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MISMATCH IN NURSING HOME CARE: LIFE AND CARE FROM THE RESIDENTS´ PERSPECTIVE

Derived from written narratives

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Preface

What factors construct a good thesis? And when is good, good enough? Just as this research will show that good care is hard to put into practice, a good thesis can too be hard to put into practice. However, throughout the entire process somehow everything slowly started falling into place. And now here it is. I could not have gone through this process without the help and support from some important people. Therefore, I would like to briefly address some of whom provided me with help and support.

First of all, I would like to thank my fellow companions Eline Roose and Jarinne de Jong. Thank you both for all the times you have read my work, for all the moments of sparring with me and helping me get back on track, and thank you for suffering along with me from time to time. Secondly, a big thank you to my supervisor Marjolijn Heerings for *endlessly tinkering* with me on this thesis. At some points it really felt endless, however, you managed to always provide me with the right directions to move along with the process. Lastly, I would like to thank Nick, my dear partner, for keeping me sane and being so very patient with me, and understanding when I spent yet another night with my laptop.

As I was in the final stages of this thesis process, I had a last look through all the books I have read and analyzed. Suddenly, my eye fell on a stamp on the title page of one of the books. 'AFGESCHREVEN EXEMPLAAR', the stamp said, which would roughly translate to 'written off copy'. This stamp did not only mark the book, but it also told the story of lots of nursing home residents. At some point, they become written off copies of who and what they used to be. With this research, I hope to give voice to those unheard and written off: the nursing home residents. Hopefully, when you read this thesis, you too will be convinced of the importance and essence of listening to their narratives. They truly are worthwhile.

I hope you enjoy your reading.

Esther Hoogendoorn
Oosterhout, June 10, 2021

Abstract

Due to the major call on nursing home care, quality of care within this setting has gotten on the public agenda. This is one of the reasons why the quality framework for Dutch nursing home care has been developed, which steers towards person-centered care and autonomy of nursing home residents. However, the quality framework does not elaborate on situations in which it is difficult to be person-centered and preserve autonomy, nor does it mention to take dignity into account at all. Moreover, the framework does not do justice to the complex care practice in which caregivers and residents need to align their views on these values and perspectives. Hence, mismatch can occur, meaning that the worlds of the caregiver and the nursing home residents do not align. This can threaten person-centeredness, autonomy, and dignity. Written narratives offer unique and elaborate insights into the experiences of residents in day-to-day life and mismatching care. This can contribute to locating both complex situations within care as well as locating where care can be improved. Thus, this research aimed to study the experiences of residents with mismatch on the domains of person-centeredness, autonomy, and dignity, according to written narratives.

In total, six books have been included. When books were written by loved ones of the nursing home resident, the loved one was seen as a proxy. This qualitative, narrative research used reflexive thematic analysis (RTA) to analyze data.

From the data analysis, three main themes have been constructed: (1) the mismatch on captivation and freedom; (2) the mismatch on age-appropriate approachment; (3) the mismatch on attention and acknowledgment. The findings of this research add to the current concept of mismatch by identifying two other dimensions of mismatch: the physical and material environment and the organization of care. Attentiveness and persistent tinkering might be considered to prevent mismatch. This research provides healthcare professionals with insights and reflections for improving their care. Nevertheless, follow-up research needs to be conducted to further define and investigate the two dimensions that this research added, as well as their relation to attentiveness and persistent tinkering.

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1. Introduction

1.1 Problem analysis

Due to longevity and the increasing number of older persons in developed countries such as the Netherlands, there has been a rising call on nursing home care (Katz & Gurland, 1991). However, care for the elderly is becoming increasingly complex because of factors such as multimorbidity. Therefore, quality of care, as well as the quality of the lives of nursing home residents are great socials concerns (van Campen & Verbeek-Oudijk, 2017). Zorginstituut Nederland acknowledges quality issues in elderly care to be a complex issue without simple solutions. Therefore, the Dutch quality framework (Zorginstituut Nederland, 2017) for nursing home care has been developed, to outline what nursing home residents and their loved ones can expect from nursing home care. Moreover, the framework indicates that nursing home residents themselves determine how caregivers and care organizations can contribute as optimally and lovingly as possible to the life of the residents. Within this framework, person-centeredness is highlighted, which includes the interpersonal values of autonomy and dignity, which are also frequently discussed in literature about quality of care and quality of life of nursing home residents (Kabadayi et al., 2020). The Dutch quality framework states that attention must be paid to those values and that organizations must align their care accordingly (Zorginstituut Nederland, 2017).

However, centralizing the residents and being person-centered seems easier said than done, as is shown in literature about mismatch (Goossensen, 2014). This literature argues that caregiver and care recipient have two different worlds that oftentimes do not align. When the care does not match, meaning that the worlds of caregiver and resident do not align, 'mismatch' occurs. The way in which caregivers connect with nursing home residents, how they establish relationships with them, and the quality of the connection and relationships determine whether care matches or not. This can result in residents feeling not seen, heard, or understood, which can form a threat to the values of person-centeredness, autonomy, and dignity that the Dutch framework aims to centralize and preserve (Goossensen, 2014).

Nonetheless, within the Dutch quality framework of nursing home care, little to no attention has been paid to situations in which perspectives of caregivers and residents do not align. The framework describes what care should look like and which values are important, such as person-centeredness and autonomy (Zorginstituut Nederland, 2017). However, it does not elaborate on situations in which it is difficult to be person-centered and preserve autonomy and dignity, nor does it do justice to the complex care practice in which caregivers and residents need to align their views on these values and perspectives. Mol (2010b) provides an account of this complexity by focusing on different values that need to be tinkered with to construct good care. Such values are not merely relational, but they can also be material. However, this material aspect is not included in Goossensen's theory on mismatch (2014), nor does it receive a lot of attention within the Dutch quality framework (Zorginstituut Nederland, 2017).

Lessons can be learned in regard to person-centeredness, autonomy, and dignity, by zooming in on situations in which mismatch occurs (Goossensen, 2014). Herein, not the caregivers, but the nursing home residents need to be listened to and heard since they are the people whom it all concerns (van Campen, 2019). Thus, it is important to first take a step back and look beyond quality quantifications and

frameworks, and to delve deeper into the experiences of the ones on the receiving and of the care delivery: the nursing home residents (Goossensen, 2014). How do they experience care and does the care they receive align with the care they long for? In other words: does the care match with their personal values such as person-centeredness, autonomy, and dignity? Lots of written narratives such as books contain stories of elderly living in nursing homes. Unfortunately, written narratives are often overlooked, despite the fact that they can contain valuable information and insights (van de Bovenkamp, Platenkamp, & Bal, 2010). For instance, analyzing written narratives can help professionals to create a better understanding of patient experiences which can contribute to care that is more person-centered. Moreover, narratives can enable the creation of a better fit between policies and the experiences of the residents. Thus, narratives, both the ones written by nursing home residents themselves as those written by a loved one (as a proxy for the residents), can contribute to research on patient experiences and their logics, values, beliefs, and expectations (Goossensen, 2014). Moreover, written narratives could provide information on situations in which care, person-centeredness, autonomy, or dignity did not match with the nursing home residents' experiences. Such mismatching situations give prominence to the complexity of care and to care that is centered around the individual and his or her personal values. Insights in these complex situations might contribute to the improvement of care (van de Bovenkamp, Platenkamp, & Bal, 2020).

1.2 Objective and research question

To be able to provide person-centered care which also preserves important values such as autonomy and dignity, it is of essence to look at situations in which this is not done optimally, or in which it is difficult to align care perspectives. Looking into mismatch regarding person-centeredness, autonomy, and dignity from the perspectives of nursing home residents could provide insights on how to better warrant good care. To be able to understand complex situations within nursing home care it is of necessity to look into the ones on the receiving end of the care delivery: the nursing home residents themselves. This thesis aims to clarify what mismatches are experienced by nursing home residents within nursing home care, especially in regard to person-centeredness, autonomy, and dignity. In some cases, nursing home residents were not able to write their narratives themselves which resulted in loved ones being the authors of the narratives. In these cases, the loved ones were seen as proxies for the nursing home residents. This clarification can be used within day-to-day healthcare practice, to better align care with the values of the residents and to therefore improve care. Written narratives will be used to shed a light on this frequently overlooked area, as well as on these overlooked sources of data. The main question this thesis aims to answer is as follows:

'What mismatches concerning person-centeredness, autonomy, and dignity are experienced by nursing home residents, according to written narratives?'

The chapters following hereafter are all built up towards answering the question stated above. The next chapter contains a theoretical framework. Within this framework, relevant concepts are elaborated upon which helps shape an understanding of the data. Methods of research, such as the study design and data analysis are discussed

in the third chapter. Chapter 4 displays the results, whereafter chapter 5, discussion, places the results into a societal and scientific context. Strengths and limitations as well as a personal reflection of the researcher are also included within this chapter. Lastly, this research closes off with the sixth chapter: conclusions.

2. Theoretical framework

Within this second chapter, a theoretical framework is provided with concepts that support the understanding of the concepts of the research question: *What mismatches concerning person-centeredness, autonomy, and dignity are experienced by nursing home residents, according to written narratives?* Firstly, person-centered care will be introduced. The most central theme of this research is that of mismatch, which will be elaborated upon secondly. Following, autonomy and dignity will be elucidated, after which the concept of good care will be explained lastly.

Within this chapter, various sources of literature are used, all using different names and terms to indicate caregivers and care recipients. Therefore, healthcare professionals, caregivers, nurses, and so on are all labeled as 'caregivers' in this chapter. 'Nursing home residents' or 'residents' is used when literature discusses clients, elderly, patients, etcetera.

2.1 Person-centered care

Person-centered care (PCC) has become an indispensable part of care delivery (Engels, Vermunt, Leers, & Spanbroek, 2017). Likewise, the Dutch quality framework for nursing home care places great emphasis on PCC and person-centeredness. Within their quality framework, four themes are provided, of which PCC is the first one (Zorginstituut Nederland, 2017). The framework states that PCC encompasses the way in which the resident is the basis of all living domains. It is emphasized that every resident is a unique person with their own history, future, and goals. According to the framework, the quality of the relationship between caregiver, nursing home resident, the resident's loved ones, and the care organization determine the quality of care. Four elements of person-centered care are distinguished, namely: compassion, being unique, autonomy, and care goals. In literature, the main themes of PCC are defined likewise, with great emphasis on interpersonal values of autonomy and dignity (Kabadayi et al., 2020).

'Compassion', the first of the four elements within the person-centered care and support theme of the quality framework, elaborates on proximity, trust, attention, and understanding. The second element, 'being unique', describes to what extent residents are seen in their personal context and identities. Those identities matter and need to be done justice. An example of this is being treated with respect, feeling safe, being helped in a respectful manner regarding self-management and autonomy. 'Autonomy' states that it should be possible for the resident to have self-determination regarding his or her own life and well-being. Lastly, the element 'care goals' states that every resident should have agreements and self-determination pertaining to his or her care, treatment, and support (Zorginstituut Nederland, 2017).

PCC can advance concordance between caregivers and nursing home residents on treatment plans and improve health outcomes. Moreover, applying PCC has shown to increase satisfaction of nursing home residents (Ekman et al., 2011; Poey et al., 2017). PCC can even be an approach to improve healthcare safety, quality, and coordination, as well as quality of life (Poey et al., 2017; The American Geriatrics Society Expert Panel, 2016).

Although the premises of PCC are very promising, implementation can be challenging since it requires organization-wide change (Rosemond, Hanson, Ennett, Schenck, & Weiner, 2012). Another complicating factor of applying PCC is that it

requires attention to the care relationship and individual wishes and needs of residents. PCC is about flexibility and variation to meet the wishes of the residents. However, this often contradicts standardized care that tries to prevent variation. Moreover, caregivers have the tendency to prioritize functional tasks, which results in less attention spent on PCC, especially when there is limited time (van de Bovenkamp, Stoopendaal, van Bochove, Hoogendijk, & Bal, 2018). Concluding, PCC might sound very promising but simultaneously it can appear somewhat difficult to apply due to external circumstances.

2.2 Mismatch

Not only external circumstances make PCC a difficult promise to fulfill but also the understanding between caregivers and nursing home residents complicate PCC. Although caregivers might try to be person-centered by focusing on the individual and unique person that is behind every nursing home resident, these efforts only succeed if the caregiver and nursing home resident understand each other well. Although PCC elaborates upon the relationship between the caregiver and the nursing home resident, understanding and aligning perspectives are not explicitly part of current conceptualizations of PCC, as is shown in the Dutch quality framework (Zorginstituut Nederland, 2017). This is of necessity since oftentimes, there is a discrepancy between the nursing home resident's values and beliefs and the ones of the caregiver. This illustrates two different worlds: the one of the healthcare professional and the one of the nursing home resident. Optimally, the two worlds align and overlap; they match. This happens when the caregiver truly gets to know the resident, and when the resident allows himself or herself to be known by the caregiver. Oftentimes however, the two worlds remain opposite to each other, meaning that information is exchanged between the two worlds, but they do not align in terms of logic and meaning (Goossensen, 2014). This is when mismatch occurs: when the views on good care of the caregiver and the nursing home resident do not align, or when both parties do not align on an individual level. This can lead to consequences such as residents not feeling seen, heard, understood, and consequently feel badly helped and not experiencing recognition for who they are.

Three dimensions of mismatch are differentiated. Firstly, '*see or don't see'* refers to the capability of the caregiver to let experiences of residents go through them as if they have experienced it themselves, from the standpoint of the residents. Secondly, '*making it count or abandoning'* describes whether the caregiver truly cares about what residents go through and if it matters to the caregiver. This dimension also revolves around the caregiver's attitude: is the caregiver close to the resident or does the caregiver remain strictly professional and distant, and does the caregiver respond emphatically? Lastly '*tuned deciding'* is about how decisions about care are made: do caregiver and resident decide together, and is the chosen solution in accordance with the ways that the resident prefers? Goossensen (2014) refers to concepts such as shared decision-making and patient-centered communication in this dimension. Moreover, she even points towards the essence of narratives: "*Narrative information, the story of the client, is thereby of great value since this creates insight in the logic of the client"* (p. 23). Logic herein is seen as the core beliefs and values from where the inner world is shaped.

Goossensen adds a nuance to the concept of mismatching care by stating that it does not inherently mean that nursing home staff should always be at the residents' beck and call to prevent mismatch. The main concern is to clarify what matters for the resident. This relates to PCC: to be able to be person-centered it is necessary to comprehend what matters for residents. However, when mismatch occurs and caregiver and resident do not align, it cannot be comprehended what matters for the residents. This results in the inability to be person-centered. Goossensen (2014) therefore claims that specific contexts, meaning, and knowing are utterly important since almost all mismatches originate in an insufficient understanding of the experiences of the residents and what matters in their experiences. Hence, the relational aspect of care and understanding the personal context are of added value to current conceptualizations of PCC.

2.3 Autonomy and dignity

Within PCC as well as in the Dutch quality framework for nursing home care, autonomy is highly valued (Zorginstituut Nederland, 2017). The quality framework defines autonomy as maintaining self-management of life and personal well-being, also in end-of-life care. Being able to shape and fill in one's own life in large and small parts of daily living is also mentioned. Next to autonomy, dignity is also important. The World Health Organization states that dignity refers to an individual's inherent value and worth and is strongly linked to respect, recognition, self-worth, and the possibility to make choices (WHO, 2015). Living a life with dignity stems from the respect of basic human rights. Autonomy is included herein. Moreover, autonomy seems crucial to certain aspects of dignity. However, dignity can exist without autonomy: long after capacity for autonomy has diminished or even vanished, basic dignity continuously exerts with normative force (Pullman, 1999). Thus, the values of autonomy and dignity are intertwined, but unique concepts.

Literature shows that both autonomy, as well as dignity, are often undermined within healthcare settings (Lothian & Philp, 2011). A multitude of factors can influence autonomy and dignity. For instance, the attitudes of caregivers can greatly affect the regard given to maintaining dignity and autonomy. Unfortunately, this takes place quite often, since professionals hold even more ageist attitudes than the general population (Lothian & Philp, 2001). Other factors such as not being seen or heard, as well as violations of personal spaces, can form a threat to a person's dignity. This shows that not only intangible factors such as attitude are crucial in preserving or threatening autonomy and dignity. Tangible factors such as the physical environment or facilities can also play a role. For instance, privacy can be lessened if residents have to share a room with another resident. These institutional environments could limit autonomy (Heggestad et al., 2015).

Strikingly, the Dutch quality framework for nursing home care does not relate institutional environments to dignity, nor does it mention dignity next to autonomy. This is remarkable since it is argued that autonomy has no moral substance without inherent human dignity (Pellegrino, 2005), and that respect and dignity are crucial to grant high-quality care (WHO, 2015). Although the Dutch quality framework does not mention it at all, dignity *is* part of national policy and common understanding of good nursing home care (van de Bovenkamp et al., 2018). This is apparent of a Dutch program that even mentions dignity as core value within the title of their program:

‘waardigheid en trots’, which translates to ‘dignity and pride’. This adds to the remarkability that the framework does not elaborate on dignity.

2.4 Good care

The quality framework for nursing home care does not elaborate on the physical environment in relation to autonomy, dignity, and PCC. However, ‘comfortable living’ is included in the framework (Zorginstituut Nederland, 2017). Factors mentioned within this theme are for instance that the nursing home resident gets to decorate its room with personal belongings, that rooms are clean and safe, and that the design of the living environment is adjusted to personal care and support needs. Notably, Goossensen does not mention the physical environment in her theory on mismatch. Nonetheless, other authors do stress its importance, as done in the book ‘Care in Practice – On Tinkering in Clinics, Homes and Farms’ (Mol, Moser, & Pols, 2010a). This book discusses the concept of good care and illustrates the complexity of this concept. The author uses the example of food and eating within Dutch nursing homes to demonstrate the various notions on good care and the complex relations between different *goods*. For instance, the taste of the food might be good. Good taste however shifts between the person who tastes the food and the food itself. Also, the coziness of having a meal, the amount of food, the plates on which the food is served, and the hygiene in the kitchen all are different factors that relate to the appreciation of food.

Annemarie Mol argues that this complexity to define what is good asks for persistent tinkering with different takes on *good*s on different dimensions (Mol et al., 2010a; Mol, 2010b). Tinkering is explained as a continuous process in which people are willing to adapt their tools (in this case: their care) to a specific situation, whilst adapting the situations to the tools. The tinkering character of care is to meticulously explore, test, touch, adapt, adjust, and pay attention to details and change them until a suitable arrangement (which can be material, emotional, or relational) is achieved (Mol et al., 2010a). Whereas Goossensen (2014) focuses mainly on the relationship and understanding of caregiver and nursing home resident in the concept of mismatch, Mol (2010b) sheds a light on a different dimension that can contribute to good care or lead to mismatch: the material dimension. Nonetheless, this dimension remains frequently overlooked.

3. Methods

3.1 Study design and data collection

Study design

This research aimed to explore mismatch regarding person-centeredness, autonomy, and dignity, from the perspective of the residents themselves, using written narratives. The data that has been used to answer the main question of this research was of qualitative nature. One of the characteristics of qualitative research is its holistic understanding of context and its aim to deduce meaning from processes (Mortelmans, 2013; Green & Thorogood, 2018), which aligns with the aim and research question of this study. The data has been derived from written narratives in book form. According to van de Bovenkamp et al. (2020), an important advantage of written stories is that they provide insights into all interrelated facets of life with a condition. Written stories offer insights into the experiences of patients in day-to-day life, without previously being structured. Moreover, written narratives are frequently overlooked, which makes written narratives relevant to study.

Data selection

The Dutch foundation 'Coleta's Chronische Circus' holds an extensive collection of books on patient experiences (Stichting CCC, n.d.). Recently, Erasmus School of Health Policy and Management acquired large parts of this book collection. Books from this collection have been included for further analysis. Books were sought and selected using the foundation's website: www.patientervaringsverhalen.nl. With the help of themes that the website provided to categorize the books, books were included. Each individual search theme has been combined with the theme ´nursing home'. An overview of the search terms used for book selection as well as the results of the book selection can be found in appendix A. The book search resulted in a selection of eighteen different books. Afterwards, inclusion and exclusion criteria have been constructed to make a further distinction in books that were or were not suitable for this research (Table 1).

Table 1
Inclusion and exclusion criteria for data selection

Inclusion criteria	Exclusion criteria
(Auto)biographical books & separate, short stories	Fictional books
Books written by healthcare professionals or loved ones of nursing home residents	Protagonist with psychiatric diseases or any form of dementia
Nursing home care as the main setting	Protagonists under the age of 70
Books published between 2010-2020	Rehabilitation care
Dutch or Flemish books	

Out of the eighteen originally suggested books, ultimately six books have been included in this research. The included books and some characteristics are depicted in Table 2. One of the six books was Flemish, all the others were Dutch. This Flemish book has been included since it provided lots of usable information for this study and there were no major differences found compared to the Dutch books and contexts. Two of the included books contain short, separate stories of different elderly, from which one of those two books was written by two doctors, and the other was written by a psychologist. Before data selection, books written by healthcare professionals

were excluded because this research focuses on the viewpoints of nursing home residents. Including books written by professionals could possibly lead to bias. However, after reading the books it appeared that almost all narratives had a dominant negativity towards care and that they were written out of discontentment. The books written by healthcare professionals had a more positive approach. After all, the books of healthcare professionals have been included in this research to prevent bias from the negative, discontent books. Notably, after reading and analyzing, the same or similar themes were mentioned in the books written by healthcare professionals as were mentioned in the other books. The only difference was that the books written by professionals had a more positive uptake of the themes.

Lastly, the four books written by non-healthcare professionals were all written by loved ones of the nursing home residents. In these books, the authors were seen as a proxy of the residents. During analysis, only the parts of the narratives about the nursing home resident have been included, not the narratives about personal views or opinions of the authors.

Table 2
Characteristics of the included books

Book title and year of publication	Author's relation to resident	Characteristics of the book/residents
Een glaasje rosé bij het ontbijt, 2014	Daughter	Female resident who suffers from Parkinson's disease
Alleen de werkelijkheid is erger, 2010	Daughter	Female resident who suffers from the consequences of a stroke
Ma komt zondag bij ons sterven, 2012	Daughter	Flemish, female resident with a wish for euthanasia, who became almost entirely blind, deaf, and immobile
Mijn vrouw is dood, 2012	Husband	Married couple who both move to a nursing home because of the disease of the wife.
Wees blij dat je ze nog hebt, 2014	No personal relationship.	Short, separate stories of nursing home residents and their children. Written by a psychologist and writer.
Het verpleeghuis is het einde!, 2017	Professional relationship.	Short, separate stories of nursing home residents to highlight positive aspects of nursing home care, written by 2 doctors.

3.2 Data analysis

The method of analysis that has been used in this study is reflexive thematic analysis (RTA) as developed by Braun and Clarke (2020). RTA suits studies related to experiences of people or studies on their views and perceptions, which aligns with the aims of this study to explore nursing home residents' experiences with person-centeredness, autonomy, dignity, and mismatch (Braun & Clarke, 2020).

The RTA approach is built on a previously developed thematic analysis (TA), from which RTA is one of multiple approaches. RTA's addition on TA is mostly about the emphasis on the importance of the researcher's subjectivity as an analytic resource, and their reflexive engagement with theory, data, and interpretation (p. 3). The researcher's subjectivity and interpretation play an essential role in RTA studies. Therefore, a separate paragraph has been constructed to reflect upon this research. This paragraph is included in the discussion (chapter 5). Furthermore, RTA captures approaches that fully embrace qualitative research values and the subjective skills that a researcher brings to the process. Analysis of data can be inductive as well as theoretically deductive and coding is open and organic, without the use of a coding

framework. Analysis within the RTA approach is a situated, interpretive, and reflexive process. Themes are the final 'outcome' of data coding and theme development (Braun & Clarke, 2020)

There are six sequential phases to RTA that form the analyzing process: (1) familiarization with the data; (2) coding; (3) generating initial themes; (4) reviewing themes; (5) defining and naming themes; (6) writing up. An overview and a brief explanation of the phases are provided in appendix B. However, Braun and Clarke emphasize that these phases are not rules to follow rigidly but that it should be an iterative process (Braun & Clarke, n.d.). Initially, the data were approached inductively, using the six steps to construct codes. These codes are included in appendix C. From the codes, themes and subthemes have been created. Hereafter, some steps were repeated, and additional literature and theoretical concepts were searched to shape and guide the results of the data analysis. Thus, it can be concluded that the data started inductively but was further constructed abductively, meaning that creative inferential processes aimed at producing new theories based on the findings of the research (Timmermans & Tavory, 2012).

The theories and concepts from the theoretical framework have been used to provide direction and guidance for the analysis and interpretation of the data (Bowen, 2006; Ensie, 2017). Moreover, they have formed the starting point of data analysis and involved attempts to discover, understand, and interpret what was happening in the research context (Bowen, 2006). Throughout this research, the theoretical framework has also been approached and adapted abductively on the basis of the results (Timmermans & Tavory, 2012). Lastly, the theoretical framework has been used to place the results of the research in the context of existing literature.

3.3 Validity, reliability, and generalizability

Various concepts for improvement of validity, reliability, and transparency (Green & Thorogood, 2008; Morse, 2015; Mortelmans, 2013) have been applied in this study for qualitative purposes.

Validity in qualitative research is described as the 'appropriateness' and 'trustworthiness' of the tools, processes, and data for the desired outcome (Leung, 2015; Brink, 1993). Reliability refers to the replicability, consistency, stability of the research (Leung, 2015; Brink, 1993). A commonly used approach to increase both validity, as well as reliability, is member-checking. Unfortunately, the design and methods of this research made member-checking difficult to apply since the narratives pre-existed and there was no contact between the researcher and the members (authors and nursing home residents). Nonetheless, to still prevent possible bias, an altered type of data triangulation has been applied. This has been done by including not only books that were written by loved ones of the nursing home residents, but also including books written by healthcare professionals and short, separate stories.

Moreover, both reliability, as well as validity, have been enhanced by applying the concept of reflexivity. This is essential in qualitative research since reflexivity is one of the ways in which researchers can take subjectivity seriously, without abandoning all claims to produce useful accounts of the world (Green & Thorogood, 2018). Reflexivity is also an important part of the data analysis method RTA (Braun & Clarke, 2020). To support this, peer deliberation has been performed throughout this entire research. Peer deliberation has been done with two fellow student-researchers

who also studied nursing home narratives. Their knowledge and viewpoints helped prevent possible bias and preconceptions of the researcher and also contributed to reflexivity, thereby increasing validity.

Furthermore, chapter 5, discussion contains a paragraph with the researcher's reflection on performing this research. This paragraph has been added to be transparent on reflexivity and the researcher's subjective share in the constructed results and conclusions.

Next to this, results are supported by bits of raw data (quotes), providing a form of thick description. This contributed to internal reliability (Morse, 2015) and transparency. Research is seen as transparent when explicit, clear, and open methods are used (Given, 2008). An audit trail and the provision of a clear account of used procedures also contributed to the transparency of the research, thereby improving reliability (Green & Thorogood, 2018).

Lastly, qualitative research aims not to describe or analyze data for representation purposes since it rather aims for an in-depth understanding (Mortelmans, 2013). Hence, some authors speak of generalizability or generalization in the form of 'case-to-case transfer' (Polit & Beck, 2010; Smaling, 2016). This so-called transferability is often discussed as a collaborative enterprise. Herein, the researcher is expected to provide detailed descriptions that allow readers to make inferences about extrapolating the findings to other settings (Polit & Beck, 2010). This research has aimed to do so. Therefore, outcomes are still valuable since they provide insights into specific situations taking place in specific contexts. This makes them purposeful for the context in which they took place, and they can have significance for similar contexts and similar places (Bold, 2012).

3.4 Ethical challenges

A common issue in narrative research is the dual role that the narrative researchers are placed in, meaning that the researchers are in an intimate relationship with the participant, but also in a professionally responsible role in the scholarly community (Josselson, 2007). Since this research uses pre-existing, written narratives, there is no intimate relationship. Hence, this ethical challenge of duality does not occur within this research.

Moreover, since books pre-existed and there was no personal interaction between authors and the researcher, there was no active consent given by authors of the books for inclusion in this research. However, all books were and still are, publicly accessible. Therefore, informed consent was deemed not necessary. Moreover, most books already anonymized the narratives themselves. Hence, there was no need to further anonymize within this research.

The pre-existence of the narratives and the absence of a relationship with participants (authors or nursing home residents) made it not possible to apply member-checking. This does not only influence the validity and reliability but could also pose a threat within the ethical spheres since the authors and nursing home residents did not get to interpret the results and conclusions of this research. A complicating factor is that none of the books were written by nursing home residents themselves. Nonetheless, by viewing the authors as a proxy, data could still be of value in representing the experiences of nursing home residents. However, the researcher must take full responsibility for what is written since the inherent ethics of

narrative research lies in the resolute and positioning of the knower and the circumstances under which the knowledge was created (Josselson, 2007). A research is therefore not about the participants, but about the researcher's meaning-making (p. 549). Within this research, reflexivity has been tried to ensure, for instance, through the researcher's reflection in the discussion.

4. Results

To answer the research question: *'What mismatches concerning person-centeredness, autonomy, and dignity are experienced by nursing home residents, according to written narratives?'*, a total of six books have been read and analyzed. From assigned codes, themes and subthemes have been created. The three main themes that have been derived are the mismatch on captivity and freedom, the mismatch on age-appropriate approachment, and the mismatch on attention and acknowledgement. Since all books are written in Dutch, quotes have been translated into English.

4.1 Mismatch on captivity and freedom

A frequently recurrent theme in the written narratives is that of captivity and freedom. Nursing home residents feel captivated, but caregivers do not seem to notice or accurately understand. Within this theme, there are two mismatches to be differentiated. The first mismatch is about physical deterioration and a decrease in health and condition. Nursing home residents become dependent and less autonomous in comparison to their younger days. This results in residents feeling as if they are captivated by their own bodies since it limits them in what they would want to do and where they want to go. An example of this bodily captivation is described in Ma komt zondag bij ons sterven (2012): "*Thirdly, there is that psychological suffering: she can no longer do anything herself, she is imprisoned in that body, she is dependent on others for everything, even for the toilet visit"* (p. 120). Oftentimes, these feelings of captivation are not accurately seen, understood, or acknowledged by caregivers, which leads to mismatch. This mismatch sometimes results in caregivers making contemptuous, disrespectful, and even insulting comments towards the residents. This is illustrated by the nursing home resident from the narrative Alleen de werkelijkheid is erger (2010), who experiences a contemptuous comment when the issue of showering is brought up. She showers once a week but showering more often would be problematic. Caregivers say to the resident who already feels captivated because she is not able to shower autonomously: "*you're allowed to take a shower as much as you like, but then you have to do it yourself"* (p. 33). In this specific situation, the caregiver does not seem to be willing or able to provide the needed support, leaving the resident helpless and left to fate. This comment made by the caregivers flawlessly illustrates the mismatch: the caregivers do not understand, or care for what it means for the nursing home resident to not be able to shower by herself.

The second mismatch that was derived from the narratives concerning captivity and freedom is about the concrete and specific restrictions that are imposed on the nursing home residents. Within this second mismatch, captivity is taken more literally. Herein, not the resident's body is the captor of freedom, but the nursing home itself, its caregivers, and its regime: institutional captivation. The nursing home and its regime captivates its residents and commands them to be submissive to their will. This is apparent from the previously mentioned example of being allowed to only shower once a week. The following example about a nursing home resident who is not allowed to walk on her own clarifies this captivation even more:

> *It's good weather, and my mother decides that she wants to go outside: she gets up from her chair and walks into the hallway with her walker to go*

> *sit on the terrace of the home for a bit. But that is not possible just like that. Soon she is, as she says so herself, 'caught' by a caregiver: 'You do know that you are not allowed to walk by yourself? You need to get back to your room immediately,' says an annoyed caregiver. 'But I would like to stretch my legs for a bit', my mother says. 'Nothing like it. You are absolutely not allowed to walk alone, and I don't have time to come with you'. She sends my mother back to her room (…).* (Een glaasje rosé bij het ontbijt, 2014, p. 22)

This example shows that this resident, as are most residents from all the narratives, is subject to certain rules, restrictions, and regulations set by the nursing home and the caregivers. These restrictions vary from not being allowed to visit a toilet when needed, to not being allowed to walk around in a room. From the caregiver's point of view, the restrictions originate from the belief that this is in the best interests of the resident. For the caregiver, the restriction of not walking alone is seen as a preventive intervention for the problem of possible falls. For the resident, however, being restricted and obliged to stay seated, touches upon core values since she has highly valued being independent all her life. The resident at her turn does not align with the caregiver because she does not think she is at risk of falling. In a similar situation in another narrative, namely, Ma komt zondag bij ons sterven (2012), the resident even refers to a second world war concentration camp, by saying: *"(…) sometimes I feel like I'm in Auschwitz. You wouldn't believe it, right?"* (p. 166). These restrictions literally captivate the residents, but caregivers do not appear to comprehend what these restrictions bring about in residents. The different views of caregivers and nursing home residents clearly illustrate a 'see or don't see' mismatch (Goossensen, 2014) and two worlds that do not align.

This mismatch seems to have severe consequences for the nursing home residents and their feelings. Residents become frightened that possible reprisals will follow if they do not strictly follow the rules, or if they (or one of their loved ones) make a complaint about the care they receive. In Een glaasje rosé bij het ontbijt (2014), the daughter of the nursing home resident describes such feelings when she talks about her mother: "*(…) she wasn't the type to speak up for herself; she feared for sanctions from the home because of my, in her eyes, too brutal, cheeky appearance"* (p. 133). The fear of reprisals that follow after disobedient behavior only reinforces the feeling of not being free to make own choices. What's notable is that in discourse about this theme, authors or residents use specific words that refer to being imprisoned. References to Auschwitz and prison are used to point towards feelings of captivation, whilst statements of being free and being able to leave the nursing home are used to describe the feeling of freedom.

The two mismatches seem to be interrelated. Starting, residents feel captivated by their own bodies. Adding to this feeling, their freedom is literally restricted since they are not allowed to do certain things or to go to certain places. These mismatches on captivity illustrate that residents long to be free and that they long to undertake whatever they want, whenever they want it, as autonomously as possible. Both mismatches demonstrate that caregivers do not fully understand, or, for that matter, act upon this longing of the nursing home residents. This leads to residents fearing possible reprisals or punishments for disobedient behavior whenever they try to heed to that longing for freedom.

4.2 Mismatch on age-appropriate approachment

The second theme of this chapter highlights the way in which full-grown, elderly human beings with capable cognitive functions are approached. Paradoxically, instead of being treated as such, nursing home residents are often approached in a childish, patronizing, sometimes even pedantic manner. In other words: they are approached as if they were little children. This results in a mismatch on age-appropriate approachment. Results of data analysis show that this type of mismatch contains four different dimensions: (1) general approachment; (2) decision-making; (3) increasing dependency; (4) physical and material environment.

The first dimension concerns the general approachment of caregivers towards nursing home residents: a childish approachment. For instance, being punished for certain behaviors or actions bears witness to an almost childlike approach from healthcare professionals towards the nursing home residents. Residents are reprimanded, almost as if they were 'taught a lesson' because the resident is not viewed as being capable to assess and act upon situations accurately. Many narratives describe situations where residents are not seen as full-fledged human beings with their own preferences, personalities, and backgrounds. This results in residents feeling like they are being approached as if they were a child, as described in Alleen de werkelijkheid is erger (2010): "*My mother is mentally competent, but if it suits, they treat her like a small child"* (p. 78). One narrative even describes that the resident is being called pet names that are commonly used for babies and children:

> *The behavior of many carers and nurses was also remarkable. My wife was constantly addressed as 'sweetie'. From time to time, I was called 'baby'. When I had a meeting with the counselor, I made a complaint. I wish to be addressed with mister and my wife as madam. He replied: it's the culture sir. So nothing changed.* (Mijn vrouw is dood, 2012, p. 19)

Not only do caregivers speak to the residents in a childish manner, but sometimes they also make pedantic comments as if the residents need to be put into place as if they were a child: "*Now listen to me closely: I've had enough of all that screaming. You can see that I'm talking, can you? If it happens one more time I will put you in the hallway"* (Een glaasje rosé bij het ontbijt, 2014, p. 97). To approach a full-grown adult in this way makes residents feel as if they are a child. The caregivers do not seem aware of how their approachment comes across and what it means for the residents, which illustrates a mismatch: making it count or abandoning, which is concerned with empathic responses or distant and indifferent attitudes of caregivers (Goossensen, 2014).

The second dimension that contributes to age-inappropriate approachment pertains to the issue of residents not being involved in decision-making or taken seriously. Complementary to this, being physically dependent does not inherently mean that people are cognitively compressed as well:

> *What strikes me in elderly care is that people assume that we don't only physically lack something, but also mentally. Patients are people of flesh and blood, whatever age they might be. My advice: ask a patient open and*

> *honest questions. About what he used to do in the past and if he enjoyed that for instance.* (Het verpleeghuis is het einde!, 2017, p. 90)

The resident from the quote above highlights something that took place in all books: residents try to have a say in how they are being treated or in how things are being done. Nevertheless, this often results in the residents feeling as if they are not heard, as if no one listens to them. In Alleen de werkelijkheid is erger (2010), the author describes that all they long for is to be seen as a serious interlocutor, but that it creates a feeling of being powerless since nobody listens. This shows that the elderly value having a say and that they wish to choose for themselves, instead of being chosen for as one would do for a child. Their feeling of not being seen, heard, or included in decision-making processes illustrates a mismatch between caregivers and nursing home residents, which fits the 'tuned deciding' mismatch of Goossensen (2014).

A complicating factor that plays a role in the arising of mismatch on age-appropriate approachment is the increasing dependency that nursing home residents need to cope with. This is the third dimension of this mismatch. Because of a decrease in physical health and conditions, nursing home residents become dependent on others to help and assist them. Getting out of bed, getting washed and dressed, even visiting a toilet might become a challenge that makes the nursing home residents dependent. These are all basic tasks that we teach children to do on their own at an early age. Being dependent on someone else for these basic things can be humiliating, shows Wees blij dat je ze nog hebt (2014, p. 158): "*Baby's shit themselves, some elderly do too"*. Situations like this are not only experienced as humiliating, but they also touch upon the value dignity:

> *My mother is unable to walk to the toilet alone, she needs help from a caregiver who she can notify via her alarm. In practice, she often has to wait so long for someone to come that something goes wrong prematurely. That means that I regularly see pants with remainder poo in the bathroom. My mother is terribly ashamed of this and therefore tries to rinse it herself at the sink, while she is not even allowed to walk and stand without supervision. But under the motto necessity breaks law, it is understandable, her dignity as a human being is seriously compromised here.* (Een glaasje rosé bij het ontbijt, 2014, p. 43)

From the caregiver's point of view, if residents need assistance with the same basic, physical things that little children need to be assisted with, it might be easy to forget that the residents are in fact not children. This might evoke an unconscious tendency to approach the residents in a childlike manner. The caregivers who approach the residents as children because they are dependent on basic tasks, do not realize that being dependent can cause feelings of humiliation and indignity. This forms the third dimension of mismatch in this theme.

Lastly, the final dimension is much related to the previous one about the dependency of the nursing home residents. Although most nursing home residents are dependent on the help and support of caregivers, the physical and material environment does not facilitate or contribute to resident's self-reliance, which also contributes to this mismatch of age-appropriate approachment. In the example of the resident who tries to rinse her soiled pants, it is mentioned that she needs to notify a

caregiver via an alarm whenever she needs assistance. This highlights the limited communication means some nursing home residents experience. To ask for help from a caregiver, most residents rely on such a 'call bell'. However, sometimes these bells are not within a reachable distance of the residents. Moreover, all books describe that lots of times, caregivers do not respond fast enough, or sometimes do not respond at all when residents use the call bell. This takes away one of the main communication means that nursing home residents have access to. Another example comes from Ma komt zondag bij ons sterven (2012). In this narrative, the resident's physical functioning is very limited due to her disease. Additionally, the resident's eye vision is limited to the point where she is almost blind. However, caregivers seem to not adjust the physical environment to the resident's disabilities, which causes the resident to spill food during meals and to accidentally knock over objects that she simply could not see. Caregivers make contemptuous comments towards the residents, such as calling her a pig for knocking over objects or commenting: "*you're such a filthy person when eating"* (p. 164). This bears witness to a mismatch in both a correct tenement of the physical and material environment, as well as a mismatch on approachment.

4.3 Mismatch on attention and acknowledgment

The last theme that is derived from analyzed written narratives shows a mismatch on attention and acknowledgement. The presence or non-presence of attention exists on a variety of levels and was mentioned often. The mismatch that is located here addresses the need of nursing home residents for individual, personalized attention. Attention herein is a means to an end: to be acknowledged as a human being. This mismatch is twofold: caregivers do not acknowledge the residents as human beings but merely as a *thing* or *task* because personnel is understaffed or busy, and they show a lack of attention and acknowledgment towards the importance of living spaces of the elderly.

Firstly, nursing home residents often experience that healthcare personnel is understaffed. This leads to the residents feeling like caregivers are in a hurry and need to rush, which leaves no time for additional attention that the residents crave. In one of the narratives, a nursing home resident elaborates on this: "*You're just like a prisoner here. You get your food and your drink and you keep hearing they don't have time"* (Een glaasje rosé bij het ontbijt, 2014, p. 33). In a different narrative, the author of the book (the resident's daughter) also describes such a situation. She does so in retrospect after her mother who had lived in a nursing home had passed. Her mother used to enjoy listening to music, but she needed help with the CD player. Unfortunately, caregivers frequently were too busy to assist the resident with turning on the CD player:

> *There is not enough staff everywhere in the nursing homes to meet all the needs of the residents (…) I think it may not have dawned on the staff how much she craved it [the music from the CD-player], in the painful conditions in which she was, because the caregivers are so overwhelmed with daily work, care for hygiene, nutrition, that they no longer have time for all those other needs that the residents also have (…) What are the specific interests of this person, and what is he or she (still) capable of,*

> *how do we help him or her to still be a little bit happy?* (Ma komt zondag bij ons sterven, 2012, p. 287)

Lots of times, busy personnel and understaffing are mentioned in the narratives. Temporary workers or caregivers that just started their jobs often are not acquainted with the personal needs of the nursing home residents. Personnel that is not properly informed compromises the quality of care and attention, moving away from person-centeredness and moving towards residents being viewed as a 'thing' instead of as a human: *"But you are a number. They come in and hop, they are already gone. They might think that I don't notice, but I really do know that they don't have time to give everybody attention"* (Wees blij dat je ze nog hebt, 2014, p. 148). In some cases, narratives elaborate upon a fear of being forgotten because caregivers do not have enough attention or because caregivers are too busy. Not only residents, but their families experience this fear as well. It sometimes also leads to residents who experience a feeling of 'being too much' or 'being too difficult' when they need something. In these situations, care does not match because nursing home residents seek attention and acknowledgment as human beings, whilst caregivers seem to pay little attention to the individual person who is receiving their care. Nursing home residents long for person-centered care, however, caregivers seem to have a more task-oriented approach, which leads to mismatch.

Secondly, the person-centered approach that nursing home residents feel like they are missing out on is not solely about spending time, valuing the human behind the resident, or having attention. Person-centeredness hides in small details, it is about *paying* attention next to *having* attention. This needs to be geared not only towards the nursing home residents themselves, but also towards the physical and material living spaces that the residents reside in. Attention to the atmosphere or ambiance is required since it plays an important role in the experiences of nursing home residents. When attention is paid to what spaces and rooms look like and what atmosphere is present, nursing home residents state that they feel at home. On the contrary, when insufficient attention has been paid to the ambiance, it can sometimes affect experiences negatively. The author of Mijn vrouw is dood provides detailed descriptions of rooms, spaces, and their appearances:

> *However, the entrance to the house was gloomy, stuffy, dark. We were led to a kind of living room. Some old-fashioned furniture. A shabby kitchen. I hung up our clothes. Tidied underwear. Toiletries in an unsightly bathroom. Because of the scare of the environment, I forgot a number of things.* (Mijn vrouw is dood, 2012, p. 16)

This description displays that minimal attention was paid to the interior and decoration of the rooms and spaces. However, these spaces were supposed to form a new permanent home for this elderly married couple. Other narratives also attest that nursing home residents find it important what their rooms and spaces look like. However, almost none of the books have mentioned that caregivers recognized this importance or mentioned that attention was paid to living spaces.

5. Discussion

This chapter first discusses the results of the research, in light of theoretical concepts and existing literature. Following, the strengths and limitations of the research are discussed. In this research, RTA has been used for data analysis. Reflexivity is an indispensable part of this analysis method. Therefore, the fore-last paragraph contains a brief overview of the researcher's reflection. Lastly, recommendations for follow-up research are provided.

5.1 Reflection of the results

This research aimed to provide an answer to the question *'What mismatches concerning person-centeredness, autonomy, and dignity are experienced by nursing home residents, according to written narratives?'.* As the results and its themes show, mismatch is eminently present in nursing home care. From the written narratives, three themes have been constructed. Every theme contains several dimensions. When looking at the concepts in the theoretical framework, each theme can be related to one of the values from the research question. An overview of the concepts from the research question, themes, and the dimension of mismatch is depicted in Table 3. Together, these themes and their corresponding dimensions illustrate what mismatches are experienced by nursing home residents and their loved ones concerning the care they receive. Moreover, this research provides a more specified analysis of the generic concept of mismatch, which is twofold.

Firstly, analysis and results illustrate what mismatch entails for residents who live in a nursing home setting. This contributes to a more specific understanding of the concept mismatch within the nursing home care settings. The insights presented in this research are also important since they highlight complex situations in care processes. These complex situations are not recognized or mentioned within the current Dutch framework for quality of nursing home care (Zorginstituut Nederland, 2017). In this regard, this research can form an addition to the quality framework since it provides insights and raises awareness to situations in care processes that might eventuate in mismatch, which can ultimately threaten person-centeredness, autonomy, and dignity. Moreover, this research can be of assistance for healthcare professionals to gain insights into how their actions and behaviors might contribute or evoke mismatch upon the values of person-centeredness, autonomy, and dignity. The analysis and results can contribute to and be of guidance for personal and professional reflection of healthcare professionals. This can ultimately help professionals to be aware of possible mismatches and contribute to their person-centered care and support for nursing home residents on autonomy and dignity.

Table 3
Values, themes, and dimensions of mismatch

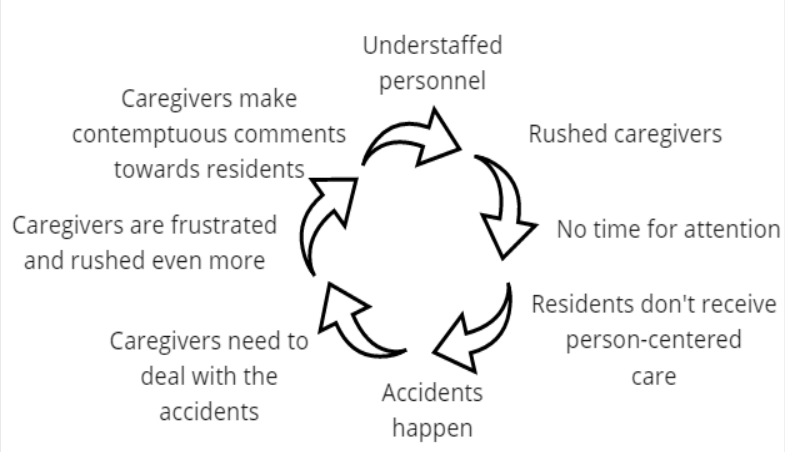
Concept	Theme	Dimensions of mismatch
Person-centeredness	Mismatch on attention and acknowledgment	Being acknowledged as human being Organization of care
Autonomy	Mismatch on captivity and freedom	Bodily captivation Institutional captivation
Dignity	Mismatch on age-appropriate approachment	General approachment Decision-making Increasing dependency Physical and material environment

Secondly, this research adds to the current theory of mismatch. Whereas the existing concept is mainly focused on the relationships between the caregiver and nursing home resident, the findings of this research highlight two different, but very important dimensions that contribute to mismatching care: the physical and material environment and the organization of care. The importance and influence of objects and the physical environment were already discussed in Mol's (2010a) research on good care and endless tinkering. However, the physical and material environments or objects can contribute to the emergence of mismatch, as this research showed. Nonetheless, Goossensen (2014) does not elaborate on this non-relational dimension within her theory.

The findings of this research also showed that the organization of care can form a dimension that leads to mismatch. The relationship between caregiver and resident seems utterly important. However, building such a relationship that is person-centered, attentive, and could possibly prevent mismatch might be hard to do in practice, since personnel is understaffed and turn-over is high (Patiëntenfederatie Nederland, 2020). This also aligns with the results of the analysis of the narratives, in which residents often speak of understaffed personnel and its consequences. As part of the analysis of the narratives in this research, a figure was developed to depict how the organization of care can contribute to mismatch (Figure 1). This figure illustrates a vicious circle of understaffed, busy personnel that has little time for attention, which leads to nonperson-centered care and contemptuous comments towards nursing home residents. As results have shown, contemptuous comments originate from mismatching situations since understandings between caregivers and residents do not align, neither does the caregiver's response. An example of a situation in which this vicious circle can be recognized is elaborated upon in paragraph 4.2. In this example, a nursing home resident accidentally knocks over objects in a room and spills food. This example illustrates how organizational factors influence mismatch.

The effect of organizational factors is also emphasized by Klaver and Baart (2011). They state: "*It is inescapable to face the structural context in which care takes place, and the possible ways it is intervening with the connection of care and attentiveness"* (p. 690). This is in line with the statement that organizational factors influence daily care. Nonetheless, the current concept of mismatch does not elaborate upon this dimension that contributes to the arising of mismatch.

Figure 1
How the organization of care might cause a vicious circle leading to mismatch



The findings of this research can also be placed into the context of existing literature. This research has similarities with literature on attentiveness (Klaver & Baart, 2011; Klaver & Baart, 2016a), and adds to it by relating it to mismatch. For instance, the theme 'mismatch on attention and acknowledgment' at some points shows a quite literal uptake on attention. At other points throughout this research, however, attention is not meant merely literal, but much broader: not only having attention but paying attention and being attentive to the residents and their (physical and material) surroundings. This touches upon existing literature that also talks about attentiveness (Klaver & Baart, 2011; Klaver & Baart, 2016a). Klaver and Baart (2016b) have studied attentiveness in care practices and found nine different types, from which some may contribute to good care and should thus be encouraged, and others not so much. The results of this research show that the degree of attention was related to care being experienced as good or not, which is also in line with existing literature. Attentiveness however is not only important within the last mismatch on attention and acknowledgement. Considering the findings of this research, one might even start to think that attentiveness could contribute to preventing mismatch on person-centeredness, autonomy, and dignity. Attentiveness is needed for caregivers and nursing home residents to connect, understand each other, and align. A key element herein is that even though caregivers might not understand nursing home residents, they must not turn the gaze away, but rather keep on watching. Attentiveness searches for an understanding of what the proper focus of care must be. Nevertheless, attentiveness does not guarantee matching care. Klaver and Baart (2016a) even argue that it is nearly impossible for caregivers to fully understand their care recipients.

Moreover, being an attentive caregiver is not about trying to determine the object of attention, but rather to postpone the interpretation, or to continue interpreting, which is a moving process instead of something static (Klaver & Baart, 2016a, p. 354). Being attentive whilst persistently tinkering (exploring, testing, touching, adapting, adjusting, and paying attention to details and change them until a suitable material, emotional, or relational arrangement is achieved) with care practices (Mol et al., 2010a) might form a solution to the complex situations in which matching care is difficult to achieve. Hence, continuous tinkering with care practices whilst being attentive might form a solid basis to prevent certain dimensions of mismatch, or to still be able to provide good care in situations in which an understanding between caregivers and nursing home residents is complex.

5.2 Strengths and limitations

Within this research, RTA has been applied to written narratives in book form. This thematic manner of analyzing data aims to make broader claims, derived from individual narratives. However, this means that narratives are cut off and lifted out of their own contexts to be actively placed into the constructed themes. The value of a narrative as a whole, with its contexts and specific backgrounds, can hereby be lost. However, analyzing pre-existing, written narratives can provide interesting findings, since there is no interruption, intervention, steering, or influencing from the researcher's side during the writing of the narratives. Studying pre-existing, written narratives presents the opportunity to truly get an inside look into the lives of the residents as is, without bias caused by awareness of being studied, or researcher's

steering. All these facets display the richness and multi-layeredness of data of written narratives.

A risky element of most of the books being written by close relatives is the entanglement of their feelings and experiences with those of the nursing home residents; their loved ones. At times, it was difficult to sift through the data because there were no clear boundaries to what experiences and perspectives belonged to whom: the resident or the author. Nonetheless, by using quotes to illustrate and support the results, this research was able to highlight the perspective of the nursing home residents themselves and to shift the perspectives of the loved ones to the background.

Another important remark is that some of the books were written because the authors (and most of the time the nursing home residents endorsed this, but more implicitly) felt dissatisfied with the nursing homes and their care. The title of the book 'Alleen de werkelijkheid is erger' accurately captures how the author sees her mother's life in this particular nursing home: o*nly reality is worse*. In the book's epilogue, the author admits that the narrative mainly focused on what did not go well in her mother's nursing home. She even speaks of 'her battle for sufficient care and voice' that the narrative represents. A complicating factor is that the nursing home discussed in this narrative is indeed selected as one of the 30 worst Dutch nursing homes. Notwithstanding, other narratives also mainly focus and elaborate upon the downsides of life and care in a nursing home. This also gets recognized: '*After all, negative emotions get more in the way than positive ones*' (Alleen de werkelijkheid is erger, 2010, p. 161). Also, one's personality and view on life are important to take into consideration when analyzing and interpreting narratives. One of the nursing home residents in Het verpleeghuis is het einde! comments on this: "*If you've never been satisfied, you are not here either"* (p. 146).

Adding to this, two of the books in this research (Een glaasje rosé bij het ontbijt; Alleen de werkelijkheid is erger) were written out of discontentment. This phenomenon can be related to Frank's concept of 'narrative type', as explained in the article of Thomas-MacLean (2004). In the epilogues of these books, authors talk about a battle they fought, and how they hoped, and still hope, that things will change. This would match with the manifesto story type, in which illness becomes a motivator for social action or change (Thomas-MacLean, 2004). The other two books (Ma komt zondag bij ons sterven; Mijn vrouw is dood) are borderline story types: they would fit the manifesto type, but also the memoir, in which events are simply related. A nuance that needs to be made here is that the narrative types as described above would fit the perspectives of the authors of the written narratives. When zooming in on the nursing home residents themselves, the story types would best fit the memoir type. From the narratives, it emerges that even in the books from which the authors aim to motivate for social action or change, the nursing home residents themselves do not seem to be motivated to change the system or to change care. They have accepted their, oftentimes unpleasant, circumstances and do not undertake further action to change them. This is remarkable since the nursing home residents are the ones who experience and need to live with and live through the consequences of mismatching care. Thus, the narratives do not only illustrate experiences with mismatch of nursing home residents and caregivers, but they also show the experiences with mismatch from the loved ones' perspectives.

Because of the limited timeframe this research had to be completed in, the research question aimed to demark the scope of this research. By choosing to focus mainly on the experiences of mismatch from the viewpoints of nursing home residents, it is inherently chosen to not focus on other facets from the data. For instance, the narratives are full of experiences and stories of the resident's loved ones. Most of the time, the loved ones were authors of the books as well. The feelings, events, and experiences that were described in the narratives provided rich and detailed narratives from the loved ones. The written narratives for instance can provide insights on how the loved ones of nursing home residents view mismatch and the prevention thereof.

5.3 Researcher's reflection

In this last paragraph of the discussion, I will reflect on my role as researcher and my personal frame of reference since the researcher's subjectivity and interpretation is an essential part of RTA. I have worked and still work in healthcare as an oncology nurse. The data analysis as well as the results and the final conclusions have been tremendously influenced by my own nursing background. During the last two years of my Bachelor of Nursing, I got employed by the hospital that still functions as my part-time working place. Patient care, caring, and elderly too are not unfamiliar. Even nursing homes are not new terrain since I have had to complete multiple internships in nursing homes. In addition, I have had side jobs in nursing homes as well. This led to me having my own, as I call it, 'caring context'.

Individual resentment and resentment of the care recipient

My personal caring context provided me with a framework to compare data from the narratives to. It helped me put things into context and to understand and relate to certain situations, feelings, and experiences described in the narratives. Sometimes, this brought clarification and was beneficial for the research. Nevertheless, at times, it resulted in feelings of resentment and rejection towards certain situations that I experienced as cruel or abominable. This resentment was twofold.

On the one hand, the resentment I experienced during this research was geared towards the nursing homes and its professionals (at a managerial level as well as on a 'bedside' level). I call this 'institutional resentment'. This resentment towards the entire nursing home institution was a consequence of a bleeding nurse-heart, that could not comprehend the way in which vulnerable residents were treated and not truly cared for in the way they needed to. It evoked a feeling of injustice and abuse of power. Moreover, as a caregiver, I have experienced first-hand that some other caregivers really can and do act in a, what I see as, unethical manner. Not only my nursing background led me to experience this institutional resentment, but also my personal, strong beliefs in equality that originates from my upbringing and my religion played a big role herein.

On the other hand, some narratives made me resent the nursing home resident themselves, or the narrative's author. I call this 'resentment of the care recipient', in which 'recipient' can both appoint towards the nursing home resident as to their loved ones or the author of the book. As I explained earlier, the majority of the included books in this research were originally written out of discontentment with the conditions and care of the nursing homes. In some narratives, this resulted in an extensive

amount of negativity, complaints, and complaining, as well as rejection of attempts of caregivers to turn around the negative experiences into positive ones. These situations sometimes annoyed me and led to resentment geared towards individual persons (residents, their loved ones, authors) on the recipient end of care. Although this resentment is targeted on and caused by individual care recipients, it also touches upon my own caring context as a nurse, since I have experienced myself that some people are never satisfied, never happy, and that even the best you try to do as a professional will never be good enough. Additionally, this individual resentment also misaligns with my upbringing and personal beliefs of having a positive mentality and attitude, my attempts to always look for the good in people and situations, as well as a personal resentment of constant complaining.

Wishful reading

Remarkably, whilst reading the narratives and analyzing them, I realized I was steering myself to not be too negative about the nursing homes. I felt like I had to emphasize positive sides as well, and I noticed a feeling of guilt that the negative aspects of living and receiving care in a nursing home appeared to be more on the surface than the positive aspects. Most narratives were written out of discontentment, so it made sense that negatives were presented more often than positives. However, throughout reading and analyzing the books, I kept on hoping things would get better. At several moments in this research, a dreadful feeling crept over me as I thought about what care would look like at the point that my own loved ones, or I myself would be dependent on it. Although this self-obliged search for positive aspects in the data has led to thorough reading and analyzing, it might have emerged out of wishful reading and analyzing to try and make myself believe that nursing homes are not all that bad. I actively searched for positives to provide myself with some hopes for myself and my own nursing home future when I get older.

5.4 Recommendations

Currently, mismatch in nursing home care is often overlooked. Therefore, follow-up research is needed. This research focused on the experiences of nursing home residents with mismatch. However, this research also argues that the relationship between the resident and their caregiver is important. Therefore, it would be recommended to study mismatch from the perspectives of caregivers. Herein, mismatches that are experienced by residents can be validated or other mismatches might come to light.

In addition, the influence of the physical and material environment, as well as the organization of care are subjects that need further scientific exploration. Adding to this, the role of attentiveness and continuous tinkering in preventing mismatch needs deeper understanding and scientific attention.

Lastly, analyzing written narratives from the viewpoints of the loved ones as individual, important actors (instead of proxies of nursing home residents) could also provide valuable insights into mismatching care. Further research might be able to explore from where and why the difference arises between nursing home residents who accept and live with lacking or mismatching care, whilst their loved ones are willing to fight and strive for better care. Therefore, the appearance of mismatch between caregivers and loved ones of nursing home residents also needs further research.

6. Conclusion

This qualitative research aimed to explore mismatch concerning person-centered care, autonomy, and dignity within nursing home settings. Written narratives show a mismatch on captivity and freedom, age-appropriate approachment, and attention and acknowledgement. By studying the written narratives of nursing home residents and analyzing their experiences with mismatch, insights and subjects to reflect upon are provided for healthcare professionals, which raises awareness and can be used to improve care. Furthermore, the existing concept of mismatch focuses mainly on the relationships of caregivers and nursing home residents and the extent to which they align and understand each other. The findings of this research however expose yet two other different dimensions that can cause mismatch: the physical and material environment, and the organization of care. These two dimensions are described in concepts of good care and attentiveness but are not yet researched in the light of mismatch. Lastly, this research shows that attentiveness and continuous tinkering towards good care could possibly play a role in preventing mismatch.

References

Angenent, F., & Bisschops, L. (2017). *Het verpleeghuis is het einde!* Het Verpleeghuis is het einde!

Bold, C. (2012). Analysing narrative data. In *Using narrative in research* (pp. 120-142). London: SAGE Publications .

Bowen, G. B. (2006). Grounded Theory and Sensitizing Concepts. *International Journal of Qualitative Methods*, 12-23.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 77-101.

Braun, V., & Clarke, V. (2020). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*.

Braun, V., & Clarke, V. (n.d.). *Thematic analysis | a reflexive approach*. Retrieved from The university of Auckland: https://www.psych.auckland.ac.nz/en/about/thematic-analysis.html

Brink, H. (1993). Validity and reliability in qualitative research. *Curationis*, 35-38.

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., . . . Stibrant Sunnerhagen, K. (2011). Person-Centered Care - Ready for Prime Time. *European Journal of Cardiovascular Nursing*, 248-251.

Engels, J., Vermunt, P., Leers, E., & Spanbroek, M. (2017). Persoonsgerichte zorg, hoe pak je het aan en wat levert het op? *Nederlands tijdschrift voor evidence based practice*, 19-22.

Ensie. (2017, 04 21). *Sensitizing concepts*. Retrieved from Ensie: https://www.ensie.nl/dit-is-onderzoek/sensitizing-concepts

Given, M. (2009). Transparency. In *The SAGE Encyclopedia of Qualitative Research Methods* (pp. 891-892). Thousand Oaks: SAGE Publications, Inc.

Goossensen (Ed.), A., van de Kamp, J., Kuis, E., Herwijnen, F., van Herwijnen, F., van Dijke, J., & Baart, A. (2014). *Schetsen van Mismatch.* Movisie.

Green, J., & Thorogood, N. (2018). *Qualitative Methods for Health Research.* London: SAGE Publications.

Heggestad, T., Høy, B., Sæteren, B., Slettebø, A., Lillestø, B., Rehnsfeldt, A., . . . Aas, T. (2015). Dignity, Dependence, and Relational Autonomy for Older People Living in Nursing Homes. *International Journal for Human Caring*, 42-46.

Houwaart, D. (2012). *Mijn vrouw is dood.* Elburg: Uitgeverij Ipenburg.

Josselson, R. (2007). The Ethical Attitude in Narrative Research. In D. Clandinin, *Handbook of Narrative Inquiry* (pp. 537-566). Thousand Oaks: Sage Publications.

Kabadayi, S., Hu, K., Lee, Y., Hanks, L., Walsman, M., & Dobrzykowski, D. (2020). Fostering older adult care experiences to maximize well-being outcomes: A conceptual framework. *Journal of Service Management*, 953-977.

Katz, S., & Gurland, B. (1991). Science of Quality of Life of Elders: Challenge and Opportunity. In L. J. Birren JE, *The Concept and Measurement of Quality of Life in the Frail Elderly* (pp. 335-343). San Diego: Academic Press.

Klaver, K., & Baart, A. (2011). Attentiveness in care: Towards a theoretical framework. *Nursing Ethics*, 686-693.

Klaver, K., & Baart, A. (2016a). How can attending physicians be more attentive? On being attentive versus producing attentiveness. *Medicine, Health Care and Philosophy*, 351-359.

Klaver, K., & Baart, A. (2016b). Managing socio-institutional enclosure: A grounded theory of caregivers' attentiveness in hospital care. *European Journal of Oncology Nursing*, 95-102.

Kroonenberg, Y. (2014). *Wees blij dat je ze nog hebt.* Amsterdam/Antwerpen: Uitgeverij Atlas Contact.

Leung, L. (2015). Validity, reliability, and generalizability in qualitative research. *Family Medicine and Primary Care*, 324-327.

Lothian, K., & Philp, I. (2001). Maintaining the dignity and autonomy of older people in. *Education and debate*, 668-670.

Mol, A. (2010b). Care and its values. Good food in the nursing home. In A. Mol, I. Moser, & J. Pols, *Care in Practice. On tinkering in Clinics, Homes and Farms* (pp. 215-234). Bielefeld: Transcript Verlag.

Mol, A., Moser, I., & Pols, J. (2010a). Care: putting practice into theory. In A. Mol, I. Moser, & J. Pols, *Care in Practice* (pp. 7-26). Bielefeld: Verlag.

Morse, J. (2015). Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. *Qualitative Health Research*, 1212-1222.

Mortelmans, D. (2013). *Handboek kwalitatieve onderzoeksmethoden.* Leuven: Acco.

Niesing, L. (2014). *Een glaasje rosé bij het ontbijt.* Voorburg: Uitgeverij U2pi.

Patfoort, P. (2012). *Ma komt zondag bij ons sterven.* Antwerpen: Cyclus.

Patiëntenfederatie Nederland. (2020, 03 25). *Personeelstekort verpleeghuizen blijft problemen opleveren*. Retreived from Patiëntenfederatie Nederland: https://www.patientenfederatie.nl/actueel/nieuws/personeelstekort-verpleeghuizen-blijft-problemen-opleveren

Pellegrino, D. (2005). Some Things Ought Never Be Done: Moral Absolutes in Clinical Ethics. *Theoretical Medicine and Bioethics*, 469-486.

Poey, J., Hermer, L., Cornelison, L., Kaup, M., Drake, P., Stone, R., & Doll, G. (2017). Does Person-Centered Care Improve Residents' Satisfaction With. *JAMDA*, 974-979.

Polit, D., & Beck, C. (2010). Generalization in quantitative and qualitative research: Myths and strategies. *International Jounal of Nursing Studies*, 1451-1458.

Pullman, D. (1999). The Ethics of Autonomy and Dignity in Long-Term Care. *Canadian Journal on Aging*, 26-46.

Rosemond, C., Hanson, L., Ennett, S., Schenck, A., & Weiner, B. (2012). Implementing person-centered care in nursing homes. *Health Care Management Review*, 257-266.

Smaling, A. (2009). Generaliseerbaarheid in kwalitatief onderzoek. *KWALON*, 5-12.

Smith, B., & Sparkes, A. (2010). Men, sport, and spinal cord injury: An analysis of metaphors and narrative types. *Disability & Society*, 613-626.

Stichting CCC. (n.d.). Opgeroepen op 05 14, 2021, van Patientervaringsverhalen:: https://www.patientervaringsverhalen.nl/?pagina=Stichting+CCC

The American Geriatrics Society Expert Panel on Person-Centered Care. (2016). erson-Centered Care: A Definition and Essential Elements. *The American Geriatrics Society*, 15-18.

Thomas-MacLean, R. (2004). Understanding breast cancer stories via Frank's narrative types. *Social sciene & medicine*, 1647-1657.

Timmermans, S., & Tavory, I. (2012). Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis. *Sociological Theory*, 167-186.

van Campen, C. (2019). Kwaliteit in het verpleeghuis. *Denkbeeld*, 34-35.

van Campen, C., & Verbeek-Oudijk, D. (2017, 09). *Happy in a nursing home?* Retrieved from The Netherlands Institute for Social Research: file:///C:/Users/esthe/Downloads/Summary+-+Older+persons+in+nursing+and+care+homes.pdf

van de Bovenkamp, H., Platenkamp, C., & Bal, R. (2020). Understanding patient exeriences: The powerful source of written patient stories. *Health Exppectations*, pp. 717-718.

van de Bovenkamp, H., Stoopendaal, A., van Bochove, M., Hoogendijk, H., & Bal, R. (2018). *Persoonsgerichte zorg, regeldruk en regelruimte: van regelreflex naar spiegelreflex.* Utrecht.

van Werkhoven, G. (2010). *Alleen de werkelijkheid is erger.* Demio.

WHO. (2015). *World Mental Health Day 2015.* Retrieved from https://www.who.int/mental_health/world-mental-health-day/2015_infosheet/en/#:~:text=Dignity%20refers%20to%20an%20individual's,the%20possibility%20to%20make%20choices.

Zorginstituut Nederland. (2017). *Kwaliteitskader Verpleeghuiszorg*. Retrieved from Zorginstituut Nederland: https://www.zorginstituutnederland.nl/publicaties/publicatie/2017/01/13/kwaliteitskader-verpleeghuiszorg

Appendices

Appendix A. Book selection

Search term	New results	Author, year	In/excluded	Explanation
Quality of care & nursing home (9 results)	Alleen de werkelijkheid is erger	Gonny van Werkhoven, 2010	Included	CVA
	De laatste kamer	Frans Pointl, 2013	Excluded	Poems and stories, more about life than about nursing home care
	Een glaasje rosé bij het ontbijt	Loes Niesing, 2014	Included	Written by daughter. 5 years of nursing home Parkinson & hip fracture
	Inge's laatste reis	Wouter B. Blokhuis, 2019	Excluded	Alzheimer
	Machtsmisbruik in het verpleeghuis	Cindy van der Tol, 2016	Excluded	Alzheimer
	Momentopnamen	Paul Peijnenburg, Bert Janssen, 2011	Excluded	Focuses on palliative care. Written by volunteer
	Pal voor u	Pal Projectgroep, 2014	Excluded	Magazine
	Uw patiënt; onze moeder	Mieka Vroom, 2015	Excluded	Alzheimer
	Wees blij dat je ze nog hebt	Yvonne Kroonenberg, 2014	Included	Collection of different stories
Client-friendly care & nursing home (6 results)	Als het maar echt is	Paula Irik, 2013	Excluded	Alzheimer
	Firma Alzheimer	Johan van Oers, 2010	Excluded	Alzheimer
	Hoe word je een Bianca?	Anne Goossensens, Dirk Pool	Excluded	Client-centered care, not written by an older-person
	Verzorgingshuis De Heuvel	Hennie Janssen, 2013	Excluded	Dementia
Well living & nursing home (2 results)	Het verpleeghuis is het einde!	Freya Angenent, Lauke	Included	Short, separate stories, written by 2 doctors. Deviant case analysis

		Bisschops, 2017		
The entire human & nursing home (2 results)	Ma komt zondag bij ons sterven	Pat Patfoort, 2012	Included	About dying, euthanasia
	Wisselend bewolkt met zonnige perioden	Ineke Wielinga, 2018	Excluded	Dementia
	Mijn vrouw is dood	Dick Houwaart, 2012	Included	About entire healthcare-trajectory, lastly about nursing home care
Care organizations & nursing home (8 results)	Niske	Jos Smit-Koornstra, 2011	Excluded	Life story of girl with TBC, ends up in nursing home
	Uit zicht	Karin Kamminga, 2012	Excluded	Dementia

Search terms that showed no new books:

- Care coordination & nursing home (2 results)
- Control & nursing home (3 results)
- Renewed patient-friendly ideas & nursing home (3 results)
- Expertise & nursing home (1 result)

Appendix B. Six phases of RTA

1. *"**Familiarisation with the data** | This phase involves reading and re-reading the data, to become immersed and intimately familiar with its content.*
2. ***Coding** | This phase involves generating succinct labels (codes!) that identify important features of the data that might be relevant to answering the research question. It involves coding the entire dataset, and after that, collating all the codes and all relevant data extracts, together for later stages of analysis.*
3. ***Generating initial themes** | This phase involves examining the codes and collated data to identify significant broader patterns of meaning (potential themes). It then involves collating data relevant to each candidate theme, so that you can work with the data and review the viability of each candidate theme.*
4. ***Reviewing themes** | This phase involves checking the candidate themes against the dataset, to determine that they tell a convincing story of the data, and one that answers the research question. In this phase, themes are typically refined, which sometimes involves them being split, combined, or discarded. In our TA approach, themes are defined as pattern of shared meaning underpinned by a central concept or idea.*
5. ***Defining and naming themes** | This phase involves developing a detailed analysis of each theme, working out the scope and focus of each theme, determining the 'story' of each. It also involves deciding on an informative name for each theme.*
6. ***Writing up** | This final phase involves weaving together the analytic narrative and data extracts, and contextualising the analysis in relation to existing literature."* (Braun & Clarke, n.d., Phases in doing reflexive thematic analysis)

Appendix C. Codes and page numbers

	Een glaasje rosé bij het ontbijt	**Alleen de werkelijkheid is erger**	**Wees blij dat je ze nog hebt**	**Ma komt zondag bij ons sterven**	**Mijn vrouw is dood**	**Het verpleeghuis is het einde!**
Afraid to be forgotten	43, 48, 88	35		105, 197	20, 21	
Agreements are not met	52, 80, 89	36, 36, 43 , 47, 52, 55, 58, 58, 76, 87, 92, 95, 1S14		43, 93, 108, 189	19	
Attention	28, *32,* 41, 42, 44, 55, 59, 77, 79, 88, 91, 126		44	75, 207, 287	36	18, 20, 38
Autonomy	17, 22, 32, 52	75, 88	17, 28, 146, 147, 148	50, 66, 69, 71, 83, 107, 108, 269, 292	21, 37, 39	40, 90, 218
Autonomy, independency		48, 75				
Be around/among people	26, 64, 92		56, 131, 145, 146	35, 39, 40, 53, 76, 77, 95, 96, 103, 117, 170, 205	35	18, 38, 46, 84, 100, 146, 153, 182, 184, 188, 216
Being found difficult	22	36, 57, 58, 75, 76, 79, 88, 107	146	97		
Being mobile	10, 11, 15, 20	48, 75				86
Being punished/reprisals	30, 107, 133	93, 62, 86		86, 113		

Busy personnel, less time	22, 32, 34, 43, 65, 68, 86	109		77, 153, 198	19, 22, 33	38, 86, 146, 189
Call bell	29, 37, 43, 48, 59, 73	35, 51, 54, 75, 78, 85, 87, 93			19, 22	
Childish	24, 29, 35, 93, 96	78	158	71, 91, 189	19, 22	90, 218
Conflict family and personnel	106	62, 65/66, 72/73, 86	139			
Contemptuous comments	24, 28, 34, 61, 70, 73, 85, 96, 101, 106	33, 63, 65, 72, 73, 79, 107	146,	111, 164, 189	19, 22, 27	
Contradiction among personnel	115	56, 61, 69, 77, 88			34	
Defending yourself, fighting	23, 37			93, 127, 152	21, 37, 38, 39	20, 153
Dependency, waiting	9, 27, 87	29, 40, 43	158	30, 35, 50, 66, 74, 99, 112, 120, 147, 271	24, 25, 39	90, 100, 152
Dignity	60, 65, 68			117	24	90
Discrepancy between experiences of resident and perceptions of personnel		28,52/53, 57, 66, 69, 70, 100, 112, 117	139	81		218 (*thinking along)*
Despair	81				37	
Fear, insecurity				42, 54, 66, 81, 123, 132, 163, 174	32	
Feeling at home, own stuff	11, 71					184, 188, 216

Filing, charting	31, 38, 45, 49, 101	66, 68, 70, 79, 91, 95, 102, 118				
Food	77			111, 196, 206		86, 184, 188, 189
Gratitude for informal care		43, 53, 57, 67				
Having fun in activities	94	31, 47	131			
Having something to do, staying busy	30, 39, 61, 70, 84, 89, 92		18,	61, 63, 106, 167, 186		18, 40, 46, 84, 102, 170, 182, 188, 218
Having something to look forward to			149	72, 126, 132, 196	32, 37	20, 48, 86
Having to do things, being forced				23, 32, 34, 35, 38, 42, 48, 93	19	
Having trouble adjusting (family perspective)		29/30				
Having trouble adjusting (resident perspective)		31, 49	30	269		40, 46, 84, 86, 100, 102, 184
Hell				38, 137, 148		
Homesick	12		45	31, 54	37, 39	46, 84
Hostile		62, 63		112		
Hygiene	35, 40, 53, 44, 53, 59, 86, 89	47, 89, 117	141	207	18, 20, 23	
Informal care		114				
Information means	32, 33, 63, 107	91				
Jail, not being free	22, 24, 33, 39, 61		146, 147	23, 32, 42, 120, 167, 169, 214	18, 22	184, 188
Knowledge and capabilities of personnel, being informed	35, 38, 53, 58, 80, 84,	36, 37, 46, 51, 58, 60,		37	17, 21, 23, 35, 36	

	90, 91, 92, 111, 124	65, 67, 88/89, 91, 95, 104/105, 105, 120/121				
Lack of trust	45, 58, 81, 95	53, 58, 60, 63/64, 73, 75, 85, 93, 120/121				
Loneliness, being alone	32	31, 37, 110	146, 148	110, 122, 171, 195	30	
Lovely personnel					16, 19, 21, 28, 29	18, 46, 100, 146, 152, 153
Made dependent	68,	65, 75, 93/94		162	22	
Meaning, religion	105					92
Minimal/limited options with regard to care (showering)		33, 36, 37, 69, 74, 83				
Not being heard, not being involved	28, 47, 95, 104	44, 59, 60, 63, 67, 68, 69, 96, 108	141, 142	38, 48, 81		184
Person-centered	25, 42, 104, 106	88/89	131, 141, 148	75, 287	39	90
Personnel doesn't want to assist		36, 39, 41, 43, 83, 85, 90, 116	146			
Personnel, shifting personnel, changes, understaffing	31, 32, 45, 53, 58, 66, 69, 78, 90	35, 44, 47, 56, 61, 64, 65, 71, 80, 88/89, 90, 91, 108			23, 24	
Physical health	20, 99		10, 68, 174	24, 25, 50, 54, 64, 119, 122, 197, 206,	21	48, 184

				214, 228, 271		
Physical areas, atmosphere	26, 72, 94		*92 (from professional),* 146		16, 17, 18, 20, 25, 26, 32, 33, 35	46, 188
Powerlessness	29	53, 59, 68, 85, 113/114	142	128		
Professional/unprofessional	64, 96, 106, 118, 124					
Pushing off		59. 60. 64. 65. 98				
Quality of life	31	112, 113	10	27, 123, 125, 292		
Safety	79, 80, 92	95				
Shame	43, 61		158	64, 86, 119, 207	24	
Toilet visits	34, 43, 59		158, 159	86, 147, 161, 207	24	20
Understaffed personnel		37, 47		33, 110, 112, 235, 287	22, 39	20
Well-being	57		174			