
TANGLED
Understanding family caregivers in a palliative care context via qualitative research, ethics, and comic art
Maaike Haan
RADBOUD UNIVERSITY PRESS
Radboud Dissertation Series

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This publication was funded by the Dutch Organisation for knowledge and innovation in health, healthcare and well-being (ZonMw): 844001310.

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Radboud Dissertation Series
ISSN: 2950-2772 (Online); 2950-2780 (Print)

Published by RADBOUD UNIVERSITY PRESS
Postbus 9100, 6500 HA Nijmegen, The Netherlands
www.radbouduniversitypress.nl

Design: Proefschrift AIO | Annelies Lips
Cover: Proefschrift AIO | Guntra Laivacuma
Cover artwork: 'Naasten' (2019) | Melanie Kranenburg (front), Niek van Ooijen (back)
Chapter pages artwork: 'Naasten' (2019) | p. 13 (ch1), 119 (ch2), 117 (ch3), 175 (ch4), 203 (ch5), 88 (ch 6 & Appendices)
Printing: DPN Rikken/Pumbo

ISBN: 9789465151380
DOI: 10.54195/9789465151380
Free download at: https://doi.org/10.54195/9789465151380

RADBOUD
UNIVERSITY
PRESS

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Understanding family caregivers in a palliative care context
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Proefschrift ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. dr. J.M. Sanders,
volgens besluit van het college voor promoties
in het openbaar te verdedigen op

vrijdag 14 november 2025
om 10.30 uur precies

door

Maaike Magdalena Haan
geboren op 14 november 1988
te Amersfoort

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Dr. G.J. Olthuis

Manuscriptcommissie:
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Paranimfen:
Simone Naber
Anne-Fleur van der Meer

"Death is the mother of beauty"

- Wallace Stevens

"Als je de macht lijkt te verliezen over grote dingen,
focus dan op wat dichtbij is en waar je van houdt"

- Charlie Mackesy (in de vertaling van Arthur Japin)

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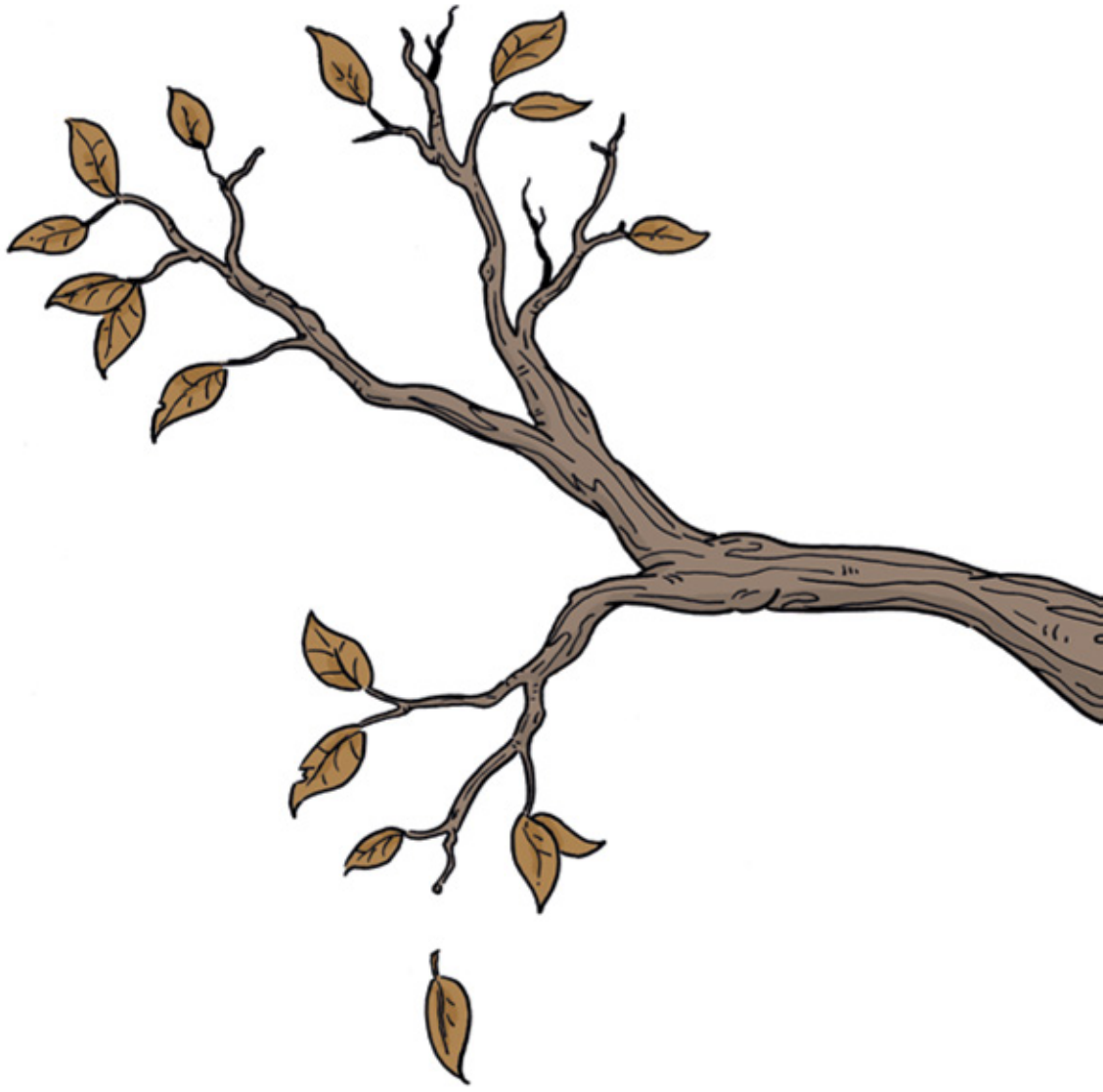

Chapter 1

General introduction

Prelude

"Everyone is preoccupied with the patient, and that makes sense. You also say it to yourself: he's miserable, he's sick, he's having a hard time, so I shouldn't whine, I should be stronger, work harder. You automatically stand completely in his shadow. But, at the same time, you are somehow also the most important person. (...) You understand what the doctors are saying; he doesn't, it all goes past him. You communicate with the hospital, with family, with friends. You're doing the cooking, the housework, take out the trash. In addition to what it all does to you emotionally, of course. Yet all the attention, all the text messages, all the cards are directed at him. When a friend of Reinier's once came to visit and, in addition to a gift for him, had brought a bunch of flowers for me, I cried." [i]

The concept of family care

Most of us will, at some point in our lives, find ourselves providing some sort of care for a loved one or someone else within our inner circles of friends and family – just like the partner in the prelude.

In this thesis, the phenomenon of *family care* is regarded as the wide range of unpaid care or assistance with activities to someone with a chronic physical or mental illness, disability or frailty, given by a person from the patient's direct social network. This *family caregiver* can be actual family – for example the partner, a grown-up child, sibling, or other relative – but also a friend, neighbor, or other acquaintance[2-4]. Activities that may be part of family care vary widely: family caregivers may be involved in household care (like doing groceries, cleaning, cooking), management care (like going along to doctor's appointments, arranging care, doing administrative tasks), or personal care (helping with bathing or dressing, giving medication, but also talking, providing emotional support)[5]. Although family care may vary in intensity and duration, it goes beyond what can reasonably be expected within the relationship[6].

Because family caregiving originates from existing relationships[7], it is difficult to demarcate at which point someone is 'just' a partner or relative, and when someone's help can be labeled as family care. The people involved already take on certain roles towards each other due to being partners, family in parent (in law)-child or sibling relationships, or having an otherwise significant relationship. These

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1. In the beginning of 2025, the Dutch actor Sander Plukaard was interviewed about his experiences with providing care for his partner with cancer[1] which eventually lead to a theatre performance.

existing relationships always involve certain expectations and norms with regard to what people do for each other. Therefore, it can be hard to strictly distinguish what exactly is family care and what is not.

In addition, in understanding the concept of family care, it is important to notice how the concept overlaps with *informal care*, another term commonly used in the literature. In this thesis, I deliberately do not use the term informal caregivers for people providing family care, as I regard informal care as the wider umbrella term for all kinds of unpaid and nonformal help to others[8], from which the care given by family caregivers close to the care receiver is only one form. Another form of informal care is the less intensive assistance or aid that can be provided by people from one's wider social network, such as colleagues or people from a sports club or church. And lastly, informal care can be provided by volunteers – people who have no previous relationship with the care receiver – for example via an organization or care institution. To exclude these types of care and explicitly focus on the type of care provided by someone already familiar and close, the terms family care/family caregivers are used throughout this thesis.

In the Netherlands, various definitions and criteria exist regarding what exactly is family care, which makes it hard to estimate the number of family carers[9]. Defined broadly, about 35 percent of people aged over 16 years and older reported providing unpaid help to someone in their direct social network who has health-related problems[9]. Box 1 gives more details about the number of family caregivers in the Netherlands.

Box 1 | Family care in the Netherlands

MantelzorgNL, the Dutch nationwide association for family caregivers, synthesized several numbers of family care in general [10]:

- 1 in 5 of people aged 12-16 years is growing up with a chronically ill family member
- 1 in 4 of people aged 16-24 years is taking care of someone close to them with health problems
- 1 in 3 people aged 16 years and older provided family care in 2019, which comes down to about 5 million family caregivers in total
- 830.000 family caregivers provide aid both that is both long-lasting (more than three months) and intensive (more than eight hours a week)
- 1 in 4 family caregivers also regards themselves as such
- 1 in 4 employees combines paid work with family care

The conceptualization of the word family caregiver and the estimation of the number of family caregivers is further confused by a lack of recognition among family caregivers that they have this role[10, 11], or an unwillingness to identify themselves as family caregiver. Figure 1 (from our graphic novel *Naasten*, which will be further explained in Box 3) illustrates this by showing one of the main characters stating that he does not feel like a family caregiver. *"I am not a family caregiver, I am her HUSBAND!"* the man exclaims to his son to the left who labels him as a 'family caregiver' and encourages him to think more of himself. *"This is the last thing I can do for her…"* Throughout the novel, he keeps trying to assist and support his dying wife.

Figure 1 | Image from our graphic novel 'Naasten' (p. 126), drawn by Melanie Kranenburg

In many countries, caring for people close to you is something the majority of people consider obvious or self-evident[12]. Especially in the context of advanced cancer, providing family care seems a responsibility that is often assumed rather than actively chosen[13, 14]. Many people just *do* it, even at considerable costs to themselves. Important to acknowledge here is that family care is not a solely private matter within people's relationships, but a societally relevant and urgent topic. The involvement of families is increasingly encouraged by governments. With aging populations, and the increase of disabilities, chronic diseases and frailty pressurizing the sustainability of care, the involvement of families in care is increasingly considered an important pillar of many long-term care systems of Western countries[15-17]. This raises questions about what we may expect and demand from each other, especially in situations where family care is intense and impactful but at the same time regarded self-evident by the people involved.

Family care in the context of anticipated dying

This thesis specifically focuses on family care in Dutch home settings within a palliative care context, mainly as a consequence of a patient's end-stage cancer or severe organ failure. Palliative care can be defined as care that *"improves the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment, and treatment of problems of a physical, psychological, social and spiritual nature"*[18].

Within a palliative care context, family care is a highly relevant topic. Especially when patients prefer to stay and die at home, the role of their partner or relatives is pivotal: due to their often unique relationship with and valuable knowledge about the patient, partners and family members are essential in providing emotional support, communicating with professionals and services, relieving the aforementioned suffering such as pain or other symptoms, or doing practical tasks[19]. Box 2 provides more details about the number of family caregivers in this context.

Box 2 | Family care in a Dutch palliative care context

Recent research, which was conducted for the nationwide association for volunteer organizations within palliative terminal care, concluded[20]:

- 1 in 8 people in the Netherlands is or was involved, in the past five years, in family care for a terminally ill person in their last phase of life who wanted to die at home. The majority of these people cared for their parent, sibling (in-law), or partner.
- 28% of these family caregivers provides this care on their own as sole caregiver, and 29% together with one other person

It should be noted, however, that estimating the number of family caregivers in a palliative care context is difficult. As mentioned before, family caregivers do not always recognize themselves as such[11]. The lack of a clear-cut point of when a patient is entering the end-of-life phase further problematizes the estimation[19, 21]. Another factor is that it can be complicated to define who exactly is a family caregiver – especially if hands-on help from members of the a person's wider social network, other than the 'primary' family caregiver, is taken into account[21], which occurs in the majority of Dutch family caregivers of terminally ill patients[22].

What is already known about how family care in a palliative care context is experienced? Previous research among family caregivers suggests that caring for a loved one who is going to die can help people to appreciate 'the little things' in life and feel closer to the patient or other family members, because of their increased awareness of life's brevity[22]. It can also be experienced as a personally meaningful, transforming and worthwhile experience[13, 23], for example through positive coping experiences, gaining new perspectives on life and death, experiencing self-growth, or achieving a sense of satisfaction or accomplishment[13].

Research has, however, also highlighted the immense physical, emotional, and psychosocial impact of care on family caregivers, recognizing the need for family support[24-28]. The need for support is also reflected by the definition of palliative care mentioned above, as well as by the one of the World Health Organization[29], which both explicitly emphasize that palliative care should improve the quality of life of patients *and their families*. Various negative outcomes for family caregivers have been reported, such as anxiety, stress, depression, sleep problems, and fatigue[13]. That caring for a loved one can be burdensome in diverse ways is a common finding in research on family care in a palliative care context. Within nursing and other healthcare-related practices, this is referred to as 'caregiver burden'[2, 30, 31] and reported to be associated with factors like distress at witnessing suffering and disease progression, uncertainty about the situation, sleep deprivation, spiritual distress, financial crises, and role strain[2, 21].

Especially if the patient desires to stay and die at home, as most people prefer initially[32], the responsibilities of their families and friends are intensified[21, 33]. At the same time, many caregivers feel unprepared for a caring role[34, 35]. This new caring role can be quite overwhelming with its demands[36] and its all-consuming nature of *"being on 24/7"* (p. 1232)[37], as their life becomes centered around caring for their dying loved one[13]. The attentiveness required of caregivers, i.e. being present and providing emotional support, is an important part of home-based palliative family care, but also disrupts family caregivers' daily lives[38]. In order to stay close to the patient, caregivers have to rearrange their priorities and planning which may cause them to struggle with maintaining normality in their social encounters[13, 21, 39]. They may experience dilemmas, as there is little time or energy for the rest of their family, work, seeing friends, or having hobbies. Tragic situations may then arise, due to competing demands stemming from one's different roles[12]. People may feel torn between being a caregiver while also being a parent, employee, partner, or friend, and experience difficulties (or even exhaustion) in balancing the needs of the patient with one's own. As such, family caregivers may feel limited – 'chained' even – in living their normal daily lives[35], and may feel socially isolated or lonely[13, 21, 39].

Increasing family caregivers' visibility

Given the challenges and unmet needs of family caregivers, it is deemed beneficial if healthcare professionals would screen for caregiver burden at an early stage[30]. Offering support to family caregivers is, however, not always part of the routine practices of healthcare professionals. Potential reasons for this are varied: healthcare professionals may not feel responsible for family caregivers' wellbeing, feel uncomfortable when having to work with them, or experience barriers such as not having enough resources to support them, lacking knowledge about referral possibilities, or having limited conversational skills[40]. Becqué et al. show that nurses' support of family caregivers in home settings often does not follow a systematic approach based on family caregiver needs[41]. Rather, their approach depends on an individual nurse's intuition and experience. Furthermore, it is influenced by the personal characteristics of both nurses and family caregivers, the rapid changes in a patient's circumstances and related changes in family caregivers' support needs, the nurses' interaction with families and other healthcare professionals, but also by palliative care services and systems, societal developments, laws and regulations. The authors conclude that a more reflective and preventive approach of supporting family caregivers is needed, amongst others grounded in a needs assessment[41].

With regard to these needs, and in line with previous research[42, 43], Hoffstädt et al.'s study across settings and disease trajectories shows that, overall, one of the most essential needs of family caregivers is to feel seen and valued[44]. Not only seen in their role as co-caregiver for the patient, but also seen as potential care recipient in having their own needs and emotions in facing the patient's deterioration, suffering and imminent death, as well as seen in their original role as being the patient's partner, child, sibling or otherwise significant other. Thus, in order for family caregivers to feel seen and valued by healthcare professionals, the visibility of their roles and experiences should be increased.

Background of this thesis: the graphic novel project

As a response to family caregivers' sense of loneliness and to increase their visibility, my research team and I undertook a project that was financed within the research and implementation program Palliantie of ZonMw ('De mantel der liefde verbeeld', 2017-2021). The central aim of the project was to develop a research-based graphic novel – that is, a comic book – in order to literally visualize the diverse palette of family caregivers' experiences and their sometimes invisible perspectives, and to engage

a broad public in thinking about family care. The rationale behind the project was that visualizing caregiver experiences through comic art can help readers to better understand and relate to family caregivers' complex experiences. Consequently, with the novel we intended, on the one hand, to increase the visibility of family caregivers and hopefully make them feel less lonely in their struggles. On the other hand, we intended to inspire readers – whether they are friends and relatives surrounding the family caregivers, healthcare professionals, or palliative care volunteers – to reflect on their involvement in the lives of family caregivers and their way of supporting them, thus contributing to the family caregivers' wellbeing. The interdisciplinary collaboration with two comic artists resulted in the graphic novel entitled *Naasten* (Dutch for 'loved ones' or 'relatives'), depicting the storylines of two family caregivers. Figures 2-4 show some parts of the book. Box 3 further explains the project and its steps.

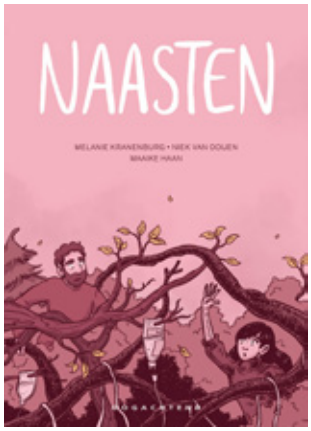

Figure 2 | Cover of the graphic novel

Figure 3 | Page from the graphic novel (p. 162), showing characters of the storyline drawn by Melanie Kranenburg

Figure 4 | Panels from the graphic novel (p. 10), showing characters of the storyline drawn by Niek van Ooijen

Box 3 | Creating and implementing a research-based graphic novel in collaboration

From 2014-2020, the ZonMw-program 'Palliantie. Meer dan zorg' was encouraged by the Dutch Ministry of Health, Welfare and Sport, to enhance palliative care for patients and families, among other things by stimulating public discussions. Our project (fully entitled *"De mantel der liefde verbeeld. De ontwikkeling van een graphic novel over mantelzorg in de palliatieve fase als bron voor publiekseducatie"*) was part of this Palliantie-program.

The intention of the project was to visually represent family caregivers' experiences via a medium that would be easily accessible to the public outside academia. Therefore, the project team turned toward the arts. More specifically, we collaborated with comic artists, inspired by the already hypothesized and advocated merits of using comics in healthcare. The central aim of the project therefore was to develop a research-based graphic novel, in order to stimulate public education, discussion, and reflection about the (moral) challenges and ambivalences in caring for a dying loved one. As such, the project is located at the intersection of family care, comic art, education in palliative care, and ethics. The project consisted of three steps:

1. *Exploration of the phenomenon of family care:* First, I conducted and analyzed in-depth interviews with family members (mostly partners or adult children, who took care of a loved one with a life-threatening condition or frailty) and patients (mostly suffering from end-stage cancer or severe organ failure). Although previous research already highlighted challenges, the interviews were conducted with a grounded theory approach to remain open to all kinds of experiences. The interviews were also essential for gathering important themes, scenes, dilemmas, and first-person stories valuable for developing the graphic novel.
2. *Development of a research-based graphic novel:* Then, I collaborated with comic artists Melanie Kranenburg and Niek van Ooijen in 2018-2019, who at that time were graduating Comic Design students at ArtEZ Zwolle. To provide a general and rich account of what it means for people to provide family care at home, two storylines with different palliative care trajectories were scripted based on the main themes formulated in the research conducted in step 1. The eventual novel *Naasten* (Dutch for 'loved ones' or 'relatives') shows the stories of Geert, who cares for his wife with end-stage cancer; and Eva, who cares for her father with severe chronic obstructive pulmonary disease (COPD). Each artist drew one storyline, in their own artistic style; the stories are interwoven in the novel. Due to its high-quality artwork, the book was published by the Belgian comic publisher Oogachtend in 2019.

3. *Using the graphic novel in practice:* Lastly, *Naasten* was used in supportive settings within palliative care. Its value was empirically explored, by analyzing the reported barriers and facilitators for using the novel as a conversation starter or supportive tool by health care professionals and volunteers in their encounters with family members.

Although outside the scope of this thesis, it is worthwhile to note that a follow-up grant by ZonMw (VIMP) and a collaboration with palliative care initiative Carend stimulated us to further develop and implement several products of the Palliantie-project within educational settings. Currently, art work from the novel is used as conversation starter in (ethics) education programs as well as in training sessions with professionals and volunteers in palliative care for VPTZ Nederland.

Using comic art in research

A graphic novel such as *Naasten* can be described as a book-length form of comic art. Although there has been debate about definitions, *comics* is nowadays the most widely used term to describe the medium[45]. Comics, to use the words of scholars La Cour and Poletti, narrate stories *"through the combination of sequential, often paneled, images and text that are often set apart from each other by gutters of space on the page"* (p. 8-9)[46]. This definition – referring to terms like sequence, panels, and gutters – demonstrates there is a whole 'grammar' behind comics[47] that may be important to understand for both readers as well as researchers interested in using comics, especially when new to the genre. Box 4 explains some key concepts of comics[45, 46].

Box 4 | Some key concepts in understanding comics

Drawing on the work in 'Key Terms in Comics Studies'[45], here, I present some concepts important to note when (one is new in) reading or understanding comics.

- Comics pages usually consist of *panels* which are frames that follow one another (see Figure 4), each depicting a single moment in time, together constructing a narrative. Exceptions are single panel pages or full-page drawings (see Figure 3).
- A sense of time or *sequence* is constructed through a series of consecutive panels that display coherent or related content. Sequence is a key word in many definitions of comics, including the ones provided by famous comic artists and theorists. Eisner, for example, labeled the genre as sequential art in 1985[48], and McCloud defined comics as *"juxtaposed pictorial and other images in deliberate*

sequence" (p. 9)[49]. With sequence, comics artists represent the passing of time. They can construct linear narratives, but many also experiment with non-linear panels or page lay-out.

- Important when understanding sequence is that panels are typically separated by a blank *gutter*: *"the illusion of 'motion' created in a comic is performed entirely in the mind of the reader, which connects two static images as the eyes pass through the gutter (the area in between two comics panels)*." (p. 204)[50] Although there is debate about how to understand this empty space – purely as a visual zone on a page for example, or as a gap in the narrative that has to be filled within the reader's mind – the gutter remains an important concept in the study of comics.

Why our turn towards comics? People's illness and caregiving experiences often are complex and ambiguous. By using visual symbols like the aforementioned concepts as well as visual and verbal metaphors, comics are able to literally *show* – rather than tell about – such embodied experiences[51-54]. They enable comic artists to convey the inner and sometimes intangible aspects of these layered experiences, as well as the related ambiguities and uncertainties, especially those that cannot easily be captured in words alone[55-57]. As such, the genre of comics is specifically interesting for the field of healthcare in narrating people's illness and caregiving stories. In the past decade, many graphic memoirs about artists' personal experiences with illness or disability were produced, which can also be labeled as 'graphic pathographies', that is, graphic illness narratives[58], for example regarding mental illness, diabetes, HIV, dementia, cancer, or hospice care[59, 60]. Nurses, doctors, and family caregivers also produced graphic narratives about their personal perspectives. Consequently, a relatively new area of comics grew, coined in 2007 as *graphic medicine* by comic artist and physician Ian Williams[45, 58]. Practically, graphic medicine is a community of various healthcare professionals, academics, artists, authors and comic fans[61]. It is also an umbrella term describing the field where the medium of comics intersects with the discourse of healthcare, expressing the role and value of comics in the study and delivery of healthcare[54, 62]. As such, graphic medicine is closely linked to the field of medical humanities, in which insights from several disciplines (the humanities, social sciences, and the arts) are applied to the study and practice of medicine[46]. Just like medical humanities, the rise of graphic medicine memoirs provides us with alternative understandings and expressions of illness, disability or caregiving, different than those common in the medical discourse[46].

The potential of adopting an artistic approach within academic research has already been acknowledged in scholarly work. Art methods like theatrical performances,

dance, poetry, music, fiction, or visual art such as comics have been emerging as novel ways for generating, analyzing, interpreting, or (re)presenting research data[63, 64]. As researchers, we started the project with the goal of representing our data, that is, translating the main findings of our interview research into a more accessible format. Regarding this representational function, arts-based works are defined by researchers Lafrenière and Cox as depicting one's raw, coded or analyzed findings in order *"to convey experience, ideas or emotions emerging from research data in a meaningful, vivid and imaginative way through the use of literary, visual or performing techniques with the aim of provoking some effect in a reader or audience"* (p. 322)[65]. In our project, we were inspired by the hypothesized potential of comics for engaging a broader public[58], especially in palliative care[57, 66]. We focused at depicting the key aspects of my interview research on family care, thereby aiming to achieve effect among a public outside academia. That is, we aimed to be emotionally supportive for family caregivers who would read the novel, and to stimulate reflection among the people surrounding them with regard to their way of supporting these family caregivers.

Research questions

This thesis presents research that has been conducted in parallel with the aforementioned graphic novel project. The goals and steps of the project in developing the novel (Box 3) were different from the goals of the research that is presented here. Two aims guided the research: a) to better understand the phenomenon of family care, and b) to better grasp how these experiences can be translated into public education and communication via comics, in order to respond to family caregivers' need to be seen and acknowledged by healthcare professionals. The following four questions were asked:

- How do family caregivers of seriously ill people in Dutch home settings experience caring for their partner or family member in the palliative phase, and how are these experiences shaped by normativity? (Chapter 2)
- What are the experienced barriers and facilitators of using the graphic novel *Naasten* as aid in supportive conversations with family caregivers of patients receiving palliative care in the Netherlands? (Chapter 3)
- How was the graphic novel *Naasten* developed and what can be learned from this process for future interdisciplinary approaches? (Chapter 4)
- Using a care ethical approach, how can we re-think family caregiver burden and support? (Chapter 5)

Methodology and outline of this thesis

This thesis presents four research chapters that build upon each other, together addressing the two aims in my research. The chapters are numbered in this thesis in the chronological order in which they were written. Below, I present them in a different order, as I explain them in the context of the aims.

a. Understanding and reflecting upon the phenomenon of family care

The research starts with thoroughly investigating and analyzing the phenomenon of family care. **Chapter 2** describes the insights resulting from my qualitative, in-depth interviews with Dutch (bereaved) family caregivers and patients, and specifically focuses on the normativity in their experiences and dilemmas. This empirical research was conducted with a grounded theory approach to remain open to all kinds of experiences. Starting from several sensitizing concepts originating from previous research on family caregiving, the analysis of the interviews provided themes, patterns, and first-person stories that were also valuable for developing the intended graphic novel.

At the end of our project, having developed and extensively used the graphic novel in educational settings, I revisited the question what drives people to provide family care and, particularly, their persistence in doing so, despite the challenges. The conversations with nurses, other healthcare professionals, and volunteers in palliative care education taught me about their struggles when supporting family caregivers. For example, they may find it difficult to see family caregivers sacrificing themselves in a way they consider to be too burdensome and unhealthy. **Chapter 5** aligns this struggle with key elements of care ethical thinking to enhance nurses' and other healthcare workers' understanding of family caregivers' underlying norms and expectations. Thus, it provides a care-ethically inspired interpretation of family caregiver burden and support, intending to contribute to a more person-centered approach of supporting people in whatever overwhelms or drives them in standing by their loved ones until the end.

b. Understanding the potential and process of translating research into comic art

In view of the assumed potential of comics to show complex caregiving experiences and offer powerful educational or science communication tools, my research team and I aspired to empirically explore whether our graphic novel *Naasten* was helpful and supportive for people in the real-world practice of palliative care, anticipated dying, and grief. **Chapter 3** presents the facilitators and barriers in using the graphic

novel *Naasten* as conversation aid. The value of *Naasten* was explored via focus groups with family caregiver consultants, palliative care volunteers, and healthcare professionals who supported family caregivers; and via interviews with family caregivers to whom the book was presented. We interpreted these qualitative data by a thematic content analysis.

The overall graphic novel project underlying this thesis started with the mere goal of translating our findings on family care into a graphic novel to reach a broader public. Along the way, however, the development of the graphic novel and exploring its potential evoked a thorough reflection on the interdisciplinary character of my collaboration with comic artists. By reflecting on my experiences in collaborating with comic artists, **Chapter 4** elaborates on three issues important for any art-research collaboration, thus aiming to inspire other researchers.

Lastly, in **Chapter 6**, I will discuss the findings and reflections of this thesis. Implications for supporting family caregivers and suggestions for future research are provided as well.

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Chapter 2

Feeling called to care: a qualitative interview study on normativity in family caregivers' experiences in Dutch home settings in a palliative care context

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BMC Palliative Care. 2021;20:183.
https://doi.org/10.1186/s12904-021-00868-2

Abstract

Background: Family caregivers, such as partners or other family members, are highly important to people who desire to stay at home in the last phase of their life-limiting disease. Despite the much-investigated challenges of family caregiving for a patient from one's direct social network, lots of caregivers persevere. To better understand why, we aimed to specify how normative elements – i.e. what is considered good or valuable – shape family caregivers' experiences in Dutch home settings.

Methods: From September 2017 to February 2019, a total of 15 family caregivers, 13 bereaved family caregivers, and 9 patients participated in one-time in-depth interviews. The data were qualitatively analyzed following a grounded theory approach.

Results: Central to this study is the persistent feeling of being called to care. By whom, why, and to what? Family caregivers feel called by the patient, professionals entering normal life, family and friends, or by oneself; because of normative elements of love, duty, or family dynamics; to be constantly available, attentive to the patient while ignoring their own needs, and assertive in managing the caring situation. The prospect of death within the palliative care context intensifies these mechanisms with a sense of urgency.

Conclusions: Our analysis showed a difference between feeling called upon in the caring situation on the one hand, and how caregivers tend to respond to these calls on the other. Taking into account the inherent normative and complex nature of family caregiving, the pressing feeling of being called cannot – and perhaps should not – simply be resolved. Caring might be something families just find themselves in due to being related. Rather than in feeling called upon per se, the burden of care might lie in the seeming limitlessness to which people feel called, reinforced by (implicit) social expectations. Support, we argue, should enable caregivers to reflect on what norms and values guide their responses while acknowledging that caring, despite being burdensome, can be a highly important and rewarding part of the relationship between partners or family members.

Keywords

Caregivers, Family care, Informal care, Palliative care, Ethics, Caregiver burden, Qualitative research, The Netherlands

Background

Table 1 | Definition and background of family care in the Netherlands

In this study, family caregiving is regarded as the wide range of aid or assistance in activities of daily living given by an unpaid and untrained person from someone's direct social network, e.g. a partner, relative, grown-up child, friend, neighbor, or other acquaintance[1-5]. Family care may vary in intensity and duration, but, in any case, goes beyond what can reasonably be expected within the relationship[4]. In the Netherlands, several definitions and criteria for 'family care' exist, leading to different estimations of the number of caregivers[6]. Defined broadly, about 35% of people of 16 years and older reported providing unpaid help to someone close with health-related problems[6]. Although the terms are sometimes used interchangeably, we deliberately do not use the term 'informal care' to explicitly exclude volunteers from this study.

Family care occurs in several settings, i.e. for people suffering from serious illness, long-term mental health problems, or a disability. This study specifically focuses on family care in a palliative care context, as a consequence of metastasized cancer or long-term organ failure. Estimations concerning the number of caregivers in this context are difficult, especially if hand-on help from members of the wider social network, other than the 'primary' caring relative, is taken into account[7], which occurs in the majority of Dutch caregivers of terminally ill patients[8]. The lack of a clear-cut point of entering the end-of-life phase further problematizes the estimation[7, 9], as does the observation that not every 'family caregiver' recognizes himself or herself as such[3].

In the last phase of a life-limiting disease, patients are often cared for by someone close from their social network, such as their partner, grown-up child, or friend[i]. These people providing family care (Table 1) are pivotal. Due to their often unique relationship with and valuable knowledge about the patient, family caregivers are essential in providing emotional support, communicating with professionals and services, relieving pain and other symptoms, or doing practical tasks[9]. However, especially if the patient desires to stay and die at home, as most people

i. We as authors are aware of the debates about the use of the term 'patient'. We acknowledge that, especially within the context of this study, people are foremost each other's partner, parent, friend, or other family member. For the sake of clarity, however, we use the more formal term patient for the person who receives family care.

prefer initially[10], the roles and responsibilities of their families and friends are intensified[7, 11] and caregiving may be burdening. This study explores why family caregivers (hereafter: caregivers) persevere, despite the challenges, and which role normativity plays.

Previous research has highlighted the physical and psychosocial challenges of family care in the palliative phase, recognizing the need for caregiver support[12-14]. Many caregivers live in permanent uncertainty about the future and feel overwhelmed and unprepared for their caring role[15, 16]. Maintaining normality in social engagements can be a struggle, for instance when a caregiver's sense of togetherness with the patient conflicts with also feeling socially isolated[7, 17]. Caregiving can limit or even 'chain' caregivers in their own life and affect their relationship with the patient[16]. About one in five caregivers of terminally ill patients experience a heavy care-related burden[8]. This much-investigated concept of 'burden' is reported to be associated with factors like distress at witnessing suffering and disease progression, uncertainty about the situation, role strain, sleep deprivation, spiritual distress, and financial crises[1, 7].

As lots of people feel burdened by caring for someone close, why do they persevere? Many empirical studies focus on predefined outcomes, but little tell us about the individual processes and context that shape the actual care[18]. Care ethical analyses, rooted in feminist studies, have argued that caring is not (only) a matter of one's free and personal choice. Rather, a caregiver's agency is deeply tied to the surrounding social and political practices: *"caregivers appear as people finding themselves in a position in which others, they themselves, and also the socio-political context expect them to have and take responsibility, as a result of socio-political, personal, affective, contextual, and ethical factors."* (p. 277)[19] In this article, we are specifically interested in these ethical factors, which we label as 'normative', e.g. the normative elements that appear to be essential to the experiences of family members providing care. Normative elements have to do with someone's convictions about what is 'good' or 'right' to do, which are particularly relevant when it comes to life and death in the last phase of a life-limiting disease. As Randall and Downie (p. 13) argue: *"… any discussion about palliative care occurs against the background of those major questions which relate to the meaning of life and death, or what constitutes a good life (and perhaps death) for a person."*[20] Normativity has already been recognized as important in palliative care and in family caregiving, but its precise role remains unclear in the caregiving literature. For example, the theoretical Informal Care model proposed by Broese van Groenou and De Boer (2016) understands family caregiving, in general, as being dependent on both contextual factors that

influence care provision as well as individual factors that shape one's intention to provide care, to which they refer broadly in normative terms, i.e. beliefs, motives, values, or norms. Prior empirical studies in palliative care also refer to normative caregiver experiences, such as feeling unprepared yet *responsible* to provide care[15], feeling a general *duty* to care[21], or feeling *obliged* to prefer providing care at home[22].

Drawing on these broad references to normativity, we aimed to specify how normativity shapes the phenomenon of family caregiving within the context of palliative home care. This article's research question is: how do family caregivers of seriously ill people in Dutch home settings experience caring for their partner or family member in the palliative phase, and how are these experiences shaped by normativity? More insight will provide us with relevant clues about how to better understand and support caregivers.

Methods

Study design

Our overall research project aimed at exploring the diverse palette of family caregiver experiences, following the characteristics that are key in the diverging views and philosophical assumptions of a grounded theory methodology[23, 24] , i.e. we used an inductive approach, we simultaneously collected and analyzed data while developing theoretical abstractions grounded in the data, we used constant comparison and kept memos, and strived for theoretical sampling. Thus, we ensured a thorough exploration of people's experiences with caregiving and remained open to both the positive, rewarding experiences that come from caring as well as the experiences of feeling burdened[8]. In line with Straussian grounded theory[23], pre-given concepts or previous studies did not dominate the data collection and analysis to keep an open mind[24-26]. In line with Charmaz' constructivist approach, however, we considered ourselves as not having an empty head[25]. We started the project with some sensitizing concepts (that were adapted into topics for our interview guides, see Table 2), based on an explorative search of scientific and gray literature, as well as interview expertise in palliative care within the project group (JvG, GO).

Table 2 | Topics in the interview guides

Caregiver interviews:

- Situation and disease process of the patient, (changed) relationship with the patient
- A (non) typical day and caregiving
  - In case of bereaved caregiver: last weeks and time after the patient's death
- Meaning of relationships with others and support
- Taking care of oneself, needs, support
- Saying goodbye, talking about death, future

Patient interviews:

- Situation and disease process, meaning of being ill, (changed) relationship with the caregiver
- Being cared for, a (non) typical day
- Meaning of relationships with others
- Saying goodbye, talking about death, future

During the cyclical data collection and analysis, our background as medical ethicists made us notice normative aspects in the interviewees' phrasing and overall stories. We became increasingly interested in what motivates caregivers to care for patients in need of palliative care. Therefore, for this article, we specified the initially broad research question of the overall project into how the collected care experiences are shaped by normativity.

Setting, participants, and materials

Based on the inclusion criteria (Table 3), three groups of Dutch interviewees were included: 1) family caregivers, 2) bereaved family caregivers (within 5 months after the patient's death) who could describe the last days before and first few weeks after the death of the patient, and 3) patients i.e. people with a life-limiting disease in the palliative phase who received family care. All interviewees were aware that the trajectory of the involved patient was regarded as palliative. We were focused on caregivers' perspectives primarily. Patient interviews were considered to be complementary data, functioning as triangulation, to better interpret and understand the context of the caregivers' data. Purposeful sampling was used to include a variety of people, based on gender, age, or caring relationship[24]. Various healthcare professionals (e.g. general practitioners, district nurses, hospital-based professionals) invited potential interviewees, leading to convenience sampling as well. Later on in the study, we strived for theoretical sampling to identify variations and relations

in the ongoing analysis[24]. When a family caregiver or patient was interested, MH contacted him or her via telephone, and sent an information letter. The interviews were scheduled within days or weeks after MH first contacted the interviewees.

Table 3 | Inclusion criteria

All interviewees:

- are 16 years old or older;
- are mentally competent to engage in the interview;
- are fluent enough in the Dutch language to participate in the in-depth interview;
- are involved in family care, as either caregiver or care receiver;
- are aware that the involved patient is in the palliative phase of life and has a limited life expectancy.

The involved patients (not necessarily interviewees):

- are 16 years old or older;
- have an incurable and life-limiting oncological or neurological disease, organ failure, or elderly frailty (dementia is excluded, because of the specifically changing nature of the relationship between caregiver and patient);
- are in such condition that their involved healthcare professional would not be surprised if this patient died within the next 12 months (e.g. the *"surprise question"* as used in palliative care);
- receive family care at home from at least one loved one (partner, child, parent, sibling, friend, etc.); or has received this care before being transferred to a hospice or other care institution.

The interview topics (Table 2) and questions were reviewed by various experts in qualitative research and palliative care. We constructed different guides for the different interview groups, that were adapted several times during the data collection to deepen the ongoing analysis and achieve saturation. First author MH received interview training from an independent senior researcher with ample experience in qualitative research and personal experience with family caregiving. The interviewing was piloted with the trainer twice.

Data collection

MH conducted the interviews. Although the interviews were guided by general topics (Table 2), they were minimally directive. Probing was mainly based on the situation and what the interviewee said. Field notes and memos were made to

facilitate the iterative process of interviewing and analyzing. The interviews were audio-recorded and transcribed verbatim. The original Dutch quotes for this article were translated into English.

Ethical considerations

Ethical approval was sought from the Medical Review Ethics Committee region Arnhem-Nijmegen (registration number 2017–3415), who determined that this study does not fall under the scope of the Medical Research Involving Human Subjects Act (WMO). Potential interviewees verbally consented to be contacted by MH. All participants gave their written informed consent, after receiving an information letter. Because healthcare professionals acted as our gatekeepers in finding participants, the potential interviewees' privacy was an important point of consideration. In addition, given the interviewees' vulnerable position, caution was needed in inviting and interviewing people. The possible emotional or physical burden of the interview was acknowledged both in the information letter and the interview itself; people could withdraw at any time. Furthermore, because the interviews involved personal and emotional topics and we did not want to disturb existing relationships, MH tried to conduct the interview individually without others nearby – unless the interviewee wished differently or practical circumstances did not allow this. Every participant received a numerical code and all interview transcripts were anonymized. The data were safely stored, as was stated in an approved data management plan.

Data analysis

Following an iterative approach, characterizing grounded theory, the data were analyzed throughout the collection process[27, 28], using ATLAS.ti software. MH first coded transcriptions individually and constantly compared the analysis to previous codes, staying close to the language used by the interviewees[25]. As the cyclical process of grounded theory allows, rereading, coding, and collecting new data occurred simultaneously to dig deeper into the research question[25]. In line with Straussian grounded theory, open, axial, and selective coding were used to find categories, overarching themes, and, ultimately, patterns[23, 24]. Meanwhile, hunches and decisions concerning codes, categories, and patterns were kept in memos[26, 29] to add to the transparency and credibility of the research. Several visual displays were made to organize ideas and discuss the theory[29]. The data collection continued until new interviews no longer provided new insights on general patterns within the group of caregiver participants. Although the use of theoretical sampling was limited, we then decided that saturation was reached.

Analytic rigor

In contrast with a classical view on grounded theory[23, 29], we followed Charmaz' constructivist approach in regarding the researcher as not being neutral or distinct from the research process[25] and stressing the importance of a researcher's reflexivity conducting grounded theory[23]. Thus, for validity reasons, JvG independently coded the first three interviews as well[25, 27]. We critically discussed our differences as coders without looking for a compromise. During the interviewing, MH verified her interpretations with the interviewee by summarizing and choosing multiple angles during the interviews. General patterns and themes were checked to employ specific interview questions in later stages of the data collection. Moreover, in June 2018, the identified themes and patterns in the data analysis were discussed during a feedback meeting with five interviewees. In addition, the authors regularly discussed their results with a sounding board of experts, mainly from various stakeholder organizations. Utilizing memo writing, but also discussion and checks both within and outside the project team, measures were taken to ensure MH's reflexivity and critically consider her role and possible biases (for example, focusing on challenging aspects of caregiving in the interviews). Throughout the study, ongoing peer review and discussion between all authors were essential.

Results

From September 2017 to February 2019, a total of 15 family caregivers, 13 bereaved family caregivers, and 9 patients participated in one-time in-depth interviews (Table 4). All caregiver interviewees were (one of) the involved patient's primary family caregivers. Six interviews were conducted with two interviewees present (caregiver and patient, or two caregivers), due to their preference or initiative. In all interviews, the main subject of conversation was family caregiving for a patient in the prospect of an approaching death. Life expectancies of the involved patients varied from weeks, months, to maximally a few years. Most interviewees were interviewed individually at home or where they resided; two caregivers preferred to be interviewed without the patient nearby and were interviewed at the researchers' department. Interview duration ranged from approximately 38 min to 2 h and 27 min.

Table 4 | Participant characteristics

Characteristics	Family caregivers (N=28)	Patients (N=9)
Male / Female	12M / 16F	4M / 5F
Age	23 to 84 years (mean 58.1)	61 to 95 years (mean 74.2)
Retrospective interview	13	not applicable
Relationship between patient and primary family caregiver		
Partner	18 partners	7 partners*
Child–parent	9 children (1 son)	1 parent*
Other family member or friend	1	2
Diagnosis		
Cancer	16	5
Organ failure (e.g. chronic obstructive pulmonary disease or heart failure)	6	2
Other, comorbidity or unclear condition	6	2

*One of the 7 partner interviewees also received care from her child and specifically told about that in the interview

Overview

Our results present a qualitative analysis of the phenomenon of family caregiving in palliative care, as seen from the perspectives of various caregivers and patients, focusing on how normativity shapes caregiving behavior (Fig. 1). Central to this study is the persistent and sometimes continuous feeling of *being called to care*. Our analysis further explains a pattern in this feeling: by whom, why, and to what?

Feeling called by whom?
- The patient
- Professionals entering normal life
- Well-intending family and friends
- Oneself

Why feeling called? - Normative elements:
- Love
- Duty
- Family dynamics

Why feeling called *now*? - Normativity in the palliative care context:
- Changes in the context and relationship
- A sense of immediate urgency

Feeling called to what? - Three responses:
- Being available
- Being attentive to the patient
- Being assertive in managing the situation

Figure 1 | Overview of the presented analysis about family caregivers feeling called to care

Caregivers feel called either by the patient's explicit or implicit calls for help, professionals entering normal life, well-intending family and friends, or by oneself. Their responses to feeling called seem to be evoked by general normative elements, e.g. love; duty; and family dynamics. More specifically, by subjecting relationships to pressure and intensifying the felt calls with a sense of urgency, the palliative care context seems pivotal in understanding to what caregivers feel called, e.g. being constantly available, attentive to the patient while ignoring their own needs, and assertive on several fronts in managing the caring situation. Our analysis, thus, revealed a difference between feeling called upon in the caring situation on the one hand, and how caregivers tend to respond to these calls on the other – reinforced by normativity.

Feeling called by whom?

We found a persistent and always-existing urge which we identified as the manifestation of feeling called to care, this study's central theme. Looking at the caregivers' stories from an ethical perspective, this feeling presents itself as pre-reflexive in their stories, e.g. not based on a well-considered choice using explicit moral arguments: caregivers often felt a strong urge to act and automatically did so, yet without having been able to thoroughly reflect on why or how. Some people reported feeling what was needed intuitively because they knew the patient so well and the two of them spent so much time together. Feeling called to care manifested itself in the caregivers' experiences in four ways: by the patient; professionals entering normal life; well-intending family and friends; or one-self.

Feeling called by the patient

The family caregiver was often the person closest to the patient. Caregivers felt called by patients explicitly, when they needed something to eat or drink, asked for assistance with going to the toilet, expressed anxiety and worries, felt ill, or even screamed in pain. Patients were fearful and stressed when they were left alone, some patient interviewees tried to maintain in control by having (multiple) phones within reach, frequently asking or calling their caregivers. As a result, caregivers experienced a, sometimes continuous call:

> *... I have the feeling that I am being deeply called upon to do so, that it is 24-hour care. Really. [...] It starts in the morning when I get up. The first thing I do is put her on the bedpan. [...] It goes on until she goes to bed; it is continuous. Sometimes you can have 15 minutes or so, a few minutes, or if someone is there, you don't even have that. But it is actually always there. [...] Every moment is an appeal, every moment. ... (i17, husband caring for his wife with a lung disease)*

This was endorsed in retrospective interviews: some bereaved caregivers felt relieved by not having to continuously respond to the urgent needs and suffering anymore, which showed the urge of feeling called explicitly.

Next to explicit calls, patients showed implicit calls, for example in their preference for and dependence on the family caregiver being the primary person to provide care:

> *Patient: Family care is everything here right now. Without it, there is nothing left. [...] Interviewer: Why do you think it's so important that she [his wife] gets more help? Patient: So she can carry on, eh? For herself. For her daughter. It sounds selfish, but also for me, eh? Because if she fails ... Tell me ... (i8, male patient with cancer being cared for by his wife)*

Feeling called by professionals entering normal life

In caring at home, caregivers also had to deal with professionals, technology, or aids. Usually, they were untrained medical laypeople, feeling overwhelmed by disease symptoms:

> *… he was in pain and felt he couldn't get air. I have no medical background or anything, so. [...] It is like being in an unfamiliar forest, so you don't even know what is there. (i11, wife caring for her husband with cancer)*

Professional home care, then, could offer relief by taking over caring tasks and responsibilities. At the same time, professionals' presence did not seem to resolve the aforementioned patient's calls. People would still feel alert and called to provide care themselves:

> *Daughter: And the best thing about it [interviewer name], that my father called me after all. "[Daughter's name], where are you?" So I had to get up. Because I heard my father, and then the girls [from the night care] said, "no, just stay put". I say "yes, my father calls me, never mind. I'm awake anyway", I say.*
>
> *Son-in-law: Yes, and he does not understand Dutch well either.*
>
> *Daughter: No, and then he started talking [foreign language] to those girls too. (i21, bereaved daughter and her partner caring for her father with cancer)*

In addition, the presence of professionals instigated a call itself in several ways. For some people, it was difficult having strangers in their home several times a day, taking-over normal life: the *"circus"* of professional caregivers stopping by according to one interviewee. Caregivers entered what an interviewed son said to be the *"new world which is called care"*, sometimes accompanied by bureaucracy. Negative experiences with institutional care or the tight schedule of professional home caregivers also urged family members to provide the care themselves. Being able to organize care in the way one chooses (e.g. time or place) was seen as an advantage of providing family care instead of waiting for professional help.

Feeling called by well-intending family and friends

Caregivers and patients were often surrounded by family or friends, by whose attention they felt supported and loved. Despite being well-intended, their visits, how-are-you-questions, worries, or advice could instigate a call for caregivers, notably when mediated by social communication technologies demanding a continuous presence. Some patients found it difficult to maintain their autonomy. Having to tell the sometimes confronting truth over and over again could be difficult for caregivers. Yet, according to some, by explaining the situation regularly, it also lost some of its emotional edges. In a way, the disease seemed to take over normal life and conversations:

> *But often you also have to talk about the disease before you can talk about other things. So when I join in – I play tennis once a week with a friend, a tennis mate. First I talk to him for 10 min about [wife's name] and the disease. Then we can play tennis. [...] And if you have had that, say, once you have bitten through the sour apple, then you can also enjoy the rest. (i14, husband caring for his wife with cancer)*

In some family contexts, talking together about death was taboo, resulting in a tension between respecting one's family norms vs. one's own desire to discuss last wishes, the upcoming funeral, or other end-of-life issues.

Feeling called by oneself

Lastly, feeling called to care could be self-imposed. Caregivers sometimes felt like they were the only, or the most capable, person in the family to arrange things, wanted to do things themselves, or specifically asked what the patient wished:

> *Yeah, maybe I'm in that [appeal] too, because I'm going to ask him, "what would you really like to eat?" [...] That appeal, I pull it towards me. It is not*

that he says "you have to do that for me". I ask him what he would like. (i29, son caring for his father with aneurysm)

Why feeling called? – Normative elements

What motivates people to respond to these calls? This section explores normativity essential to the caring situation and relationship with the patient. We found several, often co-existing, normative elements that evoked caregiver responses: love, duty, and family dynamics.

Love

First, caregivers felt called to care for the patient out of love or a special bond:

Yes, you just do that for each other. [emotionally] He is my husband you know, so I love him. You don't want someone else to do all that for you. (i28, wife caring for her husband with cancer)

Caring out of love could be based on a promise, for example between partners (for better or worse) or other family members. Caring was also seen as self-evident in a loving relationship or was valued because it enabled people to live their normal life as much as possible. One patient noticed that being cared for by her partner was different from being cared for by her son because the latter was less evident (*"he is still my child"*). According to several daughters, love is what makes family care different from professional care. Caring could also be expected because the patient only trusted family members, or it stemmed from reciprocity in a loving relationship: for some, it was important to imagine themselves in the situation of the patient to make decisions. However, siblings sometimes had conflicting opinions about what was best or most pleasant for the involved parent.

Duty

Caring out of love sometimes co-existed with feeling a duty, for example keeping a promise regardless of whether love was still felt. Care could also be provided out of obligation or duty in the relationship or in the wider family:

…, No, I don't have to be put in the limelight because this is just a part of my job. It's a piece of moral duty that belongs to the fact that I am a daughter of my mother who took care of me. (i13, bereaved daughter caring for her mother with comorbidities)

This obligation stemmed from social expectations concerning familial relationships or helping others in need. Important to note here is that we only interviewed caregivers in the Netherlands and did not specifically ask for demographic information about culture or religion. Amongst interviewees who described their culture as family-oriented, we found a moral duty to take care of one's parents in return for their upbringing. An interviewee, however, emphasized love and honor as motivating in caring for her father, instead of this norm of reciprocity or gratitude in her Islamic culture. The value of helping others in need, which was sometimes religiously inspired, was also found amongst interviewees with an intuitive intention or moral obligation to help whenever they could.

Family dynamics

Especially in parent-child relationships, the sometimes troubled family history and the specific relationship with the parent played a role in what caregivers expected of themselves and how they responded in the caring situation. For example, being the most responsible sibling, being the darling sibling of a mother, or the past conflicts between family members. In addition, contrast experiences with another family member's death or with caregiving in the past were directive in persevering:

> *… "I will take care of him until I drop, and then I can't do it anymore", I say. This will never happen to me the way it did to my mother. [...] Fortunately, I have managed to accomplish it. (i19, bereaved wife caring for her husband with a neurological disease)*

A family's hierarchy also influenced caregivers' feeling of being called to care. Having a specific position within a family, such as being the eldest or being a professional healthcare provider, could lead to being assigned to the role of primary caregiver by one's siblings.

Why feeling called now? – Normativity in the palliative care context

To some extent, the aforementioned calls and normative aspects apply to all types of long-term family caregiving at home. What, however, is markedly different in a palliative care context is the décor of deterioration and the prospect of an approaching death. This section explores normativity within this specific context.

Changes in the context and relationship

Our results showed the context to be changing and increasingly palliative, consisting of a poor prognosis and deterioration, i.e. physical changes and/or a loss of autonomy while handing over things and becoming increasingly dependent on care. Some

patients feared dying alone, choking or in serious pain, or worried about what they had to leave behind. In partner relationships, the inevitability of death could lead to feelings of loneliness, being unable to live and share (sexual) life as they used to, or having to find proximity in other ways, and no longer sharing a joint future. The deterioration and fear seriously-ill people experienced increasingly changed them into a 'patient' in the eyes of their partner or family member: the person slowly *"faded"*, for example, and was no longer always recognizable as he or she used to be. These changes invoked a role shift for the partner or family member as well, who became more or less, sometimes in an unwanted way, a 'caregiver' with new responsibilities:

> *Yes, no, you don't want that. You just want your partner to be your partner. Often that's what she is too. If I have things to deal with, then she is still the person I go to, the one who gives me advice. I always want to hear what she thinks about it. We can level with each other, we can spar with each other. But there are just considerable times when I am home help for her. (i14, husband caring for his wife with cancer)*

A sense of immediate urgency

The prospect of nearing death, which changes the relationship, also leads to a sense of urgency in responding to felt calls: caregivers believed they had one final chance to do the right thing for the patient. This seems pivotal in understanding what motivates them to immediately respond to calls, sometimes regardless of whether this is rewarding or physically or emotionally burdening:

> *…that's what I said, I only have one chance of doing this for him. And that is simply why I am putting my back into it and why I am doing it. (i29, son caring for his father)*

Feeling called to what? – Three responses

Our results showed that the aforementioned normativity within the context urges caregivers to be constantly available; attentive to the patient first while ignoring their own needs; and assertive on several fronts of their lives in managing the caring situation. Despite the dilemmas described below, it is important to note that intensively caring for the patient also evoked *positive* feelings among caregivers. Although bereaved caregivers acknowledged exhaustion, they spoke of being *"grateful"* for having persevered and having enjoyed precious moments together, feeling *"honored"* or *"proud"* to have been able to provide family care. Some spoke of a closer and more intense relationship, for instance by spending more time together and cherishing small things or meaningful moments as the *"last things"* in the light of the approaching death.

Being available

In reaction to both the urgency and insecurities in a worrisome palliative care situation, as well as the patient's fear of being left alone, caregivers strived to be always available, reachable, and alert – live or by phone. Some caregivers felt "imprisoned" in their home, feeling obliged to be constantly stand-by for help. Leaving the house was easier when someone else stayed with the patient. Yet, overall, caregivers found it hard to let go of the situation and not think or worry about it, even when the patient was out of sight or when they themselves were out of the caring situation for a moment to get groceries, see friends or family, take part in sports, or work, especially with other people's questions. This illustrates the pressure of feeling called: despite leaving the situation, caregivers still felt occupied. Some bereaved caregivers experienced feelings of guilt for not having been present all the time:

> *Interviewer: … You said that it was painful for you that you were not there with him at the last moment.*
>
> *Sister-in-law: Yes, because I left him alone […] while I knew he was so afraid. Because I assured him, "[name of brother-in-law], when the time comes, I will take care that I am there with you." But this was unforeseeable. (i22, bereaved sister-in-law caring for a male patient with chronic obstructive pulmonary disease)*

Being medical laypeople, caregivers were sometimes unable to take away pain or breathlessness. Some told of situations in which they stood by helplessly or actually preferred to not see the patient's suffering, which also shows the tragedy of being present all the time.

Being attentive to the patient first

We found a persistent tendency among caregivers that everything should be about the seriously ill patient, leading to self-ignorance, e.g. meeting the needs and wishes of the patients first, before addressing their own. The disease literally took over caregivers' normal life in their own house: medical aids on the dinner table, a bed in the living room, or shelves full of medication. Work, volunteer jobs, social activities, or trips were put on hold in light of care or spending time together. Caregivers sometimes felt lonely in their daily struggles, or frustrated about the lack of attention from professionals for their perspective:

> *… but a family doctor like that who never says, "How are you doing? Can you manage?" […] you think it's normal, you don't know any better. You think, it's not about me; it's about papa. All the while I was the pivot. (i31, bereaved daughter caring for her father with cancer)*

Caring could result in physical exhaustion, but several people also pointed to what we have identified as a normative pressure stemming from being called in light of an inevitable death:

*Yes, it was tough, really tough. And I don't mean that I was physically tired, but you reach a point where you are in a sort of tunnel, and you just go on and on. Well, also later on, you think 'my God, phew'. But there is simply no going back from there, in the sense that you want closure in a proper way. (i25, bereaved husband caring for his wife with cancer)*The feeling that one can never turn back the clock again was said to be motivating:

> *… I can get up in the morning […], I look in the mirror, I feel no guilt because I have done everything, and you can't turn back the clock. So, in a loved one's last phase, you have to try to do everything you can, try to do what you would like to do. Because after that, you can't do anything, and you could regret that. (i21, bereaved daughter caring for her father with cancer)*

Balancing attentiveness to the patient with leading one's own life could cause dilemmas for both patients and caregivers. Patients sometimes worried about being a burden for their families, acknowledging their needs and preferring to not restrain them in their activities outside the caring situation. Some caregivers would not express their burden to the patient to spare him or her from feeling guilty. Having to raise young children but not being able to share this anymore with a seriously ill partner, could further problematize finding a balance. Overall, patients, as well as caregivers, seemed to want to respect each other's wishes, even if this conflicted with their own, for example about (not) having open conversations about death, arrangements, or last wishes.

Societal expectations played a role in some dilemmas. On the one hand, going out and engaging in fun activities could lead to a feeling of having to explain one's behavior to other people, showing the persistent norm that everything should be about the patient. Bereaved caregivers sometimes experienced feelings of doubt, seeking confirmation that they had done it right and had given enough. On the other hand, a caregiver's large amount of time invested in caring or a self-sacrificing attitude could evoke critical questions by friends or family as well:

> *To fight the resistance of others [raises her voice]: "Oh, it's irresponsible." "You are sacrificing yourself and you have nothing left." […] It felt as if I had to justify everything while I know very well what my responsibility is. My responsibility is not somebody else's responsibility, so there. I know what's best for him, what's the most fun, what he likes most. ... I focus it all on that. (i19, bereaved wife caring for her husband with a neurological disease)*

Being assertive in managing the situation

While being constantly available and attentive, caregivers felt demanded to uptake an assertive attitude on several fronts of their shared lives, as a response to the diverse calls in the caring situation.

Concerning practical caring duties, caregivers often referred to themselves as *"manager"*, e.g. doing household tasks, preparing and sometimes administering medication, accompanying the patient to doctors' appointments, informing family and friends and managing visits, maintaining contact with organizations and healthcare professionals, arranging for medical aids and adjustments to the home setting, or doing the record-keeping and managing accounts. They also had to assertively call for help in time. Sometimes, a *"battle"* was fought with organizations or professionals, with caregivers being the patient's spokesperson.

Assertiveness could be required in the caring relationship itself too, in confrontation with deterioration. Some partners motivated their loved ones when they themselves no longer could, made jokes or had a laugh to make it bearable:

> *Because I was relatively stronger than the rest of the nurses. I picked her [his wife] up [to put her on the bed pan] and she went with me. I said "Let's go dancing", and then I maneuvered a bit. "A lovely dance." Then she had to laugh again. We had quite a bit of fun with everything. (i27, bereaved husband caring for his wife with a lung disease)*

Some caregivers found it hard to do nursing tasks such as washing because they had difficulties recognizing the naked and vulnerable patient as the partner or parent he or she used to be. For others, the relationship history guided their behavior, for example in taking care of a father who had always been dominant and harsh. Assertively *"switching the button"* from child role to caregiver role was helpful for some daughters to be able to do these tasks. While managing all kinds of practical caring activities could be difficult and tiring, for some, the burden of care lay in relational aspects:

> *I can discuss that with my husband, but sometimes you just notice – oh, what am I talking about? [...] I think, you should see, he looks so sick now, but I start talking about it [son in puberty] who once again did not get up [out of bed], yeah. Those are just normal things that are quite difficult for me. More difficult than cleaning or putting out the garbage cans. (i16, wife caring for her husband with cancer)*

An assertive attitude would also be demanded when several family members jointly provided care for their parent, and conflicts arose: what is best for our mother? Family caregiving could cause fights among siblings, with every child having an individual relationship with the parent while balancing their private life and needs. Sometimes, disappointments arose about the lack of involvement of other family members.

A last possibly tensed front requiring assertiveness was having a (volunteer) job while providing family care. Working and having contact with colleagues could be helpful, but some caregivers were not able to concentrate on tasks as before. Taking time off or receiving caring leave could be difficult. Some caregivers felt that they had to justify the fact they wanted to take sick leave to care for the patient themselves, instead of asking a neighbor:

> *I certainly felt abandoned when I had to defend myself before I could be present at the chemo days. I got remarks like "Do you really have to be there?" "Can't a neighbor or a good friend do that?" [...] It is, of course, completely ridiculous to say to someone who has just had very bad news, "Ask if the neighbor wants to go with her". (i12, bereaved husband caring for his wife with cancer)*

Overall, some interviewees wondered what it would be like for other caregivers, especially the less assertive ones or people with a migrant background:

> *…I am outspoken, I speak the language well, I use the medical terms correctly; and even then I don't get anywhere. How about the others who are not from the western world. [...] There are standards that you have to meet. If you don't fit, you are left out. (i31, bereaved daughter caring for her father with cancer)*

Discussion

This article presented a qualitative analysis of experiences with palliative family caregiving in Dutch home settings, focusing on the role of normativity. In sum, we first showed by whom caregivers feel *called to provide family care*, this study's central theme. Then we showed why people feel called, emphasizing how love, duty, or family dynamics motivate caregivers and in what way the palliative care context intensifies feeling called upon with a sense of urgency. These motives, lastly, explain to what people feel called.

The limitlessness of feeling called to care

Feeling called to care starts not only with the obvious cause, e.g. a patient's need for care as the Informal Care Model[18] suggests, but can also be instigated by health care professionals entering a caregiver's normal life, well-intending family and friends, or it can be self-imposed. We will elaborate on this self-imposed call in the next section. Concerning the call instigated by professionals: previous research shows how professional home care provided security, allowing caregivers and patients to focus more on their family life and prepare for death[30], and offered relief when the right assistance was given on the right time[31]. Our findings confirm this, but also show how professionals entering normal life and routines can instigate a call towards family caregivers, in line with the finding that support sometimes overwhelms or adds responsibilities[31]. Our study also reinforces the idea that previous negative experiences with the healthcare system are motivating the provision of care at home[31], thus showing how caring practices are related to their sociopolitical context. Furthermore, concerning the call instigated by family and friends: caregivers' often close relationship to the patients and their gatekeeper role places them in a complex social web, highlighting the challenge of maintaining relationships during and beyond the dying process[32], in line with what we found to be a call by well-intending but sometimes demanding friends and family surrounding the caregiver and patient.

Although our results show that caregivers often feel constantly called upon, it should be emphasized that this does not necessarily equal feeling burdened. Caregivers often express ambivalent feelings: caring can be a positive, rewarding, or honoring experience, *while* at the same time feeling occupied or exhausted. In the light of sharing last moments and activities, specifically, bereaved caregivers in our study experienced gratitude for the time spent with their partner or family member, and for having been able to persevere and to give everything they could. Previous research also suggests that although feeling burdened by caregiving in a palliative care

context, caregiving can help appreciating 'the little things' and becoming closer to the patient[8], and may be a personally meaningful and transforming experience[33].

From each of the found appearances of feeling called, it becomes clear that caring situations are, as care ethicists argue, *"situations that are given to us, that we find ourselves in, as a consequence of being related"* (p. 527)[34]. The families in this study often found themselves embedded in practices in which they felt called and responsible to care[19]. Our results suggest that – rather than in feeling called per se – the burden of care might lie in the seeming *limitlessness* to which people feel called, i.e. the self-ignorance that lies in being constantly alert and available, attentive to the patient first, and assertive in managing the situation while also facing dilemmas in balancing care with one's other needs. This resonates with the previously investigated all-consuming nature of caring in a situation of serious illness, overwhelming people with its demands [35], *"being on 24/7"* (p. 1232)[31], and with the observation that family care has an impact on a caregiver's whole personal realm, i.e. feeling the physical and emotional burden of home care and experiencing limitations in living normal daily life[16].

Previous research used existential psychology to understand the psychological complexity of caregivers' emotional challenges[36]. Our study, however, adds a further interpretation of caregiver responses to the felt calls, as they seem to be reinforced by the *normativity* essential to the actual caring situation. We suggest that it is the inherent normative nature of palliative family caregiving that invites us to rethink our concept of burden and to challenge our bias towards the negative aspects of caregiving[37, 38].

Normativity and social expectations in a palliative care context

The specific, e.g. palliative, care context seems crucial for understanding caregiver experiences, as it changes relationships[16] and intensifies the felt calls with a sense of urgency of having only one final chance to act. The assertive response to the felt calls we found resonates with findings on taking charge in coordinating home care and making important decisions, in which bereaved caregivers often *"felt thrust into this role without adequate recourses to fulfill its expectations"* (p. 1232)[39]. This reference to expectations underlines how normativity shapes caregiver experiences.

In addition to this specific context, the general normative aspects of love, duty, and family dynamics appeared to be a motivating force behind what caregivers expect of themselves. Interestingly, in family caregiving for people with dementia, the same aspects were found to be interwoven, paralleling the long-term and fluid caregiving role in that context[40]. That long-term care role was found in our

study among participants caring for someone with end-stage chronic obstructive pulmonary disease, as opposed to a role that was more suddenly imposed and more directed towards an imminent death among participants caring for someone with metastasized cancer. Previous studies in palliative care also implicitly referred to normativity, for example in caregivers being determined to care for their loved one at home out of *"love, respect, obligation, or giving back to someone who had given them so much and as a way to honor their ill family member's wishes"* (p. 1232)[31]. This article, however, focused on this normativity explicitly, aiming at providing a more complete overview of the normative aspects motivating caregivers.

A sociological perspective helps deepen our understanding of how these normative aspects are shaping caregiver experiences. Ultimately, family caregiving is an evolving experience, subject to social scripts and expectations[32]. According to sociologist Hochschild's framework about how people make sense of their emotions, we all live by 'framing rules' that govern how we view our situation, and by 'feeling rules' with which we relate to these frames and define what we should or should not feel[41, 42]. Caregivers, seen from this perspective, judge their experiences and feelings based on how well they fit with what they believe is to be expected from a 'good caregiver'[32]. Misfits inevitably lead to feelings of failure, Broom et al. (2019) argue: caregivers' actual but perhaps 'inappropriate' feelings then conflict with their intentions and, sometimes even romanticized, expectations, such as 'till death to do us part'. To a certain extent, these sociological mechanisms showed up in our study. Caregivers used such expressions as 'till death do us part' or 'for better or worse' as a motive to persevere while feeling exhausted, or they wanted to keep doing everything they could to prevent themselves from not feeling guilty afterward (the feeling of failure in Broom's terms). Or they regretted not having been able to be present when their family member died, showing the *"inevitable messiness of the dying process"* (p. 7)[32] which obstructs caregivers' abilities to achieve their desired outcomes.

However, notably, we did not observe many explicit social scripts or expectations in our participant's stories. In comparison with the other three manifestations of feeling called, the fourth – the self-imposed call, stemming from one's convictions and values, seemed less thick. Perhaps, participants could or did not articulate these social expectations by themselves. This can be explained by the fact that our interview questions were focused on personal experiences and more on the relationship between caregiver and patient while less on the phenomenon of caregiving in general.

Our results might imply that the interviewed caregivers were motivated purely intrinsically, as their limitless caring behavior would also suggest; or that these

caregivers did not recognize the social expectations as motivating. This would imply that social scripts and pressure play a more implicit and subtle role.

Further research is needed to investigate a possible difference between reacting to a felt call out of intrinsic motives or because of what is expected. Future research specifically focused on normative aspects might benefit from a serial exploration. Interviewing the same caregivers serially, both before the death of the patient and during bereavement, might allow for showing ambivalent feelings that are suppressed in the dying process and can only be revealed in the bereavement phase[32].

Practical implications: rethinking caregiver support

Studies sometimes show average or median hours of family caregiving per week to indicate burden[11], but invested time is not the only issue nor the most relevant. Caregiving is complex, as we have shown by providing more insight into the inherent normative nature of family caregiving, and is also deeply connected to one's social, cultural, and political context and related feelings of power[19]. Revealing this complexity to caregivers gives counterweight to dominant expectations[32], and may enable them to talk about their seemingly inappropriate experiences or feelings – whether negative or positive. This article's insights also provide us with relevant clues about how to better understand and support caregivers.

As our study showed, caregivers want to stay close to the person they care for, reinforced by normative aspects. In our belief, the related pressure will not likely be resolved by professional home care or respite care. Respite might offer effective relief, provided that it is adjusted to caregiver needs, for example concerning confidence about the patient being in good hands[31]. However, reduction of caring hours or organizing activities outside the caregiver's home to take time-off might not be the only suitable solution for people who do not wish, dare, or feel able to leave their loved one. It was already suggested that being both relative and family caregiver might create a reluctance in asking for professional help, due to the dynamics of these sometimes conflicting dual roles[15]. Our results help us understand this reluctance. Feeling called upon or even burdened does not necessarily mean that caregivers do not want to provide care anymore, or that they wish support or respite. Taking into account the always-existing normative and complex nature of caregiving, support should not be aimed at liberating caregivers from the situation but supporting them in whatever overwhelms them in providing family care.

This implies a responsibility for healthcare professionals regarding the already widely acknowledged need for better collaboration between family caregivers and supporting

professionals in the palliative home setting[9]. They should recognize that caregivers might be determined to enable their partner or family member to die at home, regardless of whether this is burdensome, and align their support with caregivers' own goals in caring at home[31] . In addition, support should enable caregivers to pause and reflect on (and perhaps break) the social rules implicitly guiding their sometimes automatic responses concerning what is expected or appropriate[41]. Although we acknowledge that caring might be something families find themselves in *("you just do that for each other"*, as an interviewee stated) and a caregiver is never a freely choosing person[19], we believe there is some degree of agency in how one provides family care. As our analysis showed a difference between feeling called and how people respond, we suggest that caregivers should be enabled to explore the feeling of being called upon – by whom, to what, and why –, to make them aware that, to some extent, they *do* have choices in how to respond. Such exploration helps to address their immediate and sometimes limitless caregiving behavior but also allows for tailoring support to individuals' needs. After all, family caregiving, regardless of being burdensome, can be an integral, and for some highly important and rewarding part of the relationship between partners or family members.

Strengths and limitations

As many studies focus on either current or bereaved caregivers[32], a strength of our study is that both were interviewed. In the bereaved group, however, it was difficult to distinguish between grief and the impact of the withdrawal of caregiving. The fact that we also interviewed patients has broadened our analysis. Another strength is that our analysis was conducted cyclically, and co-occurred with collecting the data.

A limitation is that it is likely that we have only interviewed people who felt able to talk about their experiences and thus consented to participate. We cannot rule out the possibility that certain caregivers were excluded from our sample, for example severely overburdened caregivers, or partners with a non-loving relationship affecting one's caregiving behavior and feelings. Theoretical sampling of such participants, although important for a grounded theory, turned out to be practically difficult, due to the unsteady and precarious circumstances of the study population, time constraints, and general difficulties in finding participants. Theoretical sampling with regard to the interviewees' personal circumstances (such as being deeply religious or having a troublesome relationship) was hindered by practical difficulties and privacy related issues. It was also difficult to reach interviewees with migrant backgrounds. The ratio of daughter/son in the sample of children who cared for a parent was relatively uneven as well, but at the same time reflects the dynamic of gender in care provision, as recognized in palliative care for

older adults[43] or among people with a migrant background[41]. A further limitation in this regard is that we did not systematically document demographic variables of each participant, such as religion or social background, but left it to the initiative of the participants whether or not to share such information.

Furthermore, the interviews likely prompted participants to give words to their experiences, as interview research often provides people with an opportunity to reflect on their situation[44]. This can be regarded as both a strength and a limitation. Normative aspects especially are often implicit until made explicit by ethical reflection or questions; our participants might not have put this normativity into words by themselves. In addition, it can be hard for people to articulate social expectations[32] or express certain 'background worries' occupying their minds in light of more pressing matters in the palliative care situation[45]. A strength, in this respect, was our background as medical ethicists, leading to sensitiveness to normative aspects in caregivers' daily speech, although we did not specifically ask interviewees about this.

Conclusions

By providing more insight into the inherent normative nature of family caregiving of seriously ill patients within a palliative care context, we have added complexity and depth to our understanding of the much-investigated concept of caregiver burden. Our study indicates that feeling called to care, as far as it is burdensome, cannot – and perhaps should not – be resolved. Caring might be something families just find themselves in due to being related. Rather than in feeling called upon per se, we believe the burden of care lies in the seeming limitlessness to which people feel called. Social expectations play an important, yet often subtle and implicit, role here. Support, then, should enable people to explore the feeling of being called upon – by whom, to do what, and because of which norms or expectations. This helps to tailor support to individuals' needs. Family caregiving, regardless of being burdensome, can be an integral and for some highly important and rewarding part of the relationship between partners or family members.

Acknowledgments

We are grateful to the people who participated in this study for sharing their stories. We also want to thank the healthcare professionals who helped us to include interviewees. A special thanks to prof. Marianne Boenink for her constructive comments on an earlier version of this article.

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Chapter 3

Facilitators and barriers in using comics to support family caregivers of patients receiving palliative care at home: a qualitative study

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Palliative Medicine. 2022;36(6):994-1005.
https://doi.org/10.1177/02692163221093513

Abstract

Background: Family caregiving at home is highly important for people receiving palliative treatment, but also a complex experience, subject to implicit social expectations. This study empirically explored the claim that comics benefit palliative care practice, through evaluating a graphic novel's value as an aid in supportive conversations with family caregivers.

Aim: To identify facilitators and barriers in using *Naasten* (Loved ones), a Dutch research-based graphic novel about family caregivers providing care at the end-of-life.

Design: Qualitative study, following thematic content analysis.

Setting/participants: Three focus groups with family caregiver consultants, palliative care volunteers, and healthcare professionals (total N = 23) who supported family caregivers; and individual telephone interviews with family caregivers to whom the book was presented (N = 4).

Results: Barriers and facilitators related to: (1) the family caregiver, (2) impact on the family caregiver, (3) impact on the conversation between the person who provides support and the family caregiver, (4) their relationship, and (5) the person who provides support. *Naasten* was reported as recognizable and supportive, and powerful in raising emotions, awareness and conversation. Barriers concerned the book's impact due to its style and guidance of a conversation, and doubts about its surplus-value.

Conclusions: Emotionally impactful comics may support bereaved family caregivers, but should be introduced with care among current family caregivers, for example, ensuring a right fit, introduction, and follow-up—while taking into account a caregiver's individual situation, needs, abilities, and affinity with the medium. Comics are preferably used in educational settings, contributing to professional awareness and tailored support of family caregivers.

Keywords
Family caregivers, informal care, graphic novels as topic, comic art, palliative care, education, arts-based research

What is already known about the topic?

- Family caregivers are highly important in the home setting, but may feel the need to be more visible to healthcare professionals and share their experiences
- To provide tailored support, healthcare professionals and volunteers should be aware of the sometimes implicit perspectives and needs of family caregivers
- The medium of comics has potential for palliative care professionals in raising awareness for people's personal experiences

What this paper adds?

- Participants were ambivalent about the value of our graphic novel as an aid to start a dialog with family caregivers about their experiences: the book raised emotions, recognition and conversations, but was also considered too directive, superfluous or even potentially harmful in support of current family caregivers
- Comics can serve as a window into the lives of others, helping readers to understand and reflect upon the dilemmas faced by family caregivers
- Participants emphasized comics' educational value for professionals and volunteers in palliative care

Implications for practice, theory, or policy

- Comics should be introduced with care in conversations with current family caregivers, due to its possible emotional impact and its effect on the conversation between family caregiver and the person who provides support
- Comics may have educational value in raising awareness of the dilemmas of family caregivers, thus enabling people who provide support to assess a family caregiver's needs with more specific questions and thus provide tailored support
- Future research should study comics' value in support practice and in (professional, volunteer, or public) education

Background

In the last phase of a life-limiting disease, especially at home, the role of a patient's close ones is pivotal[1] and intensified[2]. Partners or family members often find themselves in the role of family caregiver because they are related to the patient[3, 4]. Many family caregivers (hereafter: caregivers), however, live in permanent uncertainty about the future, while feeling unprepared for their caring role[5-7] and overwhelmed by the demands of the all-consuming nature of caring[8]. Previous research showed how caregiving impacts normal daily life and social engagements[2, 7, 9], causing physical, emotional, and psychosocial challenges that demand support[10-13].

Professional care for the patient at home can provide relief[14] but only if adjusted to the caregivers' goals and needs in caring[15]. Caregivers often feel the need to be more visible to healthcare professionals and wish to be considered important members of the caring team[16, 17]. Meanwhile, the phenomenon of family caregiving seems complex and subject to implicit social expectations[18]. To make healthcare professionals more aware of caregivers' needs and concerns and to provide tailored support, we developed the Dutch graphic novel *Naasten* (English: Loved ones) which visualizes family care at home for someone with cancer or COPD (Table 1). It has been argued that these graphic stories have potential for palliative care professionals[19-21], in obtaining patients' and families' personal experiences with serious illness and healthcare.

Graphic memoirs on comic artists' own illnesses or caregiving experiences have already been used for promoting awareness, e.g. about mental illness, cancer, dementia, or hospice care[20, 23, 24]. It has been argued that the combination of words and images allows comics to *show* how it feels to be ill or to provide care[25, 26]. This showing – sometimes in just one panel instead of large amounts of text – would enable readers to understand the various layers of often complex experiences[21, 25-29]: via visual metaphors[30] or ambiguities[20] containing multiple messages instead of one absolute meaning[29]. By creating engagement and affect[20, 21, 31], authors argue, comics facilitate understanding the fictional characters' perspective[29, 32, 33]. Thus, comics offer a window into the subjective lives of others[21, 26], which enables readers to understand the inner, intangible aspects of illness experiences [34] and the issues or worries that are not always elicited in clinical encounters[20, 21].

Table 1 | About the graphic novel "Naasten"

Research-based graphic novel

The 230-page Dutch graphic novel *Naasten* (English: Loved ones) was developed by an interdisciplinary team of researchers and two comic artists who were final-year Comic Design students of ArtEZ, a renowned university of the arts in the Netherlands. The graphic novel tells the stories of characters caring for their loved one receiving palliative care at home, based on themes and scenes from our qualitative interview study with 28 family caregivers (mostly partners or adult children) and 9 patients (mostly suffering from end-stage cancer or severe organ failure)[22]. The larger project, of which this study is a part, aimed to visualize the sometimes invisible experiences of family caregivers, thus stimulating conversations within support practice and among the wider public.

Two interwoven storylines

To provide a general and rich account of what it can mean to provide family care at home, two storylines with different palliative care trajectories were scripted: Geert, who cares for his wife with end-stage cancer; and Eva, who cares for her father with severe COPD. Both family caregivers feel called to care ("this is the last thing I can do") while balancing it with work, their own needs, changes in the relationship, involvement of friends and other family members, and professionals entering normal life. Each comic artist drew one storyline, in his/her artistic style; the stories are interwoven in the novel. The stories were developed and written by MH and the two art students, under supervision of the students' art professors who themselves were experienced comic artists. The art students were trained in writing fiction. Please see Supplemental File 1 for examples of the novel's pages.

Feedback and publication

Both content and form of the graphic novel were critically assessed, from early sketches on throughout the development process. Interviewees (bereaved family caregivers of seriously ill people), palliative care professionals, and other professionals within our project sounding board gave feedback during the development process, mainly with regard to the novel's recognizability, realism, and tone. The development of the novel was also artistically assessed by the editorial team that included an experienced comics editor and a graphic designer, and by the art students' art professors. The graphic novel was published commercially by the Belgian-Flemish publisher Oogachtend in 2019. Free copies are available for educational and support purposes (while supplies last).

Contrasting autobiographic comics[28], our graphic novel (Table 1) was based on our in-depth interview research[22], taking up insights from comics-based research[31]. In general, arts-based research (ABR) practices emerged in the last decades as interdisciplinary and rather innovative ways of conducting, analyzing, or representing research through the arts, e.g. poetry, music, dance, theatre, or visual arts[35-37]. Despite the challenges, art-based methods are proposed as worthwhile in qualitative research endeavors and the field of knowledge translation, to understand and communicate complex experiences[35, 37-39]. The potential value of introducing comics in palliative care, specifically, has already been argued[19], but empirical research regarding the use and (emotional) impact of comics in healthcare is lacking[20, 24, 33, 40], palliative care included.

This study aims to identify facilitators and barriers in the use of comics by palliative care professionals or volunteers as an aid in their supportive conversations with caregivers, thus adding to the evidence base for the value of comics in a palliative care context.

Methods

Design and research question

This qualitative study uses thematic content analysis to explore: what are the experienced barriers and facilitators of using the graphic novel *Naasten* as aid in supportive conversations with family caregivers of patients receiving palliative care in the Netherlands?

Setting, recruitment, and participants

Figure 1 provides details of the recruitment and sampling of participants. To cover diverse views and experiences, and account for triangulation, we included both people who provide support to caregivers (hereafter: support participants) and caregivers:

- Following convenience sampling, we included family caregiver consultants, unpaid palliative care volunteers, and various palliative care professionals in three mixed groups (Figure 1, step 1). Volunteers were recruited via volunteers coordinators. All participants received the graphic novel in an introductory training setting.
- These support participants were asked to approach caregivers to whom they had presented the graphic novel, thus leading to inclusion of interested caregiver participants via convenience sampling (Figure 1, step 4).

Data collection

- The introduction sessions with 27 participants (Figure 1, step 2) were guided by GO, an associate professor with ample experience in qualitative research, assisted by the volunteers' coordinator involved in our project and experienced research-assistant MK. These sessions were not audio-recorded or analyzed because of their introductory and training-nature.
- Follow-up telephone interviews with 16 support participants (Figure 1, step 3) were conducted, audio-recorded and summarized by MK.
- We wanted to enable participants to learn from their fellow participants while sharing and discussing their experiences with using *Naasten* in their (volunteering) work. Therefore, we conducted focus groups with the same groups of participants as the introductory sessions, assuming that their interaction would help to explore and clarify the participants' possibly diverse opinions[41]. Three focus groups with 22 participants (Figure 1, step 4), each with between six and eight support participants, lasted 88 min on average (range 77–94, 5 min). These were moderated by GO, using a semi-structured topic guide with open-ended questions (Supplemental File 2) and assisted by the volunteers' coordinator who took field notes. MH also assisted groups B and C.
- Four individual telephone interviews with caregivers (Figure 1, step 4) were conducted by MK, guided by a semi-structured topic guide with open-ended questions (Supplemental File 3) and lasted 32 min on average (range 22–55, 5 min). Telephone interviews were considered to be least invasive.

Data analysis

All focus groups and caregiver interviews were audio-recorded and transcribed verbatim. The transcripts were coded, assisted by ATLAS.ti 8.3 software, following five steps of thematic content analysis[42]. The eventual categories and domains were determined in an iterative process during initial coding, categorizing, and writing of the manuscript; there was no a priori coding framework (Supplemental File 5). To ensure familiarization and generation of initial codes (step 1-2), one focus group transcript and one interview transcript were independently coded by MK and MH. Discrepancies were discussed until consensus was reached and a first codebook with categories (step 3-4) was developed. MK then coded all other transcripts, with MH intermediately checking the codes and making remarks. While producing the manuscript (step 5), and supported by project team review, MK tightened the codebook and defined the categories and larger domains (step 4). Because of this study's explorative nature, data saturation was not expected.

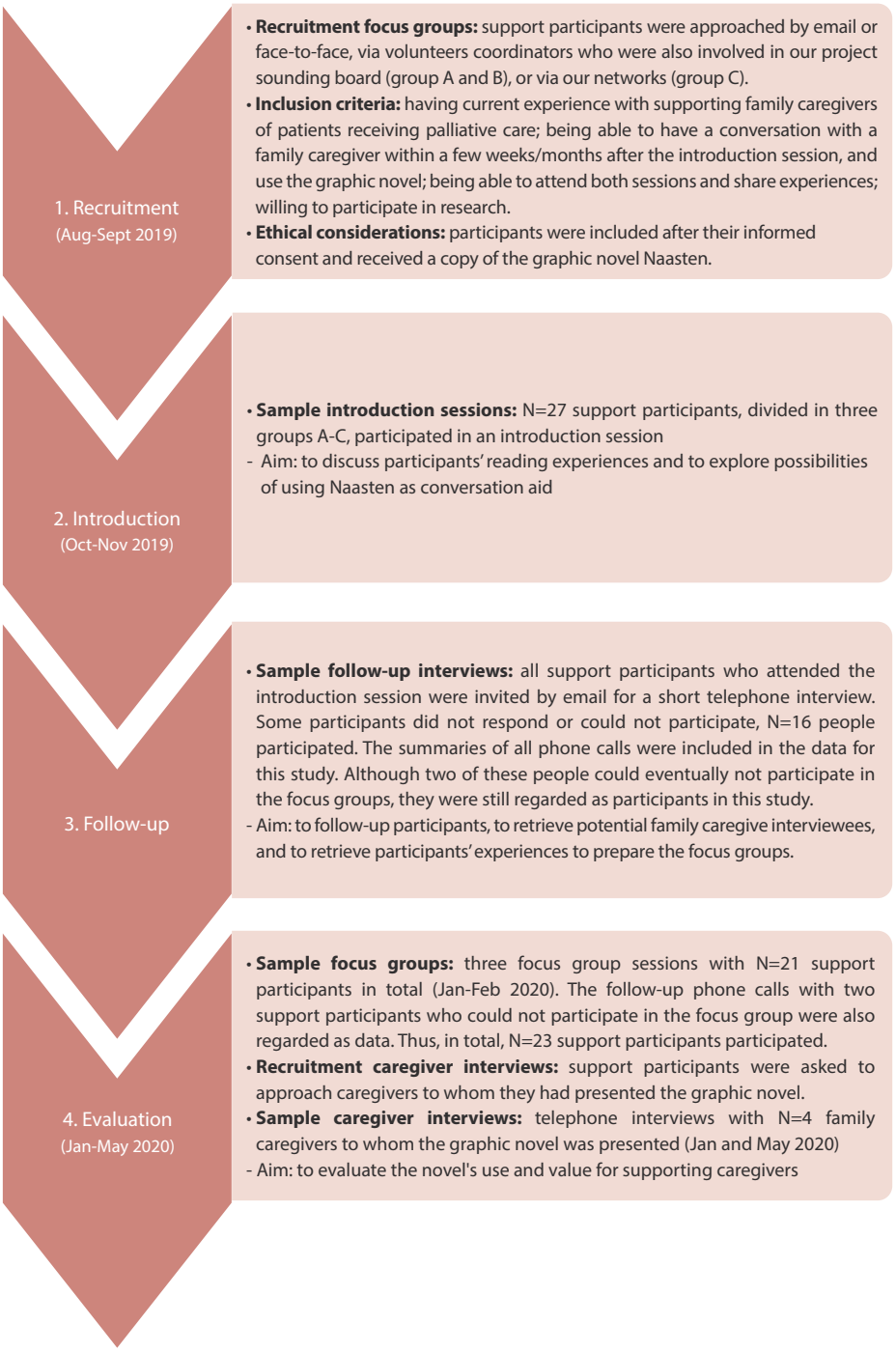

Figure 1 | Overview of the steps in the recruitment, sampling, and data collection

Ethical considerations

Ethical approval was sought from the Research Ethics Committee of the Radboud University Nijmegen Medical Centre (registration number 2017-3415), who determined ethical approval was not required under Dutch law. All participants gave their written consent, after receiving an information flyer. Pseudonymized data were safely stored, as was stated in an approved data management plan. The research was reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) guideline[43] (Supplemental File 4).

Results

In total, 23 support participants (22 female, 1 male) and 4 family caregivers (3 female, 1 male) were included (Figure 1, step 3 and 4; Tables 2 and 3). Six support participants dropped-out after the introduction sessions (three of group B, three of group C) due to personal circumstances or lack of time; two of them still participated in the follow-up telephone interviews.

Overall, the support participants reported diverse ways of using the novel in their daily practices: they browsed through *Naasten* together with caregivers, focused on specific images or storylines, used separate images as association cards, had conversations after the caregivers had read the novel themselves, placed it in a public place (e.g. waiting room, living room or library), or showed it just to colleagues/acquaintances and not to caregivers. Several participants did not use the novel at all. These diverse ways were based on the supporter's considerations about, for example, one's personal opinion about the book, time, the relationship with the caregiver, or the character of the conversation. Some participants reported not having caregivers to whom the book was fitting.

On the one hand, the graphic novel *Naasten* (Table 1; Supplemental file 1) was praised for its originality, recognizability, ability to touch readers, and the portrayal of moments of tender loving care. On the other hand, it was disregarded as being too dark and sad, confronting, complicated due to the two interwoven and rather differently drawn storylines, or just "too much" being a 230-page book.

Based on the diverse experiences, we identified: A) facilitators and barriers in using *Naasten* as conversation aid (Table 4), and B) the novel's potential value in education.

Table 2 | Support participant characteristics

Method	Group	Participants			
		Volunteer	Family caregiver consultant	Social worker in training	Nurse (in palliative or hospice care)
Introduction session (Fig. 1, step 2)	A	4	3		1
	B	6	2	1	
	C				2
Follow-up telephone interviews (Fig. 1, step 3)		6	5	1	
Focus groups (Fig. 1, step 4)	A	4	3		1
	B	3	2	1	
	C				1

Table 3 | Family caregiver participant characteristics

	Gender	Age (mean 65.75)
1	Female	78
2	Female	59
3	Female	63
4	Male	63

General practitioner (in training)	Nursing home physician	Spiritual counselor (in training)	Hospice employee family care	Psychologist	Total *N*
					8
					9
2	1	3	1	1	10
					27
2		2			**16**
					8
					6
2	1	3			7
					21

Table 4 | Overview of facilitators and barriers in using "Naasten" as conversation aid

Concerning these domains: ↓	Facilitators	Barriers
The family caregiver	Comics in general being easily accessible	Misfit with the specific person, phase, or setting
Impact on the family caregiver	Being recognizable and supportive, and raising awareness about family care	Being too confronting and not supportive in conversations
Impact on the conversation between the person who provides support and the family caregiver	– Raising specific conversation topics, deepening the conversation – Raising awareness among people who provide support in palliative care, evoking specific questions	Being too directive and having no surplus-value with regard to topics being discussed
Relationship between the person who provides support and the family caregiver	Existing relationship with the family caregiver, possibility of follow-up	Short-time contact, risk of damaging relationship or image as a professional
Person who provides support to family caregivers within palliative care	Enthusiasm about, access to, and familiarity with *Naasten*	Unfamiliarity with the comics medium

Facilitators and barriers in using *Naasten* as aid in supportive conversations with caregivers

Domain: the family caregiver

Facilitators: comics being easily accessible

Participants looked positively at comics' focus on *showing* caring experiences without using much text. This made the graphic novel easily accessible to caregivers, for example people with language difficulties or a migrant background. It was also suggested that comics could suit caregivers who cannot concentrate on reading texts:

> *Well, I think that is a very good idea because you know, when you are in misery, because you are, you have no… You do not feel like reading. If you read two sentences you do not remember what was written before that. You have no room in your head. And pictures are just easier. So yes, I think it's a really good idea. Because you just…you just can't read. You can't remember it, you can't concentrate at this time, especially when you are feeling that wretched. (family caregiver 2)*

Another suggestion was to use the images as a conversation starter for people who find it difficult to express what is on their minds.

Barriers: misfit with the specific person, phase, or setting

A misfit between the novel's setting and the caregiver's own story and experiences was considered as hindering. Affinity with visual language was also important.

Some support participants were interested in using separate images, others reported their impression that separate images or graphic metaphors were not always understood by caregivers:

> *That gentleman with COPD. Then you see that entire mountain, you know. And someone asked, "Is he still going to Austria, even though he is that sick?" I said, "No. For him it's already a… He's so short of breath, so short of breath. That threshold is already too much for him. Especially if he dreads it that much." (in response to a page of the book) (participant of focus group B) (see Supplemental file 1, image 2)*

Domain: impact on the family caregiver

Facilitators: the novel being recognizable and supportive, and raising awareness
Some participants found *Naasten* less representative for the loving moments in care, others thought it rightly depicted the *"horrible time"* of caring in the last phase. In general, the novel was considered recognizable by both support participants and caregivers. This was supportive to some:

> *"Deeply impressed with the way feelings are expressed here. I myself had to leave my mother behind after an illness. (…) The illustrations recreate this feeling. It is somehow good to know that this feeling is also experienced by others. Recognition. Very beautiful and valuable." (during the course of focus group B, a participant reads out loud what an acquaintance wrote to her about the book)*

It was both hypothetically argued as well as reported that this recognizability can stimulate caregivers to ask for help in time when feeling overburdened. The novel was considered helpful for caregivers to reflect and raise awareness of their needs:

> *Participant X: Sometimes family care sneaks up on you and is a matter of course. And it is almost an obligation because it comes about naturally. And the person involved does not see it as taxing at all. But the outside world does see it like, "Hey..." Then you could also say, "Well, look, this is how others deal with it, or you can solve it like this. You don't have to do it all by yourself." And then a book like this can also…*
>
> *Participant Y: ... Hold up a mirror. Make you reflect. (participants of focus group A)*

Barriers: the novel being too confronting and not supportive
A downside of the novel's recognizability was that its display of deterioration and death was reported as potentially too confronting for current caregivers, especially when already overburdened. Some caregivers reported feeling miserable after reading, or even being appalled by the black-and-whiteness of one storyline:

> *No, if it should be a book to support me, then I think, never mind, because it made me very sad and glum. Especially because of the drawings made by one of the two. There are two illustrators and one has a very… The drawings are sketched very harshly and are dark and depressing. Without really looking at*

> *the details of the drawing, but just by looking at the paper it was drawn on, it gave me a very gloomy feeling. (…) I can't say that I remember anything. Not the recognition or the support it is meant to give, it rather made me feel down. I think that's sad. (family caregiver 3) (Supplemental file 1, image 3)*

Due to the evoked emotions, support participants reported being hesitant in using *Naasten* as an aid in their conversations. We observed a tendency among study participants to protect caregivers, fearing to confront them and worsen their situation:

> *Yes, I also thought a little like, "hey, isn't it too confrontational? Am I not touching on too much?" Because I also thought that the darkness, that it is very confronting. And I'm already touching on a period of major grief, so am I not making it even worse? But then I also think that sometimes it can be a good thing that you might make matters even worse at that moment. And we are often a little hesitant about that, but that is when you can dig deeper. (participant of focus group A)*

Participants argued that *Naasten* would better suit bereavement support.

Domain: impact on the conversation between the person who provides support and the caregiver

Facilitator: raising specific conversation topics, deepening the conversation

Using separate images as associative cards in a caregiver support group was found to stimulate a conversation about each other's experiences. According to a volunteer, a young caregiver criticized the novel's clichés but also elaborated on how her experiences were different than the character's. Another volunteer explicitly reported having in-depth conversations due to certain images:

> *Well, for example, at one point there was a very profound conversation with the young caregiver about the question of guilt. I don't know that if I hadn't had a picture of that daughter with her father, whether you could have dug that deep. (….) Like that young caregiver, she clearly looked at the dark images of the daughter with the father. And that was her situation, and so at one point she got around to well, this story, "I have to go there because …" (…) Well, and so the story was told, "I should have stayed with you on the last day. I left in the morning, and my father was not well. And I did pass by the general practitioner, but he actually really didn't want me to, and my father said I had to go to school. So, I did go to school. And then you come*

> *back in the afternoon and he's lying at the bottom of the stairs." That's when the feeling of guilt occurred, but it was only because of this picture, then it came up (in response to a page of the book). (participant of focus group A, volunteer) (Supplemental file 1, image 4)*

Facilitator: raising awareness for supportive people, and thus evoking specific questions

Most participants were ambivalent about the novel's value as an aid in supportive conversations. However, they reported its potential for raising (renewed) awareness of caregiver experiences and needs among professionals, volunteers, or family members surrounding a caregiver. Certain experiences for which one might have a blind spot might be addressed in a conversation with the caregiver when thought necessary or helpful:

When we have a conversation, it may well be that we also have a blind spot or that it does not come up spontaneously. (…) But this [book, MH] is based on the interviews you've done. So, those are subjects or topics that people have mentioned. I don't know whether I, as a care provider, would spontaneously bring up all these different subjects or spot them easily. I can imagine that there are topics in the book that otherwise would not surface. Something someone is still struggling with, for example. (participant of focus group C) (Supplemental file 1, image 5)

Barriers: too directive and having no surplus-value

Using *Naasten* instrumentally as a conversation aid felt unnatural considering the risk of steering the conversation with a caregiver too much. According to both support and caregiver participants, people should *listen* first to what is on another one's mind, instead of making interpretations about the other's feelings, or starting a conversation with prescribed themes:

> *Well, what my neighbour [fellow focus group participant, MH] said about 'unnatural', I sometimes felt that too. In the sense of…well, my first inclination when I'm talking to someone is to just listen and see what comes up. What is going on with people, to be very open and to not directly offer something. I can imagine that if you are in this situation, that when people themselves might come out with some of the dilemmas that play out in that book, that you then grab that book. I haven't had that happen lately. (participant of focus group C)*

Some reported not needing the book to discuss certain themes.

Domain: relationship between the person who provides support and the caregiver

Facilitators: existing relationship with the family caregiver, possibility of follow up

Support participants emphasized the importance of having an existing relationship with the caregiver, enabling them to "sense" if *Naasten* would fit the setting and a caregiver's current situation.

> *I also recognize the hesitation mentioned before, like, do you start out with your own approach or have you come to listen to someone? Only this lady started talking about her sister who had just lost her husband to cancer. She came from [a country abroad, MH] and so her sister was also in [country abroad, MH]. So, she was a relative at distance from her sister. I said, "I have a book in my bag, in which both stories, your story and your sister's story, partly come together and run side by side." So, then we got into a conversation about this book. So that was great. (participant of focus group C)*

It was also recommended to take enough time for the conversation, and to read the novel together instead of handing it out to caregivers – unless one would assess the caregiver being capable of handling the possible emotional consequences. Nonetheless, follow-up care should be guaranteed:

> *It also seems to me that that is actually a requirement to give the book, well, to people, to talk to people about it. Anyway, at the very least you should say, if you want to talk about it, I'm always there for you or something along those lines. (Interviewer: Yes, so the possibility to talk about the book after it has been read should always be there.) Yes, and then also about yourself, because that is, ultimately, what it is all about. That you recognize yourself in it and can do something with it. And in order to achieve that, I don't think you should hand out this book just like that. (family caregiver 1)*

Barriers: short-time contact, risk of damaging relationship or image

A conversation about the novel was regarded as 'going deep' and therefore unsuited for first, one-time, or brief contacts, without follow-up:

> *I just have short-term contact with people. The moment - I can't give this book to someone I'm just getting to know. I am a caregiver consultant.*

> *(…) Sometimes you dig down deep, but then this is not the first thing you show them, not to someone you don't know. (…) Because at first you have to give them the space to tell their own story. So, you have to get to know them. This goes in-depth immediately. I want to be a little careful with that when it comes to the initial conversation. (…) The way I see it is that you simply can't do everything in one conversation. I want to protect people from that. People are already in over their heads. They have to tell their own story first. Do you also want to immediately share with them the deeper layer, revealed by the topics of the stories in this book? I actually don't agree with that. (participant of focus group B)*

Some feared using the book would trouble or even damage their relationship with the caregiver, or their image as a professional.

Domain: the person who provides support to caregivers within palliative care

Facilitators: enthusiasm about, access to, and familiarity with the book

Facilitating for integrating *Naasten* in supportive conversations was participants' own enthusiasm, curiosity regarding its possible value, familiarity with its themes, and always carrying the novel with them. Experience with showing the book to caregivers made it easier to suggest it to others:

> *It is essentially about giving and about doing. And if you also have it [the book, MH] with you and you think at that moment… I always carry something with me, like cards for example, but I could also use this book. (…) Yes, it has become a little easier to show it because you've used it more often now. (participant of focus group A)*

Barriers: unfamiliarity with the medium

Some support participants questioned the novel's surplus-value in comparison to other methods or their professional skills. A barrier was that the comics medium was relatively new. Some felt hesitant in using the novel as opposed to trusting their own (more guidable) conversation techniques:

> *Participant X: Well, maybe there is also this fear that is not really necessary. Of course you know about your own … You can rely more on your own conversational technique or communication and you know you can guide it more easily than sharing something that might …*

> *Participant Y: That it doesn't work at all, for instance. That he thinks: "What are you showing me this time?"*
>
> *Participant X: Yes, exactly! And that you think, "Oh, yes. Well." And then you can imagine that it will be uncomfortable – so to speak. (participants of focus group C)*

The potential value of the graphic novel in education

In all focus groups, participants considered *Naasten* to be informative for a variety of people providing home-based palliative care. Its potential value as an educational tool for professionals or volunteers in training was also emphasized by caregivers themselves, in raising awareness concerning their presence and needs:

> *"I speak from experience and even got very emotional when reading the book, it immediately brought me back to that 'hopeless' and extremely busy period when nothing else existed but caring for and organizing. I felt myself once again being pulled apart by my company, my family and my father who needed so much attention and care. (…) I advise anyone who will have to deal with family care in the future (and that includes all of us in the Netherlands) to read this book to be better prepared for what is to come. It would therefore be great if this is already available at schools and during training." (Participant of focus group B reads out loud during telephone interview what an acquainted family caregiver wrote to her)*

Consequently, it was argued, *Naasten* might enable students, for example in nursing, to ask more specific questions and provide better support:

> *The book can help people in training to see which topics are at play and once the professionals start working with family caregivers, he or she can draw on that and think, hey, that subject was mentioned in the book. I have to dig a little deeper. What specific questions can I ask to help this caregiver? (family caregiver 4)*

Discussion

Main findings

Based on a qualitative analysis of facilitators and barriers in using the Dutch graphic novel *Naasten* about family care at home (Table 1, Supplemental file 1), this study offers some support for the claim that comics can benefit palliative care practice. Participants were ambivalent about its use as an conversation aid: *Naasten* was recognizable, raised emotions, awareness, and (in-depth) conversations, and may support bereaved caregivers; it was also reported to be potentially harmful due to its emotional impact, too directive in the conversation, or superfluous. Comic art should thus be introduced with care among caregivers. Preferably, comics are used in educational settings, contributing to professional awareness and tailored support of family caregivers.

What this study adds

With respect to comics' potential for palliative care[19, 21] and specifically for supporting family caregivers, our results suggest that, first, *Naasten* indeed served as a window into the lives of others[21,26], raising issues or conversations that probably would not have taken place otherwise. Comics may help caregivers reflect on often-implicit norms and values, which is deemed important[44] as family caregiving is shown to be subject to social expectations[18].

Secondly, comics should be introduced with care. Comics' direct way of showing experiences[25,26], without apology[45], evoked contrasting responses. *Naasten* was found original and recognizable, and therefore supportive. Participants, however, also considered the novel too directive, simply superfluous, or even potentially harmful due to its emotional topics. A barrier for its use in supportive conversations was the impression that *Naasten* was too confronting for sometimes already overburdened caregivers. Previous research also reported this critique on distressing and pessimistic health comics[29]. An important question for support in palliative care is whether confrontational comics actually *"enhance (rather than dismantle) existing coping strategies"* (p. 7)[46], thus contributing to the quality of life of patients and families[47].

Third, comics' seeming accessibility can be questioned. Participants suggested that the medium may suit overburdened caregivers unable to concentrate on much text. Some caregivers, however, showed difficulties with understanding visual metaphors[30], contesting the argument that the medium can communicate complex things in a concise way[27]. Comics demand active interpretation of the narrative and

everything that is *implied*[20, 26, 29, 45] – having to slow down to fully grasp a comic[48] may not fit a turbulent palliative care context.

Overall, our results indicate that *Naasten* raises emotions and conversations, and may support bereaved caregivers. We should, however, not overestimate the possibilities of using emotionally impactful comics in supportive conversations with people who currently provide family care. Their value in education may be greater. It has already been argued that art can be powerful in educating healthcare professionals[38, 49-51]. Comics, specifically, may create awareness and understanding through using characters and narrative[29]. There may also be more time in educational settings, compared to palliative care practice, to reflect on comics and their (implicit) meanings. We hypothesize that by gaining a better understanding of caregivers' perspective through reading comics such as *Naasten* in an educational setting, people who provide support are enabled to assess an caregiver's perspective and needs and with more specific questions. Thus, we argue, reading comics may contribute to better supportive care and to the reported need of caregivers to being more visible to healthcare professionals[16, 17].

Future research

The results of this explorative study provide sufficient reason to further investigate comics' application and value, mainly in palliative care education. Our participants were experienced professionals and volunteers who recognized the graphic novel's scenes and themes in their daily practices. Future research should be focused on students or volunteers in training[19], e.g. fostering sensitivity for the perspective of partners and families within palliative care. Another area is public education and awareness, as most investigated palliative care education programs are targeted at healthcare professionals and caregivers[52].

Implications for practice

Emotionally impactful comics, such as *Naasten*, may support bereaved caregivers. When considering using comics in conversations with current caregivers, we would advise to assure:

- a right fit between the comic's content and the caregiver's situation, setting, and phase, which requires a time investment and sensitivity to both the comic's content and the individual's situation[53]
- a caregiver's affinity with the visual medium
- a caregiver's ability to view or read possibly confrontational images
- a careful introduction and follow-up, possibly within a trusting (long-term) relationship
- a conversation directed by what prompts the caregiver to react

Furthermore, we have experienced that stimulating conversations among professionals and volunteers works best when discussing pages from the novel in-depth:

1) What do you see?
2) What do these panels evoke?
3) What does this tell you about family caregiving, and about caregivers' moral dilemmas and values?
4) What do you gain from this for your daily practice?

Strengths and limitations

To our knowledge, this study's strength is that it is the first to empirically explore the use of comics within the context of palliative care. A limitation was this study's explorative nature and the heterogeneous use of our novel. This problematized its generalizability, similar to previously described difficulties with measuring 'impact' in an interdisciplinary art-science project[54] and consistently replicating artistic interventions[55]. Another limitation was the relative brief window of opportunity in palliative care settings for implementing new support methods[46], such as our novel, hindering a precise sampling of participants and making us dependent on convenient sampling. Lastly, the volunteer coordinators involved in our research project recruited participants they already knew. This hindered a systematic collection of sociodemographic variables and may have caused a bias.

Concluding remarks

Through *showing* (instead of telling about) lived experiences of family caregivers, our graphic novel can be used as an aid in supportive conversations, to raise certain topics with family caregivers. Such emotionally impactful comics, however, should be introduced with care, e.g. ensuring a right fit, introduction, and follow-up – while taking into account the caregiver's individual situation, needs, abilities, and affinity with the medium. Comics are preferably used in educational settings to stimulate a dialogue about family caregiving among healthcare professionals and volunteers, contributing to their awareness and tailored support of family caregivers.

Acknowledgements

We are grateful to comic artists Melanie Kranenburg and Niek van Ooijen (former students of ArtEZ University of Arts in Zwolle, the Netherlands), who co-authored the graphic novel on which this study was based. We thank all participants who shared their opinions and experiences with reading and using the book. Thanks to prof. Marianne Boenink for her constructive comments on our manuscript.

Supplemental file 1

Examples of pages from the Dutch graphic novel *Naasten* about family caregiving at home

Information about the book

The 230-page Dutch graphic novel *Naasten* (English: Loved ones) tells the stories of characters caring for their partner or family member receiving palliative care at home. It was based on themes and scenes from the qualitative interview study[i] that was part of our larger research project. To provide a general and rich account of what it can mean to provide family care at home, two storylines with different palliative care trajectories were scripted: Geert, who cares for his wife with end-stage cancer; and Eva, who cares for her father with severe chronic obstructive pulmonary disease. Both family caregivers feel called to care ("this is the last thing I can do") while balancing it with work, their own needs, changes in the relationship, involvement of friends and other family members, and professionals entering normal life. Comic artists Melanie Kranenburg and Niek van Ooijen each drew one storyline, in their own artistic style; the two stories are interwoven in the novel. The graphic novel was published commercially by the Belgian-Flemish publisher Oogachtend in 2019. Free copies are available for educational and support purposes (while supplies last). The art work in this supplemental file was submitted with permission of the comic artists.

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i. Haan, M.M., Olthuis, G. & van Gurp, J.L.P. Feeling called to care: a qualitative interview study on normativity in family caregivers' experiences in Dutch home settings in a palliative care context. BMC Palliative Care 20, 183 (2021). https://doi.org/10.1186/s12904-021-00868-2

Image 1: Cover of the book, showing the title *Naasten* (Loved ones) and the two main characters

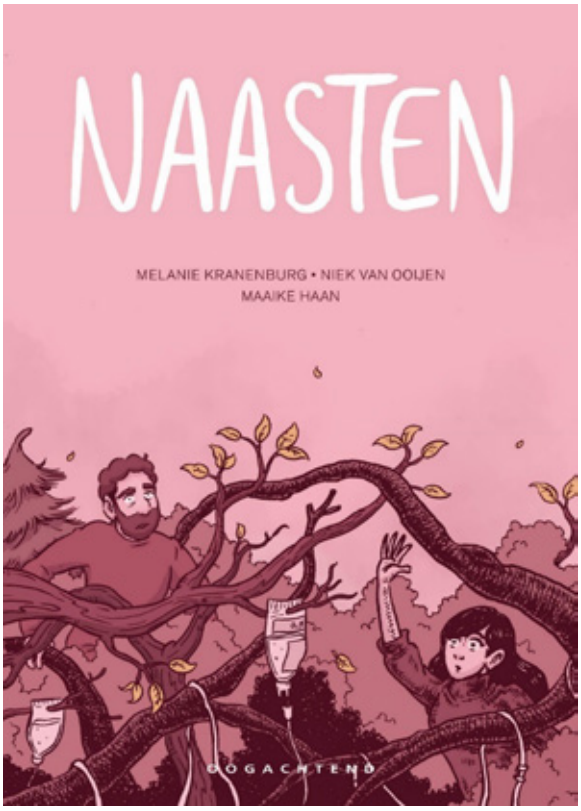

Image 2: Use of visual metaphors in the storyline of daughter Eva and her father with a lung disease ©Kranenburg, Van Ooijen, and Haan (2019), p. 116-117

(Father: "Easy … Sure … I can … walk by myself …")

Image 3: Two storylines drawn in different styles, depicting Geert caring for his wife and daughter Eva caring for her father ©Kranenburg, Van Ooijen, and Haan (2019), p. 62 and p. 119

Image 4: Daughter Eva responding to an urgent call from her father in the middle of the night, reflecting the pressure in family caregiving in the last phase of life

(Eva to her partner: "I have to go there.")

*(Father: "Will you stay?"
Eva: "If you want me to. Sure.")*

Image 5: Example of things a family caregiver may struggle with
©Kranenburg, Van Ooijen, and Haan (2019), p. 89

("It is like being in an unfamiliar forest of pain and misery.")

Supplemental file 2

Topic guide for our focus groups with professionals and volunteers who supported family caregivers

- How did you use the graphic novel Naasten?
- What were your experiences with presenting Naasten to family caregivers?
    - What was facilitating or hindering?
    - How did the people who received the novel respond?
- What differences did you experience between what you expected and what really happened?
- For what type of family caregiver would this book be suited to use? How do you judge to whom the book is suited and to whom not?
- In what way can this book be valuable? Can you give concrete examples where a conversation about a certain topic became easier?
- Do you have recommendations for using the novel?

Supplemental file 3

Topic guide for our telephone interviews with family caregivers

- Personal situation: what is your relationship with the person you are/were taking care of? How would you describe the caring situation?
- Experiences with the graphic novel Naasten
    - How was the graphic novel Naasten presented to you?
    - Did you read the novel? What did you feel about reading it?
    - What did reading the novel evoke?
    - In your opinion, what was positive about the novel? What was less positive?
    - In case of retrospective interviews: do you think your experiences would have been different if you were still taking care of your loved one?
- Experiences with the conversation based on the graphic novel
    - Did you have a conversation with the volunteer/professional? What did you discuss? Did the novel help to begin the conversation?
    - Did the novel had surplus value in the conversation? If yes, in what way?
    - What do you think about the fit of Naasten as means to start a conversation or to discuss certain topics?
    - Do you have recommendations for using the novel?

Supplemental file 4

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5-6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	5-6
Occupation	3	What was their occupation at the time of the study?	5-6
Gender	4	Was the researcher male or female?	Male: JvG, GO; Female: MK, MH, volunteers coordinators
Experience and training	5	What experience or training did the researcher have?	5-6
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	15
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Participants were informed about reasons for the research and the personal affiliations of the researchers
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	None
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5-6

COREQ Checklist Continued

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5-7
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5-7
Sample size	12	How many participants were in the study?	6-9
Non-participation	13	How many people refused to participate or dropped out? Reasons?	7, 9
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	Volunteers coordinators' or researchers' workplace
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	No, 5-6
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	8-9, 14-15
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5-6, Supplemental files 2 and 3, not pilot tested
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	No repeat interviews
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the interview or focus group?	5-6
Duration	21	What was the duration of the inter views or focus group?	5-6
Data saturation	22	Was data saturation discussed?	6
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	6
Description of the coding tree	25	Did authors provide a description of the coding tree?	Yes, in Supplemental file 5
Derivation of themes	26	Were themes identified in advance or derived from the data?	6
Software	27	What software, if applicable, was used to manage the data?	6
Participant checking	28	Did participants provide feedback on the findings?	No

COREQ Checklist Continued

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	10-13
Data and findings consistent	30	Was there consistency between the data presented and the findings?	10-13
Clarity of major themes	31	Were major themes clearly presented in the findings?	10-13
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	10-13

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Supplemental file 5

Coding tree

Explanatory note
The following pages present an overview of the coding tree. In our thematic content analysis following Braun & Clark (2006), we did not use an a priori coding framework. Rather, the codes and categories were determined during an iterative process of initial coding and categorizing. We thereby focused on which factors were positively or negatively contributing to using the graphic novel as conversational aid.

Initially, the codebook consisted of the following categories: Content of the book, Form of the book, Methods of using of the book, Barriers in using the book, Facilitators in using the book, Impact of the book, Needs of the participants, Suggestions of the participants, and Target audiences for the book. When critically re-reading the quotations associated with the codes and categories during our writing down of the results, we renamed or broke down some of the initial codes, specified the categories, and identified the larger domains to point out a pattern with regard to which factors were facilitating or hindering for what and to whom. This explains why the name of some of the initial codes in this coding tree do not, on first sight, fit the related category or larger domain. The re-arrangements were discussed by first coder MK and first author MH, and also within the peer group of the other authors. The initial codebook (in Dutch) is available on request.

Coding tree Continued

Domains	Categories	Codes

1. The family caregiver	Facilitator: Comics in general being easily accessible	• Form of the book: remarks about accessibility
		• Content of the book: remarks about accessibility
		• Facilitating factor: absence of (difficult) language
		• Impact of the book: the book evokes feelings*
		• Content of the book: images have more impact than text
		• Actual use of the book: importance of examining and 'sensing' the fit with the family caregiver*
		• Opinions about (hypothetical) target audiences
		  o Background of the family caregiver
		  o Migrant family caregivers
		  o The book has no language barrier
		  o People with low literacy skills

	Barrier: Misfit with the specific person, phase, or setting	• Actual use of the book: importance of 'sensing' the fit with the family caregiver*
		• Facilitating factors:
		  o Similar setting
		  o Story of the family caregiver shows similarities with story of the book
		• Hindering factors:
		  o Lack of knowledge about the family caregiver's situation
		  o Inappropriate setting or type of relationship
		  o Insecurities about the impact of the book
		• Opinions about (hypothetical) target audiences
		  o The fit with the phase of the illness of the care receiver
		  o Family caregiving in a non-palliative phase
		  o People with a chronic illness
		  o People with a mental illness
		• Actual use of the book: remarks about using separate images without context*
		• Content of the book: remarks about metaphors

Coding tree Continued

Domains	Categories	Codes
2. Impact on the family caregiver	Facilitator: The book being recognizable and supportive, and raising awareness about family care	• Positive impact of the book o The book evokes associations in the family caregiver o The book provides recognition for the family caregiver o The book is recognizable* o The book touches emotionally* o The book evokes feelings* o The book is supportive o The book provides bereavement support o The book raises awareness among family caregivers to ask for help o Reading the book leads to action o Reading the book leads to accepting help of others • Actual use of the book: conversation with help of the book increases recognition of the family caregiver
	Barriers: The book being too confronting and not supportive in conversations	• Negative impact of the book o The book is harsh, confronting, shocking, too direct o The book is depressing, gloomy, negative o The book evokes resistance/aversion in the family caregiver • Negative aspects of the content of the book o The black-and-white storyline is not representative, too negative, unloving* o Absence of beautiful moments in family caregiving* • Hindering factors: o The supporter wants to protect the family caregiver from becoming overburdened o The dark storyline is confronting o Insecurities about the impact of the book* o The book is not recognizable

Coding tree Continued

Domains	Categories	Codes
3. Impact on the conversation between the person who provides support and the family caregiver	Facilitators: Raising specific conversation topics, deepening the conversation	• The book is helpful as a conversation aid • Facilitating factor: the book helps in keeping the focus of the conversation on certain topics
	Facilitators: Raising awareness among people who provide support in palliative care, evoking specific questions	• Positive impact of the book o Raises awareness among professional caregivers o Raises awareness among volunteers o Raises awareness among healthcare students o Raises awareness among people surrounding the family caregiver o Colleagues share their own experiences with each other via the book • Opinions about (hypothetical) target audiences: people surrounding the family caregiver
	Barriers: Being too directive and having no surplus-value with regard to topics being discussed	• Hindering factors o The book is too directive and unnatural o The book is not useful for the conversation • The book is not helpful as a conversation aid • Negative impact of the book: the book has no surplus-value
4. Relationship between the person who provides support and the family caregiver	Facilitator: Existing relationship with the family caregiver, possibility of follow-up	• Actual use of the book: importance of examining and 'sensing' the fit with the family caregiver* • Facilitating factors: o Knowing the family caregiver well* o Importance of trust in the professional caregiver or volunteer o Time • Actual use of the book: importance of follow-up
	Short-time contact, risk of damaging relationship or image as a professional	• Hindering factors: o Time o The book goes 'too deep' for first contact o Insecurities about follow-up o Risk of damaging trust and relationship • Negative impact of the book: the book raises resistance/aversion in the person who provides support

Coding tree Continued

Domains	Categories	Codes
5. Person who provides support to family caregivers within palliative care	Methods of presenting and using the book in conversations with family caregivers (NB: as elaborated in the introducing paragraph of the Results section)	• Actual introduction of the book • Actual use of the book • Methods of using the book
	Opinions about the content and form of the book (NB: as elaborated in the introducing paragraph of the Results section)	• Positive impact of the book o The book is recognizable* o The book touches emotionally* o The book evokes feelings* • Positive aspects of the content of the book o Beautiful o Shows beautiful moments in family caregiving o Colored storyline and the tender loving care this storyline shows o Positive remarks o Title o Complementary storylines • Negative aspects of the content of the book o The black-and-white storyline is not representative, too negative, unloving* o Absence of beautiful moments in family caregiving o Complicated because of the storylines being mixed together o The aim of the book is unclear o The book is unclear o The book is 'too much' or too thick o The book lacks information • Content of the book: remarks about specific scenes or themes • Content of the book: remarks about the black-and-white storylines • Form of the book: preference for text • Hindering factor: the storylines being mixed together

Coding tree Continued

Domains	Categories	Codes
		• Needs of the participants: o The book should have shown more beautiful things and more light-heartedness o The black-and-white storylines should have been less dark o The book should have shown certain themes o More information needed about definition of family care and aim of the book o More text and explanation needed o Index of the book needed o Guide for using the book needed o Separation of the two storylines o Separate images needed o Separate images without text needed o A second book is needed
	Facilitator: Enthusiasm about, access to, and familiarity with *Naasten*	• Facilitating factors: o Having your own enthusiasm and curiosity regarding the book's possible value o Knowing the book well o Having the book's themes in the back of your head o Always carrying the book with you o Own experiences with family caregiving o Having experience with using the book o "Just do it"
	Barrier: Unfamiliarity with the comics medium	• Hindering factors: o Not needing the book as a conversation aid o Having more trust in one's own familiar conversational techniques than in this medium

Coding tree Continued

Domains	Categories	Codes
	Target audiences for the book (supporters who could benefit from reading the book) (NB: as elaborated in section B of the Results section, about the novel's potential value for education)	• Target audiences o People who provide support: professional caregiver o People who provide support: volunteer o Healthcare students or professionals in training o Importance of age • Positive impact of the book o Raises awareness among professional caregivers* o Raises awareness among volunteers* o Raises awareness among healthcare students* o Raises awareness among people surrounding the family caregiver* • Suggestions of the participants: using the book in education • Hypothetical methods of using the book

*Several codes fitted multiple facilitators or barriers and, hence, are reported multiple times in this coding tree.

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Chapter 4

Bridging comic art and research: lessons from an interdisciplinary collaboration project in a palliative care context

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Medical Humanities. 2024;50:475-485.
https://doi.org/10.1136/medhum-2023-012750

Abstract

The Dutch graphic novel *Naasten*, about palliative family caregiving, is the product of an interdisciplinary collaboration between researchers and two comic artists. This paper aims to present lessons, reflections and practical recommendations for other researchers interested in adopting (comic) arts-based research methods, in which artistic methods are used as novel ways for generating, analysing, interpreting or representing research data.

Our project started with the goal of translation: we aimed at representing research findings into a more accessible, visual and textual form to stimulate discussion and reflection outside academia on moral challenges in family care. This was inspired by comics' hypothesised potential to show complex and embodied experiences, thus enabling more understanding in readers and offering powerful science communication tools. Although this goal of translation was realised in our project, we learnt along the way that the project could have benefited from a more explicit focus on interdisciplinarity from the start and by monitoring the interdisciplinary learning opportunities throughout the project. The following issues are important for any art-research collaboration: (1) an interest in and acknowledgement of each other's (potentially diverging) aims and roles: all parties should—from the start—commit themselves to interdisciplinary collaboration and to exploring the added value of using each other's methods, thereby finding a common methodological ground and language; (2) a continuous discussion of the sometimes contrasting approaches between artists and researchers: differences in using theory and story may result in different criteria for creating good art. When balancing scientific and aesthetic aims, the trustworthiness of the art work should remain an important criterion; (3) an awareness of the potential of interdisciplinary collaboration to offering new perspectives on one's scientific data collection and analysis, for example, providing other conceptualisations or indicating blind spots, provided that artists are involved in the early phases of research.

Introduction

This paper is about a collaboration project between researchers and comic artists, in developing a graphic novel aimed at stimulating discussion and reflection on family caregiving in the context of palliative care (Box 1).

Previous empirical research into this topic showed how the role of family members in palliative care is both pivotal and intense, especially at home[1, 2]. Caring for someone close, such as one's partner or parent, impacts normal daily life and social engagements[3, 4] causing physical, emotional and psychosocial challenges that demand support[5-8]. Family caregiving is complex and subject to implicit social expectations[9]: many family caregivers become overwhelmed by its all-consuming nature[10], but still feel called to maintain care for their partner, parent or relative[11]. They also wish to be more visible to healthcare professionals and acknowledged as important members of the caring team[12, 13]. To make these caregivers' perspectives, and their often implicit and moral challenges and ambivalences better understandable and literally more visible to a broader public, we worked together with two comic artists to create a graphic novel about this topic (Box 1) based on our interview research[11].

The development of this graphic novel triggered reflections on the interdisciplinary character of such an art-research collaboration. In interdisciplinary work, the concepts, theories and methodology of different (academic) disciplines and the insights of these disciplines are integrated[14]. In hindsight, we feel that framing it as 'interdisciplinary' from the beginning would have strengthened our project, making it more well-considered from the start. In this paper, therefore, we aim at reflecting on our research-comic art collaboration, to draw lessons to support other researchers with similar aspirations.

Comic art in healthcare

Arts-based approaches are increasingly used in (nursing) education to support learning and praxis[15-17] and they are advocated as powerful tools for healthcare professionals to better understand and empathise with other people's experiences[18]. Comics in particular can be valuable. Lately, there has been an increase in comics in healthcare: short instructional ones designed to educate patients[19], and more extensive, novel-like graphic memoirs on artists' own illnesses, suffering or medical experiences[20, 21]. The latter, also labelled 'graphic pathographies'[22], have already been used for promoting awareness and understanding, for example, about mental illness, diabetes, HIV, cancer, hospice care or dementia. Advocates praise

them for really *showing* (rather than telling about) complex and embodied illness and caregiving experiences[23-25], by using visual symbols and metaphors[23-26]. This enables readers to understand the inner, intangible aspects of illness experiences[27]. Various healthcare professionals, comic artists and scholars have joined 'Graphic Medicine'[25, 28], a community expressing comics' role and value in the study and delivery of healthcare.

Rationale, aims and results of our graphic novel project

The three-step project (see Box 1 for more details) originated with the researchers, with a project proposal that focused strongly on educating a broad public outside academia by developing a graphic novel about family caregiving in the context of palliative care. The research team members were all ethicists, who specifically aimed to show the often invisible moral challenges and ambivalences in caring for a loved one, also with the intention of discussing these graphics in our (ethics) education. First, the project started with exploring experiences with caregiving through empirical interview research, which showed the various aspects of family members' often persistent and moral feeling of being called to care for their loved ones[11].

Box 1 | The interdisciplinary development process of the graphic novel Naasten

Research-based graphic novel about family caregiving in a palliative care context

The 230-page Dutch graphic novel *Naasten* (Dutch for 'loved ones' or 'relatives') was developed by an interdisciplinary team of researchers and two comic artists who were at the time final-year Comic Design students of ArtEZ, a renowned university of the arts in the Netherlands. The graphic novel tells the stories of characters caring for their loved ones receiving palliative care at home. We define palliative care as *'care improving the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment, and treatment of problems of a physical, psychological, social and spiritual nature'*[29]. The graphic novel was based on the results of our qualitative interview research centring around normativity in family caregiving[11]. In this research study and in the larger project, we regard family caregiving as the aid or support given by an unpaid and untrained person from someone's direct social network, for example, a partner, relative, grown-up child, friend, neighbour or other acquaintance[30-32]. Analysed themes, patterns and scenes from the interviews with 28 family members (mostly partners or adult children, who took care of a loved one with a life-threatening condition or frailty), and 9 patients (mostly suffering from end-stage cancer or severe organ failure)[11] formed the basis of the graphic novel. The novel was published by the Belgian-Flemish publisher Oogachtend in 2019.

Two interwoven storylines

To provide a general and rich account of what it can mean to provide family care at home, two storylines with different palliative care trajectories were scripted: Geert, who cares for his wife with end-stage cancer; and Eva, who cares for her father with severe chronic obstructive pulmonary disease. Both family caregivers feel called to care (*"this is the last thing I can do"*) while balancing it with work, their own needs, changes in the relationship, involvement of friends and other family members and professionals entering normal life. Each artist drew one storyline, in their own artistic style; the stories are interwoven in the novel. The stories were developed and written by MH and the two art students, under the supervision of the students' art professors who themselves were experienced comic artists. The art students were trained in writing fiction, and in using input from real-life in the creation of images and (auto)biographic work.

People involved in the interdisciplinary collaboration

- Project leaders JvG and GO, researchers with a background in medical ethics and social sciences, and PhD supervisors of MH.
- PhD student and first author MH: researcher with a background in medical ethics and social sciences, conductor of the interview study on which *Naasten* was based, coauthor of the novel, for whom this project was part of her PhD graduation.
- Two comic artists, at that time final-year students of the Comic Design education programme of ArtEZ University of the Arts, coauthors of the book, who graduated on this novel.
- Teachers within the Comic Design education programme who were themselves comic artists.
- Editorial board with projects leaders, head of the Comic Design education programme and a professional editor.
- People from the (palliative) care domain: bereaved family caregivers, palliative care professionals and other professionals within our project sounding board.

In the second step, inspired by the graphic pathographies' hypothesised potential for reaching a broader public[22], especially in palliative care[33, 34], we collaborated with two comic artists to develop a graphic novel based on the aforementioned research results. Since caring for a seriously ill loved one can be a long and complex moral process, we preferred the rather long comic form of a graphic novel to use the power of an extended visual story to do justice to people's experiences over time, to give insight into what family caregiving means and to enable readers to

relate to it—in contrast to shorter forms like infographics, cartoons or educational pamphlets. The choice for a novel was also influenced by the fact that the intended artists were graduate students with their own artistic aims and preferences, who shared our intuition that we should not create an instructional how-to-care-for-family members-comic. We will elaborate on all aims of the collaborating parties in lesson 1 of this paper.

Our initial target audience was a broad and not well-defined public, that is, anyone who comes across family caregiving. During the development process, the long form indeed showed the potential for readers to really relate to the novel's characters and have conversations about their experiences. That is why our broad educational goal tightened towards stimulating reflective conversations about people's own experiences with family caregiving, be it personally (providing care for a loved one) or professionally (encountering family members and supporting them adequately, reflecting on one's role towards family members).

To ensure that the graphic novel would be credible and that it would fit these conversational purposes, both its content and form were critically assessed, from early sketches on throughout the development process. Interviewees (bereaved family caregivers of seriously ill people), palliative care professionals and other professionals within our project sounding board gave feedback during the development process, mainly concerning the novel's recognisability, realism and tone. Several other techniques were adopted to ensure the novel would be a credible and trustworthy translation of our research, which we will elaborate on in the 'Discussion' section and Supplemental table 1. The development of the novel was also artistically assessed by the editorial team (which included an experienced comics editor and a graphic designer), and by the art students' art teachers. The collaboration, ultimately, resulted in the memoir-like graphic novel of 230 pages entitled *Naasten* (Dutch for 'loved ones' or 'relatives'), based on main themes and scenes from our prior empirical interview research into family caregiving[11]. The novel depicts two stories: of a daughter and of a husband, both caring for their seriously ill loved ones at home.

In the third and last step, after the development of the novel, we empirically explored barriers and facilitators in using the novel as a conversation starter or supportive tool for healthcare professionals and volunteers in their encounters with family members[35]. The novel, thus, was not regarded as health intervention; rather, we explored its potential in terms of usability. Our findings indicated that, due to its recognisability and emotional impact, the graphic novel can indeed support

bereaved family caregivers. Specifically, it can raise specific (moral) conversation topics. Because the novel can also be experienced as rather confrontational or too directive in a conversation, it should be introduced with care among current family caregivers. Preferably, the novel should be used in educational settings, contributing to awareness and tailored support of family caregivers[35]. Due to its high-quality artwork, a publisher was interested in professionally publishing the book. In consultation with the grant provider, a large batch of graphic novels was printed to distribute freely among those interested and connected to the field of palliative care or education. When this batch is exhausted, people will have to pay a competitive price, presumably influencing the novel's accessibility.

Currently, we use images from the novel as conversation starters in our ethics education programmes and workshops in palliative care. The images directly evoke reactions and lively discussions among healthcare professionals and volunteers, similar to our prior findings[35]. We, therefore, believe to have successfully translated our research findings into a more accessible educational format to stimulate discussion and (professional) reflection on family caregiving and its moral challenges and ambivalences.

Interdisciplinarity and arts-based research

As stated above, our project started with the goal of translating our scientific interview research findings on family caregiving into a graphic novel, to reach a broader public. Gradually, however, the development of the graphic novel evoked a more thorough reflection on the interdisciplinary character of our collaboration with comic artists. Such interdisciplinarity is also a core characteristic of medical humanities, defined by Cole et al as an interdisciplinary and multidisciplinary field that explores contexts, experiences and critical and conceptual issues in medicine and healthcare, while supporting professional identity formation (p. 12)[36]. Another link with medical humanities is that, in education, medical humanities is advocated as a powerful medium for students to explore complexity and uncertainty in clinical practice and in patient or family member experiences[37]. As such, similar to graphic novels, medical humanities can stimulate conversations about health, illness experiences and caregiving.

Broadly presented, in the past decades, interdisciplinary initiatives arose in education and academic research[38-40] to foster creativity, innovation, and team performance[42]. Universities are often structured along research disciplines that represent a community of scholars engaged in practices and methodologies specific to a field or topic[40]. These communities are traditionally monodisciplinary,

homogenous and self-regulating because their members share a body of knowledge and a culture of practices, norms, values and beliefs[38]. Interdisciplinary initiatives, however, have been motivated by the need for a more holistic approach to research, as well as the argument that complex problems in our 21st-century societies cannot be adequately addressed by using one particular disciplinary perspective or expertise[38, 41]. Sometimes, such interdisciplinary work even goes beyond the boundaries of the university. Given that we regard the term 'discipline' as an area or specialty of work, one of the many possible interdisciplinary collaborations is to involve the arts in one's scientific project or teaching.

Such an interdisciplinary collaboration can be more specifically understood as arts-based research (ABR)[42, 43]. In the past decade, ABR has been growing enormously, as have the terms to label this type of work[43]. In short and drawing on Leavy's definition, ABR practices are methodological tools based on the principles of the creative arts, used by researchers across disciplines to address their research questions holistically and in an engaged manner[43]. The dialogue between science and art in such methods is advocated as a way to rethink research practice and the communication of research[26]. Art methods like theatrical performances, dance, poetry, music, fiction or visual art such as comics, have been emerging as novel ways for generating, analysing, interpreting or (re)presenting research data[43]. Concerning the latter, communicating and presenting research data while using art is aimed at, for example, evoking effect in audiences or generating an understanding of other people's experiences[44].

Our project in developing the graphic novel *Naasten* based on our research about palliative family caregiving could be framed as interdisciplinary and fits the field of medical humanities, and of the ABR field in particular: we collaborated with people from outside our healthcare science discipline, that is, two comic artists and their teachers, to present our research more holistically to a broad non-academic audience. This paper centres around the specific challenges of such an arts-science collaboration. In the remainder of this paper, for the sake of clarity, we will use the term 'interdisciplinary' to refer to our research-comic art collaboration.

Aim of this paper

In this paper, we will share three important lessons we learnt about combining comic art and research to present scientific results to engage a non-academic audience in thinking about family caregiving. We will also discuss the extent to which we achieved an interdisciplinary collaboration in terms of achieving the potential of ABR with regard to generating, analysing, interpreting or (re)presenting research

data[43], and reflect on wat our project could have gained if we had been more aware of the interdisciplinary character of our project right from the start. Practical recommendations for other researchers are shared in the 'Discussion' section.

Three important lessons to anticipate when adopting comics in one's research project

Several parties contributed to our project (Box 1), but ultimately, three persons collaborated and authored the graphic novel: the two comic artists, who were final-year comic design students at the time, and the researcher and this paper's first author MH. They worked together for about 1.5 years on ideas, theme selection from MH's interview research[11], developing the narratives, sketches and storyboard, eventually resulting in the published 230-page novel *Naasten* in 2019.

Using comics in our research project fits the ABR genre of 'comics-based research'[45]. In particular, our project fits the comics-based research's goals of presenting and disseminating results to various audiences; and, to a lesser extent, to interpret and analyze data[45]. In hindsight, we share lessons, based on the experiences of the research team and on retrospective interviews with the two comic artists that were conducted in 2020 by an independent researcher from our department. The artists consented to the interviews and use of that data. These three insights can be beneficial for researchers to know *before* immersing themselves in collaboration with (comic) artists:

1. Interdisciplinary collaboration requires an interest in and acknowledgement of each other's (potentially diverging) aims and roles.
2. A continuous discussion of the sometimes contrasting approaches between artists and researchers in the collaboration process is needed.
3. Collaborating with artists benefits the communication of research results, and has the potential to offer new perspectives on one's scientific data collection and analysis.

These lessons may help others to achieve the potential of an interdisciplinary art-research collaboration. When discussing each lesson, we first report about our experiences, followed by a reflection referring to other literature.

1. Acknowledgement of each other's diverging aims and roles

The first lesson we learnt is that interdisciplinary collaboration requires an interest in and acknowledgement of each other's (potentially diverging) aims and roles.

Diverging aims and roles

The three collaborating partners felt a strong personal commitment to the project due to the subject of death and caregiving. They also shared the aim of moving away from a 'how to' guide to create a piece of art that showed the lived experience of family caregivers, and that would be recognisable, useful, accessible and supportive for other family caregivers or professionals in palliative care practice. Looking back, we observe that despite the mutual commitment, not all personal interests and aims were made explicit when the collaboration process started.

For the two comic artists the novel was their graduation project which would be assessed by their teachers, and which they wanted to be both societally relevant and corresponding with themselves and their style. In retrospect, both artists valued learning to collaborate professionally with us as clients: the project was a potential start of their professional careers as comic artists.

Researcher MH aimed at remaining true and doing justice to the experiences of people she had interviewed about family caregiving, prior to the development of the graphic novel. This motivation was reinforced by the fact that the graphic novel was part of her PhD project in which she was—as were the artists—assessed by her supervisors. Furthermore, the research team (MH and her supervisors) initially intended to develop a graphic novel and to observe and study the development process.

Thus, researcher MH began the writing of the graphic novel with three hats: that of PhD student who provided input for the novel, that of coauthor in developing the novel and that of a participant-observer trying to carefully prepare and log all steps in the development process of the graphic novel. These different hats led to conflicting responsibilities in being a coauthor as well as a supervised PhD student, staying true to the data analysis and intending to support family caregivers and healthcare professionals with the book. Moreover, 'neutrally' observing the process conflicted with simultaneously being a more personally committed and creative coauthor of the book. The focus on observing the collaboration and development of the graphic novel was gradually abandoned by the research team. However, the different roles and aims and the personal struggle they caused were never openly discussed with the artists. When asked in the retrospective interviews, the two artists stated that everyone's goals were sufficiently discussed; one of them stated that MH's coauthor role was confusing.

Reflection on the interdisciplinary character

The collaborating parties took their own as well as each other's professions seriously and shared the overarching aim of creating a graphic novel based on

research. However, they sometimes felt—as another interdisciplinary team reports about their experiences—as if they were coming from *'a very different disciplinary world with different cultures, approaches and agendas'* (p. 5)[46]. We observed that while collaborating interdisciplinary, initial aims or roles evolve, implicit aims become explicit, and sometimes even new aims or roles emerge; a process that gave rise to the question of whether all aims and roles can or should be made explicit beforehand.

In addition, we observed that interdisciplinary collaboration can be quite challenging, mainly with regard to *'finding a common language and compatible paradigms'* in our approach to developing the novel[44]. Notably, we never used the word 'interdisciplinarity' in preparing meetings with the art school or with the artists, but only started framing our work as interdisciplinary when we started to reflect on our experiences, leading to the writing of this paper. Although the definition varies and overlaps with other concepts[38, 40], the concept of interdisciplinarity may be seen as part of a broad discourse on boundary crossing[41], associated with terms like blending, fusing, or synthesizing [41]. We have learnt that to accomplish interdisciplinarity, all parties should—from the beginning—acknowledge that they aim to learn from each other's perspectives and methodologies, instead of focusing merely on translating research conducted by one party into an artistic medium by the other.

Lastly, MH's struggle with diverging roles, and the eventual decision to focus only on being a coauthor, is in line with what Leavy states: ABR is a learning process in which researchers should focus less on doing it right and more on being fully engaged and present in the process[43].

2. Discussing the diverging approaches continuously

Due to the aforementioned diverging aims and roles of the collaborating parties, various approaches emerged in this interdisciplinary process. The second lesson we learnt is that the interdisciplinarity could have benefited from a continuous discussion of these sometimes contrasting approaches between artists and researchers.

Different approaches in using theory and story

The research team and the artists shared the aim of creating a piece of comic art that would be supportive in palliative care practice. However, their interpretation of what exactly was useful or supportive varied; and they had different opinions about who has authority over which aspects of the publication.

Theory versus story

Overall, we observed a continuous tension between aiming at a representation of the interview results that would be recognisable for people in palliative care practice (research perspective), versus aiming at an appealing, lively story of family caregiving (art perspective). This resulted in different approaches to the project. MH's scientific focus led to a rather theoretical, cautious and methodologically guided approach in contributing to the graphic novel's script, whereas the artists embraced a more intuitive approach. The large number of themes from the original research and the diversity of the interviewees' backgrounds sometimes challenged the comics artists in creating the stories. Furthermore, a common anxiety in qualitative research, namely the fear of ignoring important results while condensing, made MH hesitant to choose and to provide specific scenes for the artists. She was also reluctant to add the perspectives of new characters that sprang from the artists' imagination, rather than from her empirical work.

A synthesising narrative approach solved these problems: collaborating became livelier once researcher MH also started to think from the perspective of characters instead of abstract themes or rather textual and descriptive interview transcripts. Narrativity was a key focus in the further development of *Naasten*. Moreover, to help the artists in developing a personal connection to what was to be drawn, MH shared anecdotes, and the authors visited several clinical wards and a patient.

MH's deliberative approach, wanting to do justice to the research findings and having all people involved and potential readers satisfied, seemed to sometimes hinder the flow of the artists. At the beginning of the project, the artists stated they also preferred guidelines, input and boundaries. After storyboarding, however, the artists preferred to get on with actually drawing without having to constantly adjust their work based on ongoing feedback. Having to reach compromises slowed the already tight process of reaching the deadline for their graduation.

Different criteria for creating a good story

Although approaching the novel from a story perspective was a fruitful approach, a further problem in the interdisciplinary collaboration was that the collaborators differed in their ideas about what a good story actually is and how it should be told. The research team highly valued feedback from experience experts and potential 'end-users' who are involved in palliative care practice on content as well as artwork: feedback meetings with former interviewees and healthcare professionals were organised (ie, 'member-check' in qualitative research terminology). For them, as for the researchers, the story should primarily be recognisable, realistic and

supportive for other readers who have to deal with palliative care. In contrast, at the start of the project, some art teachers felt that focusing too much on the potential readers' feedback might compromise the artists' creativity. For them, a focus on creative storytelling was highly important for the graphic novel's quality. Throughout the development of the graphic novel, the artists valued the input of healthcare professionals and family caregivers and also strived for a recognisable depiction of medical phenomena and family caregivers' daily life and experiences. However, as these experience experts would not necessarily be good writers, the artists used their creative expertise to fit the input from real-life experiences into the poetic story.

Figure 1 | Issue of light and darkness in the development of the graphic novel

Throughout the development of 'Naasten', a major discussion point was the use of light and dark in one storyline, which created a barrier for some respondents in our explorative empirical research to use the book to support family caregivers[35]. Should the graphic novel be raw and thereby truthfully depict the experiences with this lung disease? Or should it be more gentle and colourful, thereby representing the love in caring for a partner or relative? A shared conviction of both artists and researchers was that art should not be beautification. Nevertheless, the artist experimented with softening the tone and, ultimately, used accent colour in his originally black-and-white story © Kranenburg, Van Ooijen, and Haan (2019) (permission was granted for the image)

An example of a discussion point stemming from feedback meetings with people from the palliative care practice was the use of colour and light, and the extent to which presenting the harsh reality of palliative care was appropriate (Figure 1). Later on, our explorative empirical research in palliative care support practice[35] showed that *Naasten* evoked emotions and conversations, and sometimes raised certain issues that probably would not have been discussed otherwise. However, the novel's direct way of showing[23, 47, 48] was sometimes considered too confronting or even potentially harmful for sometimes already overburdened families, which was a barrier to using the novel as a conversation aid. The question remained to what extent art may shock.

The authors also sometimes differed in their ideas about how the story should be told. The research team, for instance, doubted the understandability of certain metaphors and emphasised the importance of text or voice-overs, to make sure the message (such as inner experiences or struggles of caregivers) would be understood by readers. The artists, in contrast, were hesitant to 'explain' themes or metaphors. They felt the images were powerful enough to convey inner experiences without explicit text descriptions. Retrospectively, the artists stated that comic art leaves things open for the reader's interpretation and imagination, making the reading activity more personal and interesting. Discussions also arose about images that would help tell the story but would be less realistic or too stereotypical from a medical or caregiving perspective. The research team and the artists discussed, for example, the amount of hair someone with end-stage cancer would have; an artistically great but stereotypical characterisation of medical professionals and the coughs of a character with chronic obstructive pulmonary disease showing readers he had a lung disease, while shortness of breath would be more realistic.

Reflection on balancing scientific and aesthetic aims

Balancing aesthetic and scientific aims—and the resulting approaches—in telling the story remained an important issue. As shown above, research obligations did sometimes yield to aesthetic ones and vice versa, as may be required in such a collaboration[49]. That it can be hard to balance transferring one's empirical results accurately while allowing for an innovative visual presentation was also pointed out by another research team[34]. Another example is an interdisciplinary project that used theatre techniques for exploring and discussing diabetes experiences[46]. There, a tension arose between using different sources of information to address cross-cutting themes and account for medical details, versus telling a powerful story, perhaps based on just a few storytellers' experiences.

A researcher's focus on telling a scientifically true and realistic story, using his knowledge based on the data, may conflict with a comics artist's focus on telling a more emotionally recognisable story that is an artistic success—bluntly stated: truth over effect. Framing it differently may be helpful here. Researchers who adopt artistic methods following an ABR approach should acknowledge that when different disciplinary backgrounds cross, the credibility of the eventual result is at stake and has to be reformulated. The eventual artwork, thus, is not about truth, but about *trustworthiness*[43]. This will be elaborated on in the 'Discussion' section.

Although MH, looking back, assumed that her focus on research at times hindered the artists' creativity, the interviewed artists reported not to have felt restricted in their artistic freedom. Moreover, our theory focus did have advantages: retrospectively, the artists commented on the value of creating a graphic novel with research input. Normally they would work alone and let their stories originate from their imagination, but the collaboration with researchers and healthcare professionals allowed them to dive deeper into a subject and combine different sources of information.

It is in this dynamic interplay between the two disciplines and their diverging approaches, where interdisciplinarity resides. In contrast to merely juxtaposing several disciplines and their practices within multidisciplinary collaborations, interdisciplinarity, ideally, is about integration[38]. Yet, if one adopts the view of integration as an 'open-ended learning process without predetermined outcomes' in which new relations are established between, for example, participants, thought styles or practices from different thought collectives or disciplines (p. 23)[41]—then one might question to what extent our project succeeded in truly integrating the artists' perspectives with scientific knowledge and vice versa. An ongoing explicit reflection on the diverging approaches during the collaboration might have strengthened such integration.

3. New perspectives on one's scientific data collection and analysis

Lastly, the third lesson we learnt is that collaborating with artists benefits the communication of research results, and has the potential to offer new perspectives on one's scientific data collection and analysis.

How the graphic novel expanded our communication tools and analysis

One of the main benefits of creating a comic was the artists' introduction of story-telling, emotions and metaphors as a way to present one's message, which are usually uncommon methods in a scientific discourse. These elements led to a more

conscious and lively presentation of research themes. For example, in just one metaphorical spread, the supermarket scene in our graphic novel *Naasten* (Figure 2) shows the impact of feeling called to care, which was the central theme of the underlying interview study[11]. When using this spread in our current education programmes and workshops, we noticed that healthcare professionals are able to understand this message instantly by discussing the image. Whereas in a rather textual scientific paper such a dilemma would have to be dissected and spelled out. The novel also shows how something smells or sounds, which is particularly relevant in healthcare, for instance, the worrisome coughs of one's relative or a disturbing sound of an oxygen device. In this way, our initial and perhaps rather narrow goal of translating scientific research results into a more accessible format seems to have been successful.

Figure 2 | Spread of the supermarket scene in the graphic novel
This page, where the characters go to the supermarket, metaphorically shows the impact of feeling called to care as a partner or family member, which was the central theme of the underlying interview study. © Kranenburg, Van Ooijen, and Haan (2019) (permission was granted for the image)

Throughout the development, however, the interdisciplinary character of the collaboration and its merits became more visible. In the translation process, the research team discussed their analysis with the artists. The artists' questions about specific scenes made researcher MH rethink the details of her in-depth interviews and helped her to provide the artists with more specific interview

material. Preliminary sketches and drawings also evoked feedback from healthcare professionals and family caregivers, for instance, about a lack of positivity and humour in the graphic novel. This made the research team discuss their possible biases in the analysis as well. Thus, while the artists only became involved when most of the analysis of the underlying interview had already been conducted, their involvement still influenced our analysis—although to a small extent. The researchers repeatedly questioned the way the research was translated artistically, while also reflecting self-critically on the purpose and meaning of scientific habits.

Reflection on the benefits of interdisciplinarity for one's research communication and practice

In line with other researchers[26], we are convinced that comics are a rich resource to make readers reflect upon one's research topic and, possibly, the way the research is conducted or communicated. Various scholars have argued for comic's potential to communicate scientific results in a more accessible way and for using comics as teaching tools, to reach readers outside academia[45]. In contrast to scientific reports, comics are more open to subjective interpretation; readers have to actively 'make' and interpret the story themselves[47]. The genre offers researchers new opportunities to 'highlight ambiguity, uncertainty and multiple perspectives—aspects that are often underplayed, in the seeming certainty of academic prose' (p. 7)[45]. In our project, the particular strength of using comics as a medium to convey scientific insights is that a drawing can show a dilemma or ambiguity in the phenomenon of family caregiving (and its associated emotional impact) in only one view – with the help of metaphors or comics' plurality of messages[50]. As reported above, we have experienced that comics can indeed be useful in conveying complex and embodied illness and caregiving stories[23-25], thus offering companionship[47] or serving as a window into the personal lives of others[33, 47], contributing to people's understanding of the social and psychological aspects of illness or caregiving[50]. In this way comics may offer us, researchers, powerful resources for communicating complexities to bring a subject alive in ways that textual academic publishing cannot[49]. This can be interesting for researchers who want to raise awareness, illustrate complex experiences or analyses or improve healthcare practitioners' training.

Moreover, according to Marcus (2017), research-based comics should not simply be seen as supplements to scientific research—they can be viewed as ethnographies of caregiver experiences shifted into a more popular form. By this shift, which Marcus labels as 'transduction', the original qualitative interview results become a more publicly accessible good that can be discussed by others outside academia[51]. As such, the comic – perhaps more than a scientific paper – can evoke a change in feelings

or understanding in its readers[43] and invite a broader public outside academia to have its own interpretation and to reflect on the underlying research and its communication[26]. In this way, research-based comics such as our graphic novel fit the requirement of naturalistic, qualitative inquiry to come up with *'a condensed, scientifically informed, yet accessible narrative […] that is both well connected to a body of existing knowledge and carefully grounded in empirical facts'* (p. 16)[52].

Artistic contributions within one's research project are, however, important to the broader public and to the research team: art-based methods can provide new perspectives on research practice and science communication[26] and novel ways to reflect on knowledge-building[43]. This harvest of an interdisciplinary collaboration lies in the continuous discussion of what information or knowledge should be shared with the public and how[39, 46]. The translation into comics made the research team discuss their scientific methods and assumptions. A 'conventional' scientific report of empirical research is structured in an Introduction-Methods-Results-and-Discussion way to make an argument underpinned by empirical results, in which the authors attempt to interpret their findings in the 'Discussion' section. Although reading such a report requires some interpretation, there is little room for subjectivity: alternative credible interpretations of scientific results should also be based on thorough analysis instead of personal experiences. Comics, in contrast, obey different rules. As stated before, comic artists introduce storytelling and emotions, and use visual metaphors that may help readers to conceptualise experiences[53]. We believe these elements were beneficial to the presentation of our data, especially considering our aim of reaching the broader public. A question remains what we would have gained if the artists had been involved in an earlier phase, for example, during data collection, and whether that would have influenced the communication of our results and the research process itself. This will be elaborated in the 'Discussion' section.

Comics' novel way of presenting research was beneficial to the research team. Vice versa, in the retrospective interviews, the artists reported that the scientific analysis provided them with a valuable starting point and context to thoroughly explore human experiences. Palliative care practice was relatively new to them, as was scientific practice. According to the artists, the interdisciplinary collaboration offered them opportunities to become acquainted with research and scientific methodologies. Interdisciplinarity is deemed to be associated with terms like innovation, reform and creativity, all of which are focused on achieving progress in the production of knowledge[38]. In our case, the benefits of interdisciplinarity worked both ways: the comics genre was an innovative way to present research

results outside our healthcare science discipline and to reflect on our research practice, and our scientific input was a new source for the artists in creating stories and artwork that could contribute to readers' knowledge about family caregiving.

Discussion

Summary of lessons learnt

This paper shared reflections on a project, in which we collaborated with two comic artists to develop the graphic novel *Naasten* (Dutch for 'loved ones' or 'relatives') about family caregiving. Initially, the project started with the goal of translating the main findings of our prior empirical research[11] into a medium that would be more accessible to a public outside academia. More specifically, we aimed to visually show family caregivers' experiences, in order to stimulate discussion and (professional) reflection about the moral challenges and ambivalences in caring for a loved one. Based on our explorative research on its use in supporting family members in palliative care practice[35] and our educational experiences, we believe to have succeeded in this goal of translation. However, we realised that the project as a whole could have benefited from a more explicit focus on interdisciplinarity from the beginning, instead of merely focusing on translating our findings into a graphic novel, thus achieving more of the potential of interdisciplinary ABR projects such as described in this article.

This resulted in three lessons to support other researchers: (1) interdisciplinary collaboration requires an interest in and acknowledgement of each other's (potentially diverging) aims and roles; (2) a continuous discussion of the sometimes contrasting approaches between artists and researchers is needed and (3) collaborating with artists benefits the communication of research results, and has the potential to offer new perspectives on one's scientific data collection and analysis.

In the remainder, we will further discuss these lessons, by focusing first on the issue of trustworthiness and techniques to ensure it, then on the level of interdisciplinarity in our project and how we could have achieved more of its potential, and, lastly, what interdisciplinarity in general requires from the parties involved. Box 2 provides practical recommendations for other researchers with similar aspirations.

The issue of trustworthiness in translating research into art

One of the challenges in ABR practices concerned with presenting research data through art is finding a shared vocabulary and normative framework to judge

whether the eventual piece of art is 'good'. In our case, the graphic visualisation functioned as an interpretation of the phenomenon of family caregiving that we had studied. The question that often puzzles researchers in interpretative research applied here as well: how to decide whether this (artistic) interpretation of the research data is justified?[54]

As discussed above in our reports and reflections, balancing aesthetic and scientific aims in a way that is acceptable for both disciplines is central in research-comic art collaborations like ours[49]. In their search for justification, researchers from a positivist paradigm bind themselves to methodological rules to get as close to the truth (or its generalisable representation) as possible. This methodological rigour would enable objective and 'true' claims about the world[54]. Whereas for artists, art is more about appealing to one's imagination. A story does not have to be complete or bound to scientific and methodological rules to be able to provide a justified story. The artists' intuitive, narrative and artistic approaches enable a recognisable and poetic story via images. The supermarket scene in our novel (Figure 2) is an example of how the artists' use of metaphor and emotion expanded our research tools to communicate—in only one spread—the essence of our interview research on family caregiving[11]. Both the study on the facilitators and barriers in using the novel as conversation aid[35] and our experiences with using images in ethics education suggest that the novel is recognisable and can stimulate discussion and (professional) reflection on family caregiving and its moral challenges and ambivalences, as we intended with our project.

The suggestion by Lincoln and Guba for thinking about the problem of justifying interpretations may be helpful here, that is, not in terms of rigour as a positivist paradigm in science suggests, but in terms of trustworthiness[55]. They suggest applying other criteria, similar to criteria for rigour, and offer associated techniques for it. In particular, their criterion of credibility and the suggested techniques are valuable for art-research collaborations. Supplemental table 1 provides a reflection on how we (could have) adopted the suggested techniques, adding to the novel's justification. We learnt that it would have been beneficial to explore the opportunities and limits of our own discipline in interaction with the arts discipline. Working together towards the credibility criterion can lead to new approaches, which may expand one's common scientific methods and thereby strengthen one's research project as a whole. However, before adopting the suggested techniques, it is important that all parties embrace trustworthiness as the most important aspect of the artwork—instead of, for example, precise completeness or creative abstraction.

Discussing the interdisciplinary character of our collaboration

Although the definition varies and overlaps with other concepts such as multidisciplinarity[38, 40], interdisciplinarity, ideally, is about integration[38]. Instead of merely cooperating with people from another discipline, juxtaposing the disciplines and their practices as is the case in *multi*disciplinary collaborations[38], interdisciplinarity involves an integrative synthesis in which new relations are established between, for example, participants, thought styles or practices from different thought-collectives or disciplines[41]. Holley emphasises the importance of the outcomes of such a collaboration: interdisciplinarity should lead to a new understanding of a phenomenon, not just to the addition of another perspective[38]. Viewed from this standpoint, one might question to what extent the comic artists' perspectives were truly integrated with our scientific knowledge and vice versa in our project.

Throughout the development of our graphic novel, all parties had to balance aesthetic and scientific aims—and the associated approaches and criteria—in telling the story. The fact that certain aims yielded to others, as may be required in art-research collaborations[49], suggests that our project was mainly *multi*disciplinary. We, as researchers, thankfully made use of the merits of the artistic comics medium without really integrating them into our own. Indeed, the main benefit of adopting comics in our project was to communicate the experiences of family caregivers, as was explored in our research[35] – in a more accessible way than a scientific report could have done, reaching readers outside academia[45]. However, the interdisciplinarity interaction and integration could have gone a step further, thus achieving the full potential of ABR, concerning using (comic) art to (re)present one's results and to generate, interpret and analyse data.

Requirements of an interdisciplinary art-research collaboration

What, then, is required to achieve more of the potential of interdisciplinary ARB projects? With hindsight, we strongly suggest that one should involve the other disciplinary perspective (in our case: comic artists) at an early stage of one's research project instead of when analysis has already been done, as was the case in our project (see also Supplementary table 1). An artist's early involvement in conducting the research, analysing the results and then creating the stories could lead to discussing and expanding the research[27]. Other researchers, in a project in which the comic artist was involved early on, argue that science communication via art should not be viewed as an isolated piece of the puzzle at the end of the research process, but should be an integral part of the project[26]. In their case, the merits were that the artist helped conceptualise their first ideas by using visual metaphors; he also helped

clarify their main argument, captured what had not been written and thus pointed to blind spots[26]. In another research project, a research-based graphic novel depicting Māori worldview and values in palliative care offered possibilities for including indigenous methods in common Western-based research designs[34]. These examples show how an interdisciplinary team can generate interdisciplinary knowledge that is more than the sum of its monodisciplinary parts[39]. As argued in Supplemental table 1, an earlier interaction between the different perspectives provides projects such as ours with a stronger interdisciplinary flavour, for example, via an additional artistic perspective on the scientific analysis; a more thorough observation of family caregivers and their experiences; new perspectives and perhaps new methods in the data collection, that might result in a better indication of blind spots, and in more and perhaps other original data, thus allowing for more triangulation and options for selecting the most important findings and creating the stories.

Additionally, regardless of the research phase in which the (comic) artists get involved, acknowledgement of the interdisciplinary character of the collaboration is important. Researchers should be willing to learn from artistic methods, and artists should be willing to learn from research practice and methods. One of the goals of interdisciplinary education is to teach students to look beyond the boundaries of their own discipline[39]. This requires that every disciplinary approach is respected and should not be a priori devaluated as less than one's own. According to Stein, Connell, and Gardner (2008), interdisciplinary learning should not focus on 'the truth' but on adopting various views of a phenomenon and reflecting on the underlying assumptions and methods of each disciplinary perspective—in other words, wearing different disciplinary or methodological hats when viewing a phenomenon[39]. In our case, comic art was mainly used as a medium to communicate our results in a livelier way. In contrast, to reach more of the potential of research-based art, the parties involved should dare to really wear each other's hats, ask questions, grow to understand each other and explore the added value of using each other's methods. Box 2 provides practical recommendations.

Furthermore, drawing on the previous requirement, all parties should commit themselves to work interdisciplinary: they should look forward to different perspectives on a phenomenon and be open to other ways of working towards a shared goal. The interaction between artists and researchers can be new and challenging, requiring everyone to be an entrepreneur and to show a sense of diplomacy and tolerance for change[51]. For researchers, this implies they should learn to think and act like both a researcher and an artist, which requires (an appreciation of) spontaneity, flexibility, and openness[43]. Sometimes, scientific

approaches will have to be set aside to embrace complexity, that is, *'that changing goals, plans and unpredictable outcomes are not seen as confounding variables but rather as an acknowledgement of the inevitable messy complexity that is the real world of long-term collaborative projects'* (p. 9)[46]. For researchers without artistic training or experience, it is especially important to pay attention to the craft (eg, comics) one is working with. Box 2 provides several other practical recommendations.

Lastly, being open to spontaneity and the unknown is an important requirement of working with people outside your own discipline and pursuing artistic inquiry or innovative thinking[43]. This paper provides experiences, reflections, lessons and recommendations that might help other researchers anticipate the pitfalls and opportunities lying ahead. Without wanting to diminish people's curiosity or eagerness, these may increase the chance of a productive, pleasant and mutually enriching art-research collaboration process.

Box 2 | Practical recommendations for other researchers or project leaders

Preparations for the interdisciplinary project

- Think about the opportunities for reflection and flexibility (both in style and time) when considering the artist(s) you want to work with. Experienced artists may already have a fixed style, whereas students may be more flexible but also depend on teachers and deadlines, and are less experienced in the working field.
- Consider your point of entry into the project and, if needed, learn about the craft you are collaborating with, e.g. by seeing examples in the field (reading comics, seeing plays) or taking classes[43].
- Think about the extent to which everyone's roles and aims can or should be made explicit beforehand.
- Think about who leads the project and how this might impact the interdisciplinarity.

Openness and curiosity from the start

- Discuss everyone's roles, aims, and expectations from the start.
- Adapt an open attitude. From the start, discuss and acknowledge with your collaborators that your mutual aim is to learn from and integrate each other's perspectives, rather than merely translating research conducted by one party into an artistic medium by the other.
- Be curious about each other's discipline and its associated approach and methods. Explore the potential benefits of the interdisciplinary project for all parties.

Discussions throughout the project

- Discuss to what extent everyone's roles and aims can or should be made explicit. If possible, reflect on everyone's roles, aims, and expectations from time to time throughout the project.
- Discuss the role of feedback: who has authority about what, and why? If desirable, organize feedback meetings with 'end-users' outside the bubble of the team of researchers and artists to align the work with the level and experiences of your potential audience.

Opportunities for interdisciplinary learning

- Be prepared to accept new perspectives of your collaborators, which may shed new light on common scientific methods and may well strengthen your research results. Respect and make use of the artist's intuitive, narrative, and graphic approach; focus on trustworthiness instead of truth. Keep in mind that surprise and disruption can be valuable in a scientific discourse.
- Get to know each other's worlds. If possible, let the artists be involved in your research at an early phase, e.g. during interviewing respondents and data analysis, letting them present drawings as member-check, etc. And vice versa, ask the artists to involve you in their artistic world and methods. Pay attention to their craft and aesthetics[43].
- An interdisciplinary collaboration requires negotiation and mutual trust, but also meta-reflection in observing and monitoring the collaboration process. If this cannot be expected of the actual collaborators, invite a third party, skilled in interdisciplinary work and with authoritative power to all others. This person can help foster discussions about the interdisciplinary work and harvests, by explicating basic assumptions and methods and highlighting learning opportunities. Moreover, this person can chair evaluative sessions, or raise issues on everyone's contributions.
- Discuss to what extent the artwork can be a rich resource to make the audience reflect on your topic and, perhaps, your research and methodology.

Acknowledgements

We are grateful to comic artists Melanie Kranenburg and Niek van Ooijen (and to their teachers at ArtEZ University of the Arts in Zwolle, the Netherlands), for their creation of the graphic novel *Naasten*. Our encounter with art and research has been a precious journey. A special thanks to Peter Wilkins and Ruhina Rana for having valuable discussions about the topic of this paper. We would also like to thank Marjan Knippenberg for her contribution to the project.

Supplemental table 1

Lincoln and Guba's criteria and techniques for trustworthiness, combined with our lessons about adopting these in a comic art-research collaboration

Criteria[55]	Associated techniques[55]	What we did and did not do (but should have)
Credibility	Prolonged engagement – lengthy and intensive contact with the phenomena (or respondents) in the field to assess possible sources of distortion and especially to identify saliencies in the situation	• We observed each other's crafts via the sharing of interview and analysis material, and via meetings in the art school and seeing the artists at work. • An early involvement of the artists (e.g. during data collection) would have allowed for more engagement with the palliative care practice, and would have allowed for an additional artistic perspective on the scientific analysis.
	Persistent observation – in-depth pursuit of those elements found to be especially salient through prolonged engagement	• We observed the setting of family caregiving via visiting patients and a ward together, thus helping the artists with a realistic depiction of daily life in palliative care at home. • An early involvement of the artists would have allowed for a more thorough observation of family caregivers and their experiences.
	Triangulation (cross-checking) of data – by using different sources, methods, and at times, different investigators	• We discussed all sketches, storyboard and eventual artwork from the different disciplinary perspectives. • It would have strengthened triangulation if all disciplinary parties had asked each other more questions about their perspectives, methods, etc. • An early involvement of the artists would have led to new perspectives and perhaps new methods in the data collection, resulting in more and perhaps other original data, thus allowing for more triangulation.
	Peer debriefing – exposing oneself to a disinterested professional peer to "keep the inquirer honest," assist in developing working hypotheses, develop and test the emerging design, and obtain emotional catharsis via exposing oneself to an independent professional peer	• Throughout the project, we had continuous and fruitful discussions about the artwork. • It would have been beneficial to have had more discussions about everyone's aims and approaches, perhaps via an independent observer (see below).

Supplemental table 1 Continued

Criteria[55]	Associated techniques[55]	What we did and did not do (but should have)
Credibility	Member-checks – the process of continuous, informal testing of information by soliciting reactions of respondents to the investigator's reconstruction of what he or she has been told or otherwise found out and to the constructions offered by other respondents or sources, and a terminal, formal testing of the final case report with a representative sample of stakeholders	• We informally tested the artwork by showing sketches and pieces of art to people in palliative care. After the novel was published, we empirically explored its use in palliative care support practice. • The artists had to relate to the feedback of experience experts and professionals who were not novel writers.
Dependability and confirmability	External audit requiring both the establishment of an audit trail and the carrying out of an audit by a competent external, disinterested auditor. That part of the audit that examines the process results in a dependability judgment, while that part concerned with the product (data and reconstructions) results in a confirmability judgment.	• The trustworthiness of the project should have been, and partly was, ensured via peer review and the critical stances of all authors of the graphic novel, as well as the involvement of an independent editor. • It is possible that an independent observer or monitor could have strengthened the interdisciplinary learning in the project.

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Chapter 5

A care ethical perspective on family caregiver burden and support

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Nursing Ethics. 2025 Mar 4. Epub ahead of print.
https://doi.org/10.1177/09697330251324294

Abstract

Family care—when partners, relatives, or other proxies care for each other in case of illness, disability, or frailty—is increasingly considered an important pillar for the sustainability of care systems. For many people, taking on a caring role is self-evident. Especially in a palliative care context, however, family care can be challenging. Witnessing caregivers' challenges may prompt compassionate nurses to undertake actions to reduce burden by adjusting tasks or activities. Using a care ethical approach, this theoretical paper aims to provide nurses with an alternative perspective on caregiver burden and support. Drawing on the concepts of relationality and contextuality, we explain that family care often is not a well-demarcated or actively chosen task. Instead, it is a practice of responding to an all-encompassing "call" to care flowing from a relationship, within a social and cultural context where norms, motivations, and expectations shape people's (sometimes limitless) care. We consider relational interdependence at the root of persisting in care provision. The question is then whether self-sacrifice is a problem that nurses should immediately solve. In ideal circumstances, self-sacrifice is the result of a conscious balancing act between values, but family care in the context of serious illness barely provides room for reflection. Yet, instant attempts to alleviate burden may overlook family caregivers' values and the inherent moral ambiguities and/or ambivalent feelings within family care. Family care is complex and highly personal, as is finding an adequate balance in fulfilling one's sometimes conflicting values, motivations, and social expectations. Therefore, we suggest that caregiver experiences should always be interpreted in an explorative dialogue, focused on what caring means to a particular family caregiver. Nurses do not have to liberate family caregivers *from* the situation but should support them in whatever overwhelms or drives them in standing-by their loved ones until the end.

Keywords

caregiver burden, caregiver support, ethics of care/care ethics, family care, informal care, palliative care

Introduction

Family care—when partners, relatives, or other proxies care for each other in case of illness, disability, or frailty—is increasingly considered an important pillar for the sustainability of care systems. Especially in a palliative care context, however, the role of a patient's spouse or relatives is intensified. Family care can be challenging. The concept of burden, then, is well-known. Witnessing caregivers' challenges may prompt compassionate nurses to undertake actions to reduce a family caregiver's burden by adjusting tasks or activities. Although timely identification of burden is important, attempts to immediately relieve it may overlook a caregiver's context and values.

Using a care ethical approach, this theoretical/philosophical paper aims to provide nurses with an alternative perspective on caregiver burden and support. First, to better understand why people persist, we will explain that family care often is not a well-demarcated and chosen activity but an ongoing response ensuing from a relationship. Secondly, we will elaborate on the ambiguities of self-sacrificial family care. Third, we point out that nurses' support of family caregivers should not primarily be task-oriented but should be tailored to the personal meaning that family care may have for the involved partners or relatives. We also provide some practical suggestions for supporting family caregivers. The paper concludes with a short reflection.

Background

In palliative care, especially when patients prefer to stay and die at home, the role of their spouse or relatives is pivotal and intensified[1, 2]. Daughter Eva (her fictive story can be read in Table 1) stays at her father's side until the very end. She provides "family care" which can be defined as the wide range of unpaid care or assistance with activities to someone with a chronic illness, disability or frailty, given by a person from someone's direct social network, or one's partner, sibling, relative, friend, neighbor, or other acquaintance[5-7]. With aging populations and increase of disabilities, chronic diseases and frailty pressurizing the sustainability of care, family care is increasingly considered an important pillar of many Western countries' long-term care systems[8-10].

Table 1 | Fictive story of a family caregiver, derived from our research-based graphic novel

The Dutch graphic novel *Naasten* shows people's experiences with family care in palliative care home settings. Fictive, but based on our in-depth interview research[3,4]. One of the main characters in the novel is daughter Eva (Fig. 1). She cares for her father suffering from severe chronic obstructive pulmonary disease (COPD) and tells us about her experiences:

> *"My father has been suffering from COPD for a long time. Now, he is rapidly deteriorating. I have a younger sister and an older brother, but I'm usually the one who cares for him. I am the oldest daughter, you know, I feel like I should take care of him. And the others think differently about what's best for dad. Last week, he called me in the middle of the night, completely panicked and short of breath. That was terrifying. Of course I rushed off to go to him! You never know if such a phone call is the last one you get from him. And I would not want it any other way - it's my father. You just do that for each other.*
>
> *It's tough, though. We were never that close, he was quite distant. He hasn't been very friendly during his life, he has always scared people away. But he raised me, to the best of his abilities. And now he needs me. So, I stop by every day, to prepare his food, help with medication, do some cleaning work. I even help him shower. But having to see him naked… That's vulnerable, you know. I really have to switch a button there – switch it from "daughter" to "nurse aid", that helps. I have to keep up.*
>
> *My personal life seems to be in a stand-by mode. I have difficulties focusing on my job. My boyfriend worries about me. And he sometimes complains that we cannot spend much time together. With COPD you never know what will happen next or when the last moment is. So I just do it and keep on going, there is no other way."*

Figure 1 | Image of Eva, a character in the Dutch graphic novel 'Naasten', and her father

Image of daughter Eva (her story can be read in Table 1), one of the characters in the Dutch graphic novel 'Naasten' about family care in a palliative care context. On this page, her father, who suffers from a severe lung condition and is gasping for air, asks her to stay in the middle of the night. "If that's what you want", she replies, "Sure." ©Kranenburg M, Van Ooijen N and Haan MM. Naasten. Heverlee: Oogachtend, 2019. (permission was granted for the image)

Taking on a caring role for one's relatives is often expected in current societies and self-evident for many family caregivers[11]. Our previous study, that included in-depth interviews with partners and adult children of patients receiving palliative care, showed caregivers' persistent feeling of being called upon to care[3]. Looking at these caregivers' stories from an ethical perspective, this being called upon does not seem based on a well-considered choice but presents itself as pre-reflexive. Caregivers often feel a strong urge to act and automatically do so, yet without having been able to thoroughly reflect on why or how. Some people report that they intuitively feel what is needed due to knowing the care receiver so well or having spent so much time together. And then they just *do* it.

At the same time, family care has its challenges. The multidimensional concept of "caregiver burden"[5, 12] is well-known within nursing, given the varied tools to screen for burden in practice[12, 13]. Our previous interview study, from which our story of daughter Eva was derived (Table 1), reported that family caregivers expect themselves to be attentive to the patient first while ignoring their own needs, available all the time, and assertive in managing the caring situation[3]. In another study, attentiveness, understood as being present and providing emotional support, was regarded to be the most important element in home-based palliative family care, but was simultaneously disrupting caregivers' daily lives[14]. Caring for a loved one can indeed be overwhelming and all-consuming[15, 16]: it impacts a caregiver's whole personal realm – limiting living normal daily life[17] and social engagements[1, 17, 18] – while many caregivers feel unprepared for their caring role[19]. People, such as daughter Eva, feel limited – "chained" even – in their own lives[17], as there is little time for their own families, social lives, hobbies, or work. In short, people tend to regard family care as something self-evident they wish or just have to do, sometimes at considerable personal and social costs.

As nurses spend much time with patients in palliative care settings, they usually are the first and main contact points for patients and their families[20, 21]. Compassion serves as key motivator for many nurses in their work, stimulating them to turn passion into practice by actively trying to relieve suffering[22]. It is thus fully understandable that screening is advocated to detect burden at an early stage, especially given the challenges and unmet needs of family caregivers[12]. Although timely identification of burden is important, attempts to immediately relieve it may overlook a caregiver's context and values. Assessing caregiver burden needs careful interpretation and consideration of the caregiver's context[5, 23]. What drives people to provide family care, sometimes at considerable costs? To support sustainable caring relationships between caregivers and patients, we believe it to be important to recognize the complex interplay of underlying motivations for (not) providing family care, especially cultural and societal factors that shape why and how partners or relatives care for each other[9]. In the remainder of this paper, we will provide another perspective on family caregivers' experiences and burden, by adopting a care ethical approach.

Family care as a response to feeling called within a relational and social context

Rather than viewing human beings as independent, utterly self-determining individuals that weigh alternatives and choose freely and deliberately – as the Western ideal of autonomy suggests[24, 25], care ethicists view people as interdependent and

morally motivated by the vulnerability of others[26, 27]. The concept of responsibility, understood as the task to respond to a need, is a corner stone of care ethical thinking: without people taking or accepting this responsibility, there is no care[25, 28]. Due to this mutual interdependence, relationality and contextuality are two additional key elements in care ethics. Care is a *relational* practice which cannot be understood in the abstract but should be considered in the lived experiences of the people that give and receive care within their relationships[27, 29]. These caring relationships are situated in a *context* in which power relations, norms and expectations play a role[29]. Our previous interview study also highlighted a normative dimension of family care[3], which was incorporated in the stories of our research-based graphic novel (Table 1). In this first section we will explain why family care, from the perspective of care ethics, is not a well-defined task people choose for and can simply withdraw from when it gets too burdensome.

Family care as a relational practice

Care ethics' focus on relationality, first, helps us to understand the reality of family care, i.e. how most partners or relatives just 'find' themselves in the role of family caregiver, due to their specific *relationship* with the one who is ill[25]. They often accept this responsibility without weighing all possible personal consequences in advance, and without actively choosing that role at a particular moment in time[30]. People seem to just do it. Daughter Eva (Table 1 and Fig. 1) gradually stops-by more often, day or night, because her father needs her and "*you just do that for each other".* Moreover, Barnes explains that it makes little sense to sharply distinguish the group of care receivers and care givers, especially in elderly spousal relationships[29]. It is hard to tell where care begins or ends, and, as roles often change, to depict who depends on whom. Family care can be framed as 'dependency work': a partner or family member is set free to do other things only if the dependency work of caring is taken over by others[31]. In that way, both the care receiver and family caregiver are dependent on each other.

In this relational interdependence, overburdening is a serious risk[12, 14]. As indicated in the introduction, family members sometimes persist in caring for their dying loved one at substantial costs, due to interference with their personal wishes, social activities, hobbies, or work[3, 11, 14]. Eva (Table 1), for example, experiences increasing difficulties with focusing on her job while also managing her father's household, care, and medication. Surrounding friends, family, or professionals may react with well-meant advice such as *"don't forget to think of yourself eh?!"*, as the exhausting caring activities sometimes evoke surprise, awe, or worries by others [3]. 'Thinking of themselves', however, can be quite difficult for family caregivers. A care ethical perspective helps us to understand why. The crux is in the word 'self', which

suggests that there is an autonomous 'true self', independent of the context of the caring relationship, which may be found by disconnecting from one's relations[31]. Care-ethicists argue, in contrast, that the self should be understood as ultimately relational[31]. For family care this means that instead of *having* a terminally ill father, care is about *being* a grown-up child of a terminally ill father[31]. Family caregivers cannot abandon their relationships and quit being a child or partner altogether. Eva, as her father's daughter, cannot avoid being called to care.

Of course, people may discard certain caring activities (e.g. bathing one's parent) or take some time off to catch their breaths, thus in a way temporarily resist a call. Important to acknowledge, however, is that such actions would not erase the overall call to care, due to people's ongoing alertness to the patient's needs. Drawing on care ethics, we point-out that family care should not be reduced to a clear-defined task or action with a start and an end, resulting from a well-considered choice[32]. Rather, it is an ongoing (and often messy) process within a relationship, prompted by attentiveness to each other's needs[29].

The importance of context in understanding how and why people feel called to care

Second, care ethics' insistence that care is always situated in a specific context is also helpful in understanding family care, especially people's sometimes immediate and self-nihilating responses to the felt calls. Eva, for example (Table 1), eventually quits her job and tends to neglect her relationship with her boyfriend. Our previous analysis of in-depth interviews with partners and adult children of patients receiving palliative care showed a sense of urgency in these family caregivers' responses: the décor of deterioration in the palliative care context and the prospect of an approaching death urges people to act now, having only one chance to do so[3]. Furthermore, one's capacity to care within one's family is always affected by specific expectations, existing power relations, and the degree to which caring is valued and supported – not only in the relationship between caregiver and care receiver, but also within one's broader social, cultural, and political context[29]. Being the oldest daughter for example, like Eva (Table 1), the darling sibling, or belonging to a family-oriented culture may lead to care expectations[3]. This implies, again, that living with or caring for a seriously-ill loved one often is not a matter of a straightforward, easy or even explicit choice[29]. Rather, actual family care is highly dependent on the specific context in which partners and relatives have to navigate.

By whom and why do people feel called, then? A family caregiver feels connected to (and sometimes torn by) different domains on which they are expected to act.

Our aforementioned analysis of interviews with family caregivers showed care may indeed start with being attentive to the patient's explicit or implicit requests for help, but that well-intending and worried family and friends, one's own convictions, and healthcare professionals entering normal life may also call upon a caregiver[3]. These calls, in turn, evoke caregiver responses. To better understand caregivers' sometimes limitless responses, it is wise to have an eye for the underlying moral dimension of family care. Various studies, some across cultures and different health conditions, have shown the following generic and normative elements – or a combination of them – to be important drivers for people to provide family care, i.e. out of love or affection, a sense of obligation or moral contract, reciprocity (e.g. retrospectively 'paying back' to one's parents), but also driven by the pre-existing relationship quality or by one's family history, values (e.g. solidarity), and relational dynamics[3, 11, 14]. Adding to this, we believe it is important for nurses to be aware that such motivations are not purely personal. Whether or not explicitly recognized by caregivers themselves, family care is deeply subject to social norms and expectations (e.g. 'seeing one's parents out', emphasizing 'till death do us part', or regarding it a women's responsibility)[9, 33] against the background of wider cultural values and beliefs (e.g. specific norms within one's family or community, or spiritual and religious beliefs)[9].

Ambiguity, ambivalence and self-sacrifice in family care

Family care, thus, involves more than what meets the eye. A complex and normative layer always lies beneath one's actions or emotions at the surface; and a sense of failure may arise when caregivers' feelings or experiences conflict with what they believe is expected of a 'good caregiver' in their particular social or cultural context[33]. To better understand family caregivers' experiences, the concepts of ambiguity and ambivalence are of help. In this second section, we will explain that family care – as a phenomenon – is highly ambiguous, as it realizes certain goods or values while neglecting or suppressing others. That is why family care – as an activity – often leads to ambivalent feelings. We will further explain how burden and self-sacrifice are not necessarily problems that should be solved. In finding an adequate balance for family caregivers, the ambiguities and ambivalences surrounding family care should be openly acknowledged.

Ambiguity and ambivalence

The phenomenon of family care for someone close has been described as *ambiguous*: some things of value are realized while others are concurrently – inevitably but often unintentionally – oppressed or neglected[30]. Bereaved

caregivers in our previous study were grateful for having persevered and having enjoyed precious "last things" with their loved one, spoke of an intensified and closer relationship, felt honored or proud for having been able to provide family care, but simultaneously reported challenges or exhaustion even[3]. It is often pointed-out that the immense physical, emotional, or psychosocial challenges that family caregivers face while caring for their loved ones require support[34-37]. Especially within intimate relationships and given its normative complexity, family care can be burdensome. Tragic situations may arise, due to competing demands stemming from one's different roles:[11] people may feel torn between being a caregiver while also being a parent, employee, partner, or friend, and experience difficulties (or even exhaustion) in balancing the needs of the patient with one's own. In responding to a sometimes 24-7 call, they have to deal with expectations from different sources[3], as the relational self is connected to several contexts with diverse and sometimes even contrary interests and obligations. Rather than in feeling called per se, the burden of care might lie in the seeming limitlessness to which people feel called, i.e. the self-sacrifice that lies in being constantly available and attentive to the patient's needs first[3], and the pressure on certain personal values this causes, like friendship, self-development or parenthood. Adult children or the "sandwich generation", for example, may experience dilemmas in the responsibilities regarding both their parent and their nuclear family[11].

It may be hard for family caregivers to openly discuss their dilemmas, however. Next to ambiguity, the concept of *ambivalence* has been put forward as helpful in understanding the activity of family care, and particularly the associated caregiver dilemmas and suffering when people's experiences do not precisely fit within the normative social expectations associated with their role as family caregiver[33]. In exploring experiences across death and bereavement, it was shown that the messiness of their loved ones' dying process meddled with family caregivers' abilities to meet their initial expectations and desires regarding care. People then may feel regret or shame for not doing or feeling the "right" way, e.g. not doing enough, or feeling hateful instead of loving towards the patient.

Solving the problem of burden?

Whether or not induced by social expectations, family care may lead to self-sacrificial behavior, in which people like Eva (Table 1 and Fig. 1) put their personal lives – for example their job, nuclear family, or social activities – in stand-by mode in favor of what is needed or demanded in the caring situation[3]. Excessive self-sacrifice would, simply put, be paradoxical as it would lead to a complete loss or even destruction of oneself which in the end, even leads to not being able to

care for one's loved one anymore[30]. Supporting a family caregiver then means helping them to find a healthier balance, to prevent them from overstretching or "drowning" themselves and thus being unable to maintain caring, which would lead to less care for patients. Therefore, several tools – some validated and widely used – are advocated to quickly identify perceived caregiver burden[12, 13, 23], one of which related to a classification of caregivers in different risk profiles[12].

Such screenings and classifications fit well in current healthcare systems, in which evidence-based practice is promoted for early detection of problems and adequate treatment, and nursing skills like critical and analytical thinking, problem solving and decision-making are deemed vital for efficient care[38, 39]. Concerns, however, have also been raised that this evidence-based paradigm disregards nurses' tacit and relational knowledge in their patient encounters, as well as the patient's and nurses' preferences and values that are important for decision making[39]. In line with this critique, we suggest that caregivers' preferences and values are essential to take into account to provide suitable family support. A more in-depth interpretation – which for example acknowledges the relational context – is needed when tools or questionnaires are used to identify (potential) burden or risks. Helping family caregivers to find balance is not a simple fix of activities and tasks. A narrowed focus purely on releasing people from their burden would bear the risk of paternalism and would not take into account the ambiguities and ambivalences of family care. Rather, following Gastmans' thoughts on vulnerability and nursing care[27], we believe nurses should provide care that enhances the dignity of both patients *and* their families. Caring for a family caregiver is not always about asking what is to be *done* (or which tasks have to be given up), but rather about how to preserve a person's dignity as a whole. And thus, caring for family caregivers can be understood as responding to *their* vulnerability. Then, nurses' support should involve paying attention to all dimensions in which people's vulnerability affects them – which in the case of older adults would be on a physical, but also a psychological, relational, moral, sociocultural, or existential level.[27, 40]

Helping family caregivers, thus, should take into account the trade-off and balancing of different values and expectations – stemming from the various dimensions of their vulnerability – that lie beneath all their caring duties and tasks. Nurses would do well to use their relational powers to enhance such a value clarification, i.e. jointly with family caregivers weighing the various values, and acknowledging that contrasting values sometimes lead to dilemmas and tragic situations. Building on Gastmans' work again, it is this dialogical process that should be shared between nurses and care receivers (in this case: family caregivers), to find an appropriate

answer to the question (and not necessarily the problem) of burden.[27] The third section of this paper provides some practical suggestions to engage in such a dialogue with family caregivers.

Another perspective on self-sacrificial care

Care can be depicted as a gift-sharing process[14] – especially self-sacrificial care is purely about "giving"[30]. Van Nistelrooij, however, shows us the multiple meanings of this concept (e.g. giving back, giving in, giving away, giving up) and explains why self-sacrifice does not have to lead to problematic self-loss[30]. In her taxonomy of self-sacrifice, sliding from self-limitation to self-destruction, even the extremes are not necessarily problematic but may be viewed as acts that realize a value greater than the self. This is not to imply that family care should be advocated as some heroic act that realizes an ultimate good and thus is always acceptable. Van Nistelrooij warns to always be aware of the boundary between "proper" and "improper" forms of self-sacrifice. But how to pursue balance in family care? Van Nistelrooij defines self-sacrificial care as care provided *"despite the acknowledgment by the self that one will not realize other goods (for instance, care for the self), and despite the acknowledgment that the good of this caring is not unambiguous or indisputable"* (p. 286)[30]. So, in ideal circumstances, self-sacrifice would be the result of a conscious balancing act. A certain amount of self-loss can thus be evaluated positively, if family caregivers consciously *acknowledge* that they will not realize other values (e.g., related to their own work, hobbies, family life or personal goals) and also acknowledge that the intended value or their care is not beyond doubt but can be questioned by themselves or others.

Implications for nurses' support

From a care ethical perspective, family care can be viewed as a practice flowing from a relationship within a specific cultural and social context, which has meaning for the people involved. Family care, thus, is no clear-defined task that can or should simply be taken-over in case of burden. Although caring is an integral part of being human, the concrete realization of family care is highly personal, as is finding an adequate balance in fulfilling all motivations and expectations. Next to positive interpretations (giving satisfaction, a sense of purpose or fulfilment, enabling personal growth, etc.)[11], family care can also have a negative, neutral, or – often – ambiguous or ambivalent meaning. Daughter Eva (Table 1), for example, experiences ambiguities: she finds it simultaneously rewarding and exhausting to give up her values with regard to her job while fulfilling her duty as oldest and

darling daughter. She also narrates how they haven't been very close, as her father always scared people away by not being friendly. Caring may thus be hard on her, possibly leading to ambivalent feelings deemed as "inappropriate" (such as anticipating relief in her father's death). To prevent family caregivers like Eva from social misrecognition and alienation, we should recognize the complexities of family care in *all* its meanings[33].

Supporting family caregivers is about meaning rather than solutions

As we regard consciously finding a balance between contrasting values to be important, we suggest that family caregivers should be enabled to explore and act upon what caring means to them. For nurses and other healthcare professionals, this implies they should regard family caregivers as people within certain relational and social contexts that shape their care and evoke certain behavior. Previous reviews showed the complexity of palliative care nurses' role[20, 21] , e.g. being available, coordinating care, facing clinical challenges in a high workload, while also experiencing the personal impact and helplessness when working with patients in the end stage of serious illness. Dealing with families – e.g. with them being demanding or vulnerable – can specifically be a source of stress for nurses[21]. Grasping the complex interplay of underlying values, family histories and wider social contexts may help nurses in understanding family members and why or how they care.

Furthermore, instant attempts to solve the 'problem' of actual burden by changing people's activities may overlook the inevitable ambiguity in family care, possibly depriving partners and relatives of a potentially self-affirming practice of family care. Moreover, even if burdensome tasks are relieved by practical solutions, family caregivers may still feel called upon: the tragic choices and their consequences still remain. Nurses should therefore not focus on liberating caregivers *from* the situation but support them *in* whatever overwhelms them when providing family care in their specific context.

We strongly suggest that any support for these partners, family members or other close ones should follow from and be tailored to the personal meaning behind (burdensome) experiences, which could be explored in a dialogue (Table 2). In line with Zarzycki and Morrison's advice to foster a family caregiver's critical awareness in a 1:1 conversation between healthcare professional and family caregiver, we would suggest to discuss the values that drive or keep caregivers in their roles[9].

Table 2 | Practical suggestions for nurses in supporting family caregivers

In supporting families, nurses may signal risks of burden. Before immediately taking action e.g. adjusting activities or redistributing tasks to relieve this burden, nurses would do well to first explore what caring (and the possible burden) means for a particular family caregiver. This enables nurses to tailor the type and amount of support to this meaning rather than on tasks or activities. These practical suggestions may be of help:

a) Frequently explore the (perhaps various) meanings and accompanying values with caregivers. What does the patient mean to them, how would they describe their relationship? How do they experience their caring role? What is important in caring for their loved one, and why? What motivates them to care?
b) Think along with caregivers about how these values might be contrary to one another and what may have to be sacrificed along the way. Which important things or activities are family caregivers unable to do because of their family care? What values are under pressure, and how to weigh these against the gains? Do they experience feelings of failure, and with regard to whom? Give space to feelings of regret or shame regarding their 'inappropriate' feelings or actions.
c) Jointly discuss how (in terms of space, time, activities, etc.) people aim, wish or feel able to be involved in care. Reflect on (alternative) ways in which their aims (as mentioned under a) can be obtained.
d) Be aware of self-sacrificial care in which the ambiguities and uncertainties are not acknowledged, for instance if someone is exhausted but wants to keep on going no matter the costs, or if someone does not see any other option for example due to expectations in their family, or practical reasons. Try to understand this in light of the context and relationship of the caregiver and patient. Jointly explore whether the sacrifices are reasonable and healthy. And if not, think about alternatives and how others within or outside their social network can practically help the caregivers in meeting their personal motivations and social expectations.

Reflection

The suggestions put forward in this paper come with challenges. First, emphasizing the importance of consciously finding a balance between fulfilling all expectations may seem to suggest that it is acceptable when people exhaust themselves as long as this is knowingly done. We want to add that pure exhaustion – even after weighing it in light of other values – may be a signal of excessive and thus improper self-sacrifice[30]. Then, caregivers are no longer capable of noticing that the "good"

of their care is not beyond doubt – all their other roles or activities are put on hold in favor of the goods for the patient, without any space to think about alternatives. Thus, their care would be self-destructive hence disputable. Without doubt, thus, caregiver burnout is a serious risk, prompting authors to advocate support, time-off and respite care[9, 14].

Furthermore, especially within a palliative care context of intensified care and an approaching death and grief, current caregivers as well as nurses may have neither the energy nor the capacity to thoroughly reflect on motivations or social expectations. We suggest, if possible, to cooperate with other disciplines such as social workers. Putting such deeper layers into words may, however, not be possible or helpful for everyone: due to all ambiguities and ambivalences, people cannot always voice their opinions and preferences, nor are they fully aware of the meaning or consequences of those[27]. We are aware that our suggestions to help caregivers reflect on meaning and weigh their sacrifices even bears the risk of increasing their burden, as issues become more explicit. Therefore, caution and moderation is required. As is common in advance care planning, we would recommend nurses to invest time in the beginning of a palliative trajectory to explore the family caregiver's personal situation and ties, together with this caregiver (as suggested in Table 2). This may give nurses an indication of the family caregiver's social network, familial relationships, and wider social or religious community, and any potential burdening expectations or helpful resources that may spring from them.

Lastly, familial relationships can be very complex and tensed – and some relatives may not be willing to undertake caring activities or may just be absent or hardly involved. Eva's siblings (Table 1), for example, feel that their dad should be admitted to a caring institution as caring is asking too much of them, whereas Eva wishes to persist in caring for him. From a care ethical perspective, a choice to *not* become a hands-on family caregiver (e.g. to arrange healthcare professionals to help one's partner shower, or to transfer one's mother to an institution) can still be understood as 'caring' or even 'good care' when seen in the particular contexts of the individuals involved and their relationship[29]. Again, such a decision is not an utterly individual and free choice at a specific moment in time. It is important to understand all choices in the light of the dynamics of the relationship, within the larger context. Whether any decision is "good", reasonable or healthy should, in our belief, be discussed jointly with the caregiver. Care ethics offer space for choice. Taking responsibility – crucial for care to even exist – is a moral task after all[25]: people have the freedom to respond to or resist being called upon.

Summary and conclusion

This paper aimed to provide a care-ethically inspired perspective on family caregiver burden and support in a palliative care context. We explained that family care should not be reduced to clear-defined or well-chosen tasks or activities that can or should simply be taken-over in case of burden. Rather, caring for one's partner, parent, or other proxy is an ongoing and often messy relational practice, due to being related and therefore called upon, in a particular context. Social or cultural norms and expectations shape how family care both is provided and experienced. We believe caregiver burden may specifically lie in the limitlessness to which people feel called, i.e. the self-sacrifice that lies in being constantly available and attentive to the patient's needs first, and the pressure on certain personal values or other roles this causes (e.g. caring while also being a parent, partner, employee, friend, etc.). Family care, thus, is complex and highly personal, as is finding an adequate balance in fulfilling all of one's motivations and expectations.

We conclude that nurses would do well to first explore the *meaning* of family care for a specific person, whether positive, negative, or – often – ambiguous or ambivalent, before immediate action is undertaken to relieve burden by adjusting or redistributing tasks to others. If possible, caregiver experiences – and specifically signals of burden or the results from screening tools – should be interpreted in an explorative dialogue with the family caregivers themselves (Table 2). Such a dialogue should keep into perspective the specific caring relationship between the involved people, the person's social context, and how to balance a person's values and expectations that shape the impactful experience of caring for a dying loved one.

We are fully aware, however, that this paper describes an ideal, whereas the actual world of family caregivers and of nurses' support may be tough and messy, especially in acute, brief, or intensive caring processes. Family caregivers may neither have time nor the capacity to thoroughly reflect on what caring means for them. Notwithstanding, we suggest to carefully tailor support to what lies beneath burdensome experiences. Nurses, compassionate as they often are, do not have to strive to liberate family caregivers *from* the situation but should support them *in* whatever overwhelms or drives them in standing-by their loved ones until the end.

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Chapter 6

General discussion

Background and focus of this thesis

This thesis is focused on the experiences of Dutch family caregivers who provide some sort of care, aid, or assistance to someone close to them who is seriously ill. Specifically, I studied the phenomenon of family care within home settings in a palliative care context, where this topic is highly relevant. When patients prefer to stay and die at home, the role of their close ones, if present, is usually pivotal[1-3]. As set out in the General introduction (Chapter 1), previous research among family caregivers showed the potential gains of providing family care[4-6], but also highlighted the immense physical, emotional, and psychosocial impact of care on family caregivers[7-11]. Nonetheless, for many people, taking on and maintaining a caring role is self-evident[6, 12, 13]. The involvement of families is also increasingly encouraged by governments[14-16]. Many people just *do* it, even at considerable (financial and mental) costs. Family caregivers, thus, may need support – as is also widely recognized. However, family caregiver support is not always part of healthcare professionals' routine practices when caring for a patient[17, 18]. Yet, research has also shown that one of the most essential needs of family caregivers is to feel seen and valued[19] – not only as expert co-caregiver, but also as the patient's partner, grown-up child, sibling, relative, friend, or other person significant to the patient, with their own needs and emotions regarding the whole situation of care, suffering, and approaching death. To increase family caregivers' visibility, the central aim of our graphic novel project was to literally visualize family caregivers' experiences via comic art, thus engaging a broad public in thinking about family care.

This thesis presents research that has been conducted in parallel with our graphic novel project in which key results were presented as a graphic narrative about family care. Parallel to this project, the research aimed to a) better understand the phenomenon of family care, and b) better grasp how the experiences of family caregivers can be translated into public education and communication via comic art.

In this last chapter, I will recapitulate and discuss our empirical findings and theoretical reflections. First, I will elaborate on what the research adds to our understanding of family caregivers' experiences (Chapter 2) and what this means for our thinking about burden and support (Chapter 5). Then, I will briefly discuss the lessons we learned about interdisciplinary collaboration with comic artists (Chapter 4), and reflect on the possible merits of using comics to support family caregivers (Chapter 3) or to educate a non-academic public. Lastly, I will provide suggestions for future research projects.

A broader understanding of family caregiver experiences

What can be learned from this thesis, regarding its first aim to better understand family caregiver experiences? As the General introduction explains, previous research already showed that tragic situations may arise when people feel torn between the competing demands stemming from their roles as both family caregiver as well as partner, parent, employee, or friend. Family caregivers may feel isolated or lonely when their lives are primarily focused on the patient, and often experience difficulties (or even exhaustion) in balancing the needs of the patient with their own. Surrounding friends, family, or professionals may then worry and provide the well-meant advice that the caregivers should think of themselves first. However, thinking of themselves first can be very complex for a family caregiver. Chapter 2 and 5 explain *why*, by showing what drives people to take on and maintain a caregiver role.

In this section, I will discuss the normative nature of family care, how that invites us to rethink burden and support, how societal changes and governmental policies reinforce families' responsibilities, and what all of this means for support practice.

Normativity within the phenomenon of family care

The analysis in Chapter 2 shows how people experience a 'call' to care – not only by the patient, but also by well-intending friends, or professionals. Specifically, they expect themselves to be attentive to the patient first while ignoring their own needs, to be available all the time, and to be assertive in managing the care situation. This is in line with findings in previous research, for example a study showing that family caregivers in cancer care almost naturally set aside their own needs and assume the role of 'project manager'[13]; and a study that identified four distinct profiles of people providing family care at home, which showed that the patient's situation was a constant preoccupation for the carers in each of these profiles[20]. My study confirms these findings and further explains them. Feeling called to care cannot simply be ignored: the normative elements of love, a sense of obligation or duty, and family dynamics – or a combination of these three – appeared to be important drivers to respond to this experienced call. The palliative care context further intensifies the feeling of being called upon with a sense of urgency. As argued in Chapter 5, these results may explain why it may be hard for carers to follow up on advice to do less, quit caring duties, and think of themselves first.

This thesis therefore shows that family care in a palliative care context is not a straightforward one-dimensional activity but rather a complex and layered phenomenon, with a normative nature. This is in line with other research, framing

family care as an activity shaped by societal norms, pointing to spousal moral contracts, solidarity in families, or reciprocity between generations[21]. My findings with regard to why people feel called also correspond with findings from Zarzycki et al. who synthesized insights about why people provide care, across various cultures and health conditions: their review shows that retrospective reciprocity ('paying back' one's parents), affection, relationship quality, obligation, and family values and dynamics are key determinants in people's motivations[12]. Their analysis – identifying several subdomains of concepts like obligation, affection, and reciprocity – confirms the complexity of the phenomenon of family care. Although meta-studies on a macro-level such as the one by Zarzycki et al. are important for identifying general patterns and domains of normativity, micro-level research like ours is needed to provide insight into the lived and often messy experiences of caregivers – for example what it actually means for one's daily life if people feel obliged to care for their parent, how they try to trade-off values, or how a low-quality relationship between the caregiver and patient influences family care.

Framing family care as inherently normative, and reflecting on the topic from a care-ethical point of view, may help us to better understand family caregivers' actions and sacrifices. As Chapter 2 and 5 explain, partners, grown-up children or other people significant to the patient always carry expectations and motivations with them while taking care of the patient. These inevitably influence them to act in a certain way and may push them to their limits, related to what they believe is expected from a 'good caregiver'[22]. This normative dimension of family care cannot be resolved but stays present, even if professionals take over caring duties or activities.

People's ideas about what is good or right are particularly relevant when it comes to life and death in the last phase of a life-limiting disease, and in making decisions about how (not) to act as family caregiver. As Randall and Downie argue:*"… any discussion about palliative care occurs against the background of those major questions which relate to the meaning of life and death, or what constitutes a good life (and perhaps death) for a person."* (p.13)[23]

It is important to note that family caregivers' answers to these major questions about a good life (for their loved ones, for themselves) are not purely personal. After all, in line with care-ethical thinking, people are not islands, nor 'autonomously' choosing individuals[24]. Rather, their ideas about a good life, a good death, or what constitutes being a good caregiver are deeply tied to the context – for example, the relationship, the specific family, or the wider culture – in which this caring occurs.

Family care, as such, is an ongoing, complex and often messy process due to people being connected to each other in a particular setting[25]. In other words, due to being related[26], people may find themselves *tangled* in their family caregiver role.

Rethinking burden and support of family caregivers

As I suggest in Chapters 2 and 5, the inherent and all-present normative nature of palliative family caregiving invites us, first, to rethink *burden* and better understand why it is not a straightforward but rather a complex concept.

Within nursing and other professional care practices, the multidimensional concept of 'caregiver burden'[27, 28] is well-known, given the varied tools to screen for burden in practice[27, 29]. Especially given the challenges and unmet needs of family caregivers[27], screening is advocated to detect burden at an early stage. Although Chapter 2 shows how family caregivers feel constantly called upon, it should be emphasized that this does not necessarily equal to feeling burdened. Timely identification of burden is important of course, but assessing caregiver burden needs careful interpretation and consideration of the caregiver's context[28, 30]. Experienced burden is not only a result of the presence of physical, mental, or socio-emotional challenges, but also related to how one deals with the moral ambiguities and ambivalences that are often experienced when providing family care. My in-depth interviews showed that caring can be a positive, rewarding, or honoring experience, while caregivers can at the same time experience it as exhausting. Bijnsdorp et al.'s quantitative research also indicates that positive experiences – such as enjoying nice moments together with the patient, or gaining a good feeling from caregiving – can occur simultaneously with experiencing burden[5]. More than 80 percent of the family caregivers in that study reported to enjoy caring for their parent, partner, other relative or friend. At the same time, more than 75 percent experience some degree of burden, and 20 percent a heavy burden. These findings, as well as mine, indicate that family caregivers may experience ambivalences.

In addition to these empirical findings, Chapter 5 explains, building on Van Nistelrooij's care ethical thinking on the concept of ambiguity and self-sacrifice, that the phenomenon of family care is highly ambiguous: it realizes certain goods or values while neglecting or suppressing others[31]. Rather than in feeling called per se, the burden of care might lie in the seeming limitlessness to which people feel called, i.e. the self-sacrifice that lies in being constantly available and attentive to the patient's needs first, and the pressure this causes on personal values like friendship, self-development or parenthood. That is why family care often leads to ambivalent feelings. Ambivalence is another concept, which has been put forward by sociologists

Broom et al. as helpful in understanding family caregiver dilemmas and suffering, that is, when people have mixed feelings because they feel they cannot live up to the socially induced normative expectations associated with their role as a family caregiver[22]. As family care is situated in a particular context, in which social scripts and expectations come into play, a sense of failure, shame, or regret may arise when caregivers' feelings or experiences conflict with what they believe is expected of a 'good family caregiver' in their particular social or cultural context. Another analysis of family caregiver experiences, taking a hermeneutic approach, also uses the term ambivalence, for example in feeling a moral duty and virtue in becoming a family caregiver but also having doubts and anxieties about how to cope with that role[32].

Rethinking burden of family caregivers

Secondly, this thesis invites us to reflect on how to *support* family caregivers. Attempts to immediately relieve burden may overlook a family caregiver's values and context, whereas support requires acknowledgment of and an adequate response to the moral ambivalences family caregivers have to deal with. Precisely because of the pervasive normativity in people's actions and feelings, there is no clear-cut practical way to 'solve' someone's burden – if it even can or always should be solved. Concerns about a family caregiver's wellbeing are understandable and necessary, and the use of screening tools can be of practical help, but only if followed by a tailored approach of supporting that particular person. One of the key messages of this thesis is that family care is complex and highly personal, just as finding an adequate balance in fulfilling all of one's motivations and expectations is for family caregivers. Focusing only on relieving people's burden bears the risk of paternalism and does not take into account the ambiguities and ambivalences of family care. Rather, if we take the latter seriously, family caregivers would be better supported if this support was guided by the question how to help preserve them in being an intact or *whole* person (having several roles and duties, valuing several goods, etc.). In this regard, Chapter 5 refers to Gastmans' care-ethical thinking on vulnerability and preservation of the dignity of someone who is in need of care[33]. In my view, that person can be a patient but also a partner or family member who may need care or support. According to Gastmans, caring is not always about asking what is to be *done* (or, applied to the situation of burdened family caregivers: which tasks one should be relieved from), but rather about how to preserve a person's dignity as a whole. The concept of dignity is, however, complex[34]. Nevertheless, I value Gastmans' idea of seeing a person as a vulnerable whole that can be affected in several dimensions – at a physical, but also a psychological, relational, moral, sociocultural, or existential level, as was found among older adults[35]. In Gastmans'

view, care is *"most meaningful"* (p. 148)[33] when someone is respected as a unique and embodied human person in this wholeness, in all his or her dimensions.

What, then, is important to consider when supporting family caregivers? Building on Gastmans' work, various dimensions make up a particular family caregiver as a whole person but concurrently are sources of vulnerability as well. On a relational, moral and sociocultural level, for example, family caregivers may hold different (socially induced) values and expectations, which may lead to (moral) dilemmas in dealing with the duties, tasks and activities in their various roles. In my view, good support should take into account the trade-off and balancing of these different values and expectations. Engaging in dialogue is key here. According to Gastmans, the most appropriate answer to someone's care needs cannot be deduced in the abstract, but is only reached in a dialogical process between healthcare professional and care receiver. Building on this, I argue that the appropriate answer to the question of a specific family caregiver's burden cannot be deduced from that person's score on a caregiver strain index questionnaire, but can only be found in an explorative dialogue between this family caregiver and the one who supports them. As far as possible, in a such a dialogue, all values and dimensions that play a part for that particular family caregiver can be consciously interpreted and weighed – to prevent the family caregiver from blindly sacrificing everything and drown, but also to prevent others from instantly attempting to blindly take over the caring duties. The crux is that the normative nature of family is all-present. Even if burdensome tasks are relieved by practical solutions, family caregivers may still feel called upon: the tragic choices and their consequences still remain. The people who support patients and families should not focus on liberating caregivers *from* the situation but support them *in* whatever overwhelms them when providing family care in their specific context.

Family care situated in a political context

With regard to family caregivers' specific context as mentioned above, it is important to note that while care is something highly personal within a certain relationship, it is also situated in a political context. Although my interviews in Chapter 2 mainly focused on people's personal experiences and feelings without discussing, for example, governmental policies, the political background puts the interviewees' responses in a certain perspective. Here, I can only briefly touch upon this rather large sociological matter. Still, it is worthwhile to consider how feeling called – or even obliged – to care for one's relatives is perhaps reinforced by governments.

With aging populations and increase of disabilities, chronic diseases and frailty pressurizing the sustainability of care, family care is increasingly considered an

important pillar of many Western countries' long-term care systems[14-16]. Dutch society has shifted from a welfare state to a more neo-liberal society, expecting citizens to participate actively and feel responsible for taking care of themselves and their loved ones as long as possible[36]. The idea behind this is that it will keep rising healthcare costs manageable and address the growing demand for palliative care[2, 37]. It is assumed that when generous state support is provided, this crowds out efforts of family caregivers, and that the normative discourse of less government responsibility and emphasis on family care will change societal norms towards favoring families' responsibilities in providing care[16, 38]. Research among European countries criticizes these assumptions: even though low levels of state support and societal norms favoring family care may go together with higher proportions of people providing intensive family care, family sociologist Verbakel emphasizes that such intensive caregiving often is burdensome. This might risk family caregivers' well-being, leading to low-quality family care or drop out of family caregivers, and thus jeopardizing healthcare systems' sustainability as these partly rely on families[16].

Indeed, caring for a family member will become more challenging in the future. There are several reasons for this. The number of people who need care is growing, while there are less healthcare professionals to provide care. In addition, there have been social and familial changes, such as the process of individualization and detraditionalization of how care and families are viewed, which complicates families' involvement in care[39]. It therefore makes sense that the Dutch government actively encourages citizens to think about their futures and what they can do for each other in times when care is needed, for example in the campaign 'Praat vandaag over morgen' ('Discuss tomorrow today')[40]. Although it is understandable that the government tries to relieve the pressure on formal care and explores alternatives, my concern is that it puts – moral, perhaps even improper – pressure on partners and family members if the government actively urges people to take on family care. A question, then, should be whether they feel they can choose to what extent they want to provide care, and whether active governmental encouragement would harm relationships that are already under pressure.

Another challenging factor is that, as my research confirms, people often have more societal roles than just the caregiver role. Many have a paid job, for instance. Quantitative research of Bijnsdorp et al. among family caregivers of terminally ill patients shows that about 70 percent of the working family caregivers were able to combine care and work successfully. Still, a substantial number of people struggled with doing tasks at home and having responsibilities at work, but only one in seven working family caregivers used formal care leave arrangements[5].

This may be because family caregivers have to live up to certain expectations and often simultaneously experience value conflicts. Due to the societal changes mentioned above, people often have competing values or views with regard to what constitutes a good life or what it means to be a 'good' partner or relative. For example, they value reciprocity (taking care of their parents now that they are in need of looking after) while at the same time value earning money or prioritizing their life project[36]. Such dilemmas can cause ambivalent moral feelings. Family caregivers may therefore not be inclined to openly 'complain' about their situation at work or ask for leave arrangements. However, given the normativity discussed in this thesis, there is good reason for people to discuss their care situation as well as possible solutions or leave arrangements with their employers, and, likewise, there is a need for increasing awareness among supervisors[5]. Furthermore, I suggest that policymakers should acknowledge such value conflicts and dilemmas, and support family caregivers in making conscious choices after having weighed the conflicting values. The ideal of having a choice may be hard to achieve, however, if government policies increasingly lodge responsibilities in families' hands[38].

So then, where may we find an alternative? The study among European countries mentioned earlier showed that formal long-term care support was associated with high numbers of people providing (some) care to people from their social network[16]. A more sustainable situation for our healthcare systems may thus, according to Verbakel, be a situation where *"many caregivers do a little each"* (p. 445)[16]. Her conclusion accentuates my suggestion (in Table 2 of Chapter 5) to explore the involvement of a patients' larger social network, to prevent direct family members from feeling solely responsible and from blindly immersing themselves in self-negating forms of family care.

Implications for supporting family caregivers

The reflections in this thesis may be helpful to people in support practices, such as nurses, physicians, social workers, other healthcare professionals, or volunteers (not to be confused with family caregivers themselves!). Given the highly personal and complex normative nature of family care on the one hand, and the governmental pressure to take on and maintain a caring role on the other hand, it is important that family caregivers are also supported themselves. It can be challenging, however, to adequately support family caregivers who want to keep on caring at all costs. The care ethical perspective of this thesis invites healthcare professionals and volunteers to view family care as a complex, ongoing, messy, and overwhelming process flowing from a relationship, rather than a chosen task that can easily be given up when things get too hard. To better understand why or how particular people care (or, contrarily, want to keep their distance), it may be helpful for the people

in support practices mentioned above to have a sense of the complex interplay of family caregivers' underlying values, family history, and wider social context – and the ambivalent feelings these may cause. Bijnsdorp et al. also emphasize that 'one size does not fit all' when understanding and supporting families, as they showed that the four distinct family caregiver profiles they found each have different challenges and needs[20]. Moreover, acknowledging the complexity of family care may also enable family caregivers to talk about their seemingly 'inappropriate' experiences or feelings related to their role, for which they feel ashamed or guilty[22].

Therefore, I suggest that people in support practices frequently explore a particular family caregiver's experiences, ambivalences, and sacrifices, and jointly discuss how family caregivers wish or feel able to be involved in care (see Table 2 of Chapter 5). I also emphasize the importance of reflecting on alternative ways to organize family care or considering the help of others within or outside the family caregivers' social network to meet their aims with family care. At the same time, I realize that these suggestions are not without challenges. Family caregivers as well as nurses may have neither the energy nor the capacity to thoroughly reflect on motivations or social expectations. Nevertheless, I think it is of utmost importance that family caregivers feel seen, heard, and understood in what happens to them. In the end, standing by family caregivers is about being there and being interested. It is about truly *seeing* these people, in all their roles and with all their ambivalent feelings, and then acting based on what caring means to them.

A brief last remark, however: important to acknowledge is that individual healthcare professionals or volunteers feel adequately backed by their organizations in supporting family caregivers. Hoffstädt et al. advise organizations to incorporate support of family caregivers as a structural part of their workflows[19]. Their 'Oog voor Naasten en Nabestaanden' methodology, a six-step trajectory for Dutch organizations, may be helpful for healthcare professionals to optimize their care for family caregivers and implement this structurally[41]. In this way, family caregiver support does not solely depend – and put pressure – on individual professionals and volunteers, but is part of a larger movement within organizations and teams.

Using comics in a palliative care context

The second aim of this thesis was to better grasp how the aforementioned experiences of family caregivers can be translated into public education and communication. Our graphic novel project intended to contribute to acknowledging and supporting

family caregivers by literally visualizing the complexity of their experiences: via comic art. *Naasten* is meant to invite a broad public – family caregivers themselves, but also healthcare professionals, volunteers, family caregivers' relatives or friends – to look closely at what it may be like to be a family caregiver. The rationale behind the project was to offer recognition and support to those readers who are family caregivers themselves, and to stimulate other readers to convert the stories to their own real-life situations, for example by keeping in mind the characters' experiences or the themes within the novel when supporting actual family caregivers in their professional or volunteering work.

The art-based approach within this thesis fits developments within healthcare and the field of medical humanities. As explained in the General introduction and Chapters 3 and 4, the potential of artistic approaches within education or academic research has already been acknowledged in scholarly work. In the past decennia, art-based methods have rapidly increased as novel ways for generating, analyzing, interpreting, or, as was mainly the case in our project, (re)presenting research data[42, 43]. Comics in particular may offer researchers powerful resources for communicating complexities to present a subject in ways that textual academic publishing cannot[44]. Now, after having developed our graphic novel (Chapter 4) and having empirically explored its use (Chapter 3), what can be learned about developing and using comic art in a palliative care context?

In this section, I will discuss the affordances of collaborating with the arts in one's research in a palliative care context. After reflecting on what we learned about reaching more of the potential of comics-based research, I will mainly discuss the merits and complexities of using comics in palliative care, and reflect on the educational value of comics with regard to increasing healthcare professionals' understanding of relevant topics such as family care.

Reflections on the potential of an interdisciplinary research-art collaboration

As a response to family caregivers' sense of loneliness and to increase their visibility, our graphic novel project aimed to show the complexities of home-based family care in an original piece of comic art. One of the unique aspects of our novel was that its two storylines did not stem from the artists' own memoirs, but were instead carefully built from general patterns derived from qualitative research. To do so, I closely collaborated with the two comic artists (final-year students at that time) for over a year, thus bringing together our disciplines of healthcare science and comic art. Chapter 4 reflects on this process, in which I quite often felt tangled,

having multiple roles and responsibilities. Nonetheless, the project resulted in the extensive graphic novel *Naasten*, in which the two interwoven storylines provide a rich palette of family caregiver experiences in a palliative care context. Overall, the respondents in Chapter 3 (family caregivers, healthcare professionals and volunteers) praised the novel for being original and recognizable, its ability to emotionally touch readers, and its portrayal of moments of tender loving family care. They also criticized *Naasten*, for being too dark and sad, confronting, complicated due to the interwoven and rather differently drawn storylines, or just "too much" – being a 230-page book. Regardless, in my experience, images from the novel always immediately evoke a response among its audience, from which a conversation about the relevant topic of family care can take off.

Although we seem to have reached our project goals in developing *Naasten,* from a scientific perspective, as Chapter 4 brings forward, our graphic novel project could have benefited from a more explicit focus on interdisciplinarity from the beginning. We did not use the full potential of arts (or more specifically: comics) based research. We were mainly focused on translating and representing our findings to engage a broader public into thinking about family care, whereas the involvement of artists and their art could also have been used to generate, analyze, and interpret our findings[42, 45]. As such, a collaboration with artists may bring advantages – not only for communicating one's findings, but for one's academic research as a whole. Interdisciplinarity, after all, resides in the dynamic interplay between disciplines and their diverging approaches – and ideally is more about integrating than merely placing the different perspectives next to each other, as was mostly the case in our graphic novel project.

One of the main lessons learned with regard to reaching more of the potential of comics based research, therefore, is to continuously discuss the opportunities and limits of the approaches of the collaborating disciplines throughout the project. Mutual interdisciplinary learning requires adopting various views of a phenomenon and reflecting on the underlying assumptions and methods of each disciplinary perspective – in other words, wearing different disciplinary or methodological hats (as a team or as an individual) when viewing a phenomenon[46]. It is essential, then, that all parties commit to working that way: they should intend to adopt different perspectives on a phenomenon and thus be open to other ways of working towards a shared goal.

Another lesson learned is that the involved parties should have enough opportunities to engage in the type of interdisciplinary discussion that is mentioned above. In Chapter 4, I refer to reflections of Hamdy and Nye who developed a

research-based comic narrative, and Jonsson and Grafström who explored how their involvement with a comic artist was beneficial for their scientific work – not only for representing but also *conducting* research. Based on these experiences, I argue that a truly interdisciplinary research-art collaboration requires an early involvement of artists, to ensure that researchers' common scientific methods can be expanded via new artistic perspectives while collecting and analyzing data, and creating the stories or art work[47, 48]. However, timing is not the only factor. Perhaps more influential than having enough time to jointly conduct and interpret research is the factor of people's attitudes and curiosity. Without an open attitude, the collaboration – no matter how timely its start – may not succeed. Time and space, however, is needed to practice and cultivate that attitude. An interdisciplinary collaboration is about having or allowing each other the opportunities to get to know each other's methodological perspectives, and learn from that.

In that way, collaborating in an interdisciplinary way with artists invites researchers to reflect on both *what* information or knowledge should be shared with the public, and *how* this should be shared[46, 49]. Art-based methods can provide novel ways to reflect on knowledge building, according to sociologist and arts advocate Leavy[42]. In our project, with regard to the representation of knowledge, an important issue was the balancing of aesthetic and scientific aims—and the resulting approaches—in telling the comic stories. Other research teams had similar experiences while adopting artistic approaches. A team that developed a graphic novel within palliative care points to the difficulties of transferring one's empirical results accurately while also allowing for an innovative visual presentation[50]. In reflecting on using theatre techniques for discussing diabetes experiences, other researchers observe a tension between using different sources of information to address cross-cutting themes and account for medical details, versus telling a powerful story perhaps based on the experiences of just a few storytellers[49].

These experiences, including our own, evoke the question: what exactly *is* an innovative presentation or a powerful story? This question prompts us to consider the quality of the eventual artwork and think about relevant criteria. In my case, to ensure that our graphic novel would be credible and suited to our aims, both its content and form were critically assessed by bereaved family caregivers and healthcare professionals, from early sketches on throughout the development process, mainly in relation to its recognizability, realism, and tone. It was also artistically assessed by the student's art teachers and an editorial team. As we describe in Chapter 4, we did not systematically investigate the interdisciplinary development process of the novel, but we adopted several techniques to ensure

the novel would be a credible and trustworthy translation of our research. In addition to these techniques, other people involved in arts-based research may perhaps benefit from a framework proposed by Lafrenière and Cox, as a guide to assess the quality and effectiveness of the arts-based work which is based on normative, substantive and performative criteria[51].

The merits and complexity of using comics in palliative care

Drawing on the aforementioned issue of quality of the eventual piece of art, an important question to ask oneself as researcher is: why even turn to the arts at all? In the remainder of this section, I discuss the use of comics in research – not so much to conduct research or interpret results, but mainly to represent one's findings to engage or educate a broader public, as we did. Lafrenière and Cox suggest that researchers should determine whether the arts indeed are a suitable means to represent their findings, and whether the target audience will be receptive to such a translation[51]. Although my research team did not explicitly determine this beforehand, it is worthwhile to reflect on the merits and possible downsides of using of comics in this regard.

In our graphic novel project and in my training activities afterwards, comics indeed turned out to be a powerful medium to visualize key issues of the complex phenomenon of family care in a palliative care context and people's associated feelings in a lively way. Humanities researcher Charise points to the affordances of graphic media for illuminating research phenomena and translating their significance for a broader audience – in particular, she builds a case for presenting one's research abstract in a comic form[52]. Such advocating, as well as our own graphic novel project, fits the emergence of a new interdisciplinary field of practice, described and explored as *comics-based research* by Kuttner et al.[45]. These comics scholars and artists thoroughly lay out how the growth of using comics within research does not stem from fashion but has to do with the specific features of comics. Here, I focus on a few of these.

One of the main benefits of adopting the comics genre was the comic artists' use of story-telling and depiction of emotions. Czerwiec and Huang argue that, in order for care to be relevant and effective, it should be informed by lived experiences. The stories within comics can serve as a window into the lives of patients and their families. Comics then provide "*images, stories, and perspectives we are unlikely to elicit from a bedside or clinic visit or from a textual narrative alone.*" (n.p.)[53] This can be informative for healthcare professionals, but may also be relevant for family caregivers in thinking about their own involvement in family care. Some

respondents in Chapter 3 reported that using images from the novel deepened their conversation with family caregivers by raising specific topics that would perhaps not have been raised otherwise, for example the feeling of guilt. Notably, guilt is an example of ambivalent feelings, just like regret or shame. I have argued before that such feelings should be acknowledged by people who support family caregivers, as these indicate that the person's experiences do not precisely fit within the normative social expectations associated with their role as family caregiver[22]. As such, the novel really added something new to their conversation.

Another benefit of the comics genre in our project was its use of metaphors to explain complex caregiving experiences, as these were also used by our respondents[54]. The 'rollercoaster', for example, is a metaphor reported by our respondents and also commonly used by other family caregivers to describe their mood swings related to the emotional path of hope and despair regarding the patient's illness and deterioration[6] (Figure 1). The 'circus' of healthcare professionals and other people coming into one's home is another example (Figure 2). The involvement of comic artists not only lead to representing metaphors or experiences as expressed by our interviewees (Chapter 2), but also added some. The supermarket scene is an example of how comics may communicate the essence of research – in only one spread instead of a lengthy scientific paper (Figure 3).

Moreover and specifically, it is its multimodal character that makes comics potentially beneficial for palliative care. The multimodality of comics – in short the combination of modes, that is, visuals and written language[55] – allows for a juxtaposition of images and text. Precisely in that *"complex arena of word–picture interaction"* (p. 7)[45] one can move between modes or purposefully create tension between images and words. This results in a plurality of perspectives and messages, thus enabling comic artists to show complex experiences, ambiguity and uncertainty[45, 56] – precisely relevant for a complex phenomenon like family care in a palliative care context. Czerwiec and Huang also argue that, due to its multimodality, comics are uniquely suited to capturing the multiple layers of embodied experiences within palliative care[53].

Figure 1 | Metaphor of the rollercoaster (p. 17-19), drawn by Melanie Kranenburg

These pages show the characters' reaction when a doctor delivers bad news, with Geert saying "What?" and Marie stating "Yeah, that's what I was already afraid of..."

The speech bubbles on the rollercoaster spread show the doctor's statements: "in the liver... lungs ... incurable ... further examination ... limited options ... sorry ... as long as possible ..."

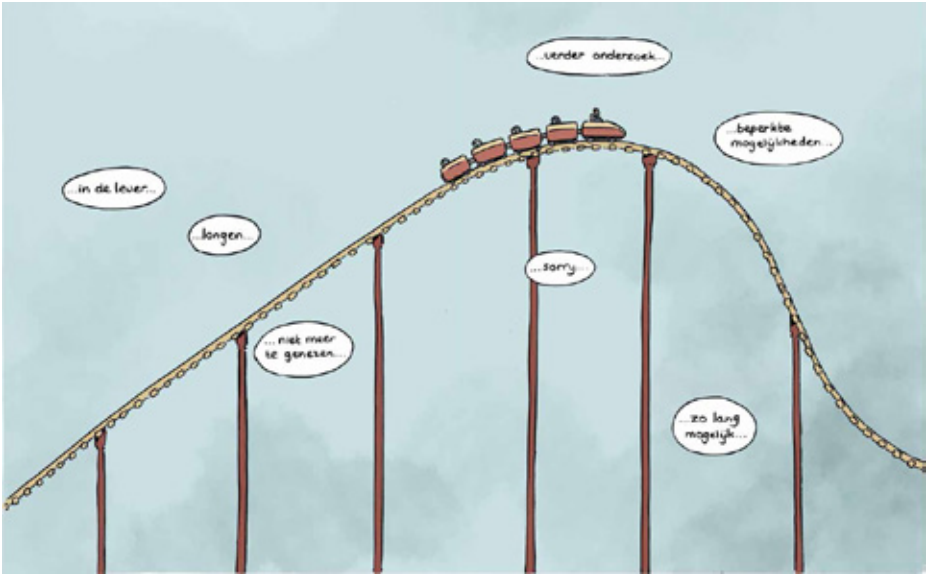

Figure 2 | Metaphor of the circus (p. 154-155), drawn by Melanie Kranenburg

Figure 3 | Spread of the supermarket, showing all main characters (p. 198-199)

Due to features like the ones mentioned above, the comics genre is advocated as a rich source of concisely and accessibly communicating complex and ambiguous issues[52, 57]. With this assumption in mind, our project aimed to translate research findings into a comic form. Focus group and interview participants in Chapter 3 praised *Naasten* for its recognizability and reported how this can be supportive for family caregivers, thereby confirming the proposal that comics can offer a sense of companionship through shared experiences[58]. They suggested that the showing of experiences via images might be particularly well-suited to the limited ability to concentrate of overburdened caregivers, and may reach people with language difficulties or a migratory background.

However, the accessibility of comics can also be questioned. Reading comics is not without challenges. The multimodality of comics requires that readers actively interpret the narrative and everything that is implied[56, 58-60]. Grasping the 'grammar' of a comic (as explained in Box 4 in the General introduction) or understanding all its metaphors and ambiguities is not always easy. Some readers, for example, expressed surprise that the terminally ill character was "still going to Austria", in Figure 4, thereby missing the metaphorical meaning of the mountains in the panel.

Figure 4 | Metaphor of the mountain (p. 116-117), drawn by Niek van Ooijen

These pages show daughter Eva and her father. Eva's story can be read in Table 1 in Chapter 5. "Easy…", her father breaths here. "I can … walk … on my own …"

Comics scholar Gardner points out this paradox of the comics genre as follows: *"on the one hand, it relies on highly compressed and distilled language and images create the illusion of transparency, while, on the other, it is so elliptical and marked by gaps that it opens up ambiguities that can only be resolved by the active engagement of the reader."* (p. 149-150)[61] Precisely because readers are offered a limited vision through guttering and gaps in the narrative, scholars La Cour and Poletti argue, the medium requires them to bridge the gaps in information themselves, and invites them to actively consider what is outside or between the panels – what more there is to the story than what is being shown[62]. Based on my empirical exploration and my teaching activities, however, I doubt whether people always read comics like this. Some readers tend to look at the panels as mere images that convey information, without much consideration of how the story is told or what the story might mean within their own contexts. That may be because *Naasten* perhaps does not contain much gaps or plural messages that invite them to reflect on their own experiences. A more solid explanation would be that fully grasping everything that is implied in a comic requires some skills on behalf of the reader that may not always be present.

Especially in the often turbulent palliative care context, it is doubtful whether family caregivers have sufficient time and/or capacity to slow down and fully grasp a comic[63]. And even if they do, comics may not always be a suitable medium. Chapter 3 reveals that the direct way in which our novel depicted things – as is common in comics[58, 60, 64] – was also considered confronting and emotionally impactful. Some family caregivers felt miserable after reading our novel, and for example felt specifically appalled by the black-and-whiteness of one of the storylines (as showed in Figure 4). Several respondents suggested that, if not introduced carefully, our novel might actually be harmful for possibly already overburdened family caregivers. As distilled from the findings in Chapter 3, it is important that the novel is introduced carefully – taking into account the family caregiver's individual situation, needs, abilities, and affinity with the medium – and there is sufficient follow up of the potential emotional impact. Overall, the respondents suggested that the novel could be used to start a dialogue about family caregiving among healthcare professionals and volunteers, contributing to their awareness and increasing their ability to offer tailored support to family caregivers. We therefore conclude in Chapter 3 that, rather than being a form of family care support itself, comics may fit better in educational activities about how best to support family care.

Merits of comics in education: a better understanding of family caregivers?

What is the potential of comics to educate (future) healthcare professionals and volunteers? Although the field of graphic medicine is booming[65], a question is what using comics really *adds* in education – more than being an original and enjoyable medium to evoke a response among its readers. Although the use of comics is generally advocated because they may increase people's awareness and understanding[56], proving the latter is problematic. Two scoping reviews highlight the lack of thorough evidence regarding the impact and efficacy of education with art and with comics in particular – which is related to the complex nature of such education, which makes it hard to objectify and test its learning outcomes[66, 67]. Although the review by Turton et al., scoping the variety of arts-based palliative care education, includes studies that demonstrate positive correlations, none of them proves that the newly acquired knowledge or understanding was applied to actual care practice[67]. Later studies that involved artistic methods also describe their difficulties with measuring impact[49] or consistently replicating artistic interventions[68]. In our project, as laid out in Chapter 3, the non-systematic use of *Naasten* by respondents made it difficult to demonstrate its impact. Moreover, the question rises whether these kinds of teaching or conversations with comic art can be evidence-based at all. Testing learning outcomes is a recurring challenge within the field of medical humanities, where teaching is less focused on factual learning or improving skills, but rather on (ethical) character building of students. Perhaps, as suggested, researchers should look for more innovative ways to address the issue of impact, without reducing art to mere mechanisms to achieve certain outcomes[69].

In addition to a few concrete examples of how the novel really influenced the conversation with family caregivers, our respondents mainly *assumed* the potential of comics. They suggested comics can help make professionals and volunteers more aware of family caregivers' existence, and how they have their own needs and concerns in the context of the patient's deterioration, anticipated death and their own grief. This is in line with the argument that comics may serve as a window into the lives of others[53, 58]. Turton et al.'s review also shows that the included aesthetic interventions aimed to increase, amongst others, professionals' awareness of others[67]. The authors point to empathic understanding of characters and plots as a key benefit of aesthetic learning experiences: the majority of their included studies reported that professionals obtained a deeper understanding of patients' and family caregivers' experiences, for example an increased awareness of emotional impacts, or of experiences of loss or bereavement. However, whether this influenced actual professional practice was not assessed.

Moreover, what awareness or understanding *is,* and how to assess it, is open for debate. Cultural studies scholar Wegner critiques the idea that readers would gain a deeper knowledge via graphic narratives compared to purely textual biographical accounts of illnesses[65]. 'Seeing' is confused here with 'knowing', she argues, which she believes to be a common false understanding in the medical field and everyday language. Interestingly, sociologist Leavy also states that comics do not – as is advocated within graphic medicine – provide a *window* into the lives of others, but instead offer a *created perspective*[42]. In line with Wegner's and Leavy's work, I suggest we should be careful in stating that we know 'what it's like' when having read a comic such as ours. Our graphic novel *Naasten* provides a created perspective as well – more specifically: its provides two perspectives, of the main characters Geert and Eva. As such, the novel should not be instrumentalized to offer a complete and factual account of family care. It is important to acknowledge the limits of such knowledge, especially with regard to someone else's experiences of illness, disability, or for that matter, family care.

Nonetheless, and in contrast to most graphic medicine comics, our novel is not a memoir stemming from a single person's experiences. Rather, the two storylines were carefully and intentionally built from extensive research and feedback, and thus offer a strong base for our audience from which to reflect on the phenomenon of family care. Not coincidentally, the novel depicts two different storylines, showing family care from distinct perspectives (with regard to, for example, gender, type of relationship, phase of life, and type of illness), thus aiming to show the diverse and complex aspects of the phenomenon of family care. In that way, comics such as ours can be powerful in making people think about this important topic and helping them to discover aspects of being a family caregiver that they did not acknowledge before.

I thus propose that the value of comics mostly lies in their ability to help readers such as professionals and volunteers to imagine family care and then reflect on what they knew *and did not know* about family caregiver experiences and feelings. Comics may well be used to help people reflect on and discuss their differing interpretations of an image, and what can be learned from this with regard to how they interact with families. And interestingly, in line with theorizations about comics offering plural ambiguous messages thanks to guttering and providing gaps information, it is the very medium of comics that illustrates the idea that there is always something we do not know. As La Cour and Poletti argue, reflecting on the future of graphic medicine, comics themselves show how people's lived experiences cannot ever be completely represented: comics offer a fragmented perspective which is "*as close as any account of life can get*" (p. 9)[62]. We as researchers and educators using comics

have to acknowledge that we are dealing with bits and pieces of information, but, more importantly, that comics provide us with gaps in between and opportunities for interpretation and discussion. Fragmented and created, and precisely therefore potentially valuable, especially for inviting others outside academia to reflect on the complexities of family caregivers' lived experiences in the context of death.

Suggestions for future research

The empirical findings as well as the theorizations within this thesis yield several opportunities for further investigation. I present my suggestions along the two lines of research of this thesis: first, regarding our knowledge of the phenomenon of family care in a palliative care context, and secondly, regarding the use of comics within research and our understanding of interdisciplinary research-art collaborations.

Family care within a palliative care context

Although Chapter 2 as well as other research highlight the general elements of normativity within family care, academic knowledge would benefit from more specific insights into the variations of normativity of family care. It is valuable to distinguish between the various types of relationships between people (spousal, adult-child, friend, etc.) and how these relate to people's motivation(s) to take on or maintain a family caregiver role: does reciprocity or moral duty mainly come into play in a parent-child relationship, for example, and in what way does this differ from spousal duties?

Additionally, it is important to take the quality of the relationship between family caregiver and patient into account. Socially induced norms, such as taking care of one another for better or worse or 'paying back' one's parents, seem very influential but may be even more distressing in case of low relationship quality. However, family caregivers may not be aware of their associated ambivalent feelings or may perceive them as inappropriate. Overall, researchers should be aware of ambivalences uttered in interviews and questionnaires, as well as socially desired responses.

Another suggestion is to conduct such research via longitudinal explorations. Interviewing the same family caregivers both before the death of the patient and during bereavement could allow for showing ambivalent feelings that may be suppressed during the dying process and only openly revealed in the bereavement phase[22]. Such a serial exploration would also provide insight into people's transition

from family caregiver to bereaved relative, and the related change of their needs after the patient's death[19].

Lastly, in this thesis I have only briefly touched upon the matter of societal pressure within the phenomenon of family care. I suggest to further investigate the position of family care as a phenomenon situated in a larger political and societal context. What role do governmental policies play in this regard? Which societal dynamics influence the norms that surround the phenomenon of family care?

The use of comics in research

Building on the reflections in Chapter 4, future research concerning interdisciplinary research-art collaborations would benefit from a specific focus on its interdisciplinary character, and what is needed to guarantee an integration of the different perspectives and methods of the disciplines. To achieve this integration, it is essential to learn more about how to integrate the specific art form into one's research process and how research can be supportive for the creation of art – ideally from the start of the project. It would be beneficial, then, if future interdisciplinary research projects would provide insight into the differences in how researchers and artists observe and analyze the phenomena being studied, what the different disciplines consider the merits and pitfalls of translating these phenomena into an artistic or scientific form, and what both researchers and artists learn from and appreciate of the perspectives of the other discipline.

Furthermore, with regard to disseminating one's research and reaching a broader public, future research should focus on the educational value of comics for professionals and volunteers in palliative care. Observing a sustainable improvement of people's professional attitude or character is difficult. What does it mean when people report to be more aware of the perspective of family caregivers, or to better understand them? What do they actually do differently? Research would benefit from a conceptualization of desired learning outcomes in the field of medical humanities, in so far as possible or desirable.

From an educational science perspective, future research should address how comics 'work' in educating professionals, and explore their added value and the related pedagogy in the classroom. What do joint reading practices or small group discussions add, and in what way can people be invited to reflect? Because people differ in their familiarity with the medium, it may be worthwhile to further investigate what discussing comics requires from healthcare professionals or

volunteers and, more importantly, which teaching tools or what kind of guidance may be helpful.

Last but not least, comics and art in general may benefit the people that were the main focus of this thesis: family caregivers themselves. Although Chapter 3 shows the barriers of using comics as a conversation aid among current family caregivers, bereaved family caregivers also experienced feeling supported after reading the stories in *Naasten,* because they felt they could relate to the stories. In that way, an art form can provide opportunities to connect to one's experiences, possibly in a new way. In that regard, it is worthwhile to point to the method of Art-Based Learning, i.e. observing an artwork and connecting the narrative to one's personal situation, which has the potential to support people with advanced cancer in creatively rewriting their life stories and finding meaning after the disruption of the diagnosis[70]. I therefore propose to explore the ways in which such an art-based method can be of value to bereaved family caregivers. Family caregivers may have gone through disrupting experiences of caring for and dealing with the death of their loved ones, and perhaps look for ways to find meaning in their lives while coming to terms with their bereavement.

Final remark

With this thesis and these suggestions for other researchers, I hope to contribute to understanding and supporting family caregivers in a palliative care context. After all, this issue concerns us all. Most of us will, at some point in our lives and to some degree, find ourselves trying to cope with the role of family caregiver of a loved one who is going to die. A research-based artistic work, such as our graphic novel Naasten, invites everyone to have their own interpretation and engage in a dialogue. And it is precisely that dialogue that remains necessary – since family care in the context of an approaching death can be a disruptive and at the same time valuable experience.

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Appendices

Summary

General introduction

This thesis focuses on family care in Dutch home settings within the context of palliative care, where individuals care for a partner, family member, or someone close to them who is terminally ill and about to pass away. As shown in the General introduction (Chapter 1), family care originates from pre-existing relationships. Therefore, the conceptualization of the term is not clear-cut, and people do not always identify with the term 'family caregiver'.

When patients prefer to die at home, the role of their partners or close ones, if they are present, is often pivotal. Previous research among family caregivers has shown that caregiving can lead to positive experiences but also emphasized the immense physical, emotional, and psychosocial impact on family caregivers. It can be an overwhelming and lonely experience for them because their entire life often becomes centered around caring for their dying love one, and their normal (social and work) life needs to be adjusted accordingly. Nevertheless, for many partners and relatives taking on a caregiving role for diseased or dying close ones is self-evident. The involvement of families is increasingly encouraged by governments, as family care is seen as a way to sustain long-term care for our aging population. Therefore, many people just *do* it, even when it costs them a lot. A need for family caregiver support is widely recognized in the scientific literature and within palliative care. Although support is not always part of the routine practices of healthcare professionals, it is crucial to pay attention to family caregivers so that they feel seen and appreciated.

To literally increase the visibility of family caregivers, we, as an ethics team, wanted to create a graphic novel about family care, based on our research. Our goal was to visually represent the diverse range of experiences of family caregivers and engage a broad audience in thinking about family caregiving. Thus, I collaborated with two comic artists. This interdisciplinary collaboration ultimately led to the book *Naasten* (Dutch for 'loved ones' or 'relatives') (see Box 3 in Chapter 1). The comics genre is often seen as a valuable and accessible medium to convey personal experiences of illness or caregiving, especially where complex or intangible experiences and uncertainties are difficult to express in words. Over the past decades, artistic methods have increasingly been used as new ways to generate, analyze, interpret, or, as in our project, (re)present scientific results.

This thesis presents the research I conducted in parallel with the graphic novel project. Through this research, we aimed to contribute to: a) a better understanding of family care in a palliative care context, and b) a better understanding of how the experiences of family caregivers can be translated into comics aimed at public education. The four chapters of this thesis are numbered in the chronological order in which they were written, but I present them here in a different order, starting from the two goals mentioned before.

Main findings

a) Family care in a palliative care context

My doctoral research began with an thorough investigation and analysis of family care in the context of palliative care in Dutch home settings, through in-depth interviews with 15 family caregivers, 13 bereaved family caregivers, and 9 patients. **Chapter 2** provides insight into their experiences through a qualitative analysis using a Grounded Theory approach. A central theme in the analysis is that family caregivers feel called to care for the person who is ill. Our analysis shows how. The feeling of being called upon may stem from the patient, but also from professional caregivers and organizations entering their daily lives, from family and friends, or from the family caregiver themselves. Responding to these calls can be difficult. At the same time, we found that family caregivers were motivated to respond to this calling and to continue caregiving for as long as possible. Sometimes out of love or a special bond with the patient; sometimes due to a sense of duty or a promise; sometimes because of their role within the family dynamics or previous family experiences – or a combination of all these normative considerations. To what, then, do family caregivers feel called? Family caregivers first respond to the perceived calling by constantly being available; secondly, by being attentive to the patient first while putting aside their own needs; and further by being assertive on multiple fronts of their lives in managing the care situation. Due to the patient's deterioration and approaching death, these expectations and activities gain even more urgency for family caregivers. Caregiving then becomes the last thing they can do and it must be done now. Understanding the complex and normative nature of family care helps to better understand the burden experienced by family caregivers. Even if caregiving tasks are taken over by professionals or the family caregivers take a break and meet friends outside the home, family caregivers may still feel called upon. Moreover, caregiving can be a meaningful and positive experience for many, despite being burdensome. To adequately support family caregivers, we should not seek direct solutions for their burden, but instead reflect

with family caregivers themselves on what drives them, which values and norms play a role, and what family care means to them.

Building on the empirical research in Chapter 2 and using a care ethics perspective, in **Chapter 5**, I explain that family care is often not a well-demarcated activity with a clear start or end, based on a deliberate choice. Family care is an ongoing process stemming from a relationship in which people are mutually dependent on each other, within a particular social context. Especially in the case of approaching death, family care is strongly tied to internalized social norms and expectations (such as "till death do us part") against the backdrop of broader cultural values and beliefs (such as religious beliefs or specific norms within someone's family or cultural community). The chapter explains, using the concept of ambiguity, that family care realizes certain values while simultaneously suppressing or ignoring others. The burden of care among family caregivers may thus not be so much related to the caring tasks they feel called to provide, but mainly stems from a nearly blind self-sacrifice. Being constantly available and attentive to the patient puts pressure on fulfilling other values, such as parenthood, self-development through work or hobbies, or friendship. Navigating such difficult dilemmas can evoke ambivalent feelings (such as failure, shame, guilt, or regret) when family caregivers feel they are not living up to expectations of being a "good family caregiver". It is therefore important to consider this ambiguity and ambivalence in supporting family caregivers – that family care can be both burdensome and meaningful. Nurses, social workers, or other caregivers and supporters may have a well-intentioned tendency to immediately solve or relieve burden, for example when they identify such a burden through a screening questionnaire. However, I believe it is important to first engage in dialogue with family caregivers to clarify what family care means to them (and what motivations, values, norms, and social expectations are involved), interpret any burden due to self-sacrifice in that light, and relieve it accordingly.

b) The potential and process of translating research into comic art

In **Chapter 3**, we explore what factors facilitate or hinder the use of our graphic novel *Naasten* as a conversation aid in supporting family caregivers in palliative care. We conducted three focus groups and follow-up interviews with 23 family caregiver consultants, volunteers, and healthcare professionals who had used the book in their interactions with family caregivers, and four individual telephone interviews with family caregivers to whom the book was presented. The analysis showed that facilitators and barriers were related to the family caregiver, the impact of the book on the family caregiver, the impact of the book on the conversation between the

supporter and the family caregiver, the relationship between the supporter and the family caregiver, and the supporters themselves. On the one hand, the graphic novel was seen as an accessible, recognizable, and supportive medium that evoked emotions and led to increased awareness of the perspective of family caregivers. It also led to valuable conversations with some bereaved individuals. On the other hand, some respondents found the book too directive, unnecessary for their work, or potentially harmful due to the emotional and confronting impact of the images. Respondents were hesitant about using it with family caregivers. They identified conditions such as a trustful relationship, a right fit with the family caregiver and setting, a careful introduction, and follow-up. To raise awareness and attention to the perspective of family caregivers, the book was recommended for use in education. I conclude that comics like *Naasten* under certain conditions can be valuable as a conversation aid to support (bereaved) family caregivers, but that their use in education or training for (future) healthcare professionals or volunteers may be more suitable.

In **Chapter 4**, I share three lessons learned by our ethics team regarding an interdisciplinary collaboration between scientists and artists, with which I aim to inspire other researchers. starting such a collaboration. The first lesson is to recognize the interdisciplinary nature of the collaboration from the start, being interested in each other's potentially different goals and roles. It is important that all participants are open to exploring each other's methods and the added value of those. Secondly, throughout the project, continuous discussions are needed about the contrasting approaches or methods, such as regarding the use of theory or storytelling. In a collaboration between scientists and artists, it is crucial to balance scientific and aesthetic aims and interests, always keeping in mind the trustworthiness of the eventual art work. Thirdly, it is important that all people involved are aware of the opportunities their interdisciplinary collaboration offers. Artists can give researchers a different perspective on their scientific data collection and analysis, and provide alternative conceptualizations or methods. In hindsight, the question arises whether our project truly involved interdisciplinary collaboration and integration of perspectives. Our project primarily aimed to translate our research results (Chapter 2) into a comics format. The collaboration could have gone further to realize the full potential of 'arts-based research', for example by involving the artists earlier and more openly exploring the interdisciplinary nature of the collaboration. The chapter ends with practical recommendations for other scientific researchers or project leaders interested in using artistic methods in their projects.

*

Reflections and implications for practice

In the concluding discussion (Chapter 6), I reflect on the main findings and ideas presented in the previous chapters. Again, I present them along the two main lines of this thesis. Furthermore, I provide recommendations for supporting family caregivers and suggest areas for future research.

a) On supporting family caregivers

- Family care in a palliative care context is a complex and layered phenomenon with a normative character. To better understand family caregivers and their self-sacrifice, it is helpful to recognize this normativity, for example via a care ethics perspective. In other words, due to being related, people may find themselves *tangled* in their family caregiver role.
- A timely identification of caregiver burden is important, but assessing it requires careful interpretation while taking into account the context and values of the family caregiver. Experienced burden is not only a result of the presence of physical, mental, or socio-emotional challenges, but also related to how one deals with the value dilemmas that create ambivalent feelings. Support for family caregivers should not focus on liberating them *from* the situation but on supporting them *in* everything they experience while providing care. Engaging in dialogue with the family caregiver is key to this.
- The values and social expectations that a family caregiver must relate to stem from their relationship with the patient but also from the broader social and political context. It is therefore important to recognize that family care is not just a private matter between people within a particular relationship, but also interwoven with societal norms and developments. In the future, with an aging population, a shortage of healthcare professionals, and changes in societal norms, family care will be a significant challenge. The ideal in which people consciously weigh values and reflect on how they wish and can be involved in the care for a loved one, may be difficult to realize, especially as governments increasingly place the responsibility for care on families.
- Support for family caregivers remains essential. It can be helpful if supporters gain more insight into the complex interplay between values and social expectations of a specific family caregiver – and the dilemmas and ambivalent feelings these may cause. Through dialogue with the family caregiver (as suggested in Table 2 in Chapter 5), it can be explored why and in what way they wish to provide care – or conversely, wish to maintain their distance. However, such support for family caregivers should not rest solely on the shoulders of

individual healthcare professionals or volunteers; it is important that they are adequately supported by their organizations or teams.

- Future research can map how normativity might differ for certain types of relationships and how the quality of the relationship plays a role. Longitudinal research through serial interviewing could provide more insight into people's suppressed ambivalent feelings and the transition from being a family caregiver to being a bereaved individual. Finally, it is important to investigate the role of governments and societal changes regarding the topic of family care.

b) On the use of comic art in palliative care

- Our project could have benefited from a more explicit focus on the interdisciplinary nature of the collaboration with the comic artists, in order to realize more of the potential of 'arts-based research'. Involving artists earlier could help with this. Even more importantly, it is crucial that all people involved are curious about each other's different perspectives and methods and are granted sufficient opportunities to learn from those.
- In our case, comics proved to be a powerful medium for visualizing family care in a palliative care context. The use of storylines, emotions, metaphors, and, specifically, the multimodal nature of comics (text and images) proved to be valuable in conveying complex and layered experiences. At the same time, reading comics is not without challenges. Especially in the often turbulent palliative care context, it is doubtful whether family caregivers have the time, space, or opportunity to slow down and fully grasp a comic. Therefore, for researchers, it is important to continually ask whether the use of comics is appropriate in a specific context. The use of comics may be more appropriate in an educational setting.
- Although it is often assumed that comics contribute to awareness and understanding among readers, providing scientific evidence for such impacts is difficult. However, the question arises whether such medical humanities education should always be based on proven impact. It is even debatable what awareness or understanding exactly *is*. A comic should not be used instrumentally to tell students or professionals exactly 'what it's like' to be a family caregiver. However, comics can be a powerful tool to make people think about what they know and, more importantly, what they still do *not* know about the experiences and feelings of family caregivers. This is precisely why the comic medium is a useful way to engage people outside academia in thinking about such a complex topic as family care.
- Future research could provide more insight into what is needed to integrate different disciplinary perspectives in a project and what both researchers and

artists learn from this. As far as possible and desirable, it is necessary to better conceptualize and study the educational value of comics and which educational methods or training formats 'work'. Finally, it seems important to explore how 'arts-based learning' can be valuable for bereaved family caregivers in (re)finding meaning in their lives.

An artistic work based on research, like our graphic novel *Naasten*, does not provide a factual representation of a theme but stimulates interpretation and dialogue. And precisely that dialogue remains necessary – since family care in the context of an approaching death can be a disruptive and at the same time valuable experience.

Nederlandse samenvatting

"Iedereen is bezig met de patiënt, en dat is logisch. Je zegt het ook tegen jezelf: hij is zielig, hij is ziek, hij heeft het zwaar, dus ik moet niet zeuren, ik moet sterker zijn, harder werken. Je gaat automatisch compleet in zijn schaduw staan. Maar ergens ben je tegelijkertijd ook de belangrijkste persoon. (…) Jij krijgt mee wat de artsen allemaal zeggen; hij niet, het ging allemaal langs hem heen. Jij communiceert met het ziekenhuis, met familie, met vrienden. Jij kookt, doet het huishouden, zet de vuilnis buiten. Naast wat het natuurlijk ook allemaal emotioneel met jou doet. Toch zijn alle aandacht, alle appjes, alle kaarten gericht aan hem. Toen een vriendin van Reinier een keer op visite kwam en naast een cadeau voor hem een bos bloemen voor mij had meegenomen, moest ik huilen."[i]

Algemene introductie

Dit proefschrift richt zich op mantelzorg in Nederlandse thuissituaties binnen een palliatieve zorgcontext, dus daar waar mensen bij henzelf of de ander thuis zorgen voor hun partner, familielid of anderszins bekende die ernstig ziek is en binnenkort zal komen te overlijden. Zoals de **algemene introductie (hoofdstuk 1)** laat zien, komt mantelzorg voort uit al bestaande relaties. De conceptualisering van het begrip is dan ook niet eenduidig. Mensen herkennen zich niet altijd in de term 'mantelzorger'. Daarom spreek ik in deze samenvatting verder over naasten.

Juist wanneer patiënten thuis willen sterven is de rol van naasten, als die aanwezig zijn, vaak cruciaal. Eerder onderzoek onder mantelzorgers liet zien hoe mantelzorg positieve ervaringen teweeg kan brengen, maar benadrukte ook de immense fysieke, emotionele en psychosociale impact ervan op naasten. Het kan een overweldigende en eenzame ervaring zijn voor naasten, omdat hun hele leven vaak in het teken komt te staan van de zorg voor de stervende en hun normale (sociale en werkende) leven daarop moet worden aangepast. Toch is het voor veel mensen vanzelfsprekend om een zorgende rol op zich te nemen. De betrokkenheid van families wordt bovendien steeds meer aangemoedigd door overheden, omdat zorg door naasten wordt gezien als manier om ook de langere termijn voor onze vergrijzende bevolking te kunnen blijven zorgen. Veel mensen verlenen deze zorg dus 'gewoon', ook als het zorgen hen veel kost. Het is dan ook algemeen erkend in de wetenschappelijke literatuur

i. Begin 2025 werd acteur Sander Plukaard geïnterviewd over een theatervoorstelling waarin hij speelde, die was gebaseerd op zijn ervaringen met het zorgen voor zijn partner met kanker. Citaat uit: Keller S. Wat doet mantelzorg met je?, vragen drie nieuw toneelstukken: 'Je gaat automatisch compleet in iemands schaduw staan'. *NRC*, 24 januari 2025.

en binnen de palliatieve zorg dat families die mantelzorg geven ondersteuning nodig kunnen hebben. Hoewel ondersteuning niet altijd onderdeel uitmaakt van de standaardroutine van zorgverleners is aandacht hebben voor naasten van groot belang, zodat ze zich gezien en gewaardeerd voelen.

Om de zichtbaarheid van naasten letterlijk te vergroten wilden we als ethiekteam een graphic novel oftewel stripboek over mantelzorg maken op basis van ons onderzoek. Ons doel was het diverse palet aan ervaringen van naasten letterlijk in beeld te brengen en een breed publiek betrekken bij het denken over mantelzorg. Daarom werkte ik samen met twee striptekenaars. Deze interdisciplinaire samenwerking leidde uiteindelijk tot het boek *Naasten* (zie ook Box 3 in hoofdstuk 1). Het genre van de strip wordt vaker gezien als waardevolle en toegankelijke manier om persoonlijke ervaringen van ziekte of (mantel)zorg over te brengen, zeker daar waar complexe of ongrijpbare ervaringen en onzekerheden niet altijd makkelijk in woorden kunnen worden gevat. Onder de noemer van 'arts-based research' zijn kunstzinnige methoden in de afgelopen decennia steeds vaker gebruikt als nieuwe manieren om wetenschappelijke resultaten te genereren, analyseren, interpreteren of, zoals vooral het geval was in ons project, (opnieuw) te presenteren.

Dit proefschrift presenteert het onderzoek dat ik parallel aan het graphic novel project heb uitgevoerd. Met dit onderzoek wilden we bijdragen aan: a) een beter begrip van mantelzorg in een palliatieve zorgcontext, en b) een beter begrip van hoe de ervaringen van naasten kunnen worden vertaald in stripverhalen gericht op publiekseducatie. De vier hoofdstukken van dit proefschrift zijn genummerd in de chronologische volgorde waarin ze zijn geschreven, maar ik presenteer ze hieronder in de context van de twee genoemde doelen en houd daarbij een andere volgorde aan.

Belangrijkste bevindingen

a) Mantelzorg in de context van palliatieve zorg

Mijn promotieonderzoek begon met het grondig onderzoeken en analyseren van mantelzorg binnen de context van palliatieve zorg in Nederlandse thuissituaties, via diepte-interviews met in totaal 15 naasten, 13 nabestaanden en 9 patiënten. **Hoofdstuk 2** geeft inzicht in hun ervaringen, via een kwalitatieve analyse volgens een 'Grounded Theory' benadering. Centraal thema in de analyse is dat naasten een appèl ervaren: ze voelen zich op meerdere manieren geroepen te zorgen voor degene die ernstig ziek is. Onze analyse laat zien hoe. Het gevoelde appèl kan vanuit de patiënt komen, maar ook vanuit professionele zorgverleners en instanties die hun normale

dagelijkse leven binnenkomen, vanuit familie en vrienden, of vanuit de naaste zelf. Gehoor geven aan zo'n appèl kan zwaar zijn. Tegelijk zagen we dat naasten gemotiveerd waren om op dat appèl te reageren en het zorgen zo lang mogelijk vol te houden. Soms omwille van liefde voor of een speciale band met de patiënt; soms vanuit een gevoel van plicht of een belofte; soms vanwege hun rol binnen de familiedynamiek of ingegeven door eerdere ervaringen in de familie – of door een combinatie van al deze normatieve overwegingen. En waartoe voelen naasten zich dan geroepen? Naasten reageren allereerst op het gevoelde appèl door voortdurend beschikbaar en bereikbaar te zijn; daarnaast door vooral aandacht te hebben voor de patiënt terwijl ze hun eigen behoeften wegcijferen; en verder door aan meerdere fronten van hun leven assertief te zijn in het organiseren van de zorg. Door de achteruitgang van de patiënt en diens naderende overlijden krijgen deze verwachtingen en activiteiten extra urgentie voor de naasten. Zorgen is dan het laatste wat zij kunnen doen en moet *nu* gebeuren. Inzicht in het complexe en normatieve karakter van mantelzorg helpt om overbelasting onder naasten beter te begrijpen. Het appèl *blijft* – ook al worden zorgtaken door professionals overgenomen of spreken naasten even buitenshuis af met vrienden. Bovendien kan mantelzorg een betekenisvolle en positieve ervaring zijn voor mensen, eervol ook, hoewel het belastend is. Voor goede ondersteuning van naasten moeten we dus niet zozeer zoeken naar directe oplossingen, maar vooral samen met hen stilstaan bij wat hen drijft, welke waarden en normen daarin meespelen, en wat mantelzorg voor hen betekent.

Voortbordurend op het empirisch onderzoek van hoofdstuk 2 leg ik in **hoofdstuk 5** vanuit de zorgethiek uit dat mantelzorg vaak geen afgebakende activiteit is met een duidelijk begin of eind waarvoor een naaste bewust kiest. Mantelzorg is een voortdurend proces dat voortkomt uit een relatie waarbij mensen wederzijds van elkaar afhankelijk zijn, in een bepaalde sociale context. Zeker in geval van een naderend overlijden hangt mantelzorg sterk samen met geïnternaliseerde sociale normen en verwachtingen (zoals "tot de dood ons scheidt") tegen de achtergrond van bredere culturele waarden en overtuigingen (zoals religieuze overtuigingen of specifieke normen binnen iemands familie of culturele gemeenschap). Het hoofdstuk maakt, via het concept van ambiguïteit, inzichtelijk dat mantelzorg bepaalde waarden realiseert én tegelijkertijd andere waarden onderdrukt of negeert. Het gevoel van overbelasting onder naasten heeft zo bezien misschien niet zozeer te maken met de zorgtaken waartoe zij zich geroepen voelen, maar ontstaat vooral door een haast blinde zelfopoffering. Het voortdurend beschikbaar en aandachtig moeten zijn voor degene die ziek is legt druk op het vervullen van iemands andere waarden, zoals ouderschap, zelfontplooiing via werk of hobby's of vriendschap. Het navigeren van zulke lastige dilemma's kan bij naasten

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ambivalente gevoelens teweegbrengen (van falen, schaamte, schuld of spijt) wanneer ze het idee hebben niet te voldoen aan wat van hen wordt verwacht als 'goede mantelzorger'. Het is dan ook belangrijk om in de ondersteuning van naasten rekening te houden met die ambiguïteit en ambivalenties van mantelzorg – dat mantelzorg tegelijkertijd zwaar én betekenisvol kan zijn. Verpleegkundigen, maatschappelijk werkers of andere zorgverleners en ondersteuners hebben soms de goedbedoelde neiging om overbelasting, zoals bijvoorbeeld gesignaleerd via een screeningvragenlijst, direct weg te willen nemen of op te willen lossen. Het lijkt mij echter belangrijk om in dialoog eerst met de naaste te verhelderen wat mantelzorg voor hem of haar betekent (en wat op de achtergrond meespeelt aan drijfveren, waarden, normen en sociale verwachtingen), en eventuele overbelasting door zelfopoffering in dat licht te interpreteren en indien passend te verlichten.

b) Het potentieel en het proces van het vertalen van onderzoek naar stripkunst

In **hoofdstuk 3** wordt onderzocht wat bevorderend of juist belemmerend is bij het gebruik van ons stripboek *Naasten* als gesprekshulpmiddel in de ondersteuning van naasten in de palliatieve zorg. We hielden drie focusgroepen en tussentijdse follow-upgesprekken met 23 mantelzorgondersteuners, vrijwilligers en professionele zorgverleners die het boek op uiteenlopende manieren hadden gebruikt in hun contact met naasten en 4 individuele telefonische interviews met naasten bij wie het stripboek was ingezet. De analyse liet zien dat bevorderende en belemmerende factoren betrekking hadden op de naaste, de impact van het boek op de naaste, de impact van het boek op het gesprek tussen de ondersteuner en de naaste, de relatie tussen de ondersteuner en de naaste, en de ondersteuner. Aan de ene kant werd het stripboek ervaren als een toegankelijk medium, herkenbaar en steunend, riep het emoties op en leidde het tot een toegenomen bewustzijn voor het perspectief van naasten. Ook leidde het in contact met sommige nabestaanden tot waardevolle gesprekken. Aan de andere kant vonden ondervraagden het boek te sturend, onnodig voor hun werk, of potentieel schadelijk vanwege de emotionele impact van de confronterende tekeningen. De ondervraagden hadden reserves bij de inzet ervan bij naasten. Ze benoemden randvoorwaarden zoals een vertrouwensband, aansluiting bij de persoon en setting, een zorgvuldige introductie van het boek en nazorg. Juist om bewustzijn en aandacht voor het perspectief van naasten te stimuleren werd het boek door respondenten aanbevolen voor gebruik in onderwijs. Ik concludeer dan ook dat strips zoals *Naasten* onder bepaalde voorwaarden waardevol kunnen zijn als gesprekshulpmiddel in de ondersteuning van naasten of nabestaanden, maar dat het gebruik van strips mogelijk beter past in onderwijs of training aan (toekomstige) zorgprofessionals of vrijwilligers.

In **hoofdstuk 4** deel ik drie lessen die we als ethiekteam leerden over het interdisciplinair samenwerken tussen wetenschappers en kunstenaars, bedoeld om andere onderzoekers te inspireren. Een eerste les is om vanaf de start gezamenlijk het interdisciplinaire karakter van de samenwerking te erkennen, en daarbij interesse te hebben in elkaars mogelijk uiteenlopende doelen en rollen. Het is belangrijk dat alle betrokkenen elkaars methoden en de toegevoegde waarde daarvan willen verkennen. Ten tweede is er, gedurende een project, voortdurend gesprek nodig over de verschillende benaderingen of methoden, bijvoorbeeld met betrekking tot het gebruik van theorie of juist een verhaal. In een samenwerking tussen wetenschappers en kunstenaars is het telkens zaak om de verschillende wetenschappelijke en esthetische doelen en belangen met elkaar te wegen, en daarbij altijd de betrouwbaarheid van het uiteindelijke kunstzinnige werk voor ogen te houden. Ten derde is het belangrijk dat alle betrokkenen zich bewust zijn van de kansen die hun samenwerking biedt. Kunstenaars kunnen onderzoekers een ander perspectief geven op hun wetenschappelijke dataverzameling en data-analyse, en daarin andere conceptualiseringen of methoden aandragen. Achteraf gezien is het de vraag of er in ons project sprake was van een daadwerkelijk interdisciplinaire samenwerking en integratie van perspectieven. Ons project was er immers vooral op gericht om onze onderzoeksresultaten (hoofdstuk 2) in stripvorm te vertalen. De samenwerking had een stap verder kunnen gaan om het volledige potentieel van 'arts-based research' te realiseren, bijvoorbeeld door de kunstenaars eerder te betrekken en het interdisciplinaire karakter van de samenwerking meer openlijk met elkaar te verkennen en daarmee te versterken. Het hoofdstuk sluit af met praktische aanbevelingen voor andere onderzoekers of projectleiders die kunstzinnige methoden in hun project willen gebruiken.

Reflecties en aanbevelingen voor de praktijk

In de afsluitende **discussie (hoofdstuk 6)** reflecteer ik op de belangrijkste bevindingen en gedachten die in de voorgaande hoofdstukken aan bod kwamen. Ook hier presenteer ik ze langs de twee inhoudelijke lijnen van het proefschrift. Verder geef ik aanbevelingen voor het ondersteunen van naasten en doe ik suggesties voor vervolgonderzoek.

a) Over het ondersteunen van naasten

- Mantelzorg in een palliatieve zorgcontext is een complex en gelaagd fenomeen, met een normatief karakter. Om de houding en zelfopoffering van naasten beter te begrijpen is het helpend om, bijvoorbeeld vanuit een zorg-ethisch

perspectief, de normativiteit van mantelzorg te erkennen. Met andere woorden, doordat mensen met elkaar verbonden zijn kunnen ze verweven en onverhoopt *verstrikt* raken in hun rol als mantelzorger.

- Een tijdige identificatie van overbelasting van naasten is belangrijk, maar het beoordelen ervan vereist een zorgvuldige interpretatie die rekening houdt met de context en waarden van de naaste. Iemands gevoel van overbelasting is namelijk niet alleen het gevolg van alle fysieke, mentale of sociaal-emotionele uitdagingen die mantelzorg met zich meebrengt, maar heeft ook te maken met hoe iemand omgaat met de waardendilemma's die voor ambivalente gevoelens zorgen. De ondersteuning van naasten moet niet gefocust zijn op het bevrijden van naasten *uit* de situatie, maar op ondersteuning *in* alles wat hen overkomt bij het verlenen van mantelzorg. De dialoog met de naaste aangaan is daarin de sleutel.
- De waarden en sociale verwachtingen waartoe een naaste zich moet zien te verhouden komen voort uit diens relatie met de patiënt, maar ook uit de bredere sociale en politieke context. Het is dan ook belangrijk om te erkennen dat mantelzorg niet alleen een privéaangelegenheid is binnen een bepaalde relatie tussen mensen, maar ook verweven is met maatschappelijke normen en ontwikkelingen. Mantelzorg wordt in de toekomst – met een vergrijzende bevolking, een tekort aan zorgprofessionals en veranderingen in maatschappelijke normen – een flinke uitdaging. Het ideaalbeeld geschetst dat mensen op een bewuste manier waarden afwegen en reflecteren op hoe zij betrokken willen en kunnen zijn in de zorg voor een dierbare, kan moeilijk te verwezenlijken zijn, zeker als overheden in toenemende mate de verantwoordelijkheid voor zorg bij families leggen.
- Ondersteuning van naasten blijft dan ook essentieel. Het kan helpen als ondersteuners meer zicht hebben op het complexe samenspel tussen waarden en sociale verwachtingen van een specifieke naaste – en welke dilemma's en ambivalente gevoelens die kunnen veroorzaken. Via een dialoog met de naaste (zoals voorgesteld in tabel 2 in hoofdstuk 5 kan samen worden verkend waarom en op welke manier diegene mantelzorg wil geven – of: juist zijn of haar afstand wil bewaren. Dergelijke ondersteuning van naasten moet echter niet alleen rusten op de schouders van individuele zorgprofessionals of vrijwilligers; het is belangrijk dat zij daarin voldoende gesteund worden door hun organisaties of teams.
- Vervolgonderzoek kan specifieker in kaart brengen hoe normativiteit mogelijk verschilt voor bepaalde typen relaties en hoe de kwaliteit van de relatie daarbij meespeelt. Longitudinaal onderzoek via serie-interviews kan meer inzicht geven in onderdrukte ambivalente gevoelens en in de transitie van naaste naar nabestaande. Tot slot is het belangrijk om nader te onderzoeken welke rol overheden en maatschappelijke veranderingen spelen in het thema.

b) Over het gebruik van stripkunst in de palliatieve zorg

- Ons project had wellicht kunnen profiteren van een meer expliciete focus op het interdisciplinaire karakter van de samenwerking met de striptekenaars, om zo de veelzijdige potentie van 'arts-based research' meer te benutten. Het tijdiger betrekken van kunstenaars kan daarbij helpen. Meer nog is het belangrijk dat alle betrokkenen nieuwsgierig zijn naar elkaars verschillende perspectieven en methoden, en voldoende mogelijkheden krijgen om daarvan te leren.
- In ons geval bleek strip inderdaad een krachtig medium te zijn om mantelzorg in een palliatieve zorgcontext te visualiseren. Het gebruik van verhaallijnen, emoties, metaforen, en, specifiek, het multimodale karakter van strips (tekst én beeld) bleek complexe en gelaagde ervaringen te kunnen overbrengen. Tegelijk is het lezen van strips is niet zonder uitdagingen. Vooral in de vaak turbulente palliatieve zorgcontext valt te betwijfelen of naasten de tijd, ruimte of mogelijkheid hebben om te vertragen en een strip volledig te begrijpen. Het is daarom belangrijk als onderzoeker de vraag te blijven stellen of het gebruik van strips in een specifieke context passend is. Mogelijk past het gebruik van strips beter in een onderwijssetting.
- Hoewel vaak wordt aangenomen dat strips bijdragen aan bewustwording en begrip onder lezers, is het wetenschappelijk bewijzen daarvan moeilijk. Het is echter de vraag of dergelijk 'medical humanities'-onderwijs altijd gestoeld zou moeten zijn op feitelijk bewezen impact. Het is zelfs de vraag wat bewustwording of begrip precies *is.* Een strip moet in elk geval niet instrumenteel in worden gezet om studenten of professionals precies te vertellen 'hoe het is' om naaste te zijn. Wél kunnen strips een krachtig middel zijn om mensen aan het denken te zetten over wat ze wel en vooral nog niet wisten over de ervaringen en gevoelens van naasten. Juist daarom is het stripmedium bij uitstek een zinvolle manier om mensen van buiten de wetenschap aan het denken te zetten over zo'n complex thema als mantelzorg.
- Vervolgonderzoek kan meer inzicht geven in wat nodig is om verschillende disciplinaire perspectieven te integreren in een project, en wat zowel onderzoekers als kunstenaars daarvan leren. Voor zover mogelijk en wenselijk is het nodig om de onderwijskundige waarde van strips beter te conceptualiseren en onderzoeken, en welke onderwijsmethoden of trainingswerkvormen daarbij 'werken'. Tot slot lijkt het me belangrijk om te onderzoeken op welke manier 'art-based learning' van waarde kan zijn voor nabestaanden in het (her)vinden van betekenis in hun leven.
- Een kunstzinnig werk gebaseerd op onderzoek, zoals onze graphic novel *Naasten*, biedt geen feitelijke weergave van het thema, maar geeft aanleiding tot interpretatie en gesprek. En precies dat gesprek blijft nodig – mantelzorg in de context van een naderende dood kan immers een ontwrichtende en tegelijk waardevolle ervaring zijn.

Research Data Management

Ethics & privacy

This thesis is based on the results of research involving human participants, which were conducted in accordance with relevant national and international legislation and regulations, guidelines, codes of conduct and Radboudumc policy on research data management. Ethical approval was sought from the recognized Medical Ethics Review Committee 'METC Oost-Nederland' (file number 2017–3415), who determined that the studies involved in this thesis were not subject to the Dutch Medical Research Involving Human Subjects Act (WMO). The participants were not exposed to significant actions or interventions. Our project was funded by the Dutch Organisation for knowledge and innovation in health, healthcare and well-being (ZonMw): 844001310. The funder was not involved in the design of the studies, nor in the data collection, analyses and interpretation, writing of the manuscripts, or decisions regarding publication.

The privacy of the participants in these studies was warranted by the use of pseudonymization. Every participant received a numerical code and all interview and focus group transcripts were anonymized. The pseudonymization key was stored separately from the research data on a secured network drive. This drive was only accessible to members of the project who needed access to it because of their role within the project.

Regarding chapters 2 and 3, informed consent was obtained from participants to collect and process their data for this research project. Regarding chapter 4, informed consent was obtained by the comic artists for the interviews and use of that data. Overall, there is no consent for reuse of the raw qualitative data (i.e. recording of the interviews, focus groups) because of the sensitivity of the content. Consent was only given to potentially share anonymized transcripts with other researchers, but only after permission of the project leaders.

Data collection and storage

This thesis is based on qualitative data. Data from chapter 2 and 3 were obtained via in-depth interviews, group sessions, focus groups and telephone interviews. Interviews and focus groups were audio recorded and transcribed verbatim in Microsoft Word. All processed data are stored in a secured folder at the department sever of IQ Health. This folder is only accessible to members of the research project working at the Radboudumc department of IQ Health. Informed consent files and pseudonymization keys were stored separately from the research data.

Data sharing

Chapter 2, 3 and 5 are published with open access. Chapter 5 is a theoretical/ philosophical paper and does not contain new research data. The datasets from chapters 2, 3 and 4 are not suitable for reuse and will be archived with closed access for 5 years after termination of the study in a Data Acquisition Collection (DAC) at the Radboud Data Repository (Table 1). The anonymized interview transcripts used and/or analyzed during the studies are available only on request via the DAC collection managers. Requests for access will be checked by project leader Jelle van Gurp, researcher Maaike Haan and data steward Janine Liefers of the department of IQ Health. We retain the right to process, select, and organize the data in a manner that ensures the anonymity of the research participants. Radboudumc is the legal owner of this data.

Table 1 | Data and research documentation on the Radboud Data Repository

Chapters	DAC
2-4	DOI: 10.34973/k868-yd57 regarding the collection 'De mantel der liefde verbeeld'

List of publications

Scientific publications included in this thesis

Haan M, van Gurp J, Boenink M, Olthuis G. A care ethical perspective on family caregiver burden and support. *Nursing Ethics*. 2025 Mar 4. Epub ahead of print. https://doi.org/10.1177/09697330251324294

Haan M, Olthuis G, Boenink M, Van Gurp J. Bridging comic art and research: Lessons from an interdisciplinary collaboration project in a palliative care context. *Medical Humanities*. 2024;50:475-485. https://doi.org/10.1136/medhum-2023-012750

Haan MM, van Gurp JLP, Knippenberg M, Olthuis G. Facilitators and barriers in using comics to support family caregivers of patients receiving palliative care at home: A qualitative study. *Palliative Medicine*. 2022;36(6): 994-1005. https://doi.org/10.1177/02692163221093513

Haan MM, Olthuis G, van Gurp JLP. Feeling called to care: A qualitative interview study on normativity in family caregivers' experiences in Dutch home settings in a palliative care context.*BMC Palliative Care*. 2021;20:183. https://doi.org/10.1186/s12904-021-00868-2

Other scientific publications, not included in this thesis

Vreugdenhil MMT, Ranke S, de Man Y, Haan MM, Kool RB. Patient and health care provider experiences with a recently introduced patient portal in an academic hospital in the Netherlands: Mixed methods study. *Journal of Medical Internet Research*. 2019; 21(8):13743. https://doi.org/10.2196/13743.

Haan MM, van Gurp JLP, Naber SM, Groenewoud AS. Impact of moral case deliberation in healthcare settings: A literature review. *BMC Medical Ethics*. 2018; 19, 85. https://doi.org/10.1186/s12910-018-0325-y

Non-scientific publications

Haan, M. Comics in palliative care: helpful or too confrontational? EAPC Blog. Accessible via https://eapcnet.wordpress.com/2022/06/27/comics-in-palliative-care-helpful-or-too-confrontational/

Kerckhaert Y, Olthuis G, Haan M. De 'achtbaan': Metaforen in de palliatieve fase. *Pallium*. 2020; 22(3):22-24. https://doi.org/10.1007/s12479-020-0273-3

Kranenburg M, Van Ooijen N, Haan M. *Naasten*. Heverlee: Oogachtend, 2019.

PhD portfolio

Department:	IQ Health
PhD period:	01/05/2017 – 14/11/2025
PhD Supervisor(s):	Prof. Dr. M. Boenink
PhD Co-supervisor(s):	Dr. J.L.P. van Gurp, Dr. G.J. Olthuis

Training activities

Courses
- Introduction course for PhD candidates at RIHS (2017)
- Workshop 'Analyseren van data in kwalitatief onderzoek' at IQ healthcare (2017)
- RU course 'Projectmanagement voor Promovendi' (2017)
- RU course 'Science Journalism and Communication' (2017-2018)
- Summer meditation course via Personeelsvereniging Radboudumc (2018)
- Scientific Integrity for PhD candidates (2018)
- RU course 'Scientific Writing for PhD candidates' (2018-2019)
- RU course 'Kinderen enthousiasmeren voor de wetenschap' (2019)
- eBROK (Basiscursus Regelgeving en Organisatie voor Klinisch onderzoekers) at NFU (2020)

Seminars
- Summer seminar 'What the humanities contribute to the university' at VU Amsterdam (2017)

Conferences
- Two-day PhD retreat organized by PhD council (2017 and 2018)
- Symposium 'Op weg naar de toekomst: nog betere pijn- en palliatieve geneeskunde' at Radboudumc department of Pijn en Palliatieve Geneeskunde (2018)
- Symposium 'Samen zorgen voor een waardig levenseinde' at VPTZ Evenmens (2019) – information stand
- EAPC world congress 'Global palliative care – Shaping the future' in Berlin (2019) – poster presentation
- Graphic Medicine conference 'Que(e)rying Graphic Medicine - Paradigms, power and practices' in Brighton (2019) – *oral presentation*

Other
- Personal interview training at IQ healthcare (2017)
- Keynote lectures at advanced European bioethics course 'Suffering, Death and Palliative Care' at Radboudumc (2018 and 2019)
- Workshop 'Transitioning outside academia' at PON PhD career day (2018)
- Workshop 'Science and Skills: Infographics' at Radboudumc (2018)
- Media training for employees at Radboudumc communication department (2019)
- Webinar 'Looking into Art/Science collaborations' at Academie van Kunsten (2020)
- Research and Review club with fellow PhD candidates of IQ healthcare (2017-2020)
- Intervision meetings with fellow PhD candidates of IQ healthcare (2017-2024)
- Workshop 'Activerend onderwijs met ICT' at Radboud online leeromgeving (2020)
- Presentation at vakgroep Ethiek van de Gezondheidszorg (2021)

Teaching activities

Lecturing

- Co-assisting CaRe course 'Kwalitatieve onderzoeksmethoden' at IQ healthcare (2017)
- Workshop and stand about graphic medicine at open day of RIHS (2017)
- Individual interview training with a junior colleague at IQ healthcare (2018)
- Yearly interactive lecture 'Kijken vanuit Naasten' at post-academic education program Ethiek in de Zorgsector (2019-2025)
- Several qualitative research activities in CKO-9 medical student education (2019-2020)
- Lecture about family caregivers together with a researcher-physician in 'Scholing palliatieve zorg: Intuïtie, wijsheid of wetenschap?' at Radboud Health Academy (2019)
- Several lectures about my research and graphic novel project – at kennismarkt Consortium Palliatieve Zorg Noord-Holland en Flevoland, ROC Nijmegen, VOSON, LUMC, Leergang palliatieve zorg voor verpleegkundig specialisten, Post-HBO Palliatieve Zorg at Hogeschool VIAA, Reliëf (2020-2024)
- Lecture and exhibition about our graphic novel at hospice Rozenheuvel (2021)
- Presentation about comic art in ethics education at NVBe onderwijsmiddag (2021)
- Acting as a simulation PhD student in a training session for PhD supervisors at RIMLS (2022)

Supervision of internships / other

- Supervision of 3-months internship of bachelor medicine student (2018)
- One-week supervision of a student during 'Meet your PhD' (2019)
- Supervision of 5-months internship of biomedical sciences student (2019)

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Over de auteur

Maaike Haan werd op 14 november 1988 geboren te Amersfoort. In 2007 verhuisde ze naar Nijmegen om daar aan de Radboud Universiteit Pedagogische Wetenschappen en Onderwijskunde te studeren. Na haar bachelor behaalde ze een master in Filosofie van de Gedragswetenschappen. Via een stage bij twee commissies ethiek en via de opleiding Ethiek in de Zorgsector ging ze zich steeds meer bezighouden met vraagstukken in de zorg.

Samen met haar promotieteam van afdeling IQ Health bij het Radboudumc werkte Maaike van 2017-2024 aan projecten rondom de beleving en verbeelding van mantelzorgers in de palliatieve zorg, waarvan dit proefschrift het resultaat is. Bijzonder was de samenwerking met striptekenaars Melanie Kranenburg en Niek van Ooijen vanuit de opleiding Comic Design van ArtEZ Zwolle. Begin 2020 was er vanuit diverse lokale media aandacht voor de lancering van het stripboek Naasten. Naderhand volgde meer onderzoek en ontwikkelde Maaike onderwijsmaterialen samen met anderen. Na afronding van het eerste project werkte ze van 2021-2022 als secretaris van de Commissie Ethiek van ZZG Zorggroep. Ondertussen bleef ze verbonden aan haar promotiewerk.

Steeds zocht én zoekt Maaike naar manieren om het gezamenlijke werk concreet van betekenis te laten zijn binnen zorg en onderwijs in de palliatieve wereld. Het vervolgimplementatieproject kwam in een stroomversnelling via samenwerkingen met Carend en de landelijke Academie van de Vrijwilligers Palliatieve Terminale Zorg (VPTZ). Door bundeling van krachten werd een e-learning en trainingsmateriaal ontwikkeld en was Maaike medeorganisator van een congres.

Sinds 2024 geeft Maaike trainingen bij de VPTZ Academie, waarbij vrijwilligers en coördinatoren onder andere vanuit beelden uit het stripboek in gesprek gaan over het omgaan met naasten van palliatieve cliënten en hospicegasten. Op het moment dat dit proefschrift verschijnt werkt Maaike daarnaast als algemeen coördinator bij VPTZ Arnhem | Midden Gelderland, waar ze zich inzet voor mantelzorgondersteuning via de hulp van vrijwilligers.

Maaike woont in Nijmegen, samen met haar man Tim en hun twee kinderen – Iris (geboren in 2019) en Victor (geboren in 2023).

Dankwoord

En nu is het *af*. Het is een boek geworden, een tastbare verzameling van 8,5 jaar werk, hart voor het thema, vragen en overwegen, schaven en schrappen, opnieuw beginnen of daar juist ver van blijven, van volhouden en van durven afronden. Een werk ook waarin voor mijn gevoel veel samenkomt. In alle projecten en zijpaden bleef namelijk telkens één lijn doorlopen – die van 'het boekje' dat er zou komen en het visioen van, ooit, de Aula. Bijzonder hoe die lijn niet alleen langs mijn werkactiviteiten liep, maar ook langs grote gebeurtenissen in mijn leven. Samenwonen, trouwen, vervreemdende ervaringen in coronatijd, maandenlang verbouwen en inwonen bij familie, ander werk buiten de wetenschap – en, bovenal, tweemaal de ervaring van de allesoverheersende kracht en kwetsbaarheid van moeder worden.

Ik ben dankbaar voor iedereen die op mijn pad kwam en me heeft gesteund en geïnspireerd in mijn onderzoek en het schrijven daarover, en bij de waardevolle vertaling ervan in een stripboek. Mijn dank beslaat vele jaren en verschillende werelden.

Mijn promotiewereld

Dit boek afronden was nooit gelukt zonder de steun van mijn copromotoren Jelle van Gurp en Gert Olthuis, en promotor Marianne Boenink. Dank voor al jullie steun, waardering en relativering die ik door de jaren heen heb ervaren. Wát een avontuur was het. En telkens wezen jullie me op een beeld in de toekomst (of dat nou die GN was die we gingen maken of een goed promotiefeestje) en lieten jullie me merken dat we daar *samen* zouden gaan komen. Marianne, jij sloot je bij ons groepje aan toen het grootste deel van het eerste project er al op zat; jouw scherpe blik, conceptuele vragen en ondersteuning bij het formuleren van de kern vond ik bij het schrijfwerk erna ontzettend waardevol. Ik dank je voor je vriendelijke duwtjes in de rug en je vertrouwen dat dit zou gaan lukken. Gert, dank voor jouw enthousiasme, luchtigheid, en hoe je in jouw precieze en soepele woordkeuze dicht bij de "geleefde ervaringen" in de zorgwereld wilde blijven. En Jelle, dankjewel voor hoe je mij vanaf het begin vertrouwen gaf en me begeleidde in het 'eigenaarschap' durven nemen in dit project; voor de tijd die je nam, je daadkracht, creativiteit en hoe je op cruciale momenten de kern wist te pakken en mij op een spoor zette waarmee ik dóór kon. Ik ben vereerd dat ik jouw eerste promovenda mocht zijn (zij het niet de eerst daadwerkelijk gepromoveerde…) – ik voelde me erkend en geliefd als "drs. Haan" en dat was een waardevolle basis voor mijn verdere werkende leven.

Dankjewel, Marjan Knippenberg, voor het aanbrengen van focus en organisatie in ons project en voor het oppakken daarvan tijdens mijn verlof rondom Iris' komst. Debby Gerritsen, bedankt voor onze mentorgesprekken en het vrolijke groeten in onze wijk door de jaren heen. Dankjewel, Inger Abma, voor je kritische blik van buitenaf en je aanscherpingen in de laatste loodjes. Dank aan prof. dr. Kris Vissers, dr. Louis van den Hengel en dr. Erica Witkamp voor het lezen en beoordelen van mijn manuscript; jullie commentaar was voor mij herkenbaar en betekenisvol.

De wereld waar het (niet) om ging

Naast mijn eigen promotiewereld dank ik alle partners, dochters, zoons, familieleden en vrienden die hun persoonlijke verhalen en ervaringen met het zorgen voor hun doodzieke naaste met me deelden – hun zorgen, angsten, frustraties en hun geluksmomenten. Vaak waren het indrukwekkende persoonlijke gesprekken op soms heel kwetsbare momenten. Dank voor jullie vertrouwen in me. Alle interviews, groepsgesprekken, feedbackbijeenkomsten, trainingen of andersoortige ontmoetingen – met naasten, maar ook met ernstig zieke mensen zelf, of zorgprofessionals of vrijwilligers om hen heen – hebben me aan het denken gezet over de ingewikkeldheid én schoonheid van (mantel)zorgen en sterfelijkheid.

Daarom dankjewel, Marianne Dees, dat je mij in aanraking bracht met de palliatieve zorg en me daarin op mijn uiteindelijke promotieweg hielp en daar op afstand betrokken bij bleef. In het dankwoord van 'Naasten' staan al veel mensen genoemd; hier bedank ik nogmaals alle zorgprofessionals die me hielpen bij het vinden van interviewdeelnemers, in het bijzonder het palliatief team van het Radboudumc.

De wereld die het durfde te tonen

Melanie Kranenburg en Niek van Ooijen, wat was het samen maken van ons stripboek een bijzondere ervaring. Het is inmiddels zes jaar geleden dat 'Naasten' verscheen, maar nog steeds vertellen mensen me hoe de platen hen aangrijpen, ontroeren, steunen of – soms – bozig maken. Het is door jullie creativiteit, artistieke vrijheid en ambacht dat het boek telkens zoveel oproept, en dat mijn onderzoeksproject uiteindelijk zo'n prachtige praktische wending kon nemen via trainingen. Mooi hoe onze zo verschillende werelden in die tijd samenkwamen. Het was heerlijk om me in jullie creatieve broedplekken te mogen bewegen. Dank ook voor de begeleiding van Sytse van der Zee, Rick Steggerda en Mara Joustra destijds, via de opleiding Comic Design aan ArtEZ Hogeschool voor de Kunsten in Zwolle. Ann Jossart van uitgeverij Oogachtend, bedankt voor de kans om ons werk aan een breed publiek te kunnen tonen. En dank aan iedereen die door de jaren heen "dat roze boek" heeft gelezen en (enthousiast) weer doorgegeven, zodat het zijn weg kon vinden in de wereld van de palliatieve zorg.

De zorgwereld om naasten heen

Gaandeweg het project werd duidelijker hoe mijn werk relevant kon zijn voor de kring *om naasten heen*. Dank aan alle mensen uit het hart van de zorg, de mantelzorgondersteuning, het onderzoeksveld of de onderwijswereld met wie ik fijn heb samengewerkt, gespard, theegedronken of gevideobeld. Wat een energie en inspiratie gaf dat!

Although our efforts after meeting at the Graphic Medicine conference in Brighton did not lead to a jointly published paper in the end, I value the conversations we had with Peter Wilkins and Ruhina Rana. I thank Peter for the casual joke that actually helped me focus in the years after ("there are two kinds of PhD theses – good ones and finished ones") and Ruhina Rana for the videocalls across the sea.

Ik ben dankbaar voor alle mogelijkheden die ik, vaak via-via, heb gekregen om mijn werk en ons stripboek in onderwijs, presentaties of workshops te mogen gebruiken. Bedankt, Daniëlle van Bennekom en Wies Wagenaar van het Netwerk Palliatieve Zorg Amsterdam en Diemen, voor de mogelijkheid om (film)materialen te maken en uit te proberen, en voor het leggen van nieuwe verbindingen. Wat gaf het een *boost* toen ons project in een stroomversnelling kwam door het contact met Sabine Netters en anderen van Carend. Heerlijk en leerzaam was het om krachten te kunnen bundelen en samen met Dian Paasman en Hinke Hoffstädt, aangevoerd door de mensen van Educared, onze onderzoeksresultaten concreet te maken in onderwijsmateriaal. Dankjewel Dian, hoe je daarin met me opliep en meedacht – het sparren heeft veel voor me betekend. En Hinke, wat was het leuk om onze resultaten uit te pluizen en bij elkaar te brengen. Fijn om, zij het op afstand, samen te schrijven, muzieklijstjes uit te wisselen en herkenning te vinden bij elkaar (bananen en biggetjes hebben sindsdien een andere lading ;)). Überhaupt was al het contact met collega-onderzoekers en projectleiders, die zich net als ik bezighielden met de ondersteuning van naasten en nabestaanden, een verrijking. Ik dank Yvette van der Linden, Marcella Tam en de andere bevlogen deelnemers aan het Netwerk Naasten en Nabestaanden voor de inspiratie die ik mocht opdoen vanuit hun projecten.

In het bijzonder wil ik hier ook de Academie van de Vrijwilligers Palliatieve Terminale Zorg (VPTZ) Nederland noemen. Marieke Zijlstra, dank voor alle mogelijkheden, en voor je fijne aanmoediging, rust en realisme daarin. Dank aan Ruth Elenbaas, Mariska van Unen en Petra Alting von Geusau, voor hoe jullie mijn trainingen en trainersvaardigheden hielpen aanscherpen. In het bijzonder dankjewel Petra, voor hoe je mij vertrouwen gaf. Ik ben blij dat mijn werk via de VPTZ-trainingen een geborgde plek heeft mogen krijgen en hoe dat weer tot zoveel nieuwe (werk) ervaringen heeft geleid.

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Mijn dagelijkse werk- en ethiekwereld

Het voelt als een eeuwigheid geleden en inmiddels zijn de meesten uitgevlogen, maar ik wil hier ook graag mijn mede-'Kelderkanjers' van (toen nog) afdeling IQ healthcare benoemen – dank voor alle gezelligheid, de lunchmomenten, en het gewoon even bij elkaar binnen kunnen lopen. Yrene Kerckhaert, dankjewel voor ons bijzondere contact tijdens jouw stagetijd in ons team en wat ik daar ook zelf weer van leerde. Ik koester bovendien de intervisiebijeenkomsten met collega-promovendi en Yvon Siebelinks rake observaties en vragen daarin.

Stephanie Vermeulen, ik denk nog altijd met plezier terug aan hoe ik als filosofie-student als notulist bij de commissie ethiek van ZZG zorggroep terechtkwam; dankjewel voor jouw rust en aandachtige manier van werken die me inspireerde. Het overnemen van jouw stokje, in mijn (tussen)jaar als secretaris zo'n tien jaar later, leerde me waardevolle lessen over ethiek in de praktijk.

Verder bedank ik alle lieve leuke mensen van de vakgroep Ethiek van de gezondheidszorg waar ik mij zoveel jaren thuis voelde – voor de aanstekelijke bevlogenheid, vrolijkheid, ontelbare ommetjes en voor het warme enthousiasme waarmee ik ook buiten mijn contracttijd altijd weer werd begroet. In het bijzonder Anke Oerlemans en *roomie* Pleuntje Verstegen (koekoek!) voor het al zo lang samen oplopen me daarin gezien en begrepen weten, en Milou Looijmans als 'friendly face' van het laatste uur. Dankjewel, Anneke van der Niet en Sanne van Oosterhout, voor het planten van het zaadje om juist tijdens het schrijven uit te kijken naar paden *buiten* de wetenschap.

En niet voor niks vroeg ik twee van mijn ethiekcollega's, Simone Naber en Anne-Fleur van der Meer, als mijn paranimfen. Simone, je hebt me bij de vakgroep zien binnenkomen en bent voor mij een belangrijke wegwijzer en meedenker geweest. Wat waardeer ik je oprechte belangstelling, hulp, gedreven nieuwsgierigheid, en je vuur. Fijn en leuk hoe we elkaar door de jaren heen in allerlei verbanden telkens weer vonden. En Anne-Fleur, wat weet jij toch altijd precies, zorgvuldig en liefdevol de juiste woorden te vinden. Ik ben dankbaar voor onze verbinding buiten de vakgroep en hoe je mij nabij bent geweest op belangrijke momenten. Lieve paranimfen, jullie aan mijn zijde weten helpt me om met vertrouwen in de Aula te gaan staan.

Mijn leuk wereldje

En dan was er ook nog een leven naast werken en schrijven. Dankbaar ben ik voor alle fijne contacten uit mijn kringen binnen en buiten Nijmegen, in onze wijk of via school. Dank aan Linda Modderkolk, mijn allereerste collega na mijn studietijd,

voor je waardevolle coaching en je aansporing om de diepte en niet te zwaarte te zoeken. Dankjulliewel, Heilige Meloenen, voor het plezier en de lichtheid in het samen spelen op de theatervloer. Dank aan Marjet Seyferth, voor de rust die je bracht rondom Victors komst. Dank aan zangcoach Anne-Marie ter Beke voor het vinden van nieuwe bronnen, en aan Marinel Slot voor de energie in het samen zingen. Dankbaar ben ik sowieso voor de kracht die ik vond in de muziek van anderen (ik weet oprecht niet hoe ik dit hele pad had kunnen bewandelen *zonder* de vele lijstjes en een noise-cancelling koptelefoon).

Een herberg die me vanaf mijn studententijd bijzonder dierbaar is geweest is de Studentenkerk op de Nijmeegse campus. Dank voor de fijne contacten met de pastores en bestuursleden, en binnen de zondagochtendgroep. Dankjewel, Marieke Fernhout, voor de wederzijdse herkenning, en voor het helpen zoeken en vinden van taal voor het haast onzegbare. Ans Metz, bedankt voor jouw geloof in mij en onze bijzondere band – ook al heb je ruim 45 jaar meer levenservaring dan ik. Dank, Iris Wierstra, voor onze verbondenheid en herkenning in het zoeken (én vinden!) – en de verdere lieve groep van 'Zaaiers' voor de inspiratie, bemoediging, kinderkerk en fijne kloosterweekends.

Intens dankbaar ben ik, tot slot, voor mijn verdere vrienden en (schoon)familie, voor alle vriendschap en gehechtheid, voor de diepgang daarin en de lichtheid ervan.

Liefste Ag, Do, Floor & Aik, Han en Zandra – voor de ontroerend vertrouwde draadjes die we altijd weer oppakken.

Fijne Zippers en kleine Zippertjes – voor onze vele vroegere kooravonturen, voor de biertjes en barbecues, jullie steun en het er altijd zijn bij de grote momenten in ons leven.

Lieve José en Paul – voor hoe jullie me opnamen in jullie gezinskringetje van drie, voor alle oppasdagen die ruimte gaven voor mijn schrijfwerk, en voor jullie voorbeeld hoe liefde ook zit in kunst, bewust leven, of praktische hulp.

Mijn lllz en Broer, lieve zwager en schone zus – voor hoe ik me door jullie begrepen en gedragen weet, en voor hoe *onvoorwaardelijke liefde* door jullie en jullie gezinnen concreet betekenis voor me heeft gekregen.

Lieve pap en mam – het is door jullie dat ik de liefde voor taal en het gewicht van woorden leerde kennen, en die (ook met dit boek) heb durven onderzoeken. Tranen

van geluk en dankbaarheid voel ik om wat we hebben en samen delen, ook met onze kindjes. Zonder jullie was dit boek er niet geweest.

Lieve Tim – wat ben ik vaak onder de indruk van onze vervlochtenheid, zowel samen als via Iris en Victor. Je geeft me het vertrouwen dat het goed is zoals het is, en jouw vertrouwen laat me stromen. Dankjewel voor je steun in het beginnen, volhouden en afronden van dit boek en alles erachter. Zonder jou had ik het niet gekund.

En tot slot Irisje en Viccemans, kleine lieverdjes in mijn leven – jullie zijn voor mij de belichaming van wat liefde en zorg ten diepste kunnen betekenen. Wat hou ik zielsveel van jullie. Jullie komst was zowel een motor als een vertrager in mijn werk (zoals met jullie alle contrasten zo vaak naast elkaar kunnen bestaan). Wat ben ik dankbaar voor de spiegel die jullie voor me zijn, en hoe jullie me altijd weer terughalen naar het hier, het nu, en al het moois daarin.

When seriously-ill people wish to die at home, the role of their close ones usually is crucial. To engage a broad audience in thinking about the (moral) challenges and ambivalences faced by family caregivers, we collaborated with two comic artists to develop the Dutch research-based graphic novel Naasten. The results and reflections of our studies, shared in this PhD thesis, are relevant for healthcare professionals who support families as well as for researchers who are interested in adopting artistic methods.

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