Master thesis

Autonomy of clients in long-term care

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Preface

This thesis was written for the completion of the Master of Health Sciences with the track Optimization of Healthcare Processes. It examines the perspective of clients in terms of their autonomy at the long-term care organization Zorggroep Almere. By identifying what is important for clients regarding the improvement of their autonomy, long-term care organizations can adjust their work processes to meet the needs of the clients. I would like to thank my supervisors, Anke Lenferink, Caroline Fischer, and Arjan Beelen, for their time, their feedback, and the opportunity they gave me to conduct this research. Not to forget, I would like to thank Lineke Verkooijen, the founder of the OER-model, for sharing her knowledge with me. In addition, I would like to thank Inge Beers and Ingrid Korts because they made it possible for me to conduct interviews at their locations at the Zorggroep Almere. Finally, I would like to thank all the clients who participated in this research.
I hope you will enjoy reading my thesis.

Mahgul Hosseini
Zwolle, July 2023

Abstract

In the literature, there has been a lot of research on autonomy with another subject or a particular clinical picture. No research was found that was conducted solely from the client's perspective concerning autonomy in general in long-term care. The focus of this research was autonomy from the perspective of clients through restructuring care processes using an alternative work model "supporting self-directing" (OER) in long-term care. For the long-term care organization, it is important to know to what extent the OER-model affects the client's autonomy. If so, other long-term care organizations can implement this model too. Therefore, the overarching goal of this study is to identify to what extent the restructuring of care processes using the OER-model affects clients' autonomy compared to the usual model in long-term care.

To answer the research question, qualitative research was conducted. Interviews were conducted with thirteen clients to explore their perspectives regarding autonomy at two locations, one with the OER-model and the other without it. Six of them were men, and seven were women between the ages of 68 and 97 with physical problems. These clients were able to speak and lived for at least one year at Zorggroep Almere. The data was transcribed with Amberscript and coded with ATLAS.ti. Then the data was thematically analyzed.

From the responses to the interviews, the most crucial difference that emerged at the location with the OER-model was the encouragement of clients' self-reliance. This means that clients were stimulated to do as much as possible by themselves to remain independent for as long as possible.

Throughout this study, it was revealed that locations with the OER-model found the OER-model too complicated and time-consuming for their employees. This location made different choices to implement certain tools of the OER-model and omit others. They kept two of the five OER-model tools. The results mostly show the differences between the two locations and their policies rather than the differences in implementing the OER-model. The fact that a minor difference is visible between the two locations may also have to do with this. Due to this, the results of this study may not be reliable or representative of other locations and organizations using the OER-model. Therefore, one of the most important implications for further research is to compare a location without the OER-model with a location where the OER-model is completely implemented. Only then can a real conclusion be drawn about the influence of the OER-model on client autonomy.

Keywords

Autonomy, clients, perspective, influence, OER-model, long-term care organization, restructuring care process, implementation

Contents

1. Introduction

People worldwide are living longer. In 2025, the world population aged sixty and older will double to 2.1 billion [1]. The number of elderly people also increases rapidly in the Netherlands. According to the "Centraal Bureau voor de Statistiek" (CBS), the number of people aged sixty-five and older will increase to 3,22 million in 2040 [2]. That means these people need help when living at home is no longer possible. They should be able to count on diligent care in long-term care [3].

Unfortunately, this is hindered by the dependent position of the client and the traditional authoritarian position of healthcare personnel [4]. For clients in long-term care, it is difficult to be autonomous because one of the main goals of long-term care is to improve or prevent the deterioration of a client's physical functioning [5]. The relationship between personal autonomy and physical independence is at the heart of a paradox [5]. Personnel assumes that the more clients can take care of themselves, the more autonomous they are and the better off they are.
Clients' autonomy decreases as they have poorer health and a limited ability to make a choice [5]. Hofmann and Hahn's study [6] found that clients with low cognitive conditions and severe mobility impairments were at elevated risk of being physically restricted. Clients with previous broken bones due to falls and clients who were aggressive were also at elevated risk of being restricted. The purpose of this intervention was to protect the client. The effects of restraints harm the clients' physical and psychological well-being. Physical restraint is an important risk factor for more health problems [6]. Furthermore, the autonomy of clients in long-term care is sometimes ignored by caregivers, as information or decisions about goals in care are not always shared [7]. In addition, daily routine activities within long-term care can reduce clients' autonomy [7].

Different authors differently describe the definition of autonomy. According to Hedman et al. [7], the concept of autonomy consists of four aspects: self-determination, freedom, independence, and fulfilling wishes. Important aspects of autonomy for clients include the ability to make free choices based on their values [7]. Clients feel autonomous when personnel recognize them, receive support for their health and well-being when needed, and participate in decision-making [7]. However, Loon et al. [8] understand autonomy as making your own decisions about your life; care, support, individual freedom, and the ability to act deliberately are fundamental to autonomy. The active participation of clients contributes to their health, independence, and life satisfaction [8]. As reported by Moilanen et al. [9], those who were satisfied with their autonomy were also more active and satisfied with the activities that were provided by the long-term care facility where they lived.

The systematic review by Loon et al. [8] shows that it is important to know clients' life stories, which gives insight into what autonomy means to the client. These stories tell about clients' values, identities, and relationships. Encouraging and empowering clients can promote their autonomy. In addition, the coping mechanisms a client has developed throughout his life also play a role. The physical environment plays a key role too in promoting autonomy, as do home furnishings that give the client a sense of home [8]. On top of that, clients need to have a good combination of shared and private spaces that contribute to their autonomy. Long-term care organizations that actively involve clients in decisions regarding menu choices and social and physical activities promote their autonomy [8]. Psychosocial factors such as visits from family and friends also contribute positively to clients' autonomy [8].

According to McParland et al. [10], with the exercise of autonomy, clients have the right to privacy. There are two diverse types of privacy: one is information sharing about the client, and the second has to do with the physical aspects of the client. The responsibility

for ensuring client privacy lies with those involved with the client. They can set standards and develop policies that ensure clients' privacy. Personnel must accommodate the client's privacy, as this is also described in their professional code [10]. Moreover, the research by Stabell et al. [11] shows that for clients, it is important that personnel consistently approach them.

Personnel who are reflective, creative, and have less prejudice towards clients support the client's autonomy better [8]. They can create an environment where clients can express their wishes and caregivers allow them to make their own decisions [9]. Awareness of the vulnerability of clients and the importance of maintaining health and well-being are key issues in promoting autonomy [9]. In addition, it is important to respect the client's autonomy. Respecting the client's autonomy means respecting the client's views, choices, and lifestyle [12]. Respect for autonomy is important because clients should be able to make decisions about what care they want and do not want without any influence from others. What is important about respect for autonomy is that the client has the will, chooses voluntarily, and is well-informed about his situation and the advantages and disadvantages of the diverse options [12]. Clients need support for practicing their autonomy to fulfill their wishes and needs [7]. Personnel can support clients by involving them in activities of daily living, creating care plans by asking for their opinions, offering choices, and having conversations. This shared decision-making is important for the right to autonomy [8]. In short, when personnel and clients have a good relationship, clients' needs are better met. Respectful communication and caring for clients' appearances contribute to this [9].

Autonomy is also one of the themes in the Dutch quality framework for long-term care [13]. This framework describes what clients and their families can expect from long-term care organizations. The professional caregivers in these organizations work according to these standards, which are also called the "usual work model" [13]. This framework defines autonomy as the preservation of personal control over life and personal well-being, including in the last phase of life. According to this framework, the client can give form and content to his own life in both large and small parts of the day. Should a client no longer be able to exercise his autonomy, the informal caregiver, for example, a family member, is allowed to stand up for the client. Furthermore, this framework advises the personnel to stimulate the self-reliance of the clients. Subsequently, according to this framework, it is important to discuss the client's wishes regarding the end of life, and this is also known to the informal caregiver.

A potential negative consequence of autonomy is that clients in the terminal phase of their lives find it difficult to make autonomous choices. These clients often find themselves a burden to those around them. Due to this, their self-confidence declines, and clients feel they no longer matter. This hinders discussion of difficult topics, for example, active preparation for dying. They tend to leave this to others [14].

In the literature, there has been a lot of research on autonomy with another subject or a particular clinical picture. No research was found that was conducted solely from the client's perspective concerning autonomy in general in long-term care. Because of that, in this study, the perspective of clients will be examined regarding autonomy in long-term care. If the client's perspective is known, then care can be organized so that the client's wishes can be fulfilled.

Healthcare and especially long-term care are under pressure due to labor shortages, an aging population, and increasing demand for care. To keep care available, accessible, and affordable for everyone in the future, the Dutch government is encouraging healthcare organizations to organize their care differently and smarter. Healthcare organizations are looking for ways to realize this. The OER-model is one of the methods [15].

The Dutch Stichting Academische Verpleeg(t)huiszorg trains and advises long-term care organizations in an alternative work model. "Supporting self-directing" (OER) is developed by Verkooijen et al. [16] to allow people who are care dependent to live their own lives as much as possible within the limits of care delivery. OER is a model of continuing care, usually activities of daily life in long-term care. The OER-model consists of five tools: (1) a quick scan to examine the work processes of personnel; (2) an intake interview with clients in which wishes for the day can be asked; (3) a wish form where clients write their wishes; (4) consultation between clients and professional caregivers; and (5) care routes based on clients' wishes for the day and time [16; 17]. The OER-model was developed and implemented in almost seventy long-term care organizations in the Netherlands in 2006 [16]. However, only Woonzorg Flevoland and Zorggroep Almere started to work according to this model in a few locations in 2022. The other locations of these organizations are working according to the usual work model.

The aim of working according to the OER-model is to give clients autonomy. However, since the development of this model in 2006, there has not been a comparative study conducted by independent parties between a location where they work according to the OER-model and a location where they do not work according to this model from the perspective of clients. So, it is not known whether restructuring care processes with the OER-model promotes autonomy. For the long-term care organization, it is important to know to what extent the OER-model affects the client's autonomy. If so, other long-term care organizations can implement this model too. In this case, implementation refers to whether the OER-model is incorporated into day-to-day operations and/or results in an improvement [18]. Therefore, the overarching goal of this study is to identify to what extent the restructuring of care processes using the OER-model affects clients' autonomy compared to the usual model in long-term care. This goal is supported by the following research question:

"To what extent does the restructuring of care processes with the OER-model influence autonomy from the perspective of clients compared to the usual work model without OER at the long-term care organization?"

2. Research methodology

2.1 Setting

The setting of this study was Zorggroep Almere. This is a care organization that provides care both intramurally, at one of their residential care centers, and extramurally, at clients' homes. Elderly people live in the residential care centers of this organization [19]. Zorggroep Almere was a cooperation partner of the Dutch Stichting Academische Verpleeg(t)huiszorg; they worked with the OER-model at a few locations. However, their cooperation has been suspended since the end of April 2023. That means that Zorggroep Almere has stopped working according to the OER-model. The reason for this is that the organization found the model too complicated and time-consuming for their employees. The clients were not aware of this model because it affected the way employees worked. This location made different choices to implement certain tools of the OER-model and omit others. They kept two of the five OER-model tools: a quick scan to examine the work processes of personnel and the intake interview with clients, in which wishes for the day can be asked. The fact that this cooperation has been stopped does not mean that the quality of this model is poor.

The interviews took place at the location Castrovalva, where they were not working with the OER-model, and the location Archipel, where they were working with the OER-model. Location Archipel had started working with the OER-model by mid-2021, and this stopped at the end of April 2023. According to the developer of this model, fully integrating the OER-model takes at least two years. However, this process has not been achieved yet. During the interviews, they were still in the process of implementing this model, so the process was not yet complete. For this research, it may mean that the effect of the OER-model cannot be fully compared to the other location. Other differences were that these two locations were separate buildings [Figure 1] and thus were built and decorated differently. There were also differences in the apartments where the clients lived. For example, Archipel had large and small apartments, while Castrovalva's apartments were the same size. Another example was that location Castrovalva had short corridors, whereas location Archipel had long corridors. Different personnel worked there, and different clients lived there. This could affect the perception of autonomy.

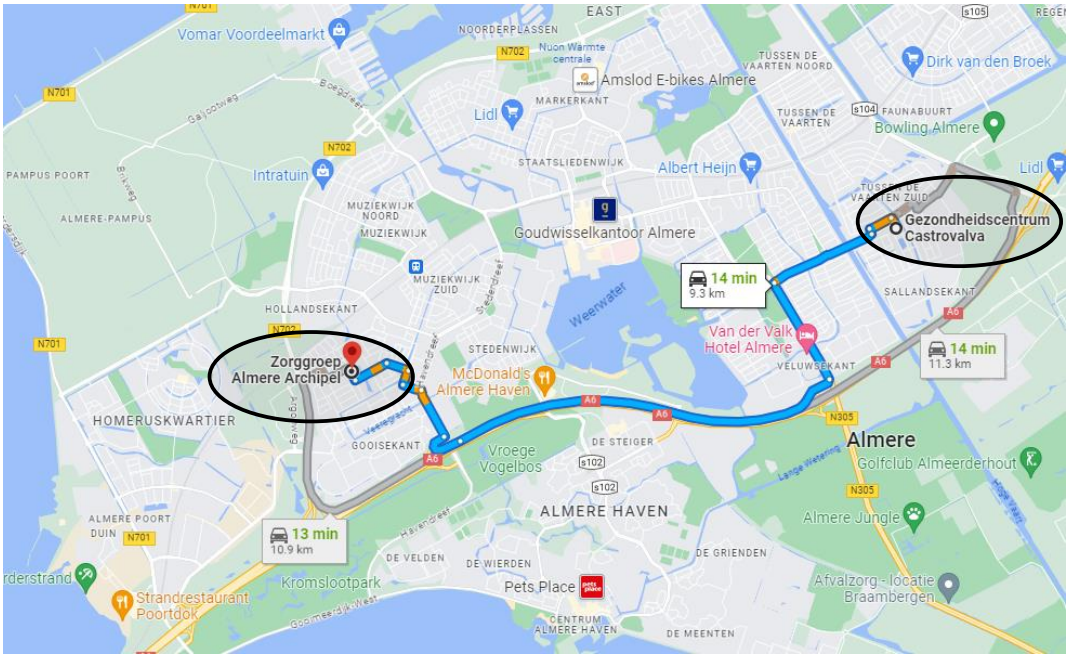

Figure 1: Zorgrgoep Almere location Archipel and Castrovalva [20]

2.2 Data collection method

In this research, a qualitative approach is used. Clients from two locations of Zorggroep Almere were interviewed, one with the OER-model and the other without. The purpose of the interviews was to explore the experiences of clients and to what extent the implementation of the OER-model influences their autonomy. The major advantage of interviews is that in-depth information can be gathered about the client's experience [21]. The aim was to continue conducting interviews until saturation was reached. This means that until no added information is obtained, initially, eight clients were approached per location, with the intention that if this were not enough, more clients would be requested to participate in this research. Clients who were able to speak, who had physical problems, and who lived for at least one year at Zorggroep Almere were included in this research. For the interviews, clients needed to be able to communicate clearly. In addition, it was not an issue that they had physical problems. Moreover, they needed to live there for at least a year. The reason is that within a year, they have experienced how the care is organized and what their perspective is on their autonomy. All clients who had any type of dementia or other cognitive problems, for example, mental disabilities, were excluded because their responses may not always be dependable [22].

For both locations, the inclusion and exclusion criteria were shared with the location manager and the head nurse because they had access to the client files. They tried to choose the clients as randomly as possible for this study within the criteria. After selection, the clients received an informed consent form (Appendix 7.1) to determine whether they wanted to participate in this research voluntarily or not. In this form, the researcher introduces herself and the research topic. Furthermore, the process of the interview and how the collected data was managed were explained. After the clients indicated that they wanted to participate voluntarily, the researcher received a list of the clients from the head nurse. During the interview, the researcher talked slowly and took breaks if needed.

The personal data of clients was anonymized, and the General Data Protection Regulations (GDPR) were applied. The data was not shared with third parties, and the data would not be used for other purposes [23]. Permission for interviews from the ethics committee of the University of Twente was sought. Before the start of the interview, the clients signed an informed consent form. Participants had the opportunity to withdraw at any time and without explanation [24].

2.3 Data analysis method

The interviews were conducted in person because the clients were not used to online meetings. The interviews were recorded digitally, and they were deleted after transcription. The transcription was done with the program Amberscript; if the recordings were of inferior quality, it was done manually. This was decided because some clients had talked unclearly, and the sentences on the transcript were illogical. The unintelligible language was corrected and breaks and other nonverbal communication were transcribed. The interviews from both locations were transcribed and coded separately to be able to compare the results afterward. The program ATLAS.ti is used for coding the interviews. A lot of data emerged from the interviews, and to structure this as well as possible, thematic analysis was chosen [25]. This way of analyzing offers much flexibility and allows the processing of large data sets by looking for themes. The process started with coding, whereby the selected text fragments got a code that described the content. The following step was to identify themes. Several codes were combined for one theme. The analysis was done carefully to identify common or overarching themes and ideas. After that, themes were compared with each other. if it did not accurately represent the data because some dates were not relevant enough or were infrequent. Then some themes were deleted or combined with other themes. The goal was to make the themes

more useful and precise. As a last step, the themes were given definitive names. In addition, differences between the locations with and without the OER-model were explored by looking for explicit quotes that demonstrate the differences. The process of coding is visible in the coding table [Appendix 7.3].

3. Results

3.1 General information about the respondents

In total, thirteen clients from Zorggroep Almere were interviewed. Six of them were men, and seven were women. The clients were between the ages of 68 and 97 with physical problems (Table 1). These clients were able to speak and lived for at least one year at Zorggroep Almere. At the location without the OER-model, eight clients were selected for this study, but only six were interviewed. One of the included clients was admitted to the hospital, and the other client proved to be hard of hearing. Consequently, these two clients were not interviewed. Two of the six clients were originally from Suriname, and the other four were Dutch. In contrast, at the location with the OER-model, eight Dutch clients were selected, but only seven were interviewed. One of the included clients was not available for the interview. After interviewing at each location, it was checked whether the moment of saturation had been reached. Since there was much repetition in the responses from the clients, no added information arose during the interviews, so it was decided not to schedule additional interviews.

General information about the respondents (n=13)							
Location without the OER-model				**Location with the OER-model**			
Client	**Age**	**Gender**	**Origin**	**Client**	**Age**	**Gender**	**Origin**
1	72	Female	Suriname	1	71	Male	Dutch
2	80	Female	Dutch	2	88	Female	Dutch
3	69	Female	Dutch	3	92	Female	Dutch
4	78	Male	Suriname	4	74	Male	Dutch
5	94	Female	Dutch	5	90	Male	Dutch
6	70	Male	Dutch	6	68	Male	Dutch
*	*	*	*	7	97	Male	Dutch
Total clients: 13							

Table 1: General information of the respondents

3.2 Themes

Four themes emerged from the data analysis: living conditions, care and personnel, mental well-being, and social support. Living conditions are about the living environment when it comes to the waiting list, sudden relocation, necessity, private and shared spaces, smaller living, and a sense of home. The second theme, care and personnel, is about long waits for care, concerns about the quality of care, tailored care, changing and rushing personnel, bonding, communication, and adapting to the situation. Mental well-being entails accepting the situation, being yourself, having freedom, and making your own decisions. The last theme: social support encompasses social contacts, commitment to family, meaningful activities, loneliness, leaving behind or losing a partner, and a few volunteers.

Since there were few differences between the two locations and many similarities, it was decided to describe the similarities as well. The reason is that there are points mentioned here that are important for the autonomy of the clients.

3.3. Similarities between the locations with and without the OER-model regarding autonomy

Under this heading, the similarities between the two locations regarding the OER-model and autonomy from the perspective of clients are described. The four themes described above will be further explained here. In Table 2, there is an overview of the similarities.

Living condition

After the general practitioner and/or family had concluded that a client had to relocate to a long-term care organization due to the necessity of physical deterioration, they were put on a waiting list. This was the case for eight of the thirteen clients. *"My family decided with the general practitioner that a long-term care organization is better for me due to the necessity of physical deterioration than staying at home." "They put me on a long waiting list." "It took a lot of effort to come and live here, but I am here because I belong here" [client 3, with the OER-model].* Some clients got a place within a month, and some had to wait a year or two. If a place became available, they had to relocate as soon as possible. The clients who were assigned a place within the same month experienced this as annoying because they barely had time to get used to the idea of relocation. This happened to two out of thirteen clients. In addition, they had no time to sort out their valuable items. *"I didn't expect that I could relocate so suddenly." "I had no time to sort out my valuable items, but my daughter did it for me" [client 1, without the OER-model].* It takes time to get used to the long-term care organization.
All clients previously had a big house or an apartment to live in, while here they only have a small apartment. *"In the beginning, I had to get used to being here." "I lived in a beautiful bungalow, and here I have a small apartment, and the other spaces I have to share with other clients" [client 6, without the OER-model].*
At both locations, all the clients had a private apartment with a kitchenette, bathroom, and toilet. Having their place contributed to their autonomy. There was the possibility of eating their meals together and performing activities in a shared space. Not every client made use of this opportunity. Some preferred to eat in their apartment or just one of the meals together. So here, they could make their own choice. All the clients who were interviewed decorated their apartments with their items, which gave them a sense of home. *"I feel at home here because I decorated my apartment with my items" [client 4, with the OER-model].*

Care and Personnel

One of the barriers that emerged at both locations was waiting too long for care. All clients find it incredibly frustrating when they must wait for care*. "When I am on the toilet, sometimes I have to wait an hour." "That is frustrating; I get a sore buttock." "When I say something about it, then they say they are busy" [client 2, with the OER-model].* At the same time, five out of thirteen clients were concerned about the quality of their care due to inexperienced personnel. One of these clients mentioned that his physical condition has declined because he has not received care according to the protocol, which is a barrier to autonomy. *"My health has deteriorated because personnel do not always follow the doctor's prescription" [client 1, with the OER-model].* All clients mentioned that it is frustrating for them that they depend on the care of personnel, especially when there is a continuous change of personnel and when they are rushed. *"It is every day a surprise who is coming; some personnel do not do their job with love, then we get different treatment." "They are, for example, less friendly and do not take their*

time for you" [client 4, without the OER-model]. As a result, this hinders clients' autonomy because they cannot influence the situation.
The autonomy of clients can be stimulated by giving care that is tailored. This means that clients receive care whenever they want it, and the care proceeds according to their wishes. Clients prefer the employment of permanent personnel because they can build a bond with them. Then, there is no need to retell their story and wishes. As a result, the client feels safe and secure, which contributes to their autonomy. Nonetheless, they realize that there is a shortage of personnel. All clients decided to look for alternatives to maintain their autonomy, which is a facilitator of autonomy. One of the clients decided to get up earlier. *"Ideally, I would like to be showered around 8:00–9:00 am, but it often happens that I am not helped until around 11:00 am." "That is frustrating, so I decided to get up at 6:00 am because I can get care right away." "In this way, I still try to tailor the care for myself" [client 3, without the OER-model]*. If a caregiver is late, all clients adapt to the situation if they know the reason for the delay.
"Some of the personnel communicate clearly when they are going to help someone else before me." "Usually, they have a good reason, so I don't mind waiting a bit longer" [client 2, with the OER-model]. Furthermore, six out of thirteen clients stated that they appreciate it when someone takes the time to strike up a conversation with them. As a result, the client feels heard and seen, which can contribute to their autonomy*. "I like it when personnel take time to have a chat with me; that makes me feel heard and seen." "Moreover, it is also good for our bond" [client 3, with the OER-model].* At both locations, clients mentioned that they get a quicker response to their alarm during the day compared to the night. They were content that they still get help and are getting used to waiting a bit longer for care during the night. This is a facilitator for their autonomy because they are adjusting their expectations.

Mental well-being

All clients believe that the feeling of being yourself and having freedom contribute to experiencing autonomy. One of these clients stated that he wanted to celebrate Christmas in his apartment with his family instead of with the other clients. He was glad that he had the freedom to do so. *"I have freedom: if I don't want to join the Christmas celebration, I can instead celebrate it in my apartment with my family." "That's okay too, and I am thankful that I can be myself here" [client 6 without the OER-model].* Five clients indicated that accepting their current situation contributes to their feeling of freedom. One of these clients said, *"I accepted my situation here, and I make my own decisions when I go somewhere; I book a taxi and I go." "Then I tell them I'm going and when I'm coming back" [client 5, with the OER-model].*

Social support

The barriers to autonomy when it comes to social support include not getting visitors, rarely getting visits, conflicts within the family, and few volunteers. Not all clients' family or friends live nearby, and not all clients have a good relationship with their family. In general, their friends are also old or have passed away. All clients have had to leave their partner behind, or their partner is deceased. *"Since my wife has passed away, I have nothing to do; she was my last responsibility." "I took care of her for a long time" [client 4, with the OER-model].* Finding their way again without their partner is sometimes difficult for them. *"The activities do not suit my needs." "I am not antisocial at all; I am in contact with a few fellow residents here, but I do not have much in common with the people here" [client 2, without the OER-model].* Nine out of thirteen clients indicated that there are fewer volunteers to do individual activities with them. One of these clients said the following: *"Since the COVID-19 period, there has been a shortage of volunteers here." "I miss that a lot" [client 1, with the OER-model].* Another client mentioned that she sometimes feels lonely. To distract herself, she regularly opens the door of her

apartment so she can have a chat with her neighbors. *"I usually leave the door open so I can chat with my neighbors and therefore feel less lonely" [client 2, with the OER-model].*
All clients believe that social support facilitators that contribute to their autonomy include social contacts, meaningful activities, and committed family and friends. One of these clients mentioned that for her, devoted family and friends are important. She is used to having regular visits*. "I am used to having regular visitors, and I need to have a committed family." "My door was and is always open to everyone" [client 1, without the OER-model].* Whereas for ten out of thirteen clients, getting an occasional visit from family or friends is enough. Clients from both locations expressed that they needed a meaningful daytime activity that suited their situation and wishes. *"I always go first to see if there is an activity that suits me or not." "Some days I participate in the activity and other days I do not" [client 7, with the OER-model].*

Notably, clients must get used to long-term care when they relocate here. For them, it is a big step because previously they had a big house or an apartment to live in, while here they only have a small apartment. Besides, it is frustrating for clients to wait for care, and every day it is a surprise who helps them.

Similarities between the locations WITH and WITHOUT the OER-model	
Themes	**Results**
Living condition	- Long waiting list - Sudden relocation - Necessity of physical deterioration - Private and shared spaces - Smaller living - Sense of home
Care and Personnel	- Long wait for care - Concerns about the quality of care - Tailored care - Changing and rushing personnel - Bonding with personnel - Clear communication - Adapting to the situation
Mental well-being	- Accepting the situation - Being yourself - Freedom - Making own decisions
Social support	- Few volunteers - leaving behind/losing a partner - Feeling of loneliness - Social contacts - Meaningful activities - Committed to family

Table 2: Similarities between the locations WITH and WITHOUT the OER-model

3.4 Differences between the locations with and without the OER-model regarding autonomy

Under this heading, the differences between the two locations regarding the OER-model and autonomy from the perspective of clients are described. In Table 3, there is an

overview of the differences. Differences were found in three themes: living conditions, care and personnel, and mental well-being.

Living condition

WITH the OER-model

The building where they worked according to the OER-model has long corridors, which in some cases hinder the client's autonomy. So, this is not a direct result of the OER-model. More explanation is given in the headings below. Moreover, personnel were less aware of the client's privacy at this location. They entered the apartment at any time; some of them did not knock on the door first. Due to this, all seven clients who are interviewed at this location do not always experience privacy and autonomy. One of these clients mentioned: *"I do not always experience privacy because some employees do not always knock on my door first, or if they do, they are already inside my apartment before I have answered" [client 2, with the OER-model].*

Without the OER-model

Locations where they did not work with the OER-model have short corridors; this was beneficial for clients because they did not have to walk long distances, for example, to go to the activity. In addition, at this location, personnel were more aware of the privacy of clients. Clients had a sign they could hang on their door if they had visitors or wanted to rest. One of the clients indicated, *"If I take a nap at noon or if I have visitors, I hang that sign on my door." "The personnel take that into account; they do not come to my apartment" [client 6, without the OER-model].*

Care and Personnel

WITH the OER-model

All clients at this location submit once a week their food choices for the whole week. One of these clients stated, *"Once a week we get to choose from the menu what we want to eat for the whole week, and we can choose from two dishes" [client 1, with the OER-model].*

The clients from this location experience this as a barrier to their autonomy; they would like to choose what to eat day by day. In addition, clients notice that the food gets cold before it is served due to the long corridor, which is also a barrier to their autonomy. This barrier has nothing to do with the OER-model but has to do with the building. One client said, *"The food is usually cold, especially if we have fries." "I suggested that one corridor get fries one day and the other corridor another day, but they did not follow my advice." "Nowadays, I sometimes prepare food for myself here." "I am lucky that I have a good condition to do that; some clients here cannot even get out of their bed" [transcription 4, with the OER-model].* All seven clients who were interviewed at this location had turned this barrier to autonomy into a facilitator of autonomy by purchasing a microwave for themselves.

Without the OER-model

At the location without the OER-model, clients can choose from a menu every day. All six clients who were interviewed experienced this as a facilitator of their autonomy. One of these clients stated, *"Every day they come by with the menu of what we want to eat." "We can choose from two dishes" [client 4, without the OER-model].* At the same time, Dutch food is more often offered, while foreign dishes are also appreciated by two out of six clients at this location. This is a barrier to the autonomy of these two clients, who enjoy eating foreign food. One of them indicated, *"I would like to eat more Surinamese dishes, but here they serve a lot of Dutch food." "So, there is less choice for me, but I am thankful that food is prepared for us" [client 1, without the OER-model].*

Mental well-being

WITH the OER-model

In contrast with the location without the OER-model, it was explicitly stated that self-reliance is highly encouraged. This means that clients were stimulated to do as much as possible by themselves to remain independent for as long as possible. On the one hand, this is something positive for their autonomy. On the other hand, five out of seven clients at this location stated that it has become a nuisance because they are no longer capable of doing everything on their own. As a result, it was a barrier to the client's autonomy because they had to ask for help every time; the personnel did not routinely offer it. An example is a lady who is in a wheelchair and cannot use one of her hands. She indicated that she is not always brought to or picked up for activities. When she goes by herself, she experiences pain in her "good hand" from pushing her wheelchair across the long corridors. *"It is good that they encourage our self-reliance, but sometimes it goes too far, I think." The corridor is long. I would like it if personnel could help me with bringing me to and picking me up from activities. I do not like to ask for help every time [client 2, with the OER-model].*

Differences between the two locations		
Themes	**Location with OER-model**	**Location without OER-model**
Living conditions	- Little privacy	- Aware of privacy
Care and Personnel	- Food often gets cold due to long corridor - Choice of food once a week for the whole week	- Less choice in foreign food - Choice of food day by day
Mental well-being	- Self-reliance - Often ask for help themselves	- Self-reliance not explicitly mentioned

Table 3: Differences between the two locations

Two notable differences were privacy and self-reliance. At the location without the OER-model, employees were more aware of privacy as opposed to the other location. The other difference was that at the location with the OER-model, self-reliance was highly encouraged, while at the location without the OER-model, self-reliance was not explicitly mentioned.

Figure 2 shows an overall view of the similarities and differences between the two locations.

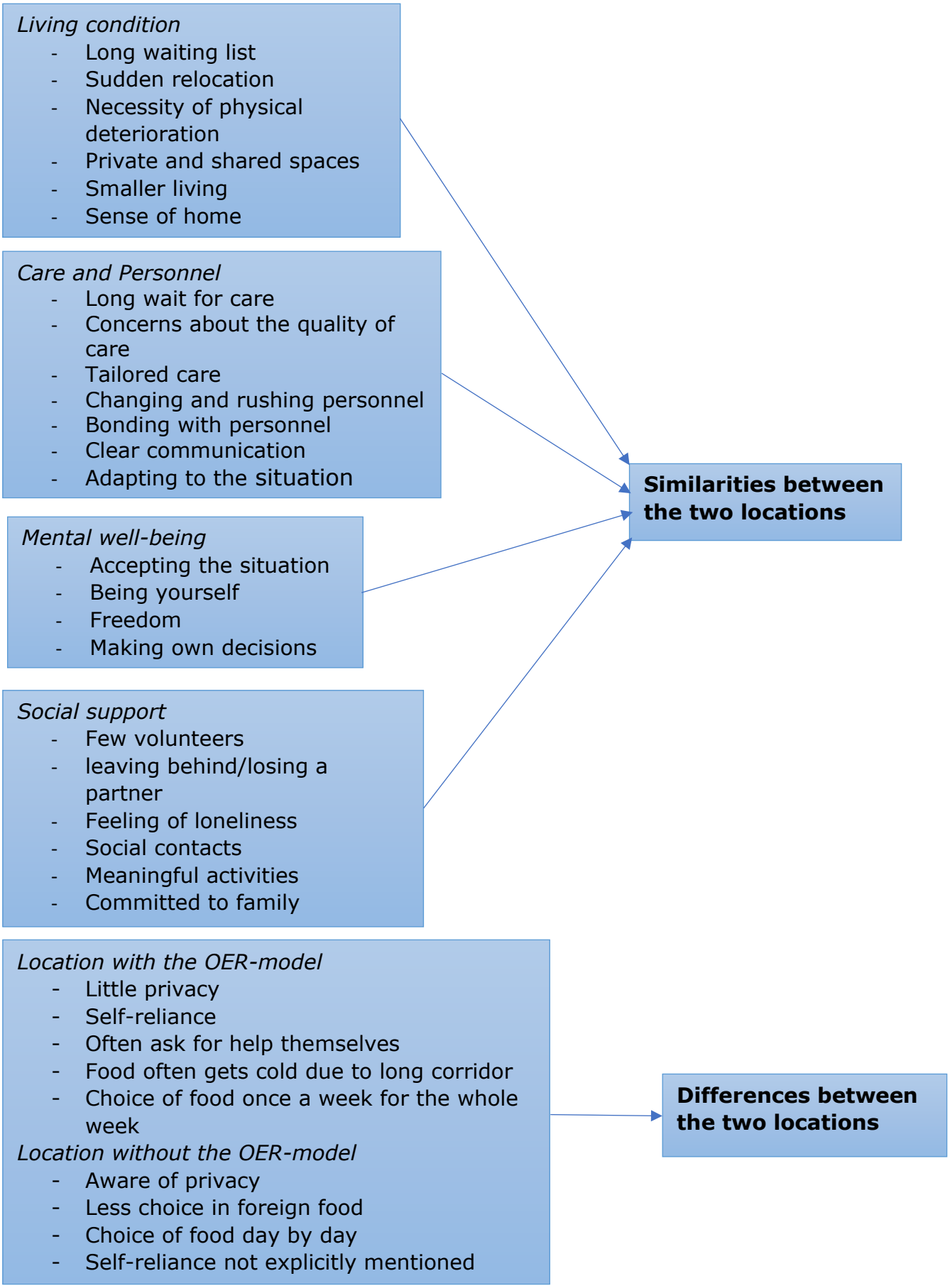

Figure 2: An overall view of similarities versus differences

4. Discussion

This research aimed to investigate if restructuring care processes using the OER-model affects clients' autonomy from the perspective of clients compared to the usual model in long-term care. The results of the interviews showed that the implementation of the OER-model has little influence on the autonomy of clients compared to the usual work model in long-term care. The notable differences in this research between the two locations were in terms of the self-reliance and privacy of clients.

At the location with the OER-model, it was explicitly stated that self-reliance is highly encouraged. This means that clients were stimulated to do as much as possible by themselves and to remain independent for as long as possible. On the one hand, this is an advantage for their autonomy. In long-term care, self-reliance is considered important. The idea behind this is that people can do more than they think. Therefore, personnel are asked to encourage clients more often to do as much as possible themselves [26]. The systematic review by Loon et al. [8] reflects that encouraging and empowering clients can promote their autonomy. When clients remain autonomous for as long as possible, it has a positive effect on their physical, mental, and social well-being [27]. On the other hand, self-reliance also has disadvantages. Five out of seven clients stated that it has become a nuisance because they are incapable of doing everything on their own. As a result, it was a barrier to the client's autonomy because they had to ask for help every time; the personnel did not routinely offer it. This caused these clients to be confronted with their limitations every time. The research by Stabell et al. [10] shows that for clients, it is important that personnel consistently approach them. This would mean that it would be better for the location with the OER-model to look at what clients need on a situation-by-situation, person-by-person basis and respond consistently to that. At the other location, encouraging self-reliance was not explicitly mentioned by clients during the interviews.

Another value that is considered in long-term care is privacy. The advantage of privacy is that, in principle, every client has the right to decide for themselves whom they want to meet and when. Privacy also allows people to protect and maintain their identities. Maintaining privacy becomes difficult when clients need care. Receiving care means allowing other people into clients' lives. That does not have to mean disturbing privacy any more than is strictly necessary. This requires the staff to be very conscious of the clients' privacy [28]. According to McParland et al. [9], personnel must accommodate the client's privacy, as this is also described in their professional code. At the location without the OER-model, personnel were more aware of the privacy of clients. Each client had a sign they could hang on their door if they had visitors or wanted to rest; this contributed to their autonomy. However, at the location with the OER-model, personnel were less aware of the client's privacy at any time they entered the apartment, and some of them did not knock on the door first. Due to this, clients do not always experience privacy and autonomy. This means that it is important for the location with the OER-model that personnel are conscious of handling clients' privacy.

Throughout this study, it was revealed that locations with the OER-model (Archipel) found the OER-model too complicated and time-consuming for their employees. The clients were not aware of this model because it affected the way employees worked. This location made different choices to implement certain tools of the OER-model and omit others. They kept two of the five OER-model tools: a quick scan to examine the work processes of personnel and the intake interview with clients, in which wishes for the day can be asked. Due to this, it is a question of whether this location can be called a location under the OER-model. The results mostly show the differences between the two locations and their policies rather than the differences in implementing the OER-model. The fact that a minor difference is visible between the two locations may also have to do with this.

Due to this, the results of this study may not be reliable or representative of other locations and organizations using the OER-model.

The main strength of this study is that the information was collected through interviews with the clients to explore their perspectives. By identifying what is important for clients regarding the improvement of their autonomy, long-term care organizations can adjust their work processes to meet the needs of the clients. The major advantage of interviews is that in-depth information can be gathered about the client's experience [21].

However, this study has its limitations as well. The main limitation, as mentioned earlier, is that the location with the OER-model (Archipel) chose to implement certain tools of the OER-model instead of the entire model. In addition, the locations with and without the OER-model were separate buildings. There were differences in the size of the apartments. The location without the OER-model had short corridors, and, in contrast, the location with the OER-model had long corridors. Due to long corridors, the food got cold before it was served. Moreover, different personnel worked there, and different clients lived there. This could all affect the perception of autonomy. Another limitation was that the clients were selected by the manager and head nurse of the locations based on the criteria established by the researcher. They tried to choose the clients as randomly as possible without using any sampling techniques. This was because the researcher did not have access to the client files. It is a question of to what extent this process was done randomly. Therefore, the clients who are interviewed may not be representative of the entire group. For example, at the location without the OER-model, a client was selected who turned out to be hard of hearing during the interview, so the researcher still decided to stop the interview because this client did not understand the questions. Another limitation is that data analysis has been conducted through thematic analysis. Thematic analysis is flexible but, at the same time, subjective [25]. It is based on the judgment of the researcher, and the results may not always be nuanced because researchers look for larger themes while ignoring certain codes [25]. What could also be a limitation of this study is that the data analysis is done by one researcher, which could negatively influence the reliability of the study.

One of the most important theoretical implications for further research is to compare a location without the OER-model with a location where the OER-model is completely implemented. Only then can a real conclusion be drawn about the influence of the OER-model on client autonomy. Another recommendation is to request access to clients' files so that the researcher can independently select clients by using sampling techniques like simple random sampling [29]. This gives all the clients at the location a chance to participate in the study if they meet the inclusion criteria. Besides, it would be better to do a mixed study to increase the reliability and validity of the research [30]. Applying this allows it to look from different directions, which contributes to the reliability and validity of the study. The quotes of clients are counted manually in this study. If a survey had been conducted, then it could be reliably and validly counted exactly how many clients made a quote.

An implication for practice is that the location with the OER-model might become more aware of their clients' privacy by, for example, hanging a sign on their door, like the location without the OER-model, which allows the clients to indicate if they want privacy. It is also recommended that personnel at this location knock on the door before entering the client's apartment. Respecting the client's autonomy means respecting the client's views, choices, and lifestyle [12]. Another implication for practice is that personnel at the location without the OER-model might encourage their clients' self-reliance more explicitly than at the location with the OER-model. This can be done by encouraging clients to do as much as possible themselves so that they remain self-reliant for as long

as possible, which in turn can contribute to their autonomy. At the same time, the advice for both locations is to encourage tailored self-reliance. This means looking at individual client situations. When a client is less able to perform certain actions himself, help should be offered.

5. Conclusion

To answer the main research question: "*To what extent does the restructuring of care processes with the OER-model influence autonomy from the perspective of clients compared to the usual work model without OER at the long-term care organization?"* two locations were compared with each other, one working with the OER-model (Archipel) and the other without the OER-model (Castrovalva).

The most crucial difference that emerged, to the extent that this location can be called an OER-model location, was the encouragement of clients' self-reliance. This means that clients were stimulated to do as much as possible by themselves to remain independent for as long as possible. On the one hand, this is something positive for their autonomy. On the other hand, for some clients, it has become a nuisance because they are incapable of doing everything on their own. As a result, it was a barrier to the client's autonomy because they had to ask for help every time; the personnel did not routinely offer it. Consequently, the advice is to encourage tailored self-reliance. This means looking at individual client situations. When a client is less able to perform certain actions himself, help should be offered.

Throughout this study, it was revealed that locations with the OER-model found the OER-model too complicated and time-consuming for their employees. The clients were not aware of this model because it affected the way employees worked. This location made different choices to implement certain tools of the OER-model and omit others. They kept two of the five OER-model tools: a quick scan to examine the work processes of personnel and the intake interview with clients, in which wishes for the day can be asked. The results mostly show the differences between the two locations and their policies rather than the differences in implementing the OER-model. The fact that a minor difference is visible between the two locations may also have to do with this.
Due to this, the results of this study may not be reliable or representative of other locations and organizations using the OER-model. Therefore, one of the most important implications for further research is to compare a location without the OER-model with a location where the OER-model is completely implemented. Only then can a real conclusion be drawn about the influence of the OER-model on client autonomy.

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7. Appendix

7.1 Informed consent

English version

Title of the research project

Autonomy of clients in long-term care

The goal of the research

You are a resident of Zorggroep Almere. The manager of the location Archipel/Castrovalva shared your information with the researcher. This research will be performed by Mahgul Hosseini, health sciences student at the University of Twente on behalf of Flever and Stichting Academische Verpleeg(t)huiszorg. I am working on my thesis, with the title "Autonomy of clients in long-term care. ` Autonomy means making your own decisions about your life, care, and support, among others. Having autonomy promotes health and quality of life. I would like to know to what extent you experience autonomy since you live at Zorggroep Almere. The duration of the interview is about 45 minutes. A list of questions related to autonomy is predefined before the interview. These questions will be discussed during the interview with you.

The interview

Before the interview, all participants will need to sign the informed consent form. During the interview, Mahgul Hosseini will ask you questions about autonomy. An example will be: "To what extent can you make your own choices in your daily life?" You will receive a summary of the main results of my research in case you are interested.

Potential risks and discomfort

There are no physical, juridical, or economic risks or discomfort attached to participation in this research. You do not have to answer questions you do not want to answer. Your participation is voluntary, and you can withdraw from participation at any moment. The only discomfort that might occur is that the interview will take some time and might be scheduled at a time when you want to go to an activity.

Reimbursement

For participating in this research, you will not receive a reimbursement.

Confidentiality

Your privacy is guaranteed. Personal information will not be made public, and the results of the interview will not be traceable to you. The research data will be anonymized and will only be shared with Stichting Academische Verpleeg(t)huiszorg, Flever, and the University of Twente.

Voluntariness

Participation in this research is voluntary. As a participant, you can withdraw from always participating. You can also refuse that your data will be used for the research project at any time, without stating an explanation. This means that you may refuse participation in the research beforehand, but you can also withdraw permission for usage of the data until at maximum five working days after participation (reflection period). This will not have any consequences for you. In this case, all your data will be deleted and destroyed. In case you want to stop your participation, after the reflection period. The data that was collected until that moment will be used in the research. But no new data will be collected or used.

In case you decide to stop participating in the research please contact the researcher. Or if you want to share your concerns or want to reveal some discomfort because of the research.

Contact details:
Mahgul Hosseini
m.hosseini@flever.nl

Statement of consent
By signing this form, you indicate that you have been informed about the research, the research method, the usage of data, and what risks or discomfort might be experienced by participating in this research.

In case you had any questions, you state by signing this form that all your questions had been answered clearly. And that you voluntarily participate in this research. You will receive a copy of this signed consent form if you want that.

I agree to participate in this research, directed by Mahgul Hosseini. The goal of this form is to capture the conditions of my participation. The questions below are to be answered by the participant. If you agree with what is mentioned, please write down 'YES' in the box behind the statement.

YES/NO

I received sufficient information about the research that will be directed by Mahgul Hosseini. The goal of my participation as an interviewee is clear to me.	
My participation in this research is voluntary. I do not feel any explicit or implicit pressure to participate in this research.	
My participation means that Mahgul Hosseini will interview me. The duration of this interview is about 45 minutes. I permit Mahgul Hosseini to record the interview and make notes. It is clear to me that I can stop participating in the research, whenever I want, without explaining. After transcription, the recording of the interview will be deleted.	
I have the right to not answer certain questions. If I feel awkward during the interview, I have the right to stop my participation in the interview.	
Mahgul Hosseini guaranteed me that I will not be identifiable in the data that will be released because of the research. My privacy is guaranteed.	
I have been guaranteed by Mahgul Hosseini that the research project is examined and approved by the ethical commission of the University of Twente.	
I have read and understood this form. All my questions have been answered and I voluntarily agree to participate in this research.	
I will receive a copy of this consent form, which is signed by interviewer Mahgul Hosseini.	

When interested in the results, you may contact Mahgul Hosseini. You may inform her right after the interview or until March 2022. At the end of the research period, she will send you a summary of the results if you are interested. After this period, you may inform Stichting Academische Verpleeg(t)huiszorg or Flever. Their e-mail addresses are: info@s-avn.nl and info@flever.nl

Signature and date

Name participant:	……...	Name researcher:	Mahgul Hosseini
Signature:	……...	Signature:	…….

Date: ……. Date: …….

Dutch version

Titel van het onderzoek

Autonomie van cliënten bij langdurige zorg

Het onderzoek

U bent een bewoner van Zorggroep Almere. De manager van de locatie Archipel/Castrovalva heeft uw gegevens met de onderzoeker gedeeld. Dit onderzoek wordt uitgevoerd door Mahgul Hosseini, student gezondheidswetenschappen aan de Universiteit Twente. In mijn onderzoek wil ik bekijken naar de autonomie van cliënten in de langdurige zorg. Autonomie betekent onder andere zelf beslissingen nemen over je leven; zorg en ondersteuning. Ik wil graag weten wat uw mening en ervaringen zijn wat betreft het hebben van autonomie sinds u bij Zorggroep Almere woont. De duur van het interview is ongeveer 45 minuten. De interviews worden in de week van 12 december afgenomen op de locatie waar u woont.

Het interview

Voor het interview vraag ik u om toestemming te geven door een formulier te ondertekenen. Tijdens het interview zal ik u vragen stellen over autonomie. Een voorbeeld: "In hoeverre kunt u uw eigen keuzes maken in uw dagelijks leven?" U krijgt een samenvatting van de belangrijkste resultaten van mijn onderzoek als u dat wilt.

Potentiële risico’s en ongemakken

Er zijn geen fysieke, juridische of economische risico's of ongemakken verbonden aan uw deelname aan dit onderzoek. U hoeft geen vragen te beantwoorden die u niet wilt beantwoorden. Het interview neemt wel tijd en zal waarschijnlijk tijdens een dagbestedingsactiviteit plaatsvinden.

Vergoeding

Voor deelname aan dit onderzoek ontvangt u geen vergoeding.

Vertrouwelijkheid

Uw privacy is gewaarborgd. Persoonlijke gegevens worden niet openbaar gemaakt en zijn niet tot u herleidbaar. Uw onderzoeksgegevens worden onbekend gemaakt en worden alleen gedeeld met Stichting Academische Verpleeg(t)huiszorg, Flever en Universiteit Twente.

Vrijwilligheid

Deelname aan dit onderzoek is geheel vrijwillig. U kunt op elk moment uw deelname stoppen. Het stoppen van toestemming tot verwerking van de informatie die u hebt gegeven, kan tot maximaal 5 werkdagen na deelname (bedenktijd). Als u de toestemming stopt voordat de 5 werkdagen verlopen zijn, dan zullen uw gegevens verwijderd worden. Als u de toestemming in wil trekken nadat de 5 werkdagen zijn verstreken, dan zal alle data die tot dat moment is verzameld gebruikt worden in het onderzoek.

Als u uw deelname aan het onderzoek wilt stoppen, neem dan alstublieft contact op met de onderzoeker. Neem ook contact op als u een vraag of klacht hebt, uw zorgen ten aanzien van het onderzoek wilt uitspreken; of enige vorm van ongemak ervaart naar aanleiding van het onderzoek. Haar contact gegevens zijn hieronder vermeld.

Contact gegevens:

Mahgul Hosseini, student en onderzoeker
m.hosseini@flever.nl

Toestemmingsverklaring

- Door dit formulier te ondertekenen, geeft u aan dat u goed geïnformeerd bent over het onderzoek, het gebruik en verwerken van de gegevens en welke risico’s of ongemakken mogelijk verbonden zijn aan dit onderzoek.

- Door dit formulier te ondertekenen geeft u aan dat al uw vragen zijn beantwoord en dat u vrijwillig deel wilt nemen aan dit onderzoek. U ontvangt een ondertekende kopie van dit formulier.
- Ik stem in met deelname aan dit onderzoek, uitgevoerd door onderzoeker Mahgul Hosseini.

Het doel van dit formulier is het vastleggen van de voorwaarden van uw deelname. De vragen hieronder zijn ter bevestiging van uw deelname. Als u het eens bent met de stelling en u bent op de hoogte van de gegeven informatie, geef dit dan weer met 'JA'.

	Ja/Nee
Ik heb voldoende informatie ontvangen over het onderzoek dat uitgevoerd wordt door onderzoeker Mahgul Hosseini. Het doel van deelname aan dit onderzoek is duidelijk.	
Mijn deelname aan het onderzoek is vrijwillig. Ik voel mij op geen enkele manier verplicht of geforceerd om aan dit onderzoek deel te nemen.	
Mijn deelname aan het onderzoek betekent dat ik geïnterviewd zal worden door Mahgul Hosseini. Het interview duurt ongeveer 45 minuten. Ik geef Mahgul Hosseini toestemming om het interview op te nemen (alleen geluid). Ik ben op de hoogte dat mijn geluidsopname na het uitwerken van het interview verwijderd wordt.	
Ik heb het recht om vragen niet te beantwoorden. Het is mij duidelijk dat ik op elk willekeurig moment mijn deelname kan stoppen, zonder opgaaf van reden.	
Ik ben op de hoogte dat de gegevens uit het onderzoek, niet herleidbaar zullen zijn naar mij. Mijn privacy is gewaarborgd.	
Ik heb dit formulier gelezen en begrepen. Al mijn vragen zijn beantwoord.	

Wanneer u geïnteresseerd bent in de resultaten, dan kunt u contact opnemen met Mahgul Hosseini (via m.hosseini@flever.nl). Dat kunt u direct na het interview aangeven, of uiterlijk tot maart 2023. Aan het einde van de onderzoeksperiode stuurt Mahgul Hosseini u een samenvatting van de resultaten als u dat wilt. Na deze periode kunt u Stichting Academische Verpleeg(t)huiszorg of Flever informeren. Hun e-mailadressen zijn: info@s-avn.nl en info@flever.nl

Handtekening en datum

Naam deelnemer:	…….	Naam onderzoeker:	Mahgul Hosseini
Handtekening:	…….	Handtekening:	…….
Datum:	…….	Datum:	…….

7.2 Interview scheme

English version

Name interviewer: Mahgul Hosseini
Name interviewee:
Date:
Place:

Recording the interview

Asking the interviewee for permission to record the interview. After the transcription of the interview, the recordings will be erased.

Introduction

I am Mahgul Hosseini, and I am a master's student of health sciences at the University of Twente. I am working on my thesis, with the title "Autonomy of clients in long-term care.' Autonomy means among others making your own decisions about your life, care, and support. Having autonomy promotes health and quality of life. I would like to know to what extent you experience autonomy since you live at Zorggroep Almere. The duration of the interview is about 45 minutes. Beforehand is a list with questions drawn up related to autonomy. These questions will be asked during the interview.

<u>Pre-defined questions</u>

- Gender (obvious)
- Age
- Place of birth
    - What do you understand by making your own decisions in your daily life?
    - What do you understand by making your own decisions about your care?
    - What do you understand by making your own decision about the support you get?
    - How are things organized here when it comes to shared and private space (for example do you have your room with a toilet)?
    - How do you feel about your current private space for example own room?
    - To what extent do residents help each other?
    - How do you feel about fellow residents helping each other with activities? How does it help you experience autonomy?
    - To what extent are you involved by caregivers in making shared decisions regarding your health?
    - To what extent are you involved by caregivers in making shared decisions regarding your daily activities?
        - ➔ Do you feel caregivers listen to your wishes? If not, why?
        - ➔ Do you feel that you are approached as an equal to caregivers while making decisions? If not, why?
    - To what extent are you encouraged by caregivers to make your own decisions in your daily life?
        - ➔ Do caregivers ask about your wishes on a daily/regular basis while providing care?
        - ➔ Do you feel you have control over your own life? If not, why?
    - To what extent are customized care and activities offered here?
        - ➔ Do you get the care and activities that suit you best?
    - How do you feel if the caregiver does not come at your desired time?
        - ➔ Are you involved in decision-making that concerns you? If yes, can u give a few examples?
        - ➔ If not, what decisions would you like to make yourself?
    - How do you experience the turnover of healthcare providers here?
    - ➔ Do you receive care from changing staff? If yes, how do you feel about that?
    - ➔ Are you informed in advance when another carer comes to help you? If not, what do you think about that?
    - ➔ Does the care fit your situation? If not, what should change?

Additional questions:

- What do you think should be changed to improve your autonomy?
- Are there other factors determining your view of autonomy that have not been mentioned?

<u>Closing note</u>

Thanking the clients for their participation.

Dutch version

Naam interviewer: Mahgul Hosseini
Naam geïnterviewde:
Datum:
Plaats:

Opnemen van het interview
De geïnterviewde toestemming vragen om het interview op te nemen. Na het transcriberen van het interview wordt het geluid gewist.
Inleiding
Ik ben Mahgul Hosseini en ik ben bezig met mijn master gezondheidswetenschappen aan de universiteit Twente. In mijn onderzoek wil ik bekijken naar de autonomie van cliënten in de langdurige zorg. Autonomie betekent onder andere zelf beslissingen nemen over je leven; zorg en ondersteuning. Ik wil graag weten wat uw mening en ervaringen zijn wat betreft het hebben van autonomie sinds u bij Zorggroep Almere woont. De duur van het interview is ongeveer 45 minuten.

Vooraf vastgestelde vragen

- Geslacht (duidelijk)
- Leeftijd
- Geboorteplaats
    - Wat verstaat u onder het nemen van eigen beslissingen in uw dagelijks leven?
    - Wat verstaat u onder het nemen van eigen beslissingen als het gaat om zorg krijgen?
    - Wat verstaat u onder het nemen van eigen beslissingen als het gaat om ondersteuning krijgen?
    - Hoe is het hier geregeld als het gaat om gedeelde en privéruimte (voorbeeld: heeft u een eigen kamer met toilet)?
        - ➔ Wat vindt u van uw huidige privéruimte?
    - In welke mate helpen bewoners elkaar?
        - ➔ Wat vindt u ervan als medebewoners elkaar helpen bij activiteiten? Hoe helpt het jullie bij het ervaren van autonomie?
    - In welke mate wordt u door zorgverleners betrokken bij het nemen van gezamenlijke beslissingen wat betreft uw gezondheid?
    - In welke mate wordt u door zorgverleners betrokken bij het nemen van gezamenlijke beslissingen wat betreft uw dagelijkse activiteiten?
    - Heeft u het gevoel dat zorgverleners naar uw wensen luisteren? Als niet, waarom?
        - ➔ Hebt u het gevoel dat u als gelijke wordt benaderd ten opzichte van de zorgverleners tijdens het nemen van beslissingen? Als niet, waarom?
    - In hoeverre wordt u door zorgverleners gestimuleerd om zelf beslissingen te nemen in uw dagelijks leven?
        - ➔ Vragen zorgverleners dagelijks/regelmatig naar uw wensen tijdens het verlenen van zorg?
        - ➔ Heeft u het gevoel dat u controle heeft over uw eigen leven? Als niet, waarom?
    - In hoeverre worden hier zorg en activiteiten op maat aangeboden?
        - ➔ Krijgt u de zorg en activiteiten die het beste bij u passen?
        - ➔ Wat vindt u ervan als de zorgverlener niet op uw gewenste moment komt?

- Wordt u betrokken bij de besluitvorming die over u gaat? Zo ja, waar blijkt dit uit? Zo niet, wat vindt u daarvan?
  - ➔ Zo niet, welke beslissingen zou u zelf willen nemen?
- Hoe ervaart u het verloop van zorgverleners hier?
  - ➔ Krijgt u zorg van wisselend personeel? Zo ja, wat vindt u daarvan?
  - ➔ Wordt u vooraf geïnformeerd wanneer een andere verzorger u komt helpen? Zo niet, wat vindt u daarvan?
  - ➔ Past de zorg bij uw situatie? Zo niet, wat moet er veranderen?

Aanvullende vragen:

- Wat vindt u dat er veranderd moet worden om uw autonomie te verbeteren?
- Zijn er andere factoren die uw kijk op autonomie bepalen die niet zijn genoemd?

Slotnota

De deelnemers bedanken voor hun deelname.

7.3 Coding table

Transcript	Codes	Themes
*"My family decided with the general practitioner that a long-term care organization is better for me due to the **necessity of physical deterioration** than staying at home." "They put me on **a long waiting list**."* *"I didn't expect that I could **relocate so suddenly**." "I had no time to sort out my valuable items, but my daughter did it for me."* *"In the beginning, I had to get used to being here." "I lived in a beautiful bungalow, and here I have a **small apartment**, and the other **spaces I have to share** with other clients."* *"**I feel at home** here because I decorated my apartment with my items."* *"I do **not always experience privacy** because some employees do not always knock on my door first, or if they do, they are already inside my apartment before I have answered."* *"If I take a nap at noon or if I have visitors, I hang **that sign on my door.**" "The personnel take that into account; they do not come to my apartment."*	- Waiting list - Relocation - Necessity - Private and shared spaces - Smaller living - Sense of home - Privacy	Living condition
*"When I am on the toilet, sometimes I have to **wait an hour**." "That is frustrating; I get a sore buttock." "When I say something about it, then they say they are busy."*	- Long wait for care - Concerns about the quality of care - Tailored care - Changing and rushing personnel - Bonding	Care and personnel

*"My health has deteriorated because personnel do **not always follow the doctor's prescription**."* *"It is **every day a surprise who is coming**; some personnel do not do their job with love, then we get different treatment." "They are, for example, less friendly and **do not take their time** for you."* *"Ideally, I would like to be showered around 8:00–9:00 am, but it often happens that I am not helped until around 11:00 am."* *"That is frustrating, so I decided to get up at 6:00 am because I can get care right away." "In this way, I still try to **tailor the care for myself**."* *"Some of the personnel **communicate clearly** when they are going to help someone else before me." "Usually, they have a good reason, so **I don't mind waiting a bit longer**."* *"I like it **when personnel take time to have a chat with me; that makes me feel heard and seen."** "Moreover, it is also good for our bond."* *"Once a week we get to **choose from the menu** what we want to eat for the whole week, and we can choose from two dishes."* *"The **food is usually cold**, especially if we have fries." "I suggested that one corridor get fries one day and the other corridor another day, but they did not follow my advice." "Nowadays, I sometimes prepare food for myself here." "I am lucky that I have a good condition to do that; some clients here cannot even get out of their bed."*	- Communication - Adapting to the situation - Food	
*"I have **freedom**: if I don't want to join the Christmas celebration, I can instead celebrate it in my apartment with my family." "That's okay too, and I am thankful that I **can be myself here**."* *"**I accepted my situation** here, and **I make my own decisions** when I go somewhere; I book a taxi and I go." "Then I tell them I'm going and when I'm coming back."*	- Accepting the situation - Being yourself - Freedom - Making own decisions - Self-reliance - Often ask for help themselves	Mental well-being

"It is good that they encourage our self-reliance, but sometimes it goes too far, I think." The corridor is long. I would like it if personnel could help me with bringing me to and picking me up from activities. I do not like to ask for help every time."		
*"Since **my wife has passed away**, **I have nothing to do**; she was my last responsibility." "I took care of her for a long time."* *"The **activities do not suit my needs**." "I am not antisocial at all; I am in contact with a few fellow residents here, but I do not have much in common with the people here."* *"Since the COVID-19 period, there has been a **shortage of volunteers** here." "I miss that a lot."* *"I usually leave the door open so I can chat with my neighbors and therefore **feel** less **lonely**."* *"I am **used to having regular visitors**, and I need to have a **committed family**." "My door was and is always open to everyone."* *"I always go first to see if there **is an activity that suits me or not."** "Some days I participate in the activity and other days I do not."*	- Few volunteers - leaving behind/losing a partner - Loneliness - Social contacts - Meaningful activities - Committed to family	Social support