

# Informal carers' experiences of collaboration with formal carers to provide long-term care to patients with physical disability and cognitive impairment

Master thesis Health Care Management

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<b>Word count</b>	10.734 words
<b>Date</b>	17-06-2024

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## Abstract

**Background** Five million people in the Netherlands facilitate care for their family members and/or friends. People with a physical disability and cognitive impairment strongly depend on the support and care provided by informal carers. Informal carers are important for care recipients to honour and convey the needs and preferences of care recipients to formal carers. Therefore, care recipients with a physical disability and cognitive impairment strongly rely on informal carers to communicate their preferences and needs with formal carers. In order to provide the optimal care to care recipients, optimal coordination and collaboration of care between formal and informal carers are necessary. The goal of this study is to explore the experiences of informal carers of people with a physical disability and cognitive impairment in relation to the collaboration and coordination of care.

**Method** Narratives of informal carers have been analysed to obtain more insight into their experiences in relation to the collaboration and coordination with formal carers. A storyline analysis is performed of six individual books. Subsequently, a comparative analysis was performed to identify similarities and differences between the different storylines.

**Results** A variety of experiences have been seen in the selected narratives. Different aspects are identified to have an impact on the experience of informal carers in relation to the coordination and collaboration with formal carers. These aspects include differences in experienced intentions and the distribution of tasks. Narrators described the impact of rules and protocols of the Dutch Healthcare system on the distribution of tasks and the feeling of being acknowledged by formal carers. These aspects influenced the experience of informal carers. In addition, the communication style of formal carers being direct or indirect and problem-solving or even problem-forming is identified as a theme that has an impact on the collaboration experienced by informal carers. All these aspects are seen to be influencing trust in formal carers by informal carers.

**Conclusion** In conclusion different situations and personalities of informal carers ask for different actions of formal carers. Although a variety of experiences are identified, it can be concluded that the collaboration with formal carers presumable will be positively experienced when formal carers act to do everything to achieve the intentions of informal carers. These actions also involve hearing and acknowledging the skills and knowledge of informal carers. On the other hand, if informal carers experience that formal carers oppose informal carers in different kinds of ways, this will presumably result in a negatively experienced collaboration.

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## Chapter 1. Introduction

### 1.1 Problem analysis

Five million people in the Netherlands facilitate care for their family members and/or friends. (Ministerie van Volksgezondheid, Welzijn en Sport, 2023) This scope of care facilitation implies that a significant part of the Dutch society undertakes a role as informal carer and this care facilitation will become more important for the population requiring long-term care. (Hoefman et al., 2011) Due to the ageing population in the Netherlands, the number of people available to work in care facilitation is reduced. Therefore, there is a shortage of healthcare personnel, which contributes to an increase in workload for formal carers. (Blees, 2023) The work performed by informal carers may contribute to a decrease in the workload of formal carers. (Hoefman et al., 2011) In order to keep care accessible and affordable, the focus of care facilitation will shift to a focus on appropriate care for society. (Zorginstituut Nederland et al., 2022) Appropriate care involves care that fits the phase of care and integrates the values, goals and expectations of the patient. (Minton et al., 2023) Collaboration between different disciplines is required to identify, carry out and provide the most suitable care and appropriate care to the patient. (Zorginstituut Nederland et al., 2022) This collaboration also includes the collaboration of formal carers with informal carers.

Informal carers contribute to the realization of appropriate care and take up different roles to provide care for their family members and/or friends. Informal caregiving entails collaboration with formal caregivers and therefore the right coordination of the work is necessary. (Barczyk & Kredler, 2019) Nevertheless, the nature of care delivered by informal carers depends on various contextual and relational factors, involving multiple stakeholders such as formal carers. (Broese van Groenou & De Boer, 2016) A specific group of people highly dependent on the care of informal carers involves patients with both a physical disability and cognitive impairment. This group of care recipients experiences difficulties in communicating their needs and preferences with formal carers. (Feinberg & Whitlatch, 2002) Consequently, informal carers have the responsibility to honour the needs and preferences of care recipients and need to act in favour of these preferences. Care recipients with both a physical disability and cognitive impairment strongly rely on informal carers to communicate their preferences and needs with formal carers.

The distinction in tasks, including medical and administrative tasks, performed by informal carers may result in an unclear collaboration and coordination between formal and informal carers. (Banadinović et al., 2023) Different elements are important for the coordination between informal and formal carers and relate to relational coordination as described by Gittel (2011). Relational coordination describes the importance of shared knowledge, shared goals and mutual respect for an efficient coordination

between professionals. However, this concept is only described for the coordination between professionals. Several studies have been conducted to examine the significance of relational coordination for the collaboration between formal and informal carers. (Stephan et al., 2015; Weinberg et al., 2007) Some research has been carried out about the collaboration between formal and informal carers. This research is mainly focused on informal carers of elderly people who need typical healthcare for elderly ailments. (Stephan et al., 2015) However, there is still little understanding of the experience of informal carers of care recipients other than elderly people. In this study, I focus on informal carers of people with a physical disability and cognitive impairment, because this group of care recipients highly rely on the care and support of informal carers. (Feinberg & Whitlatch, 2002)

## 1.2 Scientific and societal relevance

In this thesis, stories of informal carers will be analysed with a narrative storyline analysis in order to form a broader understanding of the experiences of informal carers in relation to the collaboration with formal carers and what aspects of this collaboration affect these experiences. This study is an addition to the existing studies that used methods such as semi-structured interviews, surveys and focus groups as their data collection. (McPherson et al., 2014) The data collected with these methods could be influenced by the power of the researcher or, in the case of focus groups, by other respondents. (Longhurs, 2016) The method of narrative analysis that is used in this study will provide the unfiltered data of the informal carers. Therefore, this study contributes to a more precise view of how informal carers experienced the collaboration without the interference of the researcher. (van de Bovenkamp et al., 2020) More insight into the experiences of informal carers could contribute to adjustments of the healthcare setting, and also to the increase of awareness for formal carers. This awareness could result in more understanding and improvements in the care trajectory and collaboration.

### 1.3 Objective and research question

The aim of this research is to gain insight into the perspectives of informal carers on the collaboration and coordination between formal and informal carers of care recipients with a physical disability and cognitive impairment who need long-term care. The research question formulated for this study is formulated as follows:

How do informal carers of people with a physical disability and cognitive impairment experience the collaboration and coordination of care with formal carers in long-term care?

In order to answer the research question different sub-questions are formulated.

1. What do informal carers consider important goals for their care recipient?
2. How are the tasks between the formal and informal carers distributed and how is this distribution established?
3. What are the needs of the informal carers during the collaboration with formal carers?
4. What are the different communication styles between informal and formal carers?

### 1.4 Reading guide

This thesis is divided into several chapters and starts with an introduction chapter that provides the incentives for this research supported by background information, the research gap and the formulated research question. The second chapter highlights the relevant theories that relate to the research question. This chapter is followed by a description of the used research methodology, including the data collection and the variation used for this study. The results of the conducted study are presented in the next section. Finally, these results will be discussed and the scientific and societal contributions will be described in the last chapter together with the limitations of this study and the final conclusion of the results.

# Chapter 2. Conceptual framework

For this thesis, an already existing theory that describes the important concepts related to the collaboration between informal and formal carers is analysed. The following conceptual framework elaborates on this theory.

## 2.1 The roles of different carers

The specific role fulfilled by both formal and informal carers requires a proper definition for an optimal collaboration. The two carers rely on each other to provide the care necessary for the care recipient to achieve the optimal outcome. (Barczyk & Kredler, 2019) The distribution of the tasks defines the type of collaboration. (Denton, 1997) The tasks could be allocated based on the specifics of the task when there is no overlap of tasks performed by formal and informal carers. However, there is also the possibility for tasks to be substituted. When the tasks performed by formal carers increase, the tasks performed by informal carers will be substituted. The last option is when the tasks are compensated by formal carers if the care performed by informal carers is not available.

### 2.1.1 Informal carers

The provision of informal care and the factors influencing the provision are described in the informal care model. (Broese van Groenou & De Boer, 2016) External factors such as the composition of the society, the norms and the labour market will influence the need for informal carers. However, the situation of the care receiver also determines the provision of informal care. Regarding the care they need to provide, informal carers have different needs and preferences. These needs are divided into four different subsections: organizational needs, informational needs, support needs and needs for societal recognition. (Plöthner et al., 2019) However, these needs also concern the involvement of formal carers, for example, to comply with the informational needs of the informal carer.

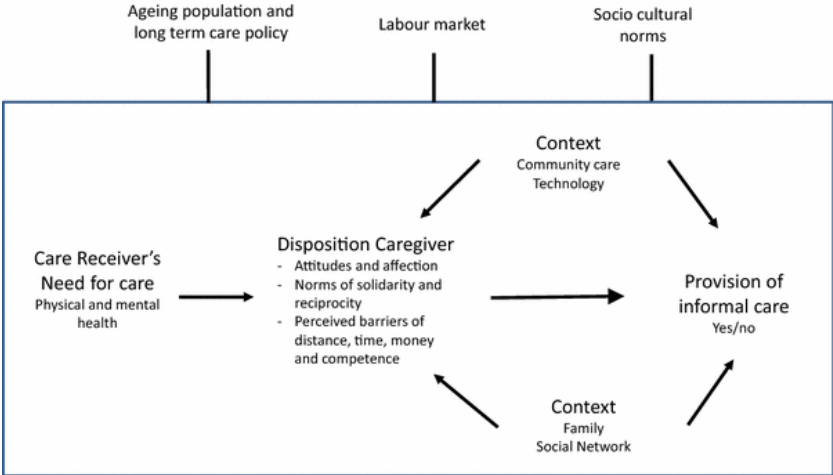


Figure 1: Informal Care Model (Broese van Groenou & De Boer, 2016)

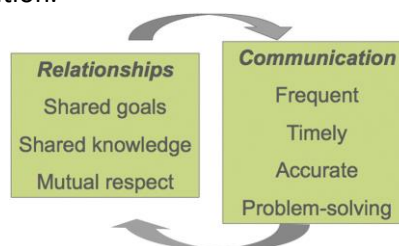


### 2.1.2 Formal carers

Formal care is provided by professionals in the formal care system. (Siira et al., 2020) Formal care is provided in different ways and depends on the different phases of the patient care trajectory and the availability of informal care. (Barczyk & Kredler, 2019) When there is a lot of informal care available for the patients, less formal care is required. (Murphy & Turner, 2017) The research of Peckham et al. (2014) shows that case managers described the role of formal carers to be the support of informal carers. In order to have a good partnership with the informal carers, it is the role of formal carers to provide information about the status of the care receiver, and knowledge about the tasks informal carers need to execute for proper care, for example, what the medication administration times are. (Weinberg et al., 2007) Providing the information and knowledge, the formal carers need to consider and respect the already existing knowledge and expertise of the informal carers. (Andréasson et al., 2018) This form of respect and consideration is necessary for a proper working relationship. The narrative analysis of stories written by informal carers could provide more insight into how informal carers experience the role of formal carers in providing the knowledge and medical information about the patient and the way the formal carers transfer this information.

### 2.2 Relational coordination

Informal and formal carers are dependent on each other to provide the most efficient care to care recipients. (Weinberg et al., 2007) This dependence requires an efficient coordination of the work. Coordination between different professionals is conceptualized as relational coordination by Gittell (2011) (figure 2). In this model, effective communication is defined as timely, accurate and problem-solving and is supported by three elements: shared goals, shared knowledge, and mutual respect. (Gittell, 2011) Although Gittell (2011) only formulates relational coordination as the coordination between different professionals, the research of Weinberg et al. (2007) shows that effective relational coordination between formal and informal carers in some cases leads to better preparation and better clinical outcomes for the patients. Nevertheless, they did not evaluate how informal carers experienced coordination and communication with informal carers. It would be insightful to explore if informal carers experience the same goals and knowledge as formal carers and how they feel and experience respect and recognition.



**Figure 2: Relational coordination by Gittell (2011)**

### 2.2.1 Shared goals

Shared goals as described by (Gittell, 2011) are part of the relationship for optimal coordination. Shared goals help to increase the motivation of both the informal and formal carers and it will help to improve the quality of the communication. (Hoffer Gittell, 2011) The similar goals will result in more problem-solving communication and therefore will be favourable for the collaboration between informal and formal carers. (Lévesque et al., 2010) This study will provide more insights to what extent informal carers experience shared goals with formal carers and what the impact is for the collaboration.

### 2.2.2 Mutual respect

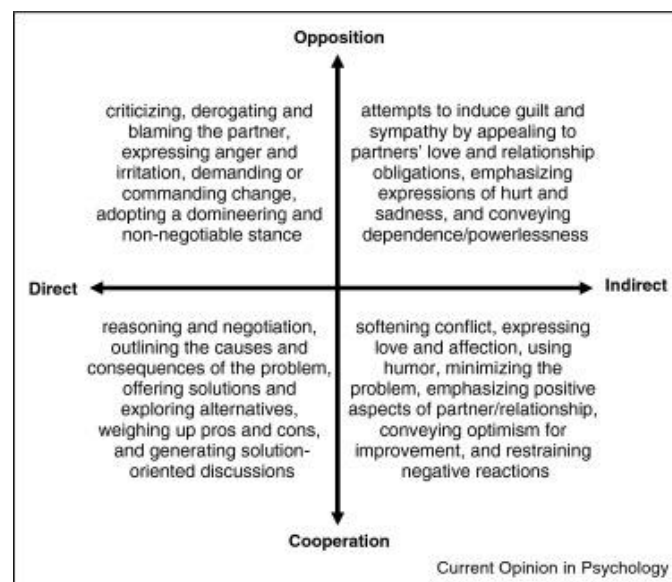
Besides shared goals, mutual respect could also be seen as a factor that is considered important for the coordination and communication between formal and informal carers. Different studies have shown the importance of respect shown by formal to informal carers and the acknowledgement they show for the role of the informal carers. (Funk & Stajduhar, 2013; Rapaport et al., 2006; Stephan et al., 2015; Wiles, 2003) Stephan et al. (2015) studied the collaboration during the care of people with dementia. The results of this study show that informal carers find it important that their advice is considered by the formal carers and that they value the knowledge and experiences of the informal carers. In addition, the study of Rapaport et al. (2006) shows the importance of recognition by formal carers to improve the collaboration with informal carers of people with mental health problems. Both studies show the importance through surveys, semi-structured interviews and interviews of informal carers for people with dementia or mental health problems. By means of this study, it will become more clear how informal carers of people with a physical disability and cognitive impairment experience the recognition and respect by formal carers.

### 2.2.3. Shared knowledge

Informal carers depend on the additional support and information of formal carers and facilities. Therefore, the collaboration between informal and formal carers is important. (Chan et al., 2020; Hoefman et al., 2011) Different aspects are important to take into account, including the distribution of all known information and the presence of a permanent contact person with the knowledge of the whole care trajectory of the patient. (Walker & Dewar, 2001) Shared knowledge of the division of the different roles and tasks is necessary for informal carers to determine their responsibilities. (Røthing et al., 2015) This research will provide more insight into how the informal carers of people with a physical disability and cognitive impairment experience the knowledge exchange and if their tasks and roles are clear.

### 2.3. Communication styles

As stated before, communication is important to maintain relational coordination. (Gittell, 2011) For an efficient coordination of care, frequent, timely, accurate and problem-solving communication is important. However, information can be communicated by using different communication styles. The use of different communication styles results in a different nature of the relationship. More cooperation in the communication is expected, as this is typical for a communication with shared goals. (Overall & McNulty, 2017) Yet, another type of communication results in a shift in the dynamic of the relationship between formal and informal carers and contributes to the experience of the conversation. The four different communication types described by Overall & McNulty (2017) are distinctions between direct and indirect communication and opposition and cooperation (figure 3).



**Figure 3: Communication style Matrix (Overall & McNulty, 2017)**

Direct communication involves the exchange of information and thoughts primarily through the use of words. This is in contrast with indirect communication where the message is not conveyed by the use of words but includes also the use of non-verbal communication. (Hendry & Watson, 2001) Indirect communication of information and thoughts are not unambiguously or straightforwardly, but it is hidden in the message of non-verbal actions. The Communication style matrix not only distinguish indirect and direct but also cooperation and opposition. (Overall & McNulty, 2017) Cooperation involves communication about aligned goals and motivations. However, opposition communication expresses conflicting and contrasting goals. This study will provide more insight into the nature of the communication styles of formal carers and the impact of these styles on the experienced collaboration by informal carers with formal carers.

## Chapter 3. Research methods

### 3.1 Study design

A qualitative study is performed to research stories of relatives of people with a physical disability and cognitive impairment. These stories were analysed through a narrative storyline analysis. (Murray & Sools, 2015) During this analysis, an abductive research approach is used to explore all possible theoretical aspects, which enabled the discovery of novel insights. (Janiszewski & van Osselaer, 2022) This method is chosen because the narratives give more insight into the uncensored experiences of the informal carers related to the collaboration with formal carers, compared to other research methods. (van de Bovenkamp et al., 2020) After the storyline analysis, a thematic analysis method is used to analyse overarching themes between the selected stories.

### 3.2 Data sampling

For this study, narratives written by informal carers of people with both a physical disability and cognitive impairment have been analysed. The books used for this analysis are collected from a collection of books managed by Erasmus School of Health Policy & Management, based at the Erasmus University. This collection consists of around six thousand books written by different authors about different types of conditions/disabilities. Through the website, patients' experience stories ("[www.patientervaringsverhalen.nl](http://www.patientervaringsverhalen.nl)"), an overview of the books was consulted for the selection of a list of books written by relatives of people with physical disabilities and cognitive impairments. Subsequently, the selection of the books used for this analysis was selected through purposeful sampling, where different variables were used. (Palinkas et al., 2015)

The variables that were used for purposeful sampling included the inclusion and exclusion criteria. The inclusion criteria were: 1. The author has experience with the collaboration in a broad sense with formal carers or the professionals within the healthcare system; 2. The author is a relative of a person with a physical disability and cognitive impairment. The exclusion criteria were: 1. Non-Dutch writers are excluded because of the difficulties with the interpretation of the words and meanings and the differences in healthcare systems; 2. Books written before the year 2009 were excluded from the selection, because of the development of the healthcare system over the years.

Apart from these inclusion and exclusion criteria, other variables were included to ensure the variability within the different selected books and to increase the variation. These variables are as follows: both male and female writers were selected, with different family relationships with the person who has the physical disability and cognitive impairment. This variability ensures the

perspective of different types of authors. Furthermore, the relatives of the authors not only included persons with just a physical disability. Out of this first selection, 6 books were selected for the storyline analysis for this thesis. The length of the selected books varies between 96 pages to 371 pages. These books are shown in table 1, which gives an overview of the variations, including the family relationship, the title, the length of the book and the disability of the relative.

**Table 1: selection of books**

Title	Author	Family relation	Disability of relative	Pages	Reference in text
<b>Een glaasje rosé bij het ontbijt</b>	Lies Niesing	Daughter (author) and mother	Parkinson's disease	138	B1
<b>Een huis voor Hannah</b>	Beer Boneschankser	Father (author) and daughter	Multiple disabilities	143	B2
<b>En toen kwam Jesse</b>	Monique Lutgens-Blom	Mother (author) and son	Mutation on SON-gene – multiple disabilities	371	B3
<b>Loslaten doet pijn</b>	Marianne Swinkels	Mother (author) and son	Metabolic disease – multiple disabilities	297	B4
<b>Brigitte</b>	Guido Bindels	Father (author) and daughter	Multiple disabilities	239	B5
<b>Judith</b>	Marlies ter Doest	Mother (author) and daughter	Multiple disabilities	96	B6

### 3.3 Data analysis

#### 3.3.1 Storyline analysis

The collected data has been analysed according to the narrative analysis described by Murray & Sools (2015). The narrative analysis described by Murray & Sools (2015) is composed of five parts. However, only some of these steps have been used for the analysis of the stories. The parts that have been used include the introduction of the narrative and the storyline analysis (table 2). The analysis starts with the general information of the book, which includes a summary and the identification of the target audience, the intention of the author to write this book and the first impression when reading the book. This general information is followed by the storyline analysis that consists of the identification and description of the important agent, actions/events, means/ helpers/ obstructors, setting/ scene, the intention/ goals and the breach. (Murray & Sools, 2015).

**Table 2: Steps of the storyline analysis**

Parts	Steps
<b>Introduction</b>	<ol style="list-style-type: none"><li>1. Formulate the title of the book</li><li>2. Book classification</li><li>3. Book summary</li></ol>
<b>Storyline analysis</b>	<ol style="list-style-type: none"><li>4. Formulate storyline title</li><li>5. Formulate storyline elements</li><li>6. Storyline summary</li><li>7. Draw conclusion based on step 4-5</li></ol>

### 3.3.2 Thematic analysis

The aforementioned steps have been followed up by a comparative analysis of the storyline elements described in step 5 of all six books. This paradigmatic analysis is constructed by the identification of in common and contrasting aspects between the different storylines within the six books. (Sharp et al., 2019) These common and contrasting aspects have been categorised into different themes and have been used to reflect on the theoretical framework. Abductive research has been conducted in order to complete the theoretical framework to make it fit the themes found within the storyline analysis. (Janiszewski & van Osselaer, 2022) Three different themes have been formulated to describe the common and contrasting aspects.

### 3.4 Validation and reliability

In order to ensure the quality and the trustworthiness of the study measures have been taken into account. The quality criteria described by Mays & Pope (2000) have been used to ensure the validity of the study. A clear and comprehensive description of the methods is used in this study, including the analysis of the books. This description ensures the transparency of the research process and the collected data. The description of the storyline analysis also allowed for a thick description. The introduction of the book, including a summary and a book classification that outlines the narratives, allows the reader to trace the logic of the research and increases the transferability of the research. Respondent validation could not be initiated to validate the results of this research and increase the credibility. The books used for this research have been written without the interference of the researcher and are independent of this study. However, to increase the credibility, a peer debriefing allowed the researcher to validate the interpretations of the data by consulting with peers and care recipients to provide feedback on the findings of this research. In qualitative research, confirmability is challenging because of the role as the researcher. The experiences of the narrators are interpreted

by the researcher to form the results of the study. Nevertheless, in order to explain the role of the researcher, a reflexivity statement on the background of the researcher is enclosed to determine the influences of the background of the researcher on the results of this study.

### 3.5 Ethical aspects

Qualitative research requires the consideration of different ethical aspects: anonymity, confidentiality and informed consent. (Shaw, 2003) All the used books are conducted for this study are published by the authors, so the stories are accessible for everyone. Therefore, the informed consent by the authors was covered for this study. No confidential information was written down in this report, but personal information, such as names, was not anonymised, because all the written information is publicly accessible. Furthermore, a power difference between the researcher and the author is not applicable for this study. (Eide & Kahn, 2008) The authors have written their books without the interference of the researcher. As a result, the books are not affected by the input of the researcher.

## Chapter 4. Results

Different aspects that have an impact on the experience of informal carers in relation to the collaboration and coordination with formal carers are identified in the analysed storylines. These themes are described as follows: (1) the role of informal carers; (2) equality between formal and informal carers, and (3) trust in formal carers (table 3). The experiences depend on whether the intentions of the informal carers are met and the different themes will likely contribute to this. These themes will be further explained and subdivided into different subcategories (table 3). Below, an in-depth description of the different subcategories will be presented.

**Table 3: identified themes and subcategories that influence collaboration**

Themes	Subcategories
Role of informal carers	Intentions of informal carers
	Tasks of informal carers
	Distribution of task between carers
Equality between formal and informal carers	Bureaucracy
	Recognition
	Communication
Trust in formal carers	Fast changes through the labor market
	Information exchange
	Emotions

### 4.1 Role of informal carers

The role of informal carers is considered important related to the collaboration and the coordination of care with formal carers. The role of informal carers is influenced by the intentions and roles of informal carers and the different tasks and the distribution of those tasks between formal and informal carers. These intentions and tasks will be further explained in the following section.

#### 4.1.1 Intentions and goals

In the narratives, the intentions of informal carers are the drivers behind their actions. Different intentions are identified in the analysis of the six books. The intention, which is most often described by the narrators is the intention to provide the best possible care for the care recipient by both formal and informal carers to create an optimal quality of life for the care recipient.



*“All doctors told us that Bryan’s disease and symptoms are simply too complex. But I had to believe that there was something that could make the life of Bryan a little bit easier.” p. 133 (B4)*

In this case, the informal carers of the care recipient wanted to find something to increase the quality of life for the care recipient. However, in some cases, informal carers experience that the care standards of formal carers do not align with their standards. Additionally, narrators experience misleading information provision where the stated information provided by formal carers does not align with practice.

*I send a letter with my complaints to the director of the nursing home. It takes long before I get a reaction. After a number of reminders from my side, I finally got a response after a month and a half. The director understands my complaints, but despite the understanding, he believes that the provided care is still adequate.” p. 44 (B1)*

The narrator experienced that formal carers also had the intention to provide the best care to the care recipient. Nonetheless, a difference in the perceptions of ‘the best care’ is experienced between formal and informal carers. Despite this difference, informal carers still experience the drive to provide their perception of the most optimal care.

Another intention that occurs frequently is the intention for informal carers to lower the care burden with the collaboration with formal carers.

*“The home care is there till eight o’clock and I make sure that I am home around half past seven. Today I worked until six o’clock and I had a glass of wine with my girlfriend in a café afterwards. It is a bit strange to make time pass like this, but it is also strange to be at home the whole time while someone takes care of Hannah. That is not something I can do well, I would automatically take over the care. And the home care is here to relieve my burden.” p. 29 (B2)*

One of the identified intentions of informal carers is to relieve the burden they experience by collaborating with formal carers. Yet, different informal carers mention in the stories that it is difficult to let go of the tasks initially performed by them, because of guilt towards the care recipient. The collaboration with formal carers results for different informal carers in an increase in different burdens, including an increase in feelings of guilt.

*“Judith goes to the guest house [logeer huis] every first Friday of the month. I find this terrible. However, it is the right thing so that I can refuel, but my goodness, what do I feel guilty and what do I miss her!” p. 33 (B6)*

Besides an increase in burden as a consequence of the increase in emotions and feelings of guilt, informal carers also experience a loss of control over the situation when collaborating with formal carers or an increase in administrative tasks.

*“I felt pressure, tenseness, anger and incomprehension and ideally I wanted to scream from the top of my lungs because I did not have control over the situation [care recipient was not yet welcome to a daycentre and the informal carer needed to arrange the stay to another facility]” p. 148 (B3)*

Although in some cases and circumstances informal carers experience an increase in care burden, informal carers also describe the experience of a decrease in care burdens. In the following case, the care recipient needs care for a longer period of time in the hospital and the informal carer is with the care recipient the whole time. The formal carer advises the informal carer to take some time off to take care of herself.

*“Our paediatrician told me that I need to spend the night at home. I needed to rest for a while, the nurses would call when something was wrong. Although this was hard for me, I went home after the song ritual. [...] This had not happened to me in years, but the next morning I overslept. [...] ‘Sorry, I overslept,’ I said hurriedly. ‘That is not something you need to apologize for.’” p. 243 (B4)*

The assurance of formal carers experienced by informal carers results in a decrease in the burdens of the different tasks carried out by informal carers.

#### 4.1.2 Tasks of informal carers

In the narratives, different tasks carried out by informal and formal carers are identified. The first task described by informal carers includes the task to provide paramedical and medical care to the care recipient. This type of care is performed by both informal and formal carers. However, a shift is identified in the distribution of tasks between informal and formal carers. Firstly, informal carers experience more paramedical and medical care provided by formal carers, but after a longer period, this care is shifted to be provided more by informal carers.

*[After a few tries to describe the medication plan] "She had tried it six times, but it just did not work. 'I just do not understand how this is possible,' she [the nurse] said disappointed. 'Would you please do his medication yourself?' p. 250-251 (B4)*

Although in this case, the informal carer did not mind taking over the task to provide the medication, in other cases informal carers experience aversion to carry out paramedical care. Narrators of the stories experience that their role as a parent suffers from the paramedical tasks and that they are not able to carry out the role as a parent for the care recipient.

*"Every day we practice with Judith. We try to get her to turn from her belly to her back. We lay her on her stomach in order for her to lift her head. We 'cycle' with her legs, we let her feel different materials... Just, because she does not do anything on her own. Are we specialists, physiotherapists, or dad and mom? At a certain point, I am done with it. Every evening practising with her leads to frustrations, and I am not a physiotherapist but her mother, thus I am going to behave like her mother and leave the physio work as it is." p. 21 (B6)*

The stories also identify the importance of the family bond between informal carers and care recipients. Because of this family bond informal carers experience a more closer relationship with the care recipient compared to formal carers. The narratives describe the care provided to care recipients with both a physical disability and a cognitive impairment. The stories show the responsibility experienced by informal carers to speak up for the care recipient and to make sure the voice of the care recipient is heard by formal carers.

*"Jesse could not stand up for himself, we as parents had to do that for him." p. 114 (B3)*

In addition to the task to stand up for the care recipient, informal carers also experience the responsibility to take on administrative tasks. The tasks described by the narrators include among other things the arrangement of finances, transportation and medical equipment. In the following case the informal carer needs to apply for a request for an administration order [Verzoek tot onderbewindstelling] in order to make decisions for the care recipient. This request needs to be applied to the court

*"We [court in Dordrecht] sent you a form that you need to fill in. Thereafter, you need to appear before the subdistrict court judge. And after that we expect you to completely keep records of all the income and expenses of your daughter, in detail." p. 133 (B4)*

#### 4.1.3 Distribution of the tasks

As seen in the case described above, informal carers experience the task, to keep up the administration, to be enforced by the court and not voluntarily performed by the informal carer. Other stories also display tasks performed by informal carers where they experience that these tasks are enforced by formal carers. Moreover, the stories show that the tasks are distributed because informal carers take on the tasks themselves when they experience that the tasks are not performed by formal carers. In the next case, the informal carer experiences that the procedures that the informal carer needed to perform would probably lead to a change in bond with the care recipient and chooses not to perform this task.

*“At first, the intention was that I would perform this procedure with Jesse. I did not think that was a good idea, because I did not want to do unpleasant procedures to him, I wanted to be there for him, to comfort and reassure him during the colonic irrigation. [...] Fortunately, this is not a problem and it was decided that home care would come and do this daily for two weeks.” p. 170 (B3)*

In this case, the informal carer chose not to perform a certain task and experienced the distribution of tasks as a mutual agreement, resulting in the task being performed by formal carers. This case shows a mutual agreement, however informal carers experience an impact of rules and protocols of the Dutch Healthcare system on the distribution of tasks between informal and formal carers. The impact experienced in the stories will further be explained in the next section.

#### 4.2 Equality or inequality between informal and formal carers

Informal carers experienced that equality positively influences the collaboration with formal carers. However, informal carers also encounter inequality, because of rules and protocols within the healthcare system. This experience of equality and inequality will further be explained below.

##### 4.2.1 Bureaucracy

Informal carers experience that rules and protocols as part of the healthcare system in the Netherlands are adhered to by formal carers. They encounter that all the rules and protocols are followed for every situation, even when the specific situation for the care recipient differs from the standard situation. The next case indicates a situation where the health status of the care recipient remained the same even when the care recipient grew older. The informal carer applied for a new disabled parking card, but additional information about the health status of the care recipient even when the health status remained the same. The rules for the application of a disabled parking card involve the need for an appointment with an independent doctor in all situations.

*“he looked from behind his desk only to Brigitte and then to use and asked: “What are you doing here?” We told him that we needed a paper with his signature and he shook his head. “What a nonsense that they send you here with your daughter.” Nonsense or not, they continue to do that.*

*Rules are rules. What has to be done, has to be done. Right?” p. 135-136 (B5)*

Despite the explanation of the informal carer about the situation and the impossibility to meet the requirements of the stated rules, it is still necessary for informal carers to adhere to the rules and protocols indicated by formal carers. These rules and protocols depend on the formal carer and their personal opinion and their interpretation of the rules and protocols. In some cases, a firm explanation by informal carers does not lead to a change in protocol. However, in other cases, a firm explanation resulted in a change in decision by the formal carer.

*“I find we have the right to have an overhead lift. I tried both an overhead lift and a moving lift [rijdende lift], and I ‘hung’ in both lifts. ‘Being transported’ with the moving lift [rijdende lift] (the so-called ‘iron nurse’) is very unpleasant. [...] An overhead lift, on the other hand, is awesome. [...] It would be ideal for Judith. [...] An ‘iron nurse’ is sufficient, according to these gentlemen [ombudsman of health insurance company and representative of the Mentally Disabled Act]. This is something really unexpected! But the discussion continues and eventually, I succeed in convincing them.” p. 66*

*(B6)*

In this case, the formal carers change their opinion and their decision because of the information that is provided by the informal carer. The information includes the care that is provided by the informal carer. Nonetheless, in other cases, the additional information provided by the informal carer does not result in a change in the decision of the formal carer. This results in some cases in non-adherence by informal carers to the rules and protocols imposed by the government and formal carers.

*“This is it. He is not going to get this medicine anymore! I was furious. Furious on the metabolic doctor with his stupid theory.” p. 274 (B4)*

As seen in this case a disagreement about the protocol results in a resistance of the informal carer against the rules and/or protocols, but also against the opinion and decision of the formal carer. This resistance is a consequence of whether informal carers and care recipients feel like they are heard by formal carers and healthcare system and that their needs are heard and met.

#### 4.2.2 Recognition

Different narrators described the experience of not being heard by formal carers providing care to a care recipient. The knowledge they have about the care status of the care recipient and the care that is necessary in order to increase the quality of life is experience to be missing for formal carers. However, in the process of providing the optimal care informal carers experience that their knowledge is not always taken into account when decisions about what care to provide are made.

*“We make an appointment for the preliminary meeting with my mother, where we can once again point out all the problems, which will then be discussed in the multidisciplinary consultations and then again in a debriefing with me and my mother so that there will finally be a real care plan in which the staff can read how my mother should be cared for. [...] I list all my complaints regarding the inadequate care. [...] But when I received the results of this consultation in August, I did not find anything of the point addressed by me.” p. 45-46 (B1)*

This case shows that informal carers experience ignorance of their input and knowledge by formal carers even when their input has the goal to improve the quality of care and life of the care recipient. Informal carers experience that formal carers do not take them seriously. Additionally, in different cases, informal carers experience the feeling that the care recipient is not recognized as a human being that needs care, but as a medical case.

*“He introduces himself as a geneticist. “I already see it, I know this from my practice, this is nothing and will become nothing,” he points to Roger’s sister. “This girl will not get old,” he says, staring at our daughter. [...] This is the first real information that we get. So we keep on asking. The geneticist answers with confidence. A man of practice. Right? A man of books and above all science, a man who, it turns out, sees Brigitte as a ‘beautiful medical case’ and not as a ‘beautiful person’.” p. 19-20 (B5)*

The experienced lack of recognition results in an aversion to the collaboration with formal carers, but also results in experienced differences in communication by informal carers.

#### 4.2.3 Communication

The equality and recognition between formal and informal carers are also seen in the narratives as the way formal carers communicate with informal carers. Different communication styles of formal carers are identified in the narratives. In some cases, informal carers experience a communication style where the information is communicated directly. Additionally, in cases where informal carers encounter a

decision communicated directly that they do not agree on, they experience no room for discussion for a solution for a mutual agreement.

*“We also had to handle with the insurance company who decided that five diapers were sufficient. ‘Five diapers per day is the standard’, they said. Hannah uses six or seven diapers per day, but that did not count.” p. 64 (B2)*

In this case, the formal carer did not provide room for the informal carer to react and explain their personal situation. It is rather a statement than a conversation among equals. As a result, informal carers perceive that there is no room for them to be involved in the solutions and just need to follow the decisions and solutions brought by formal carers. Informal carers need to deal with it and think of a solution by themselves instead of together with the formal carer.

However, the narrators also described a case where informal carers experience communication with formal carers where formal carers only show their emotions. In this case, informal carers are not always aware of the intention behind the reaction of formal carers and experience difficulties in responding to this reaction.

*“When after five minutes of alarm sound still no one enters the room, I decide to help my mother to the toilet myself, but by then it is already too late. While I am changing my mother, Lara comes in, a nurse I do not know yet. I express my dissatisfaction about the way things are going, and then an incredible outburst of anger follows on her part. [...] She does not even want to stand in the elevator with us and demonstratively gets out when I go upstairs with my mother to the dining room. [...] In the hope that Lara will not take out her aggression towards me on my mother, we melancholically go home.” p. 106-107 (B1)*

The informal carer was left with more questions and fear after the conversation with the formal carer. Therefore, this way of communication experienced an increase in burdens for informal carers.

On the other hand, some informal carers encountered formal carers who left room for discussion and opened up about the options in a direct manner. In the following case, informal carers did not agree on the observation method provided by formal carers at first. The informal carers experienced some room for discussion and the formal carer did agree with the opinion of informal carers. Together, formal and informal carers came to an agreement.

*“Do you have a camera with which you can film Bryan during an episode?” he [neurologist] asked. ‘If you can send me the footage, I can take a look at it.’ We agreed on this.” p. 182 (B5)*

This way of communication is experienced as a more problem-solving manner for all parties. This results in a solution that works for both formal and informal carers instead of only a solution that works for formal carers that informal carers need to agree on.

### 4.3 Trust or distrust in formal carers

Informal carers consider trust to be important when they collaborate with formal carers. Different factors influenced the amount of trust in formal carers, including the regularity of carers and the information exchange. These factors will be further explained in the section below.

#### 4.3.1 Regularity of carers

Having a collaboration with a regular formal carer or multiple regular formal carers is seen as a positive experience by informal carers. Collaboration with a regular formal carer ensures that both the informal and formal carer have knowledge about the whole trajectory of the patient/client. Without the proper knowledge about the client/patient, the right care is not provided.

*“I immediately got straight to the point and told what was going on. This general practitioner did not know Bryan and I hoped to clarify to him how serious the situation is. [...] I really need the other crème. [...] I knew all the medication he had ever received by name, so I knew very well what I was talking about. He [the general practitioner] understood what I meant, but did not know the situation of Bryan that well to make decisions on his own. Our own general practitioner was on holiday and we had to wait till he came back ” p. 153-154 (B4)*

In this case, the regular formal carer was not able to attend the appointment, and therefore a substitute formal carer handled the situation. Due to the tight labor market in healthcare in the Netherlands, a high employee turnover is experienced. This tight labor market also results in the deployment of temporary staff in healthcare organizations. As a consequence of the high employee turnover and the deployment of temporary staff, informal carers experience that some formal carers have a lack of knowledge of the care needs of the care recipients, as well as the needs of the informal carers.

*“But no matter how often I come, I cannot be present all the time. [...] I see to my horror that she is sitting at the table on a dining room chair without armrests. [...] I immediately sound the alarm and*



*contacted the nursing director. That evening, my mother appeared to have been nursed by temporary staff who apparently had little sense and had not received specific instructions about the residents. The nursing director herself calls it a disaster that was prevented because I came by.” p. 80-81 (B1)*

As mentioned in the example above, the temporary staff did not receive specific instructions about the client. As a result of the lack of knowledge of the formal carer, the informal carer and their relative experienced a lower quality of the. Moreover, the informal carer experienced a lack of knowledge about the formal carer, which resulted in a decrease in trust.

*“This week two home carers work independently while I am at work. Then I have to give up the care completely. That is nerve-wracking. Although I am used to people walking around my house, but these home carers have only just arrived and I need to fully rely on them.” p. 22 (B2)*

In this case, the informal carer experienced doubt and distrust in whether his relative is taken care of in the right way. The doubt occurs, because of the lack of knowledge about formal carers when they need to fully rely on them for the care formal carers provide and the lack of information exchange between informal and formal carers.

#### 4.3.2 Information exchange

As stated above, the information exchange between the informal and formal carers is important for the collaboration and to achieve a high quality of care by the formal carers due to the high employee turnover. Formal carers have the autonomy to decide what information to share with informal carers. However, the narrative analysis shows that the information exchange between formal and informal carers results in an increase in trust in the formal carer. Leaving out important information about the provided care and/or the health status of the care recipient during the collaboration between formal and informal carers results in some cases in a negative experience of the collaboration between the carers.

*“I did not like seeing this and I was not informed about this. At that time, I did not even know that this involved a restrictive measure for which caregivers had to ask for permission from the parents or guardians and that upon agreement we as parents had to sign for the use of the child restraint”  
p. 107 (B3)*

In this case, the informal carer was present when her relative was restrained. Regardless, the informal carer was not informed about the procedure performed even being present. This withholding of

information results in confusion and anger, but also in distrust in what the actions would have been if the informal carer had not been present during the situation. Additionally, informal carers might experience doubts about what other important information formal carers might have withheld. It also contributes to different care methods between the formal care and the informal care the relative receives. On the other hand, there are cases in which leaving out information resulted in more positive emotions for the informal carers.

*“One day the head of the neurological team at the university hospital called. He told us that they maybe knew what was happening to Bryan. [...] It was about a serious syndrome that they wanted to rule out with certainty. [...] On the internet, we found information about the syndrome and we were terrified. ‘I told you not to go looking for it,’ he said angrily. [...] He was absolutely right, the internet was not a reliable source, but I really did not hear it. We agreed that names of suspected syndromes no longer would be mentioned.” p. 106-108 (B4)*

In this case, the information about the health status of the relative told by the formal carer brought more damage to the collaboration. The informal and formal carers came to a consensus to refrain from giving the information about the health status when the formal carers are not yet completely sure about the medical information. Besides the choice of whether or not to provide each other with the necessary information informal carers also experience the exchange of untruthful information.

## Chapter 5. Discussion and conclusion

This research focuses on the exploration of the collaboration and coordination of care between informal and formal carers. The experience of informal carers related to this collaboration and coordination is studied. The use of narratives of informal carers about their experiences of their lives with a relative with a physical disability and a cognitive impairment helped to find an answer to the question:

*How do informal carers of people with a physical disability and cognitive impairment experience the collaboration and coordination of care with formal carers in long-term care?*

A variety of experiences of informal carers in relation to the collaboration and coordination have been seen in the selected narratives. Different aspects have been identified to have an impact on the experiences of informal carers. This starts with the intentions of informal carers to provide care identified in the narratives to obtain the most optimal health status for the care recipient. This is in line with the intention described in the Informal care model as one of the drivers for informal care. (Broese van Groenou & De Boer, 2016) However, intentions described in the narratives also include the intentions for the collaboration with formal carers, which include a decrease in burdens. This finding is in line with the supportive role of formal carers described by Weinberg et al. (2007). The collaboration will likely be negatively affected when informal carers experience a difference in intentions with formal carers and if informal carers do not experience any contributions or support from formal carers to achieve their goals. When informal carers feel that their intentions are acknowledged and shared by formal carers, the collaboration will presumably be positively affected.

Secondly, the narratives showed that tasks performed by informal carers depend on whether informal carers experience the contribution and support to achieve the intentions by formal carers. When informal carers experience differences in intentions or acknowledgement, the distribution of tasks is different than for informal carers who experience similarities in intentions or the support of formal carers. The tasks identified vary from administrative tasks and (para)medical tasks, but also the task to ensure that the needs and preferences of care recipients are heard and pursued by formal carers. This is in line with the already existing theory about the reasons why patients with a physical disability and cognitive impairment strongly rely on informal carers. (Feinberg & Whitlatch, 2002) The distribution of tasks without input from informal carers will likely result in a negatively experienced collaboration with formal carers.

In addition, the impact of protocols and rules of the Dutch healthcare system presumably influences the experience of informal carers. When formal carers fully comply with protocols and rules without recognizing the knowledge of informal carers, this will likely negatively influence the experience of informal carers. The negative influence because of the lack of recognition and consulting the skills and knowledge of informal carers is in line with the support needs and societal recognition and shared knowledge of the relational coordination concept. (Gittell, 2011; Plöthner et al., 2019) Relational coordination describes the importance of shared knowledge for the coordination between professionals. This is partially in line with the experiences of informal carers. In some cases, the choice to not share certain information by formal carers is preferred by informal carers.

Mutual respect also plays an important role in the collaboration. By experiencing to be recognized and important, informal carers will likely feel heard and respected by formal carers. This recognition will likely contribute to a better coordination of care experienced by informal carers. This experience is presumably also influenced by the communication style of formal carers. In a collaboration where informal carers experience a more opposite communication, direct and indirect, as described by Overall & McNulty (2017) the collaboration is experienced negatively, compared to a more cooperative experience communication. The negative experiences are in line with the contextual effects described in the research of Overall & McNulty (2017).

The results also show the importance of trust in the experience of informal carers. In situations where informal carers gain the trust in formal carers, the experience of the collaboration will likely have a more positive outcome than in situations where there is a lack of trust. Without trust informal carers will not have the confirmation about the quality and sincerity of the work of formal carers. Informal carers find it difficult to gain the trust in formal carers when there is a high variety of carers due to the tight labor market. However, also without a regular carer, an optimal information exchange will contribute to an increase in trust and therefore will result in a more positive experience for informal carers.

### 5.1 Scientific relevance

The results of this study are mostly in line with the already existing theory about collaboration between professionals. However, the experience of informal carers provides additional knowledge about how this theory is experienced in practice. This will be further explained in the next sections.

The provision as described in the Informal Care Model is in line with the results of this study, where one of the drivers is the intention to obtain the most optimal health status and situation for the care

recipient and the affection and familiar bond with the care recipient. (Broese van Groenou & De Boer, 2016) However, this model does not describe the drivers for the collaboration with formal carers. These drivers include the goal to decrease burdens when providing informal care. This model only describes the external factors that influence the provision of informal carers to support formal carers, but the results of this study identified additional knowledge about the factors that influence the collaboration in the opposite direction. These factors include the need for support in order to reduce the burdens of informal carers. The expected role of formal carers to support informal carers is experienced differently by the narrators. (Peckham et al., 2014) The narratives show that the supportive role of formal carers evokes a positive experience, but mostly this supportive role is not experienced. Informal carers experience differences in intentions, that result in a conflicting experience instead of a supportive experience.

Although the concept of relational coordination by Hoffer Gittell (2011) describes the coordination between professionals, with the components: (1) shared goals; (2) shared knowledge, and (3) mutual respect form the basis for the collaboration and coordination experienced by informal carers. Yet, as mentioned above, informal carers do not always experience shared goals/intentions with formal carers. However, informal carers did not always experience shared goals with formal carers. Differences in intentions and goals also had an influence on the information exchange as an important part to have shared knowledge. However, the results showed a nuance in the concept of shared knowledge. Informal carers did not positively experience shared knowledge in every situation. In some cases sharing knowledge by formal carers increases the burden for informal carers. This is an addition to the informational needs and the shared knowledge described is already existing theories. (Gittell, 2011; Plöthner et al., 2019)

All these factors of the coordination of care between formal and informal carers cohere with the communication between formal and informal carers. Although relational coordination concept describes communication as something to be accurate, timely, frequent and problem-solving, the result showed mainly the importance of the problem-solving aspect of communication. (Hoffer Gittell, 2011) However, the results that add to this theory showed that although the communication is opposite communication it is more important that it is communicated directly instead of indirectly. (Overall & McNulty, 2017)

All the elements of the collaboration described are based on trust. However, this is not taken into account in the available studies about the collaboration with informal and formal carers. Available research that describes trust as an important component of collaborations is described about the

collaboration between formal carers, instead of informal carers and formal carers. (Sangaleti et al., 2017) However, this research shows the importance of trust between informal and formal carers.

## 5.2 Practical implications

The already available research about collaboration between formal carers corresponds with the wishes and needs of informal carers related to the collaboration with formal carers. However, the results of this study show that the experiences of informal carers are not in line with the theory presented by the existing literature and the collaboration is negatively experienced in different situations. This research will contribute to new implementations to improve the experiences.

The results of this study could contribute to increase awareness of the importance of care provided by informal carers and their involvement in the Dutch healthcare system. Their needs and wishes to collaborate with formal carers optimize this collaboration. One of these needs is the recognition and involvement despite the rules and protocols. Informal carers experience limitations in their involvement because the Dutch healthcare system is not yet fully designed for this type of care and the collaboration between formal and informal carers. Alterations could contribute to an improvement in being involved by formal carers.

Not only the adaptation of new rules and protocols could contribute to more awareness and involvement of informal carers. By adding information on the needs and wishes of informal carers to the curriculum of studies that educate formal carers, more acknowledgement will be created which could improve the experience for informal carers. This would increase awareness and knowledge for formal carers, but educating informal carers could also improve the collaboration with formal carers.

## 5.3 Strengths and limitations

This study brings new insights, because of the methodology used. Narratives that are used are written by informal carers themselves. The motivation for writing a book was not influenced by the intention that it would be used for research. Therefore, the written stories described their real stories without any interference from the researcher. This will lead to other insights than with other research methods where the researcher is more involved in the data collection.

However, this methodology also causes limitations which need to be taken into account. The first limitation relates to the method used for this study. The books used for this study are written by informal carers. Only a small part of the population that provides informal care has the time and the resources to write a book. The population that writes a book does not represent the whole population.

This also includes the motivation of the writers for writing the book. In general, books are written only when narrators want to convey important insights to the writer's target audiences. These important insights could include both positive and negative insights, but it is less likely that a writer writes a book about a situation that had a neutral impact on the writer. It is necessary to take into account that these books do not represent all the cases of informal carers. However, for scientific and mainly societal improvements the negative and very positive insights are most important to consider. Therefore, it is still relevant to analyse these books.

Furthermore, the sample size is also a limitation that needs to be accounted for. Due to the small sample size only a limited variation is available within the collected data. The small sample size is the result of the book collection and the focus of this study. Because of the sample size and the low variation the results of this study are not generalizable. However, the results are still relevant as a basis for more indebt research and for new implementation in society.

### 5.3 Future research

Future research would provide more in-depth knowledge about the collaboration between formal and informal carers. In this study, exclusively experiences of informal carers were taken into account. However, the collaboration between formal and informal carers also includes the experiences of formal carers. In order to improve the entire collaboration for both formal and informal carers, the experiences of formal carers are relevant to study further. The experiences of the collaboration from both the perspectives of informal and formal carers are required for future implementations to fit the preferences of both informal and formal carers. This study shows the aspects that will likely have an impact on the experience of informal carers. Nevertheless, further research should be carried out in order to establish a more in-depth representation of these aspects. This future research could include interviews, surveys or focus groups with a focus on one specific aspect. This way the exact impact of this one aspect could be analysed. This analysis could be useful for further practical implementations.

### 5.4 Conclusion

In conclusion, the experience of informal carers in relation to the collaboration with formal carers depends on different aspects and vary for different situations. These aspects include the support and acknowledgement of formal carers, information exchange, differences in intentions and trust in formal carers and the healthcare system. Although the differences are identified between different informal carers it can be concluded that the experience will likely be negatively influenced when the importance of informal carers is not acknowledged and when formal carers do not take informal carers seriously. More awareness of the importance of informal carers needs to be gained, which can start with the

education of new formal carers. But also more in-depth research on specific aspects that show their influence on the experience is necessary in order to make changes to the healthcare system. Based on these results can be concluded that changes need to be made to positively change the experience of informal carers to increase the quality of care for care recipients that rely on formal and informal care.



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## Appendices

### Appendix A – Personal reflection

The researcher has an active role in the method performed for this study, which leads to some subjectivity in the results, which could influence the results of this study. In this section, the researcher will reflect on her role in this study and the influence she had on the storyline analysis and subsequently on the results. The researcher has personal experience in providing care as an informal carer to a family member with a physical disability since a young age. Some problems described by the narrators of the books have been experienced by the researcher. Therefore, the impact of these problems is well known to the researcher, which ensures that the researcher can understand their problems well. However, this also brought up emotions during the analysis of the books which could have influenced the interpretation of the feelings of the narrators. This could have caused researcher bias by reflecting on her own experiences. (Wadams & Park, 2018) On the other hand, the experience of the researcher could also contribute to the identification of the small, underdeveloped problems written in the books that could have been missed by a researcher without any experience in providing informal care. The experiences of the researcher increased the motivation to find an answer to the formulated research question. Secondly, the researcher is currently pursuing a master in Healthcare management. During this master's program, the researcher learned about different concepts important for this study, including relational coordination, appropriate care and patient-centered care. This could have influenced the used theoretical concepts, which could have caused researcher bias. However, the researcher kept in mind that her background could have influenced the results of this study.

## Appendix B – storyline analysis

### BOOK 1

#### EEN GLAASJE ROSÉ BIJ HET ONTBIJT – LOES NIESING

##### I BOOK CHARACTERIZATION

###### General Impression of the Book

The book is written in chronological order and is divided into chapters, each describing a year in the life of the author and her mother. The author has written it from her perspective, but also incorporates many aspects of her mother's opinions and her mother's interactions with the caregivers. It is an easy-to-read text that evoked a lot of emotion in me. The emotions that surfaced while reading were horror at how people are treated this way. Sadness, I found it very tragic to read how the author's mother lived her last years.

###### Who is the audience/target group the author is addressing and why?

The author wrote the book to provide insights into how things are in nursing homes and to convey the understanding that something needs to change. She actually wrote it for everyone working in nursing homes, such as directors, team managers, trainers, and other staff members, but also policymakers or government employees. They can drive the changes. She also wrote the book for the children of residents and the residents themselves to create more clarity for the children about what goes on behind the scenes.

##### II STORY AS A WHOLE

My mother was a Parkinson's patient. She made the conscious decision to move to a small room in a nursing home. She noticed that, as a Parkinson's patient, she needed more help in daily life. My mother had been living in the nursing home for just half a year when she had an unfortunate fall, making hospitalization unavoidable. A nursing home was a more suitable option in her situation: rehabilitation could continue there, which would not have been possible in the home she lived in before her fall. Since my mother is an easy going woman who quickly adapts to given situations, she agreed. Soon, we met the responsible care manager, to whom we could direct all our questions and comments about care and her stay. She didn't tell us anything about daily routines. After a week in her new place, an examination and x-rays revealed that she had broken her hip. In the hospital, we were told she could certainly learn to walk again. At the end of January, the care manager told us that my mother would never be able to walk independently again and mentioned that an "adjusted" care plan was being made. I had never heard of a care plan. I also had no knowledge of a care dossier.

My mother had a neck alarm that she could use at any time, even at night, to call for help from the caregivers. She told me that the alarm was not always placed within reach when she went to bed in

the evening. Calling out in the closed room was useless, and apparently, no one noticed that my mother could not signal for help with her alarm. I wondered how well they were actually looking after my mother. There was an annual meeting where the project "Living My Way" was explained. This didn't really align with how my mother experienced the care. The breakfast prepared by the caregivers consisted of currant bread and a glass of fruit juice. The juice tasted strange, and when the caregiver showed the bottle, my mother saw it was a bottle of rosé. Because so much was going wrong with my mother's care, I kept a close watch on her medication. It was fortunate that I did this because the wrong amount was left in her medication container every day.

My mother's room was a mess. When I asked why the trash was lying there, the caregiver replied, "No idea, it's been there for a week." "I'm fed up with this," my mother said. "This is no life. They barely pay any attention to you. I think of the slogan 'Living My Way.' I suspect that 'my way' here refers more to the caregiver than the resident. I think I know my mother well enough to understand what's on her mind; she's had enough. Sadly, I concluded that the last weeks of my mother's care were entirely in line with my experiences during her entire stay: inadequate.

### III STORYLINE ANALYSIS

#### Storyline 1: Differences in the Definition of Adequate Care

**Agent:** Loes Niesing is a caring person who wants the best care for her mother, so she can get the most out of her life. Her perseverance helps her ensure the care she deems important for her mother is provided. During the care for her mother, Loes also shows her sensitive side, expressing her emotions and dissatisfaction.

"I love my mother very much and want to do everything to help her enjoy her life as much as possible" (p. 16).

**Acts/Events:** In many situations, Loes takes a lot of initiative to ensure the care for her mother is properly carried out. "I inform the care manager that I will personally monitor my mother's care as much as possible and will inform her, as the responsible care manager, of everything that goes wrong" (p. 46). Loes feels that taking the initiative is necessary because there are several incidents where the information provided does not match the care she and her mother actually experience. "As a result, there have been conversations with the residents, and the caregivers are now better informed about the care each resident needs,' she says" – "This doesn't really align with the way my mother experiences the care and the image I have of it." – "Moreover, my mother never had such a conversation" (p. 30). When Loes takes the initiative and communicates this to those involved, she often finds that the care staff acts without informing her first. "I don't know who instituted this ban,

so I decide to remove the sticker and put the walker back next to her seat" (p. 52). When Loes takes the initiative in her mother's care, she finds that communication from the care staff can lead to highly emotional interactions, such as anger. "The on-duty (substitute) caregiver calls me back, saying that her alarm is working fine. 'Your mother has lived here for years, she surely knows how her alarm works,' she says somewhat irritably. When I explain that it's probably due to Parkinson's disease, I get a sharp response. 'Listen, lady, I'm not your grandchild,' she shouts over the phone" (p. 73-74). Although Loes feels powerless and frustrated during these events, she does not show these emotions outwardly. Loes remains calm. "I leave it at that, but I do call the night supervisor that evening" (p. 74).

**Setting/Scene:** This storyline is set in a risky environment where inadequate care can cause problems for Loes' mother's health. "It turns out that my mother was cared for that evening by a substitute who apparently had little insight and had received no specific instructions about the residents. The head nurse called it 'a disaster averted' because I stopped by" (p. 80). Because Loes wants to reduce this risky environment, a competitive atmosphere develops between her and the staff. "I also give the lists to the care manager, suggesting that it might be a good idea to make such instructions for other residents as well, especially for substitutes, as a practical tool. The care manager doesn't seem too happy about it, but she does agree to include them in the care plan and dossier" (p. 58).

**Intention:** Loes' goal is the best and most optimal care for her mother and other residents of the care center. "After all my complaints over the past two years, I continue to hope for an improvement in the care for my mother and the other residents, perhaps against better judgment, which is why I agree to a conversation" (p. 57).

**Means/Helpers/Opponents:** The caregivers in the care center are both helpers and opponents in this storyline. Without the caregivers, Loes couldn't provide all the necessary care for her mother, so they are helpers. "Thanks to Jacomijn, a compassionate caregiver, we were made aware that my mother could have lunch with a few other residents in a kind of living room instead of alone in her room" – "We are grateful to Jacomijn for pointing this out to us" (p. 26). However, they are also opponents because, during several incidents, they do not act correctly, and Loes' mother does not receive the right care from them. "This total lack of empathy for someone who is completely dependent on the help of others is also evident in the carelessness regarding the alarm. ... The night staff knows that she needs to urinate at least once every night. How that goes exactly at night, I don't know, but I'm shocked when my mother tells me that it sometimes happens that she cannot operate her alarm at night and has to wait until the morning staff comes to get her out of bed" (p. 29). Nurse Sanne is a special helper in this storyline. Loes describes Sanne as knowing exactly what her mother needs. Even in her free



time, she comes to help Loes' mother. "That would be a good choice in itself because Sanne gets along very well with my mother" (p. 66). The occupational therapist is a helper in this storyline. She aligns with Loes' vision of the best care for her mother and helps Loes achieve this. "She also thinks a restraint belt is a bad idea and decides that another wheelchair should be obtained. ... So, we think it's a good idea to get her a lighter chair" (p. 85). A minor helper in maximizing the situation is her sense of responsibility and the trust or lack of trust. "In some cases, when I don't trust it, especially if there is a substitute, I go by to see for myself how things are" (p. 81). During these checks, Loes has had to help her mother several times because the care was not optimal.

Due to her sense of responsibility and problem-solving skills, Loes provides care for her mother herself, but it is not enough to improve the system within the organization. "I'm glad my mother has found a friend, but the care staff pays no attention to it. That's why I try to arrange a visit or phone call between them when I'm with my mother" (p. 27). This problem-solving ability has also led Loes to voice her concerns several times, including to the director of the care center. However, the director believes the care provided is adequate. The director is an opponent for Loes and her intention in this storyline because the adequate care described by the director does not align with how Loes experiences her mother's care. "The director is sympathetic to my complaints but still believes the care provided is adequate" (p. 44). The labor market shortage is also an opponent. Because of the shortage, many substitutes are needed. Loes finds that they are not aware of the care her mother needs. "It turns out that my mother was cared for that evening by a substitute who apparently had little insight and had received no specific instructions about the residents" (p. 80). The labor shortage is also noticeable because Loes and her mother experience many moments where the caregivers indicate they don't have time for certain care tasks. As a result, not all the care Loes' mother needs is provided. Protocols and work rules also play a role in the care provided to residents and Loes' mother. Due to various rules, such as during certain activities in the residential center, Loes' mother is not always included in these activities, even though Loes feels her mother enjoys them. "I see that my mother enjoys it; this is well-being in the truest sense of the word. However, it's a shame that the in-house activities often pass her by because the activities coordinator is not allowed to fetch residents from their rooms, and the caregivers often forget to remind her and bring her to the activities, even when I personally remind them on the day" (p. 70).

**Breach:** The break in this storyline involves a clash between Loes' intention, to ensure the most optimal care for her mother and other residents of the care center, and the risky environment in which Loes' mother lives and where Loes feels that optimal care is not provided.

**Storyline Summary:** When my mother is reasonably recovered from her hip surgery, we see what care for a nursing home resident looks like. My mother needs help getting in and out of bed and, with the help of her walker and a caregiver, can walk to the toilet by herself. She has a neck alarm with which she can ask for help at any time. Only after the first real conversation with the care manager do I realize that the care manager did not address my mother at all. In August 2006, an annual meeting is held for residents and family members. The project manager explains the project "Living My Way" in detail. This does not align with how my mother experiences the care and the image I have of it. I file a complaint, and after an investigation, I am proven right, but it does not lead to any improvement. The caregivers prepare my mother's breakfast based on the list I posted in her kitchenette and with the items I bought. My mother talks about her morning. The caregiver had set out bread and a drink, but the juice tasted strange, so my mother asked, "Is this fruit juice?" The caregiver showed her the bottle from which the juice came. "Oh," says my mother when she sees the bottle of rosé in the caregiver's hand, "no wonder it tasted strange." After a day with the family, I take her back to the nursing home. Upon arrival, I immediately turn on her neck alarm, but it takes twenty minutes before the loud, piercing sound stops when the caregiver finally comes in. "Why did you only respond after twenty minutes?" I ask her. "My mother could have been in an emergency."

### **Storyline 2: Communication is Key**

**Agent:** In this storyline, Loes is a persistent person who knows what care her mother needs and fights for it. She is not afraid to express her displeasure and anger to those involved. "I send a letter with my complaints to the director of the nursing home. A response takes a long time. After several reminders from me, I finally get an answer after a month and a half." (p. 44). Her helplessness also becomes apparent, as she is dependent on others. "Tirelessly, I report it all again to the responsible manager who promises improvement. In practice, we notice nothing; the care remains inadequate." (pp. 88-89). Despite the lack of response, she continues to take the initiative in making contact.

**Acts/events:** Loes experiences multiple incidents where agreements regarding the completion of certain administrative tasks for her mother's care are not upheld. "During this conversation, the care plan is discussed. According to her, 'the guideline for the care of every resident.' This care plan, after being revised earlier this year by the care manager, has never been discussed with us again, nor signed by us." (p. 31). Loes also experiences several incidents where her complaints about inadequate care are not addressed to improve the care. Moreover, she notices that there is no feedback on the complaints she submits. "After all my complaints over the past two years, I continue to hope, perhaps against better judgment, for improvement in my mother's care and that of the other residents, so I agree to a conversation." (p. 57). Due to the frequent turnover of care managers and directors, Loes

finds herself repeatedly explaining everything anew, with no action being taken. "I sum up all my complaints regarding the inadequate care. The list is diligently noted down. But when I receive the results of this meeting in August, I find none of the points I raised. The care plan is practically the same as the previous, uncompleted care plan." (p. 46).

These incidents, where Loes experiences significant communication issues, lead her to find ways to clearly communicate her needs to the caregivers. She attempts to convey information in different ways. "Meanwhile, I try to make it as easy as possible for the caregivers: in addition to the list of instructions that has been hanging in the kitchen for a long time regarding meals, I make a second list for the bathroom." ... "I have underlined the word cold because I have noticed several times that the caregivers leave her with a glass of lukewarm water." (p. 58). Loes also frequently asks for explanations when she perceives that information transfer is inadequate or when things are unclear. "Outraged because no one told me this, I inquire about the person responsible on the ward." (p. 107).

**Setting/Scene:** It is a volatile environment with frequent staff changes. This creates uncertainty about who the point of contact is for complaints, adjustments, and questions. "I try to immediately make an appointment with the care manager, but I am told that it makes little sense because she will soon be working elsewhere." (p. 31). It is a competitive/hostile environment where Loes's input is often met with hostility, and she is not always taken seriously in her communicated concerns.

**Intention:** Loes's goal is to be listened to and for actions to be taken based on her complaints and input.

**Means/Helpers/Opponents:** An opponent in this storyline is the departure of staff in the care sector. This results in many changes in care managers and directors, causing all information to constantly need to be transferred. "I try to address the problem many times with various responsible persons within the organization, such as the personal supervisor, team manager, project manager, coordinator of volunteers, etc., but I find no hearing." (p. 95). The information transfer is not adequate enough, resulting in Loes submitting complaints multiple times, which then lead to little or no action because new people have to pick it up. It is also unclear to Loes who is responsible, making it unclear whom to approach with questions, complaints, and changes. "Due to the rapid changes combined with the poor communication the nursing home excelled in, it was hardly possible to keep track of who was in charge." (p. 127).

A helper in this storyline is Loes's perseverance and tenacity. She continues to seek contact with new staff to ensure improvements and does not give up even though her trust is diminished. Her emotions/feelings are also a helper because they motivate her to take action. However, the emotion of the caregivers is a hindrance. When they communicate emotionally, no useful information is exchanged, and the communication between Loes and the caregivers is not optimal. "Loudly talking and irritated, she defends her late arrival. I don't know what hit me and try to signal with a hand gesture that she shouldn't shout so loudly near my mother, but that fuels the fire: 'Stay out of my way!' she yells." (p. 64).

**Breach:** The elements in this storyline that clash are Loes's intent and the story's setting. Loes's goal is clear. She wants to be listened to, for actions to be taken, and to be taken seriously. However, the setting consists of a volatile environment, making it difficult for Loes to build a consistent and effective relationship with those involved to achieve her goal.

**Storyline Summary:** The first real conversation with the care manager takes place when my mother has already been in the care center for six months. At the end of the conversation, I am told that an 'adjusted care plan' will be made, which can be signed again by my mother or by me on behalf of my mother. I am unaware of any care plan, let alone that I have signed one. In August 2006, there is an annual meeting where the project manager explains the project "Living My Way" in detail. This does not align with how my mother experiences care and my perception of it. Therefore, I decide to request a personal meeting with this project manager. During this conversation, the care plan is discussed. This has never been discussed with us since it was revised. I immediately try to make a telephone appointment with the care manager, but I am told it makes little sense as she will soon be working elsewhere. As long as there is no successor, two caregivers are designated as responsible. Changes reported to the medical service of the nursing home are not properly handled. When I finally get to speak to the care manager, he is busy. I file a complaint about the hygienic condition, and after investigation, I am proven right, but it leads to no improvement. I escalate the issue and send a letter with my complaints to the director. A response takes a long time. After several reminders from me, I finally get an answer after a month and a half. The director is sympathetic to my complaints but still believes that the provided care is adequate. I am invited to a meeting with the new care manager. She is shocked by my stories and wants to improve the situation. She says the care plan is indispensable for this. By now, I have lost all trust, but I don't want to be uncooperative. Almost indifferently, I agree. I sum up all my complaints regarding inadequate care. The list is diligently noted down. But when I receive the results of this meeting in August, I find none of the points I raised. The care plan is practically the same as the previous, uncompleted care plan. The situation does not change.

**Conclusion of the whole story:** Loes's mother has Parkinson's disease and must move to a nursing home due to its effects. The care professionals, including caregivers and care managers, along with Loes, are responsible for her mother's care, supporting each other in their roles as formal and informal caregivers. The collaboration between Loes and the care professionals requires shared goals as part of relational coordination (Hoffer Gittell, 2011). The goals set by the nursing home, communicated to Loes and her mother through brochures, state:

"Living My Way. During regularly recurring individual well-being conversations, you can discuss your wishes with us so that you can live your way as much as possible." (p. 22)

This aligns with Loes's goal for her mother, which is that she can continue her life in a similar way. However, due to the lack of timely conversations with both Loes and her mother, Loes does not experience the desired outcomes for her mother. The absence of these well-being conversations means there is no clear transfer of information indicating her mother's care wishes and needs. This information transfer is described by the care institution in the care plan. However, this care plan is not revised and discussed again, resulting in no accurate information in the care plan. This ensures that at least through the care plan, there is no common knowledge between Loes and the care professionals. When raising this issue, Loes does not experience problem-solving communication. There is no negotiation or joint discussion possible in the conversations Loes has with the care professionals because they express themselves with a lot of emotion. It can be concluded that a direct information transfer, where no nuance is possible, negatively influences Loes's experience regarding collaboration with the care professionals

## **BOOK 2**

### **EEN HUIS VOOR HANNAH – BEER BONESCHANKSER**

#### **I BOOK CHARACTERIZATION**

##### **General impression of the book**

The author expresses a lot of frustration about the care given to his daughter and how the communication and system work. The book is easy to read and consists of short chapters/days. There is a lot of emotion from the author, and this emotion is palpable when reading the book. The format of the book is to show the author's perspective.

##### **Who is the audience/target group the author is addressing and why**

The book starts with a Christmas story the author wrote for his friends. It is a diary of the period when his daughter Hannah moves back in with him. A diary is generally written to express one's thoughts, which is evident in the book. I think the book was published to give an insight into the author's life.

#### **II STORY AS A WHOLE**

The institution where the girl with beautiful red hair lived merged with another institution. It all seemed great, but they didn't actually know how to manage such a large institution. Where previously the wishes of parents and children were listened to, now both directors were very good at deciding for others without really listening. The institution was closing, and the only solution from the care office was not a good alternative. I could not and would not let Hannah go to a large institution. In recent years, efficiency and protocols had become more important than personal care and attention. Therefore, I took Hannah back home from the day the institution closed. Fortunately, Hannah could continue to go to her familiar day centre during the day. Only because it can't be helped, Hannah goes to a large-scale institution in IJburg on weekends, where there are only people with multiple disabilities. I can't manage the care alone, so from four to eight o'clock, home helpers come to the house to take care of Hannah when she is brought home by bus, feed her, and put her in the shower. I'm used to having home help around. These helpers are new, and I have to trust them completely. I have to blindly trust them. My ex found a special place for Hannah, the Maartenhuis, a tiny anthroposophical living community. The intake interview was good. Friendly people who are interested in Hannah. So different from the staff we knew from the years with the old care institution.

A lot is communicated about Hannah. The day centre has been writing a short email every day for years, and the home helpers communicate with me via a group app. The boarding house uses an old-fashioned notebook, but I want everyone to be informed about each other. "Hannah's well-being comes first" easily rolls off the tongues of directors and care offices, but in concrete terms, nothing

has been done for Hannah. This is not a game; Hannah's happiness is at stake. The Maartenhuis genuinely wants Hannah to come. They beautifully express that they believe Hannah not only has much to gain but also much to give. I am immensely relieved that this marks the end of the struggle, with arguments, false promises from institutions, manipulation, and the loneliness in advocating for Hannah. No more institutions treating Hannah like livestock, shuffling her between living spaces solely to secure high compensation due to the severity of her disability. Yes, we have a fantastic care system—perfectly detailed and regulated. But for whom? For Hannah? No, it's a brilliant system for advisors, therapists, and everyone else earning their living from it. But without a personal relationship, you cannot provide good care. The staff at the day treatment centre asked if I wanted to celebrate the farewell grandly. They wrote a sweet card for me and Hannah. It's not just a farewell for Hannah, but also for me. Hannah now lives here on Texel in the Maartenhuis. She lives in the place her mother and I envisioned: a home-like house. And I am no longer a caregiving father, but simply a father.

### III STORYLINE ANALYSIS

#### Storyline 1:

**Agent:** Beer is a caring father who wants the best for his daughter Hannah. He knows what he wants for his daughter and ensures it happens. “She is my most vulnerable child. I could not and would not let Hannah go to a large institution. Hannah needs to be seen, and you can only discover who she is by staying very close to her.” (p. 13-14). He knows his rights and is persistent in getting everything he and Hannah are entitled to. “Because Hannah has an intramural place there and the care institution receives full compensation for it, the institution must do it... So, I write a very pedantic email in which I refer to the compensation regulations in intramural care.” (p. 45).

**Acts/Events:** Beer experiences multiple events where something is asked of him that is not his responsibility and should be handled by others instead of being shifted onto Beer. “I found an email from the boarding house asking if I could send porridge. They had run out. Normally, Hannah gets her food from the boarding house, so this is a strange request. I didn't respond, but yesterday I got the same request for the porridge again. It remains a peculiar situation that the system contains an incentive that encourages employees to shift a problem elsewhere instead of solving it.” “I write to the boarding house that they can simply buy the porridge at the supermarket around the corner” (p. 98-99). Beer also experiences several events where communication by and with the care professionals is not optimal, which costs Beer extra time and energy. “At half past four, I text the home help but get no response. I call the coordinator of the home helpers, but she can't reach her either.” ... “When the bus arrives at five past five and I go upstairs with Hannah, I get a call from the coordinator that the home help thought she didn't have to work and that she is also sick at home in bed.” (p. 131).

**Setting/Scene:** The environment of this storyline is, on one hand, a supportive setting where the care professionals take care of Hannah, thus relieving Beer of some of the burdens. “Fortunately, Hannah could continue going to her familiar day centre” (p. 14). But it is also a rigid environment where the care system does not allow much room to make care easier for the family. The protocols and rules are written to make things easier for the care professionals.

**Intention:** Beer wants help so he can be relieved of the care for Hannah. “I wouldn’t be able to handle it well; I would automatically take over the care. And the home helpers are there to relieve me” (p. 29).

**Means/Helpers/Opponents:** In this storyline, the day centre, the home helpers, and the boarding house are helpers. They take over the care from Beer at certain times, thus relieving him. However, they are also opponents. The obstructive communication and the shifting of tasks create extra work for Beer. “I do all the laundry for Hannah, but not the bedding and towels used at the boarding house. Because Hannah has an intramural place there and the care institution receives full compensation for it, the institution must do it.” (p. 45). Protocols and rules can be helpers or opponents. “The delivery of the magazine for Hannah seems to be bogged down in bureaucratic rules again” (p. 119). They help Beer substantiate his argument that certain tasks are not his responsibility. However, they also create more tasks because Beer has to explain why Hannah is entitled to something and follow up to ensure it happens. “That indeed mentions that a new magazine must be delivered. But we already knew that! ... After another five minutes, I hang up the phone. Welzorg does not help! (p. 111-112).

**Breach:** Beer’s intention is to get help to be relieved of the care for Hannah. However, this conflicts with the setting, which is the care system. He relies on the support of the day center, the home helpers, and the boarding house. However, the setting creates additional obstacles and stress for Beer instead of relieving him.

**Storyline Summary:** Yesterday, today, and tomorrow, the new home helpers are coming because I cannot manage the care alone. Most Friday evenings, Hannah is with her mother. The rest of the weekend, Hannah is at the boarding house. The boarding house is the place where the care directors and the care office thought Hannah could spend the rest of her life. Only because there is no other option, she now goes there on weekends. This week, two home helpers are working independently. That is exciting. I must have blind trust in them! A lot is communicated about Hannah. I want everyone to be informed about each other; otherwise, I have to inform everyone. But the boarding house doesn't



even have an email address, so I have to forward the emails to the boarding house coordinator. Another task added. Hannah has an intramural place at the boarding house, so the institution must wash Hannah's sheets. However, these sheets came back dirty from the boarding house. So, I write a very pedantic email in which I refer to the compensation regulations in intramural care. With the diapers, we had to deal with cost-cutting measures at the old care institutions every so often. Then I had to explain repeatedly which diaper was best for Hannah. A year later, they tried to cheat again. I guess I'll write another email to the coordinator about it. Also, when Hannah doesn't need to be picked up by the driver, I'm not allowed to inform the driver. Because if people just inform each other that Hannah isn't coming, then the whole automated system won't work. Everything must go through the system. And who was that system for again? Not for Hannah or her father, that's for sure. It remains a peculiar situation that the system contains an incentive that encourages employees to shift a problem elsewhere instead of solving it themselves.

### **Storyline 2: Appropriate Care According to Beer**

**Agent:** Beer is a caring father who wants the best for his daughter Hannah. He knows what he wants for his daughter and ensures it happens. "She is my most vulnerable child. I could not and would not let Hannah go to a large institution. Hannah needs to be seen, and you can only discover who she is by staying very close to her." (p. 13-14). He knows his rights and is persistent in getting everything he and Hannah are entitled to. "Because Hannah has an intramural place there and the care institution receives full compensation for it, the institution must do it... So, I write a very pedantic email in which I refer to the compensation regulations in intramural care." (p. 45).

**Acts/Events:** During the care for Hannah, Beer has experienced multiple events where rules and protocols obstruct the care he believes is right for Hannah. These rules and protocols are followed not in Hannah's interest but in the interest of the care professionals. "We have always arranged the medication ourselves because we believe it is our responsibility as parents. The coordinator says they cannot work that way and that the medication must be packed in a Baxter roll. Who is that good for? For Hannah? No, for the caregivers. They must not make mistakes, so everyone must work according to protocols, which brings a lot of rigidity" (p. 49). Beer has also experienced several events where cuts by insurers and the government have led to fewer or no supplies being delivered, to Hannah's detriment. "At the old care institution, we had to deal with cost-cutting measures from time to time, and a manager would come and say that Hannah needed different diapers because those were the regulations" ... "Just cheaper diapers." (p. 63) and "We also had to deal with an insurer who decided that five diapers were enough. 'Five diapers a day is the norm,' they said. Hannah uses six to seven a day, but that didn't matter." (p. 64).

Besides the protocols and rules, Beer has also experienced multiple instances where care professionals acted in their own interest rather than Hannah's. "I get angry when I think about the ease with which Hannah is then placed somewhere random." (p. 42). Beer also frequently observes that the words of the care professionals do not match their actions. "'Hannah's best interests come first!' comes very easily out of their mouths, but concretely, nothing, absolutely nothing, is done for Hannah." (p. 51).

**Setting/Scene:** It is a bureaucratic environment where many rules and protocols take center stage, and care does not always come first. However, it is also a loving home environment where Beer creates the best living situation for Hannah. "She is my most vulnerable child. I could not and would not let Hannah go to a large institution. Hannah needs to be seen, and you can only discover who she is by staying very close to her. ... Therefore, I took Hannah home from that day, even though I didn't know if or when a place would be found for Hannah." (p. 14).

**Goal/Intention:** Beer's goal is for Hannah to receive the care she needs and that is in her best interest.

**Means/Helpers/Opponents:** In this storyline, the protocols and rules established by the government, insurers, and even the care professionals themselves are obstacles to providing appropriate care for Hannah. The protocols are followed blindly when it suits the care professionals, even if it's not the best situation for Hannah. "The delivery of the magazine for Hannah seems to be bogged down in bureaucratic rules again" (p. 119). However, several home helpers are helpers in this storyline. They look at what Hannah needs and adapt routines accordingly. "She arranged Hannah's pureed food on the plate like a flower with four petals. The white pills of her medication as decoration in the center. She gets it" (p. 27). Hannah's mother is also a helper. She ultimately found a suitable home for Hannah that provides the right care and is a helper. "Last week I heard from my ex that there might be an opportunity for Hannah on Texel" (p. 30) [...] "Hannah is allowed to come there... A weight lifts off my shoulders, and tears well up. I am immensely relieved that the struggle, with arguments, false promises from institutions, maneuvering, and the loneliness in standing up for Hannah, is over" (p. 39).

**Breach:** In this storyline, there is a clash between Beer's intention and the setting with its protocols and rules. The protocols and rules hinder Beer in his quest to provide Hannah with the care she needs.

**Storyline Summary:**

In the meantime, the care facility had transferred Hannah's residence to another care institution and, with the help of the care office, unilaterally terminated the care agreement with Hannah. Initially, the

other care institution promised to keep Hannah's house open, but those were just empty promises. Since I didn't find a new facility in IJburg to be a good alternative, I took Hannah back home from that day onward. In the facility, efficiency and protocols had become more important than personal care and attention in recent years. During the weekends, Hannah stays at the respite care house. At the old care facility, we frequently had to deal with cost-cutting measures regarding diapers, with yet another manager telling us that Hannah needed different diapers because those were the regulations. Just cheaper diapers. Each time, we had to explain what the best diaper for Hannah was. I was also given the protocol for cancelling Hannah's transportation. I have to call that number, where a lady enters Hannah's absence into the system. And who was that system for again? Certainly not for Hannah or her father, that's for sure.

**Conclusion of the whole story:** In this storyline, various aspects have influenced Beer's experience with the collaboration with professionals. Beer hoped to find that the assistance from care professionals would ease the care for Hannah. However, tasks described in protocols/rules were not executed as Beer had expected. As a result, Beer did not experience relief from care but rather additional work. Beer found this negative because he assumed care professionals would lighten the burden. Not only the tasks established through protocols but also agreements Beer made with care professionals were not always positively experienced by Beer.

The distribution of tasks and the communication about these tasks were also not always positively experienced by Beer. It cost him a lot of extra time, and he did not find the communication from the care professionals problem-solving and accurate. Missing communication led to more tasks and a different distribution of tasks for Beer. The information Beer and the care professionals had about a particular situation did not match. Beer experienced extra effort to ensure that the information was aligned again but missed this initiative from the care professionals. This led to less collaboration and more burdens for Beer

## **BOOK 3**

### **EN TOEN KWAM JESSE – MONIQUE LUTGENS-BLOM**

#### **I BOOK CHARACTERISATION**

##### **General Impression of the Book**

The book is a collection of various events from the life of Monique and her family and how they cope with Jesse's limitations. It is written in chronological order but also includes flashbacks to earlier times, which are well-described. The book presents Monique's perspective in a deeply personal way. There is a lot of emotion and misunderstanding, which evokes similar feelings in the reader. It is extensively detailed, which at times felt a bit lengthy to me. Despite this, it is a gripping story that you want to keep reading.

##### **Who is the Audience/Target Group the Author Aims at and Why?**

Monique wrote the book for herself. As she describes in her book: "This book is for my self-reflection, and I am glad that by writing this book, more things have become clear to me, and I have become more aware of things. I have gained a different perspective on life and see what is and isn't important." (p. 250) By writing this book, she has gained clarity on her role in the entire process described. She has also been able to process her emotions during the writing. This is evident not only in the afterword but also throughout the story, where she reflects on the events and her perspective on them.

#### **III THE STORY AS A WHOLE**

After trying to conceive through IVF for seven years, I eventually got pregnant spontaneously. It was a miracle! During the ultrasound, a male doctor explained in detail what could be seen. He pointed out all the organs of our little one and checked if everything was fine. By then, I was already thirty-six weeks pregnant. In the late afternoon, the midwife arrived. She examined me and concluded that there was a tear in the membranes. That same day, I had an ECG, and the result was: total rest! Finally, after thirty-six weeks and four days, I could meet our Jesse. Jesse was quickly taken away from me. He was weighed and measured and immediately placed in an incubator upstairs. After a whole day of labor, I finally had Jesse in my arms.

Yay! Jesse could come home! He drank all his bottles independently after three long weeks. When I picked Jesse up to cuddle him, he often cried. It was as if he wasn't used to being picked up without being fed. Soon, I thought, if only he could sit up. I always looked ahead instead of enjoying the moment. When Jesse was four and a half months old, he came to my work, to the daycare centre. Jesse's mentor told me she felt something remarkable was going on. They hadn't discussed it with me

or looked for a solution together, but instead followed the rules in the work instructions. When Jesse was fourteen months old, we went to the store. I looked at Jesse and saw his head fall forward onto the edge of the shopping cart. At that moment, a horror film started for me. I just wanted someone to tell me everything would be fine at the hospital. At the hospital, they thought it might be a febrile seizure or epilepsy.

Over the years, communication was a recurring issue. What I noticed was that Jesse's behavior was often negative. He also always sought a lot of closeness with the staff. I found it hard to accept that Jesse was different from other children. I wished for a normal child. I saw that he was in pain. I hoped they would find the cause of his pain and that my worries would disappear. The investigation revealed that Jesse was withholding his stool. I wasn't sure about it; I secretly doubted it. I thought something else might be wrong. The gastroenterologist wanted to do an MRI scan to check if the nervous system was intact and if there were any abnormalities. I also wanted an MRI scan of his head. There had never been a clear diagnosis of epilepsy. Kempenhaeghe diagnoses and treats people with complex epilepsy. Jesse was given Depakine, and we knew by then that Depakine could cause behavioral problems and/or hyperactivity in children. If Jesse was already hyperactive, Depakine wouldn't be a suitable medication. In addition to an MRI scan, blood was also taken from Jesse by a clinical geneticist. Later, out of the blue, I received a phone call. The professor told me they had found a mutation in the SON gene. They still didn't know much about this gene. The results from the Kempenhaeghe investigation were in, and Jesse could start weaning off Depakine. He seemed to be more aware of things and changed significantly in a short period.

Jesse has a different way of communicating, and I am Jesse's translator and guide to the outside world. I have gained a different perspective on life and see what is and isn't important. I was amazed that at Jesse's last school, they immediately spoke the truth and admitted it, which made me feel at ease. It was remarkable that Jesse had more peace of mind now that I was home for him. Gradually, I could let go of everything and find peace. Because I took more time for myself, I could tolerate more of Jesse, and there was less irritation, anger, misunderstanding, and unrest; I had unconsciously transmitted this to Jesse, who was super sensitive to it and immediately expressed it in unwanted behavior.

### **III STORYLINE ANALYSIS**

#### **Storyline 1: Achieving Proper Communication Alignment with All Stakeholders**

**Agent:** Monique is the primary actor in this storyline. She is someone who doesn't always control her emotions well, but this is mainly an internal struggle rather than something that manifests in physical actions. "I felt pressure, tension, anger, and incomprehension and wanted to scream because I had no control over the situation." (p. 149) She is someone who can admit her mistakes but also sees herself

as culpable. "Asking questions through writing was easier and faster. Another mistake I made was that if they left my question unanswered, I didn't pursue it further." (p. 121)

**Acts/events:** During various events, Monique experienced instances where information communicated was incorrect and not aligned with reality. "The overview did not match the moments when Jesse was supposed to wear the brace as stated in the communication notebook." (p. 154) "They didn't even report truthfully why Jesse had been in the brace." (p. 154) Monique not only encountered misinformation but also instances where communication about Jesse was lacking or delayed. "I didn't like seeing this, and I hadn't been informed about it. I didn't even know it involved a restrictive measure where caregivers needed parental consent, and we as parents had to sign off on the use of the brace." (p. 107) This led Monique to feel that not all information was effectively conveyed between them and the healthcare professionals, nor among the professionals themselves. "Our pediatrician was shocked and asked, 'Did Jesse fall out of bed?' He looked at the resident and told him he hadn't been informed. That was what I had feared all along. That's why I repeated the story a hundred times when we were in the hospital with Jesse, to prevent information from being communicated or passed on incorrectly." (p. 300)

**Scene/Setting:** For Monique, the care institution was a highly frustrating environment. Communication did not meet Monique's expectations, prolonging many events unnecessarily and reducing Monique's control over the situation. "Hopefully, everyone communicates well and clearly with each other, otherwise, we'll have another problem, and it will take even longer." (p. 277) The tone of frustration is palpable in these events. When communication was effective, it provided a supportive and helpful environment. Monique experienced this as reassuring and collaborative. "This was everything I had wished for all these years! Transparent communication and collaboration." (p. 142)

**Intention:** Monique's goal was to receive honest information about Jesse's situation so that healthcare professionals and Monique were aligned in Jesse's care.

**Means/Helpers/Opponents:** An adversary in this story is the communication methods themselves. There were various communication methods in this storyline that Monique did not find helpful. "I also didn't like communication through writing. Sometimes my questions remained unanswered, and sometimes I did receive an answer to my question via the communication notebook." (p. 111) Communication via writing meant that not all of Monique's questions received answers, and this was not addressed adequately by the healthcare professionals or by Monique herself. This left aspects of Jesse's care unclear.

Another adversary was Monique herself. When there was incomplete or unclear communication, Monique, as she describes, would fill in the gaps herself. In several cases, this was not positive. "It seemed like, but that's what I filled in, that nobody dared to enter, horrible." (p. 264) This resulted in misunderstandings about Jesse's situation, preventing Monique from making accurate assessments of Jesse's health and causing discrepancies in the care provided and by whom.

Especially the healthcare professionals at Jesse's daycare and school were adversaries. Monique experienced many instances where these professionals did not communicate clearly or accurately with her and François, causing distress for Monique.

One helper in this storyline was the Adelante care group. Monique indicates that communication with Adelante felt very good, and everything was discussed with Monique and François, taking their opinions into account. They were closely involved as parents in the entire process. "This was everything I had wished for all these years! Transparent communication and collaboration." (p. 142)

This analysis highlights the challenges Monique faced in achieving clear and effective communication in Jesse's care, as well as the impact of communication (or lack thereof) on her understanding and ability to advocate for Jesse effectively.

**Breach:** This storyline contains a clash between Monique's intention to obtain honest information from healthcare professionals and the adversaries in this storyline. The adversaries are the communication methods, which prevent Monique from receiving all the information about Jesse that she needs to provide the right care

**Summary of the Storyline:** I thoroughly enjoyed that moment. It's a pity I only realized how valuable this was for Jesse when I wrote about it. I had looked up the information myself. As parents, we were unaware because none of the nursing staff had told us earlier. To make matters worse, it was decided that a procedure would have to be done via a tube. I was shocked because no one had informed me that this might happen. At the daycare center, communication to us was through a notebook, and there was a multidisciplinary meeting once a year. During the first few weeks, there was only praise for Jesse. I felt that things were not going well with Jesse at the daycare center. We were not informed of changes and new approaches. It's a shame these important things were not communicated to us. If they had alerted us immediately, we as parents could have contributed to the right approach and implemented it at home so we could all be on the same page.

**Conclusion of the whole story:** As Monique essentially states in her book, she experienced that transparent communication leads to much greater collaboration. When communication was done correctly, Monique felt more involvement and understanding from the healthcare professionals. This indicates that communication is a crucial aspect of how Monique perceived the collaboration. Without optimal communication, there is no consistency in how care should be provided. Monique also points out that not only is the information communicated important for collaboration, but so is the manner in which it is communicated. When there is no direct communication, the transfer of information is less optimal compared to direct communication, such as through a conversation with multiple stakeholders. Monique shows through various events that direct communication through a conversation leads to greater mutual understanding compared to indirect communication via a notebook.



## **BOOK 4**

### **LOSLATEN DOET PIJN – MARIANNE SWINKELS**

#### **I BOOK CHARACTERISTICS**

##### **General impression of the book**

The book is written in a roughly chronological order and is divided into chapters, each representing an event or phase in Bryan's life. The author narrates the story from her perspective, with a great deal of emotion. This emotional writing evokes strong feelings in the reader as well. The emotions described and the tone used are very palpable. Anger and sadness are the two predominant emotions that stand out, along with a strong sense of disbelief regarding the way situations are handled.

##### **Who is the audience/target group the author is addressing and why**

Marianne has not specifically stated who her target audience is and why, but considering how the story is written, it seems she aimed to raise awareness about what it's like to be in such a situation. Additionally, it appears she wanted to highlight that there is still much to be improved in the healthcare profession regarding appropriate and inappropriate actions in such scenarios.

#### **II THE STORY AS A WHOLE**

Our joy knew no bounds when I found out I was pregnant with our second child. We envisioned a future with two children playing on the lawn. Yes, we saw the perfect picture. After six months of pregnancy, I immediately knew something was terribly wrong. The gynecologist looked at me seriously but unconvinced. My feeling was so strong that I was convinced something was being overlooked. What was that tumor, was it dangerous? "I told you something was wrong. I've been saying it for months, but no one believed me." A week after the bad news about our baby, we were at the university hospital. The gynecologist turned to us. "I suspected it already, but the baby has a teratoma of seven centimeters on its tailbone." "You will be under our care from now on," she continued. Before we knew it, we were outside. "Is it just me, or do you also find this all a bit strange?" I was prescribed complete bed rest.

"My water broke. They are going to deliver the baby," I said to Marty. Slowly, I woke up in the recovery room. I had to ask the question. "Is he okay? Is the teratoma very large?" "He is okay," Marty said in a soft, broken voice. A few days later, Bryan underwent surgery, and after three hours, the pediatric surgeon gave us the relieving news that the operation had gone well. The days following the surgery went by very quickly. His sucking reflex was unusual, and he constantly hyperextended, which not only looked painful, it was painful. "Well, he had a difficult start," was all the clinic had to say. I had heard that so many times. I felt completely unheard and wondered if Marty and I were the only ones who

saw that something was terribly wrong. The GP saw what was happening with Bryan, and that's how the ball started rolling. Now that we had someone to rely on and seek advice from, I felt a huge weight lift off my shoulders.

The physiotherapist's explanation of his movements hit us like a bolt from the blue. "He is clearly very spastic. There is no medicine for that; he will always remain spastic." Bryan's blood needed to be tested, but after multiple failed attempts, we couldn't bear to watch anymore. We had to protect our son, even from some doctors, and we always would. We knew what this did to Bryan, and they didn't. We became increasingly worried and were still searching for answers. I had pinned all my hopes on a muscle biopsy; without that biopsy, I was convinced there would never be a diagnosis. Later, another doctor took the muscle biopsy while performing a colostomy to relieve his symptoms. The results of the muscle biopsy came in, and the metabolic specialist told us which metabolic disease it was and where exactly it went wrong in Bryan's body. There is no treatment possible, but a medication was prescribed. This seems like a very bad idea. Bryan's condition worsened by the day. Marty and I agreed; this was no longer a humane existence. November 2 is the day Bryan will pass away.

### III STORYLINE ANALYSIS

#### Storyline 1: Struggling for a diagnosis

**Agent:** The main actor in this storyline is Marianne, Bryan's mother. She is someone who follows her instincts and acts accordingly. "My feeling was so strong that I was convinced something was being overlooked. 'It's not right, something is wrong,' I said resolutely." (p. 12) She knows what she wants and stands her ground when things don't go as she indicated. She knows her limits and those for her son and is determined to communicate this to others. "It was our duty to protect Bryan, even from some doctors, and we would always do so." "We had no other choice but to leave; we had to make choices that not everyone would understand. But we knew what this did to Bryan, they didn't." (p. 93)

**Acts/Events:** Throughout the process of searching for Bryan's diagnosis, Marianne experienced that the doctors at the university hospital often overlooked the human aspect of the journey. "Other tests that were done were, in hindsight, more interesting for the medical world than for Bryan or us." (p. 64) Marianne showed initiative during the process. However, she often felt that her knowledge and opinions were not considered by others, despite having more insight into Bryan's condition from her perspective than some others. "You're absolutely right, but we'll start with a skin biopsy," said the doctor who was clearly tired of our questions and comments." (p. 131) Marianne encountered multiple instances where the communication between her, Marty, and the healthcare professionals was not optimal, causing confusion and misunderstanding. "I grabbed the letter irritably and showed it to her.

The confusion was complete. I didn't understand why this was necessary. The doctors at the university hospital were aware of Bryan's seizures, but there was no mention of any potential admission or observation." (p. 180) In these instances, Marianne experienced that the way of communication did not align with her preferred style of communication. "These were learned people, doctors, but their empathy was below par." (p. 62)

**Scene/Setting:** It is a competitive setting. "It is quite something that you think you are doctors." His look clearly showed that he was not pleased with our own research." (p. 131) In this storyline, there are differences in knowledge that are not always accepted by others. It is also a loving home environment where Bryan's parents fight for him out of their love for him and will thus uphold his and their boundaries. "We looked at Bryan lovingly. 'Child, what are they saying about you? You have beautiful ears. You are a beautiful boy.' My eyes became moist and my heart broke." (p. 62)

**Intention:** Marianne's goal in this storyline is to get a diagnosis for Bryan's complaints so that the necessary actions can be taken. "We were still looking for answers. We really wanted to know what was wrong with Bryan; maybe there was a medicine that could make his life more bearable." (p. 106)

**Means/Helpers/Opponents:** The family doctor is a helper in this storyline. He noticed that Bryan wasn't doing well and took Marianne and Marty's concerns seriously and provided help. "'I am so glad that the family doctor saw what was happening to Bryan,' I said to Marty when we got home. It was, of course, very sad, but I finally felt taken seriously." (p. 58-59) This was the start of the search for a diagnosis.

They then went to the university hospital where the doctors were both helpers and opponents. They eventually ensured that Bryan got a diagnosis. "He explained which metabolic disease it was and where exactly it went wrong in Bryan's body.." (p. 262) However, this diagnosis turned out to be incorrect years later. Yet, in many cases, they doubted and ignored Marianne and Marty's opinions and feelings, causing the process to take longer than necessary and straining their relationship with Marianne and Marty. "Your colleague thought very differently about that.' I explained how the other doctor had dismissed our idea and performed a skin biopsy." (p. 249)

The rarity of Bryan's disease is also an opponent in this storyline. The complexity of Bryan's symptoms made it harder to determine the cause and thus arrive at a diagnosis. The nature of Bryan's symptoms also made conducting tests difficult. "Why didn't the doctors and specialists understand him? The medical world was so advanced... but not advanced enough for Bryan." (p. 160)

**Breach:** This storyline contains a clash between Marianne and Marty's intentions and the competitive setting. The competitive setting led to their opinions and feelings being questioned, making it harder to achieve their goal of getting a diagnosis for Bryan.

**Summary of the Storyline:** 'I am so glad that the family doctor saw what was happening to Bryan,' I said to Marty when we got home. It was, of course, very sad, but I finally felt taken seriously. We drove to the hospital, hoping to get answers to our questions. However, that day went differently than we expected. We felt the tests were more like an examination. In hindsight, the tests were more interesting for the medical world than for Bryan. 'He is clearly very spastic, and there is no medicine for that; he will always remain spastic,' was the harsh answer from the physiotherapist. Bryan's blood needed to be tested, and we had too often taken Bryan home covered in bruises, which we would no longer accept. They got three chances, but the doctor was not pleased with our decision and kept insisting on the importance of getting blood. We had to protect our son. Later, they said they might know what was wrong. More tests were needed. We agreed. We had no choice; we had to. I had pinned my hopes on a muscle biopsy, but he dismissed our idea without further explanation. There were no differences between the first and second scans, and we decided not to allow any more tests. Even the doctors had no confidence in them. During Bryan's last surgery, they took a muscle biopsy, and finally, we got a diagnosis.

### **Storyline 2: The Right Care for Bryan**

**Agent:** Marianne is the main actor in this storyline. She is a mother who strongly relies on her instincts and acts accordingly. She is a very caring mother and wants the best for her son, Bryan, even when it goes against her own feelings. "'Oh, Bryan... if you need to go, just go. You don't have to stay here for us.' ... Within seconds, I regretted it. How could I have said it was okay for him to go? It wasn't okay at all. That's not how it should be. Parents aren't supposed to outlive their children. No! That was unacceptable." (p. 228) She also reacts emotionally and doesn't always consider the feelings of others. "Have you gone mad?' I waved the syringe in the air. 'This is boiling water, going straight into his stomach. You should know that.' ... She clearly felt guilty. 'No, you don't have to,' I said furiously. 'You've done enough.'" (p. 257)

**Acts/Events:** Marianne often experienced that healthcare professionals only looked at how Bryan was doing in their presence rather than listening to what she and Marty said about Bryan's condition at other times. His condition often differed when a professional was present. "At first, we tried to make it clear that he wrapped everyone around his little finger. That he always smiled, even when he wasn't doing well. Later, we stopped trying to explain. They didn't believe us anyway and we often heard that

we shouldn't be so negative or that we should be happy when he was doing well." (p. 113) Marianne also experienced that healthcare professionals didn't always follow through with agreements or rules. "The occupational therapist said this was better for Bryan because it calms his body," said the leader, shocked by my reaction. "She said she had discussed it with you and that you had agreed." (p. 141) Marianne felt that her knowledge was not considered, leading to diminished trust during certain events. "But I didn't trust it, why was she wearing gloves if she only wanted to look? Afraid that she wouldn't take my words seriously, I emphasized once again that she could only look." (p. 247) Bryan's life was full of ups and downs, and not all events were handled by their regular doctors (family doctor and especially the pediatrician). Marianne experienced that due to the lack of familiarity with Bryan's situation, actions taken during these times were not always beneficial and sometimes even harmful to Bryan.

**Scene/Setting:** It is a supportive environment where many healthcare professionals want the best for Bryan and do their best with the knowledge they have to make the situation as good as possible. "But our pediatrician didn't give up. 'We'll wait a few days; Bryan's stomach needs to rest. Then we'll try again,' he said. I admired his optimism." (p. 116) However, due to Bryan's complex symptoms, it is also a very risky environment. Bryan doesn't respond typically to treatments, making mistakes easy. "I want the cream I asked for! This one doesn't work, I told you that! ... 'This is not the right cream for Bryan's situation,' he said. 'You just need to be patient.'" (p. 153)

Because of this complex situation, it is not only risky but also a combative environment, where there is a struggle between Marianne, Marty, and healthcare professionals over the best treatment options for Bryan. This combative atmosphere is fueled by the medically protocol-driven environment that leaves little room for deviation.

**Intention:** Marianne's goal was to make Bryan's life as pleasant as possible. "But I had to keep believing that there was something that could make Bryan's life a little bit easier." (p. 133)

**Means/Helpers/Opponents:** An opponent is the complexity of Bryan's condition/symptoms. This complexity means that medications often have different effects than intended, sometimes worsening his symptoms. Along with the complexity, the protocols for medication use also pose a challenge. These protocols make doctors less likely to deviate from the book and listen to Marianne. Consequently, they miss critical information about Bryan, leading to poor decisions. Marianne's diminished trust in the doctors was both an opponent and a helper. It was an opponent because she

was less likely to accept potentially good advice from doctors, but a helper because her mistrust made her fight harder for the right care for Bryan.

The pediatrician is a strong helper in this storyline. Marianne and Marty could approach him for all of Bryan's issues, and they had great confidence in his abilities and the decisions he made for Bryan. "We told him that we couldn't have wished for a better pediatrician. Bryan couldn't have been luckier." ... "Without him, Bryan's short life would have looked very different." (p. 287) Helpers also include the surgeries Bryan underwent and the doctors who performed them. These surgeries alleviated Bryan's symptoms, making his life more bearable. "Bryan was still groggy from the surgery and lay there motionless. I carefully removed his diaper, hoping he wouldn't notice. No one in the room could believe what they saw. Bryan's anus was completely healed; there was nothing left to see." (p. 254-255)

**Breach:** The intention of Marianne and Marty is to make Bryan's life as pleasant as possible and to ensure he receives the best care. However, the setting of this storyline, which revolves around medical protocols, conflicts with this intention. The focus remains on these protocols, without considering alternatives.

**Summary of the Storyline:** Bryan and I arrived at the clinic full of hope. We were taken to a room with just a sandbox. 'He can't do anything, can he,' said the therapist, looking at me questioningly. I was so stunned by her insensitivity, so incredibly harsh, that I could only sit with Bryan on my lap, staring at that stupid sandbox. 'There's really no point in coming back,' said the therapist. But our pediatrician didn't give up. To our great frustration, Bryan developed a red anus. The family doctor prescribed a cream and took a swab. After a few days, Bryan's anus was almost healed, and the swab results were in. We had to pick up new cream, but it didn't work. This family doctor didn't know Bryan, and I tried to convey the seriousness of the situation. 'You just need to be patient,' he said. Bryan was admitted to the hospital. I stayed in his room, and our trust in the hospital doctors was so shattered that we didn't dare leave him alone. To relieve the pain in his anus during diaper changes, he got an ostomy next to his MIC-KEY button. I had to trust the doctors, and that was very difficult for me. Not that I doubted their expertise, but I was so scared. Bryan's anus was completely healed; there was nothing left to see. The metabolic doctor explained which metabolic disease it was. 'There is no treatment possible, but I will prescribe medication that might reduce his seizures,' he said. This seems like a very bad idea. After some time, we decided to try it anyway. Soon, the metabolic doctor's words proved wrong, quite the opposite. Furious at the metabolic doctor with his stupid theory. But I was mostly furious with myself. I always trusted my intuition, and this time I hadn't. 'I know the date... November

2 is the day Bryan will die.’ We stood by Bryan and wanted to give our pediatrician a private moment to say goodbye to his little patient... because even heroes are allowed to cry.

**Conclusion of the whole story:** This story of Marianne about life with Bryan and everything that comes with it reveals that Bryan doesn’t respond well to protocol-driven care and that Marianne and Marty are aware of this. However, due to the protocol-driven care and the lack of consideration for the knowledge and information provided by Marianne and Marty, the care outcomes do not align with what they envision for Bryan. These care outcomes aim to make Bryan’s life as pleasant as possible. Marianne and Marty feel unheard, and the healthcare professionals’ execution is a form of direct opposition communication. This type of communication is not a problem-solving way of communicating for Marianne and Marty. Problem-solving communication is an important aspect of relational coordination that promotes collaboration between professionals. Marianne and Marty also find this an important aspect of collaboration and for achieving their goal. They experience their cooperation with Bryan’s regular pediatrician as problem-solving, presented in a direct cooperative manner by the pediatrician. They view this communication style positively for their collaboration with the pediatrician. “What if this pediatrician also didn’t know what to do with Bryan? What if he said there was nothing he could do for him? What would we do then? These thoughts made me nervous. But he examined Bryan attentively and listened to our story. What was even more important: he believed us. We were finally taken seriously.” (p. 66)

Where the cooperation between the pediatrician and Marianne and Marty is based on trust and mutual respect for choices, such as stopping medication that Bryan, according to Marianne and Marty’s knowledge, doesn’t respond well to, the cooperation between the university hospital doctors and Marianne and Marty lacks mutual respect. Marianne feels that the healthcare professionals are not supporting her in the process but are instead hindering her in achieving her goals. She has experienced quick conclusions and decisions being made instead of using problem-solving communication with various stakeholders to determine the best conclusion and treatment option. Feeling unheard and not involved, Marianne and Marty have described a negative experience regarding their cooperation with various healthcare professionals

## **BOOK 5**

**BRIGITTE – GUIDO BINDELS**

### **I BOOK CHARACTERISTICS**

**General Impression of the Book**

The book essentially describes the author's life, highlighting both the struggles and beautiful moments he experienced with his family, especially in caring for his daughter Brigitte. He vividly portrays how challenging it was to care for Brigitte, yet he frequently mentions the immense love he has for her. This makes every event he writes about, even the negative ones, resonate with the deep love he feels for his daughter. He is willing to do anything for her, often putting his own issues aside. The frustration he feels in managing important matters for Brigitte is strongly conveyed, particularly in the letters he has written.

### **Who is the Audience/Target Group and Why?**

Guido Bindels wrote the book to show that not only the healthcare system but also society needs to have more understanding and compassion for each other. Everyone is human and deserves to be treated with humanity. He also aimed to draw attention to how care for the disabled has deteriorated due to budget cuts, seeking to garner more support from society. This book effectively illustrates his plea for greater societal support and compassion.

## **II THE STORY AS A WHOLE**

Our second child, a beautiful daughter, has just been born. My work is my hobby, and I am married to the love of my then-young life. Of course, everything is fine! But then the midwife's voice echoes through the bedroom, sounding unreal. 'Sorry, but something is not right,' she says, rocking Brigitte in her arms. That 'not right' remains undefined for a while. 'A clear case of Turner syndrome,' says the doctor. A few years earlier, Marion had a miscarriage, and the conclusion then was that it was due to Turner syndrome. The doctor probably thinks it's the same now and quickly makes a note in the file. At the hospital, Marion is allowed to stay with Brigitte at night. She immediately gets up and fully engages in 'the fight' for our child. Later, it will become clear how lonely our battle for our child is.

The geneticist introduces himself and says, 'I see it already; I know this from my practice. This is nothing and will be nothing.' 'She will,' he says, 'often be sick and weak. Very susceptible to everything.' The geneticist clearly sees Brigitte as a 'nice medical case' rather than a 'beautiful little person.' A name is given: microcephaly. We go home, determined to fight for our child. Trying everything: that's what our life revolves around during that time. Where conventional medicine fails or doesn't know, we seek other options. Marion becomes pregnant again soon after Brigitte. Our beautiful family is complete, and it is good for both parents and all three children that the focus is not solely on Brigitte. When Suzanne, the younger sister, goes to 'real' school, Brigitte goes to daycare. Leaving Brigitte with others, how do you do that? It takes a lot of effort for us. At daycare, we hear about 'de Boldermanege,' where mentally and physically disabled children can ride horses. We see her beaming, proud, and confident on a horse. Whenever possible, we take her there every week. But at some point, caring for Brigitte



becomes more challenging. I retreat into myself and then into my work. Eventually, my life comes to a grinding halt. 'Divorce.' When Marion finally says the word out loud, it causes an earthquake in my mind. Marion and I immediately decide to continue sharing the care for our children. The responsibility I suddenly feel all by myself weighs heavily on me. 'Have you ever heard of Stichting Hulp op Maat?' asks a friend at one point. When would I need help? Not everyone can dress Brigitte when she wakes up. Besides, that's a very important moment between us. There are also more and more budget cuts in care, more new rules, and people are becoming less human. The government turns the loving care of parents into something cold and businesslike. Marion and I share these problems with the government and the love we feel for Brigitte. We still do everything together.

Now that Brigitte is 21, we receive a responsibility form for the Personal Budget (PGB). The reason: our signatures are no longer valid. Brigitte needs to sign herself, or we need a declaration that we are her legal representatives. Sorry, but those are the rules. Do people realize how much time all this administrative hassle takes? How much the cold, distant words of all those rule-followers hurt? If we place Brigitte in a residential facility, she will receive the care covered. We continue to resist. I hear another budget cut from the AWBZ is coming. We decide to enroll Brigitte in a new residential location, and she is selected. Living at the residential location is not as promised, and there is no improvement yet. Caring for a childlike Brigitte is heavy and only gets heavier. But it also brings a richness that wouldn't have been there otherwise.

### III STORYLINE ANALYSIS

#### Storyline 1: Bureaucracy and Rules are Rules

**Agent:** Guido is the main actor in this storyline. He is a determined person who knows what he is striving for but often oversteps his own boundaries. When he has too many negative emotions during interactions, he usually doesn't express them. "But as often, my mouth reacts differently than my body. I swallow everything and call the care office again, dejected." (p. 134) He is someone who takes initiatives to draw more attention to the issues but struggles to let things go, leading him to frequently overextend himself. "Let me do it! That was often the case. I couldn't let go of anything, not the work, not the children, not Marion, I couldn't let go of anything." (p. 103)

**Acts/events:** Throughout several events, Guido experiences that protocols and rules are followed blindly instead of considering specific situations. Rules are rules and are not deviated from. "The judge takes the trouble to read my rather long and overly emotional letter and can empathize. But his response is clear. He cannot make exceptions; we simply have to adhere to the legislation. So, we have more paperwork to deal with." (p. 142) In response to the rules, Guido resists and fights against them. "No, I cannot do that; I first need permission from the Account Holders Legal Department."; bank

personnel. "But sir, please listen, that is already a done deal, that permission is definitely there, just put it into the computer." (p. 150)

Guido finds that rules arise in several instances when Brigitte is an adult and care is managed by the government instead of the municipalities. "But Brigitte is no longer 'small,' at least not in years of life, so she falls under adult rules. This brings many changes to our lives with our child. Because the government gets more involved, and as becomes clear in much of the rest of this book, it brings additional stress and often bizarre rules and situations." (p. 115) Following all these rules causes Guido stress and he responds by wanting to flee. "I don't want this anymore, I want to run away. Together with Brigitte. Away from all these crazy people, away from all these bizarre rules." (p. 147)

**Setting/Scene:** It is a highly bureaucratic environment with many government regulations where specific situations are not taken into account. Rules are rules, and there is no deviation from them. "These are the rules, sir; if you come with your daughter and can prove what you say, you will get the money back." (p. 146) Additionally, there is a very loving home environment, where his ex Marion supports his decisions, and unconditional love from Brigitte is evident. "Everything you give Brigitte, she gives back twice over. All the love you feel for her, she sends back to you in abundance." (p. 137)

**Intentions:** Guido's goal is to reduce the administrative tasks associated with Brigitte's care, thus allowing more time for actual caregiving.

**Means/Helpers/Opponents:** A major helper is the love Guido has for his daughter Brigitte. For her, he is willing to do anything and continues to manage all the tasks, despite the overwhelming amount of administrative work involved. He wants the best for her and will persist in organizing everything. "What now? I have to pay for Brigitte's care, but with what? How can they take money that isn't even theirs, money that was just in the bank account? This is theft!... I don't sleep a wink that night and call the bank first thing in the morning." (p. 146)

The opponents are the rigid rules that are strictly enforced, as well as the pressure on employees to adhere to these rules. This leads to a gradual loss of humanity. "I really have to do it this way, sir, a colleague of mine was recently fired for not following the rules." (p. 148)

**Breach:** The clash between Guido's intentions and the setting dominated by rigid rules is central to this storyline. His goal is to reduce the administrative burdens. As Brigitte becomes an adult, the setting shifts to government involvement, which adds numerous administrative tasks, such as detailing all income and expenses for Brigitte.

**Storyline Summary:** As Brigitte grows older, she must leave the daycare center. Brigitte is no longer 'small,' at least not in years of life, so she falls under adult rules. This brings significant changes to our lives with our child. The responsibility form for the Personal Budget (PGB) is rejected. Reason: our signatures are no longer valid. Brigitte needs to sign herself. But madam, you see that she cannot do that; she cannot even grasp something intentionally. Or we must have a declaration that we, her parents, are her legal representatives. "Those are the rules, sir. You need to call the court, request a 'Request for Guardianship,' and then send it to us." "With the court in Dordrecht. Before you get something like that, you have to go through a whole process. We will send you forms that you need to fill out. Then you must appear before the magistrate. And then we expect you to keep a complete administration of all income and expenses of your daughter, down to the details." How about expenses and income? "Sir, please don't be so cheeky. We expect a serious administration from you, including what you spend on clothes, etc." Nonsense or not, they keep doing it every time. Rules are rules. And what has to be done has to be done. Right? The municipality undoubtedly has a thick file on Brigitte, but someone from outside is apparently not allowed to just make a copy of a file from someone inside. This may sound cynical, but some things just don't become easier with time.

### **Storyline 2:**

**Agent:** The main actor in this storyline is Guido. Guido is a loving father who would do anything to give his children, especially Brigitte, the best life possible. "We wanted her so much, we made sure she came into this world. We have waited all these years for her. And we are so happy she is here and will do everything to make her happy, to be happy together, with each other." (p. 24) He is a sensitive person who feels a lot of emotions but finds it difficult to express them and processes anger and sadness internally. "I wanted to drag him by his hair through the room, shake him, beat him up. But instead, I kept quiet, sat meekly in my chair, and stared at the ground, defeated." (p. 25) Additionally, he is someone who continues to fight for others, often overstepping his own boundaries.

**Acts/events:** In several instances, Guido has experienced that the human side of care is lacking and that Brigitte and her care needs are seen as a medical case or a number. "A man of the books who, it turns out, sees Brigitte as a 'nice medical case' and not as a 'beautiful little person.'" (p. 20). Rules and procedures are strictly followed, which Guido feels is not always beneficial for Brigitte's quality of care. "Why couldn't we be there? What do you mean standard procedure? This is about Brigitte, and I don't care about the procedures in this stupid hospital." (p. 55) The adherence to procedures and rules meant that during several instances, there was no room for negotiation or considering other options. "There are more and more cuts in healthcare, more new rules, and people are becoming less flexible, less human, less empathetic." (p. 112)

Guido also experiences that due to budget cuts, the care Brigitte needs cannot always be provided. "Yes, they are cutting back again; we now work with floating staff," she replied.... "But of course, I can no longer give them the attention they usually get and need." (p. 196-197). This leads to a decline in Guido's trust in the care system, prompting him to take action to bring about change. "The horrifying story makes me decide to follow through on what I have been planning for a while: I am going to start a Petition against the cuts in Healthcare." (p. 164) This made it difficult for Guido to let go of the care during several events. "Seeking help for Brigitte's care? Why? I can take care of her best myself." (p. 86)

**Setting/Scene:** The home environment is very loving, with Brigitte giving a lot of love and the rest of the family being close-knit and supportive of each other. "Everything you give Brigitte, she gives back twice over. All the love you feel for her, she sends back to you in abundance." (p. 137) Additionally, it is a highly regulated environment, where regulations dictate what care will be provided for what amount/deductible. "Yes, you will have to come with your daughter, sir, until then the account is blocked." "Those are the rules, sir, if you come with your daughter and can prove what you say, you will get the money back." (p. 146-147) This creates a combative environment for Guido, who fights against these rules. "We keep resisting. We keep writing letters." "We start with 'a request for reconsideration' with the Legal Affairs department of the health insurer." (p. 160)

**Intentions:** Guido's intention is to ensure the best care for Brigitte and to make her happy. "And we are so happy she is here and will do everything to make her happy, to be happy together, with each other." (p. 24)

**Means/Helpers/Opponents:** Helpers in this storyline include Marion, his ex-wife, whose determination helps Guido persist. "Marion's determination gets me through it" (p. 20). This is beneficial for Brigitte's care, but Brigitte herself is also a helper. Her positivity and the love she gives Guido motivate him to make the best out of the situation and fight for her. Brigitte attends a daycare center and later a residential facility, which helps relieve the burden of care, and the caregivers and other employees at these locations are helpers in providing the best care for Brigitte. "So, it certainly isn't the people working at Schouwenhof. Of course, you have more confidence in one than another. One has a better grasp of care than another. But from the cleaner to the cook, from the caregivers to the students, interns to volunteers, they are all fantastic; they do more than their best." (p. 223). However, budget cuts are an opponent for the care at these locations and for the care Guido and Marion provide. Certain care services are no longer reimbursed, such as physiotherapy, and less staff

is employed, resulting in lower quality care. "Agencies cutting back on hard-working staff and the quality of care." (p. 226). Additionally, the rules and protocols that must be followed are opponents. Specific cases are not considered; instead, there is a standard procedure that is not always the right one for Brigitte's care. "We should have been there when our girl woke up from the anesthesia! They could have at least called us when they were putting the cast on her legs, even if she was still under anesthesia. Why couldn't we be there? What standard procedure?" (p. 55)

**Breach:** In this storyline, there is a clash between Guido's intention to make Brigitte happy and provide her with the best care and the bureaucratic environment he finds himself in, with inflexible rules and procedures.

**Storyline Summary:** We are so happy she is here and will do everything to make her happy, to be happy together, but more and more often, doctors talk about Brigitte as if she is not a lovely person of flesh and blood. There was even a doctor who exclaimed: "Oh, how beautiful and interesting this is." These kinds of reactions and differences of opinion about treatment methods made us decide, against the doctors' wishes, to take Brigitte home and care for her ourselves as soon as possible. Brigitte can go to the daycare center to ensure everything goes as 'normal' as possible again. It is enormously difficult for us. How do you entrust Brigitte to others?

It's not the people because, from the cleaner to the cook, from the caregivers to the students, interns to volunteers, they all do a fantastic job; they do more than their best. It all has to be cheap and cheaper. While care agencies receive a lot of money. Official care agencies are cutting back on hard-working staff and the quality of care. To arrange the Personal Budget (PGB), we need to sign. The new rules now require a court document because they can no longer accept my signature. Each municipality has its own rules, so this can vary by municipality, but rules are rules. We simply have to adhere to the legislation.

**Conclusion of the whole Story:** Guido and Marion split Brigitte's care and each take care of her half of the time. Formal care supports them, and later on, formal care plays an increasingly significant role as Brigitte moves to a residential facility. The affection Guido receives from Brigitte ensures that he takes on the caregiving role and does not fully delegate it to care professionals. However, the supporting role and task distribution are determined by protocols and regulations. These protocols require formal care professionals to ask Guido to perform specific tasks, shaping the collaboration between Guido and the care professionals. Guido experiences the collaboration with the caregiving staff at the daycare center and the residential group as positive due to the involvement he feels from the staff.

"They had a kind word for everyone, were involved, and did their work with love." (p. 153)

Based on the collaboration rooted in protocols and rules, it can be concluded that both parties work from different goals. This results in suboptimal collaboration, as described through relational coordination. Differences in communication are evident. When care professionals show understanding of the need to follow rules, Guido responds with more understanding than when this understanding is absent from the care professionals. This can be categorized as the presence or absence of mutual respect. It can be concluded that when communication is respectful and understanding, it positively influences Guido's experience of the collaboration, despite the differing goals.

## **BOOK 6**

**JUDITH ONS ZONNIG ZORGKIND – MARLIES TER DOEST**

### **I BOOK CHARACTERISTICS**

#### **Overall Impression of the Book:**

The book is written quite positively, and Marlies writes about her daughter Judith with a lot of love. This also evokes positive emotions in me. While reading the book, you really get a glimpse into Marlies' life and her family, with various moments described, focusing mainly on the joyful ones. Even when a negative event occurs, such as when Judith's health is not good, Marlies describes Judith's sweet and lovely character. This turns the negative event into something positive.

#### **Who is the Audience/Target Group the Author is Addressing and Why?**

Marlies wrote the book to show that life with a child with multiple disabilities is not only doom and gloom. It is much more than just caregiving; they also enjoyed Judith and the pure and sincere moments with her.

### **II THE STORY AS A WHOLE:**

No pink cloud, no dad cutting the umbilical cord. Romance was far from present when Judith was born. Her birth, which lasted almost two days, was a long, arduous, and painful struggle. And then she's finally here, our child.... But something is clearly very wrong... An ultrasound of her head and an EKG are done. Everything is still fine, but how quickly would that change? Van der Wagen becomes our pediatrician. In retrospect, we are very happy with the choice of Van der Wagen because he turns out to be a pediatrician in a million! Things keep getting worse... Judith continues to have convulsions. At one point, they had to sedate her completely because the seizures kept coming. What turns out? Our daughter is a fighter, a tough cookie, really not planning to give up. Judith turns out to be a stretching baby. She tenses the muscles in her back and throws her head back, becoming stiff as a board. July 23, 1992, is a holiday. Judith comes home! But girl, you are already a care child, but you look beautiful! We would have loved to have you healthy, but we are absolutely in love with you. Officially, it's said that Judith 'suffers' from psychomotor retardation with epilepsy.

When Judith is 8 months old, we step into the world of care centers. The Kleine Wereld in Hengelo starts a care project for babies and toddlers to relieve parents for a part of the day. It feels terrible and empty to drive home without her. No, I don't trust it yet. The staff gets to know Judith better, and we gain more confidence in them. It's also very nice that they involve parents in everything. When Judith outgrows her stroller, we have to fight for Judith with the Disability Provisions Act (WVG) for a 'real'

wheelchair. The lady handling the application looks indifferently past our child. 'Is that really necessary?' she asks in a scornful tone, 'that child is better off in the stroller, you know!' 'Where do you get the nerve to deny me something like that?' I snap at her. If my child were 'normal', I would never, ever have had to meet that bitch. I'm not asking for this for fun! Judith gets her wheelchair. But ultimately, I win the battle. She shook my hand and said I should keep fighting for Judith. She found it so beautiful... The fighting spirit for my child... And so many more battles followed.

We live day by day, and as Judith is at that moment, she is wonderful! But doctors mainly emphasize what goes wrong, and they have no eye for the beautiful sides of our life with Judith. Like how she can enjoy bike rides in the specially made reclining cargo bike. Despite this, we are very aware that we must consider the worst. Judith could die from pneumonia or other respiratory infections. We keep walking and cycling with Judith, but there you went... We saw the life drain out of you. Our champ, who had to fight and struggle so much in her life. How beautifully she lies there... So entirely Judith! Our sunny care child... our champ...

### **III STORYLINE ANALYSIS**

#### **Storyline 1: Relieving/Reducing the Care for Judith**

**Agent:** Marlies is the main actor in this storyline. Marlies is a caring person who wants the best for others, especially for Judith. When things don't go as Marlies had hoped or when they go as she feared, she feels enormous guilt. "We feel very bad when we sit with the pediatrician, who is treating Judith's little hand. Fortunately, Judith didn't suffer any lasting effects. We, as parents, did: a lot of guilt!" (p. 21). She is someone who can stand up for herself and fight for what she believes in and what she is entitled to. "My first battle to get something done... Many more will follow." (p. 22)

**Acts/events:** During several events, she finds it difficult to relinquish care for Judith due to her concern and desire to care, thus preventing her from being relieved. "Every first Friday of the month, Judith goes to the guest house. I find it terrible. It is good that I can recharge, but my goodness, I feel so guilty, and I miss her so much!" (p. 33). Her feelings get in the way and have the opposite effect of what the guest house is supposed to provide. Marlies also experiences during various events that bureaucracy doesn't take the specific situation into account but follows rules. This initially doesn't yield the desired outcome Marlies wants. This stirs a lot of fighting spirit in Marlies, so she doesn't give up easily during various events. She ensures that certain things within her power are arranged. "It is happening more and more often that either the outpatient counselor or I bathe her, but Arnoud has to get her out again because she is too heavy for us. So, it's time to fight again: there needs to be a ceiling lift above the bath." (p. 73). Marlies's fighting spirit during certain events results in more initiative from Marlies to contact those responsible. Marlies experiences that communication does not happen in a timely



manner. "In April, I submit an application, in September I still have nothing. I make the umpteenth call to Amicon." "So, I write a complaint letter, which is answered weeks later by Mr. G.B., the ombudsman." (p. 57).

Besides the responsibility to get certain things done, Marlies also experiences resistance to certain tasks expected of her during various events. When this feeling arises, Marlies responds by stopping these tasks and letting those she believes are responsible handle them, relieving herself of those duties. "Are we now medical specialists, physiotherapists, or mom and dad? At a certain point, I'm done with it. Practicing with her every evening causes frustrations, and I am not a physiotherapist but her mother, so I will behave like her mother and leave the physiotherapy work as it is." (p. 21).

**Setting/Scene:** I see a very loving and warm home environment at Marlies's house and her family. Marlies mentions several times that she misses Judith a lot when she is not home, and therefore, does not enjoy her day. "Although we still do it occasionally, because it's so cozy when she's in bed with us." (p. 56), but it is also a very combative setting. This is evident in the battles Marlies fights against certain institutions to get adjustments made but also a struggle in her own mind. The struggle between, on the one hand, feeling guilty about temporarily handing over care, but on the other hand, needing the rest very much and feeling good about it. The struggle arises from a bureaucratic setting, with many rules and protocols needed to get adjustments reimbursed and arranged. "The municipality does not give permission for it. The responsible alderman even personally came to see our newly built house, but it didn't help. The municipality of Delden rejects our application because there is a risk that granting the lift facility would set a precedent." (p. 56).

**Intention:** Marlies's intention is to be relieved in the care for Judith in both the burden and the time involved.

**Means/Helpers/Opponents:** In this storyline, the protocols and rules of insurers and municipalities are obstacles for Marlies in achieving her goal. "And then there are problems with Amicon over the reimbursement of the seat orthosis. Who bears the costs? Amicon? The WVG? Then it turns out the insurer is responsible because it's a home chair." (p. 57). Another obstacle is that the assessors who grant the care (resources) also decide themselves whether or not to grant something. This can vary from person to person and moment to moment. "The applications must be approved by several people. Once one person has stamped it, the application is sent to another. And that takes an awful lot of time and money!" (p. 73). But relieving the care also requires letting go of the care, and there is also an obstacle for Marlies in this, namely the lack of trust and the empty feeling Marlies is left with.

“Will she be scared, unhappy, will she cry for mommy? It feels terrible and empty to drive home without her. No, I don’t have confidence in it yet...” (p. 27).

A helper is Marlies’s positivity. She views everything from a positive perspective. This ensures that all new opportunities are seized when the current situation is no longer adequate. “We can ride bikes with Judith again! Fantastic, what a joy... Thanks to the reclining cargo bike, designed exclusively for her. ... We get a lot of attention, but we don’t care!” (p. 71). Additionally, Marlies’s fighting spirit is also a helper in this storyline. Applying for the aids needed to reduce the care burden requires a lot of patience and convincing those involved in the approval of these aids. “So, it’s time to fight again: there needs to be a ceiling lift above the bath.” (p. 71).

**Breach:** The clash between Marlies’s intention and the setting in which Marlies finds herself is a central conflict in this storyline. Marlies’s goal is to be relieved of the heavy burden of care, but this conflicts with the bureaucratic setting with protocols and rules of insurers and municipalities.

**Storyline Summary:** And then we enter the world of care centers. Child day care center De Kleine Wereld, to relieve parents for part of the day. We do that right away. Judith loves it! And then I leave my child behind for the first time, entrusted to ‘strangers’. It feels terrible and empty to drive home without her. No, I don’t have confidence in it yet. We gain more confidence, and it’s also very nice that they involve parents in everything. But what guilt that she is away three days a week. Indirectly, I keep busy with her because there are always medications to be arranged for her or phone calls to be made about her. We have to fight for Judith with the Disability Provisions Act (WVG). Eventually, I win the battle. The desk lady said I should keep fighting for Judith. A lot of hassle with institutions, where not always reasonable communication occurs. I just want aids in my house so that I can take care of Judith more easily! So, I write a complaint letter, which is answered weeks later. We actually get an apology note and approval. Fortunately, all that hassle was not for nothing. We have won!

**Conclusion of the whole story:** Marlies has taken on the care of Judith and plays a significant role in her care. She has done this out of the great love she feels for Judith. This means that the role of formal care is smaller, as seen in the story where formal care is mainly involved for relief and tasks that Marlies depends on professionals for, such as funding for aids and 'real' medical care. Although there is no exact equal distribution of tasks between Marlies and the healthcare professionals, it is important that there is good collaboration between both parties.

In the beginning, Marlies found the collaboration with the daycare center difficult because she had to entrust Judith's care to others. Trust played a significant role in this. Marlies appreciates it when the

daycare center involves her in the care they provide, which can be seen as sharing information and knowledge. They have frequent exchanges of information through a notebook where both parties write information about Judith. Marlies experiences good care for Judith at the daycare center and indicates that there is excellent communication between all parties. This form of communication ensures consistency in the care Judith receives at home and at the daycare center. Marlies notes that the staff at the daycare center provide good care and feel involved in Judith's care. From this, it can be concluded that there are shared goals between Marlies and the daycare center. While Marlies views this as a positive collaboration, her experience with health insurers and municipalities is not always as positive.

From Marlies's experience, it can be concluded that health insurers and municipalities are not aligned with Marlies in terms of goals. An example of this is the municipality's statement:

“The municipality of Delden rejects our application due to the risk that granting the lift provision could set a precedent. All parents with disabled children will request such a provision, and the costs will skyrocket, the municipality fears. ... A mobile lift provision is sufficient, according to the officials. But a mobile lift provision is not suitable for Judith.” (p. 56)

From Marlies's perspective, their unrealistic fear is not based on relieving Marlies and creating the right care for Judith. One reason for this could be that the municipalities do not have the right information about what Marlies needs in terms of resources, leading to a lack of problem-solving communication. In another situation, Marlies does communicate with the municipality about the situation and the reason for the request. Marlies states that after this, the provision was approved, resolving the issue. However, Marlies feels that it is a battle with the professionals rather than a collaboration.

“Girl, if you didn't have a mother fighting so hard for you, would we have gotten everything you are entitled to? It's all so unfair... They act like I'm applying for everything because I enjoy it!” (p. 57)

There is little room for negotiation from the municipality and health insurers. This can be categorized as opposing communication. In contrast, the communication with the daycare center is a form of cooperative communication. Unlike communication with health insurers and municipalities, which is primarily initiated by Marlies, the communication with the daycare center involves joint effort.

It can be concluded that the manner and reason for communication from all parties determine how caregivers perceive the collaboration as cooperative rather than merely dependent. Marlies experiences opposing communication as negative and a battle, while cooperative communication is seen as helpful.