

Roles of informal caregivers in shared decision-making for ALS patients: a qualitative study

Thesis MSc Health Care Management

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Being an informal caregiver is a task that you don't just do on the side. Because I'm his translation computer for people who don't see hem often or people who can't understand it. I'm also the one who always answers the phone, because he can't make himself understood on the phone either. Moreover, I am the one who arranges everything for him, because everything has to be agreed, discussed and coordinated with regard to the care. A day job that I try to fill in with love (B2, p. 32).

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Date	17-06-2024
Word count	13579 (including in-text reference)

Abstract

Introduction

Zorginstituut Nederland developed a policy framework to define appropriate care. The appropriate care framework of Zorginstituut Nederland was introduced to meet society's demands about the future of the Dutch healthcare system, also stating that shared decision-making is crucial for the self-determination of the patient. The informal caregiver is not a significant subject in this framework, which contradicts the fact that informal caregivers offer personal assistance and experience burdens. When patients cannot fully communicate, the informal caregiver becomes even more important, especially in shared decision-making. ALS patients and their informal caregivers are a case of this. How exactly informal caregivers are involved in shared decision-making is under-researched, leading to the research question: *What are the roles of informal caregivers in shared decision-making in care decisions for patients with Amyotrophic Lateral Sclerosis (ALS)?*

Methods

To answer this question, a narrative analysis, of existing written books by informal caregivers is conducted. In total, seven books are included in this research. Five books are written by informal caregivers, and two books are written about the informal caregiver, including quotes from the informal caregiver. After the narrative analysis, a thematic analysis is conducted, following different roles found in the theoretical framework that are used as sensitizing concepts.

Results

Shared decision-making is being practised in decision-making for ALS patients. The medical context of the patient influences the family involvement and can change over time. For ALS patients, this distinction can be made in whether the patient is able to speak or not. When the patient is able to speak, the informal caregiver takes on the role of *providing & receiving information* or *supporting the involvement and participation* of the patient. When the patient is not able to speak, the informal caregiver takes on the role of *spokesperson, advocate* and/or representative. These roles are interchangeable, as the context in which the decision is made changes, depending on contextual factors. Furthermore, a facilitating role is found, in which the informal caregiver arranges conditions to make shared decision-making happen. It is also found that, with the informal caregiver having an active role in shared decision-making, the informal caregiver sometimes influences the decision made, depending on the (medical) knowledge and initiative of the informal caregiver.

Discussion

This study combines the roles of informal caregivers in shared decision-making that are found in literature about elderly care with the experiences that are written down by informal caregivers of ALS patients. This research then shows that more attention should be given to the informal caregiver in the policy context to provide more support for informal caregivers and recognition of their importance. Given the explorative aim of this study, limitations include the limited sample size of seven books and the exclusive inclusion of the informal caregiver's perspective, leaving out the perspective of the patient and the formal care (institutions). Further research

could research that perspective as well and combine these perspectives into one research to get an integrated perspective on the exact role of the informal caregiver in shared decision-making. This, then, could lead to better support for informal caregivers from formal caregivers in future policy.

Table of Contents

1. Introduction	4
1.1 Objective and research question	6
1.2 Reading guide	6
2. Theoretical framework	7
2.1 Shared decision-making	7
2.2 Family involvement in shared decision-making	8
2.3 Roles of the informal caregiver in shared decision-making	9
3. Research methods	11
3.1 Included books	11
3.2 Data analysis	12
3.3 Validity and reliability	13
3.4 Ethical considerations	14
4. Results	15
4.1 Shared decision-making	15
4.2 Different roles	18
4.3 Able to speak	18
4.4 Not able to speak	22
4.5 A facilitating role	25
4.6 Influence of the informal caregiver	26
4.7 Burdens	27
4.8 Need for informal caregiver support	27
5. Discussion and conclusion	28
5.1 Policy implications	30
5.2 Reflection on the role of the researcher	30
5.3 Strengths/limitations and recommendations	30
6. References	32
7. Appendix: narrative analyses	35

1. Introduction

Zorginstituut Nederland (2022) developed a policy framework to define appropriate care. The appropriate care framework of Zorginstituut Nederland (2022) was introduced to meet society's demands about the future of the Dutch healthcare system. The framework aims to ensure that care is people-centred, care becomes sustainable, and that sustainability should be more applied in healthcare. This framework describes what the movement to appropriate care entails and describes what expectations the government has of all different actors in Dutch health care (Zorginstituut Nederland, 2022), aiming to make health care contribute to the health of the Dutch population by 2040 (Zorginstituut Nederland, 2022).

The framework defines four principles of appropriate care: positive health (appropriate care is about health instead of disease), self-determination (appropriate care is determined with and around the patient), resilience (appropriate care takes place at the right place), and value-based healthcare (appropriate care needs to be value-based) (Zorginstituut Nederland, 2022).

A key component of the self-determination principle of the appropriate care framework is shared decision-making (Zorginstituut Nederland, 2022). Shared decision-making can be defined as *'an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options to achieve informed preferences'* (Elwyn et al., 2012, p. 1361). Shared decision-making is then important for ensuring that care aligns with the patient's personal situation and wishes (Zorginstituut Nederland, 2022).

The appropriate care framework underscores the importance of shared decision-making but does not adequately address the role and importance of the informal caregiver in shared decision-making, leaving the informal caregiver out of current policy. Informal caregivers, usually the partner, relative or friend of the patient (Mockford, Jenkinson, & Fitzpatrick, 2006), take different roles in patient care, from emotional support to coordinating care (Klerk et al., 2015), and are involved in shared decision-making (Politi & Street, 2010). The involvement of the informal caregiver in shared decision-making becomes particularly more crucial when the patient is less able to communicate effectively with physicians. The caregiver, relative and patient then together decide what appropriate care is for the patient, to fit the personal situation and to align with the patient's wishes (Zorginstituut Nederland, 2022) and to develop informed preferences (Elwyn et al., 2012).

A case of patients losing the ability to communicate with the physician is the disease ALS. Amyotrophic Lateral Sclerosis (after ALS) is a disease that affects neuronal cells, leading to severe physical disability and eventually death (Stichting ALS Nederland, 2024). In the Netherlands, ALS has an average prevalence of 1500. Every year, about 500 people die, and more than 500 new diagnoses are made (Stichting ALS Nederland, 2024). Given the progressive dysfunction of ALS (Oskarsson, Gendron, & Staff, 2018), personal assistance is increasingly needed throughout the disease (Mockford et al., 2006), and informal caregivers offer this assistance (Gauthier et al., 2007).

Research has demonstrated that ALS patients value independent or shared decision-making with their informal caregiver more than transferring full responsibilities to informal caregivers (Nolan et al., 2008). Foley and Hynes (2017) conducted a systematic review of the literature regarding ALS patients and their informal caregivers in shared decision-making, stating that the impact of informal caregivers can directly or indirectly impact “*whether patients request, accept or decline care interventions*” (Foley & Hynes, 2017, p. 18). The involvement of the informal caregivers impacts the patients' care decisions and could lead to more effective health care, as it helps the health-care provider understand the illness of the patient better with multiple perspectives (Siminoff, 2013). However, how informal caregivers of ALS patients are involved, how they impact the shared decision-making process and what role they have in the shared decision-making process is not described by Siminoff (2013). Whereas these roles are not defined for ALS patients, some research is conducted to these roles for elderly patients (Dyrstad, Laugaland, & Storm, 2015).

The role of informal caregiver is associated with a high burden (Gauthier et al., 2007). The psychological well-being of the informal caregiver worsens over time. Related to shared decision-making, the informal caregiver is more likely to feel more anxious about making care decisions than the ALS patient (McKim et al., 2012), but does not elaborate why informal caregivers are more anxious. When combining the policy context of the appropriate care framework of Zorginstituut Nederland (2022), the importance and influence that the informal caregiver has in shared decision-making and the experienced burden by the informal caregiver, it can be said that too little attention is given to the informal caregiver and its role and that the informal caregiver should be part of the policy context.

Foley and Hynes (2017) underscore that too little policy attention is given to the participation of family members and their role, and that further research can contribute to developing decision-making tools in ALS care (Foley & Hynes, 2017). Together with the inattentiveness of informal caregivers in the appropriate care framework, the importance and anxiousness of informal caregivers in shared decision-making (McKim et al., 2012) and the increasing amount of informal caregivers in the future (Kooiker et al., 2019; Rijksoverheid, 2024), this defines the societal relevance for further studying the role of informal caregivers in the shared decision-making process for ALS patients. By exploring this role, this research aims to offer more support to informal caregivers in future policy, not only for informal caregivers of ALS patients but also for informal caregivers in general, as ALS will be used as a case in which patients lose their ability to communicate with physicians.

The scientific relevance of this study lies in foregrounding the perspective of the informal caregiver of the ALS patient and identifying their role in shared decision-making. Literature such as the systematic review of Foley and Hynes (2017) looks from the perspective of the ALS patient to the role of informal caregivers in shared decision-making. It does not report on the informal caregiver's specific role in the shared decision-making process. Roles in shared decision-making are described more in the systematic review of Kraun et al. (2022) but are focused on transitional care, not ALS patients. This research aims to fill this gap in the literature by looking from the perspective of the informal caregivers of ALS patients to their role in the shared decision-making process.

To achieve this, a narrative analysis of books written by, or about informal caregivers of ALS patients is conducted, following the method of Murray and Sools (2014) and a thematic analysis to organize the results. This approach will explore the perspectives of informal caregivers and their roles in shared decision-making that can be used for future research and policy development.

1.1 Objective and research question

This research aims to explore the role of informal caregivers in the shared decision-making process for ALS patients. More insight into the roles of informal caregivers will contribute to future policy regarding informal caregivers and provide more support for informal caregivers.

The research question will then be the following:

What are the roles of informal caregivers in shared decision-making in care decisions for patients with Amyotrophic Lateral Sclerosis (ALS)?

The sub-questions will then be the following:

1. What does the shared decision-making process look like for informal caregivers of ALS patients in practice?
2. What role does the informal caregiver have in the shared decision-making process for ALS patients?

1.2 Reading guide

This paper consists of five chapters, the first being this introduction chapter. In the theoretical framework, relevant concepts are mentioned regarding shared decision-making. These concepts are linked to the relevance of this study, the appropriate care framework, and are linked to what perspective the concept brings to the data analyses. The third chapter describes the research methods, including statements about validity and reliability and ethical considerations. The fourth chapter consists of an exposition of the results that are organised according to the sub-questions. The sensitising concepts found in the theoretical framework are used to organise the results in the second sub-question. Lastly, in the fifth chapter, conclusions drawn from the results. Furthermore, these conclusions are discussed in the light of the theoretical framework, ending with policy recommendations and limitations of this study.

2. Theoretical framework

Zorginstituut Nederland (2022) introduced the appropriate care framework to meet society's demands about the future of the Dutch healthcare system: care needs to be people-centred, care should be sustainable, and sustainability should be more applied in healthcare (Zorginstituut Nederland, 2022). The goal is to make health care contribute to the health of the Dutch population in 2040 (Zorginstituut Nederland, 2022). Four principles of appropriate care are defined in the framework: positive health (appropriate care is about health instead of disease), resilience (appropriate care takes place at the right place), value-based healthcare (appropriate care is relevant for patients with a proportional number of resources) and self-determination (Zorginstituut Nederland, 2022). For this research question regarding shared decision-making, self-determination is the essential aspect, as Zorginstituut Nederland (2022) states that *“appropriate care is defined in a shared decision-making process with and around the patient”* (Zorginstituut Nederland, 2022, p. 8), in which Zorginstituut Nederland (2022) also indicates that shared-decision making is essential to provide appropriate care.

In the literature, different perspectives and definitions of shared decision-making can be found. Most literature is about the perspective of the patient and the physician; the perspective of the informal caregivers has comparatively less literature available. This theoretical framework will discuss these three perspectives, starting with a definition of shared decision-making.

2.1 Shared decision-making

As Zorginstituut Nederland (2022) finds shared decision-making essential for the patient's self-determination, it is first relevant to define shared decision-making. According to Charles, Gafni & Whelan (1999), shared decision-making is a cognitive, emotional, and relational process in which provider and patient collaborate on a decision after discussing the options, evidence, and potential benefits and harms while considering the patient's values, preferences, and circumstances (Charles, Gafni, & Whelan, 1999). Zorginstituut Nederland (2022) aligns with this perspective and states that the personal perspective of the patient needs to be considered, and different (treatment) options need to be explored (Zorginstituut Nederland, 2022). The caregiver, relative and patient then together decide what appropriate care is for the patient, to fit the personal situation and to align with the patient's wishes (Zorginstituut Nederland, 2022) and to develop informed preferences (Elwyn et al., 2012). The ultimate aim is to decide together what proper care is for the patient to fit the personal situation and align with the patient's wishes (Zorginstituut Nederland, 2022).

Starting with the physician's perspective, Ubel, Scherr and Fagerlin (2018) state that proper practice in shared decision-making is that the physician informs the patient about treatment alternatives and helps patients align with their values and goals in their choices. Elwyn et al. (2012) provide further guidance for the everyday practice of shared decision-making of physicians by introducing a three-step model that breaks down the concept of shared decision-making into three 'talks': choice, option, and decision talk, which are key steps in practising of shared decision-making (Elwyn et al., 2012). Choice talk is the step in which patients learn that reasonable options are available, option talk is the step in which patients learn what options are available, and decision talk is the step in which patients, family and the physician consider

preferences and decide what is best (Elwyn et al., 2012). Table 1 gives an overview of the characteristics of these three talks.

Choice talk	Option talk	Decision talk
Step back	Check knowledge	Focus on preferences
Offer choice	List options	Elicit preferences
Justify choice - preferences matter	Describe options - explore preferences	Move to a decision
Check reaction	Harms and benefits	Offer review
Defer closure	Provide patient decision support	
	Summarize	

Table 1: Choice, option, and decision talk, derived from (Elwyn et al., 2012)

These characteristics will be used in the thematic analysis of the narrative stories of informal caregivers of ALS patients to identify each step of the shared decision-making process and to see to what extent shared decision-making is practised for ALS patients. According to Elwyn et al. (2012), shared decision-making is only practised as proposed if these characteristics are visible. As stated above, these talks and the definition of Ubel et al. (2018) look from the physician's perspective and offer guidance for professionals but leave out the perspective of the patient and the informal caregiver.

Shay and Lafata (2014) take the patients as a point of view, researching the patients' perceptions of shared decision-making. They defined a conceptual model that includes four components for patients: mutual information exchange, patient self-advocacy, physician-personalized recommendation and open-mindedness and respect for one another (Shay & Lafata, 2014). Patients value these aspects and an interactive exchange of these components is needed to make the shared decision. Shay and Lefata (2014) leave the informal caregiver out of their study. Furthermore, they state that there is no one-size-fits-all process to label a decision as shared (Shay & Lafata, 2014). This no-one-size-fits-all approach can be added to the talks of Elwyn et al. (2012), and offer the perspective on the data that not all aspects of these talks need to be found in the stories of informal caregivers to indicate shared decision-making as such.

2.2 Family involvement in shared decision-making

Before moving to the informal caregiver's perspective, it is relevant to examine what family members' involvement in shared decision-making can look like.

The patient's ability to engage in shared decision-making depends on the patient's health and life circumstances (Rennke et al., 2017). Rennke et al. (2017) reviewed the literature to integrate different concepts related to shared decision-making into a conceptual model in which the patient/family, care provider/team, and the medical context are included. This model, presented

in Figure 1, intends to give a framework to develop interventions to improve quality and patient safety through shared decision-making.

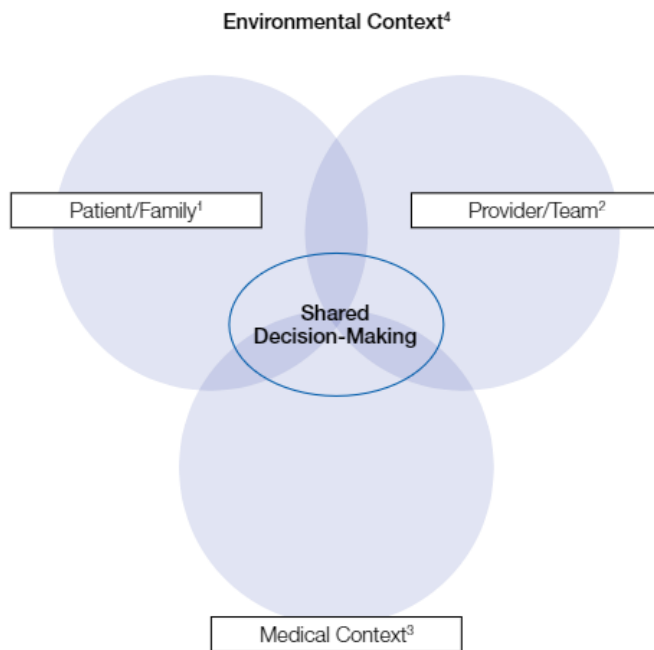


Figure 1: SDM 3 Circle Model (Rennke et al., 2017)

The conceptual model visualises the overlap between these three categories, which are affected by the environment in which they occur (Rennke et al., 2017). Shared decision-making is then influenced by the three circles in Figure 1. This also indicates that the level of involvement of the patient/family is influenced by the other two circles. Furthermore, Rennke et al. (2017) state that these circles and their related factors can change over time. This offers a new perspective on the roles that informal caregivers have in shared decision-making: family members are relevant in this process, and this relevance can change over time, as the family/patient involvement depends on the other two circles (Rennke et al., 2017), and the medical context is subject to change during the disease, especially for ALS patients, as this ALS leads to progressive dysfunction (Oskarsson et al., 2018). The informal caregiver's involvement level depends on the patient's medical condition and might change over time. This perspective is relevant when analysing the books written by informal caregivers, as it learns that informal caregivers can take more than one role, depending on the context they are involved in.

2.3 Roles of the informal caregiver in shared decision-making

To study the exact role of the informal caregiver in shared decision-making, literature that includes the informal caregivers becomes relevant. Comparatively, less literature is available compared to the perspective of the physician and the patient. Kraun et al. (2022) conducted a systematic review of elderly and their informal caregivers in care decision-making. In 10 studies, they found different involvement roles in shared decision-making. Informal caregivers sometimes advocate on behalf of their relatives to ensure that their relatives receive appropriate care (Byrne, Orange & Ward-Griffin, 2011; Kraun et al., 2022). Others were insufficiently involved in the shared decision-making process (Dyrstad et al., 2015; Kraun et al., 2022), as

they felt left out of the conversation, even when the elderly could not answer or remember questions (Kraun et al., 2022), or experienced a loss of control (Dyrstad et al., 2015).

When involved in shared decision-making, informal caregivers take on different roles. They can be *spokespersons, advocates, and/or representatives* (Allen et al., 2017; Kraun et al., 2022). Older people also believed that informal caregivers played an important role in *providing and receiving information* and *supporting the involvement and participation* of older people in decision-making (Dyrstad et al., 2015; Kraun et al., 2022). These roles are displayed in Table 2, which also indicates the difference between these roles.

<i>Roles of the informal caregiver</i>	<i>Patient present?</i>	<i>Who is talking?</i>	<i>Who makes the arguments?</i>
Providing & receiving information	Present	Patient	Patient
Supporting the involvement & participation		Informal caregiver	Informal caregiver
Spokesperson			
Advocate			
Representative	Absent		

Tabel 2: Involvement roles of informal caregivers

In the roles *providing & receiving information* and *supporting the involvement & participation*, the patient communicates with the physician. In contrast, in the other roles, the informal caregiver speaks on behalf of the patient.

Whereas Kraun et al. (2022) focused on elderly in transitional care, this research is about the informal caregivers of ALS patients. The roles identified above will be used as a sensitising concept during the analysis. This offers a new perspective on the data, in which the involvement, direct or indirect, of the informal caregiver in shared decision-making can be categorised and interpreted. During the thematic analysis of the analysed books, these roles will be a starting point to see whether these roles also exist for informal caregivers of ALS patients and identify the roles of informal caregivers of ALS patients in shared decision-making.

Knowing informal caregivers' roles in shared decision-making relates back to the appropriate care framework of Zorginstituut Nederland (2022), that does not mention informal caregivers in shared decision-making. These roles show that informal caregivers are, in theory, sometimes indispensable in the shared decision-making process, or, at least, can have a significant impact on the shared decision-making process. This might lead to informal caregiver burden that Gauthier et al. (2007) describe and shows the need for informal caregiver support and policy.

3. Research methods

To research the role of informal caregivers in the shared decision-making process of people with ALS, an explorative qualitative narrative analysis, such as Murray and Sools (2014) offer, based on ego documents from the perspective of the informal caregiver, has been conducted. Ego documents are important as the views of patients and service providers differ (Condon, 2019) and are propagated for research (van de Bovenkamp et al., 2020). Ego documents provide a better understanding of experiences than questionnaires with health care services, treatment, and daily life with a condition (Bate & Robert, 2006). In this research, existing public books written by the informal caregiver will be used as ego documents. After the narrative analysis, a thematic analysis, as described by Nowell et al. (2017), is conducted. Data collection

Data is primarily collected from existing books managed by the Erasmus School of Health Policy and Management. The online database of these books is accessible online via <https://www.patientervaringsverhalen.nl/>. These stories are written from the informal caregivers' perspective. Four books are included from this database, as no more suitable books were available based on the inclusion criteria. To expand the richness of the data, three more books were included. These books are found on the website of Stichting ALS Nederland. The inclusion criteria in Table 3 are used for sample collection. A short explanation of the criteria follows these inclusion criteria.

Inclusion
(1) The story is written after 2000
To align with recent SDM developments.
(2) The patient of the informal caregiver is only diagnosed with ALS.
To avoid interference with other diseases.
(3) Informal caregiver and patient are over the age of 18 years.
To avoid legal complications of underaged SDM and another role for the informal caregiver.
(4) Informal caregiver and patient live in the Netherlands.
To be able to make policy recommendations.
(5) The patient of the informal caregiver receives (inpatient or outpatient) care in a Dutch health care organization.
To be able to make policy recommendations.
(6) The story is written from the perspective of the informal caregiver.
This eliminates books written from other perspectives.

Table 3: Inclusion criteria for sample selection

3.1 Included books

Table 4 shows all seven books included in this research. For each book, the original title, translated title, author, year of publication, disease period and the relationship between informal caregiver and patient.

Reference in results	Original title	Translated title	Author	Year of publication	Disease period	Relationship informal caregiver - patient
B1	Komt een man bij de dokter	A man visits the doctor	Saskia Zandvliet	2023	2008-2011	Partner
B2	ALS heb je niet alleen	You do not have ALS alone	Mariska van Genneep	2020	2015-2017	Partner
B3	ALS, Hoe vaak kan een hart breken	ALS, how many times can a heart break	Carla de Vries – Van den Heuvel	2004	2001-2002	Partner
B4	ALS u dit leest ...	When (ALS) you read this...	Eddy Veerman *	2014	2010-2013	Partner
B5	Fernando Rickson, De Finale Strijd	Fernando Rickson, The Final Battle	Vincent de Vries * & Veronika Rickson	2020	2013-2019	Partner
B6	Canto Obstinato	Canto Obstinato	Anje Bereman	2022	2020-2021	Daughter
B7	ALS je de handen, voeten en stem van je Lieve bent geworden	When (ALS) you became the hands, feet and voice of your Love	Joanna Schoemaker	2024	2004-2007	Partner

Table 4: Included books

For two books, the author is marked with an asterisk. These books are not (book B4) or partly (book B5) written by the informal caregiver but by a third author. In both books, however, the author quotes the informal caregiver directly. These parts of the book are used for analysis in this research, as this includes the perspective of the informal caregiver.

3.2 Data analysis

A narrative analysis is conducted to analyse the books of informal caregivers. Murray and Sools (2014) offer guidelines for analyses. Table 4 gives an overview of the research approach of Murray and Sools (2014). Only the first two parts of Murray and Sools (2014) are conducted for this research, followed by a thematic content analysis, to be able to identify themes in the narrative analyses and provide an answer to the research question.

<i>Part</i>	<i>Step</i>
I. Introduction	1. Formulate case title
	2. Introduce case
II. Storyline analysis	3. Formulate storyline analysis

	4. Identify and describe storyline elements and breach
	5. Write narrative summary of storyline
	6. Draw conclusions regarding your research question based on steps 3-5 and discuss your findings

Table 4: First two steps of the step-by-step guideline for narrative analysis, derived from Murray and Sools (2014)

All books were analysed individually in the first part of the analysis. Per story, a narrative summary of the book as a whole is made first. After, a selection of storylines is made that is analysed in the storyline analysis. In this storyline analysis, the central actor, act, scene, purpose, and agencies will be identified. A breach is then also identified to see what tensions are visible in the storyline. Then, the narrative storyline is rewritten to make the breach more visible in the narrative storyline. Based on the storyline, a conclusion is written per storyline, in which the relevant elements regarding to the research question are highlighted.

In the second part of the analysis, a thematic content analysis is conducted to formulate an answer to the research question. In the thematic content analysis, the literature and concepts from the theoretical framework are applied to the storylines of informal caregivers. Nowell et al. (2017) defined six phases of thematic content analysis: familiarizing yourself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report (Nowell et al., 2017). The different roles in the theoretical framework (*providing & receiving information, supporting the involvement & participation, spokesperson, advocate and representative*) are used as sensitizing concepts during this thematic content analysis.

3.3 Validity and reliability

Mays and Pope (2000) describe various ways to enhance the validity of qualitative research. Different aspects will be used and paid attention to in this research. Data triangulation will be applied in a story variation, as described above, all suitable books are included in this study. Mays and Pope (2000) also mention that attention should be paid to negative cases to enhance validity and Hanson (2017) states that an understanding of outliers provides a greater understanding of the strengths and limits of the data. For that reason, for every theme in the results section, the books in which the theme occurs are mentioned. This research will examine outliers and contradicting outcomes in the informal caregivers' stories. Mays and Pope (2000) also mention fair dealing, in which the truth of one individual is not to be seen as the truth of a group (Mays & Pope, 2000). Fair dealing will be used by incorporating different stories from different informal caregivers.

Lastly, reflexivity means attention to the role of the researcher and how the researcher has shaped the collected data (Rolfe, 2006). The data consists of books written by informal caregivers, indicating that they had the chance to revise their work and agreed with the stories' content. However, in this research, attention still needs to be paid to reflexivity, as the researcher will interpret these stories. To encounter this, a thick description of the research object will be included. This will provide the context of the story of the informal caregiver in detail. The narrative analyses in the appendix will give such context. Furthermore, the role of the researcher will be a subject in the discussion chapter to discuss possible interpretation biases.

3.4 Ethical considerations

When conducting this qualitative research, the following ethical considerations were made. The informal caregivers published as writers their books publicly, indicating books are available for everyone and available for research purposes. No other information than information in the books is included. No other information is asked of the authors. Using written books, the researcher had no influence on the raw data.

4. Results

This results chapter presents the results of the narrative and thematic analyses of the books written by informal caregivers of ALS patients. Every book written by informal caregivers of ALS patients includes anecdotes about care decisions. The storylines mention different examples of care decisions, varying from diagnosis to transitional care decisions to euthanasia decisions.

This chapter follows the structure of the sub-questions. The first sub-question relates to how shared decision-making is being practiced for ALS patients. The second sub-question relates to what roles informal caregivers have in the shared decision-making process. Lastly, this chapter describes the burdens that come with these roles.

4.1 Shared decision-making

All seven analysed books include anecdotes about care decisions. The level of in-depth writing varies per book. Book B4 and book B5 are more focussed on the (earlier) life of the patients and tell more of a life story, but lack in-depth descriptions of care decisions. The patients in these books are also more of a public figure. Books B1, B2, B3, and B7 are more pointed to the disease period of the patient and talk more about care decisions. Book B6, at last, writes about the relationship between the informal caregiver and the patient, the informal caregiver's mother, but also mentions some care decisions.

4.1.1 Types of care decisions

There are different types of care decisions. Every book, except book B6, mentions the diagnosis phase, in which the patient and informal caregiver learn about ALS. In all books, except book B6, which does not discuss this subject, ALS is a disease that the patient and informal caregiver have rarely heard about. In some books, the informal caregiver has more knowledge and helps the patient get information about the disease. This knowledge advantage will be discussed in more depth later. Later in the disease stage, ventilation becomes an essential issue in all books. ALS patients slowly lose the ability to breathe properly and are designated to ventilation. Also, a stomach tube is commonly inserted for ALS patients, as the risk of choking increases during the disease. Lastly, the books usually talk about euthanasia or palliative sedation decisions, as every book, at least, tells about thinking about how the life of the patient should end.

4.1.2 Settings of shared decision-making

In all analysed storylines, decisions are made at various locations. The diagnosis phase takes place at the local physiotherapist and hospital. Later, those ALS patients were referred to the ALS centre at the UMC Hospital in Utrecht for their second opinion. In those books, the final diagnosis is made in the ALS centre. Afterwards, those books also discuss the treatment plan being made at this ALS centre. Then, the physical location where decisions are made slowly moves in the direction of the patient's home, which is, except for book B6, also the home of the informal caregiver. Only in book B1 the patient is admitted into a nursing home, where decisions are made in the last phase of that book. Lastly, in some books, the informal caregiver takes on the role of representative, in which the informal caregiver communicates without the

patient's presence, for example, when they are at work. This will be discussed in more depth later in this chapter.

4.1.3 Shared decision-making in practice

In the theoretical framework, different talks are distinguished that should be part of shared decision-making: choice, option, and decision-talk (Elwyn et al., 2012). Although not explicitly visible, every talk comes forward in the informal caregiver's storylines. Two examples will be given to show that shared decision-making is being practiced for ALS patients. The quote below is an example from one book of how shared decision-making is being practiced, but it is representative of all books, as other books show the same kind of examples.

Last Friday we went to see doctor van den B., the ALS doctor at the UMC hospital. He can't add that much anymore. "Do what makes you feel good. Physio? Fine, but doesn't help. Do what you feel comfortable with!"

He also again drew our attention to the following. If Jan [patient] gets into trouble with his breathing again and we end up in the hospital again, will he go on a ventilator? Then he'll never get rid of it. In other words, if you have made the decision together that Jan does not want to be on invasive ventilation, then you should no longer go on a ventilator in such a situation. His lungs are now at such a stage that he can't pick it up on his own after that. Realistic and intense. If he starts to feel uncomfortable with the increasing shortness of breath, we can administer some morphine. (B7, p. 69)

Although the informal caregiver does not have an active role in this short fragment, it does give an example of the talks of Elwyn et al. (2012). *Choice talk* is being practised here, as the ALS doctor offers a choice (whether to get treatment at the physio). The ALS doctor practices the *option talk* by listing and describing two different options (taking invasive ventilation or not, adding physio as an option), asking for preferences (whether the patient wants invasive ventilation) and listing harms and benefits (the risk of not getting off the ventilation again). These are elements that Elwyn et al. (2012) list as option talk. In this example, no final decision is made, but the ALS doctor has a strong focus on preferences (physio is allowed, even though medically it does not help, and focus on that patient and informal caregiver together can decide on ventilation). This is part of the *decision talk* of Elwyn et al. (2012). Together, the choice, option and decision talk are represented, and according to the definition of Elwyn et al. (2012), shared decision-making is being practised in this fragment.

Another example of shared decision-making is the following fragment from book B5.

Because hospitals make him [patient] depressed, Fernando only did the necessary examinations. Until today. Because the food gets stuck in his throat more and more often and he has to cough loudly more and more often while swallowing, he no longer has a choice. It's time for tube feeding. A wise decision, according to the neurologist. 'If you have difficulty eating and drinking, this, of course, has consequences for your quality of life,' explains the neurologist. 'Because then you have less energy. Because if you don't eat or drink, you get a headache and feel

tired. A PEG probe would therefore be ideal'. Fernando clears his throat. "Yes, fine," he says. "Let's do that" (B5, p. 201).

According to Elwyn et al. (2012), shared decision-making is being practised here, as the three talks of Elwyn et al. (2012) are visible in this quote. The neurologist practices *choice talk* and offers the patient the option of whether to treat or not in the first place, saying that it is time for feeding, but the patient decides. In *option talk*, the neurologist provides support for decision-making by talking about the harms and benefits (quality of life and difficulties with eating and drinking). Lastly, *decision talk* is practised, as the neurologist moves to a decision but lets the patient make the final decision.

In these two examples, the informal caregiver is already slightly mentioned. Knowing now that shared decision-making is being practised for ALS patients, the next step is to shift to the exact involvement of the informal caregiver in shared decision-making, which will be discussed next, starting with the observation about saying 'we'.

4.1.4 Saying 'we'

Related to the role of the informal caregiver in shared decision-making, it is first noticeable that every author in every book who writes about care decisions says 'we' instead of 'I' or the patient's name. An example is provided below for clarification.

We immediately agree to this plan and Sjonny [patient] is admitted the next day so that he can learn how to use the device himself (B2, p. 21).

Saying 'we', instead of 'I' or 'him/her', when referring to the situation in the conversation that only includes the patient, creates a common understanding and the feeling that the informal caregiver and the ALS patient are one in the conversation. This also implies the close connectedness of the informal caregiver in the shared decision-making process. The question is then whether the informal caregiver suggests that the informal caregiver and the patient decide together or whether the informal caregiver and patient feel that they are present together in the meeting with the doctor.

Almost immediately after the diagnosis of ALS became known, Jos [patient] resolutely opted for euthanasia in the final phase of the disease. The situation may arise that Jos is ready, but the GP is not yet. In that case, she will refer us to another doctor. We have a lot of confidence in her and are familiar with her. We prefer not to have another doctor. In our next conversation we ask about this and fortunately this turns out not to be the case (B3, p. 113).

In the quote above, the informal caregiver talks about the connection she has with the patient's GP. Because of talking about feelings in this quote, the 'we' perspective claims a common understanding and a decision made together between informal caregiver and patient. This is not always the case.

We are going to discuss with Dr. Agatha whether Martin [patient] can receive a double dose of medication for the psyche. He had this medication in the past, when he was in a day admission in a psychiatric group (B4, p. 138).

In the quote above, the ‘we’ perspective is also included, but there is no sign that the decision is made in a close relationship between informal caregiver and patient. The ‘we’ seems to be used as a simple way to tell about a decision. Lastly, the quote below shows the close involvement of the informal caregiver in the treatment plan.

Within two weeks we were being treated at a rehabilitation centre (B7, p. 169).

In this quote, the informal caregiver writes about the treatment as if it is her treatment as well. This also shows the close involvement of the informal caregiver.

By saying ‘we,’ the informal caregiver means that the patient's wishes and desires are included. However, this does not mean that the wishes of the patient and informal caregiver always align. In some quotes shown in this result section, there is a difference between opinions, but the informal caregiver always supports the patient's decision.

4.2 Different roles

The ‘we’ can be used in different ways, indicating that the informal caregiver has different roles in the shared decision-making process for ALS patients. This relates to the second sub-question.

The informal caregiver can take different roles and is able to switch between them. The data analysis demonstrates that the informal caregiver's role mainly depends on the level of communication the patient can bring into the conversation. As ALS leads to progressive dysfunction (Oskarsson et al., 2018), patients lose their ability to speak. This is the same in all analysed books. The following quote is an example of the fact that physicians have difficulties understanding the patient and that the informal caregiver plays a crucial role in communication between the informal caregiver and the patient.

Diana [informal caregiver] has to stay with the surgery, not only for mental support, but also because of the fact that Martin [patient] is difficult to understand. Together, one word is enough (B4, p. 145).

The informal caregiver becomes crucial for communication and can act as a spokesperson, advocate or representative. However, in the first phase of the disease, patients still have the ability to speak. The informal caregiver then takes on a different role, either providing & receiving information to the patient or supporting the involvement & participation of the patient. These roles will be used as sensitising concepts and align with the roles found in the theoretical framework. In the text below, this differentiation in the ability to speak is made. In this differentiation, the roles are displayed arbitrarily. Later, it will become visible that roles are also more fluid, and that one informal caregiver can take multiple roles at different moments.

4.3 Able to speak

When the patient is still able to speak and communicate, the informal caregiver usually takes the role of *providing and receiving information* or *supporting the involvement and participation* of the patient. These two roles are elaborated on below.

4.3.1 Providing and receiving information

One role that the informal caregiver can have is *providing and receiving information*. This role is found in books B3 and B4. The other books do not have explicit examples of this role but show the role of *supporting the involvement and participation*. The role of *providing and receiving information* is found at the beginning of the disease period. As ALS is, for most informal caregivers and patients, a relatively unknown disease, being a cause for the need for information. The books show a difference in ways of *providing and receiving information*. Book B4 shows the need for information from the informal caregiver herself, as shown in the quote below.

In addition, Diana [informal caregiver] searches a lot of things about ALS on the internet and shares this with Martin [patient]. He indicates that he does not feel the need for this, he thinks that he lives so well with his illness and has asked her to leave him alone. Diana: "But that's about practical things, I read tips that are useful to him". But he also doesn't want to talk about the funeral yet (B4, p. 86-89).

In this quote, the informal caregiver searches for information, even though the patient clearly indicates that there is no need for this. The informal caregiver, on the other hand, thinks it is important for the patient to learn about valuable tips that he can use in daily life during the disease.

Book B3, on the other hand, shows the same role, but in this book, the patient is eager to receive as much information as possible about his disease, as the quote below shows.

'You most likely have ALS', the neurologist says two weeks later. In the past two weeks, Jos [patient] has received more and more information about what ALS entails. Now, he asks matter-of-factly how long he has left to live. Tears are rolling down my cheeks. Jos looks at me [informal caregiver] and continues to ask questions, seemingly calmly. (B3, p. 21). We have a huge need for information. Jos asks questions, and I [informal caregiver] answer them. I translate the medical jargon, from my background as an ex-physiotherapist, into Dutch so that he understands it and give him unsolicited information if I think he should know. I surf the internet, we get information, and I dive deep into the books. Jos wants to know what is in store for him (B3, p. 27).

The patient finds it difficult, but important, to obtain information, and the informal caregiver helps him with that. Furthermore, the medical background of the informal caregiver herself becomes relevant. Her medical experience helps her in this case to understand the information she finds, and it helps to inform Jos about his condition. This information is needed for Jos to participate later in the decision-making process to make informed decisions.

The informal caregiver's medical background is even more relevant in a later stage of the patient's disease, as the following quote from the same book shows.

After several minor complaints and a few weeks of physiotherapy, I [informal caregiver] advise Jos [patient] to consult with Paul, the physiotherapist, and to

have a second therapist perform a second opinion examination. I tell them that I'm worried and that I'm even thinking about ALS. I agree with Paul that he will examine Jos again. After his research, Paul calls me. He tells me his findings and shares my concerns. An appointment at the UMC Utrecht is not possible, so I make a round of calls to hospitals, and we can go to the Oudenrijn Hospital in Utrecht.

On June 27 we will be with the neurologist for the first time. We are referred to the laboratory and to an MRI. I ask him, while Jos is getting dressed, about the exact location of the front horn, an area in the spinal cord where things go wrong in ALS. The neurologist assesses my question and answers it by drawing a cross-section of the spine B3 (B3, p. 13-14)

In this quote, the medical background of the informal caregiver leads to an earlier diagnosis, as she is the first to think about ALS and persists in having a second examination. Even in the conversation with the neurologist, the informal caregiver points out that ALS might be the diagnosis. This, then, goes beyond the role of *providing & receiving information*, but only appears in book B3. The informal caregiver, furthermore, arranges the appointment in the hospital in Utrecht, which relates to a facilitating role. This role will be elaborated later in 4.5.

4.3.2 Supporting the involvement & participation

Whereas the role of *providing and receiving information* is more important for the patient to be informed and to participate in shared decision-making in the first place, the role of *supporting the involvement & participation* more directly forces the patient to participate in shared decision-making. In this role, the informal caregiver more directly pushes the patient into the decision-making process, for example, by saying things the patient can say later or making the patient think about arguments or other important things he may not forget.

Books B2 and B6 explicitly show this role of the informal caregiver, indicating that books B1, B5 and B7 neither show the role of *providing & receiving information* and *supporting the involvement and participation*. In books B1 and B7, the informal caregiver takes on the roles of *spokesperson, advocate or representative earlier*, either because this is preferred by the patient, or it is not explicitly described. Book B5 gives too little information about these two roles.

The quote below shows an example of *supporting the involvement & participation* of the patient in shared decision-making from book B2. In this quote, the informal caregiver is closely involved in the decision-making process, whether to get the stomach tube inserted already or not. Whereas both the informal caregiver and the patient are well aware of the need for this surgery, the patient still fears the surgery. In contrast, the informal caregiver tries to support both the need for the surgery and the patient's feelings.

A week before the operation in which a peg probe will be inserted, Sjonny [patient] and I [informal caregiver] have a conversation. He dreads the operation. Very much so. We're talking about how if he doesn't have it done, he won't be able to eat at a later stage. Sjonny is well aware of this. But he dreads the tube that goes down the throat to his stomach. I tell him, even at the very last moment, that he

can indicate if he doesn't want to. He is the only one who can and should decide about his body and his life. What an intense, difficult, painful conversation. Still, he stands by his decision: to get a surgery (B2, p. 48).

By telling the patient over and over again that it is his decision and pointing out the self-determination of the patient, the informal caregiver supports the involvement of the patient in the decision-making process, even when the outcome is not the outcome the informal caregiver wants. She describes the conversation as intense, difficult and painful, indicating the burden that informal caregivers might experience as an effect of decisions that need to be made.

The quote below is another example of *supporting the involvement and participation* of the patient in shared decision-making from the same book.

The nurse, Harry, starts talking about the peg tube. I [informal caregiver] am tempted to interrupt him, because this is all already in the report that the doctor has drawn up. Sjonny [patient] doesn't want it and as much as I regret that, I have to resign myself to it. However, Harry says that he knows what the report says, but since we agreed to be honest and open with each other during the first meeting, he still wants to talk about it. He tells Sjonny that his voice is still partially there and that it is not so bad, and he can still swallow. He also says that Sjonny himself had expected not to make it to Christmas. Sjonny nods. Then Harry asks him if he would like to starve, because if Sjon can't swallow anymore and doesn't want a peg probe, he starves. Harsh but true. He goes on about how the probe is placed and that any medication will be easier at a later stage. (B2, p. 45)

In this quote, the informal caregiver has another opinion on placing the stomach tube than the patient. The patient is in control and has a decisive voice in the decision-making process. It also shows that the informal caregiver does not always say what he wants to say, leaving space for the opinion of the patient and the formal caregiver.

Book B6 also shows this role in a decision whether to go to a hospice or to stay at home. The informal caregiver and her sister are convinced that their mother would like to go, but it turns out different, as the patient is in control in the quote below.

My mother [patient] didn't want the hospice. It's better to be stuffy and alert than to lose control. "She's in charge," the doctor said. My sister also thought that our mother would like the hospice. With a throwaway gesture, she made it clear that this really wasn't going to happen. Apparently, the care coordinator had already suggested it. So I decided to look for good volunteers who might be able to offer some extra support (B6, p. 21).

Both the roles of *providing & receiving information* and *supporting the involvement and participation* of the patient show that informal caregivers find it important that the patient stays fully aware and informed and participates in shared decision-making.

However, this does not mean that there is no interference with other roles. In the books, a pattern is found, in which the patient is first able to speak, and the informal caregiver takes one of the

roles mentioned above. However, as the patient loses the ability to speak, the informal caregiver usually unknowingly switches to other roles, which will be elaborated on down below.

4.4 Not able to speak

When the patient is not able to speak, the informal caregiver takes on the role of *spokesperson*, *advocate* or *representative*. This is arbitrary, as in all books, the patient is still able to communicate, but not on the level the patient could at the beginning of the disease. The patient uses a speech computer or another technological appliance to communicate. This, however, takes too much time or is too exhausting for the patient, so the informal caregiver takes over the conversation and takes on one of the roles discussed below. This also means that, for example, the role of spokesperson also consists of elements of *providing and receiving information*, a role that has been discussed before. However, in the role of spokesperson, the informal caregiver is the actor who talks to the physician. In contrast, in the role of *providing and receiving information*, the patient is the actor who talks to the physician.

Furthermore, roles are interchangeable and depend on the situation. As mentioned earlier, the role of the informal caregiver can change based on the setting, which includes the severity of the illness and physical locations are included. This leads to the same books used in different roles. Still, all books are represented in the roles below, indicating that it is essential for an ALS patient to have an informal caregiver who can speak on their behalf, as they are themselves less able to communicate.

4.4.1 Spokesperson

When the informal caregiver takes on the role of *spokesperson*, the patient is present in the shared decision-making process. Although the patient makes most of the arguments, the informal caregiver is the person who talks. This role becomes visible in books B1, B2, B3, and B5.

The first example of the role of *spokesperson* is the quote below.

Jos [patient] was struck down by pneumonia in the weeks that followed. We discuss with the GP what the options are for administering oxygen. We wonder what the effect will be. While we [the GP and the informal caregiver] are talking, Jos shakes no and the possibility for the time being, just as he previously rejected the possibility of artificial respiration. A few days later, after I had a telephone consultation with the GP on duty, I give extra morphine again (B3, p. 119).

In this example, the informal caregiver is having the conversation with the GP. The patient is present, but can only shake his head to indicate his opinion. The informal caregiver then implicitly assigns herself the role of *spokesperson* because the patient can no longer express himself properly when talking to people other than his caregiver. When talking to the informal caregiver, this problem does not exist that much. Jos is still clear-minded but can no longer express himself properly. The caregiver then acts as a *spokesperson*, in which the caregiver expresses the patient's wishes and questions. In this way, the caregiver then tries to ensure that the patient's wishes are included and enhances the patient's self-determination. Also, in this

quote, a facilitating role becomes visible, as the informal caregiver is the one who connects with the GP on the phone.

Another example of the role of *spokesperson* is the quote below from book B2.

The speech therapist calls to ask how Sjonny [patient] is doing, and whether he already uses the speech computer a lot. I [informal caregiver] tell her that Sjonny is currently using the iPad on loan. She also asks me about Sjonny's food and drink, if he often chokes. 'A little more than before', is my reaction. She indicates that all the food will soon have to be ground. To avoid choking when drinking, Sjonny can then use thickener. You then drink coffee at custard thickness. I will pass it on to him, but here too I have my doubts. When I walk up to Sjonny a little later and tell him what was said in the conversation, he looks at me with a look like 'are you serious?'. The thickener is indeed refused (B2, p. 44).

In this example, the informal caregiver and the speech therapist have a phone call about the progression and how things are going. The speech therapist indicates that a decision regarding the ability to eat needs to be made. The informal caregiver finishes the conversation, in which the patient is not present, and informs the patient about the conversation. The patient then makes the call to refuse the thickener, which the informal caregiver communicates later. This is typical for the role of *spokesperson*, in which the informal caregiver leaves the decision to the patient.

4.4.2 Advocate

In the role of *advocate*, the informal caregiver speaks on behalf of the patient, with the patient present in the decision-making process. In contrast to the role of *spokesperson*, the informal caregiver makes his own argument, on behalf of the patient. These roles are explicitly visible in books B1, B2 and B4. An example is the quote below.

'I'm just saying, maybe it's important', says Saskia [informal caregiver], 'Ben's carbon dioxide amount is higher than normal according to the CTB. 'That's certainly important!', says the gastro in surprise. 'The rehabilitation doctor didn't write anything about that'. She turns to Ben: 'Would you like an anaesthetist just to be sure?'. Yes, Ben nods. It visibly reassures Ben (B1, p. 116).

This quote describes a situation when a patient is preparing for surgery. The informal caregiver remembers something from earlier and mentions this. By doing that, the outcome of the decision-making process changes and an anaesthetist is added to the upcoming surgery.

Another example of the role of *advocate* is the storyline below. The patient and informal caregiver plan to go on holiday, but the pulmonologist does not agree. Without the interference of the informal caregiver in the decision-making process, the patient would not have been able to go on holiday.

Then the doctor pronounces his verdict: 'As a pulmonologist, I would advise you not to take this flight in your condition. At an altitude of 10 km, the air is much thinner, in a normal state you will breathe faster. The question is whether Sjonny can do this'. We look at him in shock.

Early the next morning, I call the UMCG, home ventilation department. I am very quickly put through to the pulmonologist in question. He emphasizes once again that flying is not an option for Sjonny. However, he offers a solution: Sjonny can be admitted in the hospital the next day for almost a week, to be put on respirators. This equipment can then be taken with him during the flight, so that Sjonny gets help from the device if breathing becomes too difficult. Tears come to my eyes. How nice that this doctor understands how important this trip is for our family. We immediately agree to this plan and Sjonny is admitted the next day so that he learns to use the device himself (B2, p. 21).

The informal caregiver takes the role of advocate and tries to find ways to go on holiday either way.

4.4.3 Representative

When taking the role of representative, the informal caregiver acts in absence of the patient. This could either be because of practical reasons, the informal caregiver could be at work for example, or because the patient is not able anymore to address issues related to decision-making.

Ben is undergoing some more tests. The rehabilitation doctor calls Saskia at work about the results. "There are signs in the blood that Ben is compensating, and that the quality of his breathing is deteriorating. I think it's time for a probe'. 'But isn't the vital capacity taken into account in a peg probe?', Saskia asks. 'No, it's a combination of capacity and blood gas analysis'. In the evening, she can retell the conversation almost verbatim to Ben. He is very shocked, says: 'It's going very fast all of a sudden'. The next day they both go back to work. Saskia calls the gastro department and explains that Ben is not yet ready for the peg probe. 'Then it won't happen', the assistant simply says (B1, p. 95).

In this quote, the patient is not present during the conversation, as the informal caregiver is at work. As a representative, the informal caregiver passes the information on to the patient on a later moment. The informal caregiver then gives space to the patient to make a decision, and announces the decision made herself.

We discuss with your GP what the options are for administering oxygen. We wonder what the effect will be. While talking, Jos rejects the possibility for the time being, just as he previously rejected the possibility of artificial respiration. A few days later, after a telephone consultation with the GP on duty, I give extra morphine again (B3, p. 119)

Taking the role of representative may also be without the inclusion of the patient, as the following quote shows.

Because the symptoms of ALS seem to be gaining momentum, I called the neurologist, worried as I was, to ask what precautions I should take for our trip through America and Canada. What deterioration do I have to take into account? Does it make sense to have a wheelchair ready? (B3, p. 29).

In this quote, the informal caregiver calls the neurologist on her initiative without consulting the patient. This is typical for the representative role, as the patient is not involved in this role. The informal caregiver takes on this role because of her concerns in this quote. She fears the consequences of not asking for precautions, afraid she cannot deliver the care needed when on holiday. This relates to the informal caregiver's responsibility and the responsibility the informal caregiver feels in shared decision-making, afraid to make the wrong decision. This will be elaborated on in 4.6.

4.5 A facilitating role

This last role of representative also slightly relates to an earlier mentioned, but not elaborated on, role, the facilitating role. This role is not mentioned in the theoretical framework but is additionally found in the informal caregivers' books. This role involves the facilitation of shared decision-making. For example, maintaining contact with different formal care institutions and being a coordinator for practical care decisions. Also arranging meetings and providing logistical support are part of this role. These actions ensure that shared decision-making takes place, whether the patient is directly involved or not.

Another example of this facilitating role is the following text fragment, in which the informal caregiver and the formal caregivers are looking for a place to stay for her husband after admission to the hospital due to emergency reasons.

One hospice calls: between 07:00-09:00 and between 13:00-15:00 there is no nurse present. 'Let's hope Ben [patient] doesn't just get a shortness of breath attack at that time', Saskia [informal caregiver] says. Their buddy calls, another hospice comes by. But without an appropriate indication, Ben can't go there. The home care calls, they want to know what the conclusion of the hospice is. Maybe they can do something for Ben?

'The regulations in healthcare are obstructive', the manager of the Leiden hospice calls. "I'm going to do my very best to be able to take Ben in. It is a special clinical disease, what your husband has'. Everyone is surprised by the regulations. For health insurance, the hospital is more expensive than a hospice, but apparently it cannot be arranged. Networking is used, Saskia understands. It turns out that Ben does not have supplementary insurance for the hospice. Saskia just lets it all happen, doesn't put any pressure on it at all. Ben is in a good place here and they won't just send him home, she thinks (B1, p. 205)

Later on, in the same storyline, the informal caregiver is advised by a nurse to call the Zorgkantoor herself.

'You don't have to, but it could be beneficial for your husband, personal contact'. Saskia calls immediately. The lady on the other end of the line immediately knows who she is when she says her name. "We are very concerned about your husband's situation, and don't know what to do." (B1, p. 222).

This storyline consists of multiple aspects. The informal caregiver is not primarily involved in the decision-making process, as the nurses are trying to find a solution where the patient can

stay after admission. In fact, the informal caregiver and patient does not seem to be in such a rush as the nurses, as they are quite content with the current admission in the hospital. The coordinating aspect lays in the fact that the informal caregiver is constantly informed about possible options, all steps taken and why they did not succeed yet in finding a new place, and even has a decisive say, as the informal caregiver can reject options, as the following quote in the same storyline points out.

Hoofddorp [the proposed is so far away, now I can cycle to my husband. Is there no place for him in Leiden, do you think?' 'I agree with you that he should be able to stay in Leiden and advise you not to accept Hoofddorp.' 'Wouldn't that have any adverse consequences for my husband?'" 'No, I can promise you' (B1, p. 222).

This quote also puts a decisive voice on the role of the informal caregiver, as the informal caregiver can reject options that are proposed by formal care. This shows that the coordinating role is so an extensive role, even more extensive than addressed here, and necessary to accommodate shared decision-making in the first place. This is also seen in earlier mentioned quotes, in which the facilitating role overlaps with another role. For example, the informal caregiver mostly is the person who calls the formal care, in order to facilitate the shared decision making. The quote in 4.4.2 from book B2, p. 21, is such an example.

4.6 Influence of the informal caregiver

Some quotes above show the importance of the informal caregiver in the shared decision-making process. Not only because informal caregivers give a voice to patients, who can no longer communicate effectively with the physicians, but also because they impact the decisions that are made.

In the quote from book B3 in 4.3.1, the medical background of the informal caregiver influenced the diagnosis phase, as the informal caregiver already had a suspicion of ALS and steers the neurologist in that direction.

Another example is the quote mentioned in book B2, mentioned in 4.4.2, concerns the decision whether to go on holiday. Without the persistence of the informal caregiver, the pulmonologist would not have come up with a solution to go on holiday, leading to sadness by both the informal caregiver and the patient for not going or leading to severe risk to patient when going either way. The same is seen in a quote of book B3 in 4.4.3, in which the informal caregiver took the responsibility to call the neurologist herself, to discuss possible precautions for their holiday.

These are examples of the influence that an informal caregiver can have in the decision-making process. In these examples, the informal caregivers feel a high responsibility for the patient. Not only regarding shared decision-making but moreover for the entire care path of the ALS patient. This feeling of responsibility can lead to burdens, which are discussed next.

4.7 Burdens

Informal caregivers experience burdens when caring for ALS patients. This indirectly relates to shared decision-making and the research questions, as informal caregivers can only participate in shared decision-making when their well-being is sufficiently good. However, this is not the main research subject, but it relates to the societal relevance of this study and is elaborated upon. Two quotes are given below; the first is more about burdens in general, and the second relates to the ability to participate in shared decision-making.

After Jos [patient] got a TIA, which fortunately is unrelated to the ALS, I don't sleep with Jos for five weeks and I recover completely. My goal is to enable Jos to do what he wants as much as possible, and to stay fit so that I can continue to take care of him optimally and pay attention to the children (B3, p. 96).

In this quote, the informal caregiver only realizes after a threatening event that she is exhausted and needs five weeks of good sleep to recover. This indicates that being an informal caregiver requires a lot from them and that they need to be adequately supported so they do not lose the ability to care for their patient. The following quote aligns with this but also discusses the fear that an informal caregiver can experience.

Jan [patient] was rushed back to the hospital after an acute choking. Jan needs a lot of care, but I [informal caregiver] also clearly ask for support. At the moment I don't dare to take responsibility for taking care of Jan at home. The fear is huge in my body. The hospital has taken a close look at this and is taking it well. At the moment I can listen to a lot and also let go of a lot: is taken care of (B7, p. 106).

In this quote, the informal caregiver fears to give the patient the care he needs, as she feels she cannot provide adequate care without a medical background. In this case, the hospital acknowledges her fear and starts to take care of the informal caregiver, as well as taking over some elements of the facilitating role found for informal caregivers.

4.8 Need for informal caregiver support

The results show that shared decision-making is practised by formal care and that the informal caregiver experiences shared decision-making as such. The informal caregiver then has different roles, depending on the current circumstances of the decision-making (ability to speak of the patient and the circumstances, such as location). Furthermore, the informal caregiver has a facilitating role in shared decision-making. The informal caregiver ensures that appointments are made and maintains contact with all 'stakeholders' involved. Combining this leads to the conclusion that the informal caregiver is almost essential for ALS patients in shared decision-making.

The burdens that informal caregivers experience add an extra layer to this. The quotes above show that informal caregivers sometimes fear that they cannot deliver the needed care and are so unable to participate in shared decision-making anymore. This, then, again shows the need for policy support for informal caregivers to prevent them from falling out and leaving the patient alone.

5. Discussion and conclusion

This research aimed to answer the question: *What are the roles of informal caregivers in shared decision-making in care decisions for patients with Amyotrophic Lateral Sclerosis (ALS)?* Two sub-questions were distinguished to answer this research question. These questions help to identify the roles of informal caregivers of ALS patients in shared decision-making. The informal caregiver has a lot of responsibility, but these roles are not yet researched in literature, as described in the introduction, and little policy attention is given to the role of informal caregivers in the appropriate care framework of Zorginstituut Nederland (2022). Identifying these roles can help develop future policy and support for informal caregivers. These questions will be discussed below.

The first sub-question is about what shared decision-making looks like in practice for informal caregivers of ALS patients. Shared decision-making is practised in all books written by informal caregivers. Elwyn et al. (2012) defined three *talks* to define whether shared decision-making is being practised, from the physician's perspective. According to this definition and the *talks*, shared decision-making is being practised in each book. However, the way in which informal caregivers are involved differs per book, but informal caregivers of ALS patients are closely involved in shared decision-making processes. This is seen when writing about care decisions; informal caregivers almost exclusively write about 'we' instead of writing about the patient or he/she. The informal caregiver will always put the wishes and desires (and so the self-determination of Zorginstituut Nederland (2022) of the patient upfront, even though the informal has a different opinion. The patient remains in control and has a decisive voice in shared decision-making, leading to emotional effects. For example, the informal caregiver in book B2, p. 48, is also mentioned in the results. In this quote, the informal caregiver keeps pushing on the fact that the patient can still decide not to get the surgery for stomach tube insertion, even though she knows how much this is needed. She describes the conversation as intense, difficult and painful, indicating the burden that informal caregivers might experience.

The second sub-question relates to the informal caregiver's role in shared decision-making. In the theoretical framework, five roles were distinguished and used as sensitizing concepts to organize the data. However, a sixth role, the facilitating role, is also found in the data. In this role, the informal caregiver ensures that shared decision-making can take place. All roles will be elaborated on below.

The roles used as sensitizing concepts are all found in the data. When the patient is still able to communicate and speak with the formal caregivers, the informal caregiver usually takes the role of *providing & receiving information* and *supporting the involvement & participation* of the patient. Regarding to *providing & receiving information*, the informal caregiver also has a role in finding medical information regarding the disease. For all informal caregivers and patients researched, ALS is a relatively unknown disease, and there is a need for information after the diagnosis is made. The informal caregiver is usually the person that provides this information, but does not only rely on the information from the formal caregiver, but also on information found on the internet or, in one book, the medical knowledge obtained in the

medical background of the informal caregiver. This impacts decisions as well, as the decision is made based on obtained information.

When the patient is not able to communicate with formal caregivers, other roles of the informal caregiver in shared decision-making become visible, the informal caregiver then takes the role of *spokesperson*, *advocate* or *representative*. Depending on the setting at a specific moment, the informal caregiver takes on one of these roles. The setting then may vary because of physical location (the informal caregiver may act as contact person, but is not physically near the patient, which leads to the role of spokesperson) or medical condition of the patient (the ability to communicate with the informal caregiver varies per situation), but all roles are visible in the stories of informal caregivers.

These variables (whether the patient is able to communicate or not and the setting) align with Rennke et al. (2017). In their conceptual model, the level of involvement of the family depends on the other dimension, including the medical condition, and this might change over time, as the medical condition can change during the disease, and most certainly does for ALS patients (Oskarsson et al., 2018).

In the theoretical framework, the roles mentioned earlier are found. Kraun et al. (2022) & Allen et al. (2017) found the roles of *spokesperson*, *advocate* and *representative*. Dyrstad et al. (2015) and Kraun et al. (2022) found the roles of *providing and receiving information* and *supporting the involvement and participation* of the patient in shared decision-making, but did not elaborate that much on these roles. Furthermore, these roles are found in elderly care and are thus written about elderly people. This research adds the application of these roles in another patient group, ALS patients, to existing literature and adds another role to the literature, the facilitating role.

Although the roles of informal caregivers of ALS patients in shared decision-making are not yet described in literature, these roles did become visible in the stories of informal caregivers of ALS patients, but not in an either/or form. Informal caregivers take on multiple roles and can switch roles depending on the situation.

As a final role, the facilitating role needs attention. The facilitating role is not a role that is described as sensitizing concept, but it is an additional role found in the stories of informal caregivers. In this role, the informal caregiver arranges appointments and maintains contact with formal caregivers. As the facilitating role is also present for patients who are not able to communicate anymore, the informal caregiver is usually a contact person between formal caregivers and the patient. The informal caregiver can then be, for example, a spokesperson when the patient is present, but can also be a representative, when the informal caregiver is being called when the patient is not present. During all roles and stages of the disease, the patient's self-determination is the most important aspect for informal caregivers, as they try to align with the patient wishes and communicate everything they discuss with formal care to the patient.

It can be doubted whether this facilitating role is a role in shared decision-making, or whether this is a role that makes shared decision-making possible in the first place. Nevertheless, it is a role that all informal caregivers write about. For ALS patients, it is even crucial to have someone

taking that role for them, as the ability to communicate fades as ALS progresses. This, then, can also be applied to other patient/informal caregiver groups, other than ALS, for diseases in which the ability to communicate also fades.

Dyrstad et al. (2015) also report about an experienced feeling of loss of control of elderly people or insufficiently involvement of elderly people in the decision-making process. These feelings are not found in the stories of informal caregivers. An important sidenote to that claim is that the books analysed in this research are written from the perspective of the informal caregivers and not from the perspective of the patient, who are more likely to report on such feelings than informal caregivers.

5.1 Policy implications

In the appropriate care framework of Zorginstituut Nederland (2022) the role of the informal caregiver is barely mentioned, especially not related to shared decision-making. This research shows the importance of informal caregivers for ALS patients in shared decision-making and in facilitating shared decision-making with the ALS patient. The informal caregiver always puts the patient's self-determination upfront, leading to conflicts between experienced responsibilities and burdens. Only in one quote the informal caregiver experienced support from the hospital (B7, p. 106).

This research then shows that more attention should be given to the informal caregiver in the policy context to provide more support for informal caregivers and recognition of their importance. This could be accomplished by creating policy support for physicians to ensure that attention is given to the informal caregiver and prevent them from experiencing burdens and losing the ability to fulfil other caring tasks. This underscores the conclusion of Foley & Hynes (2017) that too little policy attention is given to the participation of family members in shared decision-making. At the same time, this study does provide some more insights into how informal caregivers are involved in decision-making by taking the roles of Kraun et al. (2022) and Dyrstad et al. (2015) to informal caregivers of ALS patients.

5.2 Reflection on the role of the researcher

The role of the researcher is particularly important when conducting narrative research, as the researcher interpreted the books written by informal caregivers. It is relevant to notice that the researcher has no experience with ALS and has never been in contact with a patient diagnosed with ALS. This might cause interpretation biases, as the researcher aimed to make meaning out of the written books and storylines. When analysing, quotes are used to substantiate the meaning found by the researcher. All narrative analyses are included in the appendix to provide full transparency in the research process.

5.3 Strengths/limitations and recommendations

This study combines the roles of informal caregivers in shared decision-making that are found in literature about elderly care with the experiences that are written down by informal caregivers of ALS patients. These informal caregivers of ALS in specific are used as a case of informal caregivers in general for patients that have difficulties in communicating. By combining these two aspects, this study contributes to obtaining knowledge about the exact role of informal

caregivers in shared decision-making, that can contribute to forming new policy about informal caregivers in the Netherlands, as there is a gap between the importance of informal caregivers in the Netherlands and the policy regarding to this subject, represented by the appropriate care framework of Zorginstituut Nederland (2022).

A limitation is that this study is conducted by reading only 7 books, which decreases the generalizability of this study. This is not a problem, as this study only aims to explore the different roles informal caregivers have in shared decision-making. Furthermore, no more books were available in the database of *patientervaringsverhalen.nl*, as three more books are included that were already not in this database, making it less possible to include enough books for generalizability from the Dutch perspective. Also, not all books provided the same amount of information regarding decision-making, leading to the over- and under-representation of some books in this research.

Furthermore, five books are written by the informal caregiver and two books are written about the informal caregiver, leading to two different perspectives on the same issue. From the two books written about the informal caregiver, as much as possible quotes are used that are directly coming from the informal caregiver, and are not the interpretation of the author, but any interpretation bias by the author of the book cannot be ruled out.

Another limitation of this study is that only the perspective of the informal caregiver is included, and the perspective of the ALS patients or formal caregivers is not incorporated. Then, for example, the conclusion that ALS patients do not experience a feeling of loss of control or are not insufficiently involved in shared decision-making is biased, because of the missing perspective. Incorporating these perspectives could lead to a more extensive review of the role of the informal caregiver in shared decision-making, but was not the focus of this research. Further research could research that perspective as well and combine these perspectives into one research, leading to an integrated research that can contribute to both literature and policy frameworks.

6. References

- Allen, J., Hutchinson, A., Brown, R., & Livingston, P. (2017). User experience and care for older people transitioning from hospital to home: Patients' and carers' perspectives. *Health Expectations*, 21(2), 518-527. doi:10.1111/hex.12646
- Andersen, P., Abrahams, S., Borasio, G., Carvahlo, M. d., Chio, A., Damme, P. V., & etal. (2012). EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)-revised report of an EFNS task force. *Eur J Neurol*, 19:260-75. doi:10.1111/j.1468-1331.2011.03501.x.
- Bate, P., & Robert, G. (2006). Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Qual Saf Health Care*, 15:307-310. doi:10.1136/qshc.2005.016527
- Byrne, K., Orange, J., & Ward-Griffin, C. (2011). Care Transition Experiences of Spousal Caregivers. *Qualitative Health Research*, 21(10), 1371-1387. doi:10.1177/1049732311407078
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med*, 49(5), 651-661.
- Condon, L. (2019). How patient stories can improve health services around the world. *Health Expectations*, 22(5), 837-837. doi:10.1111/hex.12987
- Dyrstad, D., Laugaland, K., & Storm, M. (2015). An observational study of older patients' participation in hospital admission and discharge - exploring patient and next of kin perspectives. *Journal of Clinical Nursing*, 24(11-12), 1693-1706. doi:10.1111/jocn.12773
- Elwyn, G., Frosch, D., R, T., Joseph-Williams, L. A., Kinnersly, P., Cording, E., . . . Barry, M. (2012). Shared Decision Making: A Model for Clinical Practice. *Journal of General Internal Medicine*, 1361-1367. Retrieved from 10.1007/s11606-012-2077-6
- Foley, G., & Hynes, G. (2017). Decision-making among patients and their family in ALS care: a review. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 19(3-4), 173-193. doi:10.1080/21678421.2017.1353099
- Gauthier, A., Vignola, A., Calvo, A., Cavallo, E., Moglia, C., Sellitti, L., . . . Chiò, A. (2007). A longitudinal study on quality of life and depression in ALS patient-caregiver couples. *Neurology*, 68(12), 923-926. doi:10.1212/01.wnl.0000257093.53430.a8
- Hanson, A. (2017). Negative Case Analysis. *The International Encyclopedia of Communication Research Methods*, 1-2. doi:10.1002/9781118901731.iecrm0165
- Klerk, d. M., Boer, d. A., Kooiker, S., Plaisier, I., & Schyns, P. (2015). *Informele hulp, wie doet er wat. Omvang, aard en kenmerken van de mantelzorg en vrijwilligerswerk in de zorg en ondersteuning in 2014*. Den Haag: Sociaal en Cultureel Planbureau.

- Kooiker, S., de Jong, A., Verbeek-Oudijk, D., & de Boer, A. (2019). *Toekomstverkenning mantelzorg aan ouderen in 2040*. Den Haag: Sociaal en Cultureel Planbureau.
- Kraun, L., De Vliegheer, K., Vandamme, M., Holtzheimer, E., Ellen, M., & van Achterberg, T. (2022). Older peoples' and informal caregivers' experiences, views, and needs in transitional care decision-making: a systematic review. *International Journal of Nursing Studies*. doi:10.1016/j.ijnurstu.2022.104303
- Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *BMJ*, 50-52.
- McKim, D., King, J., Walker, K., Leblanc, C., Timpson, D., Wilson, K., . . . Woolnough, A. (2012). Formal ventilation patient education for ALS predicts real-life choices. *Amyotroph Lateral Scler*, 13(1), 59-65. doi:10.3109/17482968.2011.626053
- Mockford, C., Jenkinson, C., & Fitzpatrick, R. (2006). A Review: Carers, MND and service provision. *Amyotrophic Lateral Sclerosis*, 7, 132-141. doi:10.1080/14660820600601028
- Murray, M., & Sools, A. (2014). Narrative Research in Clinical and Health Psychology. In A. Lyons, & P. Rohleder, *Qualitative Research in Clinical and Health Psychology* (pp. 133-152). Palgrave Macmillan.
- Nolan, M., Kub, J., Hughes, M., Terry, P., Astrow, A., Carbo, C., & etal. (2008). Family health care decision making and self-efficacy with patients with ALS at the end of life. *Palliat Support Care*, 6, 273-280.
- Nowell, L., Norris, J., White, D., & Moules, N. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*, 16, 1-13. doi:10.1177/1609406917733847
- Oskarsson, B., Gendron, T. F., & Staff, N. (2018). Amyotrophic Lateral Sclerosis: An Update for 2018. *Mayo Clinic Proceedings*. doi:10.1016/j.mayocp.2018.04.007
- Politi, M., & Street, R. (2010). The importance of communication in collaborative decision making: facilitating shared mind and the management of uncertainty. *Journal of Evaluation in Clinical Practice*, 17(4), 579-584. doi:10.1111/j.1365-2753.2010.01549.x
- Rennke, S., Yuan, P., Monash, B., Blankenburg, R., Chua, I., Harman, S., . . . Satterfield, J. (2017). The SDM 3 Circle Model: A Literature Synthesis and Adaptation for Shared Decision Making in the Hospital. *Journal of Hospital Medicine*, 12(12), 957-1023. doi:10.12788/jhm.2865
- Rijksoverheid. (2024). *Hulp voor toenemend aantal mantelzorgers*. Retrieved from Rijksoverheid: <https://www.rijksoverheid.nl/onderwerpen/mantelzorg/hulp-voor-toenemend-aantal-mantelzorgers>
- Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, 304-310. doi:10.1111/j.1365-2648.2006.03727.x

- Shay, L., & Lafata, J. (2014). Understanding patient perceptions of shared decision making. *Patient Education and Counseling*, 96, 295-301. doi:10.1016/j.pec.2014.07.017
- Siminoff, L. (2013). Incorporating patient and family preferences into evidence-based medicine. *BMC Med Inform Dec Mak*, 13(Suppl 3):S6.
- Stichting ALS Nederland. (2024). De ziekte ALS. Stichting ALS Nederland. Retrieved from https://www.als.nl/wp-content/uploads/2021/06/StichtingALS_infographic_Wat-is-ALS_v3_compressed.pdf
- Ubel, P. A., Scherr, K. A., & Fagerlin, A. (2018). Autonomy: What's Shared Decision Making Have to Do With It? *The American Journal of Bioethics*, 18(2), W11-W12. doi:10.1080/15265161.2017.1409844
- van de Bovenkamp, H., Platenkamp, C., & Bal, R. (2020). Understanding patient experiences: The powerful source of written patient stories. *Health Expect*, 717-718. doi:10.1111/hex.13053
- Zorginstituut Nederland. (2022). *Kader Passende zorg*. Zorginstituut Nederland.

7. Appendix: narrative analyses

In this appendix, all narrative analyses are displayed. This provides full transparency in how this research is conducted.

1. Komt een man bij de dokter – Saskia Zandvliet (B1)

1.1 I. Book characterisation

1.1.1 Overall impression of the book

This book describes Ben's last years. Ben is diagnosed with ALS and suffers from this disease. Saskia is his wife and informal caregiver. Saskia wrote this book about her experiences. However, she wrote this book in third person about herself. As a reader, this gets confusing sometimes, as she is referring to her and Ben as *them* and to herself as *she*. The book consists of lots of dialogues, between her and Ben, but also with all different caregivers. She also has nicknames for most of them, which is also confusing for the reader. She talks, for example, about the hippie and the ski instructor, while referring to nurses.

1.1.2 Target audience

All revenues of this book go to Stichting ALS. Saskia writes this book to honor Ben and to write off the story to process all that she went through in Ben's disease. Mentionable is that the book is published in 2023, whereas Ben died in 2011, indicating that Saskia took a long time to process and be able to write the book.

1.2 II. Main storyline

1.3 Narrative summary

"Your husband has nothing wrong with his throat, madam," says the ENT specialist wryly. Saskia immediately takes over the conversation while she continues to look at him. We come back in and say, 'Good afternoon!'. Stunned, the doctor looks at her as she tells her story. The doctor's gaze changes during her story. "I'll send you to the pulmonologist," the doctor says. 'After that, speech therapy seems best to me. All my colleagues come to the same conclusion: there is nothing abnormal to be observed, but I am not entirely reassured' (p. 9).

After a series of examinations, Saskia calls the Leiderdorp hospital. She calls herself Mrs. Rutten, normally she always uses her own surname. She will be called back. The research results should have been sent to Utrecht for further research in a specialised centre. 'I just call Utrecht myself and ask if the forms have arrived', she says to Ben (p. 38). A few weeks later, the diagnosis comes: ALS. 'ALS is rare', the GP begins. 'You're at the beginning of the disease', he explains, 'and you can't just suffocate'. A relief for Ben. The GP talks about the possibility of euthanasia. He has experience with it himself, is an assessing doctor. 'That's not an issue yet', he soothes at the same time. 'That's something for the future. Things may turn out differently than you think now' (p. 46).

Exactly four weeks later, the second diagnosis follows at the ALS center in Utrecht. The doctor confirms the earlier result from Leiderdorp. This means that the diagnosis of ALS must indeed be made. Ben and Saskia look at each other..., touch each other.. sit down for a while.... They don't know what to ask. 'What's the best advice you can give us?', Saskia asks. 'The best thing to do is just pick up where we left off. You don't have to stay at home.' (p. 58). A week later, the next interview will follow. The doctor reports that Ben should be on a ventilator in the not too distant future and will need a peg stomach tube. Ben's lung function is too low and his respiratory function has decreased. Ben has too little carbon dioxide in his blood, a theme that will continue to emerge throughout the book. They will be referred to the Centre for Home Ventilation (CTB). They have never heard of it (p. 66).

CTB has given Ben a letter that he belongs to a risk group and is therefore recommended a coccus vaccine. For that, they go to the GP. They briefly speak about euthanasia. Because it's important to talk about these kinds of things while Ben is still good at talking, Saskia thinks it's appropriate. She first consulted with Ben that morning, but he hardly gives a damn. The GP says that it is more of a legal document and that it takes about two weeks to arrange things. Saskia decides to leave it at that and not bring it up again (p. 86).

A peg tube and ventilation will be arranged in the following months. Ben has been hospitalized several times for this. Saskia tells her GP that she doesn't want to talk about euthanasia anymore. 'I find it very confronting. Because we may have to decide in the end. I don't want to and can't do that' (p. 156).

That ventilation seems to be desperately needed. A few weeks later, Ben wants to go back on a ventilator in the morning. He is short of breath and looks pale. In the car, it seems to be less. It's just a short car trip. When Saskia helps him fasten his pants after the toilet, Ben holds on to both sides. The mucus is stuck in his throat. At half past four, Ben wants Saskia to call the doctor's office and the doctor arrives a few hours later with an ambulance lady. She thinks Ben has pneumonia and wants Ben in the hospital. 'No', Ben responds shocked. 'I go mad when I don't have freedom of movement' (p. 185).

The GP comes. Ben's lungs are good and so is his heart rate. Ben himself starts talking about euthanasia and Saskia is already crying. The GP says to Saskia: 'You shouldn't look at it so gloomy! It's just something you sign and put away. It is not yet on the agenda. You don't have to be so emotional about it.' So let's get emotional, Saskia thinks, it just makes me cry. The GP promises to come back on Monday (p. 190).

Ben suffers from acute oxygen deficiency and is admitted to the hospital for this. Here it is decided that it is not possible to take care of Ben back home due to his care needs. Ben ends up in a hospice, the Gasthuis. Ben will lie here for exactly one year, before he dies due to palliative sedation.

1.4 Storyline 1: PEG stomach tube

Ben is undergoing some more tests. The rehabilitation doctor calls Saskia at work about the results. "There are signs in the blood that Ben is compensating and that the quality of his breathing is deteriorating. I think it's time for a stomach tube'. 'But isn't the vital capacity of a

stomach tube taken into account?', Saskia asks. 'No, it's a combination of capacity and blood gas analysis'. In the evening, she can retell the conversation almost verbatim to Ben. He is very frightened, says: 'It's going very fast all of a sudden' (p. 95). The next day they both go back to work. Saskia calls the gastro department and explains that Ben is not yet ready for the peg stomach tube. 'Then it won't happen', the assistant simply says. "What I know is that your husband has recently been diagnosed with ALS and that the feeding tube is being placed as a precaution. Then that's probably done'. "For my husband, every month, every week, and every day is a bonus if something can be postponed. He dreads this so much that I want to do my best for it. And no one can tell us why it has to be done now'. 'I can imagine that. We'll keep your husband's pace," the assistant responds. 'We're going to schedule it later' (p. 114).

After their holiday, 20 letters and e-mails were received about the peg probe. Ambiguity everywhere. Such as the phrase 'in principle, the hospital or the general practitioner arranges the district nursing'. Who is taking care of it now? And how do you find out? Saskia is quickly many phone calls further, everyone refers to each other. Imagine, you'll live alone, be older, and be upset like Ben. You are at the mercy of the gods (p. 115)!

A month later, they are back at the gastroentologist. She is very friendly and understanding of Ben. She was finally able to explain to them why it is necessary for the probe to be placed. And it makes so much sense when they hear her statement. But no one has been able to tell them before..., not a neurologist, general practitioner, rehabilitation doctor or nurse! The gastro tells us that she prefers to apply the tube with a sedation. But when that buzz wears off, you have to start breathing again. You have to be able to do that. Later in the disease, this is all a bit more difficult, because the respiratory muscles function less well. That explanation makes it easier for Ben to accept. It's just necessary. The gastro takes all the time for them. With great difficulty, Ben types that he is afraid that he will end up in the recovery room opposite the waiting room of the scopy. Afraid that the alarm will keep going off and the nurse will say sternly: 'You have to breathe well, otherwise the alarm will go off'. This is what he experienced when he came in for a scopy a few months ago. 'You stay overnight and you are watched in a room other than the corridor until you are completely recovered', says the gastro. Another relief for Ben.

'I'm just saying, maybe it's important', says Saskia, 'Ben's carbon dioxide content is higher than normal according to the CTB. 'That's certainly important!', says the gastro in surprise. 'The rehabilitation doctor didn't write anything about that'. She turns to Ben: 'Would you like an anaesthetist just to be sure?'. Yes, Ben nods. It visibly reassures Ben (p. 116).

Another letter from the Leiderdorp hospital. Ben will get a peg stomach tube on July 9th. A little faster than hoped. At the end of the day, the assistant calls the anaesthetist to keep an intensive care place in reserve. Ben and Saskia feel that everything is being done to prepare Ben for the peg stomach in the safest possible way.

Actor

Central in this story is. Saskia is Ben's wife and caregiver. Saskia is characterized by a great devotion to Ben (*'If Ben is doing well, I am doing well too', she replies, p. 203*) and would like to have things arranged well for him.

Action/Events

Wanting to have things properly arranged is expressed by the fact that she first consults with Ben before communicating a decision. If Ben doesn't want the peg stomach tube yet, there won't be a stomach tube. *He dreads this so much that I want to do my best for it. And no one can tell us why it has to be done now'. 'I can imagine that. We'll keep your husband's pace,' the assistant responds. 'We'll schedule it later' (p. 114).*

Setting/scene

The setting of this storyline is first at Saskia's work, then at home with the decision-making and later with the gastroenterologist. Mentally, the setting is confusing, because Ben and Saskia both don't understand why the peg stomach tube should be placed.

Purpose/Intent

The goal of the caregiver is to carry out Ben's wishes in the best possible way and at the same time provide the right care to Ben.

Resources/helpers and counter-workers

Initially, the doctors are counter-workers because they cannot explain why the probe should be placed now. In the end, the gastroenterologist is a helper, because he can finally explain to them why the peg tube is necessary now.

Breach

There is a breach between the goal of providing the right care and the means. This breach is eventually resolved by the gastroenterologist, who can explain why the stomach tube is necessary.

1.4.1 Conclusion

The breach shows that without being well informed, it is difficult for the caregiver and patient to make a good decision in the joint decision-making process. If the information is complete, it is easy for the patient and caregiver to make a good choice.

The quote below shows the involvement of the informal caregiver as *spokesperson*.

Ben is undergoing some more tests. The rehabilitation doctor calls Saskia at work about the results. "There are signs in the blood that Ben is compensating and that the quality of his breathing is deteriorating. I think it's time for a stomach tube'. 'But isn't the vital capacity of a stomach tube taken into account?', Saskia asks. 'No, it's a combination of capacity and blood gas analysis' (p. 114).

The patient is not directly involved in communication with the doctor, but is involved in the decision-making process. In this case, this is because of practical reasons. The informal caregiver is appointed as contact person, and she is called when at work. However, the informal caregiver still does not make any decisions herself, as she discusses the dilemma with the patient before answering.

In this case, the decision-making process is also influenced by the input of the caregiver.

'I'm just saying, maybe it's important', says Saskia, 'Ben's carbon dioxide content is higher than normal according to the CTB. 'That's certainly important!', says the gastro in surprise. 'The rehabilitation doctor didn't write anything about that'. She turns to Ben: 'Would you like an anaesthetist just to be sure?'. Yes, Ben nods. It visibly reassures Ben (p. 116).

Without the informal caregiver's input into this storyline, Ben would have been treated in a different way and the anesthesiologist would not have been present. In this case, the care decision is influenced by the intervention of the informal caregiver.

1.5 Storyline 2: Transitional care decision

After Ben is picked up by an ambulance due to acute oxygen shortage, the conversation starts in the hospital about how to proceed. "How are you?" the nurse asks. "I know about your husband, but I don't know about you." "If Ben is doing well, I'm doing well," she replies. Ben is recovering a bit. 'It also puts such a strain on the children. They don't say anything about it. But later in the hospice you will also be alone more often and strangers will take care of you'. Admission to a hospice is accompanied by all kinds of rules. Saskia is called by one after the other: their buddies, hospices. The busy doctor at the CTB also calls. "I want to warn you against being too optimistic, your husband continues to deteriorate. Wherever your husband goes, nursing needs schooling first. We give instructions for this'. 'I pass everything on to the case manager', is Saskia's response (p. 203).

One hospice calls: between 07:00-09:00 and between 13:00-15:00 there is no nurse present. 'Let's hope Ben doesn't just get a shortness of breath attack', Saskia says dryly. Their buddy calls, another hospice comes by. But without an appropriate indication, Ben can't go there. The home care calls, They want to know what the hospice's conclusion is. Maybe they can do something for Ben?

'The regulations in healthcare are obstructive', the manager of the Leiden hospice calls. "I'm going to do my very best to be able to take Ben in. It is a special clinical picture, what your husband has'. Everyone is surprised by the regulations. For health insurance, the hospital is more expensive than a hospice, but apparently it cannot be arranged. Networking is used, Saskia understands. It turns out that Ben does not have supplementary insurance for the hospice. Saskia just lets it all happen, doesn't put any pressure on it at all. Ben is in a good place here and they won't just send him home, she thinks (p. 205)

The rehabilitation doctor calls, talks about the problems of finding the next home for Ben. "Many people don't reach your husband's stage, give up." Saskia feels weary afterwards (p. 211).

'The hospice in Hoofddorp doesn't have space and they think the demand for care is too heavy', reports a nurse. 'There will be another meeting next week. The department manager of the hospital will consult with the Care Office. Maybe it will be the Leiden hospice after all, that's what the Care Office judges, about the financing guarantee for it'. Ben and Saskia look at each other. We'll see, their looks say (p. 219).

The busy doctor at the CTB calls. "I've been on the phone about your husband this morning. It is appalling that the money flows are so intertwined in healthcare. Organizations simply refuse

because they have to put money in. Is Gouda an option?' 'That has already been tried'. 'Would you like to discuss with your husband whether Rotterdam is too far away? Actually, I think so, but yes...' (p. 219).

A nurse advises Saskia to call the Care Office herself and gives her the phone number. 'You don't have to, but it could be beneficial for your husband, personal contact'. Saskia calls immediately. The lady on the other end of the line immediately knows who she is when she says her name. "We are very concerned about your husband's situation." 'I understand that. We are unknown in the land of health care rules and can do no more than wait. Hoofddorp has come so far, now I can cycle to my husband. Is there no place for him in Leiden, do you think?' 'I agree with you that he should be able to stay in Leiden and advise you not to accept Hoofddorp.' "Won't that have any adverse consequences for my husband?" "No, I can promise you" (p. 222).

'I also called the Care Office again, ma'am', the nurse says later. 'There is high-level consultation, even with the Board of Directors. Preparations are being made to transfer your husband to Gasthuis next week.' 'That's fine, we'll just wait and see', Saskia says (p. 222).

When Ben had been in the hospital for seven weeks, a doctor and coordinator from the Gasthuis came to visit. They want to know exactly what happens in a day and at what time everything takes place. The names of all parts of the devices are carefully noted. There are also three suction devices in the Gasthuis itself and there is always a nurse present. Another great conversation with people who know their stuff. Next Monday, all eight nurses will be trained by the CTB, in the Gasthuis. Next Tuesday they want Ben to come by ambu (p. 223).

Actor

At the heart of this story is Saskia. Saskia is Ben's wife and informal caregiver. Saskia is characterized by a great devotion to Ben (*'If Ben is doing well, I am doing well too', she replies, p. 203*) and would like to have things arranged well for him.

Action/Events

This dedication is characterized by arranging and driving the fact that a decision has to be made about where Ben should go. At the same time, she thinks it should be a good decision for Ben, after all, he is also fine in the hospital (*Saskia just lets it all happen, doesn't put any pressure on it at all. Ben is in a good place here and they won't just send him home, she thinks, p. 205 & Ben and Saskia look at each other. We'll see, their looks say, p. 219*).

Saskia is continuously informed of the steps that are being taken and the options that are available. At one point she is even asked to call the care office herself, because there is a suspicion that this can speed up the course of events (*A nurse advises Saskia to call the care office herself and gives her the phone number. 'You don't have to, but it could be beneficial for your husband, personal contact'. Saskia calls immediately, p 222*).

Setting/scene

This storyline takes place in the hospital where Ben is currently admitted. Ben has been admitted after an acute lack of oxygen and is unable to return home. This worry would be too

much for Saskia. For Saskia, the mental environment is difficult, because she would like to take care of Ben, but no place has yet been found for him.

Purpose/Intent

Saskia would like a new suitable place to be found for Ben, where he can be optimally cared for. At the same time, she wants Ben to be cared for comfortably.

Resources/helpers and counter-workers

Ben's illness is a counter-worker. Not many people make it to this stage of ALS, which means that Ben needs very specific care. (*This care is so specific, that wherever Ben goes, the nurses need to be trained. Wherever your husband goes, the nursing needs schooling first, p. 203*). The healthcare system is also not cooperating, but it is not entirely clear why (*'The regulations in healthcare are obstructive', the manager of the Leiden hospice calls. "I'm going to do my very best to be able to take Ben in. It is a special clinical picture, what your husband has'. Everyone is surprised by the regulations. For health insurance, the hospital is more expensive than a hospice, but apparently it cannot be arranged, p. 205*).

On the other hand, the nurses and the care office are working hard to find a new place in Ben. Many nurses give their own suggestions or call any shelters themselves. They are hindered by the healthcare system.

Breach

There is a breach in the desire to find a good solution for the patient and the fact that the patient and caregiver think that the hospital is actually a good place to stay. So they don't make much of a rush to find a good solution. This is a break between two different intentions.

1.5.1 Conclusion

The breach shows that caregivers take on different roles. The caregiver has a coordinating role, but also a caring role. There is a balance that must be struck between wanting to take care of the patient comfortably and looking for a new place to stay.

The coordinating role should also be highlighted here. The caregiver is primarily not involved in the process of finding a new place to stay for the patient. The caregiver is kept informed of all the steps taken by the nurses in the hospital to come to a decision about where the patient could go. However, the caregiver has a decisive say in this and can reject options, as the following quote shows.

Hoofddorp has come so far, now I can cycle to my husband. Is there no place for him in Leiden, do you think?' 'I agree with you that he should be able to stay in Leiden and advise you not to accept Hoofddorp.' "Won't that have any adverse consequences for my husband?" "No, I can promise you" (p. 222).

This storyline also shows that decision-making is broader than just choosing a treatment option. Moreover, it shows that there are limits to what the care can provide, but the informal careprovider does have a voice in the final decision-making, even if this goes against the wishes of the care providers.

2. ALS heb je niet alleen – Mariska van Genneep (B2)

2.1 I. Book characterisation

2.1.1 Overall impression of the book

The book tells about the disease progression of Sjonny, who is diagnosed with ALS. Mariska is the informal caregiver and wife of Sjonny and wrote this book from her perspective. The book is focused on the disease and everything that happens around the disease, meaning that there is lots of focus on care decisions. Every formal caregiver that is involved is mentioned and their role in the decision-making process is described. Less focus is put on previous life of Mariska and Sjonny. Yet, the reader gets to know them really well, as all feeling in care decisions are extensively described. That is also the reason that the reader feels emotionally involved in the story.

2.1.2 Target audience

The book targets to fellow informal caregivers. Mariska wants to encourage all informal caregivers and aims to give practical tips for others in the same situation. (*If there is only one person that I can help, that recognizes my story, then my mission is successful, p. 9*). This is also visible in the text, as the main storyline is sometimes interrupted with blocks to give specific tips like “*Go regularly outside. I liked to go outside, with or without Sjonny in the wheelchair. You move and see the world with fresh eyes*” (p. 135).

2.2 II. Main storyline

Sjonny, husband of Mariska, is diagnosed with ALS. The book describes the period from diagnosis to the death of Sjonny

2.3 Narrative summary

May 4, 2015. Our world is at a standstill. My husband Sjonny is diagnosed with ALS (p. 9). He was already referred to the UMCU at the end of April, but as a 'wife-of' a not-yet-patient I can't influence a quick appointment. That's why I call the hospital in Assen. There's something wrong with Sjonny, but what? I hear from the secretary of the Neurology department in Assen that the neurologist on duty wants to see my husband immediately. We drive urgently to the hospital in Assen. Sjonny has already undergone some tests in April, which the neurologist is now repeating. After this small examination, Sjonny is allowed to sit down again and the neurologist asks what we already know. In the conversation at the end of April, the word 'muscle disease' was mentioned. The neurologist hesitates for a few seconds and then the lightning strikes: 'We suspect you have ALS. That is also the reason for the referral to the UMC in Utrecht, where there is a specialised ALS team that can determine whether you have ALS.' The neurologist continues with his story, but his words largely pass me by. Something to do with speech, something to do with muscles, whatever (p. 12).

We receive information: the specialist nurse explains that there are two forms of ventilation available for ALS patients, a machine and a cannula. In the vast majority of cases, the device is chosen, partly because the cannula makes speaking even more difficult. We also have an

appointment with the WMO consultants of the municipality. For example, they ask if we have thought about the possibility of moving. We have not considered this option and we do not think it is desirable. Soon after, we have an appointment with an employee of the wheelchair company. To our surprise, the lady in question has already brought a wheelchair. It all makes me a bit dizzy. This appointment was so quick and now there is even a wheelchair in the house. Very pleasant for Sjon, but quite confrontational for our family (p. 27).

My life sometimes feels ambiguous: I would like to have a job, small talk with colleagues. On the other hand, I'm grateful that I don't have to go out to work and be with Sjonny. Being a caregiver is really a task that you don't just do on the side. Because I'm his translation computer for people who don't see it often or people who can't understand it. I'm also the one who always answers the phone, because Sjonny can't make herself understood on the phone either. Moreover, I am his 'regular aunt' because, everything has to be agreed, discussed and coordinated with regard to the care for Sjonny. A day job that I try to fill in with love (p. 32).

Sjonny thinks he has a blister and asks me to puncture it. I look and don't really see one. That's why I call the doctor to ask if he wants to come by. The doctor tells me that he is already planning to do this, it has been a month already. The doctor recommends an arch support for under the forefoot, so that the toe gets a good position again. Sjonny wants to think about this for a while. The doctor asks if Sjonny is sleeping well. He replies that it is difficult for him to fall asleep when he is cold. He is then advised to wear an electric blanket, but that seems much too warm for Sjon. Then the doctor very empathetically asks if there is anything he can do for Sjonny or me. No, not for me at the moment. It's all going his way. Sometimes I don't want this question asked. Then I'm afraid that I'll soon have to tell them that it's no longer possible. Now it's just fine. And what happens to us if I don't keep it up? Such things sometimes haunt my mind (p. 43).

In recent weeks, the nights have become more difficult for Sjonny. He sits up more often because he is short of breath. For a while now, a social worker has been involved in our family, which is very helpful to us. I'm sending an e-mail, I cannot allow myself to suffer this burden in the future. She contacts the GP and we schedule a meeting. The options are: a hospice, a unit in the garden or finding a solution in the house first. For example, that the home care sleeps here and they can go to Sjonny, if there is anything. I don't have to do the latter every night, but it does ensure that I get a good night's sleep every now and then. The next day Sjonny already has a solution for all my puzzling with beds and bedrooms. I had come up with several variants, but I think his is the best. I'm not ready for a unit yet (p. 79)

That unit arrived anyway. I can no longer cope with home care and think that a limit has been reached with regard to the concept of elastic informal care. The GP thinks that is clear and justified. He indicates that I should take the initiative to arrange 24-hour care (p. 92).

After this, things go fast. About three weeks before his death, Sjonny indicated that he wanted to put an end to it. He tells me first. I cry with him and he comforts me. A few days after his fiftieth birthday, I hold his hand for the very last time (p. 140).

2.4 Storyline 1: Holiday & Ventilation

During the explanation, the pulmonologist comes in. He indicates that Sjonny has to be admitted to set up the ventilator. I say a bit jokingly, that this should be done after our holiday. "Where are you going?" the doctor asks. 'To the Dominican Republic', is my answer. Then the doctor pronounces his verdict: 'As a pulmonologist, I would advise you not to take this flight in your condition. At an altitude of 10 km, the air is much thinner, in a normal state you will breathe faster. The question is whether Sjonny can do this'. We look at him in shock.

Early the next morning, I call the UMCG, home ventilation department. I am very quickly put through to the pulmonologist in question. He emphasizes once again that flying is not an option for Sjonny. However, he offers a solution: Sjonny can be admitted the next day for almost a week, to be put on respirators. This equipment can then be taken with him during the flight, so that Sjonny gets help from the device if breathing becomes too heavy. Tears come to my eyes. How nice that this doctor understands how important this trip is for our family. We immediately agree to this plan and Sjonny is admitted the next day so that he learns how to use the device himself. Later, I also get instructions. It's strange and quiet in the house those few days that Sjonny isn't there. The children and I can't imagine that this is our future (p. 21).

Sometime later, the pulmonologist asks Sjonny how things are going. In the meantime, he reads on his computer who Sjonny is, and yes, recognition comes: the Dominican Republic. He says that he didn't think it was responsible at the time and was really afraid of Sjonny's flight without a ventilator. He wants to know from Sjon what it was like and whether he also used the device in the air. Sjonny agrees that he used the device, it was nice to get more air. He also tells us that from then on he slept with the device every night, even during our holidays (p. 42).

Actor

The story is written from Mariska's perspective. She is the informal caregiver of Sjonny, who is diagnosed with ALS. She's persisting to go with her and Sjonny's plans to go on holiday.

Action/Events

Sjonny is getting more and more wheezy in this storyline, leading to the fact that the doctor doubts whether Sjonny can go on holiday with Mariska and tries to prevent the holiday from happening.

Mariska's persistence is reflected by the call to the UMCG, the morning after the initial conversation with the pulmonologist. Mariska does not agree with the initial decision that Sjonny is not able to fly, and calls to see whether there are possibilities. Without this tenacity, it is likely that Sjonny had not been able to go on his final holiday.

Setting/scene

The story takes place at different locations. First, the setting at the hospital in conversation with the pulmonologist, second at home, in a phone conversation with the pulmonologist and lastly back in the hospital.

Purpose/Intent

Mariska's intention in this storyline is to go on holiday with Sjonny, as it will be their last holiday together. However, Mariska understands the concerns of the pulmonologist. Another intention of Mariska is that Sjonny should receive the best care possible, without putting him at risk.

Resources/helpers and counter-workers

Given the intention of Mariska to go on holiday, the pulmonologist is an opponent. However, as Mariska persists, the pulmonologist becomes a helper, by offering a mobile ventilator to take on the plane.

Breach

There is a breach between the intention of Mariska and Sjonny to go on holiday and the event that Sjonny is getting increasingly less breath. By the means of the thoughtfulness of the pulmonologist, this breach is partly solved, as Sjonny is able to receive the ventilation earlier, so he can take the ventilation with him on holiday and in the airplane.

2.4.1 Conclusion

Mariska, as the informal caregiver, takes the role of advocate and tries to find ways to go on holiday eitherway. Without her persistence, the pulmonologist would not have come with a solution to go on holiday, leading to sadness by both Mariska and Sjonny for not going or leading to severe risk to Sjonny when going eitherway. This is an example of the influence that an informal caregiver can have in the decision-making process. The informal caregiver has the role of advocate or spokesperson, the patient is present in shared decision-making, but does not participate in.

Furthermore, the informal caregiver influences the thinking and cooperation of the pulmonologist.

2.5 Storyline 2: PEG stomach tube decision

The speech therapist calls to ask how Sjonny is doing, and whether he already uses the speech computer a lot. I tell her that Sjonny is currently using the iPad on loan. She also asks me about Sjonny's food and drink, if he often chokes. 'A little more than before', is my response. She indicates that all the food will soon have to be ground. For choking when drinking, Sjonny can then use thickener. You then drink coffee at custard thickness. I will pass it on to him, but here too I have my doubts. When I walk up to Sjonny a little later and tell him what was said in the conversation, he looks at me with a look like 'are you serious?'. The thickener is indeed refused (p. 44).

A few days later, the nurse from the Centre for Home Ventilation (CTB) comes by. After Harry is gone, Sjon and I look at each other. You don't want to deal with such heavy issues at the age of 48. In the weekend I notice that Sjonny is clearly working on thinking about the peg probe. On Sunday, he indicates that he has clearly decided to go for the probe. Starvation does not lure him. A meeting with the specialist nurse is scheduled for Monday and Sjonny indicates to him that it can be set in motion. (p. 45).

A week before the operation in which a peg probe will be inserted, Sjonny and I have a conversation. He dreads the operation. Very much so. We're talking about how if he doesn't have it done, he won't be able to eat at a later stage. Sjonny is well aware of this. But he dreads the tube that goes through the throat to his stomach. I tell him, even at the very last moment, that he can indicate if he doesn't want to. He is the only one who can and should decide about his body and his life. What an intense, difficult, painful conversation. Nevertheless, he stands by his decision: to operate (p. 48).

Actor

The story is written from Mariska's perspective. She is the informal caregiver of Sjonny, who is diagnosed with ALS. In this storyline, Mariska acts as the spokesperson of Sjonny in contact with the speech therapist, as Sjonny is not able to address his own issues. She also acts as sparring partner for Sjonny, She cares for Sjonny and makes sure his opinion and thoughts are included in the decision-making process. Furthermore, she lets Sjonny make his own substantiated decisions and supports that decision, no matter what his decision will be.

Action/Events

The storyline tells about the decision to take a peg stomach tube for Sjonny. Acting as a spokesperson, Mariska is in contact with the speech therapist, who tells her that the stomach tube will be needed in the near future. Although she already knows what Sjonny thinks about this matter, she still goes to inform him and give him the opportunity to decide (*Ik zal het hem doorgeven, maar ook hier heb ik mijn twijfels, p. 44*). This behaviour is seen throughout the storyline (*Ik vertel hem, ook al op het allerlaatste moment, dat hij mag aangeven als hij het toch niet wil. Hij is de enige die over zijn lijf en zijn leven kan en mag beslissen, p. 48*).

Setting/scene

The story is set at Mariska and Sjonny's home, which is considered their safe environment. In this environment, there is a phone call between Mariska and the speech therapist and the nurse comes to visit to talk about the stomach tube.

Purpose/Intent

Mariska's intention is to support Sjonny's participation in decision-making and to facilitate the decision-making, with the intention of letting Sjonny keep control of the situation (*I tell him, even at the very last moment, that he can indicate if he doesn't want to. He is the only one who can and may decide about his body and his life, p. 48*), even though the outcome is not as Mariska would like to see +

Resources/helpers and counter-workers

Seeing from Mariska's perspective, Sjonny is both a helper and opponent. Sjonny takes his role in decision-making, because Mariska supports and encourages this role. However, as Sjonny is, at first, against the placement of the stomach tube, Sjonny can be seen as an opponent in this case. Harry, the nurse, is a helper to Mariska, as he goes against the guidelines and brings the topic of the stomach tube back, even though everyone agreed not to talk about it again, as Sjonny was clearly against the stomach tube (*Ik heb de neiging hem te onderbreken, want dit staat allemaal al in het rapport wat de arts heeft opgesteld, p. 45*).

Breach

In this storyline, there is a breach between the intention of Mariska to let Sjonny participate and decide and the initial refusal of Sjonny to get something like a stomach tube. This breach is partly solved by having a conversation with the nurse and Sjonny, and by informing Sjonny of the consequences of the decision, such as the eventual starvation.

2.5.1 Conclusion

This storyline shows the organization's work for shared decision-making and the informal caregiver's involvement in shared decision-making.

Without the initial conversation between Mariska and the speech therapist in this storyline, there would be little awareness of Sjonny's upcoming feeding problem. The nurse's visit enhances this awareness and stimulates the talk between Mariska and Sjonny about the stomach tube.

In this talk, Mariska supports Sjonny's involvement and participation in the decision-making process without putting her own opinion and thoughts first. Furthermore, she stimulates Sjonny to make his own decision, regardless of the outcome, even when the decision to place the stomach tube has already been made. The decision is still the patient's decision, not the informal caregivers' decision. This is also a supportive role, the informal caregiver gives space to the patient to think about decision and consequences, but also informs the patient.

By supporting Sjonny in making his own decision, contradictionally, Sjonny wants the stomach tube despite his initial resistance.

To conclude, Mariska is involved in decision-making. She has different roles. At first, she acts as a spokesperson in the talk with the speech therapist. Later, she takes the role of supporting the involvement and participation of the patient in shared decision-making.

3. ALS: Hoe vaak kan een hart breken? - Carla de Vries – Van den Heuvel (B3)

3.1 I. Book characterisation

3.1.1 Overall impression of the book

The book is mostly written from the perspective of Carla, who is wife and informal caregiver of Jos, who is diagnosed with ALS. The book tells from the diagnosis to the inevitable death of Jos. The change in perspectives is remarkable. Whereas Carla tells about the course of the disease on the right pages in the book, do the formal caregivers tell on the left pages of the book. The formal caregivers align with Carla's story and tell about their perspective and point of views, specifically for this book. For the storyline, these perspectives are not included. Carla tells about her feeling in an emotional and concerned way. While reading the book, I could really feel the love she has for Jos. Sometimes events are described humorous, but also emotionally.

3.1.2 Audience

The book not only aims to reach people with ALS and their social environment, but also their caregivers, as the book states that most caregivers don't come into contact with ALS as disease. The author aims to inform people about ALS.

3.2 II. Main storyline

Jos is diagnosed with ALS. In the year and a half that the book describes, Jos deteriorates rapidly, ALS has the most progressive form for him. In this book, Carla, his wife and caregiver, describes her experiences with the disease, dealing with Jos and her experiences with care institutions and agencies.

3.3 Narrative summary

After several minor complaints and a few weeks of physiotherapy, I advise Jos to consult with Paul, the physiotherapist, and to have a second therapist perform a second opinion examination. I tell them that I am worried and even think about ALS. I agree with Paul that he will examine Jos again. After his research, Paul calls me. He tells me his findings and shares my concerns. I call Dorette [the GP] for consultation and a referral. An appointment at the UMC Utrecht is not possible, so I make a round of calls to hospitals and we can go to the Oudenrijn Hospital in Utrecht (p. 13/14).

'You most likely have ALS', the neurologist says two weeks later. In the past two weeks, Jos has received more and more information about what ALS entails. Now he asks matter-of-factly how long he has left to live. Tears are rolling down my cheeks. Jos looks at me and continues to ask questions, seemingly calmly. We are referred for a second opinion to the UMC Utrecht, a normal course of events with ALS (p. 21).

A week later we fly to America for a holiday. Because the symptoms of ALS seem to be gaining momentum, I called, worried as I was, to ask what precautions I should take for our trek through

America and Canada. What deterioration do I have to take into account? Does it make sense to have a wheelchair ready? He reassures me. Stubborn as I am, I buy a lightweight cane just to be sure and I reserve rooms where wheelchairs can be placed (p. 29).

On November 11, I fill in a series of forms for Jos, the most important of which is the euthanasia declaration. He can then just sign the forms with a scribble that remotely resembles his original signature. Because I want to be sure that we do everything legally, I record the signing of the forms together with a short statement by Jos on video (p. 37). In anticipation of the final diagnosis, in view of the highly disabling nature of ALS, I submitted an application to the municipality on July 11, 2001 for a wheelchair and home adaptation. A lot of that arranging is done without Jos's involvement. He doesn't have to put any energy into it and is okay with that (p. 51).

Jos's voice becomes weak, but the articulation is sufficient. Is amplifying the voice not an option, one of Jos' sisters wonders. We're going after it. In collaboration with speech therapy, a speech amplifier is recommended (p.73). In the end, that speech amplifier will only be delivered a few months after Jos' death. The physiotherapist recommends a walker in November. We decide to do this anyway, despite the relatively short period of use. Indeed, it comes too late to be really useful (p. 75).

After a TIA, which fortunately is unrelated to the ALS, I don't sleep with Jos for five weeks and I recover completely. My goal is to enable Jos to do what he wants as much as possible, and to stay fit so that I can continue to take care of him optimally and pay attention to the children (p. 96).

From the moment we have four nights of intensive home care, it is, contrary to the agreement I make with home care, a coming and going of night care. It makes me very ticklish that the home care organization is not able to manage a permanent team of employees. Even though there is a care file, in which I have put general information about ALS, every new help can count on at least fifteen minutes of information and instructions. I tell them, show them and let them feel it (p. 97). Several times I have been in contact with the coordinators about the problems with the night helpers. They understand that at a certain point I only want people who have been trained. With the big holiday approaching, this means that I agree with the coordinators not to accept any new helpers and so I sleep more nights with Jos (p. 101)

Jos was struck down by pneumonia in the weeks that followed. We discuss with your GP what the options are for administering oxygen. We wonder what the effect will be. While talking, Jos shakes no to reject the possibility for the time being, just as he previously rejected the possibility of artificial respiration. A few days later, after a telephone consultation with the GP on duty, I give extra morphine again.

Moments later, he makes his decision. He whispers: 'Grab the agenda'. Immediately I know why he asks me that. I ask what he wants and at the word 'fall asleep' he says: 'Yes'. Tears spring to my eyes. I put my hands on his hands and tell him for the umpteenth time that I love him and that I respect his wish. A few weeks later, the time has come. I'll make sure it's right for the last time. I focus entirely on Jos. Brave man, go (p. 129).

3.4 Storyline 1: Euthanasia

Almost immediately after the diagnosis of ALS became known, Jos resolutely opted for euthanasia in the final phase of the disease. In this so-called terminal phase of ALS, the GP visits us very regularly to inform us about all kinds of procedures and choices. The situation may arise that Jos is ready, but the GP is not yet. In that case, she will refer us to another doctor. We have a lot of confidence in her and are familiar with her. We don't want another doctor. In our next conversation we ask about this and fortunately this turns out not to be the case (p. 113).

I fill in a series of forms for Jos, in a later phase of the illness, the most important of which is the euthanasia declaration. He can then just sign the forms with a scribble that remotely resembles his original signature. Because I want to be sure that we do everything legally, I record the signing of the forms together with a short statement by Jos on video (p. 37).

Jos is not afraid of death, but he is afraid of the necessary emergency IV. In order not to burden Jos, we discuss whether omitting an emergency IV during euthanasia is an option. No, and so we agree that an anaesthetist from the hospital will put in the emergency IV (p. 113).

Jos was struck down by pneumonia in the weeks that followed. We discuss with your GP what the options are for administering oxygen. We wonder what the effect will be. While talking, Jos rejects the possibility for the time being, just as he previously rejected the possibility of artificial respiration. A few days later, after a telephone consultation with the GP on duty, I give extra morphine again (p. 119).

We talk to the GP about quality of life. Thinking about the decision is taking on more and more concrete forms for Jos. Since he can barely talk and certainly not too much, I ask him if it helps if I talk about it with friends who are visiting. He nods and as we talk I can see in his eyes that things are getting clearer in his head (p. 121).

Moments later, he makes his decision. He whispers: 'Grab the agenda'. Immediately I know why he asks me that. I ask what he wants and at the word 'fall asleep' he says: 'Yes'. Tears spring to my eyes. I put my hands on his hands and tell him for the umpteenth time that I love him and that I respect his wish. I inform the GP of his decision. A few weeks later, the time has come. I'll make sure it's right for the last time. I focus entirely on Jos. Brave man, go (p. 129).

Actor

Carla is the main actor in this storyline. The storyline is written from her perspective. Carla is Jos's informal caregiver and wife. Carla feels emotionally connected to Jos and clearly loves him, and she will always put his interest first. (*I tell him for the umpteenth time that I love him and that I respect his wish, p. 129*)

Action/Events

Carla arranges a lot for Jos. This is reflected in the story because she writes a lot in the we-form when it comes to decisions for Jos (*We talk to the GP about quality of life, p. 121*). She also fills in the euthanasia declarations and ensures that they are legally valid. (*Because I want to be sure that we do everything legally, I record the signing of the forms together with a short statement by Jos on video, p. 37*). She also speaks on behalf of Jos in the care process (*I ask*

what he wants and when he hears the word 'fall asleep' he says: 'Yes'. I inform the GP of his decision, p. 129). Jos is unable to communicate properly, so he uses Carla as a spokesperson for him. This inability is shown in the following quote. *He whispers: 'Grab the agenda'. Immediately I know why he asks me that. I ask what he wants and at the word 'fall asleep' he says: 'Yes'. Tears spring to my eyes, p. 129).*

Setting/scene

The storyline takes place at Carla and Jos' home. Jos is cared for at home by the actor. For Carla, it's an emotional environment. She takes care of Jos non-stop in this environment and is emotionally very involved (*Tears spring to my eyes, p. 129*).

Purpose/Intent

The actor's goal is to give Jos as much support as possible in the euthanasia process and to allow it to continue as Jos would like it to be. Carla wants to respect Jos's wishes and make sure that this is possible. She does this, for example, by filling in the paperwork and recording it.

Resources/helpers and counter-workers

Carla aims to support Jos as much as possible in the euthanasia process. The care given, for example from the GP, helps to reach this goal. Also friend of Jos and Carla can be seen as helpers, as the conversations they have with Carla regarding the euthanasia are helpful for Jos (*Since he can barely and certainly not talk too much, I ask him if it helps if I talk about it with friends who are visiting. He nods and as we talk I can see in his eyes that things are getting clearer in his head, p. 121*)).

However, the inability of Jos to express himself is obstructing the euthanasia process. For Jos, it is difficult to obtain all information and to react. He depends on Carla for these matters.

Breach

A breach occurs in Carla's wish to ensure that Jos receives euthanasia on a moment he wishes and Jos' inability to fully participate in this decision-making process. This is a breach between intentions and actions. Carla is aware of this and therefore talks to friends about it, in the presence of Jos (*Since he can barely and certainly not talk too much, I ask him if it helps if I talk about it with friends who are visiting. He nods and as we talk I can see in his eyes that it is getting clearer in his head, p. 121*)).

3.4.1 Conclusion

In this storyline, the we-form is always used when it comes to decision-making, for example: *We discuss with the GP what the possibilities are to administer oxygen. We wonder what the effect will be, (p. 119)*. The role of the caregiver here is therefore the role of spokesperson, among other things. Carla assigns herself this role because Jos can no longer express himself properly when talking in a conversation with people other than his caregiver. In conversation with Carla, this works significantly better. *While talking, Jos rejects the possibility for the time being, just as he previously rejected the possibility of artificial respiration (p. 119)*. Jos is still clear-minded, but can no longer express himself. The caregiver then acts as a *spokesperson*, in which the caregiver expresses the patient's wishes and questions. In this way, the caregiver then tries to ensure that the patient's wishes remain in the foreground.

However, there is shared decision-making in this storyline, despite the fact that this is not explicitly stated. As an example, the following quote:

We discuss with your GP what the options are for administering oxygen. We wonder what the effect will be. While talking, Jos rejects the possibility for the time being, just as he previously rejected the possibility of artificial respiration. A few days later, after a telephone consultation with the GP on duty, I give extra morphine again (p. 119)

In this article, the caregiver, patient and general practitioner discuss the possibilities of administering oxygen and what the effect of this will be. This is part of the option talk by Elwyn et al. (2012). The final decision for this lies with the patient, who rejects it in this case. In this storyline, the GP also regularly visits to coordinate and share information, including examples of shared decision-making. Furthermore, in this small quote, both the role of spokesperson and representative are visible.

One role that the informal caregiver can have is *providing and receiving information*. The breach shows that Jos is having trouble with receiving information, and Carla offers this by talking to friend. This also shows that, when communication issues appear, the informal caregiver take multiple roles in shared decision-making.

Furthermore, the facilitating role of the informal caregiver becomes visible in this storyline. Carla fills in the euthanasia forms and tells the GP about the final decision for euthanasia.

3.4.2 Storyline analysis 2: Diagnosis & Organisation of care in early ALS stadium

After several minor complaints and a few weeks of physiotherapy, I advise Jos to stay with Paul, the physiotherapist, and have a second therapist carry out a second opinion examination. I tell them that I am worried and even think about ALS, because of my background. I agree with Paul that he will examine Jos again. After his research, Paul calls me. He tells me his findings and shares my concerns. I call Dorette (the GP, ed.) for consultation and a referral. An appointment at the UMC Utrecht is not possible, so I make a round of calls to hospitals and we can go to the Oudenrijn Hospital in Utrecht (p. 13/14).

On June 27 we will be with the neurologist for the first time. We are referred to the laboratory and to an MRI. I ask him, while Jos is getting dressed, about the exact location of the front horn, an area in the spinal cord where things go wrong in ALS. The neurologist assesses my question and answers it by drawing a cross-section of the spine (p. 14).

'You most likely have ALS', the neurologist says two weeks later. In the past two weeks, Jos has received more and more information about what ALS entails. Now he asks matter-of-factly how long he has left to live. Tears are rolling down my cheeks. Jos looks at me and continues to ask questions, seemingly calmly. We are referred for a second opinion to the UMC Utrecht, a normal course of events with ALS (p. 21).

We have a huge need for information. Jos asks questions and I answer them. I translate the medical jargon, from my background as an ex-physiotherapist, into Dutch so that he understands it and give him unsolicited information if I think he should know. I surf the internet, we get information and I dive deep into the books. Friday afternoon, Paul (the physiotherapist)

and Dorette (the GP) are sitting at the kitchen table. Jos wants to know what's in store for him. In the presence of Paul and Dorette, he repeats his wish to opt for euthanasia in the final phase of his illness. He asks Dorette if she wants to think about her cooperation. My tear glands are overloaded (p. 27).

Actor

Central to this storyline is Carla, the first person in the story. She arranges a lot for Jos and consults a lot with the care together with Jos. This is reflected in the story because she writes a lot in the we-form when it comes to decisions for Jos (*We are referred for a second opinion, p. 21*). In addition, she supports Jos in communicating. Carla has a background as a physiotherapist, this comes in handy during the diagnosis of Jos (*I ask him, while Jos is getting dressed, to the exact location of the front horn, an area in the spinal cord where things go wrong in ALS. The neurologist assesses my question and answers it by drawing a cross-section of the spine, p. 14*)

Action/Events

The support that Carla offers to Jos includes looking up medical information and making medical jargon understandable. (*I translate the medical jargon into Dutch so that he understands it and give him unsolicited information if I think he should know, p. 27*). She does this from her background as a physiotherapist.

Setting/scene

This storyline revolves around the diagnosis and the first phase of Jos's disease. The setting is both the hospital (the visit to the neurologist), the visit to the physiotherapist and at home.

Purpose/Intent

There is a great need for information in this storyline, both about what the diagnosis is and what it entails. Carla tries to help Jos with this by filtering information and conveying it in an understandable way.

Resources/helpers and counter-workers

Resources include using the internet to look up information and the neurologist, who also provides a lot of information.

Also, Carla's medical background is a helper in this story, as this gave directions to the physiotherapist in the early diagnosis phase. She knows her way in the medical environment, helping the physiotherapist in the first place to diagnose and helping Jos to understand his medical condition.

Breach

In the beginning of this storyline, there is breach between the means of Carla (her medical knowledge) and the medical means, the physiotherapist. Whereas Carla has an earlier suspicion of the diagnosis, the physiotherapist is not thinking about ALS. Carla pushes the physiotherapist to think further and asks for a referral.

3.4.3 Conclusion

The role of the caregiver in this diagnosis process is considerable. Also in this storyline there is a lot of speaking from the we-form, the patient and caregiver actually speak from the same person. There is also a facilitating role. The caregiver contacts the physiotherapist, for example, to arrange an appointment and speaks with the GP to arrange a referral. The patient does not do this himself, even if he would have been able to do this (*I call Dorette (the GP, ed.) for consultation and a referral. An appointment at the UMC Utrecht is not possible, so I make a phone call to hospitals and we can go to the Oudenrijn Hospital in Utrecht, p. 13/14*).

In addition, the caregiver is the first to suspect that the diagnosis could be ALS. (*I ask him, while Jos is getting dressed, about the exact location of the anterior horn, an area in the spinal cord where things go wrong in ALS. The neurologist assesses my question and answers it by drawing a cross-section of the spine, p. 14*). Her background as a physiotherapist is of great importance in this regard. This background also ensures a certain form of tenacity, both in this substantive role, but also in the facilitating role.

4. ALS u dit leest ... - Eddy Veerman (B4)

4.1 I. Book characterisation

4.1.1 Overall impression of the book

The book is written by Eddy Veerman, a friend of Martin, who is diagnosed with ALS. During the disease, Eddy followed Martin during his disease for three years, including the perspective of Martin, Diana, his informal caregiver, and his own perspective. The book is written chronologically, describing different stages during the disease. The book also dives a bit into the past of Martin, who used to be drummer in a band and is a big fan of the local football club. The book feels like a long read, lots of details are included. However, as the story is more about the last phase of ALS, I felt more empathy with not only Martin and Diana, but also with his sons, who were about to lose their father.

4.1.2 Audience

The book targets on a broader audience and aims to inform people about the burden and the course of the disease. As more awareness of ALS is achieved, more funds will be available to research the ALS disease. The book also aims to achieve more awareness. Furthermore, as mentioned halfway in the book, the book is also written for Martin's sons, for them to have a legacy of their father.

4.2 II. Main storyline

For a month and a half, ALS has dominated Martin's days. When the envelopes are placed on the table, the logos of the AMC and UMC Utrecht tell the story of the follow-up process that awaits him (p. 8). Part of his future will be mapped out in May. Then the occupational therapist and someone from the municipality come. Then it is examined which adjustments are needed in the house (p. 18). Diana runs into several walls, which costs her a lot of energy. Diana: The occupational therapist at the AMC had already had a report made of the house. I asked the wife of CIZ if she had read the AMC report. "No," she said. 'I'm not going to do it either, because I'm going to make my own report'. That's how it started. Then I distanced myself from it, this is working against each other. That also costs me so much energy, you don't really want that (p. 49).

In addition, Diana searches a lot of things about ALS on the internet and shares this with Martin. He indicates that he does not feel the need for this, he thinks that he lives so well with his illness and has asked her to leave him alone. Diana: "But that's about practical things, I read tips that are useful to him" (p. 86). But he also doesn't want to talk about the funeral yet (p. 89).

One of those practical things is a medical trial that Martin has recently joined in. Diana: 'It's all very official, the trial, I as a caregiver also had to sign (p. 94). At the AMC, the conversation is about, among other things, Martin's participation in the trial. Martin: 'Even if it doesn't do anything for me, you might be able to help others in the future'.

Martin's deterioration is going fast. Martin is becoming less and less intelligible. "It's the way it goes. I can talk and read via the speech computer'. He controls the mouse on the floor with

his right foot (p. 136). Diana: 'If you talk, sometimes someone else will think you're drunk'. Martin nods: 'My handwriting is also becoming less legible. I can still sign my name, that's for sure' (p. 99).

The illness is also mentally difficult for Martin, also because of his psychiatric background. Diana: 'Fortunately, he joins me with going to my psychiatrist every now and then. What I noticed was that Martin was telling me things there that I didn't know. For Martin, these are obvious feelings, but apparently he had not shared them. That's why it's good that we're always talking about all kinds of things now' (p. 81). "We're going to talk to Dr. Agatha about whether he can get a double dose of medication for the psyche." Martin already had this medication in the past, when he was in a day admission in a psychiatric group (p. 138).

An interim score via Diana: 'Martin has decided definitively not to go on such a way of ventilation, with a hood over his mouth lying on the machine. The doctor then came up with another option, oxygen bottles and from there get oxygen through a nasal cannula. Martin was more in favour of that. A day later we had everything we needed (p. 142). The insertion of the PEG probe was also discussed with the doctor. Martin immediately asks if he can choke. It's his fear, the feeling that he might suffocate. That is why he indicates that he does not want to lie flat during the operation. Diana then has to stay there, not only for the spiritual help, but also because of the fact that Martin is difficult to understand. Together, one word is enough (p. 145).

4.3 Storyline analysis 1

There are regular tensions between the nurses who come to the house and Diana, Martin's wife and caregiver. There are also tensions between nurses, Diana experiences a prestige struggle between the nurses who come to the house. Diana discusses this with Lies, treatment coordinator. The storyline below is a dialogue between Lies and Diana.

Narrative summary

Diana thinks it is difficult, but starts the conversation with Lies again, about how things regularly go difficult between nurses and Diana. About the sometimes rising tension and that as the wife of a slowly dying patient, you can't really have that. Lies is our contact person and treatment coordinator at Evean, the home care organization. Perhaps she can set up a conversation with colleagues and the manager at Evean, so that things will go more smoothly in the coming months; That you dare to express everything to each other and that there is understanding for each other.

Lies: 'Everyone wants the best, sometimes it can even turn into a prestige battle, more out of a sense of honour that things are going well. But it can sometimes happen that an idea or a finding is not shared internally with the whole group, but is simply immediately ventilated. As far as walking outside is concerned: if the weather protocol is not called by the boss, then you just go outside. The special thing is that at Martin's own request, initially only a small group was allowed on the roster, in terms of caretakers. You had held off the care yourself for a long time, did it yourself, and then we were allowed in. But now it's a large group of carers.'

Diana: 'Being outside is very important to Martin, so I'm going to go for a walk with him. A prisoner is also allowed to go outside, so is Martin. It takes half an hour to get dressed.'

Lies: 'He's stable now, he's doing better than he was three months ago. Then it ran backwards, I didn't like Christmas... But I'll bring it all up with Ingrid, the care coordinator'.

Diana: 'Yesterday it was chaos here, with the arrival of the new bed. We sleep under one duvet, that is. And we are on the same level. I put our sons' two mattresses on it. It was quite an operation and it is certainly necessary, for the transfer from bed to shower, but we were very hesitant. It means that you no longer sleep together in the same bed, but we made the decision anyway. And the bed was there very quickly.'

Lies: 'We always have to wait and see, because Evean's supply is not inexhaustible (p. 169).

Actor

At the center of this storyline is Diana. Diana is Martin's caregiver, diagnosed with ALS. Diana is concerned for Martin's well-being and clearly wants the best care for him. If she sees that things are not going well, in this case the communication between the home care workers and Diana herself, she will discuss this with the home care organization. Diana wants things to go well and is caring.

Action/Events

The concern is expressed in the conversation with Lies, the contact person of the home care organization. Together with Lies, Diana enters into a conversation about the care that is provided. Despite the initial tension, she manages to mobilize Lies to address the problems internally.

Setting/scene

The physical setting of this conversation is at Diana and Martin's home. For Diana, this is her comfortable place and the place where she takes care of Martin. Diana does have some tension before the conversation, she finds it difficult to start this conversation with Diana, but she would like to have this conversation. (*Diana finds it difficult, but starts the conversation with Lies again, p. 169*).

Diana finds this difficult because she wants to keep the relationship with the nurses good, and she doesn't want the quality of care to deteriorate because she starts this conversation (*Perhaps she can set up a conversation with colleagues and the manager at Evean, so that things will go more smoothly in the coming months; that you dare to express everything to each other and that there is understanding for each other; p. 169*).

Diana experiences a lot of pressure from the pressure that is placed on her when there is tension between her and the home care workers. (*About the sometimes rising tension and that as the wife of a slowly dying patient you can't really have that, p. 169*).

Purpose/Intent

Diana's goal is to provide the best care for Martin as possible. She hopes that through this conversation everything will go more smoothly in the care for Martin (*Perhaps Lies can set up a conversation with colleagues and the manager at Evean, so that things will go more smoothly in the coming months, p. 169*) and thus the prestige battle will stop. For example, nurses no longer went outside with Martin and the care was delivered differently by each nurse. She also

wants the home care workers to go outside with Martin again if possible and that there is no more hassle about this. This is also the intention of Lies, the contact person of the organization. However, it also runs up against its organizational limits, not everything is possible given the resources of the organization. For example, it is not possible to get a fixed pool of home care workers for every day of the week, as Diana and Martin would like to see and actually expect.

Resources/helpers and counter-workers

There is a tension between Diana, Lies and the home care workers. Everyone wants the best for Martin and wants good care. Lies can be seen as a helper, she seems to understand Diana's point of view (*But I will bring it all up with Ingrid, the care coordinator, p. 169*). There is also a prestige struggle in the actions of the home care workers, (*Everyone wants the best, sometimes it can even turn into a prestige battle, more out of a sense of honour that things are going well. But it can sometimes happen that an idea or a finding is not shared internally with the whole group, but is simply immediately ventilated, p. 169*), the resources of the organization that sometimes seem to work against you. They want to be better than their colleagues and therefore do not always communicate well with each other and with the organization. Moreover, they do not always communicate well about smaller matters, so that there is a big difference in quality between the different home care workers (*But it can sometimes happen that an idea or a finding is not shared internally with the whole group, but is simply immediately ventilated, p. 169*).

Breach

There is a visible disconnect between the resources of the home care organization and Diana's goal/intention. As a result, Diana will take over tasks that are actually part of home care. If the home care doesn't go outside with Martin, then Diana will (*Being outside is very important to Martin, so I'll just walk with him. A prisoner is also allowed to go outside, so is Martin, p. 169*). Diana thinks it is important that the communication between her and the home care workers runs smoothly.

4.3.1 Conclusion

Whereas this storyline fragment is not directly talking about shared decision-making in its pure form, the choice, option and decision talk of Elwyn et al. (2012), this storyline is about the involvement of the informal caregiver (Diana) in the care pathway of Martin and how she communicates on behalf of Martin with the home care organization. Furthermore, this fragment shows that the Diana is not only involved in decision-making, she also needs to arrange lots of things, like buying a new bed for Martin.

Martin is not directly involved in this storyline, indicating that Diana is taking the role of advocate in this fragment. She is not a spokesperson or representative, as the initiative of this talk is Diana's. It is not Martin's opinion that she is representing, it is her own opinion. Furthermore, there is no active participation of Martin in this fragment, he is not involved before or after the conversation, yet he is the main character in care decisions.

Shared decision-making is then not only about initial care decisions, but also about how to behave and which steps to take when the care delivered is not as expected, or arrangements need to be made. The informal caregiver takes, in this storyline, an active role to start the

conversation and has a facilitating role: without the initiative of the informal caregiver, the conversation would not have happened. Furthermore, this storyline shows tensions that can occur in shared decision-making. The wish of the informal caregiver as advocate and the patient's wish do not always align with possibilities within the caring organization.

5. Fernando Ricksen, *De Finale Strijd* – Vincent de Vries & Veronika Ricksen (B5)

5.1 I. Book characterization

5.1.1 Overall impression of the book

The book is about former professional football player Fernando Ricksen, who has been diagnosed with ALS. The book tells about the course of the disease, but also about all the things that come with being ill as a former professional footballer. Many anecdotes from the past pass by and there is extensive attention to meetings that still take place. The somewhat more difficult relationship with his wife Veronika is also highlighted. The book tells chronologically from the moment of the diagnosis with ALS to Fernando's death.

5.1.2 Audience/Target Audience

The book is written for a wide audience. The goal of the book is to show that anyone can get ALS and to raise money for research. The last page of the book is also a qr code with which money can be donated to the ALS Netherlands Foundation.

5.2 II. Main storyline

Anyone who sees Fernando walking with Veronika and their one-and-a-half-year-old daughter Isabella through the streets of sunny Maaseik, behind a bright pink buggy, can hardly realize that he has had half a life full of drink, drugs, wild parties and countless women (p. 27). We still have to wait for the diagnosis of ALS. Fernando doesn't want to hear about it: 'I wouldn't be surprised if I get a phone call from the hospital today or tomorrow. That they were wrong and that they apologize. That I don't have ALS after all and am therefore just healthy. You can see that I'm healthy, don't you?' (p. 29).

A few days later, Fernando announces in *De Wereld Draait Door* that he has ALS. His wife Veronika tells us how she feels about this: 'A shitty feeling, of course, but what do you want? After all those problems, after all that stuff with the booze and drugs, everything seemed so calm. We had just started our new life. And that was finally possible, because Nando had just retired from football. And then all of a sudden you get this' (p. 48).

After a period that included a charity match and a meeting with FIFA boss Sepp Blatter, Fernando is deteriorating. His voice sounds bad, a bit worse than before, but he can still be understood. 'Yes', says Fernando, 'that's probably because of the Russian medicines I've been taking for a while. As a result, I am a lot fitter. I noticed it the other day when climbing stairs. And I also choke less often. The Russian medicines are some kind of suppository. I got it through Veronika's family. He got it from a doctor from Russia. It was not recommended by my doctor in the Netherlands because of possible side effects. But I thought, why not? I'm going to die anyway' (p. 105).

The first results of the Russian medicines are encouraging, but that does not mean that Fernando can do everything again. 'Certainly not', says Veronika, 'that's why I have to keep helping him.

Although Fernando doesn't allow me to do everything for him. For example, he does not want to accept help with drinking' (p. 109).

Veronika: 'Ever since Fernando announced that his striking way of talking is not due to alcohol, but to ALS, we have been bombarded with all kinds of emails from people who have indicated that they have a miracle cure or a super medicine. No matter how well-intentioned, we won't comment on it anymore. Fernando still wants to think about stem cell therapy. Also because research has shown that it can support or even repair diseased or damaged tissues and organs (p. 129).

Of course, Fernando will not wait until it has been scientifically proven that a drug has been found that can stop ALS. For example, he regularly scouts the internet, looking for something that will allow him to stay fit without using too much strength and energy (p. 129),

Because hospitals make him depressed, Fernando only did the necessary examinations. Until today. Because the food gets stuck in his throat more and more often and he has to cough loudly more and more often while swallowing, he no longer has a choice. It's time for tube feeding. A wise decision, according to the neurologist in Glasgow. 'If you have difficulty eating and drinking, this of course has consequences for your quality of life,' explains the neurologist. 'Because then you have less energy. Because if you don't eat or drink, you get a headache and feel tired. A PEG probe would therefore be ideal'. Fernando clears his throat. "Yes, fine," he says. "Let's do that" (p. 201).

In this way, Veronika not only becomes Fernando's wife, but in addition to being his 'translator', she now also becomes his informal caregiver. One that assists him 24/7. 'And that's pretty tough', she says.

A few months later, the book jumps in time, the hospital announces that this morning they have decided to give Fernando palliative care immediately, because they do not expect Fernando to live long. They just haven't talked to Fernando about it yet, because he's still convinced he'll be able to fly again next week, but that's really impossible.

A few weeks later, things are really bad for Fernando. After he hasn't woken up for three days, a little after 10 o'clock in the morning, his last muscles, his respiratory muscles, also stop working.

5.3 Storyline: Emergency

Narrative summary

In Valencia, Fernando is hospitalized again. On the phone, Veronika explains that she is now driving behind Fernando and hopes that everything is going well with him, also because it took four hours for the ambulance to arrive at their home to pick him up. Veronika: 'I have no idea what happened, but at one point Fernando couldn't breathe anymore and could hardly breathe'.

A little later Veronika sounds a lot calmer, doctors have drained his throat and trachea because they were completely full of tough mucus. Fernando is angry, not furious. Not only because he was told by the doctors that he is not allowed to go home for a long time. Fernando also freaked out because he turns out not to be insured and therefore has to pay 800 euros for every day he

is in the hospital. The only way he can be discharged, Veronika tells us, is when they sign a document in which they indicate that the hospital cannot be held liable in any way for the possible consequences if he leaves the hospital. Because Veronika realizes that they don't even have that money and she knows better than anyone how Fernando, stubborn as he is, will react if she leaves him there, she has no choice. Less than an hour later, Fernando is back in the place where Veronika almost suffocated him less than ten hours ago. At home, in his own bed. And she can only hope that this doesn't happen again tomorrow or the day after tomorrow (p. 233)

Actor

In this storyline, Veronika is the main actor. Veronika acts as the informal caregiver of Fernando, suffering with ALS. Veronika is closely related to Fernando, and cares about him.

Action/Events

When Fernando is being transported to the hospital, Veronika is panicking a bit (*A little later Veronika sounds a lot calmer, p. 233*).

Setting/scene

This storyline takes place on the way to the hospital and in the hospital. Veronika is in a difficult situation mentally. She wants Fernando to be helped in the hospital, but also wants to fulfil his wishes. These wishes are sometimes somewhat contradictory. Fernando wants to be helped, also notices that he needs help, but does not want to be in the hospital.

Purpose/Intent

Veronika's intention is to give Fernando the best care possible, even in this emergency situation. She is happy when things seem to be going well with Fernando in the hospital (*A little later Veronika sounds a lot calmer; doctors have sucked out his throat and trachea because they were completely full of tough mucus, p. 233*).

Resources/helpers and counter-workers

In this story, there are missing resources: there is not enough money and there is not enough insurance to be able to keep Fernando in the hospital, which is an opposing factor in this story. Fernando himself is also not cooperating, by being stubborn and not wanting to stay in the hospital.

Breach

In this story, there is a breach between Veronika's intention and the resources she has at her disposal. Veronika wants the best care for Fernando, but the resources ensure that Fernando is out of the hospital quickly.

5.3.1 Conclusion

Some elements in the story can be related to shared decision-making, some not. The fact that the hospital tells Fernando that he cannot go home at all, is not a decision that includes the patients' voice. However, after a discussion that includes Veronika, the informal caregiver,

Fernando is only allowed to go home after Veronika signs a liability waiver for the hospital. However, staying was not an option, as resources (money) ran out and there was no insurance.

Veronika, here, does follow Fernando wishes, even though she might realize herself that following his wishes is not the best decision to make. She goes against the wishes of the doctors and signs the liability waiver, to get Fernando out of the hospital. This is also considered a risky situation for her and Fernando, and shows the need for enough resources and support from the doctors. She does support the involvement of Fernando in shared decision-making in this storyline, but is also spokesperson, as she is the one who negotiates with the hospital, on behalf of Fernando.

6. Canto Obstinato - Anje Bareman (B6)

6.1 I. Book characterization

6.1.1 Overall impression of the book

The book is written chronologically about the last phase of the disease progression of the author's mother, who has ALS. The book tells from the author's perspective, with special focus to the difficult relationship the author has with her mother. (*Many trips to and from my mother are affected by resistance. I spent some therapeutic sessions trying to figure out why I let my soul take hold emotionally. At least that's how it feels. As a creditor, she is above me.*) The book is easy to read. As a reader, you are constantly catching and reviewing the emotions of the informal caregiver in the relationship with her mother. Sometimes you can relate with Anje's emotions and sometimes with her mother's emotions.

6.1.2 Audience/Target Audience

The book offers a perspective of a daughter's troubled relationship with a sick mother with ALS. The book seems to have been written to bring out this perspective and to allow it to exist, to help other people who are struggling with this.

6.2 II. Main storyline

Anje's mother has been diagnosed with ALS. Anje is a caregiver for her mother, but also experiences a difficult relationship with her.

Many journeys to and from my mother are full of resistance. I spent some therapeutic sessions trying to figure out why I let my soul take hold emotionally. At least that's how it feels. As a creditor, she is above me (p. 5).

Once, for example, she sat pale in her chair. She was barely approachable. The doctor called in said she had to go to the hospital because she was dehydrated. I hesitated. Did we have to 'intervene'? "Mom, do you want to go to the hospital?" I asked. She shook her head no. But she was dazed and later didn't remember what had happened. Finally, the ambulance left after at least 10 minutes. She found it boring in the hospital and wanted to go home. After permission from the internist, she was able to go home after a few nights (p. 6).

To my dismay, she too often commanded me with purposeful gestures that I should do things for her. She had four types of sun protection and each type had its own gesture.

The occupational therapist would arrange a special bed. He arranged and rustled a lot. By the way, the insurance company had insisted that my mother would fall into the category of chronic care. Then she had to pay a hefty personal contribution. I thought that was strange. So I saw a task for myself to find out in depth soon (p. 8). Caregivers were expected to do and arrange a lot. She had two private helpers, but they didn't change her bed. I could do that for a while, couldn't I? The caregivers did other things, which were more important. She could get extra help through the WMO, but she didn't think it was necessary (p. 12).

Normally I have an excessive amount of energy, but now the bucket is full and threatens to overflow. That bucket is largely filled with plodding around my mother (p. 15) I feel tossed back and forth by my mother and her behavior. She can be so demanding. And at the same time, it's degrading to see her deteriorate like that. But she keeps it up. On her mental ability (p. 19).

I found it uncomfortable that my mother, even during healthier periods, had the family doctor come for a home visit at the slightest thing. I sometimes found her talent for putting everyone in her shoes shameful. The GP listened to her complaints. He advised, patient as ever, that she could take morphine more often to feel better. My mother didn't want that. It's better to be stuffy and alert than to lose control. 'She's in charge,' the GP said (p. 20).

My sister also thought that our mother would like the hospice. With a throwaway gesture, she made it clear that this really wasn't going to happen. Apparently, the care coordinator had already suggested it. So I decided to look for good volunteers who might be able to offer some extra support (p. 21)

As a result of corona, the quality of care decreased. A thorn in my mother's side. An even bigger one in mine (p. 23)

My mother had hoped that she could persuade others to actively put her out of her misery. But apparently there were conditions and ethical objections from doctors, I thought. We sat together on Monday morning. She had made a decision over the weekend. The GP was called in again. She let it be known that she wanted to be fed for the last time on Tuesday. The GP nodded in understanding, he would inform the care. It seemed as if she was reviving a bit, the finish line in sight (p. 42).

At half past six in the morning I hear a telephone somewhere in the distance. It's my sister with the news that mom has passed away. I was proud (p.45).

6.2.1 Storyline 1: Euthanasia

The GP listened to her complaints. He advised, patient as ever, that she could take morphine more often to feel better. My mother didn't want that. It's better to be stuffy and alert than to lose control. "She's in charge," the doctor said. My sister also thought that our mother would like the hospice. With a throwaway gesture, she made it clear that this really wasn't going to happen. Apparently, the care coordinator had already suggested it. So I decided to look for good volunteers who might be able to offer some extra support (p. 21).

On the stairs to her apartment, I met the care coordinator and we discussed the situation. There were boundaries for those who had to provide the care, so the hospice was definitely in the picture. I asked if money was a factor, otherwise I would take a different tack. After all, I had arranged a terminal declaration from the GP, so there was no ceiling on the costs to be reimbursed. I did my research well (p. 22).

My mother texted early this morning that she wanted to see the doctor, because she can't keep it up anymore. She was in her new wheelchair. I saw that it was serious and called the doctor. We discussed her considerations. The acting GP asked what my mother wanted. "I can't take it anymore and want palliative sedation," was her answer. It sounded very convinced. "The

hospice is for people who are going to die very soon. Some are only there for 24 hours or a few weeks at most. For you, that phase has not yet arrived, I would rather think of nursing home care,' the GP said. My mother and I looked at each other and raised our eyebrows as a sign that this was an undesirable perspective. "And if not, of course, you can consider euthanasia. (p. 34).

My mother had hoped that she could convince others to actively put her out of her misery. But apparently there were conditions and ethical objections from doctors, I thought. We sat together on Monday morning. She had made a decision over the weekend. The GP was called in again. She let it be known that she wanted to be fed for the last time on Tuesday. The GP nodded in understanding, he would inform the care. It seemed as if she was reviving a bit, the finish line in sight (p. 42).

Actor

The actor is Anje. Anje is the daughter of and primary informal caregiver for her mother, who suffers from ALS and is in her last phase of life. Anje offers an almost inexhaustible and unconditional care for her mother and arranges a lot for her.

Action/Events

Anje arranges a lot for her mother and is in contact with the various care organizations. She also arranges a lot of things in advance (*After all, I had arranged a terminal statement from the GP, so there was no ceiling on the costs to be reimbursed. I had that well researched.*)

Setting/scene

The events take place in the physical environment of the actor's mother's home. This is the domestic environment in which her mother is cared for. At the same time, there is the environment of caregivers. Many caregivers, the care coordinator, occupational therapist and the general practitioner appear in the story.

Purpose/Intent

The actor tries to carry out the care for her mother as well as possible and to organize the care as well as possible. She tries, as far as she can, to put her mother's wishes first. (*As a result of corona, the quality of care decreased. A thorn in my mother's side. An even bigger one in mine, p. 23*)

Resources/helpers and counter-workers

The actor's sister and the care coordinator are helpers in this story. They also try to organize care as well as possible. The actor's mother resists at the beginning of the story, but ends up advocating more intensive care, as her health condition has deteriorated.

The GP does not want to go along with the ultimate wish of the actor and mother to undergo palliative sedation. The GP thinks it is still too early for this.

Breach

The breach in this story is the contradiction between the actor's desire to get euthanasia/palliative sedation for her mother and the GP's refusal to do so, because the GP is not yet ready for this according to her own convictions. The GP is more likely to be interested in nursing home care.

6.2.2 Conclusion

Shared decision-making is used to a limited extent in this storyline. There are two decision moments in the storyline in which the GP plays a major role:

The GP listened to her complaints. He advised, patient as ever, that she could take morphine more often to feel better. My mother didn't want that. It's better to be stuffy and alert than to lose control. "She's in charge," the doctor said.

In the example above, shared decision-making is applied by the general practitioner. The first part, listening to her complaints, can be seen as *choice talk*, advising as *option talk*. The decision, the *decision talk*, is left to the patient by the GP, the patient's preferences are then leading.

De waarnemend huisarts vroeg wat mijn moeder wilde. 'Ik houd het niet meer vol en wil palliatieve sedatie,' was haar antwoord. Het klonk heel overtuigd. 'Het hospice is voor mensen die zeer binnenkort doodgaan. Sommigen liggen er slechts 24 uur of hooguit enkele weken. Voor u is die fase nog niet aangebroken, ik zou eerder denken aan verpleeghuiszorg,' vertelde de huisarts. Mijn moeder en ik keken elkaar aan en trokken onze wenkbrauwen op ten teken dat dit een ongewenst perspectief was. 'En anders kunt u natuurlijk euthanasie overwegen'.

In bovenstaand voorbeeld wordt ook shared decision-making toegepast volgens dezelfde methodiek van Elwyn et al. (2012). De huisarts geeft hier alleen duidelijker de medische grenzen aan.

Ook laat deze storyline zien dat het belangrijk is dat de mantelzorger en patiënt volledig zijn geïnformeerd. De huisarts gaat niet zomaar mee in de wens van de patiënt tot palliatieve sedatie. (*Mijn moeder en ik keken elkaar aan en trokken onze wenkbrauwen op ten teken dat dit een ongewenst perspectief was.*) Dit ongewenste perspectief had voorkomen kunnen worden door volledig van tevoren geïnformeerd te zijn.

De rol van de mantelzorger komt in deze voorbeelden niet expliciet naar voren. Gezegd zou kunnen worden dat de mantelzorger de betrokkenheid en deelname van de patiënt actief aanmoedigt, en op die manier betrokken is in het shared decision-making proces.

7. ALS je de handen, voeten en stem van je Lieve bent geworden - Joanna Schoenaker (B7)

7.1 I. Book characterisation

The book consists of several e-mails that Joanna sent to her family and work. The book is written 13 years after the period of disease of Jan, who got diagnosed after

7.1.1 Overall impression of the book

By using and combining used e-mails, the book is descriptive about the disease. It is descriptive, as the e-mails are written as a short summary to friends and family. Also, this influences the way she writes about the disease period. It gives the impression that the informal caregiver is writing more 'political correct' than she would do when writing down the stories for her own memory.

7.1.2 Target audience

The back cover of the book that it is purpose of this book to keep gaining attention for ALS over the years.

7.2 II. Main storyline

I could try to make the quality of the time we had left together. That became my motivation, I could use my fighting mentality for that, two hundred percent (p. 7)!

In March 2004, my husband began to notice that he had less strength in his hands. This loss of strength continued to slumber through the summer. At the beginning of September we went on holiday to Greece together. We have made walks of thirty kilometres a day in mountainous areas, without any problems! Two months later, on a Sunday, we were walking at home, to the neighbours, a mile away. Jan didn't want to think about the fact that he would still have to walk the thirty kilometres.

Just before Christmas, December 22, 2004, on our daughter's birthday, we had an appointment with the UMC. The doctors in our area, where Jan had been under examination since the beginning of October, could not find anything. There we had all the studies one after the other. At 2.45 pm we were told by doctor van den B. that Jan had ALS. This disease was totally unknown to us. When it was explained to us, our world collapsed. With the ALS folder under his arm, we walked out of the hospital together. 'This is where my future lies'.

Within two weeks we were being treated at a rehabilitation centre and we also started plans to add a piece to the farm house. The municipality did not want to cooperate. 'In our experience, ALS goes so fast, we only install a unit'. We didn't agree with it at all. I work at the town hall myself and from that moment on I started fighting for my Jan: two hundred percent quality and I succeeded! Christmas 2005 our extension was finished.

Jan was in hospital in February 2005 and February 2006 with a double pulmonary embolism. Because of his strength, he has always come out on top. He was and has remained very calm,

under all circumstances. Acceptance was his word, don't waste energy, be careful with everything.

Gradually, the tools came into the house. In November 2005 Jan went on a home ventilator. Continuously acted sensibly, but also cried. On the 17th of February he choked and after an afternoon evening with two to four ambulances and a trauma helicopter in our yard, he was finally transferred to the UMCG hospital. At home, he had already died. Suddenly, his eye twitched. Very slowly he regained consciousness. After a week in Groningen, where a PEG probe was placed, Jan came home. 'I want to die at home on the farm'.

The doctors gave him a few more days at most. It turned out to be four weeks, in his own familiar surroundings. With a nursing team around us and all the empty hours in between taken care of by family, we were able to take care of Jan at home.

In the early morning of March 25, my Lieve, surrounded by the children and me, went to sleep peacefully (p. 163).

7.2.1 Storyline 1: Care decisions

Monday January 10, we went to the rehabilitation center in Zwolle for the first time. Jan is examined again and then you are reminded that you have to request all kinds of aids in advance and not do it when you need it. Okay, that makes sense (p. 11).

Jan had made an appointment that he would be admitted to the UMCG hospital next Wednesday, November 2, but he has postponed it, possibly to next week. Why? The men want to start sorting potatoes this week. He no longer does this himself, but he wants to help with starting the process. If he is called into the hospital next week, the work can continue as usual and he will also stay a bit more relaxed in Groningen (p. 29). On 9 November, Jan was admitted and the ventilator was installed.

On December 24, Jan is rushed to the hospital after mucus formation in the lungs. The pulmonologist then contacted the Home Ventilation at the UMCG hospital. I have to contact them tomorrow, presumably the equipment needs to be raised to dilute and dissolve the mucus formation. From tomorrow he will have to be put on a ventilator more often (p. 58)

Last Friday we went to see doctor van den B., the ALS doctor at the UMC hospital. He can't add that much anymore. "Do what makes you feel good. Physio? Fine, but doesn't help. Do what you feel comfortable with!" He also again drew our attention to the following. If Jan gets into trouble with his breathing again and we end up in the hospital again, will he go on a ventilator? Then he'll never get rid of it. In other words, if you have made the decision together that Jan does not want to be on invasive ventilation, then you should no longer go on a ventilator in such a situation. His lungs are now at such a stage that he can't pick it up on his own after that. Realistic and intense. If he starts to feel uncomfortable with the increasing shortness of breath, we can administer some morphine. Me: 'That's the beginning of the end'. The doctor: "Yes" (p. 69).

There is now also more help in the house. Names are suggested to us, which have to be put into the week. Do you, does Jan, want to have someone around him and on him? Jan must feel good about it (p. 69).

We have been working for over a week to get Jan's ventilator support back on track, but it is not going the way we want. In the morning I had contact with the CTB again, during my work, and they said what we had lightly discussed at home in the morning: 'We may be at the end of our possibilities to support Jan and this is the end of it...'. Then I had to endure such a hard blow. I felt Jan slip out of my hands. In the evening I had to tell this to Jan, he was quietly reading the newspaper. It took him by surprise, he was shocked, at first he didn't say anything, then only: 'Don't panic' (p. 91).

Jan was rushed back to the hospital after an acute choking. Jan needs a lot of care, but I also clearly ask for support. At the moment I don't dare to take responsibility for taking care of Jan at home. The fear is huge in my body. The hospital has taken a close look at this and is taking it well. At the moment I can listen to a lot and also let go of a lot: is taken care of (p. 106).

Actor

Joanna is the main actor, she is wife and informal caregiver of Jan, who is diagnosed with ALS. She made it her mission to give Jan the best care possible (*I could try to make the quality of the time we had left together. That became my motivation, I could use my fighting mentality for that, two hundred percent, p. 7!*), but she also want Jan to make his own decisions and puts his interest first.

Action/Events

As an example, Jan wants the admission in the hospital to be postponed, so he can help on the farm he lives. (*Jan had made an appointment that he would be admitted to the UMCG hospital next Wednesday, November 2, but he has postponed it, possibly to next week. Why? The men want to start sorting potatoes this week. He no longer does this himself, but he wants to help with the start-up. If he is called up next week, the work can continue as usual and he will also stay a bit quieter in Groningen, p. 29*). Joanna supports that decision.

Setting/scene

Most of this scene happens at home: the farm where Jan and Joanna live. Mentally, this scene is difficult for the actor, Joanna. (*Jan was rushed back to the hospital after an acute choking. Jan needs a lot of care, but I also clearly ask for support. At the moment I don't dare to take responsibility for taking care of Jan at home. The fear is huge in my body. The hospital has taken a close look at this and is taking it well. At the moment I can listen to a lot and also let go of a lot: is taken care of, p. 106*), as Joanna is not able anymore to deliver the amount of care that is needed for Jan.

Purpose/Intent

The actor's intention is to give Jan the best care possible, without losing Jan's self-determination. She wants to do most of the caring for Jan herself, but is not always able to.

Resources/helpers and counter-workers

The doctor is a helper in this story, he assures that Jan does what feels good for him, and supports the decisions (*Last Friday we went to see Dr. van den B., the ALS doctor at the UMC hospital. He can't add that much anymore. "Do what makes you feel good. Physio? Fine, but doesn't help. Do what you feel comfortable with!, p. 69*). Although it is not what both Joanna and Jan wants to hear, the CTB is a helper, and confirms the initial thoughts of Joanna and Jan about the current status of the disease: (*In the morning I had contact with the CTB again, during my work, and they said what we had slightly discussed at home in the morning: 'Possibly we are at the end of our possibilities to support Jan and this is the end of it..., p. 91*). Joanna herself can also be seen as a resources, as she tries to fulfil the caring job herself as much as possible.

Breach

In this storyline, there is a breach between the intention of Joanna to respect the self-determination of Jan, and the limited amount of resources Joanna can offer herself. Joanna realizes this, and writes then about the burden she experiences. At the end of the story, she fears caring for Jan, and is afraid to make mistakes. (*Jan was rushed back to the hospital after an acute choking. Jan needs a lot of care, but I also clearly ask for support. At the moment I don't dare to take responsibility for taking care of Jan at home. The fear is huge in my body. The hospital has taken a close look at this and is taking it well. At the moment I can listen to a lot and also let go of a lot: is taken care of, p. 106*).

7.3 Conclusion

Several elements need to be highlighted in this storyline. The breach shows that the informal caregiver experiences a high burden, that progresses during the disease period.

Furthermore, shared decision-making is practised in a proper way. The doctors put the self-determination of the patient upfront and let him make decisions: *Last Friday we went to see doctor van den B., the ALS doctor at the UMC hospital. He can't add that much anymore. "Do what makes you feel good. Physio? Fine, but doesn't help. Do what you feel comfortable with!" (p. 69)*

Also, the doctor points out elements for consideration of the patient and informal caregiver, but does not make or steer to a decision.

He also again drew our attention to the following. If Jan gets into trouble with his breathing again and we end up in the hospital again, will he go on a ventilator? Then he'll never get rid of it. In other words, if you have made the decision together that Jan does not want to be on invasive ventilation, then you should no longer go on a ventilator in such a situation (p. 69)

The informal caregiver has different roles in shared decision-making in this storyline. Sometimes, she is put into a role of contactperson by the hospital, which causes her to take role of representative:

On December 24, Jan is rushed to the hospital after mucus formation in the lungs. The pulmonologist then contacted the Home Ventilation at the UMCG hospital. I have to contact

them tomorrow, presumably the equipment needs to be raised to dilute and dissolve the mucus formation. From tomorrow he will have to be put on a ventilator more often (p. 58).

Furthermore, the informal caregiver contacts care herself, even when the patient is not present. In the quote below, she contacted the CTB herself in the morning, to discuss things she previously discussed with Jan as a representative.

We have been working for over a week to get Jan's ventilator support back on track, but it is not going the way we want. In the morning I had contact with the CTB again, during my work, and they said what we had lightly discussed at home in the morning: 'We may be at the end of our possibilities to support Jan and this is the end of it...'. Then I had to endure such a hard blow. I felt Jan slip out of my hands. In the evening I had to tell this to Jan, he was quietly reading the newspaper. It took him by surprise, he was shocked, at first he didn't say anything, then only: 'Don't panic' (p. 91).