

Accessibility of aids; Appropriate care for patients with a physical disability

Thesis

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Abstract

Background

Patients with a physical disability benefit from good access to aids like a wheelchair or stairlift. With aids, they are able to live their life as they want. Zorginstituut Nederland has written a framework about appropriate care, wherein is described what is expected from different stakeholders in the organization of care. For patients with a disability, the care around aids must be value based, patient centered and has to focus on positive health. For municipalities, multiple dilemmas about values emerge, wherein they have to choose between performance or procedural values. Several burdens appear for patients, out of the organization of healthcare. This gives them an extra workload, besides the fact that they are disabled. The goal of the research is to explore how patients with a physical disability experience access to aids.

Methods

To get insight into the perspective of patients with a physical disability, stories have been used which are written by patients in the form of books. The stories have been analysed with the use of narrative analysis. Different themes have been abductively identified during the narrative analysis. Six books of patients have been included.

Results

Waiting time and poor access to material or repair for aids have a big impact on the experienced access of patients to aids. The results of the narrative analysis presented different cases wherein patients have to wait for the approval of an application or the implementation of an aid in their daily life. For patients, it can be hard to understand why a municipality does not always give them (quick) access to aids. It can be a big dilemma for a municipality what is more important in the delivery of aids. Municipalities have their own values like effectiveness, efficiency and equality, but also have to consider what is best for the patient in the light of Value Based Health Care (VBHC), positive health and Patient Centered Care (PCC). Where dilemmas occur for the municipality in the process of applying and implementing aids, patients do experience several burdens as the effect of the healthcare system. Burdens which are identified with narrative analysis are administrative workload, frustration, uncertainty and the impact on the daily lives of patients with a physical disability.

Conclusion

Patients with a physical disability want to participate in social and civic life. Good access to aids is crucial to be able to participate. Municipalities are not able to perform according to the values of VBHC, positive health and PCC. This is leading to burdens for patients, these burdens are negatively influencing the experienced access to aids. To improve the experienced access to aids, it is important that municipalities are performing the values in practice, which will lead to more appropriate care for patients with a physical disability. The municipalities should get help from the government to be able to provide this appropriate care to patients.

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1. Introduction

Patients who have to adapt to their disease and who continuously need to explore what they can do, are especially patients with a physical disability who need aids like a wheelchair. Despite the fact that these patients have a physical disability, they want to live their life without limitations. They have wishes and desires for their personal life (Walburg, 2016). Nevertheless, they are dependent on aids like a wheelchair and/or adjustments at home. To realize proper care for patients, Zorginstituut Nederland (2022) has written a policy document about Appropriate Care, as a normative framework to concrete this care in practice. This framework describes what is needed in healthcare to provide appropriate care to patients and what the expectations are of the government of the different involved stakeholders.

Next to describing the expectations of all the involved parties, Zorginstituut Nederland (2022) also describes important principles, which emphasize the way of thinking about appropriate care. An important principle of the framework of Appropriate Care is to provide care that has the best possible outcome for the patient, but also consider costs. To achieve the best possible outcome for the patient, the framework uses the principle of Patient Centered Care. The organization of care should focus on the individual needs of a patient, to provide the most appropriate care. The framework has also attention to positive health, this entails that the focus is not only on the disease that people have but also on what their lives look like, and what they want and can do despite their disease (Zorginstituut Nederland, 2022). This is not always evident for patients with a physical disability, they face activity and participation challenges in daily life (Bertrand et al., 2017). The accessibility of aids has a huge impact on the capability of patients with a physical disability to be self-reliant.

In 2017, Nivel did research on the organisation of extramural aids. On a yearly basis, the Inspection gets thousands of complaints about the service of aids. These complaints are about technical defects, risky situations and poor communication and collaboration of involved actors (Mol et al., 2017). An important stakeholder in the delivery of wheelchairs and aids to patients is the municipality. In the framework of Appropriate Care (Zorginstituut Nederland, 2022), the role of several actors has been described to make appropriate care feasible, but the role of the municipality in the provision of aids is not mentioned.

In multiple stories of patients is described that the action of the municipality is not always optimal (Mol, Verweij & de Bruijne, 2017). Mol et al. (2017) describe in their research how the care for people in a wheelchair is organized, what the bottlenecks are and how policy can help to improve the care for these patients. More research is needed, to know how patients are experiencing the performance of the municipality, and how this role could be developed according to the framework

of Appropriate Care (Zorginstituut Nederland, 2022). In practice, the municipalities cannot or do not want to act always like the values of the framework of Appropriate Care. The framework of Appropriate Care is one side, the values and policy of individual municipalities are on the other side. The municipalities also have their values like efficiency, effectiveness, honesty, equality and lawfulness (De Graaf & Paanakker, 2015; Jørgensen & Sørensen, 2012). The values of the framework and the values of the municipality can collide with each other, which is causing dilemmas for the municipality in the effectuation of their policy.

Dilemmas emerge for municipalities because they have a double duty, they have to consider the cost of care but also the task to deliver good quality of care. The Netherlands have a healthcare system which is operating in a market system. This means that insurers negotiate with healthcare providers about the price of the provided care (Ursum et al., 2011). The patient chooses a healthcare insurer that fits their needs best. The concept behind this system is that market forces have to lead to a higher quality of care and more efficient delivery of care (Ursum et al., 2011). The value for patients with a physical disability is the use of proper aids, the cost considerations are mainly for the municipality (Zorginstituut Nederland, 2022). Interesting to research if the perceptions of providers and patients about the definition of valuable care are corresponding to each other.

What the impact of the organisation of healthcare is on the daily life of patients with a physical disability is another factor that is missing in the conducted research. To fill this gap, it is important to investigate how patients with a physical disability experience access to aids like a wheelchair and to additional facilities like training and maintenance. Besides the experienced access, it is needed to know what patients have to do by themselves to have access to aids. Gallacher et al. (2018) describe that the organisation of care can lead to a heavy workload for patients. This workload can result in burdens, which could have a huge impact on the daily life of patients (Tran et al., 2015). The burdens can have a negative effect on the quality of life of a patient (Gallacher et al., 2018). Research is needed to get insight into the kind of burdens patients with a disability experience with the application of aids at the municipality. How is it influencing their daily life and what is exactly the role of the municipality in managing the situation of individual patients?

Objective and research question

In this research, the focus will be on patients with a physical disability in a wheelchair. They are dependent on their wheelchair and adjustments at home to be able to move independently. Like is explained in the research of Mol et al. (2017), the provision of aids for this group of patients is not always optimal. In addition to their research, it is needed to explore what the experienced impact is of the organisation of care around the aids on the daily life of patients. The experience of the patients

will be researched by analysing books. In these books, they tell their story about their experience with the accessibility of aids and the role played by municipalities. Analysis of these stories will give insight into their perspective, which is a valuable addition to the existing literature. Identified in the patients' experiences stories is that accessibility to public space is an important burden for patients with a physical disability, but for the reason that public space is not directly linked to access to aids, this has been left outside the scope of this research. The experiences of the patients will be compared with the values of accessibility of care and positive health as described in the framework of Appropriate Care (Zorginstituut Nederland, 2022). In this way, it is possible to explore the differences and similarities between patients' experiences and policy.

The research question is as follows:

How does the experienced accessibility to aids for patients with a physical disability and the experienced role of the municipalities in facilitating access to these aids influence their lives, and how does this experience correspond to the framework Appropriate Care of Zorginstituut Nederland (2022)?

The sub-questions will be:

1. What kinds of elements are important for a positive experience of accessibility by patients?
2. Which values of the municipality conflict with the values of patients and the framework of Appropriate Care?
3. What kinds of burdens do patients experience as a result of the healthcare system?

2. Theoretical Framework

2.1 Conflict of values

The framework of Appropriate Care (Zorginstituut Nederland, 2022) described how care for patients should be organized. Different values and norms for the design of healthcare are elaborated. For this research, it is meaningful to know how the norms of the framework are corresponding to the values of municipalities and patients with a physical disability in practice.

A municipality and a patient could have different values, which are possibly conflicting with each other. For the municipality, it is a challenge to serve the interest of the public. For example, services which are fully appropriate for the needs of an individual patient can be not so efficient in terms of the needs of the wider community (De Graaf, Huberts & Smulders, 2016). For the municipality, it is a dilemma to manage the tensions between conflicting public values. Public values are supposed to be the foundation of all governmental actions. (De Graaf, Huberts & Smulders, 2016). Values which are important for good governance (of the municipality) are performance values like effectiveness and efficiency, but also procedural values that indicate the quality of the process like integrity, transparency, equality, lawfulness and honesty (De Graaf & Paanakker, 2015; Jørgensen & Sørensen, 2012). The procedural values indicate the morality of the governance of the municipality. Doing things right does not mean that the right things are done. Sometimes is the consequence of doing things right that the whole procedure is less efficient. For a municipality, it can be a dilemma to perform well, according to the performance values, or to be good, according to the procedural values (De Graaf & Van Der Wal, 2010).

Assuming that the municipalities are acting in line with the mentioned public values, it will be hard to effectuate all these values at the same time for individual patients (De Graaf, Huberts & Smulders, 2016). The empirical data should be researched on what the values of patients with a disability are, how they are conflicting or corresponding with the values of the government and what kind of dilemmas the municipality has to execute their values.

This thesis focuses on four different concepts which are mentioned in the Framework of Appropriate Care (Zorginstituut Nederland, 2022): accessibility, Value Based Health Care, positive health and Patient Centered Care. How these concepts are important for patients with a disability will be elaborated below. The possible conflicts for the municipality, following these concepts, will be described in the result section.

2.2 VBHC, accessibility, positive health & PCC

Healthcare should deliver a relevant contribution to people's health, considering a proportional use of money. The task of municipalities is to deliver care which is effective and appropriate for the individual patient (Zorginstituut Nederland, 2022). Porter & Teisberg (2006) have introduced Value Based Health Care (VBHC), wherein the value of healthcare is the health outcome per dollar or euro of cost expended. The goal of VBHC is to have the best possible outcomes for the patient, for acceptable costs (Groenewoud, Westert & Kremer, 2019). It is hard to define what a good health outcome is because what a healthcare professional defines as a good outcome does not always align with the desired or relevant outcomes for patients (Elf et al., 2017).

For patients with a disability, a relevant outcome is to have access to aids. The concept of accessibility appears in different principles of the framework Appropriate Care (Zorginstituut Nederland, 2022). Having the ability to use aids like a wheelchair is related to accessibility. Accessibility is defined by Levesque, Harris & Russel (2013) as access to a service, a provider or an institution. Accessibility is also the right or opportunity for patients to be able to use appropriate services in proportion to their needs. In this research the focus is not on the physical access, like entering a building, but on the access to services which are needed to make proper use of aids (Levesque et al., 2013).

According to the framework of Appropriate Care (Zorginstituut Nederland, 2022), patients may expect to have access to care that is effective, whereby is room for their personal situation. The government and healthcare organisations have the job to create equal accessibility to care for every patient (Zorginstituut Nederland, 2022). Having a wheelchair is step one, but important is that patients have access to a wheelchair that fits them, that they get training and that they have access to repairment and replacement parts of the wheelchair (Toro et al., 2015). With a fitting wheelchair, patients can explore what they want and can do in their daily life.

Accessibility to aids is the facilitator for participation in society and employment (Toro et al., 2015). Patients with a physical disability want to participate in social and civic life and aids like a wheelchair give them independence and the ability to go to work or social activities (Bertrand et al., 2017). This attitude of patients is also described in the framework of Appropriate Care (Zorginstituut Nederland, 2022). The framework introduces a perception of health wherein the focus is on what a patient still could do, instead of what they cannot. This concept is known as Positive Health: "the ability of a patient to adapt and self-manage, in the face of social, physical and emotional challenges" (Huber et al., 2016, p.1). This definition is not defining how healthy a patient is in a biomedical way, but how the patient can deal with their situation.

As described before, part of accessibility is to have the opportunity to make use of aids which meet the personal needs of patients. In different literature is a growing recognition that Patient Centered Care (PCC) is associated with quality of care. Patient centered care is defined “as care that respects and responds to the individual patient’s preferences, needs and values and ensures that clinical decisions incorporate patients’ values” (Jayadevappa, 2011, p.15). PCC leads to an improved understanding of patients’ needs when care providers acknowledge the perspective of the patient. Effective communication is crucial to achieving mutual understanding (Constand et al., 2014). Individual patients are different in what they can do, with or without aids. Zorginstituut Nederland (2022), has the principle that appropriate care is established with the patient. Time and communication are needed to explore the perspective of the patient and to discuss what will fit the individual patient. The implementation of patient centered care leads to more efficient and effective treatment, which is leading to a lower cost of care (Jayadevappa, 2011).

2.3 Burden of the healthcare system

As described before, having access to proper aids, which are designed for individual circumstances, has great value for patients. Interesting to add to these concepts is the theory of the burden of treatment. Gallacher et al. (2018) describe burden of treatment as the workload of healthcare and the implications it has on the well-being of patients. Separate from the illness a patient has, the workload which follows out of the healthcare system requires extra time, effort and cognitive energy for the patient (Tran et al., 2015). Relevant burdensome features are poor coordination and a lack of adequate information (Sav et al., 2013). Reduced quality of life and waste of resources can be the effects of an exorbitant treatment burden (Gallacher et al., 2018).

Patients with a physical disability will usually not be cured of their disability. The responsibility of managing their situation is shifting from healthcare services to the individual patient. In the framework of Appropriate Care (Zorginstituut Nederland, 2022), there is a lot of attention to the abilities of what a patient can do for themselves. Patients have to anticipate the burdens which are belonging to their treatment and the organisation of care (Ridgeway et al., 2014). It can be a struggle for these patients to handle the extra tasks, with result of burdens, which are occurring beside the demands of everyday life (May et al., 2014). There are several categories of burdens which patients could encounter. Tran et al. (2015) make a distinction between three categories of treatment burdens. An overview of the described types of burdens is presented in Table 1 below. The first is healthcare tasks which are imposed on patients, an important element of this category is paperwork tasks. Administrative paperwork is a possible burden for patients with a physical disability, due to the applications they have to do for aids. The second category contains

factors that exacerbate the burden of treatment. Structural poor access to aids has a huge impact on the life of patients who need those, having poor access to aids does exacerbate the burden for a patient with a physical impact. Structural access to aids contains also the access to maintenance, training and replacement parts of aids. The third category encompasses the consequences of healthcare tasks imposed on patients in daily life. Treatment burdens can have an impact on the social and civic lives of patients. The lack of access to aids denies the chance to participate in social or labour activities for patients. Furthermore, the tasks which are expected from the patient can lead to an emotional burden, like frustration about the process of getting access to aids. The last impact is financial, getting aids reimbursed from the municipality has a big meaning to patients. If their application got rejected, they have to pay by themselves, which is not possible for everyone (Tran et al., 2015).

Table 1: overview of the burden of treatment, based on Tran et al. (2015)

Category of treatment burden	Relevant subcategory for patients with a physical disability	Example
<i>Healthcare tasks imposed on patients</i>	Paperwork tasks	Administrative tasks like doing an application
<i>Factors that exacerbate the burden of treatment</i>	Structural factors	Access to aids, maintenance, training and replacement parts of aids
<i>Consequences of healthcare tasks imposed on patients in their daily lives</i>	Impact on professional, social, family life and leisure activities	No or restricted participation in social or civic life.
	Emotional impact	Frustration
	Financial impact of healthcare tasks imposed on patients	No access to reimbursed aids means own financial contribution

3. Research methods

3.1 Study design

People share information in the form of stories, these stories are useful for the understanding of individual experiences (Novak et al., 2020). Patients with physical disability have their own stories about their experiences with the organisation of the care they need. For this thesis, stories are used which are written by patients in the form of books. A qualitative analysis of books is chosen for this research because this makes it possible to research unfiltered patient experience stories. Patients' stories are often researched in the form of interviews or questionnaires, which implies control from the researcher. Analysing stories already written by patients gives patients the chance to tell their stories without any influence or steering from a researcher (Van De Bovenkamp et al., 2019). The books are studied systematically by the use of narrative analysis (Bailey, 1996). The narrative analysis gave the possibility to structure the stories of the patients, and it is a way of making sense of the stories (Murray & Sools, 2014).

3.2 Data collection methods

The books with stories of patients are collected from a database of the Erasmus University. This database is built by the *Stichting Coleta's Chronische Circus* and was acquired in 2019 by the Erasmus School of Health Policy & Management (ESHPM). The database is the biggest collection of stories about the experiences of patients and their families about having a disease (ESHPM, n.d.). Collecting data by analysing books allowed getting insight into the life of a patient with a physical disability and all the complex layers and variety. Another advantage of analysing existing books of patients is that relatively easily could be selected on the diversity and variety of the authors (Van De Bovenkamp et al., 2019).

For this study, there were inclusion- and exclusion criteria for the authors of the books which are analysed. The inclusion criteria are as follows: (1) the writer has experience with needing the support of a municipality by doing an application for aids or has received aids; The exclusion criteria are as follows: (1) the writer is not Dutch, Flemish authors are excluded because of the different healthcare system of Belgium; (2) book is written before the year 2000.

Within these criteria, there have been different dimensions included to get a maximum variation within the sample. To not get a one-sided image, attention has been paid to select books from authors with different perspectives. In this way, writers who had the experience of being unable to live their daily life due to accessibility problems are selected, but also writers who had positive experiences with being able to live their life due to aids and the organization around it. Furthermore, there has been ensured that a variation of gender, age and abilities to participate in the social and

civic life of the authors are included. Table 2 presents the included books and authors in this thesis. Title, name of author, gender and age are described. Also is the kind of participation in the civic life of the authors appointed. People can participate in social and civic life in many ways, to make it structured is been chosen to make the distinction between employed, unemployed and volunteer. The results will be referenced to the books according to the presented numbers. Considering the timeline for this thesis, 6 books have been selected for the analysis. The length of the books ranges from 69 pages to 256 pages.

Table 2: an overview of included books

Title	Reference	Author	Gender	Age (at the publication of the book)	Participation in civic life
Woman on wheels; ervaringen in een rolstoel	R1.1 - 1.2	Carry-Ann Tjong-Ayong	Woman	70	Volunteer
Gehandicapt voor Gevorderden	R2.1 - 2.3	Marloes Beemsterboer	Woman	29	Unemployed
Het raam kan niet open. Gevangen, maar niet gekooid	R3.1 - 3.3	Gerard Elferink	Man	60	Employed
De brievenbus van mevrouw De Vries	R4.1 – 4.2	Stephan Steinmetz, describing the story of Mrs De Vries	Woman	81	Unemployed
Eindelijk Invalide	R5	Boudewijn Paans	Man	68	Employed
Is er versh?!!	R6.1 – 6.2	Marianne Ames, editor of the story of Maurice Wiegman	Man	37	Volunteer/Employed

3.3 Data analysis

The data has been analysed according to the step-by-step guide to narrative analysis of Murray & Sools (2014). The reason for using narrative analysis is that this analysis puts the perspective of the patient with a physical disability in the foreground and with this analysis it is possible to tell their story holistically (Sharp et al., 2019). This analysis method contains five parts, each divided into steps. The main five parts are the introduction, storyline analysis, interactional narrative analysis, contextual analysis and comparative analysis of storylines. In this thesis, only the parts of introduction and storyline analysis have been used. The parts and steps in this analysis are meant to be flexible, the analysis is an iterative process (Murray & Sools, 2014). This is in line with the style of abductive analysis, which contains a back-and-forth process between research evidence and considerations of theory. With abductive analysis, the researcher is open for surprises, theory could be altered in response to discovered insights in the patient stories (Earl Rinehart, 2021). The collected insights from the patient stories have been summarized and analysed. During the analysis, key themes and contrasting themes are identified (Sharp et al., 2019). These themes may have occurred deductively from the theory which is described in the theoretical framework or they have been developed inductively, during the process of the narrative analysis (Sharp et al., 2019). The narrative analysis of the included books has been attached in Appendix B.

3.4 Validity, reliability and generalizability

Since the researcher had an active role in the analysis of the data, there is inevitable subjectivity in coding the data and theme generation (Braun & Clarke, 2022). The new insights, which are discovered through abductive analysis, are related to the beliefs, knowledge and views of the world of the researcher. So, the meaning of the surprise can differ between researchers (Earl Rinehart, 2021). It is important to be reflexive of the ways the researcher could have influenced the interpretation of the collected data, for example through prior assumptions and experience (Mays & Pope, 2000). A personal reflection to the role of the researcher has been attached to Appendix A.

To improve the validity there has been made use of triangulation of data. Within the patient experience stories, there is a selected diversity of authors (Mays & Pope, 2000). This suits the concept of fair dealing because, with sampling within the inclusion criteria, a wide range of different perspectives has been ensured. In this way, the viewpoint of one perspective will not be presented as the truth (Mays & Pope, 2000). Another tool to represent different perspectives and to improve the validity of the research is to have attention to negative cases. The intention of finding negative cases is to have awareness of cases which are contradictory to the majority of the studied cases (Mays & Pope, 2000). By using negative case finding, it was possible to avoid highlighting only cases which have the same content. In addition, the tool of thick description has been applied. With a thick description,

the context of the research object is included. The narrative analysis gives a complete picture of the included books, with the description of elements like the event, the helpers and the background information of the patient. The analysis gives insight into the emotions, thoughts and perceptions of the patients. Thick description leads to thick interpretation, which gives a better understanding of the analysed stories in their context (Ponterotto, 2006). To support the thick description, quotes from the analysed stories have been inserted in the result section. The information of the stories is in this way as specific as possible and in a meaningful form displayed (van Zwieten & Willems, 2004).

Generalizability is part of the external validation of research, external validation contains the degree of generalizability of the research conclusions in comparison to other persons, situations or time (van Zwieten & Willems, 2004). Thick description of the analysed patient stories provides the context of the patients in detail. With a rich description of the context of the researched patients stories, it is feasible to extrapolate the results to a broader framework so that they are suitable for policy applications (Hays & McKibben, 2021). Another way which improves the generalizability of this thesis is the use of analytical generalization. With analytical generalization, a certain set of results are generalized by using an established concept. But analytical generalization does also occur when a new concept or theory appears as important out of the found results. In later research, this new concept can be significant, which makes the research analytically generalizable (Smith, 2018). The abductive analysis of the patient's stories contributes to analytical generalization by using established concepts, but also being open to new insights.

3.5 Ethical considerations

The books which are analysed for this thesis have been published publicly. The authors are patients themselves or have collaborated intensively with the patient. The patients have written down their stories, with the goal to tell their experiences to the outside world. They were aware that everyone could read their book. In this way, it is not a problem to use their books in this thesis. The information of the books is publicly available, it is the responsibility of the authors to not publish privacy sensitive information. Because of this reason, the real names of the authors and other actors are used in the narrative analysis. Other data such as age, employer and living environment have not been fictitious either.

The authors of the books have written down their stories to give other people the chance to read them. The authors did not have the intention to be part of research with their book. Within this research, their story has been linked to other stories and their stories have been analysed in detail. Their stories have been used to tell a bigger and more general story about the experienced accessibility of aids in the Netherlands by patients. Although the authors are not informed that their book is used for this thesis, it can be substantiated that it is ethically justifiable. With this research, their stories

have been told again, only in a different context. The authors wanted to tell their story, otherwise, they did not write a book. To use their books in this thesis is ethically responsible because the books are public and are in line with the goal of the authors to distribute their stories.

4. Results

Analysis of several patient experience stories has led to different themes of experiences which patients had in the accessibility to aids. Three themes have been identified, which will be presented below. The first theme is about the actual (un)accessibility to aids for patients, different aspects of accessibility will be described. Secondly is described the kind of dilemmas municipalities are facing in the delivery of appropriate aids to patients. These dilemmas have been linked to the concepts of Positive Health, PCC and VBHC. At last, there are different burdens experienced by patients with a physical disability. These burdens have impact on the experience of accessibility of aids, the impact for patients will be defined.

4.1 (Un)accessibility of aids

Accessibility contains different aspects. From the analysed books emerged two important themes: waiting time and the access to materials of aids and repairment. These themes will be elaborated in the next section.

Dimension of time

Having access to aids like a wheelchair or a mobility scooter has a big impact on the life of patients with a physical disability. With an aid, they are able to go out and do things which they cannot do without an aid. Access to aids is very important for these patients, they have the aid rather today than tomorrow. An overarching theme in the analysed stories of patients is that they have to wait very long before an aid has been approved or implemented by the municipality. This waiting time has a negative influence on the experienced accessibility of aids by the patients.

'After half a year of talking to the municipality, they finally see that I really need this bus. Why did they not see that immediately? (R2.1)'

In this case, the patient had to wait because the municipality was not immediately convinced that she really needed a bus. This is an example of waiting time in the application process, the municipality has to examine the request carefully, which can take a frustratingly long time for a patient. But also when the municipality has approved an application, it does not mean that the waiting time is over:

'One and a half years ago, I started with an application for a new electric wheelchair and a manual one. The approval for both chairs came quickly. But sadly enough, chairs of paper are not working (R2.3).'

For the patient, it was very frustrating to have approval for new wheelchairs, but still have to wait such a long time before they are delivered. The waiting time reduces the experienced feeling of having good access to aids, the patient is for one and a half years busy every day with questioning when the new wheelchair will finally arrive.

That quick work by the municipality has an impact, is shown in the case of a patient who could get home after being in a revalidation centre. Before the patient was able to go home, several adjustments at his house were needed. In this story, there were no difficulties identified in the application for aids and when the patient got home, everything was arranged by the municipality.

'For the first time in my life, I am sitting in a stairlift. With the speed of a funeral procession, I am going up. Upstairs is more news, a walk-in shower, new non-slip tiles and a shower seat (R5.1).'

When the patient came home, everything he needed was arranged for him by the municipality. The provided aids made it possible to have a smooth transition from the revalidation centre to home, which helps the patient with being able to live in his own house. With little to no waiting time, the experienced accessibility has been magnified.

Access to material and repairment

Having a fitting aid and the possibility for the repairment of this aid is a part of accessibility. Having access to an aid is worth nothing when this aid, like a wheelchair, is not appropriate for the patient or when the aid is broken. In this part of accessibility is not only the municipality involved but also an aid supplier. In the analysed stories, the municipality is outsourcing the delivery and repair service of aids to external suppliers. The external suppliers are not always providing adequate work, the patients are describing how wheelchairs are not delivered in the right condition. These wheelchairs were made according to the requirements of an individual patient. The repair of aids is also described as a difficult process, wherein mechanics do not have the right tools or components to repair the aid properly. This has the consequence that repairing it does take a long time, wherein multiple appointments with mechanics must be made.

The suppliers are doing the job, but it is still the responsibility of the municipality to provide adequate aids and adequate repairment of aids. A patient is telling about the delivery of a wheelchair. The municipality approved her application, but the supplier is struggling with the delivery of the right chair, over and over again. The patient had to send the chair back, multiple times.

'Nothing is correct about the chair. The frame weighs + 200 kilograms, the sit/frame ratio is way too wide, the wheels are too small and the chair is too low. There is no headrest, no belts and no tray. This chair can go back again... (R2.3).'

It is the job of the municipality to create access to a supplier, who can give patients the wheelchair they need. The accessibility to the aid is questionable in this storyline. The patient got approval from the municipality for a wheelchair, but the municipality leads her to a supplier who is not delivering a good chair.

The municipality has also the job to create access to the repairment of aids. For patients in a wheelchair or a mobility scooter, it is a disaster when that aid is broken. They are losing their ability to transport themselves independently. The aid supplier has to repair the aids accurately, has to provide the right components for the aids and has the job to equip their mechanics with the right tools to be able to repair. Having these essentials not stand by can cause waiting time for the patient. Waiting time wherein they cannot use the aid they need, which can result that they cannot move independently. It has an impact on their daily lives, on the activities they planned and it has impact on their mental wellbeing. Not having the opportunity to use an aid properly gives frustration and impotence.

The implications of being dependent on good repairment have been shown in the story of a patient. The mobility scooter of the patient needed repair. The patient got stuck on the road, a mechanic arrived soon and was able to get the scooter working again. But, this was at the expense of other parts of the scooter like the light.

'I drive since August 24 without light, horn and direction indicators. Now I am waiting for months of repairment of that (R3.3).'

The patient had to wait for a very long time for the repairment of those parts, which caused that he had to drive an unsafe aid. Where first the mechanic arrived very soon, now the patient had to make several appointments before a mechanic showed up. This influences the joy of the patient generated by using the aid, which is not safe. It causes hesitation to use the scooter and it brings frustration.

In another situation, the wheelchair of the patient got a flat tire. The mechanic arrived soon, but he did not have the right tools to lift the chair of the patient. The mechanic had to lift the chair manually, at the risk of hurting his back. In this situation, the patient was 'lucky' to have a mechanic who would take that risk. Otherwise, he had to wait longer until the mechanic had the right tool to repair the chair correctly. The story shows that accessibility can be dependent on the equipment of a

mechanic, the right tools are essential for repair. Quick repairment of an aid improves the experienced accessibility to the services around aids and will enhance the patients' pleasure of using aids.

Summarized, it is frustrating for patients with a physical disability when they have to wait before they can use the aid they need. It brings uncertainty when a patient does not know if a municipality will endorse their request. Also when an aid has been approved by a municipality, there is a waiting time identified for the implementation or repairment of an aid. This has the impact that the patient's life comes to a standstill until the accessibility to the aid is restored. In this section, the focus was on the perspective of the patient. The perspective of the municipality has to be explored to be able to compare the different points of view.

4.2 Values of municipality versus values of framework Appropriate Care

The values of a municipality can collide with the values of a patient and with the values which are described in the framework of Appropriate Care (Zorginstituut Nederland, 2022). The next section will elaborate on which values are not aligned with each other, following the analysed stories of patients.

Positive health – individual needs versus community needs

With the help of aids, patients can reach positive health. A wheelchair, mobility scooter or other kinds of aids, gives patients with a physical disability the ability to do more on their own. It can give them independence and freedom. With the use of aids, they can go to work or do social activities.

A patient did experience some hesitation from the municipality by doing an application for a Canta. With this vehicle, she is allowed to drive on the road, which makes it possible to travel longer distances independently. The patient describes the process of the application for the Canta:

'With a lot of effort, energy and persistence and the help of a smart lawyer, you can get a Canta LX, which is given on loan by the municipality (R1.1).'

The patient indicates that it cost a lot of effort, energy and persistence to get the Canta. With the Canta, the patient is able to adapt to her situation and she can travel to places to participate in social life. The Canta helps to overcome the challenge to travel somewhere independently, without the help of others, which contributes to her Positive Health. But the road to getting a Canta is obtained with difficulty and she gets it only on loan from the municipality. A Canta is a very expensive vehicle which should be used in the right way, by people who are needing it. The municipality has to consider carefully if the patient really needs the Canta. Giving the Canta on loan to the patient indicates a form of control over the vehicle, by which they can take back the vehicle when they think the patient does not need it anymore. This is not contributing to the individual needs of the patient, but the

municipality has also to consider the needs of other citizens as well. The fair distribution of goods is highlighted in another story, the patient describes the impact of having a mobility scooter:

'With the mobility scooter, I can visit projects in the neighbourhood, independently visit the physiotherapist, the hairdresser, friends and so. In short: participating in society and keep working (R 3.2).'

It is very frustrating for these patients when municipalities do not approve or slowly approve their application for aids. From the patients' point of view, it is really simple: the aid is helping them in facing the physical disability they have. Because of the aid, they can focus on the things they still can do, instead of what they cannot do anymore. The mobility scooter of the patient, who describes above what the impact this aid will have on his life, was rejected by the municipality. The patient had told that he needed the scooter also for his work. For that reason, the municipality tells him that he has to do his application at another institution.

'To our surprise, the civil servant announced that we have to be at the UWV, according to the law (R3.2).'

For the patient, it is frustrating that he has to do the application again at another institution. However, the municipality has multiple values, to which they must adhere. They have a budget, from which they cannot deviate. The municipality has limited availabilities, and the resources they have must be divided equally among all the patients who require an aid. The patient has to do his application to another organisation, which is inconvenient for him, but it means that another patient can use a mobility scooter from the municipality. The municipality has to do accurate research if a patient is really in need of an aid. That accurate research is taking a long time and has sometimes the outcome of rejecting an application, which is not the best outcome for the patient but is better for the whole community.

PCC – efficiency versus patient centered

Implementing Patient Centered Care in the delivery of aids to a patient is not simple for a municipality. Multiple patients have the feeling that the municipality is not acknowledging their perspectives and individual needs. In the application and implementation of aids is little to no room for the preferences of an individual patient. Patients can have their preferences for specific types of aids, this is shown in a case where a patient got an adjustment in his bathroom from the municipality. The municipality did not involve him in the process of deciding how this adjustment would be done, which caused that the patient was unhappy with the result. The patient needed an adjustment at his shower cubicle. To

separate the changed cubicle from the rest of the bathroom, the municipality suspend a shower curtain from the cubicle. But the patient would prefer to have a wall instead of a curtain.

'I did a declaration for an adjustment at my bathroom. Instead of a shower curtain, which gets stinky and will crack, I let build a wall. The municipality thinks that is crazy and brutal (R5.1).'

The municipality did not agree with the declaration for the wall in the bathroom of the patient. A shower curtain is much cheaper and less time-consuming than building a wall, which is aligned with their values of efficiency. But for the patient, it is extra work. The municipality has rebuilt his bathroom and he is doing that again, at his own expense. If the municipality had taken the time to investigate the desires of the patient, they could have made the bathroom appropriate at once. The municipality could have given information to the patient on what will be reimbursed and what kind of adjustments are not reimbursed by the municipality.

Patients are doing an application for their own, individual situations. They have an idea about what kind of aid will contribute to their life. Municipalities have to handle a lot of applications at the same time. A patient is elaborating that the municipality only looks at his medical situation, he has the feeling that his social life is wiped away. The patient is doing an application for an adjusted car, but the municipality assesses that he can use the provided cab service. But for the patient, an own car has huge advantages for his social life:

'With an adjusted car, I can go out without the help of others. Living a life in society as I did before: working, going out with the family and driving my kids to the soccer club (R6.2).'

Technically seen, the patient can transport himself with the cab to places he wants to go. But he does not have the same freedom as he will have when he has an adjusted car. Possibly, the municipality rejects the application of the patient because of their values of efficiency. It is more efficient to provide one cab service for all patients with a physical disability than to assess each patient if they need an adjusted car.

VBHC – effectiveness versus equality

The value of VBHC is to have the best possible outcomes for the patient, for acceptable costs. This corresponds with the value of the framework of Appropriate Care. Handling according to this value is difficult for municipalities, has emerged from the patient experience stories. A woman is describing that she is ineligible for a certain ceiling lift, which is cheaper than the one she can get:

'I do not get a ceiling lift of €1559,- because this is a construction modification, but a lift of €7000,-, which I cannot use because of lack of space, I can get immediately (R2.2).'

In terms of VBHC, the municipality makes a questionable proposal to this patient. The municipality is not looking for effective and appropriate care for the patient. They are following the rules exactly, but are not considering which impact that has on the life of the patient. The expensive lift does not fit in her house, which means she has no lift. From the view of the values of the municipality, they cannot do anything else than refuse the lift with the construction modifications. Probably, it is the policy of the municipality to not reimburse these kinds of lifts. The procedural values of the municipality like equality and lawfulness count more than the value of effectiveness in this case.

With moving from one municipality to another municipality, a patient encounters two different ways of organizing aids, which are not aligned with each other. The patient got one year ago a brand-new wheelchair from the municipality where she used to live, but she had to give it back when she announces that she is moving to a new municipality.

'The new municipality is a loan municipality. This means that all social services (wheelchair, walker, patient lift system) by the municipality are loaned by the supplier. The old municipality bought the services. This means that the services stay the property of the municipality unless the new municipality will buy the service. But, as you can guess, the new one does not want that (R2.3).'

For the patient it will be the best outcome to keep the chair she got from her old municipality. Cost-effectively, this will also be the best outcome. The chair was specially designed for the patient and was an investment of the old municipality for a couple of years. But this does not fit the policies of both of the municipalities. The wheelchair is the property of the old municipality and the new one does not buy aids, they loan them from a supplier. These are two different systems, which are not working aligned with each other. It would not be fair to other patients in the new municipality when this patient gets a wheelchair which is bought and made brand-new. It will go against the procedural values of integrity, equality and lawfulness. Municipalities have the responsibility to make their own policy, in this case, the system is hindering them to perform VBHC and it makes it hard to have cross-municipal cooperation.

As is shown in the presented cases in this section, it can be a big dilemma for a municipality what is more important in the delivery of aids. Are the values of effectiveness and efficiency more important, or the procedural values like equality? Several dilemmas have been described, concerning the concepts of positive health, PCC and VBHC and in relation to the values of a municipality. Where dilemmas occur for the municipality in the process of applying and implementing aids, patients do experience several burdens as the effect of the healthcare system.

4.3 Burden of organization of aids for patients

Several burdens are identified in the analysed storylines of patients. These burdens are administrative, emotional or they have an impact on the social and civic life of the patient. These burdens will be elaborated in the next section.

Administrative workload for aids

Identified in the storylines are several burdens which are linked to administrative burdens. For an application of an aid, several actions must be done. Actions like filling in forms, writing letters to the municipality and having conversations with the municipality. These actions are influencing the daily life of the patients and are sometimes disproportionate. A patient is describing that he would like to have a job, but through the amount of work which is coming with arranging the needed aid, he has no time left to work. Doing the needed paperwork is already a full-time job.

'I want to work, but I have to arrange so much. Following the procedure for construction at my house, doing the application for the adjustment of a car, and getting my wheelchair adjusted. That causes so much stress; I just cannot work. Every day institutions call me about something they need, a form or a signature (R6.1).'

This patient has recently become disabled and for him doing an application for aids was new. This can make the burden extra heavy. Another patient had already had an aid for a longer time but is still experiencing administrative burden. The patient has a Canta but has to prove over and over again that she really needs this vehicle. The municipality is sending her letters and is calling her. She has to drive enough kilometres in the Canta, otherwise, the municipality will take it back.

'You have to do an extra effort to make kilometres because you receive regular phones and letters that the municipality considers to get the expensive means of transport back (R1.1).'

This pressure from the municipality has an impact on the patient's life and also on her pleasure of having the Canta. The task of paperwork does not end with the approval for an aid, it goes on when a patient is using it. This makes it a structural burden.

Influence on daily life

Having no or poor access to aids has a huge impact on the daily lives of patients. As described in the sections about positive health and patient centered care, the patients want to participate in social and civic life. Sometimes, participation is not possible due to the lack of access to an aid. This lack of access has consequences for patients in their daily lives. A patient did an application for adjustments at his

house and this application was rejected by the municipality. They had the opinion that moving was a more adequate solution for this patient. But moving would have a big impact on the social life and daily activities of the patient:

'I want to stay where I live, in the centre of the district where we are grounded, built up a network and where I could contribute via my work to the liveability of the district (R3.4).'

The place where this person lived was the centre of his social and civic life. Moving would not only have the impact of living in another house but would also have the consequence that it would be more difficult for this patient to participate in his social and civic life. This gives burden for not having access to reimbursed adjustments at his current house. Having no access to a certain aid can also influence the family life of a patient. A patient is describing that he is doing an application for an adjusted car, which he can drive by himself. It will give him the opportunity to do things he is now not able to do independently.

'My wife would not have to bring the children always to sports, I can go to my work with the car, to the pool and physiotherapy (R6.2).'

Having no access to an adjusted car, in this case, creates also a burden for the family of the patient. The wife of the patient has to take care of bringing the kids to sports and the kids cannot share that moment of going to sports with their father.

Uncertainty and frustration

Patients are experiencing an emotional burden in the process of the application of the implementation of aids. The whole process of uncertainty, waiting time and administration is negatively affecting their mental well-being. Rejection of an aid by the municipality is leading to disappointment and despondency. Do they have to agree with the decision of the municipality or are they going to fight against it? In the analysed patient stories, there were multiple occasions in which the patient had difficulties with proving that they needed an aid. This is a serious burden for these patients, they are putting a lot of energy and time into the application of aids, without knowing if the application will be approved. The application process of aids leads to frustration and it costs a lot of energy, like in the case of a patient who heard after six months that his application for a mobility scooter was rejected.

'And they tell me that after six months of waiting, after six months of hard work of my caregivers to transport me (R3.2).'

The emotional burden is also an aspect of waiting time. The time that some patients with a disability do not have. Without an aid, like a wheelchair or mobility scooter, their independent life

stands still. Not knowing if or when you get an aid affects the mental state of patients, by knowing that their disease does not stand still.

'You do not get any time, because the race against the clock is beforehand lost. The slow-working organizations and your own process of decline will take care of that (R3.1).'

Also when an aid is approved, it will not mean automatically that the emotional burden has gone:

'The application for extra hours of Personal Care help was honoured at the last minute, but really happy about the victory are you not anymore, because oh, what energy that takes, which affected me and my loyal wife (R3.1).'

It is hard for patients to be constantly confronted with the fact that they have a disability. This can be hard for them, emotionally, and it makes it harder when the municipality is not working along with them. This form of emotional burden is highlighted with a story of a patient who got constantly information from the municipality about several aids or help she got from them. This patient was not understanding the information by herself, which causes stress and panic for the patient (R4.1).

In summary, the process of getting or retaining aids has a big impact on the daily lives of patients with a physical disability. The burden is intertwined with their daily life, it causes that they are not able to go to work or to participate in social activities and it has an influence on their mental well-being, through the uncertainty and frustration of the application process.

5. Discussion and conclusion

In this thesis, research has been done to explore how patients with a physical disability experience the accessibility of aids. With the help of narrative analysis of stories of patient experiences, several topics have been identified to be able to answer the research question:

How does the experienced accessibility to aids for patients with a physical disability and the experienced role of the municipalities in facilitating the access to these aids influence their lives, and how does this experience correspond to the framework Appropriate Care of Zorginstituut Nederland (2022)?

The experienced (un)accessibility of aids by patients contains different components. Waiting time and actual access to repairment and materials are influencing the experienced accessibility of patients. Waiting to get approval for an aid, or repairment of an aid, has an impact on the daily life of a patient. This impact contains that the lives of patient come to a halt because without essential aids like a wheelchair they are not able to do anything independently. Unfortunately, the municipality and patients do not always have the same vision and values about how to achieve accessibility to aids. Patients want to have access to aids, to be able to focus on the things they can still do. This is aligned with the concept of positive health, which is also described in the framework of Appropriate Care. But the municipality cannot simply give everyone access to aids, they have to distribute their resources in a fair and equal way. Patients could experience the role of the municipality like they are working against them, instead of helping them, which can cause a bad experienced role of the municipality. For patients, the aids they apply to or receive must be adjusted to their personal situation and needs. It is hard for them when they are experiencing that the municipality does not pay attention to their individual situation. But for the municipality, it is a constant consideration between providing patient centered care or being efficient. The municipality should have the aspiration to have the best possible outcome for the patient but they also need to consider the cost. This can give dilemmas in the approval process of certain aids. The collision of difference in values between patients and municipalities is causing some treatment burdens for patients, they experience burden on an administrative and emotional level, but also burden that has impact on their social and civic life. These burdens are affecting the experienced accessibility and the role of municipality in the facilitation of aids.

5.1 Appropriate care of aids

The framework of Appropriate Care (Zorginstituut Nederland, 2022) is prescribing how care providers and patients could work together to achieve appropriate care for individual patients. Based on the norms and values of the framework, multiple concepts are identified to answer the research question. To involve the perspective of the patient, several patient experience stories have been analysed. With

the analysis of these stories, it became clear what was important for the patients in the process of having access to aids. Another topic that appears indirectly out of the stories is the dilemmas which municipalities are facing in the provision of aids to people with a physical disability.

For the values of PCC, Positive Health and VBHC is much attention in the framework of Appropriate Care (Zorginstituut Nederland, 2022). For patients these values contributing to receive better accessibility to aids, which are aligned with their individual needs and wishes. Aids are helping patients to execute their daily activities. Aids have a big impact on how much patients are able to do things, independently or not. Patients are describing that an aid like a wheelchair, mobility scooter or an adjusted facilitates the opportunity to go to their work and to participate in society. The vision of positive health, wherein the focus is on how patients are dealing with their situation and adapting to their disability (Huber et al., 2016) is confirmed by the patients themselves. Patients describe in the analysed stories how gladly they want to work, bring their kids to school or participate in social activities. Their stories are in line with the theory of Bertrand et al. (2017), who describes that a wheelchair gives people with a disability independence and freedom to live their desired life. To live their own desired life, patients are in need of aids that are matching to their personal situation and requirements. The execution of the values of patient centered care and positive health leads to a higher quality of care (Jayadevappa, 2011).

When the municipality is acknowledging the perspective of the patient, it will lead to better mutual understanding between the patient and the municipality (Constand et al., 2014). The storylines of the patients showed that it can be frustrating for the patient when the municipality is not on the same page. Patients are doing an application with the belief that they need a specific aid. When the municipality is rejecting that aid, it feels for the patient like the municipality has no attention to their personal situation. The framework of Appropriate Care prescribes that care suppliers have to take time to explore the wishes of an individual patient, whereby effective communication is used (Constand et al., 2014; Zorginstituut Nederland, 2022). Jayadevappa (2011) outlines that PCC is leading to a more efficient and effective treatment. For municipalities it is in practice incredibly difficult to perform PCC, since they are balancing between having a general policy for everyone and having room to provide aids at an individual level. Zorginstituut Nederland (2022) has contrasting norms, which makes it hard for municipalities to have an unambiguous policy. The framework of Appropriate Care has the norm that appropriate care is based on the state of science, which is in practice effective at the group level. But the framework also advocates the value to offer care, adjusted to the personal wishes of patients. This dilemma was shown in a storyline of one of the analysed books. The patient wanted a ceiling lift, but she did not get approval for it, because it needed a construction modification.

A ceiling lift which was way more expensive but does not fit in her house, she can get immediately. The municipality has policy which is effective on group level but does not fit the personal situation of the patient. This example is in line with the theory that it is hard to define VBHC because the municipality and the patient both have a different perspective on what the best outcome contains (Elf et al., 2017). The framework of Appropriate Care (Zorginstituut Nederland, 2022) does not elaborate on how municipalities and patients can handle this difference in vision.

Negatively influencing the experienced accessibility of aids are several burdens, which are the result of the system wherein patients operate. Healthcare tasks which are imposed on patients are causing extra work for the patient (Tran et al., 2015). Administrative tasks that has to be done for an application of an aid are taking much time and energy from patients. Structural poor access to aids has a big influence on the daily lives of patients. The burden has impact on their professional and social life, on their family life and their mental well-being (Tran et al., 2015). This impact is shown in the patient experience stories, for one patient the administrative burden around aids blocked his opportunity to find a job. Patients got frustrated and hopeless when aids were not approved by the municipality or when proper repairment of an aid took months. An aid can be the key to participation in social and civic life, as is described before. When the access to an aid is not arranged, people do not have the opportunity to take their places in society.

Municipalities are not able to execute the values of positive health, accessibility, PCC and VBHC as described in the framework of Appropriate Care (Zorginstituut Nederland, 2022). The conditions to provide these values properly are not captured in the framework. The framework does not elaborate on the dilemmas which municipalities are facing in the assessment of applications for aids. The delivery of aids must be appropriate for patients with a physical disability, but how does a municipality need to perform this? They are working with limited resources and abilities. Patients are noticing this in the application and implementation process for aids. They are experiencing laborious access to the aids they need. They need aids not only to focus on positive health but to live a common life, to be able to move or to live independently. An aid is an essential aspect of their life, the municipality does not meet that urge. The framework of Appropriate Care should focus more on the basics; creating a good basis for the delivery of aids. When that is arranged, patients can focus on positive health, to live the life they want. Municipalities should create more room to focus on a smooth assessment of applications, to reduce waiting time and frustration of patients.

5.2 Practical and scientific relevance

This thesis presents the perspective of patients, compared with the values which are described in the framework of Appropriate care of Zorginstituut Nederland (2022). The perspective of the patient provides an overview of the obstacles they encounter in the accessibility of aids. The narrative analysis made clear that the necessities of the patients, like having access to an aid, have to be arranged. When patients do not have a foundation with good access to aids, they are not able to execute positive health. The relevance of this thesis is to elaborate and underline the perspective of patients, to represent their view in addition to the framework of Appropriate Care.

Moreover, in-depth research has been carried out in addition to the existing literature. De Graaf et al. (2016) has done research on public values and has identified a conflict between performance and procedural values. This thesis describes what it means for municipalities to have to deal with these conflicting values in the provision of accessibility of aids. Besides, this thesis shows the perspective of the municipality in light of the framework of Appropriate Care (Zorginstituut Nederland, 2022). This framework emphasizes the advantages of using concepts like positive health, PCC and VBHC in the provision of care. The patient does benefit from the use of these concepts but it is hard for the municipalities to perform them. The existing literature (Huber et al., 2016; Jayadevappa, 2011; Porter & Teisberg, 2006) and the framework of Appropriate Care (Zorginstituut Nederland, 2022) do not pay much attention to the difficulties of implementing these concepts in practice, which are presented in this thesis.

A last practical aspect of this thesis is the insight that having access to aids contains several dimensions. Having no or poor access to aids is highlighted by the rejection of applications, long waiting times and lack of materials and repair. Underlying these fundamental aspects of access, burdens emerge. Having no access to aids has a big impact on the daily lives of patients with a physical disability. These burdens should have a more prominent place in literature and policy. Aids are life-changing for patients with a physical disability, if they have no access to these aids it influences their daily lives dramatically. This point of view must be underlined in creating accessibility of aids for this target audience.

5.3 Strong points and limitations

This thesis is bringing a different way of conducting research to the existing literature. Narrative analysis has been done of books which are written by patients. The patients have told their stories, without having the intention of collaborating with academic research. This had the result that the authors of the books have written their real stories, without any influence of external researchers. This gives another perspective than the perspective of participants in previous research. The narrative

analysis shows patterns often occurring around the accessibility of aids in the different stories, in which the stories confirm each other.

How this research is carried out brings some limitations with it. The books are written by patients who want to tell their stories, the majority of the analysed books are containing active agents. These agents are fighting for the rights they have and are active in applying for the aids they want to have. Their activeness and feistiness are maybe also the reason that they wrote a book. This may affect the results and can give a one-sided image. To prevent only negative stories about the accessibility of aids appeared in this thesis, the researcher has made sure to include contradictory cases by selecting patients with different perspectives of the experienced accessibility of aids.

Another limitation of this thesis is that only the perspective of the patient has been researched by analysing books written by patients. The role of municipalities is described, but their perspective has not been analysed. The vision and background of the municipalities have not specifically been researched, but the dilemmas which municipalities are facing became clear in the analysis of the stories of patients and by analysing the framework of Appropriate Care. In this way, the perspective of the municipality has been represented.

5.4 Conclusion

Patients are facing several problems with the application and implementation of aids, which influences their experienced access to aids. This thesis provides different aspects which have impact on the experienced accessibility by patients. The presented aspects of waiting time and access to materials and repairment are negative implications which come forward immediately in the experienced access to aids and the experienced role of municipalities to these aids. Underlying outcomes of having poor access to aids have been identified as several burdens for patients. Possible values for municipalities are also explored, and how these values are conflicting with the values of the framework of Appropriate Care (Zorginstituut Nederland, 2022). Municipalities have to step up to improve the experienced access for patients, but the municipalities also have to be helped by the government with good conditions wherein the municipality can improve access to aids.

6. References

- Bailey, P. H. (1996). Assuring Quality in Narrative Analysis. *Western Journal of Nursing Research*, 18(2), 186–194. <https://doi.org/10.1177/019394599601800206>
- Braun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*, 9(1), 3–26. <https://doi.org/10.1037/qup0000196>
- Constand, M. K., MacDermid, J. C., Dal Bello-Haas, V., & Law, M. (2014). Scoping review of patient-centered care approaches in healthcare. *BMC Health Services Research*, 14(1), 271. <https://doi.org/10.1186/1472-6963-14-271>
- De Graaf, G., Huberts, L., & Smulders, R. (2016). Coping With Public Value Conflicts. *Administration & Society*, 48(9), 1101–1127. <https://doi.org/10.1177/0095399714532273>
- De Graaf, G., & Paanakker, H. (2015). Good Governance: Performance Values and Procedural Values in Conflict. *The American Review of Public Administration*, 45(6), 635–652. <https://doi.org/10.1177/0275074014529361>
- De Graaf, G., & Van Der Wal, Z. (2010). Managing Conflicting Public Values: Governing With Integrity and Effectiveness. *The American Review of Public Administration*, 40(6), 623–630. <https://doi.org/10.1177/0275074010375298>
- Earl Rinehart, K. (2021). Abductive Analysis in Qualitative Inquiry. *Qualitative Inquiry*, 27(2), 303–311. <https://doi.org/10.1177/1077800420935912>
- Elf, M., Flink, M., Nilsson, M., Tistad, M., von Koch, L., & Ytterberg, C. (2017). The case of value-based healthcare for people living with complex long-term conditions. *BMC Health Services Research*, 17(1), 24. <https://doi.org/10.1186/s12913-016-1957-6>
- Gallacher, K. I., May, C. R., Langhorne, P., & Mair, F. S. (2018). A conceptual model of treatment burden and patient capacity in stroke. *BMC Family Practice*, 19(1), 9. <https://doi.org/10.1186/s12875-017-0691-4>
- Huber, M., van Vliet, M., Giezenberg, M., Winkens, B., Heerkens, Y., Dagnelie, P. C., & Knottnerus, J. A. (2016). Towards a ‘patient-centred’ operationalisation of the new dynamic concept of health: A mixed methods study. *BMJ Open*, 6(1), e010091. <https://doi.org/10.1136/bmjopen-2015-010091>
- Jayadevappa, R. (2011). Patient Centered Care—A Conceptual Model and Review of the State of the Art. *The Open Health Services and Policy Journal*, 4(1), 15–25. <https://doi.org/10.2174/1874924001104010015>
- Jørgensen, T. B., & Sørensen, D.-L. (2012). Codes of Good Governance: National or Global Public Values? *Public Integrity*, 15(1), 71–96. <https://doi.org/10.2753/PIN1099-9922150104>
- Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *BMJ*, 320(7226), 50–52. <https://doi.org/10.1136/bmj.320.7226.50>

- Mol, T., Verweij, L. M., & De Bruijne, M. (2017). *Kwaliteitsborging van extramurale medische hulpmiddelen: Een rolverkenning van gebruikers van medische hulpmiddelen, zorgverzekeraars, gemeenten en de Inspectie voor de Gezondheidszorg en Jeugd*.
<https://www.nivel.nl/nl/publicatie/kwaliteitsborging-van-extramurale-medische-hulpmiddelen-een-rolverkenning-van-gebruikers>
- Murray, M., & Sools, A. (2014). Narrative Research. *Qualitative Research in Clinical and Health Psychology*, 133–154.
- Novak, L. L., George, S., Wallston, K. A., Joosten, Y. A., Israel, T. L., L Simpson, C., Vaughn, Y., Williams, N. A., Stallings, S., Ichimura, J. S., & Wilkins, C. H. (2020). Patient Stories Can Make a Difference in Patient-Centered Research Design. *Journal of Patient Experience*, 7(6), 1438–1444.
<https://doi.org/10.1177/2374373520958340>
- Ponterotto, J. (2006). Brief Note on the Origins, Evolution, and Meaning of the Qualitative Research Concept Thick Description. *The Qualitative Report*. <https://doi.org/10.46743/2160-3715/2006.1666>
- Porter, M. E., & Teisberg, E. O. (2006). *Redefining health care: Creating value-based competition on results*. Harvard Business School Press.
- Sharp, N. L., Bye, R. A., & Cusick, A. (2019). Narrative Analysis. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (pp. 861–880). Springer Singapore.
https://doi.org/10.1007/978-981-10-5251-4_106
- Smith, B. (2018). Generalizability in qualitative research: Misunderstandings, opportunities and recommendations for the sport and exercise sciences. *Qualitative Research in Sport, Exercise and Health*, 10(1), 137–149. <https://doi.org/10.1080/2159676X.2017.1393221>
- Tran, V.-T., Barnes, C., Montori, V. M., Falissard, B., & Ravaud, P. (2015). Taxonomy of the burden of treatment: A multi-country web-based qualitative study of patients with chronic conditions. *BMC Medicine*, 13(1), 115. <https://doi.org/10.1186/s12916-015-0356-x>
- van Zwieten, M., & Willems, D. (2004). Waardering van kwalitatief onderzoek. *Huisarts en Wetenschap*, 47(13), 38–43. <https://doi.org/10.1007/BF03083653>
- Walburg. (2016). De winst van positieve gezondheid. *Skipr*, 9(7–8), 40–42.
<https://doi.org/10.1007/s12654-016-0103-8>
- Zorginstituut Nederland. (2022). *Kader Passende zorg*.
<https://www.zorginstituutnederland.nl/publicaties/adviezen/2022/06/28/kader-passende-zorg>

Appendix A: Personal reflection on the role of the researcher

As described in the section of research methods, the researcher has an active role in this thesis. Inevitably, the active role of the researcher could bring some subjectivity and influence to the research. To enhance the credibility of the results, the researcher will reflect in this section on the way she could have influenced the narrative analysis and the results of the research.

The attended studies of the researcher provide some background knowledge about the healthcare system. The researcher did study for her bachelor's degree in Health Policy and Management and is currently following a master's in Healthcare Management. In these studies, the researcher learnt a lot about the different concepts which were important in this thesis. The concepts of positive health, PCC and VBHC were often emphasized positively in the mentioned studies. This could have influenced the way the researcher approached the concepts because she was biased about the function of those concepts. The researcher was aware of her background which could influence the research. The researcher was open to other insights, which can also be seen in this thesis. The thesis has shown that the concepts of positive health, PCC and VBHC not always are realistic and feasible solutions and that the execution can be hard in daily practice.

Secondly, the researcher did not experience the problems which the authors of the books have to face in their daily life. The researcher is able to walk and is not dependent on a wheelchair or other kinds of aids. This could have the effect that the researcher has downplayed the problems of the patients, by not knowing what the actual impact was to have no accessibility to aids. On the other hand, the researcher had a fresh look at the books which are analysed. The researcher was not aware of the problems which the patients had to deal with and was surprised about the system that patients with a physical disability have to deal with.

Appendix B: Narrative analysis

1. Woman on wheels; ervaringen in een rolstoel

Carry-Ann Tjong-Ayong

1 Introduction

The author of the book, Carry-Ann Tjong-Ayong, got a stroke in 2000. Since that day she is going through life, paralyzed on one side. She has experienced a life without a wheelchair and a life with a wheelchair. She was a radio journalist by an immigrant broadcaster. She won the ZAMI Award for a poem named 'De Wasvrouw'. After reciting this poem in a subway, Carry-Ann got a stroke. After revalidation, she resumed her life as poet and writer of books. And as Woman on Wheels.

Carry-Ann wrote down her stories, the obstacles and also the fact that she is enjoying life. To be mobile Carry-Ann is using a wheelchair, mobility scooter, adapted bicycle and a Canta. "I go cycling on an adapted bicycle. I am driving everywhere with the mobility scooter and Canta. I travel to places where I never went before. I am enjoying."

Carry-Ann has a husband, Wim, and a son and a daughter. Her roots are in Suriname, she is travelling regularly to this country. The hobbies of Carry-Ann are swimming and horse riding.

The next storylines of this book will be discussed:

1. Request for aids to the municipality
2. Organization of public space for people in a wheelchair

Storyline 1: Request for a Canta to the municipality

Agent

Carry-Ann is the main agent of this story. She is having a Canta to be able to move independently further distances. Carry-Ann is a persistent agent and did not give up before she got the Canta "*With a lot of effort, energy and persistence (...) you can get a Canta LX.*" The municipality is the agent she needs to get a Canta. Wim is also mentioned in this storyline, he goes with Carry-Ann to the park.

Acts/events

Carry-Ann describes that it costs a lot of effort and energy to get aids from the municipality. Big part of her freedom is a Canta, which is an adapted vehicle. The Canta drives a maximum of 45 km/h, whereby it is allowed on the public road but also bicycles- and footpaths. The Canta gives Carry-Ann the opportunity to do things spontaneously, without being dependent on others. *'It is a sunny day, I want to go to the park to have lunch. Wim wants to go with me, but not in the Canta, as I propose. I want to travel cheerfully in red, like my mood.'* She can travel distances independently, which are too far to travel by wheelchair. The Canta is the mean to go independently to the park, while Wim can travel the distance by foot.

Sitting in a wheelchair does not mean that Carry-Ann is automatically nominated to get a Canta. *“With a lot of effort, energy and persistence and the help of a smart lawyer, you can get a Canta LX, which is given on loan by the municipality.”* When she finally got one, Carry-Ann has constantly to prove that she really needs the vehicle. *“You have to do an extra effort to make kilometres because you receive regular phones and letters that the municipality considers to get the expensive means of transport back.”* The process of getting a Canta is not clear described, but with the overall feeling of the described situations, Carry-Ann makes clear that it is a process where she does not get the trust of the municipality. She gets the Canta on loan, after the involvement of a lawyer, and when she gets the Canta she still receives letters from the municipality which are doubting whether it is correct that she has the Canta and whether she has to make enough kilometres with the Canta, otherwise they will take it back.

Means/helpers

A helper to get the Canta should be the municipality. Carry-Ann describes not in detail how the process of requesting a Canta is going, but it is clear the municipality is not easily convinced about the request: *“With a lot of effort, energy and persistence and the help of a smart lawyer, you can get a Canta LX, which is given on loan by the municipality.”* The lawyer in this quote is also a helper, how they actually helped is not further described.

Setting/Scene

The storyline has not a particular setting. The atmosphere of the scene is hesitant from the side of the municipality. Carry-Ann has the desire to get the Canta, to have more freedom.

Purpose

Carry-Ann needs aids like a wheelchair and Canta to move independently from one place to another. The purpose to get the Canta on loan from the municipality, but also the underlying goal to be independent in travelling longer distances, like the park, without being dependent from others for transportation. *‘It is a sunny day, I want to go to the park to have lunch. (...) I want to travel cheerful in red, like my mood.’*

Breach

Carry-Ann wants to get access to the Canta, a useful resource to have more self-direction. The municipality is not very helpful in serving these access, that is why it seems they work against Carry-Ann. The clash is that the Canta is a *‘expensive mean of transport’*, which causes hesitation by the municipality to give it on loan to Carry-Ann.

Researchers narrative Summary

‘I have a Canta, it gives me so much freedom. If I want to the park with my husband, I hop in my Canta and I get there. It costed me a lot of energy and effort to get the Canta. The municipality was just convinced when I made use of a lawyer. I feel the hesitation of the municipality and I feel like I am not be trusted. I got the Canta on loan, which I get reminded of constantly, by the municipality. They call me and send me letters and I have to prove that I really need the Canta by making enough kilometres. Is it not clear enough that I am in a wheelchair and cannot transport in another way

independently? The Canta gives me so much joy, but also a lot of pressure with the municipality who is constantly looking on my shoulder.'

Conclusion

With the vision of Positive health, as described in the theoretical framework, patients are expected to self-manage and face the challenges of life. With the Canta, Carry-Ann is adapting and managing her situation, she can travel to places to participate in social life. For Carry-Ann, the Canta helps to overcome the challenge to travel somewhere independently, without the help of others, which contributes her to positive health. But the road to getting a Canta is obtained with difficulty. And when she has it, she needs to drive enough kilometres to prove that she needs it. It seems like the municipality is working against her, instead of facilitating her in getting the Canta and stimulating her Positive Health.

Carry-Ann got a Canta from the municipality, but it cost a lot of effort and energy. Also when she has the Canta, she needs to prove constantly that she is really needing it. The role of the municipality, experienced by Carry-Ann, is not very helpful. The letters and phones that keep coming about the Canta are showing that there is no basis for trust. This shows that the municipality is not on the same page as Carry-Ann. The concept of PCC describes that effective communication is crucial, to achieve mutual understanding. PCC leads to an improved understanding of patients' needs when care providers acknowledge the perspective of the patient. Carry-Ann has a different perspective than the municipality, good communication and understanding of each other will help to have more trust in each other. The letters and phones from the municipality to Carry-Ann are putting pressure on her to use the Canta enough. If the municipality understands why the Canta is so important for Carry-Ann, they will have an improved understanding of her needs, which could lead to more patient centered care.

The letters and phones from the municipality to Carry-Ann are coming from a value the municipality has. Effectiveness is important for them, the Canta is an expensive vehicle which should be used effectively. If Carry-Ann is not using it very much, it would be more effective if someone else gets the Canta, who could use it more often. The municipality has not endless budget and has to use the money they have for the people who are needing it. This contains also the procedural value of honesty. In the eyes of the municipality it would be fairer if someone else to get the Canta if Carry-Ann is not using it that much.

In this case, Carry-Ann has negative effects on the existing healthcare system. She has the burden to have to prove again and again that she needs the Canta. The way of working by the municipality can lead to having less fun and satisfaction by having the Canta. On the other hand is it important to consider the incentives of the municipality, a Canta is a very expensive vehicle which should be used in the right way, by persons who are really needing it. It is a thin line between having, as a municipality, control over their vehicle on the one hand, and having trust and encouraging the use of it for Carry-Ann on the other hand.

Storyline 2 Organization of public space for people in a wheelchair

Agent

Carry-Ann is the agent in this story, her son and daughter are also involved in this storyline. Carry-Ann wants to go out to have fun with her children, by going to the city. Carry-Ann is an active agent, although she has also doubts about the challenge to get into the city. *'My son is free and calls: 'Mom go you with me, to the terrace?' I hesitate, for just a moment. Amazingly, such a young boy wants to go with his disabled mum to the city. (...) But I also look up to ride the familiar route over bumpy stones.'*

Acts/events:

Going somewhere outside her house is a challenge for Carry-Ann. Her son asks her to go to the inner city. *'I look up to ride the familiar route over bumpy stones, which is causing shaking legs. Along small footsteps full of obstacles, crossing the road by way too steep slopes of the bus lanes, and over poorly laid cobblestones of through sand.'* Carry-Ann is happy that her son is with her, and that he wants to go to the city with his mum. But the unfriendly road for wheelchair users is an extra obstacle to doing it.

Another day, Carry-Ann's daughter takes her to Utrecht, they are going by train. They have to get on the train at Overvecht. *'The architect of the station has invented a deep pit with very steep stairs where elderly, disabled people, mothers with strollers, children and people with fear of heights always remain dazzled.'* *'No fear, there is a ramp, if you dare to ride 50 meters over loose planks at loose sand. The ramp has at the beginning and the end iron fences, but with my manoeuvrable "Quickie 2" is that easy.'* Finally, at the platform, Carry-Ann needs to get helped in the train with the boarding service of the carrier. Her daughter finds some info for this service. *'We learn that you have to call the service 24 hours ahead, besides that Station Overvecht is the only (?) station where no service to get in the train is available... Also, the bus is not an option for Carry-Ann, 'the steps are too high'.*

There are different challenges for Carry-Ann in this storyline. Carry-Ann wants to go with the train, getting at the platform is the first obstacle she encounters. When she is upstairs, she found out that the service for getting on the train is not available at that station. The last option is the bus, but also that kind of public transport seems not so public, because she cannot get in due to the steps. Besides the transport is also the public space like the road a challenge for her, because of the bumpy stones and other obstacles she encounters.

Means/helpers:

Helpers in this story are the son and daughter of Carry-Ann. They are inviting her to do something and help her to figure out how they can reach their goal. *'My fast daughter rushes up. Soon she is back with a flyer, which contains all the information for wanderlust disabled people.'* A means to be able to travel with the train is the boarding service, but that turns out not to be helpful. The lack of it makes it impossible for Carry-Ann to get on the train.

Setting/scene:

The setting of this storyline is the public space. The road to the inner city and the station. The condition of the public space is causing hesitation by Carry-Ann if should face the ride with her wheelchair.

Purpose:

Carry-Ann has the purpose to go out with her children and to do something for fun.

Breach:

Carry-Ann wants to do something fun with their children. But the public space makes it complicated to move smoothly without trouble. Travelling by train is even not possible by the lack of service at the station. For reaching her goal she needs public space and transport to be accessible for wheelchairs, but the fact is that the public space and transport now not are arranged for people in a wheelchair.

Researchers narrative Summary

'Lately, my children asked me out, to do something fun. That is so sweet, I appreciate that they want to do something with me. But every time I will go somewhere, I bump into the public space which is not arranged for people like me. The first thing I feel is hesitation, to go with my son to the inner city, instead of joy. I feel hesitant because of the wheelchair-unfriendly road, which I have to encounter to come somewhere. Also, the trip with my daughter by train did not turn out like I wanted. In the end, we couldn't get where we want. If you want to go by train in a wheelchair, you need to let the service know 24 hours beforehand. Spontaneous does not apply to people in a wheelchair.

Conclusion

The storyline of Carry-Ann who travels through public spaces and by public services like the train shows that society is not organized for people in a wheelchair. She just wants go to with her children to the city, but she has to face multiple obstacles for that. Well-organized public spaces and public services for people in a wheelchair are needed to be able to face and self-manage challenges in life. It is means to be able to travel independently. Public space is not the task of health care, but accessible roads/stations/trains are leading to easier participation in society for people in a wheelchair. This topic is now not covered in the theoretical framework and is an interesting theme to do more research. When patients have a good wheelchair, it is also important that they can travel with it on public roads and with public transport.

2. Gehandicapt voor Gevorderden

Marloes Beemsterboer

Introduction

Gehandicapt voor Gevorderden describes the story of the author: Marloes Beemsterboer. Marloes has Friedreich's ataxia, which caused that she is dependent on a wheelchair. The book is describing the daily life of Marloes. She lives together with her husband Marcel, dog Baloo and cats Lucifer and Bandit. Due to her disease, Marloes is dependent on other people. If she wants a glass of water, she has to ask Marcel to get it for her. With Personal Budget (PGB), Marcel can stay home and care for her. Marloes her mother works also for Marloes as a caregiver. Marcel is autistic, which sometimes leads to struggles, but also to funny situations. Marloes describes that and also makes jokes about them as a couple. Also it is telling about their relationship as partners and as caregiver-care receiver. *'The fact that my husband plays two roles, namely the role of partner and caregiver, is sometimes hard for the both of us. If I got into a fight with him as a partner, he has to provide me care as well.'*

Marloes focuses in her book mostly on the daily activities she can do. From watching every night Goede Tijden, Slechte Tijden, to getting a diving certificate to a ski vacation in Austria. Marloes is facing many obstacles in carrying out her daily activities. These obstacles will be more explained in-depth with individual story analysis. The next storylines will be described:

1. Bus is coming soon!
2. Moving for disabled persons
3. A rolling life goes not on slick tires

Storyline 1: The bus is coming soon!

Agent

The characters of this storyline are Marloes and the municipality. Marloes wants help from the municipality to get a bus. Marloes is an active agent, she doesn't give up: *'For three years I am fighting for a Budget and for three years I get rejection after rejection.'* The municipality is an institute which is not easily convinced of the need for help from Marloes: *'I'm saying that for half a year, but they didn't want to hear that. But now, the municipality has returned to its own decision.'*

Events

Marloes has done an application to the municipality for a wheelchair bus or other decent transportation. The application is rejected by the municipality. *'I got a letter from the municipality with the information that they had enabled an independent consultancy company, in other words they would do research to look if could travel with regional transportation. I made an appointment with the company and they gave the municipality the advice to deliver individual cab service (without picking up or dropping off other people).'* After the advice, Marloes got a letter that the application is rejected, based on the income of Marloes and Marcel together. *'Why would his income be counted, while I did the request? Is this not something like a waste of money? An expensive consultancy doing research, while they already knew our income.'*

After a few conversations, the municipality has decided that Marloes get a financial contribution to purchase a bus. *'The last conversation has turned out that I am not helped by cabs. I'm saying that for half a year, but they didn't want to hear that. But now, the municipality has returned to its own decision.'* Marcel and Marloes go to the dealer and purchase a bus which is within their budget. Some small things have to be made in order, Marloes can't wait to pick up the bus and to be no

longer independent from others. *'No more arrangement of transport, no fixed departure time and mostly no ride with detours!'*

Rides with detours refer to the times when Marloes is dependent on transportation by cab. Marloes goes to an old classmate Letje. *'She lives only an hour's drive from our home and because I want to go away without Marcel (and he wants to rest WITHOUT me), I decided to go with the taxi. The taxi arrives right on time at 8.45 in the morning. 'But when I sit in the cab, it turns out that I'm not picked up earlier without reason.'* The cab driver tells that they have to go to IJmuiden and Heemskerk first before he can drop Marloes at her destination. *'When I finally am unloaded it is almost eleven o'clock.'*

After a nice day with her friend, Marloes is picked up by the cab at 20.30. *'In the cab are already people, a man with presumably his mother. They talk barely, but the sweat smell speaks volumes. (...) Then I get also a nice announcement. We have to pick up somebody else 10 kilometres beyond and after that someone else. After a long ride, Marloes gets finally home at 23.15. 'That means that I had to travel for almost five hours, while it is possible in two.'* *'I'm going away for a day with Valys and I can recover for a week. And that is then transportation for people with a disability. It is more: transportation for people but through limits!'* This is a very important aspect, the cab service is for people with a disability. Vulnerable people, who have to go with a cab which costs them very much energy. It is not normal that Marloes has to recover for a week after she goes in the cab for a day.

Besides the good news of a contribution for the bus, Marloes gets more good news. *'The letter goes about the High Mileage Budget for the Cab. It is unbelievable?! For three years I am fighting for a Budget and for three years I get rejection after rejection. Now I have a sweet neurologist behind me who has sent a clear letter, and I get suddenly green light.'* It seems that Marloes was not taken seriously by the municipality, but when a neurologist writes a letter, the municipality approved suddenly the request.

Marloes has now the bus and a budget for transport by cab. This makes it able to go away easily with Marcel, but also without him.

Means/helpers

The municipality in this story is a helper. They are giving Marloes a budget for purchasing a bus and for the rides by cab. This is helpful for her to have easy access to transport without a fixed departure time by bus and when she wants to travel alone, she can go by cab. The municipality was not in the first place helpful, because of the long time to admit the budget for Marloes they hinder her to get a bus and budget for the cab. Indirectly, they are hindering Marloes to have more freedom through a bus and to be less independent in transportation. This gives Marloes less opportunity to deal with her challenges by herself.

The consultancy company is a helper in this story, they are giving the municipality the advice and evidence that Marloes needs individual cab service. The municipality takes the advice but also rejects the request, based on the income of Marcel and Marloes together. In this way, Marcel is working against the goal of Marloes, which seems unfair to Marloes. When a neurologist writes a letter, the application is finally approved, so the neurologist is a big helper in convincing the municipality.

Another means in this storyline is the bus, which helps Marloes to travel with her transport. An example of how the bus is helping Marloes is a visit to her mother-in-law. She lives in Zierikzee, a three-hour drive. *"It is a challenge if you realize that I also have to take a push wheelchair because*

otherwise, I cannot come to her house. It is a good thing we have a bus! Equipped with two wheelchairs and all other necessities, we can go when Marcel has fastened his seatbelt.'

Setting/Scene

This storyline has multiple settings. One setting is in the cab, where Marloes gets frustrated that she has to travel in the cab with other people. This setting is giving her stress and costs lots of energy. The opposite is the bus, where Marloes is not dependent on the cab driver and the other people who have to be picked up. The bus is giving her freedom and a relaxed feeling, it just goes where and when she wants to go.

The setting of the conversations with the municipality is not described in the book.

Goal

The goal of the storyline is to get a bus, with financial support from the municipality. The deeper goal is to get more independence. *'I am sure, especially for me, it will be a relief to be no longer dependent on others.'*

Breach

Marloes wants a bus, which gives her access to more independent transport. The municipality is not easily convinced of the need for a bus for Marloes. It cost her half a year of conversations to convince them, which leads to frustration. *'The last conversation has turned out that I am not helped by cabs. I'm saying that for half a year, but they didn't want to hear that.'*

Researchers narrative summary

'It will give me so much freedom to have a bus for just me and my husband. The cab service which is now provided by the municipality costs me so much energy. I have to recover for a week after going one day out. It is frustrating to have to pick up other people and bring them home. After half a year of talking to the municipality, they finally see that I really need this bus. Why do they not see that immediately? They are not very helpful or thinking along with me to have a good way of transportation which gives me independence. It would save a lot of energy and frustration. But now they finally give me the bus, my husband and I would enjoy it very much.'

Conclusions and discussion

By providing Marloes with the right help, and a budget for the bus and the taxi, the municipality is delivering Patient Centered Care. The municipality is facing Marloes' needs and preferences. The bus gives Marloes more independence to go to places she wants to go, without being dependent on other transportation forms with fixed time slots. This meets the concept of positive health, with the bus Marloes can self-manage the challenge of transportation and does not need the cab service anymore. Although it took a while, in the end, the municipality is supporting Marloes with financial help for the bus. In terms of accessibility, the request could be quicker assigned, which will lead to better Patient Centered Care and a sooner opportunity for Marloes to experience Positive health.

The long time before the municipality is approving the financial help for the bus, can be seen as a burden for Marloes. She had given much energy to convince the municipality, for half a year. She describes that she had multiple conversations with the municipality and that these conversations were leading to frustration. To do the application for the bus was for Marloes an emotional burden, she was putting energy into the application, without knowing if it will lead to approval.

According to VBHC, the research of the consultancy was not contributing to effective care. It would be when the municipality has immediately admitted the individual cab service, as prescribed. With more conversations and more bureaucracy like checking the income of Marcel and Marloes

together, the process cost more money than needed. Eventually, it has led to appropriate care for Marloes, but it could happen way more efficiently.

This storyline is on the other hand meeting VBHC when Marloes got approval for the bus. A bus is more cost-efficient because she does not need the cab service anymore. The bus is partly paid by herself, the cab service is paid from a budget from the municipality. The bus meets the preferences of Marloes and is for her the best possible outcome. The municipality is delivering effective and appropriate care by giving Marloes a budget for the bus.

It was a dilemma for the municipality to examine the application of Marloes for the finance of a bus. The municipality had to consider which would be more cost-effective: financial help for a bus or only financing the cab service. The municipality did first not see that Marloes was needing the bus. Probably, the value of equality played also a role. Was Marloes different from other patients, who also want a bus? They have to perform their policy in a way that is honest and lawfulness for everyone who wants to have financial help for a bus.

Storyline 2: Moving is not for disabled persons

Agent

Marloes is the main agent of this storyline. She has moved because the old place where she live was not a good place for her. Moving to another municipality brings struggles around the aids Marloes needs, because of another system in the new municipality. Marloes doesn't understand the method of the municipality, but she cannot change it. *'This is something I do not understand. What with all those cuts? Everywhere you get less, and if you ask for less you get an expensive aid. Which, in our situation, the garage is getting dusty.'*

Other agents are the old and new municipalities, who are not making it easy for Marloes to move to another place. *'Time after time, I have to hear that we moved voluntarily out of an adequate house.'* (...) *'In other words: it turns out that when you have a challenge (in the vernacular this is called a disability), you are not free to live where you want.* The old municipality is purchasing aids from the supplier, the new municipality has aids on loan from the supplier.

Events

Marloes and Marcel have moved to another place, within another municipality. Marloes is reading information about the municipality. *'Information from the municipality, which is so complicated, that I cannot believe that they understand by themselves what it means.'* She will let read her mother the information when she comes another day. *'As promised I let my mom read the letter. I see that my mum slowly gets boiled with anger.* Since the move to a new municipality, Marloes conflicts with them. *'I do not get the services I need, and I don't have the advantages of their concessions.'* An example of on useless offer from the municipality: *'I do not get a ceiling lift of €1559,- because this is a construction modification, but a lift of €7000,-, which I cannot use because of lack of space, I can get immediately.'*

Marloes lived in a house, where you may live if you need specific care. The care, which is related to the house, was not adequate in Marloes' perspective. *'Hours of waiting before you get help and then with a snarl and snap.'* Now she gets the help she needs from Marcel and her mum. But the municipality does not agree with her movement. *'Time after time, I have to hear that we moved*

voluntarily out of an adequate house.’ (...) ‘In other words: it turns out that when you have a challenge (in the vernacular this is called a disability), you are not free to live where you want. The municipality assigns you a house, and they do not care if you want to live there or not. You have to accept. But I am someone who stands in the centre of life and I let no one tell me how I have to live my life and especially not the municipality!

Means/helpers

A helper who is working against the wish of Marloes is the municipality. Marloes describes the role of the municipality as follows: *‘My disease makes not everything always easy, but I can live with it. The whining of the municipality makes me really DISABLED. They try to make it people hard, which leads that people being satisfied with less.’*

The new municipality is not helpful with delivering the aids she needs, but also they are against the movement of Marloes at all. It perks her in her freedom to live where she wants to live.

Marcel and her mother are helpers who give Marloes the chance to live in a new place. They are giving her care, so she is not anymore dependent on professional caregivers. In this way, she can live in her own house together with Marcel.

Setting/Scene

The setting is full of frustration of Marloes. The attitude of the municipality is working against her, which makes her angry. *‘I did not choose for this challenge, aids or inadequate care! I just want to live my life, for as long as possible. But preferably, I did not have to use this all!*

Goal

Marloes moved to a new home, together with Marcel, where she can live her life in the way she wants and where she gets the care she needs. The care delivered by Marcel and her mum had the advantage that her disease goes less further back. To be able to live in the new house, the goal is to get the aids which Marloes needs.

Breach

Marloes has moved to get the care she need, and whereof she knows it is better for her. But the municipality has a negative attitude against her movement. Also, the aids Marloes needs to live in her house, are provided poorly by the municipality, which leads to no smooth movement.

Researchers narrative summary

I have moved to another home, in another municipality. I did this to get the care of my husband and mum, care where my disease will go slower and get worse than the care I got in my last home. But the municipality gives me the idea I am stupid to move from my ‘adequate’ home to this one. The new municipality is also not very helpful. I can get a lift of 7000 euros but not the one of 1559 euro I want! How can they explain this, do they not want to save cost? I do not understand why it is so hard for them to provide me with the right aids. I just want to live my life. In my way. And not prescribed by anyone else, especially not the municipality! They should help me to live my life, not dictate it.

Conclusion and discussion

The obstacles which Marloes is facing to just move to another place is hard to believe. When she moves to the new municipality she has to apply again for all the aids she had already in the old municipality. This is leading to a view of the bigger picture: how is the care of patients actually organized? Does it work that every municipality makes their policy around the supply of aids?

The comments of the municipality to Marloes about her desire to move are also something to consider. They discouraged her to move out of the house where care was provided for her to a new house, where Marloes get care from Marcel and her mum. Positive health is something that is encouraging people to adapt and self-manage their situation. But when Marloes is doing that by moving out, where she does not need professional care anymore, the municipality is highly questioning that. Positive health means for Marloes to live independently with Marcel in another house, while the municipality thinks why would you leave your house with provided care?

The comments of the municipality on the moving plan of Marloes are an emotional burden for her. It makes an impact when a governmental institution advised against the ideas you have. Patients who are less persistent than Marloes could have cancelled their moving plans and stayed at the place where they are less happy. Such strong comments have impact on patients and could be leading to stress and doubts.

In terms of VBHC, the municipality makes a questionable proposal to Marloes. She cannot get a lift of 1559 euros, due to construction modifications. But with a lift of 7000 euros, she can get it immediately. In this case, the municipality is not looking for effective and appropriate care for Marloes. They are following the rules exactly, but are not considering which impact that has on Marloes her life. The expensive lift does not fit in her house, which means she has no lift. Delivering an appropriate lift would have a positive impact on Marloes her living situation and well-being, which could lead to a better health outcome.

From the view of the values of the municipality, they cannot do anything else than refuse the lift with the construction modifications. It is the policy of the municipality to not reimburse this kind of lift. The procedural values of the municipality like equality and lawfulness count more than the value of effectiveness in this case. It makes sense that the municipality is handling this way. They have their own policy, which is not made light-hearted. They cannot deviate from the rules for Marloes, because that will not fit the procedural values. But where is the room to depart from the rules? Not every individual patient is the same and not everyone can be helped by following the policy exactly. In the Framework Appropriate Care, there is not explicitly described how municipalities should handle this kind of dilemmas. Zorginstituut Nederland has the norm that appropriate care is based on the state of science, which is in practice effective at group level (ZiN, p7). But the framework has also the value to offer care, adjusted to the personal wishes of patients. It is hard for the municipality to make policy on these two kinds of values, which can collide with each other.

Storyline 3: a rolling life goes not on slick tires

Agent

Marloes is the main actor. She needs a new wheelchair. The second actor is the municipality, they approved the request of Marloes for the wheelchair. A third actor is involved in this story: the

supplier of the wheelchair, they are not delivering a wheelchair accurately and on time. Marcel, the husband of Marloes plays also a role in this story, he understands and feels Marloes her frustration and is helping her.

Events

In her old municipality, Marloes got a brand new wheelchair, which is now barely a year old. This chair needs only a new sitting orthosis. She had requested that from her old municipality. *'That request is halted by the old municipality when was announced that we would move to another municipality.'* And there started some problems for Marloes. The new municipality has another system of aids than the old municipality. *'The new municipality is a loan municipality. This means that all social services (wheelchair, walker, patient lift system) by the municipality are loaned by the supplier. The old municipality bought the services. This means that the services stay the property of the municipality unless the new municipality will buy the service. But, as you can guess, the new one does not want that.'*

Meanwhile, Marloes is already 8 months busy with a request for a second-hand wheelchair. The municipality *'refresh preferably a second-hand chair of five years old, which will lead that about two years I have to request again another wheelchair.'* Adapting another wheelchair to a suitable wheelchair for Marloes turns out not so easy. *'The second-hand wheelchair is 2 times delivered but also 2 times retrieved. Bullet holes stickers on the frame, a woman unfriendly belt, missing calf braces, a tray that does not fit, control which could not be controlled by someone with crooked fingers and so on.'*

In this event, Marloes got the approval of the municipality for a 'new' wheelchair. *'One and a half years ago, I started with an application for a new electric wheelchair and a manual one. The approval for both chairs came quickly. But sadly enough, chairs of paper are not working.'* Marloes started one and a half years ago with the application, after a quick approval of the municipality, the supplier of aids is the next actor that Marloes got to deal with. *'Apparently have companies which manufacture aids, like my wheelchair, the assumption that my challenge improves, if they work slow enough.'* (Marloes names her disability a challenge). *'And that they are slow, Marcel and I can confirm.'* So in this event is not the approval of the municipality that is the problem, but the slow working of the supplier of the aids.

A year after the application, Marloes got an electric chair, the process to get the manual chair from the supplier is still running: *The electric chair is after more than a year on my property, unfortunately with de wrong coating, so he has to go back, but fine. The manual chair is a whole other story.'* To get the right manual chair, lots of patience is needed by Marloes. *Appointment after appointment is cancelled. After a little threat from Marcel, the chair is delivered at 23.15 in the evening. What a time! To our surprise, nothing is correct of the chair. The frame weighs + 200 kilograms, the sit/frame ratio is way too wide, the wheels are too small and the chair is too low. There is no headrest, no belts and no tray. This chair can back again...*

After a month of waiting, the chair is again delivered to Marloes her home. But also this version of the chair is not correct. *'upholstery with pleats (in such a way I cannot sit in it without getting wounds), the seat which cannot be clicked on the frame and a completely other colour than prescribed. I burst into tears, another one I can do nothing with!'*

Marloes calls with the supplier of the chair, she cannot get someone on the phone who can help her. It is too much for her. *'Marcel grabs the phone out of my hands. The words coming out of his mouth are not snatched from the air. After months of annoyance, this is the last straw that breaks the camel's back. The municipality is informed and they are also done with it!*

The municipality puts pressure on the supplier. The supplier got an ultimatum from them, Marcel and me. Marloes is ready and waiting for the delivery of the chair in the hallway. Hopefully, the last attempt to get the right chair. 'The front door goes open and again is there anger and frustration. Again de chair can go back. This time the frame is correct, the orthosis is fitting and the colour is right. Purple.' But what is wrong about the chair is that the upholstery of the skai is pleated on the orthosis. *'What kind of losers are working there?'*

Means/helpers

The helpers in this storyline are the municipality and Marcel. They both stand with Marloes and are also done with the long process of the right chair provided by the supplier. The supplier is the mean which is working against Marloes in this story. They are leading to frustration by constantly delivering the wrong wheelchair.

The policy of the municipality to work with second-hand wheelchairs is not so helpful for Marloes, it turns out that it is hard to make a suitable chair for her out of an already used chair.

Setting/scene

The setting is at Marloes her home. In her home the wheelchair is delivered again and again. And from their home, she has to explain over and over again why the chair is not right. At some point, she even goes to stand in the hallway. *'It is good I followed Marcel his advice: next time you go stand in de hallway, if the chair is not correct, then it can return immediately. And so I stand with my good behaviour in the hallway.'*

Goal

The goal of Marloes is to get a manual chair, she has the approval of the municipality. A supplier of aids has to provide her with this chair.

Breach

To reach her goal, Marloes only have to get the right chair delivered by the supplier. There is a breach of her goal because the supplier delivers over and over again a chair which is not correct. Missing parts, wrong material and coating which can give Marloes wounds are a few reasons why the chairs are not suitable. Even after an ultimatum from the municipality, the supplier cannot deliver good work. *'Gradually this is becoming a never-ending story...'*

Narrative summary

I need a new manual wheelchair. With moving to a new municipality, I also moved into a new system. The new municipality loans aids from the supplier instead of buying them like my old municipality. Weirdly, not every municipality has the same kind of policy, now I have to give my brand-new wheelchair back and ask for another one from my new municipality. Luckily I got quick

approval from the municipality, that is one thing that works for me. Sadly, they are using second-hand wheelchairs, which are built into fitting chairs for new users. Apparently, it is really hard to make a wheelchair that is fitting my needs. After several appointments were cancelled, finally there is delivered a wheel. But that chair was such a joke. Sadly that was not the last time they delivered the wrong chair. They even made the same mistake twice: coating which pleats which will lead to wounds. It costs me so much energy and frustration. Luckily, I have the back of the municipality and my partner. There are also very tired of this supplier which makes mistake after mistake. I am curious about when I finally get the right chair.

Conclusion

This storyline turns out that an assignment by the municipality for a wheelchair does not mean that the process of getting a chair is easy after that assignment. Marloes who has to send back the chair over and over again is a really bad story. Something is wrong in the way the supplier works if a client has elaborated multiple times what she needs in a chair and they still cannot assemble a chair with all the right parts. In terms of Patient Centered Care, nothing is going right in this storyline. Marloes her individual preferences are not met, and these are not only preferences but essential needs for her to be able to use the chair.

It is the job of the municipality to create accessibility for people like Marloes to a supplier, who can give them the wheelchair they need. The accessibility to the aid is questionable in this storyline. Marloes got approval from the municipality for a wheelchair, but the municipality leads her to a supplier who is not delivering a good chair. How much access does she really have? The system of outsourcing the delivery of aids to the patient is lacking in this case. It is needed to research in the framework of Appropriate Care if there are statements or advice on how the municipalities can manage this properly.

For Marloes is it an administrative burden. The wheelchairs are constantly going back and forth between her and the supplier. She had to schedule multiple appointments, for wheelchairs which were not appropriate. It is also an emotional burden, she thinks she gets the right chair and then she gets disappointed several times.

Another thing which is highlighted in this case is the fact that every municipality has their own system for the delivery of aids. Remarkably, Marloes has to swap in her wheelchair, which is custom-made a year ago, because it is the property of the municipality. What are they going to do with that chair? This sounds not like effective care, which is appropriate for the patient like VBHC describes. For Marloes, the best outcome will be to have the chair she got from her old municipality. Cost effectively, this will be also the best outcome. The chair is designed for Marloes and was an investment of the old municipality for a couple of years. The system of the Netherlands, where each municipality has their own policy around aids hinders the municipalities to perform according to the VBHC theory.

Maybe it is not the most effective way of delivering care, but from the view of the new municipality they have to handle it like this. They have the policy that they are loaning the aids from the supplier. The old municipality bought the aids. These are two different systems, which are not working in line with each other. It would not be fair to other patients of Marloes her new municipality that she will get a wheelchair which is bought and made brand-new. It will go against the procedural values of

integrity, equality and lawfulness.

3. Het raam kan niet open. Gevangen, maar niet gekooid

Gerard Elferink

Introduction

This book is written by Gerard Elferink. He lives together with his wife, whose name is unknown, who is a caregiver to him. As a kid, he had not an untroubled youth, full of emotional neglect and abuse of power. He had no safety at home or school. Later in his life, in 2005, he was diagnosed with the disease Multiple Sclerosis (MS). *'Looking back, I had had my whole life physical complaints like trembling knees, balance disorders, not being able to stand on one leg and a swinging walk like you are drunk.'* The disease causes Gerard to be slowly less able to do. He started to write this book by typing with one finger. At the end of the book, he did that with the use of using voice commands. He worked in the municipality, and in this organisation were multiple reorganizations, Gerard is describing the impact was of this insecurity for him. Gerard is telling multiple stories about his life with MS and the situations where he ended up while asking for aids like a wheelchair. Also describes Gerard in this book his view of the world, he accuses the government multiple times of bad policy. Climate change, refugees, the healthcare system of the Netherlands and other social themes are discussed.

The next storylines of this book will be described:

1. Kafkaesque fights for aids
2. Request for a mobility scooter at the municipality
3. Repair process
4. Moving

Storyline 1: Kafkaesque fights for aids

Agent

The agent in this storyline is Gerard, he wants to be active and is applying for aids, but that costs so much energy that he is getting tired of it. Gerard his wife is also an agent, her life is also affected by the slow assignment of aids. Another agent is the municipality, which has a very slow procedure for processing the requests for aids.

Events

In his book, Gerard is describing how much energy and frustration the *'Kafkaesque fights for aids by the WMO'* consume. He is mentioning in different situations what the impact is on his life to have to fight continuously for his rights. For example, Gerard did a request to get extra hours of personal care by the municipality. *'The application for extra hours of Personal Care help was honoured at the last minute, but really happy about the victory are you not anymore, because oh, what energy that takes, which affected me and my loyal wife, care supplier and misunderstood caregiver.* Gerard cannot enjoy the fact that he gets extra hours, the energy he had to use to achieve this takes over his feelings. And it has not only an impact on his life but also on the life of his wife.

Gerard mentions another insight. He has already a disadvantage with his disease, but he is double harmed by the process to get the needed aids. *'As a chronic patient you need extra energy and fuel*

because as a sick person and especially as a disabled person, you have to make an extra effort to reach or get something. The energy you need for the application of aids, the decision-making process, inclusive the selection process for an adequate aid and after that the implementation phase is indescribable much.'

The municipality is also not working with what Gerard wants and needs. The long waiting time for aids is mentioned in other storylines. In this storyline, Gerard emphasizes that the speed of the development of his disease is not in line with the slow working of the municipality. *'Energy is needed when you with the speed of a TGV-Train rush backwards and consider the fight with the cumbersome organisations in the health care field. They are still in the era of the tow barge, both in the allocation and implementation.'*

Gerard is describing the effects of the slow working of the municipality on his mental health. *'You are asking yourself, in despair, how long you can self-direct.'* The mental aspect of accepting his disease and on the other hand fighting hard for aids is difficult for Gerard. He puts very much energy into the application for aids, but he does not get anything back as, for example, time. *'You do not get any time, because the race against the clock is beforehand lost. The slow-working organizations and your own process of decline will take care of that.'*

Means/helpers

The municipality is a helper providing aids to Gerard, which will make his life easier. But through their complicated and slow procedures around the assignment of aids, it costs Gerard more energy than needed. His wife is a helper, she helps Gerard extra until he gets the needed extra hours of personal care.

Setting/scene

This storyline has not a physical setting but has an emotional one. Gerard is getting tired, despondent and frustrated by the slow working of the municipality. It cost him so much energy that he is not even happy when he gets help or an aid assigned by the municipality.

Goal

The goal of Gerard is to get aids from the municipality, which will help him to support with deterioration in his illness and which will give him the feeling that is able to have self-direction.

Breach

To reach his goal, Gerard has to consume very much energy in the application process for the aids. Valuable energy, he could use very well as a chronic and disabled patient. Also, it has an impact on his mental health, the slow working of the municipality feels for him as lost time, which he will never get back. Eventually, he is reaching his goals, but he is not any more happy with it because of the energy waste.

Narrative summary

To do applications at the municipality is costing me more and more energy. It has had a big impact on my life. As a chronic and disabled person, I need extra energy for everything I want to reach. So, I

do not want to spoil my energy to do applications at the municipality. I feel like I am double harmed, I have a disease and I have to put much energy to get aids which will help me. I have the feeling that the municipality is not aware that they are working with vulnerable people, who need already a lot of energy to handle their disability. Besides the energy, our disease is causing what we are less able to do. Aids would be helpful to overcome the things we cannot do anymore, but the municipality is working much slower than our disease is causing deterioration. Also, my wife is now the victim of my disability because the municipality was not helpful to assign the extra hours of personal care, she had to overcome that missing hours by caring for me. And, it is not the application only. When you finally get permission, the route after that is also taking much time with the decision-making process, the selection process for an adequate aid and the implementation phase. Before I really can use the applied aid, all my energy is gone. I cannot even be happy with the fact I finally got it.

Conclusions

Gerard is describing the impact of the application process on his energy. It is frustrating to have to wait for so long, and to do so much effort, to get aids from the municipality. Accessibility is about the right and opportunity to be able to use appropriate services in proportion to the needs of the patient. The accessibility to aids is questionable in this storyline. In the end, Gerard gets aids assigned, but it takes so much time and energy that it is doubtful of this is in line with the needs of Gerard and appropriate. Added to the theoretical framework should be that accessibility also goes about waiting time for aids, and the energy a patient needs to apply for aids. This is added to the concept burden of treatment. The waiting time and the spoilt energy to apply for aids is a big burden for Gerard. It is a burden which had nothing to do with his disease, it is purely caused by the application for the aids he needs. It is an emotional burden because Gerard has to put so much effort and energy into the applications of aids. He mentions he cannot be happy if the aids is approved, because of the amount of energy it costs. The process of applying for aids influences his mental well-being. This is also made clear by Gerard when he says that his disease evolves faster than the municipality goes, this can be scary for patients, worrying if they will get the aids soon enough. Gerard is mentioning this aspect of time, the clock is ticking, and he will never get his time back.

Less persistent patients than Gerard would maybe have already given up, and would never get the needed aids. The books analysed contain, up to now, only active agents, which could be a possible limit of this study.

Gerard is mentioning that the municipality is working with the speed of a tow barge, while his disease is developing like a TGV-Train. The care Gerard is experiencing is not according to the values of Patient Centered Care. He does not have the feeling that the municipality is respecting his needs and is acknowledging his perspective. The situation is that Gerard has to put a lot of energy into his application, without having the feeling that the municipality is caring about his chronic disease and disabilities.

Storyline 2: Request for a mobility scooter at the municipality

Agent

Agents in the story are Gerard, his employer at the municipality and another department of the municipality which provides aids. Gerard is active in asking help for with a mobility scooter so that he will be still able to work. His employer thinks along with Gerard, they make it able for him to work in another district of the municipality, as the office is very close to his home. The same municipality is not working with him to provide the aids he needs to work. So that means that one organisation has a conflicting policy.

Event

After the diagnosis of MS, Gerard did an application by the municipality for a mobility scooter. At that time he was still working at the municipality, and he was assigned through his employer to another district, which was very close to his current home. He experienced resistance while doing this application, the municipality takes their time. Multiple municipal officials came to visit his house to judge the situation. Gerard had to call the municipality multiple times to get information about his application. After six months of waiting for a mobility scooter, Gerard has still no green light. He starts an objection procedure against the rejection of the scooter and some other aids. *'The civil servant asks if I need the mobility scooter for my work. I answered yes, unsuspecting, but of course also for participation in social life, from doing groceries to visiting friends. To our surprise, the civil servant announced that we have to be at the UWV, according to a law.'* If Gerard had not said that he needs his mobility scooter for his work, he would have gotten the scooter from the municipality. He is using it for work, but also for his daily life because he answered the question with yes, Gerard has to go to another organisation to do his application again. *'And they tell me that after six months of waiting, after six months of hard work of my caregivers to transport me.'* For Gerard it has a big impact that the process is spending so much time, he is dependent on caregivers to transport him, which could be easily solved with the scooter.

Luckily his employer helped him. *'The necessary mobility scooter for my work was eventually temporarily hired by my employer, also the municipality, and by delivery it was captured on camera through my colleagues from that district.* This was a really weird situation for Gerard: *'It shouldn't get crazier, one service of the municipality had to hire a mobility scooter, which is rejected by the other service of the same municipality'*. The department of the municipality where Gerard works wants that he can go to work and that he continues to work for them. That gives the situation that another department, of the same organisation, is rejecting the application so the other department has to hire a mobility scooter from an external supplier.

Means/helpers

Gerard's employee is a helper which has a positive effect in this storyline. They are encouraging Gerard to keep working by making it possible to work closer to his home. When the municipality is not helpful to Gerard in providing a mobility scooter, his employer decides to hire a scooter for Gerard. The municipality part which provides aids is working against the part of the municipality that wants to help Gerard keep working. Because the municipality assesses the application of the mobility scooter as a task for the UWV, Gerard has to do his application again by that organisation. The story does not tell how helpful they are. Anyway, Gerard does need a temporal solution. His employer hires a scooter for him until he gets one of the UWV.

Setting/Scene

The scene is unique because it feels for Gerard like the municipality is working against the municipality. There are two different departments with their own tasks, one is the department that wants to keep Gerard working by them, and the other department assesses the application of the mobility scooter. He is in a weird situation because another department in the organisation where he is working is not thinking along with him. In this story, you can read the incomprehension of Gerard: *'It shouldn't get crazier, one service of the municipality had to hire a mobility scooter, which is rejected by the other service of the same municipality.'*

Goal

The goal for Gerard is to receive a mobility scooter, with the deeper goal to be able to continue working. With the scooter, Gerard can move independently from his house to the office and continue participating in civic and social life. *'with the mobility scooter I can visit projects in the neighbourhood, independently visit the physiotherapist, the hairdresser, friends and so. In short: participating in society and keep working, so joining and not be cut at your future payment, because you do nothing.'*

Breach

The breach in this story is that the municipality would not provide a mobility scooter to Gerard, they think it is the task of the UWV.

Narrative summary

My work has given me the chance to work in another district, their office is on the opposite side of my house. But to be able to come to my work, I need a mobility scooter. I did an application for a scooter at the municipality, but after six months of visits from officers, multiple phones and a lot of waiting my application is rejected. Because I have said I need my mobility scooter for work, they are referring me to the UWV. Did they need six months to figure that out? Why could I get this information not beforehand? Now I need to do my application completely again at the UWV. Besides, I need the scooter not only for work but also for social activities and to do groceries for example. I think it is a weird situation that my employer (the municipality) has to hire a scooter temporarily from an external supplier because the municipality does reject my application. The slow process is frustrating me and it stops me from going to work and other places by myself. I had to get help for the last six months from people around me to transport me, which is not necessary if I just get a mobility scooter.

Conclusion

Without the mobility scooter, Gerard is not able to manage the situation of going independently to work and social events. He and his employer are adapting to the situation so that it is workable for both of them. Gerard wants to deal with his situation, due to MS he is not able to walk to work anymore. But he wants to keep working with his disease, and that is possible with a mobility scooter. The long waiting time for getting clarification about his request is holding Gerard back in life. During that six months of waiting he is dependent on caregivers to bring him where he wants to be. After the rejection, his employer is giving him a temporary solution by hiring a scooter for him. In this way, Gerard is able to self-manage his situation.

The municipality is not helpful in facilitating Positive health of Gerard, mostly through the long waiting time. It could be fair that he has to apply for the mobility scooter at the UWV, but it would be helpful if this information would be available for Gerard immediately after his application. Gerard has waited six months for nothing, and that has a big impact on his life. In terms of accessibility, in this case, it is important for Gerard to have the right information. Then he had known straight away, that he had to apply at the UWV for the mobility scooter and would reduce the waiting time.

The municipality has to do their job. From their point of view, Gerard does need the mobility scooter mainly for his work. For that activity, there is another organization, which should reimburse the scooter. For the municipality it is more effective and efficient if Gerard is doing his application at the UWV, they can use the sources for the mobility scooter for somebody else, who does need the scooter not for their work. They handled according to their procedural values, honesty, equality and lawfulness. It would be against their values if Gerard gets a scooter, which is not according to their policy because he is using it for work.

The lack of access to the mobility scooter causes Gerard to be dependent on caregivers to participate in social and civic life. The municipality is not looking to the bigger picture and what the impact is for Gerard to reject his request. They only are mentioning that this is not their task to do, which leads to a very bureaucratic and narrow-minded performance of the policy. Besides that, the goal of the mobility scooter is a grey area. Gerard is applying it to be able to go to work, but as he mentions, he is also using it for participation in social life, like doing groceries or visiting friends. It would be helpful if the municipality would think along with Gerard, instead of following the policy precisely. Maybe they could offer him a temporary scooter until the UWV approves his application. It will fit the Framework of Appropriate Care to look at the whole picture of Gerard and to give an individual solution to him.

Storyline 3: Need for repairment

Agent

The agent in this story is Gerard, he has several issues with his mobility scooter and wheelchair. He has to be very active in this story, otherwise, nobody would help him. *'This would be fixed next week, by another mechanic. Well, do not think so, nobody was seen or heard, so I had to ring the phone myself.'* Other agents are several mechanics. They are different in how far they go with their help to Gerard. The organisation which is supplying the aids and repair to Gerard is the last actor. That organisation is very passive and not well organized: *'The supplier was not able to deliver timely this kind of tools to the mechanics'*.

Event

Gerard is not happy about the procedure when something got broken. *'You expect that organisations in health care are equipped and do not flight in sheer methods like 'own responsibility' or 'too little manpower.'* *'It is noticeable with the waiting times or the delivered quality.'* Gerard blames these shortcomings on budget cuts by the general government.

Gerard is on his way to an appointment when his mobility scooter got stuck in the middle of the street. A friendly truck driver pushes him off the road to a safe place and Gerard calls the breakdown service. Gerard has the next conversation with the call centre: *“where are u?” ‘I am at the Conradkade at The Hague, opposite number 9.’ ‘What is the zip code of that house?’ ‘I do not know.’ ‘But I need to have a zip code.’ ‘Madame, I have forgotten my zip code book.’ ‘Can you not ask the zip code in a store in the neighbourhood?’ Slowly, I get really angry. ‘Madame, why do you think that I am driving a mobility scooter, which is now broken?’”*

After half an hour a mechanic comes to fix the mobility scooter, and he was able to get the scooter working again. *‘This was at the expense of the lights, horn and direction indicators. They were not working anymore.’* A colleague would come for the repair of that next week. But the colleague did not show up, so Gerard has to arrange by himself that the supplier comes to repair his scooter. When they do not react, Gerard is e-mailing the accountable director at the WMO. *‘I drive since August 24 without light, horn and direction indicators. Now I am waiting for months of repairment of that.’* The email was the solution to the problem, but it cost Gerard valuable energy.

Gerard is hoping for a period of rest, but unfortunately, the next problem arrives soon. *‘A flat tire, with a wheelchair is that a disaster. You can immediately no longer go back- or forward.’* The mechanic is arriving soon but then begins the next challenge. The mechanic arrives at Gerard’s home. *‘It was the plan to jack me and the chair up at one side, whereafter the flat tire could be repaired, but what turned out, the man had ordered weeks ago a jack for this type of chair. The supplier was not able to deliver timely this kind of tools to the mechanics, so he had to lift the wheelchair with me and all, while my wife slide an iron pipe under the chair.’* Thanks to the mechanic who not worked following the rules and his wife, the tire of Gerard could be repaired. But the next Monday, the tire is flat again. Another mechanic arrives soon at the house. This one is not so flexible and does not want, deservedly, to screw up his back. With the help of the neighbours, Gerard can be lifted out of his chair and the tire can be repaired.

Means/helpers

The mobility scooter and wheelchair are normally for Gerard means to be able to be mobile. By being stuck they are working against Gerard, he is stuck at the place where they decided to go broke. A helper is the truck driver, who pushed Gerard to a safe place when his mobility scooter got broken in the middle of the street.

The woman on the phone causes frustration by Gerard because she does not understand that he is not able to move. She is helpful in the way that she sends a mechanic to the place where Gerard got stuck with his scooter. The mechanic who came for the mobility scooter was also questionable helpful, he got the scooter running again but left Gerard with a scooter without light, horn or direction indicators. The repair of that was also not quickly done by the supplier. For unknown reasons, the colleague mechanic did not show up the next week, which is the responsibility of the supplier to come up with a solution by sending him another moment. But Gerard had to arrange a new appointment by himself.

The mechanics of the wheelchair are also helpers in this story. They are all very helpful, one goes further than the policy is described, and the other stands by his rights: *‘Another mechanic, he*

sputtered rightly not wanting to screw up his back.' The supplier, the employee of the mechanics should provide the mechanics the right tools to do their job, which is not the case in this story.

Setting/Scene

The setting of this storyline is that Gerard is stuck in his mobility scooter/wheelchair. Without help, he is not able to move 1 centimetre. He is in a very dependent setting, where he has to wait for the help of others.

Goal

The goal is to repair the broken mobility scooter and wheelchair.

Breach

The breach to the goal is that the mobility scooter is running again, but other parts are not working anymore which is leading Gerard has to put much energy into letting repair the other parts. The wheelchair is repaired in the end, but it cost extra energy because the supplier did not equip the mechanic with the right jack to be able to change the tire.

Narrative summary

I got stuck with my mobility scooter in the middle of the street. A truck driver pushed me to a safe spot. I called the repair service, but that was not enhancing my mood. The way they communicated with me upset me, as they did not account for my disability. The mechanic did his job partly, I can drive with the scooter again but other essential parts, like my light, are not working anymore. The promised colleague did not show up for a week. I had to drive for months with a mobility scooter which was not safe to drive with. The supplier does not want to help me, they are not repairing the parts, which they broke, quickly.

Also with the repair of my wheelchair, the supplier did a bad job. The mechanics who came by had not the right equipment to repair my chair safely following working conditions. One mechanic did risk his back by lifting my chair himself. It is frustrating when there is a mechanic, but they are not having the right tools, and it happened twice. The supplier must be prepared for every situation and have to give the mechanics the right equipment to do their job safely. They are humans who want to help me but have also their limits.

Conclusion

The repair of the mobility scooter and the wheelchair are costing Gerard very much energy and frustration. Having access to repair and replacement parts of the wheelchair is part of accessibility as described in the theoretical framework. It is the job of the municipality to outsource the repair service to suppliers who can deliver adequate work. The suppliers are in the service of the municipality. The framework of Appropriate Care describes that there only should be cooperation with organisations who are contributing with their services or products to the mission of appropriate care. This vision could be more emphasized in the theoretical framework, municipalities have a responsibility in the choice of the supplier for aids and also in monitoring how this supplier is doing their job.

Noticeable is that a mechanic who has to come multiple times to fix a problem is not the most efficient way of working and has not the best outcome for the patient. The task of the municipality is to buy and deliver care which is effective for the patient. The mobility scooter and wheelchair were both not repaired by one mechanic. The outcome, in the end, is that the aids are repaired for Gerard, but the value of the care has decreased because there were more euros of cost expanded. Also, the slow repairment caused frustration by Gerard and a feeling of unsafety. Like he had to ride a scooter which has no lights, it can cause that Gerard chooses not to ride in the dark anymore, which is perking him in his daily activities.

Storyline 4: Moving?

Agent

Gerard is the agent of this story, he is told that he would better move to another house. But he does not agree with that and he is willing to prove that he could stay in his current house. Gerard is very active and is doing research by himself to find out what his rights are. The municipality is playing a big role in this story, they decide about Gerard's application of home adjustments.

Event

Gerard did an application by the municipality for some adjustments at home. He needs some adjustments in his current house, like an automatic door opener, so that he could stay in his house. Gerard is just transferred from his work to another district, where the office is on the opposite side of his house. But Gerard does not get the good news of the municipality: *'rejection of home adaptation costs because with the requested adjustments, the house will not be adequately adjusted and moving to a ground floor house is seen as the cheapest and most fitting solution.'* The municipality decides for Gerard that his home will not suit his situation with the aids he applied for. They think that moving will be a better solution for Gerard, and it is cheaper for the municipality.

This is not the solution Gerard wants, and he does not agree to move to another place. He feels at home at the place where he lives now, moving will also have a big impact on his ability to work because he lives now very close to his work. *'I want to stay where I live, in the centre of the district where we are grounded, built up a network and where I could contribute via my work to the livability of the district.'*

Another reason why the municipality prescribes moving is that they have not a good image of the course of Gerard his illness. *'Considering my clinical picture, moving would be an adequate solution to my problem.'* Gerard has a slow form of MS, according to his medical specialist. The municipality has another picture of the progress of his disease, they are thinking that Gerard will need more aids than he is applying for at the moment.

Later, Gerard is calling with a legal assistant. She sends him some policy rules about adjustments of a home. Gerard is not giving up and finds out what his rights are around the application of adjustments in his house. *'The only thing I could find in the rules was that you once in the seven years are eligible for adjustments of your house unless there is deterioration. So why move? With a few simple adjustments and maybe a stair lift, I can go forward for seven years. Gerard has the idea that he can live for another seven years in his current house if he gets the adjustments.'*

Means/helpers

This means in this story would be some adjustments at home of Gerard so that he could stay in his house. The municipality is working against that wish of Gerard, by rejecting the application with the message that he *'could better move.'* The municipality and Gerard are not on the same page regarding the information about his disease, Gerard knows he has a slower form of MS than the municipality thinks. A legal assistant of the municipality is helping Gerard with sending him policy rules, so Gerard knows his rights with these rules.

Setting

The setting of the story is Gerard's home. This house is now not adjusted to Gerard his situation. To be able to stay in his house, he needs some adjustments. Also, the neighbourhood is important, it is the place where Gerard has his work and where he feels at home with a network. This is causing that Gerard wants to stay where he lives.

Goal

The goal for Gerard is that he can stay in his current house. This house is at a place where he feels at home and could contribute to society, which is important for him. *'I want to stay where I live, in the centre of the district where we are grounded, built up a network and where I could contribute via my work to the livability of the district.'*

Breach

To reach his goal, Gerard needs some adjustments in his home, so that he can live there. But the municipality does not agree with these adjustments because they think that the house will not be adequately adjusted for Gerard his situation, and moving to a ground-floor house is seen as the cheapest and most fitting solution.

Narrative summary

I did a request to the municipality for some adjustments at my home. But that application is rejected because it will better for me to move. And cheaper for them. They are saying that a ground-floor home would better fit my clinical picture. I have the feeling that they are not well-informed about my clinical picture. I have a slow form of MS, whith the right adjustments I can easily live another seven years in this house. The municipality does not understand what kind of challenges I am dealing with, I should know the best what I need to live in this house. They force me to move, without listening to me. But this situation makes me more feisty, I will prove that I am right. A legal assistant sends me some policy rules. The only objection against adjustments I could find was that you have only once in the seven years the right to adjustments at your home. The adjustments I asked for will be enough for seven years. I will not give up this house, close to my work and in a neighbourhood I am feeling home.

Conclusion

The municipality thinks that moving would be the more adequate solution for Gerard, and also will contain less cost. In the eyes of the municipality, according to the VBHC principle, moving is the best possible outcome for the patient, for acceptable costs. But there is a difference between what

Gerard thinks is the best possible outcome and what the municipality thinks it is. Gerard thinks it is a better outcome when he can stay in his home and in the district where he lives. In this home, he can still participate in civic and social life, which is also very important for his well-being.

Positive health means Gerard stays in the neighbourhood where he lives, to be able to keep working and where he is having a social network. To be able to self-manage his social and civic challenges he should stay in the house where he lives right now. He wants to stay working, which is possible at the house he lives. The municipality should encourage his civic participation in society and it would be helpful if they think along with Gerard how that is possible with adjustments in his house.

The municipality has an information backlog or the wrong information about Gerard his clinical perspective. They think that Gerard, with his form of MS, will soon be able to do less. Gerard has other information, that he has a form whereby he will go slowly backwards in his abilities. Patient Centered Care will lead to an improved understanding of Gerard his needs. The municipality is now not acknowledging the perspective of Gerard, which leads to frustration at his side. This information gap could be solved with effective communication to achieve mutual understanding. The performance of the municipality of PCC is not highly appreciated by Gerard.

4. De brievenbus van mevrouw De Vries

Gekmakende post van onze (semi)overheid

Stephan Steinmetz

Introduction

The book 'De brievenbus van mevrouw De Vries' is written by Stephan Steinmetz. Stephan is the neighbour of Mrs De Vries. He is helping her with the mail she got from the government and other institutions like healthcare insurers, home care organizations, tax authorities, energy companies and so on. Because of the massive amount of mail and his growing astonishment, Stephan decided to write a book. He wrote the story of Mrs De Vries.

Mrs De Vries is born in 1932 and had never had an easy life. She grew up in a children's home and during the second world war, she had to hide. After the war, she finishes domestic school and starts working as a nurse. A fall on her back makes her incapacitated. Out of a one-night stand, she got her first daughter. Later, she met her first husband with whom she got a second daughter and her son. The marriage ends, and Mrs De Vries has to take care of herself and her children. Mrs De Vries stays in the same neighbourhood, the 'Indische buurt' in Amsterdam. She is 51 years old when she got a new build house because her old house was demolished. At that time she and Stephan met each other, they live in the same apartment building. The children live on their own, with the eldest daughter and son there is no contact anymore.

Her health is slowly going downwards. She gets cancer, rheumatism, intestinal disease and an eye complaint. She develops into a chronically sick and disabled old woman. From the municipality, she gets a mobility scooter, an electric wheelchair and a stair lift. Also, she has an assistance dog, which helps her to pick up things so Mrs De Vries does not have to bend anymore. Also, she got domestic help from Gerry, she works for a home care organization.

The help Mrs De Vries receives goes along with many mails. Mails from which she does not understand the content. She calls Stephan when she got a mail, he decided to do the mail together once a week.

The next storylines will be described:

1. Unclear information
2. Transportation about the region

Storyline 1 Unclear information

Agent

The agent in this story is Mrs De Vries. She gets information from the municipality and from a health insurer, which are other agents in this story. Stephan, the neighbour and Gerry, the household help, are helping Mrs De Vries to understand the information.

Mrs De Vries is an agent who does not understand the information she got on her own, she is dependent on the help of Gerry and Stephan.

Events

Domestic help is essential for Mrs De Vries. She had different helpers, with whom she not could get along. Now she has a help called Gerry, they have a click. Gerry is helping Mrs De Vries three times a week with cleaning and doing groceries. Stephan, Gerry and Mrs De Vries fill in a questionnaire, which came with the mail. The questionnaire goes about domestic help, the indication of Mrs De Vries was retired and new research is required. Mrs De Vries has to prove that she is still in need of domestic help. A question from the questionnaire goes about if she is still sick. *'You were disabled and sick, but are you still sick? Can you prove that? Doctor's notes must be added and bank statement copied.'* A few months after the questionnaire, Mrs De Vries got a thick letter with the message that the research has been completed. Inside the envelope are four pages. *'All four pages are even cryptical. Together with Gerry, we have the quartet of appendices examined, to search for a code which tells us how many hours of domestic help are granted. And yes, under the heading disposition, it was mentioned: K3 (4-6,9h).'*

Later, Mrs De Vries has an eye surgery, which is successful. But she needs new, complicated glasses, which cost 369 euros, money which Mrs De Vries does not have. Because she knows the optician very well, she gets the glasses at home. The bill will follow later. Mrs De Vries gives the bill to the Social Service. *'Within two weeks, this service is responding that first must be tried if the health insurer Zilveren Kruis Achmea wants to reimburse the account.'* Mrs De Vries gets the following answer from the health insurer: *'This transaction will be not (fully) reimbursed, according to the terms of your insurance.'* The insurer is not reimbursing the glasses of Mrs De Vries, which is not very clearly written in the letter they sent to her. *'It is remarkable to decide to describe no reimbursement as not (fully) reimbursed. Completely not reimburse does the insurer mean of course, but that sounds so rude.'* What also is very confusing is that the letter has the heading Message of Reimbursement and at the bottom of the page it says Evidence of Reimbursement.

Means/helpers

Gerry and Stephan are helpers of Mrs De Vries to understand the information. The municipality is helping her by providing domestic help. The letter from the municipality with the result of the research is a means which is causing confusion with hard-to-find information. Mrs De Vries could not read that on her own, this mean is causing stress to Mrs De Vries. The health insurer is helpful by providing an answer to the question if they reimburse the glasses, but the information is unclear and meaningless. It slows down the process of searching for the right institute which has to help Mrs. De Vries.

Setting

The setting is the house of Mrs De Vries. Stephan and Gerry came to help her read the mail.

Goal

The goal of Mrs De Vries is to continue to retain domestic help and to understand what the result is of the research which is done. Another goal is to get reimbursement from the insurance company for her glasses.

Breach

Mrs De Vries does not understand the information she got from the municipality and insurer. She gets help but also for Gerry and Stephan is the information confusing and not 100% clear. Only after a long search or an extra ask for help, it gets clear what the message of the letter is.

Narrative summary

I got unclear information from the municipality as well as from the health insurance company. Luckily, my household help and neighbour are willing to help me. I am just not understanding the information on my own. Every letter I get leads to stress and panic. I do not understand what all these institutes want to tell to me. It is confusing and unclear. It causes a feeling that I am not in control. It causes also uncertainty, I am not knowing if I still get domestic help or if I get reimbursement for my glasses. I have not so much money and every financial help I can get is welcome.

Conclusion/discussion

The load of mail Mrs De Vries gets is an emotional burden for her. She does not understand the information in the letters, and that makes her stressed and is causing panic. It is also an administrative burden, to read every letter. It is a burden for her and for her neighbour Stephan, who is helping her with reading the mail.

From the procedural value of transparency, it makes sense that the municipality and insurers are sending these letters. Mrs De Vries has the right to know how it works and whether she gets some reimbursements or not. It is leading to an equal level of knowledge between supplier and receiver.

Seen the situation of Mrs De Vries, where she is not understanding the information, this kind of mail is not very patient centered. If the municipality knows that these letters are causing stress and panic, they could change how they are sending the information. This could be more aligned with Mrs De Vries's capabilities and needs.

Storyline 2 Transportation outside the region

Agent

Mrs De Vries is the agent of this story. To travel distances outside her municipality, she is dependent on the taxi service which is provided by the municipality. So, the municipality is also an agent in this story. The train operator is also an agent, they have influenced how Mrs De Vries can travel to her grandson and great-grandchild.

Mrs De Vries is an agent who is accepting the information she got, with the changes. She is not willing or able to fight back.

Event

Mrs De Vries is dependent on external transportation services to travel further distances. Transportation for disabled people is the responsibility of the municipality. The municipality is contracting transportation companies who are delivering the transport for the whole municipality.

Valys is the company with which Mrs. De Vries can travel for further distances, within her municipality. She has also a pass for travelling outside her municipality. *'With that, she can travel 550 km per year at most.'* Mrs De Vries wants to apply for a higher amount of kilometres so that she can travel to her great-grandchild in Capelle more often. She fills in some forms and hands in the application. *'The institution which is reviewing the application of Mrs De Vries is called Argonaut Advice. They are rejecting her application. She can take the train anyway?'* The rejection for more kilometres is in line with the policy of the State. *'To save cost, the ministry wants disabled people to travel by train instead of the taxi.'* For Mrs. De Vries it is no problem to travel by train, she has taken the train several times. *'As well as in Amsterdam as in Capelle, she got help by getting in and out of the train, which was necessary because of her mobility scooter. But that help is going to change. Mrs De Vries got a letter from the NS, the train operator: 'At stations where the use of assistance services is very low, the help has been stopped. Which station that is exactly is not mentioned.'* Mrs De Vries asks for a flyer and can read that she cannot travel to her grandson anymore by train.

Setting

Mrs De Vries is receiving the information at her house. She wants to travel out of that house, but she is less able to do that because of the decision of the municipality and the train operator. Mrs De Vries has the feeling of powerlessness, she cannot go by train and cannot do anything to change the decisions of the train operator and municipality.

Means/helpers

Helpers in this story should be the municipality, by providing more kilometres to travel by cab, and the train operator, by providing train assistance at the station. They both are not giving that help to Mrs De Vries and are making it impossible to travel to her grandson more often.

Goal

The goal for Mrs De Vries is to travel outside the region, to go for example to her great-grandchild and her grandson.

Breach

The breach of the goal of Mrs De Vries is that she does not get extra kilometres to travel on an annual basis with the reason that she can go by train. Unfortunately, the train assistance service is stopped at the station she needs to go out to Capelle, the place of her grandson.

Narrative summary

I want to travel to my grandson and great-grandchild more often. I did an application by the municipality for more kilometres to travel by cab. They rejected me for the kilometres because I could go by train. I am wanting to go by train, but the train operator has decided to stop the assistance at the Station of Capelle, where I need to get out of the train. I am powerless in this situation. I cannot get kilometres because I have to travel by train, but I cannot travel by train because there is no assistance! Is the municipality aware of the situation at the stations? The train is not as accessible for disabled patients as they think. Now I have just the standard amount of kilometres for a year, I can travel less to my grandson than I want to travel to him and his family.

Conclusion

The policy of the municipality is to encourage people to go by train, instead of by cab. This is more cost-effective and efficient for them, they need fewer cab drivers and cabs to transport people with a disability. The train operator has decided to stop the assistance at some stations, also the station which Mrs De Vries has to be at. It is a dilemma of whose responsibility this is. The municipality has the job to provide good transport to Mrs De Vries. If they had used PCC, they had seen that Mrs De Vries is not able to go by train. This is an individual situation, care should be provided on her specific situation. But on the other hand, it is not very efficient for the municipality to examine every individual situation of patients who need cab service. Also, if Mrs De Vries gets extra cab kilometres, it would be not fair to other patients who have access to a train station and have to pay for the train tickets by themselves.

The train operator is only handling out of cost-effectiveness, there are stations where the train assistance is barely used, so the service costs more than it yields. But with this policy, they lock out people from having the possibility to use the train. From an accessibility perspective and the value of equality, the municipality should encourage the train operator to have assistance service at every station. Every disabled person should have the chance to travel by train, the municipality could think about solutions, together with the train operator.

5. Eindelijk invalide

Autobiografie van een handicap

Boudewijn Paans

Introduction

The Book 'Eindelijk invalide' is written by Boudewijn Paans. Boudewijn was born spastic, but he refused his whole life to see himself as a disabled person. In his book, Boudewijn is describing his whole life story, from going to school to getting to work and to marry with Anna, his wife. He tells the reader how it is to grow up, being different. Due to his spasms, he could not do everything like the other children could do. Later in his school life, he goes to a special school. Boudewijn is also describing how his father is seeing him as a disabled person, while his mother is ignoring his condition. Typing stories is important for Boudewijn, he enjoys doing it. This is a recurring element in the book. It started with a typewriter at school, later Boudewijn is working as a journalist. At the end of his book, Boudewijn is not able to do much anymore, but he can still write his life story on his laptop, which gives meaning to his life. Through the book you can read that Boudewijn does not accept that is a disabled person. There is a story that he buys a mobility scooter by himself, instead of doing an application for it by the municipality. Boudewijn does not want to stay in the same queue as disabled persons for a mobility scooter. At the end of the book, Boudewijn describes that he is going to a concert, where he is sitting in a wheelchair place. He is finally accepting he is disabled.

The following storyline of this book will be discussed:

1. Return to home

Storyline 1: Return to home

Agent

Boudewijn is the main agent of this storyline, he is returning home after a long period in a rehabilitation centre. An occupational therapist and physiotherapist are other agents, they play a positive role in the return to home for Boudewijn. The municipality is the last agent, they are providing aids for Boudewijn, so he can go home.

Boudewijn is playing mostly a passive role in this story, the therapists and municipality are examining what is needed to change in his house. He has no voice in the adjustments which are made.

Event

Boudewijn has had a cerebral infarction. He has been for several months in hospital and later in a rehabilitation centre. He had to learn to walk again in this centre. Also, he gets therapy to learn other daily stuff again, like opening a door and baking an egg. At the end of his stay in the rehabilitation centre, he goes together with a physiotherapist and occupational therapist to his house, to examine what he needs to live in that house again. He has to sit in a wheelchair, also inside his house. The caregiver is doing an observation of the current situation. *'In the bathroom, the*

shower cubicle has to go away, the wheelchair needs more room. The stairs down and up are suitable for a stairlift, although there are two bends in it.' Boudewijn gets approval from his doctors to go home when the stairlift and the bathroom are ready. *'The occupational therapist does everything to have a fast rebuild of my home, the municipality is working along.'* The day that Boudewijn may go home is tense, for him and his wife. He is describing his homecoming: *'For the first time in my life, I am sitting in a stairlift. With the speed of a funeral procession, I am going up. There is waiting for more news. A walk-in shower, new non-slip tiles and a shower seat.'* Boudewijn got beside the adjustments at home also a wheelchair and a mobility scooter from the municipality. Boudewijn is not one hundred per cent satisfied with the adjustments, he has preferably a wall in his bathroom instead of a shower curtain. *'I did a declaration for an adjustment at my bathroom. Instead of a shower curtain, which gets stinky and will crack, I let build a wall. The municipality thinks that is crazy and brutal.'* The municipality does not agree with the declaration and tells Boudewijn that he has to be grateful for the aids he already got from them.

Setting

The setting is Boudewijn's house. The place needs to be adjusted, so Boudewijn can live there again after his cerebral infarction. Several external people are examining what is needed to be adapted.

Means/helpers

Helpers in the story are the municipality, the physiotherapist and the occupational therapist. They are helpful with investigating what is needed for Boudewijn to be able to live again in his house. The municipality is doing hard work, they adjust the house to all the needs of Boudewijn. There are no difficulties described with the application of these aids. The negative part of their help is that they are not asking what Boudewijn wants. It seems to happen to him, and afterwards, he is not happy with the shower curtain.

Goal

The goal for Boudewijn is to be able to live in his own house again, after the cerebral infarction he got.

Breach

The goal of Boudewijn has been achieved, with the help of the municipality. Less nice for Boudewijn was that he had no voice in the adjustments of his home. He is not happy with the shower curtain.

Narrative summary

After being for weeks in the rehabilitation centre, I could finally look forward to going home. Together with my physiotherapist and occupational therapist, I did a visit to my house, to examine what is needed to change. The municipality was working hard to adjust my house to my current abilities. When I got home, there was a stairlift, a walk-in shower, new non-slip tiles and a shower seat. I am happy that I am now able to live in my own house again. But the municipality is acting like I have to be very grateful for all their hard work. I did not choose to be dependent on all these adjustments. When I hand in a declaration for the wall in my bathroom, they laughed at me and looked like I am stupid. Because I am in a wheelchair I cannot have my wishes anymore?

Conclusion

Boudewijn relatively easily several adjustments at his home, and a wheelchair and a mobility scooter. Compared to other analysis stories, there were no difficulties of frustration described in this storyline by the application and implementation of these aids. Nevertheless, Boudewijn does not seem happy with the aids he got from the municipality. This has the underlying reason that Boudewijn is not accepting that he is disabled.

The accessibility of aids is very good for Boudewijn. The physiotherapist and occupational therapist did a visit to his house, and they told the municipality what was needed for Boudewijn to live in the house again. The municipality starts directly with implementing the adjustments, so Boudewijn can return home quickly.

The delivery of Patient Centered Care could be better in this storyline. In the description of Boudewijn, there is nowhere described that he gets involved in the process. He got home and he had several adjustments, if he wanted or not. He is not happy with the shower curtain and does not get finance for the wall he builds afterwards.

From the municipality seen, a shower curtain is much cheaper than building a wall, which is aligned with their values of efficiency. From their view, of course, they give Boudewijn a curtain and not a wall, it would give so much more work. But they could have given an honest explanation to Boudewijn, instead of saying that he had to be just grateful.

6. Is er versch?!

Het openhartige verhaal van Maurice Wiegman over zijn ziekte, de tekortkomingen van zijn lichaam en over de gehandicaptenzorg in Nederland.

Introduction

Maurice Wiegman was 37 years old when he lost control over his legs. After several examinations in the hospital, he got the diagnosis of spastic paralysis. Maurice is a very sportive person, he had always been fanatical about sports. Cycling, running, swimming and boxing, he did it all. After his diagnosis, he had resistance to start with sports for disabled people. After a while, he started with hand biking. He is training very hard and his goal is to join the Paralympics. Besides his sports, he is working for a foundation that rebuilds a historic ship. After his diagnosis, he started as a volunteer, and later he is hired as an employee. Maurice is married to his wife Hanneke and together they have two children. In his book, Maurice is describing how his life as a disabled person and how he is handling his disability. Maurice is an optimistic person, who wants to live his life. He is looking to the things he still can do, instead of what he cannot. He is very strong mentally, he led his head to rule his life and not his legs.

The following storyline of this book will be discussed:

1. Work & workload
2. Road to independence

Storyline 1 Work & Workload

Agent

Maurice is the agent in this storyline. He is an active agent, despite he has a disease, he wants to work and be independent. Maurice is looking for a job, but he has the idea that he gets stopped by the other agent, the municipality, to have the ability to find a job.

Events

After his diagnosis, Maurice has to search for a new job. Due to his disease, he has not worked for a year. He did volunteer work, but he is looking for a job which will be paid. He is working at a foundation which is rebuilding a historic ship. *'Lovely work, but preferably I want to have paid work. It gives self-esteem to earn money yourself, instead of holding up your hand.'* Although Maurice would like to work, he has the feeling that he is held up by institutions like the government and employers. Also, he is in the middle of processing that is not able to walk anymore. He is in the transition from a life where he was able to walk to a life wherein he is disabled. For the fact that he is not able to walk, he has to arrange many things like aids and adjustments at home. *'I want to work, but I have to arrange so much. Following the procedure for construction at my house, doing the application for the adjustment of a car, and having my wheelchair adjusted. That causes so much stress; I just cannot work. Every day institutions call me about something they need, a form or a signature.'* Maurice has the idea that the municipality is working against him, he wants to work and to live his life independently. But they are putting pressure on him and they need several things of

him, which hinders him to live his life. *'I got the idea that I every time get stopped by those authorities. When I am balanced, I have to come to them or I get a letter. I want to go further.'*

Setting

The storyline has not a physical setting, but Maurice is trapped in the feeling of being stopped in his desire to have a paid job. This is a mental space, which is hard for him and causes stress.

Means/helpers

The municipality is a helper which is Maurice holding back in his wishes. He is in the transition from a life he was able to walk to a life wherein he is disabled. Because of the attitude of the municipality, Maurice has no time and energy left to get to work. Maurice has the feeling that they are working against him. The foundation where is doing a volunteer job is helping him, in the way that he has the feeling of working.

Goal

The goal of Maurice is to have a paid job. The result of having a job is to earn money by himself, which gives him self-esteem and independence. Also is there a deeper goal, to continue the life he had when he was still able to walk, working is a big part of that.

Breach

The breach to the goal of Maurice is that he has to arrange many things for his disability. These things are causing that he has no energy and time left to find a job. Applications for adjustments are taking time and energy, and are causing stress. Also, the municipality is needing things from Maurice, like a conversation or a filled form.

Narrative summary

I am disabled now, but that does not mean that I just want to sit down and get my money from the government. I want to earn my own money, I want to have self-esteem. Control over my own life instead and having independence. But I have to arrange so much for my disability. I have to do applications for aids, my house needs construction. It costs so much time and it causes stress. I am also processing the events of the last year. This all summed up, I have no energy left to find a job. It is already hard to find a job as a disabled person. Through the municipality, I have already a job, with all the things I need to do for them. When I finally think it is over, they sent me a letter again.

Conclusions

Maurice wants to focus on the things he is still able to do after he got the news that he will not be able to walk anymore. He wants to keep working, this gives meaning to his life. Work is also giving him the status that he is still able to earn his own money and have self-esteem. Maurice is internally motivated to look from a positive health view: focus on what he can instead of what he cannot. The municipality should encourage him to keep this mindset, but Maurice is only experiencing resistance from the municipality. He is experiencing the burden of the paperwork tasks he has to do for the application for aids. It costs him so much time and energy that it gives him the feeling that he already has a job. The paperwork tasks are leading to consequences in the daily life of Maurice. It

has the impact that one is not able to search for a job or to work. It has also an emotional impact, Maurice wants to work to have self-esteem. He cannot achieve that because he cannot work, due to the workload he has of arranging aids of the municipality.

Storyline 2 Road to independence

Agent

The agent in this story is Maurice, he wants to be independent in travelling. He is an active agent, he does not give up till he achieves his goal. Another agent is Hanneke, his wife. She has to take care of bringing the children to places by car, it costs her also extra energy when Maurice does not get an adjusted car. The last agent is the municipality, which is not willing to approve the application of Maurice.

Events

Maurice has to apply for different services of the municipality. He crosses different obstacles to get the aids he wants, which he is describing in his book. Maurice has to do several things before he gets access, in this process he has the feeling of getting impersonal treatment, which is leading to getting further away from his goals. Maurice is describing the general procedure at the municipality: *'They know how it works with my disease, but constantly, I have to fill in a new form and undergo a new inspection. They only look at the medical aspect, while the social element is wiped away.'* Maurice has an example whereby the municipality is not looking at his personal, social situation. Maurice wants a different, adjusted, car wherein he can drive. He wants to get the adjustments reimbursed by the municipality. A car would have a great positive impact on his life: *'Hanneke would not have to bring the children always to sports, I can go to my work with the car, to the pool and physiotherapy.'* However, the municipality says that Maurice can use the cab service, but this service is hindering Maurice in his independent life. He has to count half an hour of extra travel time because he has to wait often for the cab. With an own car, he can go whenever he wants to go. *'With an adjusted car, I can go out without the help of others. Living a life in society as I did before: working, going out with the family and driving to the soccer club.'* For Maurice would his own car have a big impact on his life, he would have the feeling that he can do the things he did before he got disabled. The car gives him the opportunity to live the life he always did.

Means/helpers

The car is in this storyline a means for Maurice to get more independence and the ability to drive wherever and whenever he wants to go. To get the ability to have this car, the municipality is not really a helper. They are thinking that Maurice has had enough of the cab service. His wife Hanneke is a helper with bringing the kids to sports, something Maurice is not able to do anymore.

Setting

The storyline has not a particular physical setting, but emotionally it is for Maurice a frustrating setting. Due to his disease, he is not able to drive in a normal car anymore. Now he is dependent on

other people if they want to drive him somewhere. The municipality is not approving his application for an adjusted car.

Goal

The goal of Maurice is to get a car, which provides independence, flexibility and freedom for him.

Breach

The breach is that the municipality is not approving the application of Maurice for an adjusted car, so he stays dependent on the cab service, which gives him no independence and flexibility.

Narrative Summary

I would like to have an adjusted car, it will give me so much freedom. I am no longer dependent on others to travel by car. I could help my wife in the care of bringing the kids to sports and other activities. The application for an adjusted car is rejected by the municipality, they say that I can use the cab service. With the cab service, I can reach the same things as with my own car, but the feeling is so much different. I have often to wait for the cab and I always have to arrange that the cab is coming when I want to go out. With my own car, I can drive whenever and wherever I want to go. It will be so much easier to travel. And it will give me the feeling that I am still able to do the same things as I could before I got disabled. My life will be more feeling as my own familiar life.

Conclusion

For Maurice is a car not only a means of transportation, but it has the bigger value of freedom. He would be able to travel on his own, bring his kids to sports and be no longer dependent on a cab. Also, having a car will give him the feeling that he has the same life as before he got disabled. It can be an emotional burden for Maurice that he is no anymore able to drive his kids to activities and to go to work independently. Having no access to an adjusted car has also impacted his social and family life. Maurice his wife is now the only one who can bring the kids by care somewhere, it is also a burden for her that she has to take of care them on her own. If Maurice wants to go to social activities, he is dependent on the cab. He mentions he has to wait often at the cab, which is costing him time. He has to plan his activities and travel time precisely, which can be an obstacle to doing social things spontaneously.

From a PCC point of view, the cab service is not aligning with Maurice's personal preferences, needs and values. He would be more helped to have his adjusted car. The municipality is rejecting that request, they have decided that Maurice is been helped with the cab service. The municipality has some values, which can be the cause that they have made this decision. The procedural value of equality is important, if Maurice gets an adjusted car, all patients who could use such a car have to be able to get that reimbursed from the municipality. Probably, it is more efficient and effective when all these patients make use of the cab service, instead of giving them an adjusted car to their situations.