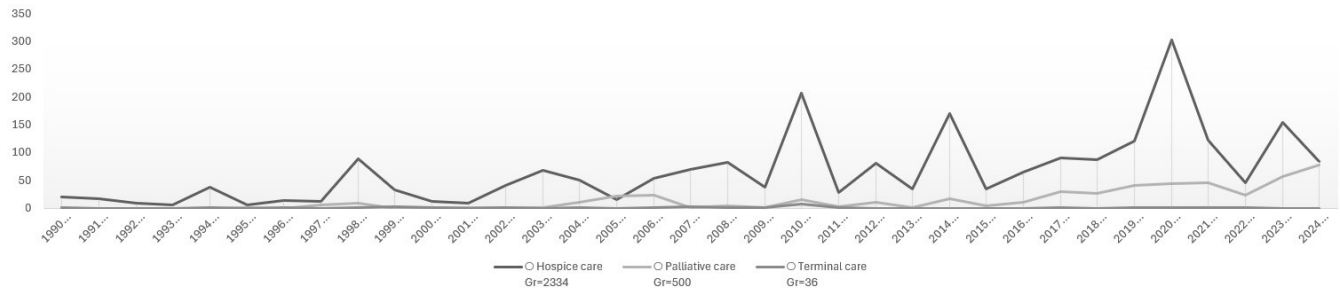


Figure 1. Conceptual shifts care in care discourse over time

The concept of palliative care emerged gradually after the mid-1990s, with its integration into hospice discourse expanding through hospice movement agency up to the 2024s. A guiding question was used to assist in the analysis of the data: *How have discursive practices surrounding end-of-life care and the concept of care changed?* After this, the coded material was analyzed discursively by separating key quotations that reflected theoretical underpinnings and recurring discursive practices. Eight recurring discursive practices were identified and categorized in the data, which then were synthesized into four main discourses: *From Curing to Caring*, *Institutional Care Responsibility*, *Shared Vulnerability Mobilization* and *Regulated Care* (see Tables 1-4).

These media discourses have changed over time simultaneously creating new meanings and practices. Discourses do not merely describe symbolic reality but have actively created new ways of understanding and organizing (death) care. Next, I will examine each period in more detail from the perspective of the main discourses and discursive practices, highlighting how practices change as language changes.

Table 1. Discourse 1.

Period	Discourse: <i>From Caring to Caring</i>	Examples in News Media: <i>Conceptual Transformation</i>	Examples in News Media: <i>Redefining Death</i>
Era 1: <i>Conceptual Definition</i>	Discursive Practices: <i>Conceptual Transformation, Redefining Death</i>	"The model of care for the dying patient focuses on improving the level of inpatient care in the last days of a patient's life, the terminal phase [...]. The starting point for the programme was the common in-hospital death, which [the specialist nurse] considers at worst to be restless and too procedure-oriented [...]. Death should not be hidden. The nurses involved in the working group assure us that death is not a scary troll. It should be talked about much more. [...] The most important thing is to guarantee the possibility of choice and a dignified and safe death, both in an institution and at home." (News article, 13.3.1990) "The word hospice care entered the Finnish language in 1986 to replace the word terminal care, which had been used until then. According to the 1982 guidelines of the Finnish Medical Council, it includes "adequate symptomatic basic care of the patient and all other care respecting human dignity, as well as emotional support of the persons close to him/her." (Specialist, Opinion, 27.11.1998) "In 1982, the Medical Board issued guidelines for hospice (then terminal care). The guidelines define hospice care as care given to a patient at a stage of illness when the available treatment methods can no longer improve the prognosis of the patient's illness, as well as care when death is imminent. Accompanying care includes basic care for the patient in accordance with adequate symptoms and all other care that respects the patient's dignity, as well as support for those close to him or her." (Vice-judge, Opinion, 4.1.1999)	"Keeping a dying person in a hospital whose job is to heal is absurd. It is bullying a person who is dying. A dying person needs an empathetic listener, a hand holder and pain medication. Cold machines and fancy measuring equipment do not provide the human touch. Hospital staff have their hands full even with the convalescent; they do not have the time to comfort and listen to the dying around the clock [...]. When there is no cure, the focus must be on dying. A person must be allowed to face the approaching end with dignity. If this is to be done in hospitals, specialist nurses should be trained as a matter of urgency." (A family member, Opinion, 20.4.1991) "The lack of care for the dying may reflect the perception that it is the doctor's job to prevent death. The terminally ill is like proof of failure. It is difficult for doctors to give up and move on to symptom-relieving treatment when they are focused on saving the patient's life. Even relatives sometimes resist." (News article, 16.3.1998) "In the columns of [Helsinki's News] there have been reports of dead bodies being packed in garbage bags and also thrown away like garbage. Due to lack of space, time and staff, some hospitals have to store the dead in inappropriate facilities. [...] Hospice care is fundamentally different from acute care. The patient and their family must feel safe and able to cope with the situation as death approaches. They must also be convinced that they will be treated with respect, appreciation and gentleness both before and after death." (Hospice doctor, Opinion, 14.6.1997).

Table 2. Discourse 2.

Period	Discourse: <i>Institutional Care Responsibility</i>	Examples in News Media: <i>High Quality Health Care vs. Low Quality Death</i>	Examples in News Media: <i>Caring for in an Unequal System</i>
Era 2: <i>Criticism and Awakening</i>	Discursive Practices: <i>High Quality Health Care vs. Low Quality Death, Caring for in an Unequal System</i>	"The treatment of pain and other symptoms of the critically ill before death and the treatment of the deceased after death continue to pose problems for hospital institutions. [...] While the general idea of hospice care was being propagated, it was still accepted that if the patient had a pain pump, adequate hydration and a single room, things were fine. [...] Dame Cicely Saunders, the foremother of the modern hospice movement, has expressed the purpose of caring for the dying patient: "Our task is to manage the illness and the resulting problems of patients and families to the point where people can cope with their lives as they wish and control their lives as much as possible." (Hospice doctor, Opinion, 14.6.1997) "Studies show that the care of dying patients is worse organised in Finland than in other Nordic countries or elsewhere in Europe. For example, the treatment of cancer pain in Finland is, according to WHO criteria, the worst of all EU countries. [...] Finland has a very well organized primary health care system by international standards. All municipalities have a health centre and home health care, which guarantee basic health care for all Finnish citizens by law. A good death should be a basic right for every citizen, regardless of where their home is. [...] The current health centre system is able to provide good hospice care at low cost. But not for free, and not without know-how, training and interest." (Physician, Opinion, 19.1.1998) "Care of the dying is a global problem and [it] is not at the same level as care for serious illness, for example. [...] There is a lack of discussion between the patient, relatives and health professionals on the difficult issues of the end of life, and the patient's pre-expressed wishes are not known or are difficult to interpret. [...] The concept of care in hospice care would be extended by the Advisory Board to a much broader scope than usual. "Presence, emotional and spiritual support and respect for the patient's life, beliefs, culture and customs are part of good care. Involving the next of kin in the care in a way accepted and desired by the patient is important," the [Eitene] advisory board says. [...] There is a complete lack of guidelines for the care of dying patients in Finland. As recently as the 1980s, such guidelines existed under the name of the Medical Board's terminal care guidelines. Now, hospitals, health districts and nursing homes have very different practices." (News article, 12.2.2004)	"The hospice care of dying patients is very unequally organised in different parts of the country. [The director of a hospice home] says hospice care is inadequate. "Of course not everyone who dies needs to be treated in hospices, but everyone must be guaranteed as painless and dignified a death as possible. Patients must have the right to refuse treatment, but also the right to receive all the care that has been developed to ease their suffering." [he] says. So far, no medical faculty in Finland has organised any courses in hospice care." (News article, 9.1.1998) "During my time at Hospice Home, I realised how necessary the work [hospice care] is. We got support ourselves. I (the relative of the dying person) was also taken care of: forced to rest and eat. When you can rely on someone to be by your bedside, you can get away for a while. [...] When the call [from the hospital] sometimes comes, she says she is now ready to go [as a volunteer] hospice nurse. That call is not frightening." (News article, 31.1.2002) "[In a hospice] a world of goodness is opened, and people can truly be who they are." [...] The patient is acknowledged every moment in the nursing home. Their word is law, and all their wishes are fulfilled, if only within the bounds of possibility. That is why there is a cat there, because its owner was promised that it would be looked after. [...] The researcher believes that life is worth celebrating near death. "That's why every day is a celebration." The purpose of hospice care is to talk openly about everything, including death. The idea is to support and strengthen the patient and those close to them. [...] "Caring for the dying requires the courage to be truly human. It is a vocation that requires imagination and ingenuity," says the researcher." (News article, 21.3.2002)

Table 3. Discourse 3.

Period	Discourse: <i>Shared Vulnerability Mobilization as an Extreme Context, Care-Ethical Agencies</i>	Examples in News Media: <i>Death as an Extreme Context</i>	Examples in News Media: <i>Care-Ethical Agencies</i>
Era 3: <i>Radicalization and Advocacy</i>		"You get used to anything, but not the death of a loved one. People refuse to think about their own death and their own dying. They fear suffering, anger, disappointment, loneliness, pain, sadness, abandonment. Fear is one of the strongest basic emotions, just like joy. The death of loved ones is what people mourn most: the possibility of death is a source of profound despair, nothing could compensate for the loss. Seeing someone close to you die is perhaps the worst thing that can happen to you; you can't help, the pain of another is terrible to see, the anguish is deep. [...] The sick and the healthy alike should find within themselves the strength to find spiritual balance, acceptance and recovery, for all of us, life is about dying, which we celebrate with death, the opposite of birth." (News article, 2.4.2007). "Once the disease is no longer treated, the patient no longer needs specialist care. They are transferred to general health care. [...] Practices are highly variable and patients are very unequal. [...] As the population ages, illnesses are increasing and the cost of care is only going to rise. Is it not time to develop well-functioning centres of excellence in palliative medicine? In Finland, there are some palliative outpatient clinics [in two university hospitals]. The palliative outpatient clinic has never really been developed properly because there is no budget for it. [...] We will all die one day. It is sad and feels wrong when a young person, a child, an adolescent or a young mother or father dies before the children reach adulthood. You can never get used to that." (Psychotherapist, Opinion, 5.3.2010)	"A significant proportion of complaints to the Health Insurance and Social Security Agency and to the provincial governments concern the behaviour of health professionals towards patients. Interpersonal skills can have an impact on the preferred place of care. Both interpersonal skills and empathy can be developed through training; every professional has room for improvement. [Dying patients] are among the modest users of health services who take the praise and criticism with them. Their relatives are often so exhausted by watching their loved ones suffer that they are unable to provide constructive feedback on their care. [...] there is a need for urgent change so that the level of care for dying patients is no longer dependent on where they live or where they are treated." (Cancer specialist, guest author, 14.10.2006). "A care environment where staffing levels are reduced to a minimum, where every expense has to be cut and saved, and where employees are suspicious of who is on the drop list in which unit, is an environment of employee burnout. Indifference and cynicism take over. [...] Empathy and the ability to cooperate, sensitivity to hear and see the distress of fellow human beings are also vulnerable qualities. Thus, nursing workplace management should be of a special quality, valuing work and employees, "caring" for the nursing staff. I know from personal experience that such a "caring care community" is possible. My loved one spent the last week of her life in a regular ward in a regular health centre, which at the same time felt like they were listening to me, the relative. A royal could not get better treatment! [...] The management of the ward felt like "shared" leadership, so that everyone could lead their own work, be independent and creative in their work without envying anyone. It seemed that employees valued their own work and themselves. They were appreciated by patients, relatives and other people close to them." (Family member, Opinion, 26.7.2009)
		"In Finland, resources for hospice care are scarce. In the EU, we are competing in the same league with Bulgaria and Albania. 95% of patients in hospice care die peacefully in their sleep if good hospice care is provided. In Finland, less than half of those who die receive good hospice care. The provision of good care in Finland is a matter of chance and depends on the availability of people interested in hospice care in the locality. Finland has a law on fire and rescue services. When a house catches fire, no one has to go out into the street and shout if there is someone here who is interested in putting out the fire. In hospice care you have to do that." (Specialist doctor, President of the Finnish Association of Palliative Medicine, Opinion 21.3.2012)	"In developing care for the dying, we should see the possibility offered by different forms of care as a safe route to "helplessness". Once curative care has ended, we move on to symptomatic care, which continues into hospice care and ultimately death. [...] Caution also makes it difficult to start a conversation about impending death and the treatment options available. Although the idea is to protect the person being helped, the result is repressed fear, uncertainty and despair. Shared conversations are reduced to information-sharing sessions. Reaction to death is postponed to the terminal phase, when death is inevitably imminent. [...] Death, which we all fear, is not taken seriously enough, or is taken too seriously. In any case, it is left out of our actions, sidelined." (Nurse and trainer in hospice care, Opinion, 31.5.2010)
		"A brutal collection poster is confusing [...]. The boy was so skinny it was a bit scary. We wondered if it would tempt people to donate money to the fundraiser. The picture could have had more of a hopeful aspect," says [the church's international work secretary]. On the other hand, a person in hospice care can be very withered, and hospice workers say that's what hospice care is like." [...] [The secretary thought] that the images initially seemed harsh and too depressing. [...] A representative of [the hospice] spoke at the event [...] the way of interpreting the images changed. "I started to see them in a new way and I realised that in many people's lives this is reality. It's about support and grieving. I found in myself the courage to look at the sadness and pain that is in the pictures." [The images] also been praised for their courage and their message. The point has been to attract attention and debate." (News article, 28.11.2013)	"[The President of the Republic] believes that there is room for improvement in hospice care -- in particular, there is room for improvement in the availability of care to alleviate the symptoms and pain of dying patients across the country. "We carry with us all the time the memories of our loved ones who have passed away. These memories are especially comforting when a loved one has died at peace, without unnecessary suffering, and prepared for it. That is how many people would surely wish their own journey to end." [the President] said on Sunday." (News article, 2.2.2014)
		"[The collection posters] that have appeared on the street have been too much for some churches. Some have refused to put them up on their walls. [...] We wanted to talk about death as death and bring the reality of death into the open," says [the fundraiser's director]. [The posters] show loved ones holding a dying person with grey make-up on their laps or gathered around a bed. The images are splashed across outdoor advertisements [telling] people to donate to a good death. "At first it was a shock, but it's part of life," comments a lady who wishes to remain anonymous. "I've been in that situation twice." [...] The feedback has been exceptionally strong. In addition to the criticism, there have been comments from people who have experienced hospice care saying that the image was close to their reality. "Whether the pictures are ugly or beautiful is secondary," [the collection manager] points out. "People need hospice care. One child of a hospice patient described the situation by saying that he had taken part in a big Finnish hospice lottery." (News article, 4.2.2014)	"Hospice care got people interested in fundraising. The Common Responsibility fundraiser has attracted a lot of interest this year. According to [the director of the collection], the collection has been more successful than expected, although the proceeds are not yet known. "People feel that hospice care is an important topic that has been hidden from the public [...]. What has attracted attention is the collection's "Donate a Good Death" posters, which show relatives visiting the dying, painted grey. According to [the collection manager], the collection has at least succeeded in making an impact, as hospice care is now being discussed in earnest. "More new collectors have signed up than usual. Often they have had a loved one die, and they have experiences of good or bad hospice care." (News article, 10.4.2014)

Table 4. Discourse 4.

Period	Discourse: <i>Regulated Care</i> Discursive Practices: <i>Responsibilities and Rights, Increased Supervision and Regulation</i>	Examples in News Media: <i>Responsibility of the Rights</i>	Examples in News Media: <i>Increased Supervision and Regulation</i>
Era 4: Systemization and Institutionalization		"Patients' autonomy is poorly exercised in the most crucial of situations, when death is imminent. It is therefore essential to clarify patient law so that all terminally ill and intolerably suffering patients can, if they so wish, be spared further pain and face their inevitable death with dignity. They must be guaranteed adequate, pain-relieving medication for the last moments of their lives." (Vice-judge, Opinion, 3.9.2016)	"In a survey of several hundred [...] responding to the Good Death project, 68% said they would prefer to die at home. In the light of the figures, few people's wishes are fulfilled: the majority of people aged 70 and over died in a health centre in 2011, the same number as in 2004. They had been taken from their homes to a health centre for treatment and died there. This should change as the hospice project moves forward. Part of the proceeds from last year's Common Responsibility Fundraiser went to the development of hospice care. The project, called Good Death, has held 10 regional training seminars on hospice care since the autumn [...]. The seminar was told that hospice care plans are well advanced across the country. 'When I started hospice care in the 1990s, I could never have imagined that there would be such a network,' said [the chief physician] who is leading the project. There is strong progress across the country [...]. The hospice plans are well advanced [...] they include the establishment of a palliative outpatient clinic and hospice department in each of the five hospital districts in the district. In addition, each municipality will have inpatient hospice beds and a home hospital." (News article, 13.5.2016)
		"The expertise and accessibility of hospice care have been significantly strengthened, thanks to the Donate a Good Death project funded by Common Responsibility, among other things. I have wanted to make things easier for doctors and relatives by drawing up a Living Will for myself. Making decisions is demanding in a situation where there are many alternative treatment options, each with its own justification. I do not want my relatives to have to have a discussion with a doctor about whether or not I should be resuscitated, for example. I want both the medical staff and my loved ones to know my will, even if I am no longer able to express it myself. In addition to the living will, I have drawn up a kind of quality-of-life testament in which I have written down my wishes for my care in situations where, for example, I am unable to say what I like and what I don't like because of my memory problems. I want to make it easier for carers to provide patient-centred care for me. [...]" (Director of collection, Opinion, 13.9.2016)	Two years ago, the British magazine The Economist conducted a study measuring the ability of 80 countries around the world to provide palliative care. Finland ranked 28th. [...] One reason for the poor ranking may be that palliative care is a new concept in Finland. [...] In December, the Ministry of Social Affairs and Health published a recommendation proposing a [three-tier] model for the whole of Finland. [...] The starting point for care is that professionals are able to recognize when death is approaching. [the chief physician at a palliative care center] says. The entire care team, i.e., the doctor and nurses, then work with the patient to draw up a plan for how the end of life will be managed. [...] Why is this not done? One reason is that doctors are not trained to do so. They simply do not know how. Palliative medicine is part of the basic training of doctors at only two universities." (News Article, 21.1.2018)
		"The Finnish Medical Association, together with other healthcare professional organizations, has appealed to government negotiators to include the provision of palliative care for all in the government program. According to the Finnish Medical Association's calculations, this would cost around €3.5 million. More than 50 000 people die in Finland every year, of whom around 30,000 need palliative care, i.e. treatment to alleviate symptoms, as they approach death. Only some of them receive adequate palliative care." (Editorial, 20.5.2019)	"According to The Union of Health and Social Care Professionals, private nursing homes are cutting back on staff by not hiring replacements, shortening shifts, and skipping overtime pay. Problems related to staff shortages are clearly more widespread and serious in private nursing homes than in facilities run by municipalities and cities, estimates [senior lawyer]. The National Supervisory Authority for Welfare and Health has ordered [the nursing home] to suspend its operations [...]. Responsibility for care has been transferred to the city. 'The problems at [the nursing home] have been the most serious. Similar problems also exist with other large corporate care chains,' says [lawyer]. According to [her], the underlying cause is unhealthy competition. When municipalities seek to save money by outsourcing services to care companies and companies in turn seek to make a profit, the cycle of understaffing and inadequate care is complete." (News article, 26.1.2019)
		"The coronavirus crisis does not change the requirements for end-of-life care. Patients dying from coronavirus are also human beings who, as death approaches, need humane treatment, professional care, adequate medication, and the presence of their loved ones. [...] Finland has recommendations for palliative and end-of-life care, but we lack legislation that makes end-of-life care mandatory. Legislation would ensure equal access to end-of-life care throughout Finland. At the end of life, people should receive high-quality and humane end-of-life care regardless of where they are being treated or what illness they have." (Doctor of Medicine, Member of Parliament, Opinion, 16.5.2020)	"There has been a debate about palliative care in the opinion section throughout the year. It is often thought that receiving good palliative care is a matter of luck. Many articles have expressed concern about inadequate pain management, especially in cancer patients. However, pain is often the easiest symptom to treat at the end of life. [...] It is important to make a care plan in good time. Many healthy middle-aged people have their care wishes recorded in their medical records and, nowadays, quite often their funeral wishes too. [...] This can help ease the challenging paperwork after death. Good end-of-life care can include home care and dying at home. Home care is often what the patient wants and is pretty easy to arrange." (Specialist, Opinion, 14.9.2024)

Findings

In this section, I address how SMOs shape the discourse of palliative care in this extreme context from the perspective of the ethics of care. In longitudinal research, timelines enable researchers to observe how discourses evolve, connect these changes to broader social and cultural shifts, and identify important turning points in understanding social phenomena. This approach also facilitates a deeper understanding of the challenges encountered in this extreme contexts and the strategies implemented to address them.

The analysis revealed four phases as key eras: 1. Conceptual Definition (1982-2000), 2. Criticism and Awakening (1997-2004), 3. Radicalization and Advocacy (2005-2014), and 4. Systematization and Institutionalization (2015-2024). These periods are not entirely distinct in all cases but rather overlap and intertwine. Each period was identified as having its own main discourse: 1. From Curing to Caring, 2. Institutional Care Responsibility, 3. Shared Vulnerability Mobilization, and 4. Regulated Care. Following sections examine each phase and discourse within respective eras, highlighting key events in hospice care discourse and institutional development.

Phase 1: The era of conceptual definition (1982-2000)

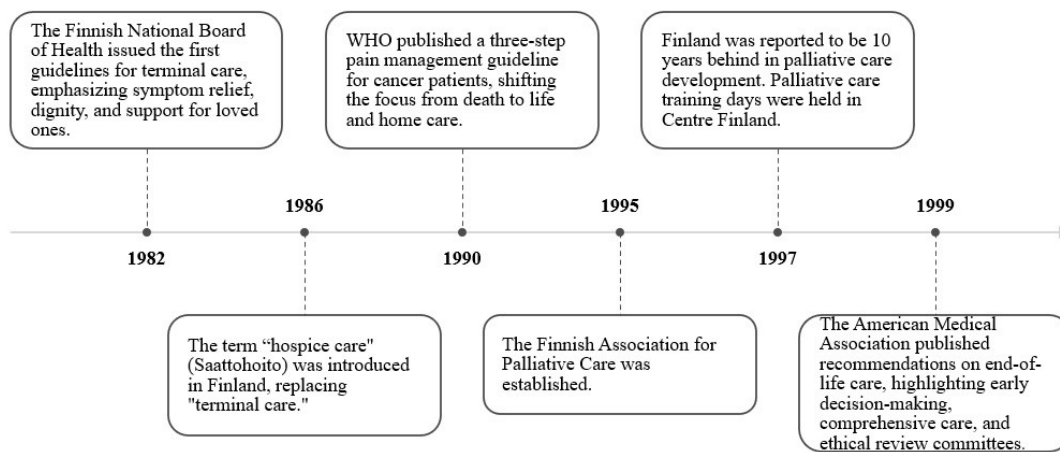


Figure 2. Phase 1: Timeline of the main events 1982-2000

The early phase of the timeline highlights the conceptual clarification and shift in terminology, a transition from "terminal care" to "hospice care" in the late 1980s. In the late 1990s, "palliative care" emerges as a distinct concept, reflecting the development and expansion of the field. In the conceptual definition era, a critical development was the establishment of guidelines for dying patient care by various national and international institutions (Figure 2). The timeline demonstrates the first attempts in institutionalization of end-of-life care, and the emerging approach oriented toward dying patients—a concept still unfamiliar in 1980s healthcare. The term "hospice care" was deliberately chosen over "terminal patient care" to emphasize accompanying the dying toward death.

The first discourse "From Curing to Caring" emerged through conceptual transformation, fundamentally redefining end-of-life care from medical failure to dignified care practice. In the media discourse, key SMO participants defined end-of-life care in a new way: death was no longer seen as a professional defeat, but also as part of end-of-life care in the form of hospice care and, ultimately, palliative care.

Medical professionals' roles underwent significant discursive reconstruction through this transformation. The doctor's role was previously described in the media as preventing death, with the terminally ill being proof of their failure. In this context, symptomatic treatment was described as giving up when curative treatments were discontinued. Critical discussion appeared in the media, as this attitude towards care was described as linked to inadequate symptomatic treatment. Previously portrayed as death's opponents, doctors were repositioned as caregivers who could provide empathetic listening, physical closeness, and effective pain management. These care practices reflect well the philosophy of hospice care (see Graven & Timm 2021).

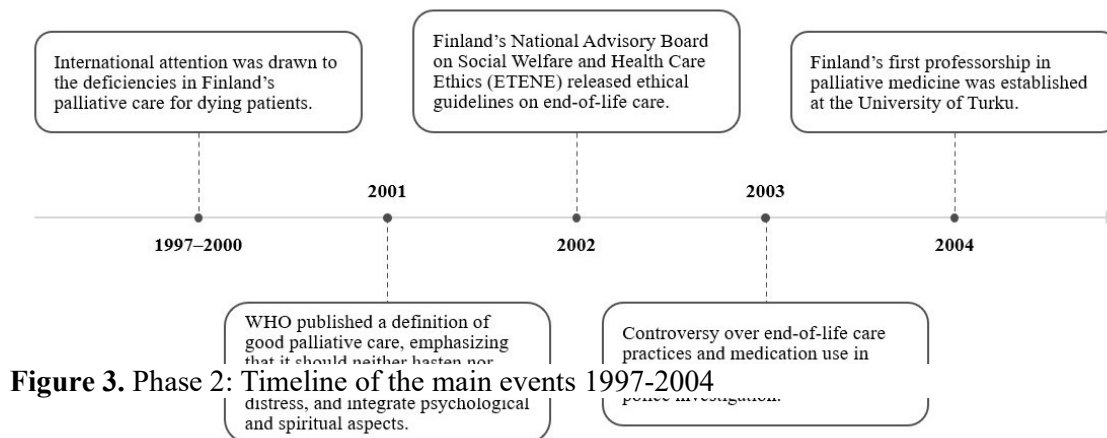
Ten years ago, the medical government issued guidelines for the care of the dying, [...] the idea has remained mainly an ethical goal that has not changed much in practice. I would not put the blame for the current situation solely on doctors. It's a cultural issue: how we relate to death as professionals, as relatives, as ourselves, all of whom face death at some point. (News article, 25.1.1993)

The discourse extended care temporally beyond the moment of death itself. As evidenced by the "Hospice Doctor's" (Table 1) statement addressing inappropriate handling of deceased bodies, SMOs advocated for respectful treatment of both dying persons and their families before, during, and after death. This temporal expansion reflected hospice care philosophy while establishing new institutional obligations for dignified death practices, positioning care as encompassing the entire dying process rather than ending when curative treatment ceased.

This discourse demonstrates early SMO agency through definitional work - the reconstruction of central concepts to create new possibilities and realities. By transforming death from medical failure to care opportunity, SMOs established the conceptual foundation for alternative end-of-life practices that would later become institutionalized, showing how caring agency begins with reimagining core assumptions about professional purpose and institutional responsibility.

Phase 2: The era of Criticism and Awakening (1997-2004)

In the late 1990s and early 2000s, public discourse on hospice care expanded as criticism of inequalities and shortcomings intensified. Family members began suspecting in the media that financial considerations were driving care decisions, while experts highlighted resource deficiencies and insufficient training. Figure 3 shows a timeline of the WHO's publication of a definition of good palliative care shortly after Finland began to wake up to the poor quality of care for the dying. SMO participants emphasized Finland's lack of proper national guidelines



for dying patient care. In 1998, Finland established a national healthcare ethics advisory board (ETENE), which published end-of-life care's ethical guidelines in the early 2000s. Healthcare providers were criticized for avoiding death confrontation and blamed for abandoning patients after curative treatments ceased. End-of-life care in Finland appeared to lack a cohesive philosophical foundation at the national level as well. Quality end-of-life care was described as accessible only to severely and terminally ill patients in few select hospices—facilities that were scarce nationwide and to which municipalities resisted referrals due to high costs. SMOs then engaged with media to highlight these deficiencies, involving key organizations in care quality improvement and good death facilitation. Through various non-profit associations', NGOs' and grassroot organizations' involvement, Finland received its first palliative medicine professorship, funded through donations from several for a five-year period.

The second discourse, "Institutional Care Responsibility," relates to awareness of the level of healthcare provided to dying and criticism of the system at the time. From a care ethics perspective, this discourse on care related to institutional power and responsibility. The statements of key SMO actors emphasized the poor organization of end-of-life care compared to other areas of healthcare highlighting systemic neglect. SMO leader ("Hospice doctor," Table 2) highlighted the stance of the modern hospice movement's founder on care; Dame Cicely Saunders emphasized symptom-based treatment and caring as fundamental but undervalued practices.

This discourse mobilized legal and ethical frameworks to challenge institutional inadequacy. SMOs invoked existing healthcare guarantees, arguing that good death should constitute a fundamental right for all citizens regardless of location or circumstances. One SMO participant described the system as capable of providing quality care at a reasonable cost, but would require interest, framing system failures as choices rather than inevitable constraints (Table 2).

The discourse on power and institutional responsibility in the care of the dying also emphasized everyone's right to choose their care, but also the right to receive all care available to alleviate suffering. The discourse thus emphasizes a key element of the ethics of care: care receiving (see Moriggi et al. 2020), to which, according to these SMOs vulnerable people should be entitled. SMOs highlighted systemic unfairness through contrasts between rare hospice environments described as "worlds of goodness" and widespread inadequate care elsewhere. These hospices were portrayed as celebrations of life's final period, emphasizing human ingenuity and interaction skills as essential care components often missing from institutional settings.

Health care cuts and attitudes to the culture of dying have also been a public concern for relatives of dying and deceased patients. [...] The aim is to let the dying patient live until they die. Part of caring for the relatives is that the deceased is also treated appropriately (Hospice doctor, Opinion, 14.6.1997).

The discourse also highlighted care's mobilizing potential through stories of relatives who became volunteers after hospice experiences, demonstrating how encounters with dignified death could transform grief into caring action. This transformation reflected care ethics' emphasis on continuity and community-building, showing how proper institutional care could generate caring networks extending beyond conventional general care. Through this critical discourse, SMOs established institutional responsibility for care quality while bringing up how caring environments could mobilize broader community engagement, positioning themselves as advocates for systemic transformation.

Phase 3: The era of radicalization and advocacy (2005-2014)

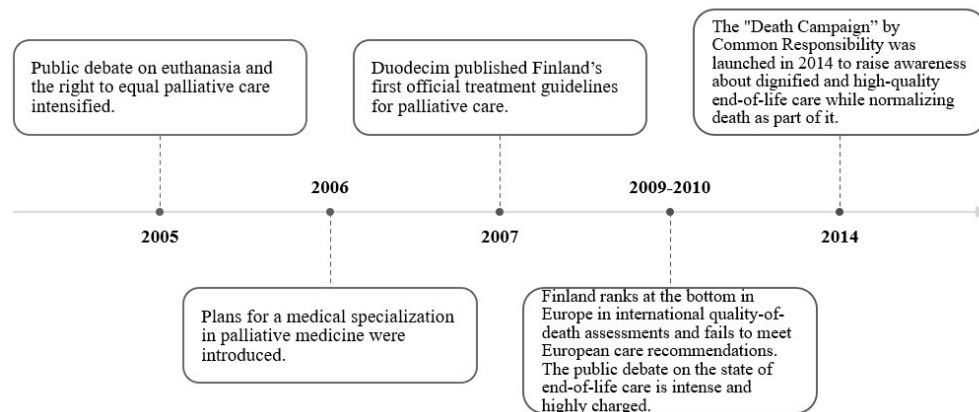


Figure 4. Phase 3: Timeline of the main events 2005-2014

From the mid-2000s onward, various SMO participants championed hospice care development while the 2014 Common Responsibility Campaign's "Donate a Good Death" initiative exemplified this movement. Figure 4 highlights a significant public debate surrounding euthanasia and the right to adequate, quality palliative care. SMOs emphasized that quality palliative care must be established as a nationally effective service accessible to all approaching death. The palliative care professorship gradually catalyzed broader and initial educational system reforms, addressing the previous near impossibility of studying palliative medicine due to lack of professors. The Finnish Medical Association (Duodecim), in collaboration with SMO participants, published the first official palliative treatment guidelines. After, Finland ranked at the bottom in Europe in international quality-of-death assessments and failed to meet European care recommendations. The public debate on the state of end-of-life care was intense and highly charged. Despite the recommendations, no progress seemed to be made, as responsibility for the provision of palliative and end-of-life care was identified as unclear. The necessary resources were not being allocated to the development of health care even though the debate has created a boiling point.

On the organization of hospice care in Finland, [...] the problem is not a lack of information but poor organization of care. What is known about hospice care is how it should be organized. It is just not organized. (Hospice doctor, Opinion, 17.2.2008).

The third discourse "Shared Vulnerability Mobilization," represented the shared vulnerability in death as a catalyst behind caring with. Recurring discursive practices were death as an extreme context and care-ethical agency. Through these practices, it was possible to access media discourses that showed death to be an extremely emotional experience that positions both the dying and their loved ones in a particularly vulnerable state. SMO participants described it as "the worst thing that can happen", yet "something that connects us all" (News Article, Table 3). Through this framing, SMOs developed care-ethical agency that mobilized shared human experience as the foundation for social change.

Nevertheless, SMO participants described how it is impossible to ever come to terms with the idea of death and called for the development of specialized healthcare at the national level to standardize the diverse and varying quality of care ("Psychotherapist", Table 3). The media discourse pointed out that less than half of people receive adequate end-of-life care, because it is not enshrined in law. This discourse aimed to influence politics, in which

case it can be seen as SMO agency (see Kriesi 1996) and caring with (see Moriggi et al. 2020) as drivers of social change.

It is said that all people are equal in the face of death; everyone dies one day. But the terminally ill are very unequal in the last months and weeks of their lives. A patient's treatment depends on the municipality in which he or she happens to live. [...] The organization of hospice care is largely a question of attitude. Information and training in the skills needed for hospice care are available and it is not even prohibitively expensive to provide it [...] The right to die with dignity is a fundamental human right [...] (Editorial, 15.8.2010)

SMO activism became increasingly radical during this period, exemplified by campaign posters that visualized end-of-life care with unprecedented realism. The initially shocking imagery provoked opposition until SMO experts reframed the interpretation from "depressing and too harsh" to empathetically evoking identification with grief and support for loved ones (Table 3). This discursive transformation proved powerful, as the campaign mobilized more new SMO participants than previous efforts, most drawn through personal experiences with death's extreme context. The success demonstrated how shared vulnerability could be mobilized as collective strength rather than individual burden.

Solidarity is not only about fundraising, but also about addressing social challenges. This was one of the reasons for choosing hospice care as the focus of the campaign. The campaign has touched Finns deeply and raised hopes that the development of Finnish hospice care would be supported [more broadly]. (Director of collection, Opinion, 28.3.2014)

Care-ethical agencies were also evident in the changing discourse on care in terms of the importance of interaction skills and empathy from the perspective of practical care work (*caring for*). Caregivers were therefore expected to adopt a more caring ethical approach to care work, which was described as lacking at the time. They advocated for caring work communities with shared leadership that could increase listening and appreciation, positioning interpersonal skills as essential for helping dying people and relatives navigate extreme situations. This approach demanded that caregivers adopt care-ethical approaches while acknowledging the systemic conditions that undermined such caring practices. ("Nurse and trainer in hospice care, Table 3").

The discourse's political impact became evident when even the president participated in media discussions, calling for improved symptomatic care while highlighting how comforting memories could provide lasting solace. This presidential engagement demonstrated how SMOs had successfully transformed private grief into public political concern, using shared vulnerability in achieving greater visibility for end-of-life care as a collective rather than individual responsibility. (News article, Table 3)

Phase 4: The era of systematization and institutionalization (2015-2024)

The 2010s and 2020s have witnessed numerous initiatives and recommendations for the legal safeguarding of hospice care and its integration into the healthcare system.

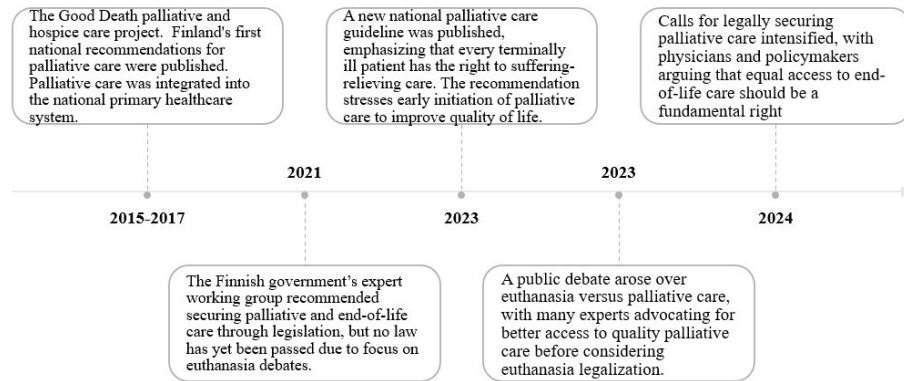


Figure 5. Phase 4: Timeline of main events 2015-2024

In 2015, the Common Responsibility fundraiser launched the three-year "Good Death" project through its campaign (Figure 5). The primary objective of this initiative was to enhance professional competence in end-of-life care by expanding palliative care education for caregivers and nursing professionals, including the introduction of a hospice care certification program (hospice pass). Multiple investigations conducted within the project revealed significant disparities in palliative care accessibility at the national level. The research also identified critical deficiencies in and requirements for standardized guidelines regarding palliative care and pain management protocols, subsequently establishing these as priority areas for development. The Ministry of Social Affairs and Health established an expert working group that included members from the Good Death project (incorporating SMO participants) to develop a comprehensive final report in 2017. This document outlined necessary developmental measures for hospital districts and categorized palliative care into three distinct levels, aiming to facilitate earlier intervention. These initiatives have been described as a transformative advancement in end-of-life care practices.

As the death awareness movement entered the 2020s, the advocacy landscape became more complex and politically charged. Hospice SMOs intensified their efforts to secure legislative codification of hospice care, but these efforts became entangled with contentious debates surrounding assisted dying within palliative care frameworks. The discussion culminated in a citizens' initiative submitted to Parliament, though not necessarily with the outcomes the hospice movement had hoped for. Consequently, SMOs continue their advocacy efforts to secure international recognition of palliative care as a fundamental human right.

New palliative care guidelines were recently published in Finland with the aim of eliminating the current regional disparities in the availability of end-of-life care and palliative care. [...] binding legislation is needed, including sanctions if the desired level of care is not achieved. Recommendations alone are unlikely to be sufficient. In Finland, the law should guarantee equal and high-quality end-of-life care for all those who suffer. (Exitus, Medical expert, Opinion, December 28, 2019)

The fourth discourse, "Regulated Care," marked a fundamental shift toward development-oriented care discourse and systematic accessibility improvements in palliative care provision. Two recurring discursive practices were identified that relate to the responsibilities associated with caring for the rights of the dying and re-institutionalizing care through increased regulation, legislative measures, and enhanced supervision. The discourse transformed care ethics from advocacy position to institutionalized practice through concrete arrangements and systematic development initiatives.

SMO participants demonstrated this institutionalization through practical actions such as publishing living wills in media as exemplary templates, emphasizing dying persons' responsibility to communicate care preferences while capable. This approach facilitated patient-centered care organization within healthcare facilities by ensuring dying persons' wishes remained accessible to caregivers. The success of campaigns like "Donate a Good Death" became catalysts for broader end-of-life care reform, with the Finnish Medical Association subsequently appealing to government for palliative care program inclusion. ("Director of collection"; News Article, Table 4.)

An activist and retired [palliative care physician] took a stance [...]: "Palliative care has been my life's work. I have been advocating for it for almost 30 years, and now this situation shows that its importance is still not understood." [...] in a hospital, where people wanted to keep dying patients away in the 1980s, when hospice care was introduced in Finland. It was thought that hospitals were no longer needed once radiation therapy had ended and MRI scans were no longer useful. What was needed was time and peace, a home-like environment. Now, [...] the circle has come full. Hospices are struggling, and the role of hospitals is growing. (News article, 27.9.2020)

The discourse gained momentum during the pandemic as SMOs emphasized that COVID-19 victims also deserved humane treatment, reinforcing calls for legally enshrined end-of-life care. These appeals reflected broader demands for fair, accessible care while positioning institutional responsibility as fundamental to meeting citizens' needs. Media discourse highlighted concrete research-based developments that SMOs had promoted, including Finland's adoption of Norway's three-tier healthcare model to address poor international rankings in palliative care provision. SMO participants focused on developing skills related to recognizing death so that care can be tailored to the extreme context.

Regulatory transformation became evident through enhanced monitoring of care institutions, with supervisory authorities imposing sanctions including operational suspensions for inappropriate conduct. This regulatory intervention represented care-ethical practice through institutional power, while new dying and caring practices became systematically organized including home dying generalization, volunteer work development, and legally strengthened relative rights. (Table 4.)

This discourse demonstrates how SMOs successfully transformed care ethics from alternative philosophy to institutionalized practice, achieving systematic reform through regulatory mechanisms while maintaining focus on dignified, accessible end-of-life care for all.

Discussion and Conclusions

In this section, I respond to the research question and present some general conclusions and reflections, with regards to our contribution to the study of SMOs and ethics of care. Please note that these results are preliminary, as the article will be further developed before and after the conference. Due to the limited number of words available, there is little scope for discussing the results, which is why it has been kept brief.

This qualitative, longitudinal study employed a discursive approach paired with abductive reasoning to examine: *How SMOs shape the discourse of care in the context of palliative care over time?* Through media discourse analysis, I explored SMO participants' active role in producing and shaping care discourse. Temporal bracketing identified four key eras: Conceptual Definition (1982-2000), Criticism and Awakening (1997-2004), Radicalization and Advocacy (2005-2014), and Systematization and Institutionalization (2015-2024). Discourse analysis distinguished four main care ethical discourses: From Curing to Caring, Institutional Care Responsibility, Shared Vulnerability Mobilization, and Regulated Care, revealing how care discourse evolved and created new meanings.

In Discourse 1, conceptual transformation and the redefinition of death reflected a paradigmatic shift in the discourse of palliative care from cure to care (see Thornton & Phillips 2009; Graven et al. 2013; Graven & Timm 2021). The paradigm shift from death as a failure to death as part of care may also be linked to the redefinition of professional identity, as doctors transitioned from healers to carers. In addition, a temporal dimension was recognized extending care before and after death, while adopting holistic approaches encompassing patients and relatives (see Graven & Timm 2021). Discourse 1 actively constructed new care understanding and organizing practices rather than merely describing reality.

Discourse 2 constructed care as a social responsibility, recognizing personal care relationships while emphasizing systemic responsibility (Santos 2020). Care was positioned as the responsibility of intimate networks requiring institutional support, manifesting across levels from individual to collective care. This discourse revealed care's reciprocity, aligning with care ethics' understanding that care creates communities and continuity rather than operating unidirectionally. The discourse demanded concrete, contextual care for all, combining justice and care—elements identified as crucial for care process commitment (see Moriggi et al. 2020). Discourse 2 sought transformation at individual and systemic levels by reframing death and care as social issues.

Discourse 3 focused on collective agency and mobilization, positioning care ethics and shared vulnerability as meaningful for political influence and social change (Pettersen 2011). Vulnerability was reframed as empowering force rather than weakness (Jakimow 2022; Takala 2025). The discourse revealed visual rhetoric's power through campaign imagery in death's extreme context (see Hällgren et al. 2017), concretely transforming discourse. Discursive change progressed from resistance to empathy, mobilizing more SMO participants (Santos 2020). Caring agencies emerged across levels, individual to political, while highlighting temporal dimensions where memories shape future care. Discourse 3 demonstrates how multi-stage caring materializes into concrete (political) action (Moriggi et al., 2020).

Discourse 4 highlighted systematic development, shifting from SMO activism to concrete reforms and re-institutionalized practices (see Jepperson 1991; Leitzinger & Waeger 2023). Institutionalization manifested across levels—from individual care preferences to systemic legislation implementing the international care model in healthcare. Care materialized through increased supervision and power exercise as official organizations and supervisory bodies regulated the field more strictly. The discourse emphasized recognizing death and preparing for it, reflecting proactive responsibility (see Pavlish et al., 2013). This final period represents discursive change's most mature stage, where activism yielded to systematic reform. Discourse 4 demonstrates how care ethics functions as both critique and constructive system development force (see Moriggi et al. 2020).

While SMOs achieved many goals and established new regulated care practices, complete success remained elusive. SMOs can sustain activities despite partial goal achievement, though movement discourse may create mobilization obstacles, particularly when positions prove potentially polarizing (Wang et al. 2023). Examining movement context reveals possibilities for more compassionate organizing in extreme contexts, even amid ethical conflicts, demonstrating care ethics' transformative potential for organizational theory and practice.

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