Reflection on giving meaning to Integral Quality of life

"The face of the other is a revelation"

- Emmanuel Levinas

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University
Erasmus University Rotterdam

Department
Erasmus School of Health, Policy and Management

Study
Master Health Care Management

Name
Anna Merijne Hazenoot-Hoorn

Student number
578703

Tutor
Dr. Pleuntje van Meer

Reading committee
Dr. Marleen de Mul

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Organization
Zinzia Zorggroep

Mentor by Zinzia
Drs. Linda Myszka-Jansen

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"The face of the other is a revelation, not an object among other objects. The face of the other is a command that opens my consciousness to conscience: I am responsible for the other from the start, whether I want it or not. This is a unique personal experience, so personal in fact that I cannot say that the other is just as responsible for me as I am for him: I am more responsible for the other than the other for me. (…) My bread is a material thing, but the bread that the other needs is my highest spirituality."

Immanuel Levinas (Ten Kate & Poorthuis, 2018)

Abbreviations

AR	Action Research
hcp(s)	Healthcare professional(s)
HRQoL	Health-Related-Quality-of-Life
IQL	Integral Quality of Life
PG-resident	Psychogeriatric Resident (dementia)
WHO	World Health Organization
Zinzia	Zinzia Zorggroep

Preface

The only way to give real attention to my feelings, thoughts and emotions, and therefore to the needs of others, is by deciding to have focus; by eliminating all other stimuli, by making time to 'let my thoughts be' instead of 'keep running'. Only then, when there is 'room' in my mind to pay real attention, I can connect with the world around me and understand my *emotionally driven logic.* I want to see that our world has much more to offer than our post-modern society makes us believe. Giving real attention to the most important stimuli will make it possible to hear the things that are not said and see the things that are hidden away. This will make it possible to connect on a higher level with the people around me, with the people I talk to, and with the people I love. Through which I hopefully see what is needed and which role I can play in this. That's one of the most important lessons life has taught me and which I tried to express during this research. I want to live life in full connection with the people I meet, by focusing on well-being, meaning, and justice.

My experiences of feeling lonely during illness[1], not because there is no one there, but because it is a personal battle, inspired me to contribute to the resilience of people who are in need of help because of their vulnerability and lack of autonomy. To give them a voice, so that they feel seen and supported in a battle that will always be lonely. This battle is only because uniqueness holds a form of sadness within the fact that we can never truly understand each other. However, on the other hand, because of that uniqueness, we can bind our perceptions of the world together, through which we get a better picture of reality than an individual will ever have. With this research, I hopefully contribute to that process of awareness.

Besides, I want to give a voice to people who try to give meaning to an Integral Quality of Life experience of someone who is in need, despite all things that are not fixable anymore. I want to tell a story of dedicated compassion because most things that are told in public hold tragedy and sadness. Even though the world is broken, there are stories worth telling about the love people have for each other.

I have already worked 1.5 year at the Nursing Home Zinzia. First as Healthcare Technology employee, but now as Quality and Innovation Advisor. In addition, I did this research at Zinzia for my thesis of the Master Health Care Management at Erasmus University Rotterdam. During this research process, I was supported by my husband. I want to thank him for that. He listened to me every time I had to organize my thought about the research process. He supported me when there was a moment of desperation because of my dyslexia, and he gave great tips about how I could design all the figures. I want to thank my mother, who helped me transcribe the interviews. Besides, I want to thank Pleuntje van Meer, who give me feedback by asking questions about my thinking process. This helped me a lot to deepen the things I wrote. I want to thank Linda Myszka-Jansen. I could talk with her about the research process and the decisions I made about the topic and the method, which made it better possible to connect the research with Zinzia Zorggroep. At last, I want to thank the Board of Directors and the management of Zinzia Zorggroep and all the healthcare professionals who were involved in this research. Thanks for your contribution.

[1] Appendix 1

Summary

Introduction: A Psychogeriatric resident at Zinzia Zorggroep is dependent on the help of the healthcare professionals for the experiences of Integral Quality of Life (IQL). For PG-residents, the role of the hcp is to interpret their needs in order to give meaning to IQL. However, it cannot be prevented that the actions of the healthcare professionals are influenced by their perception of what IQL must look like. Zinzia states that healthcare professionals struggle with this complexity, while they want to learn through openness in *Reflexive spaces.* Literature does calculate IQL quantitatively. However, that is not usable to understand how healthcare professionals give meaning to IQL through their perceptions and actions. Therefore, this topic was investigated qualitatively through the skill of reflexivity, with the question: "*How do healthcare professionals who work for Zinzia, give meaning (through perception and action) to Integral Quality of Life of psychogeriatric residents, how do they reflect on this and what can these healthcare professionals and the policymakers of Zinzia learn from this research and what does reflexivity teach me"?* **Theoretical Framework:** The *care ethics* discourse gives insights into how healthcare professionals influence the process of 'giving meaning to IQL' because this discourse sees the resident, not as a patient with only biomedical needs. Besides, *positive health* gives insights. This re-conceptualization of health looks at health more integrally by considering social, physical, and psychological components of life. Healthcare professionals reflect on this in *Reflexive spaces.* **Method:** In this research, an Action Research approach was followed, in which the researcher has involved herself while trying to make connections with the persons studied and theorizing practice. This can be divided into first person- and second person Actions Research. Data were collected through interviews, observations, and journaling. **Results:** Healthcare professionals give meaning to IQL by involving the whole system around the resident. Teamwork is important because by using different perceptions about the resident's situation, they get a better understanding of what someone needs. They reflect on their contribution, the team, and the whole care process, in both formal- and informal settings. **Discussion:** Not every healthcare professional is aware of his/her influence on the care process. Therefore, training reflexivity among healthcare professionals is essential. Besides, I had a personal interest in this research, which could have resulted in an 'overconfidence barrier', or in a deeper investigation. **Conclusion:** Healthcare professionals have an eye for individual needs. They reflect on the question 'what is good care?' within *Reflexive spaces.* In this, the skill of reflexivity is essential to give meaning to IQL. Reflexivity gave insights into how I influenced the research process and how healthcare professionals influence the care process.

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Chapter 1 Introduction

This Chapter holds the background of the research (1.1) and explains Zinzia Zorggroep's role (1.2). Besides, the academic- and social relevance are described (1.3&1.4), whereafter the objective of the research is explained (1.5).

1.1 Background

During the1.5 year I have worked at Zinzia Zorggroep (Zinzia), a four-location nursing home in Gelderland, I have seen differences in how hcps give meaning to Integral Quality of Life (IQL). These differences depend on their perceptions and actions regarding the care process, and on the difference in needs of psychogeriatric (PG) (dementia) residents and somatic residents. Instead of most of the somatic residents, PG-residents can hardly tell if they experience IQL. The healthcare professional's role (hcp) asks for different approaches for this target group. For PG-residents, the role of the hcp is to interpret their needs through observation to give meaning to their IQL experience. However, it cannot be prevented that the actions that follow from these observations are influenced by their perception of what IQL must look. They frame IQL in a certain way (Ruijters, et al., 2015) because IQL is a Social Construct (Barry & Yuill, 2016). So, here is a complex relationship between the needs of the PG-resident and the perceptions and actions of the hcp in the care process towards IQL. *Care ethics* is a philosophical discourse that acknowledges this complexity by focusing on the question 'how to give good care with the needs of the person as the starting point?', realizing that the care receiver is vulnerable and has a lack of autonomy because of their need for help (Tronto, 1993). In this, the person is not seen as a patient but as a unique human. Besides, a suitable treatment is not the only factor regarding good care, like a biomedical discourse approaches (Barry & Yuill, 2016). In fact, 'health' is a personal experience, something *positive health* emphasizes (Huber, et al., 2011). In this, the interaction between caregiver and the care receiver is also determinative. However, one must remain alert to the risk of abuse towards the vulnerability of the care receiver (Tronto, 1993).

Zinzia states that hcps struggle with this complexity while they want to learn through reflection. Therefore, I was asked to reflect on this topic. In this, I want to 'give a voice' to the hcps because they deal with complexity. A *care ethics* discourse and *positive health* could help with this because it gives insights into how a hcp influences the process of 'giving meaning to IQL'.

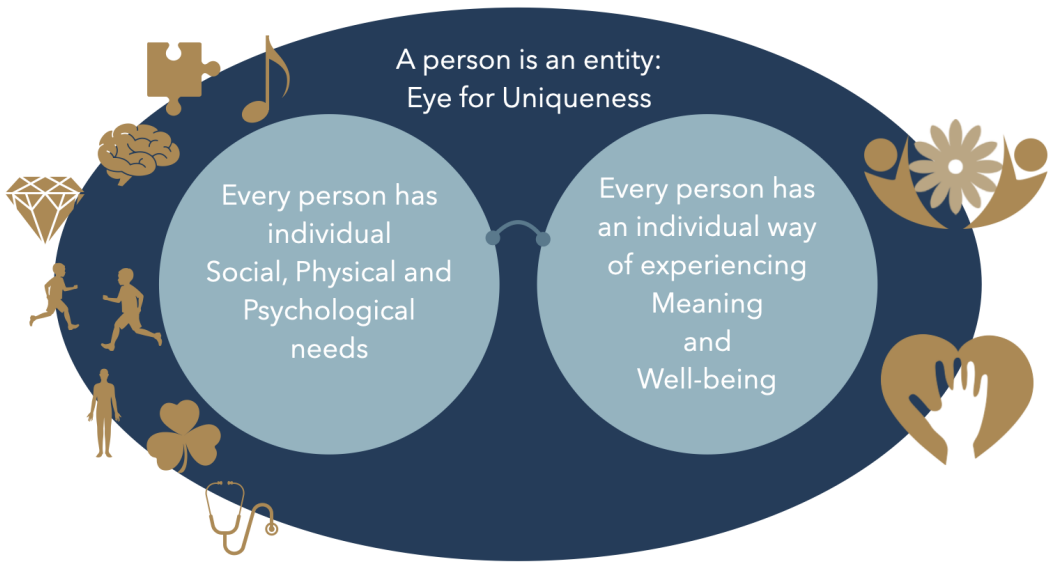
1.2 Zinzia Zorggroep

Zinzia is an example of a nursing home that wants to see 'the needs of a person'. They strive for Integral Quality of Life (IQL) for PG-residents who are insufficiently capable of self-reliance or participation and therefore require intensive care on daily live activities (Van der Ham, Den Draak, Mensink Schyns & Van den Berg, 2018; Zinzia Zorggroep, 2021). Perhaps

because of this focus on intensive care, Zinzia states that a biomedical discourse, in which there is much focus on someone's physical state (Barry & Yuill, 2016), is a common perception among hcps. For example, giving medication preventively with side effects is normal in the last phase of life. However, only focusing on treatment could neglect other personal needs and experiences towards IQL.

Integral means 'comprehensive', 'nothing is missing' (Encyclo.nl, 2021). IQL means 'there is nothing neglected to reach quality of life'. The perception of Zinzia towards IQL is based on their 'perception on human'; how should we look at humanity, disease, and disability? The answer to this question, according to Zinzia, is in line with the *care ethics* discourse. Instead of focusing on universal principles of 'good care' for all people, Zinzia wants to have an eye for individual needs, which relates to *positive health*. In their Mission, (care) Vision and Strategy document, they describe that a person is a unique entity in which the body and mind are interrelated. Every individual has his own social, physical, and psychological needs and his/her way of experience meaning and well-being in life (Zinzia Zorggroep, 2021) (figure 1). IQL came to fruition through roughly three factors mentioned during an interview with the Director: personal passion, organizational- and societal (historical) developments. Background on this can be found in appendix 3. The societal developmental factors are deepened in the theoretical framework.

Figure 1: Zinzia's 'perception of human' *(self-made based on interview and document study)*



Zinzia does see people as 'an entity'. Everything in their life is interrelated. Because people are born differently and had have different experiences in life which lead to different needs on social, physical and psychological level, it is important to have eye for this uniqueness or individuality. Also, because of this uniqueness, individuals have their own way of experience meaning and well-being.

So, an IQL experience by the PG-resident is not universal for all the PG-residents. It will be reached when there is an eye for individual- needs and experiences. Then hcps give meaning

to IQL. So, according to Zinzia, not only are biomedical matters important when giving meaning to IQL, it results from different services, and activities, which lead to different IQL experiences for everyone (Zinzia Zorggroep, 2021).

> *'Eating and drinking are not only about getting the right nutrients, but it is also a moment of experience in which the senses are stimulated, and someone is conscious about life. (…) In this, we must always look for a connection with the person: what suits him or her? What does someone need? Through this, we could add well-being and meaning' (Zinzia Zorggroep, 2021).*

These different services, and activities are addressed in the basic attitudes of Zinzia: *hospitality*, *presence,* and *openness* for the residents, guests, and employees. Further background can be found in appendix 2. Here I want to address *openness*. *Openness* is crucial for Zinzia. Through this, they stimulate learning with and from each other, improving the quality of care. Being reflective as an individual hcp or with a team or discipline plays an essential role in this. Therefore, Zinzia stimulates conversation constantly to stimulate learning through reflection. This could be explained through the concept *of Reflexive spaces* (Wiig, Aase & Bal, 2019): 'physical or virtual platforms in which reflexive dialogical practice occurs between people' (p.2). Because Zinzia mentioned that hcps are struggling with the complexity of the care process (1.1), I wonder how they reflect on this within the *Reflexive spaces* there are.

1.3 Academic relevance

Although Zinzia sees IQL not only as a need for good treatment, literature does. It focuses mainly on the biomedical discourse. If quality of life is mentioned, this is always related to a qualitative 'health'-rating: health related quality of life (HRQoL), to value the impact of care (Banerjee, 2007; Nijsten, Leontjevas, Smalbrugge, Koopmans & Gerritsen, 2018). HRQoL has biomedical purposes, because social and psychological domains of life are neglected (Derkx, 2003) and the personal needs and experiences are not considered. Besides, from research of Nijsten, et al. (2018) it appears that there could be a difference between their HRQoL experiences according to the PG-residence and how hcps define this for the PG-residence. However, the researchers did not acknowledge the fact that they could not know how the PG-resident feels. Instead, they justify the difference in results by explaining them from a biomedical perspective: 'these differences would be caused by the memory problems and problems in self-awareness and executive functioning' (p. 755) of the PG-residents. This emphasized that not everyone is aware of the power tension between caregiver and care receiver. *Care ethics* pays attention to this tension (Tronto, 1993). I conclude that HRQoL measurements are not usable to understand how hcps at Zinzia give meaning to IQL, even though PG-residents' quality of life depends on the support of the hcps (Custers, Westerhof, Kuin, Gerritsen & Riksen-Walraven, 2012). Therefore, in this research a qualitative method is

used. To my knowledge, less research is done towards an (I)QL experience and the complexity of the care process, in a more narrative way. That is what this research aims too.

The two theoretical discourses mentioned could help with this. *Care ethics* (Tronto, 1993) and a new perception on 'health'; *positive health* (Huber, et al., 2011). In this Huber, et al. (2011) re-conceptualize the biomedical discourse on health to a more integral discourse by considering social, physical, and psychological components of health. However, even though positive health has the potency to help understand the needs of PG-residents in an early state (IPH, 2018), it is nevertheless difficult to interpret the needs (Nijsten, et al., 2018; Vilans, 2021a; Vilans, 2021b) of PG-residents in a severe state. That is why *care ethics* emphasized the importance of the role of the hcp in interaction with the PG-resident. However, I have not found any existing research in the EUR library or on Google.scholar about the contribution that *care ethics* and *positive health* could make to each other. I only found one existing research in which those two discourses were mentioned (Zorgethiek.nu, 2016). Despite, this research did not bring these two discourses in discussion or contribution, while this could be relevant to the stated problem.

1.4 Societal relevance

This research is not only relevant for Zinzia, but for other nursing homes in The Netherlands as well. 'Every nursing home has the same task in essence' (Director – Zinzia Zorggroep – Personal communication, February 24, 2021). They ask themselves the question, 'how to give good care?' However, not only is this relevant for long-term elderly care, but this could also give insights in the care process of other chronic (progressive) diseases, like the one I experience myself (appendix 1).

Besides, the connection between *care ethics* and *positive health* has, to my knowledge, never been made before. Especially not in relation with *Reflexive spaces.*

1.5 Objective

Because of all mentioned above, via Action Research, while doing interviews and observations, I will describe the social construction of IQL by hcps. This involves both perception and actions (Barry & Yuill, 2016). Besides, I investigate how they reflect on this. Further, through reflexivity (Costley & Fulton, 2019) I will reflect on the complex interaction between the hcps and the PG-resident. This I will do through journaling and with *care ethics* and *positive health* principles as starting point while making new connections between them. I aim to connect logic and emotion via narrative writing. I want to tell a story academically by focusing on the interaction between 'mind' and 'heart'. I call this *Emotionally driven logic* (appendix 4). Besides, I want to learn from this study myself.

Hcps are operationalized as Physicians, Physician Assistants, Quality Nurses, Physiotherapists, Occupational Therapists, Ergo therapists, Speech Therapists, Dieticians, Psychologists, and Spiritual Caregivers. Almost all of them are professionals who deal with treatment. They are deemed to give practical meaning to IQL. Quality Nurses, Spiritual Caregivers, and Psychologists do not give treatment, but their perceptions of 'giving meaning to IQL' could be interesting. Nurses and daily life caregivers are not included in this research as active actors because they have a different role concerning the residents from the mentioned hcps. The caregivers are involved in the daily life activities, whereas the mentioned hcps focus on treatment. This emphasizes the differences between 'living, guidance & support' and 'care & treatment' (Zinzia Zorggroep, 2020). There is much interaction between both types, which is covered in this research. Besides, this is also a practical decision; there are many more nurses and daily life caregivers than other hcps at Zinzia Zorggroep, which includes only mentioned hcps more representative.
This research focuses on how Hcps give meaning to IQL of PG-residents. These are psychogeriatric residents with a form of dementia[2].

This leads to the following research question: **"*How do healthcare professionals who work for Zinzia, give meaning (through perception and action) to Integral Quality of Life of psychogeriatric residents, how do they reflect on this, and what can these healthcare professionals and the policymakers of Zinzia learn from this research and what does reflexivity teach me"?***

This leads to the following sub-questions, which can be divided into reflection and reflexivity questions:

Reflection

1. Want kind of perception do healthcare professionals have on IQL?
2. How subsequently influences this perspective of IQL how they give practical meaning to IQL?
3. Which themes concerning IQL are most important according to healthcare professionals looking at strengths and areas of improvement?
4. How do healthcare professionals reflect on their perceptions and actions in practice regarding IQL?

Reflexivity

5. What recommendations follow from this for further development and implementation of IQL in Zinzia for healthcare professionals and policymakers?
6. What does this research teach me (about how IQL is socially constructed)?

[2]For the target group of readers, I assume that everyone knows what dementia is, and how this brain condition could result in specific behaviour and evolvement of certain physical, mental and social problems.

First, the theoretical framework is outlined, in which you can find theoretical background on the social construct IQL by describing the societal developments that led to IQL. Also, reflexive spaces are mentioned (Chapter 2). Then the approach and methodology of this research are explained (Chapter 3). After that the results are described (Chapter 4) which will be discussed. From this, a conclusion follows (Chapter 5).

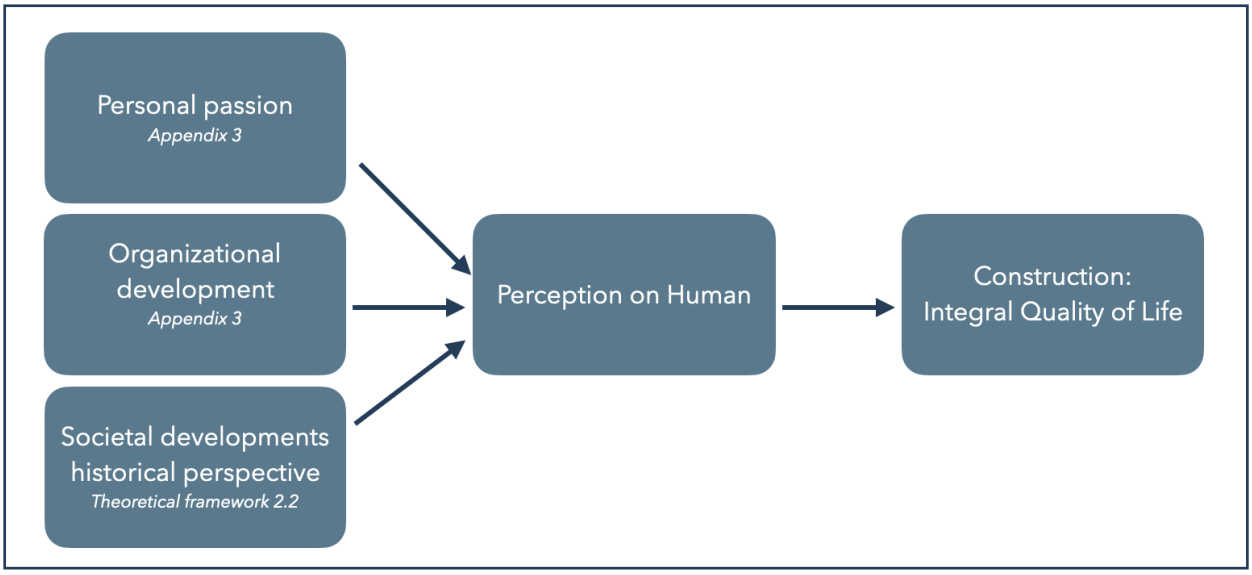
Chapter 2 Theoretical framework

This chapter holds the theoretical grounding of the societal developments that have contributed to the construction of IQL (2.1&2.2). As mentioned in the introduction, this is based on *care ethics* and *positive health*. However, inspired by the board of directors, I want to make a sidenote. It is not about the word IQL and to bring precisely this into practice; it is about what it aims and having an eye for that aim, instead of the concept, the method, or the tool. Besides, I give theoretical background about reflexive spaces (2.3).

2.1 The social construct of Integral Quality of Life

As mentioned, (1.2 & appendix 3), roughly three factors played a role in the construction of IQL, summarized in figure 2.

Figure 2: Factors towards the 'perception of human' and the construction of 'Integral Quality of Life' by Zinzia (self-made based on an interview with the Director and document study)



In this figure, you can see the essence of what *social constructivism* means. 'It is characterized by an emphasis on the extent to which 'society' is actively and creatively produced by human beings' (Barry & Yuill, 2016, p. 22-23). Society could be relating to a community or to culture of a country and an organization. This frames our perceptions and explains how people look at the world around them. A frame steers the interpretation and gives meaning to a situation. This results in the belief that this perception is reality itself, even though there are more ways to conceptualize situations. We should be aware of this unconscious process (Ruijters, et al., 2015). Besides, a social construct is a result of certain developments. It is a *perception*, which results in *action* because of that perception. When asking how hcps give meaning to IQL, I refer to their perceptions and actions (Barry & Yuill, 2016). Perceptions hold ideas in light of history and a prediction of the future, corresponding

with a frame. The Board of Directors gave an example of how societal developments towards history, presence, and a future prediction about double aging, altogether resulted in how Zinzia is looking at IQL today.

> *"This all means that the throughput speed (…) of people who live in a nursing home, (…) continues to rise. (…) We now see an average stay of 9 months from multiple years, as result of how old people get and how severe they are. I expect that this will further decrease to three to six months. (…) What does this imply? They will live here shorter; they can do and have less in this period (physically); and these people are already palliative or will be very soon. All nursing homes then become palliative care programs.*
>
> *(Board or Directors - Zinzia Zorggroep, personal communication, February 24, 2021)*

2.2 Societal developments which led to Integral Quality of Life: a theoretical basis

In this paragraph I will briefly explain the societal developmentally theoretical basis of IQL, from historical perspective[3]. These roughly three schools of thought played a role (figure 4).

The construction of Health

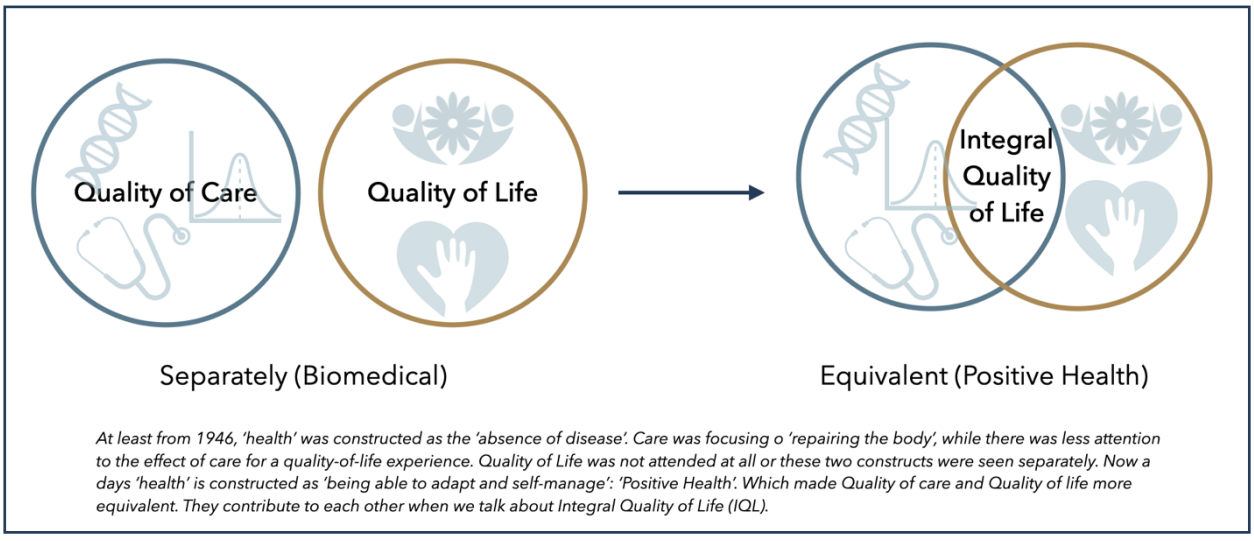
First, the construction of 'health'. Nowadays, we talk about *Positive Health*, in which health could be constructed as a combination of Quality of Care and Quality of life (figure 3). While in 1946, the WHO constructed health in a more biomedical way (Barry & Yuill, 2016): '…an absence of disease or infirmity' (Huber, et al., 2011; Seligman, 2008). In this, 'health' is approached physically and dichotomously; you are ill, or you are not, whereas there is less attention to how you experience and deal with your illness yourself (quality of life). The body is a 'machine' that needs repair for dysfunction with effective treatment (quality of care). I think this way of constructing 'health' and 'sickness' is a result of the enlightenment, in which the ratio was defined as the most crucial source of finding the 'truth'. From then, mind and body were separated, in which the body became only *functional.* Descartes' and Kant's philosophies are examples of this (Bolt, Verweij & Van Delden, 2010; Ten Kate & Poorthuis, 2018). Besides, the epidemiological transition in the 19th and 20th centuries has influenced how 'health' was constructed (Mackenback & Stronks, 2016). When infectious diseases cause significant causes of death for which you can find effective treatment, it is logical to think you can 'repair' the body without looking at other aspects of the human being, like social and psychological factors towards health. However, towards chronic

[3] Realize that this historical overview of (philosophical) ideas is a simplification of reality. Every factor could hardly be known and researching this goes beyond this thesis. Besides, the philosophical ideas describe 'how things should be'. However, the reality of IQL is also based on practical (im)possibilities. So, the ideal is probably a utopia.
The light-blue boxes, represent the used constructs in this research.

diseases, those other factors turned out to be important as well. Therefore, without a re-construction of 'health', chronic diseases are medicalized (Huber, et al., 2011). Based on this, Huber's, et al. re-construction of 'health' in 2011 is a logical result. They constructed 'health' as 'the ability to adapt and self-manage physical, mental and social challenges, despite illness', which they call *positive health*. This concept emphasizes the possibility for growth towards a feeling of health, even though there is an illness. This makes it possible to reach personal goals (Huber & Jung, 2015). Physical adaptation focuses on the 'maintenance of physiological homeostasis through changing circumstances' (p. 2), called 'allostasis'. The mental adaptation focused on 'a sense of coherence and successful capacity to cope and recover from strong psychological stress' (p.2). Moreover, social adaptation is looking at the capacity to participate, manage life, and fulfill potential and obligations (Huber, et al., 2011). Huber was inspired by Viktor Frankl (Frankl, 1983) (figure 4). This psychiatrist sees the human being as a creature that wants to give 'meaning' to his/her life because we are conscious about our existence (physical, psychological and spiritual). This is a view on humanity that relies less on following your instincts towards pleasure and power, as was thought by Freud and Adler (Frankl, 1952).

Because this construction of 'health' is looking at health more integrally - it combines many dimensions of life -, it acknowledges that it is the sum of things that makes someone experience health. This results in an individual IQL experience because then 'health' differs for everyone. *Positive health* looks beyond illness (Huber, et al., 2011; Huber & Jung, 2015), like Zinzia 'wants to see a person as an entity' within IQL (Zinzia Zorggroep, 2020).

Figure 3: Relationship between Quality of Care and Integral Quality of Life (self-made based on the literature)



Care ethics

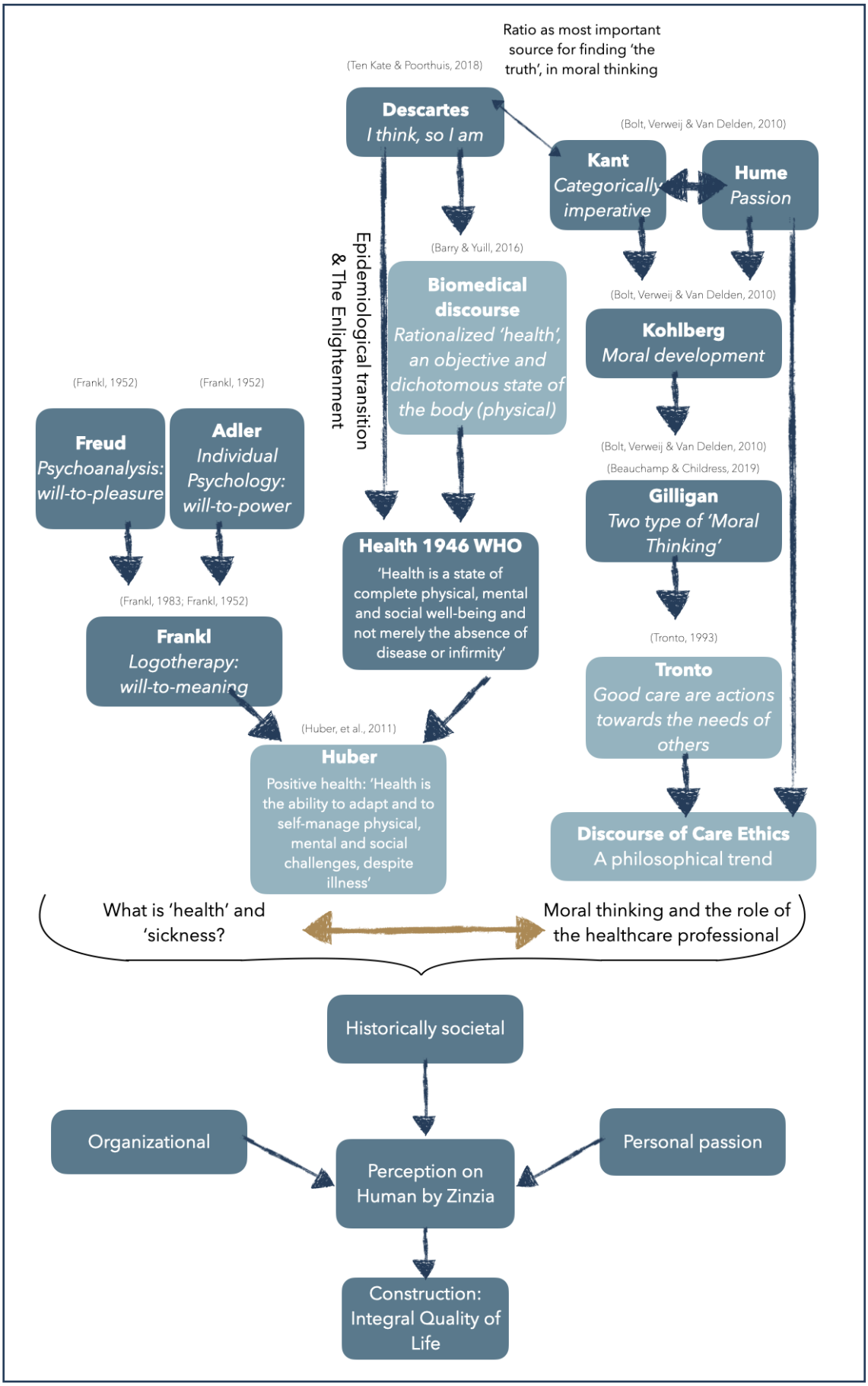
Second, the *care ethics* discourse gives insights in the role of the hcp towards IQL. This discourse was in-depth by Tronto in 1993. Her line of thought followed Gilligan's research, who claimed two types of 'moral thinking': Ethics of Right and Justice and Ethics of Care. This statement was a result of the research of Kohlberg and herself towards the moral development of children. In this, the ethics of right and justice is based on applying (universal) rules, a more Kantian way of thinking (Bolt, Verweij & Van Delden, 2010). This is about 'impartial principles, accompanied by dispassionate balancing and conflict resolution' (Beauchamp & Childress, 2019, p. 36), it is about the application of general guidelines and what you 'owe' someone regarding your profession as a caregiver (Bolt, Verweij & Van Delden, 2010). So, you could say a more biomedical way of thinking. However, an ethics of care (*care ethics*) focusses on responsibility and responsiveness from the caregiver (table 1), by having an eye for the interconnected network of needs regarding the personal history and the prevention of harm towards someone who needs help (Beauchamp & Childress, 2019; Bolt, Verweij & Van Delden, 2010). It is about the question; what is good care regarding *this* situation to increase someone's well-being? Instead of only following guidelines (Bolt, Verweij & Van Delden, 2010). The *care ethics* discourse has an eye for the caregiver's actions towards the IQL experience of the care receiver. Tronto deepens this by highlighting four core elements (table 1). For this, passion and sympathy are needed, which, according to the philosopher Hume, is our motivator to think and act morally (Bolt, Verweij & Van Delden, 2010).

Hcps are crucial in giving the proper treatment and giving actual attention to a care receiver's needs. That is why Tronto acknowledges that care receivers can experience vulnerability and lack of autonomy because they cannot influence the treatment they receive (Tronto, 1993). Especially for nonautonomous, incapacitated people (like the PG-residents), this could result in a paternalistic power tension, 'we know what you need' (Tronto, 1993). Therefore, hcps must realize that their perceptions towards IQL always influence their decisions. Besides, they could never know for sure if they do precisely what the PG-resident needs to increase his/her well-being, which highlights the complexity of the care process for this target group. They must remain alert to the danger of abuse of the vulnerability and the lack of autonomy of the care receiver (Tronto, 1993). In order to prevent this, the role of the caregiver must be attentive, responsible, competent, and responsive (table 1). To learn this, reflexivity is necessary (2.3).

Table 1: Four elements of care ethics (Tronto, 1993)

ELEMENT	DEFINITION
ATTENTIVENESS	Attention to the needs of others. Seeing what is going on (Tronto, 1993). Observing, listening and act reflexive.
RESPONSIBILITY	This is not an obligation but embedded in implicit cultural practices. We have a responsibility to our loved ones but also humanity in general.
COMPETENCE	The professionality of a healthcare provider is necessary to give good care.
RESPONSIVENESS	The care receiver must be responsive to the received care. However, this expresses a problem; the need for care goes hand in hand with vulnerability and a lack of autonomy. Responsiveness, therefore, implies that we remain alert to the danger of abuse of this vulnerability.

Figure 4: Schools of thoughts towards Integral Quality of Life



Care Ethics and Positive Health: a contribution

As a result of the plea above, in my opinion, *care ethics* and *positive health* could contribute to each other to understand the process of 'giving meaning to IQL'. Both discourses have an eye for the unique experience an individual has towards IQL. *Positive health* has attention for the unique experience of 'health' and 'sicknesses'. Whereas from a biomedical perspective only, it is unthinkable that a person who has a diagnosed disease could still experience 'health'. This gives a whole new perspective to the role of the caregiver, which *care ethics* discusses. That discourse highlights the health care professional's role towards this unique experience of 'health' and 'sickness' by emphasizing the attention needed towards 'the needs of the person in need' as the most essential factor in giving 'good care' in a specific situation. In this, *care ethics* points out the complexity and possible power tension between the perception of the hcps towards 'good care' and the care receiver's needs towards the increase of well-being. This is made open for discussion and reflection (Tronto, 1993) (2.3). This is essential because of the enormous responsibility of a hcps towards a care receiver's needs (Custers, Westerhof, Kuin, Gerritsen & Riksen-Walraven, 2012). After all, PG-residents are no longer able to do this themselves, otherwise, they would not need help. From this, I can conclude that a hcp must act towards a care receiver's needs, which matches receiver's perception of 'health' (for instance, a maximum increase of well-being in the given situation). Only focusing on an effective treatment from a medical perspective is not enough to make someone experience IQL (figure 3).

However, acting on this complexity and being aware of the power tension is a difficult skill. Therefore, it asks for learning through reflection because every caregiver and care receiver is unique. There is not *one* way to do it. Eventually, it is all about the experience of the care receiver and what he/she needs to feel as healthy as possible and to deal with life and disability. You could say that the role of the hcp now becomes also *coaching* (Dutch: begeleiden) the residents, an aspect the Director described in its essence in the last sentence of this quote.

> *'It is no longer enough only to give the pills on time, making rehabilitating as good as possible after an operation (…), taking someone through the car wash, a sandwich is pressed in, someone seated at a table for coffee at 9/10 o'clock and that is it. That is no longer enough. It is about the Integral Quality of Life, which is a combination of things. Yes, there must be taking care of someone, and someone needs the right medication. However, we also must have attention to increasing well-being to the optimum or maximum.'*
>
> *(Board or Directors - Zinzia Zorggroep, personal communication, February 24, 2021)*

The dilemma that *care ethics* recognizes and the question that *care ethics* asks to reflect and discuss how we have socially constructed 'good care', could partly be answered by the way

positive health constructs health. Together, both the perception and actions of the care receiver towards 'good care', are mentioned and recognized. Through this, there is attention to both quality of care (effective treatment) and quality of life (a feeling of health and well-being). Within an IQL experience, these two aspects are made each other's equivalents (figure 3).

The complexity of the care process

However, even though theoretically those two discourses contribute to each other and to IQL, this is very complex to reach in practice. Therefore, I will deepen three concepts of IQL from a *care ethics* and *positive health* perspective, to highlight the importance and practical limitations of these concepts.

Individuality

An IQL experience is individual and unique. It differs for everyone because everyone is different. Having an eye for this difference and therefore act on the needs of that specific individual (Tronto, 1993) is one of the most important, and at the same time, most challenging thing to reach for a hcp. Personal actions of hcps when trying to give meaning to IQL, are always influenced by their perception of how they frame IQL (Maisel, 2013; Ruijters, et al., 2015). Besides, the hcp is a unique individual. So, every hcp has a different perception of the needs of a resident. That is why it is essential to reflect on this and learn from each other. Therefore, to have an eye for the individual, *Reflexive spaces* are needed (2.3).

Meaning

According to Viktor Frank (1954), ones will-to-meaning is *the* essence of being 'human'. He states that people could decide to see their meaning in life. Besides, the feeling that your life has meaning[4], is an essential factor in experience health (Frankl, 1983). However, meaning in life is not something you can 'grab'. It depends on the person, the day and even the hour what it defines[5]. Every person has a responsibility to *decide* for this because no one else can reach, define or make this for you (Frankl, 1983; Maisel, 2013).

Meaning could for instance be discovered through *action* (Frankl, 1983). When people reflect on life, their *perception* on 'how it should be' concerning 'how it is', can result in a particular *action* (Boyd & Fales, 1983; Maisel, 2013) when there is no satisfaction. For instance, hcps can give meaning to IQL for PG-residents through a rich daily routine (Zinzia Zorggroep, 2021) because the residents depend on the professionals' help (Tronto, 1993). Or through *experiences*. For instance, love could 'gate-crash' to the interior 'the other', to the core of this personality' (Frankl, 1983. p. 139). Zinzia tries to do this by focusing on intimacy

[4] This means: the meaning your life could have if you 'decide' to see it. This sentence is not a reflection of the question 'what is the meaning of life altogether?' Because this is question is still not answered (Frankl, 1954).
[5] Metaphorically explained: there is no such thing as the best move in the chest because the best move is your decision regarding this specific situation (Frankl, 1983).

(Zinzia Zorggroep, 2021). At last, meaning could be discovered through *suffering.* We can ask ourselves the question how we bear our suffering and what this suffering has brought us in terms of meaning (Frankl, 1983). Although PG-resident can no longer reflect on this, hcps can contribute to their short-term experiences of meaning and well-being.

These ideas of Frankl were inspiring for Huber when defining 'health' as the ability to adapt and self-managing life. A research of Huber & Jung (2015) confirmed the idea that meaning is essential for health. They found that people who had experienced illness and diseases defined existential dimensions of life as more valuable than physical dimensions compared to physically healthy people. They also defined their experience of 'health' more positively than expected regarding their physical state. They still experience 'health', even though they were physically ill (Huber & Jung, 2015). Through focusing on IQL, Zinzia hopes to contribute to this kind of meaning in life.

Well-being

While having attention for meaning, well-being also grows—well-being in the existential (spiritual and psychological) sense. For Zinzia, also well-being on the social and physical parts of life are essential to reach IQL. According to Tronto (1993), adding value to well-being in the social sense is possible when a hcp interacts with the care receiver and when the needs of the care receiver are considerate and act on. In this way, the care receiver's vulnerability and lack of autonomy are not constraints to experience well-being because the hcp is taking responsibility. Well-being in the physical sense is supported through the medical knowledge of the professional. To reach a feeling of well-being by the care receiver, the caregiver has to act according to table 1.

> *"These people are vulnerable and depending. The trick is to deal with this as well as possible. (…) We want to add things which are of the emotional, psychological or physical value of these people."*
>
> *(Board of Directors – Zinzia Zorggroep, personal communication, February 24, 2021)*

2.3 Learning and reflection

As mentioned, Zinzia asked me to reflect on the complexity of the care process. Being a good professional in this requires constant learning through reflection on your actions. Zinzia stimulates this through openness or *reflexive spaces.* This paragraph will give a better understanding of what this learning through reflection in reflexive spaces means and why this is necessary.

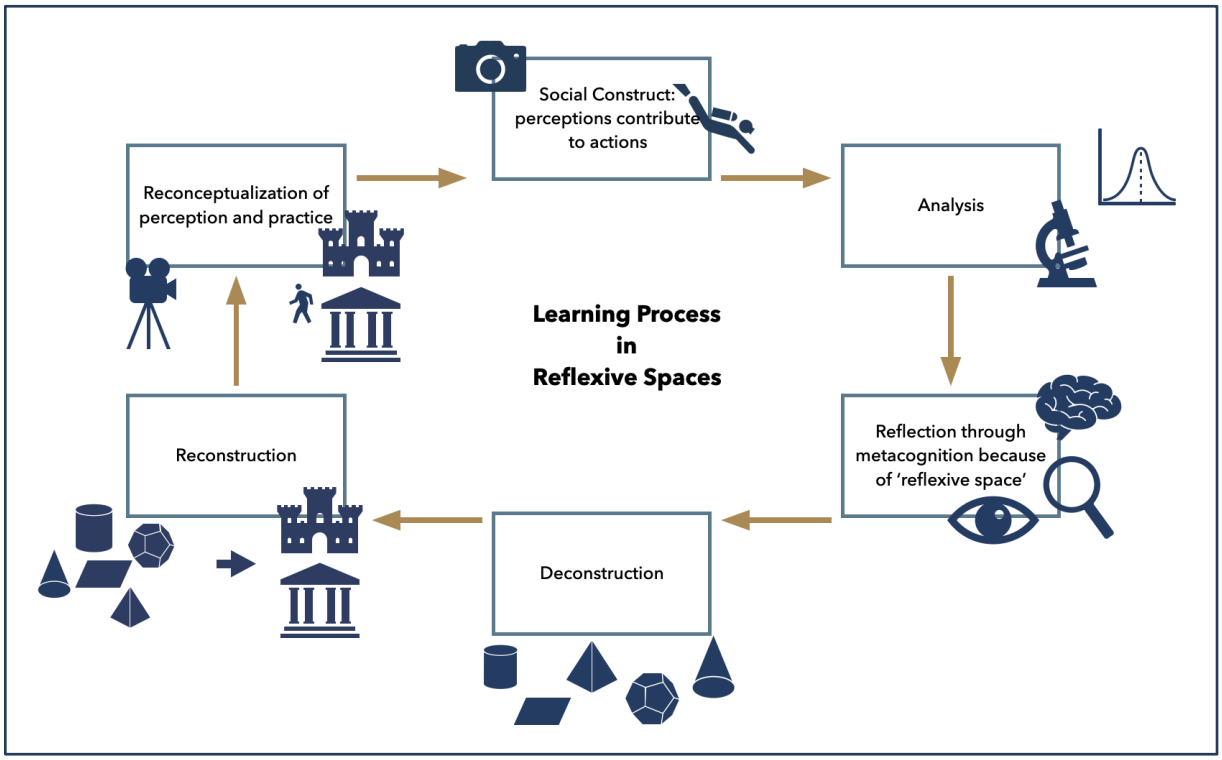
In order to learn from their actions, through experience, hcps need to *analyze* and *reflect* on their perceptions and actions towards IQL (Boyd & Fales, 1983). In this, the process of how they learn is essential rather than the outcomes because learning through experience is not

intentional (Boyd & Fales, 1983; Snoeren, Niessen & Abma, 2013). *Reflection* can therefore be defined as 'the process of creating and clarifying the meaning of experience (present or past) in terms of self (self in relation to self and self in relation to the world)' (Boyd & Fales, 1983, p. 101). This reflection of hcps on how they give meaning to IQL can be stimulated by asking questions such as: what is good care for this person? How can I contribute to the meaning of someone's life (Ruijters, et al., 2015)? Or what are my nonobvious perceptions that contribute to my action (Johnson & Duberley, 2003)?

The effect of this reflection is that the construct IQL *deconstructs* because they look at the underlying assumptions, values, and definitions given to IQL (Johnson & Duberley, 2003). The deconstruction of the concept (re)presents it for reflexive analysis (Johnson & Duberly, 2003), resulting in *the re-construction* of the concept. When someone *re-conceptualizes* his/her conceptual perception (Helyer, 2015), this could result in learning (Boyd & Fales, 1983) which could therefore create new meaning (Boyd & Fales, 1983). Besides, it could *re-conceptualize practice* when someone changes his actions (Helyer, 2015) (figure 5).

However, in order to do so, *metacognition* is necessary: making connections between ideas and thoughts. This creates awareness about *how* (reflection) you think of specific constructions through thinking about your thinking and learn from this. Reflection is also 'an important form of human thought' (Denton, 2019). Because of this metacognition, people can reflect on mistakes, which implies a form of vulnerability, for which people need a safe place (Wiig, Aase & Bal, 2019). This learning, through reflection and being vulnerable about it, can take place in *reflexive spaces* (Wigg, Aas & Bal, 2019), where metacognition enables people to go from reflection to reflexivity. This makes it possible for people to ask even more profound questions about *why* (reflexivity) they think the way they think, or why they do what they do; and how this *influences* (reflexivity) their own life or the world around them. *Reflexive spaces* are 'physical or virtual platforms in which reflexive dialogical practice occurs between people. The reflexive dialogical practice is a key in learning processes because it bridged tacit and explicit knowledge' (p. 2). Reflection in a *Reflexive space* is not something you can do alone. People do it with each other to be accountable and give each other feedback on how they act in practice and the effects that actions generate by binding and reflecting on their experiences (Wigg, Aas & Bal, 2019).

Figure 5: Learning process *(self-made based on literature)*



Chapter 3 Research method

This chapter explains the Action Research (AR) approach and methodology that was followed. In table 2, you can find the structure of this chapter. This approach can be divided into first- and second-person AR, which holds different methods.

Table 2: Overview content Chapter 3

3.1 Action Research Approach *What is Action Research?* *Why this approach?*	
3.3 First person AR What is first person AR? *Why this approach?*	**3.2 Second person AR** What is second person AR? Why this approach?
	Aim
Method Reflection through journaling**.** Reflection on my impact on this research, because of emotional motivation for this theme.	*Method* *Who*? Description of research population and selection process *How*? Interviews and Observations *Why these methods?*
Data analyzes How did I analyze the data?	*Data analyzes* How did I analyze the data?
3.4 Validity, Reliability and Ethical considerations	

3.1 Action Research Approach

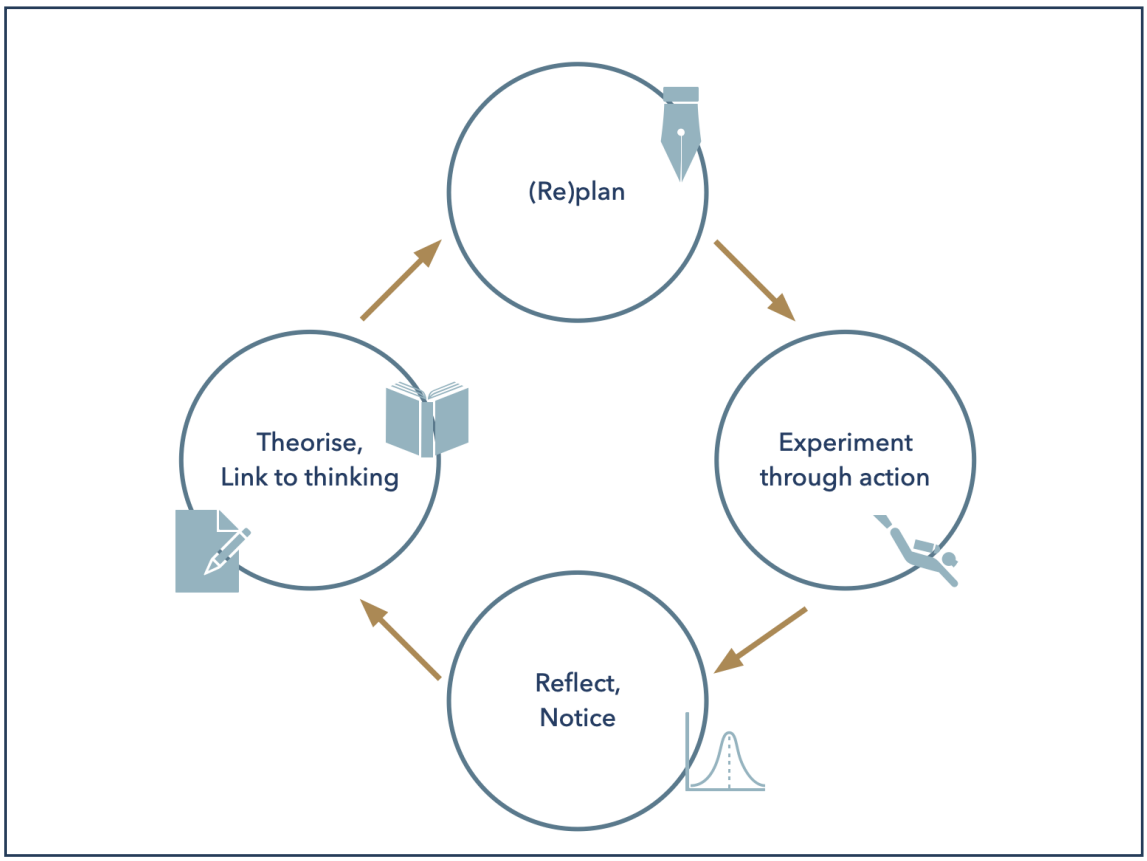
What is Action Research?

AR is a form of research that evaluates and reflects on practical activities in which the researcher is involved him/herself. Besides, AR aims to generate new theory inductively (McDonnel & McNiff, 2017). Through theorizing practices both practices and theories can be changed' (Cordeiro, Baldini Soares & Rittenmeyer, 2017, p. 397). According to McDonnel & McNiff (2017), this could contribute to social transformation, which I think is true.
Sometimes only 'mentioning' something you observe, can make someone aware of his/her perceptions and actions which could result in transformation. Therefore, through first- and second-person AR, I strived to gain insight to transform practice. I used this triangulation to increase the reliability of this research.
Second person AR holds research *from* practice. I generated data by reflecting on topics with people involved: what is going on? Through the skill of reflexivity in first-person AR, I focused on in-depth theorizing *about* practice: meta-reflection, which has a philosophical component (Coleman, 2019, in Costley & Fulton, 2019). This difference between reflection and reflexivity can be seen in the sub-question headlines.

Because being reflective is an essential characteristic of an AR researcher (McDonnel & McNiff, 2017), observing and reflecting on my actions has influenced the theorization. It gave insights and therefore changed my way of framing the things I investigated. Probably this research has the same effect on practice. If only because I 'mention' things observed.

Gaining insights through an AR process can be seen as a cyclical, interactive (Costley & Fulton, 2019; McDonnell & McNiff, 2017), fluid, open, complex, and responsive process (figure 6), instead of linear (Cordeiro, Baldini Soares & Rittenmeyer, 2017). This means that every choice, perception, and action made affects subsequent choices, perceptions, and actions. Nothing stands alone; it is all interrelated. While much research has to be as objective as possible to be valid and reliable, in AR the interrelatedness and (personal) reflections are used to gain new insights. The researcher's influence on the conclusions is seen as a contribution rather than the interference of objectivity. The detailed description of the process, acknowledging and reflecting on this influence, and the subjective perceptions that are part of the motivation and results are the part that strives for validity, rather than pure objectivity (McDonnel & McNiff, 2017). The Action Research Cycle (Costley & Fulton, 2019; McDonnell & McNiff, 2017) (figure 6) shows the steps to be taken to validate this 'subjectivity'. However, concluding too fast and unconsciously might hurt the validity and reliability of this research. That is why reflexivity is essential.

Figure 6: Action Research Cycle (Costley & Fulton, 2019; McDonnell & McNiff, 2017)



Why this approach?

I chose this approach for different reasons. First of all, for this setting, a quantitative approach was not sufficient enough. For more scientific themes, quantitative research is of great effort, but for research in the context of organizational-, sociological-, psychological- and philosophical approaches, it does not fit when you try to explain practice. There is a risk of getting too far from reality, something I wanted to prevent. This would have less value in practice because it only serves as an abstract description of reality rather than experiencing what is going on.

Second, with this research, I want to bring two worlds together that are often seen as separate entities of humanity, as recognized through Kant and Hume (Bolt, Verweij & Van Delden, 2010) (figure 4): the mind and the heart, the logic and the emotion, academics, and experience. With this research, I want to show the emotions of reality from an academic point of view. So, the reader could 'feel' the importance of this topic, which is argued logically and theoretically. This research goal has a personal motivation. From experience, I know the difficulty of the interaction between logic and emotion, which could result in discrepant feelings, because they are not always corresponding with each other. Often, they are even contradictive, while I think they could contribute to each other. *Emotionally driven logic* (appendix 4) is better substantiated and considered more deeply, which makes the conclusions more reliable. I believe that through this, you come to the essence of human capacities and ways of being. This makes theory more 'human'- we could understand reality more clearly. This motivation describes my ontology (Mc Donnell & McNiff, 2017); *emotionally driven logic* is how I view myself; this is how I view the world and what my values are based on. It informs who I think I am.

3.2 Second Person Action Research

What is Second Person AR?

Second Person AR 'addresses our ability to inquire face-to-face with others into issues of mutual concern (…). Its inquiry starts with interpersonal dialogue and includes developing communities of inquiry and learning organizations' (Reason & Bradbury, 2008, P. 8; Costley & Fulton, 2019). So, I interacted with the hcps to learn about IQL. Through this approach, every participant could be heard and 'given a voice to' (Costley & Fulton, 2019). Therefore, everyone involved was acknowledged as equal; so, everyone felt free to point out personal interests, which were the starting point of the research experience (McDonnel & McNiff, 2017).

Why this approach?

Through Second Person AR I wanted to 'show' rather than 'tell' what is going on within the complexity of the care process (Marshall, 2016), through collaboration with the hcps by

‘giving them a voice’. I hope that people who read this are automatically triggered to learn through reflection. Because things are ‘mentioned’.

I also wanted to give a voice to the PG-residents themselves, not by talking to them but by observing the complexity of care. Through this, I hope to ‘show’ the influence hcps have on their IQL experiences.

Aim

The fact that Zinzia stimulates this research shows their interest in *Reflexive spaces* because you could argue that this research is a reflexive space. Therefore, second-person AR aim to bring this *Reflexive space* into practice. While doing, this has created new theoretical knowledge about practice. This theorizing could lead to new strategies because it deepens the knowledge *about* practice (Cordeiro, Baldini Soares & Rittenmeyer, 2017).

Method

I used different methods regarding second-person AR: interviews and observations. Through this, ‘I wanted to say what I know and how I have come to know it and explain how I have checked that what I say may be believed’ (McDonnel & McNiff, 2017. P. 4).

Who?

I chose to investigate how hcps contribute to the IQL experience of PG-residents, because this care process is especially complex regarding the condition of the PG-residents. After the ‘hcp’ operationalization, I talked to their manager, who gave me six names of department coordinators of different disciplines: psychologist, physiotherapist, physician, occupational therapist, spiritual caregiver, and quality-focused nurse. The manager told me that these people were capable of more metacognitive thinking, which made them valuable for this research. Researching with hcps of different disciplines gave me insight into the complexity of the network around the PG-resident. I contacted all of them via e-mail. Except for the ‘quality-focused nurse’, all of them responded. I scheduled five interviews. After that, I observed the spiritual caregiver during a *group session* with residents in a less severe state of dementia. I observed the physiotherapist and the psychologist at the same time during a *behavioral visit*. This gave me some insights into the multidisciplinary part of this complex care process. I did not observe the physician because this could only be done via the telephone, through which I could not observe. This would have affected the validity and reliability of the research. With the occupation therapist, I had failed to schedule an observation.

How?

The interviews had an open and narrative character. The topics were based on an interview with the Board of Directors of Zinzia and a policy and history document study of Zinzia (appendix 3 and 5). This information I also used as an introduction for this research, which

led to their ‘perception of human’ (figure 1). I asked the director questions about how the construction IQL has come to fruition at Zinzia, what it means within Zinzia and how this construct is part of an interaction between the history of the organization and society, and the prediction of the future. For the document study, I read the ‘basic attitude’ (grondhouding) of Zinzia, the ‘mission (care)vision and strategy,' Quality plan’ and two research reports of action research from 2017, which was done by Zinzia through the university of Humanistic. These documents also gave an overview of the fundamental starting points of ‘what good care is’ according to Zinzia. I analyzed these documents from the same topics I talked about with the Board of Directors (appendix 3).

Interviews

With this topic-list in mind, I interviewed five hcps individual about how they (this specific person) looked at IQL and how they reflect on their perception and actions (with their colleagues) (appendix 5). This was an open interview (Verhoeven, 2014), with a narrative component (Anderson & Kirkpatrick, 2016). An open narrative interview is characterized by a spontaneous conversation, not only a ‘question-answer’ one, in which I have tried to ‘bring’ myself, to listen, and understand what they were saying (Costley & Fulton, 2019: Anderson & Kirkpatrick, 2016: Verhoeven, 2014). I kept asking questions and asked if I understood them correctly by repeating their sentences in my own words. This aimed to collect people’s own stories, which include their perceptions and experiences (Anderson & Kirkpatrick, 2016). Opinions differ between researchers if this is a narrative interview or a semi-structured one (Anderson & Kirkpatrick, 2016; Ziebland, Coulter, Calabrese & Lockock, 2013). I think it was more narrative because I asked open and brought questions, from which the interviewee told for a couple of minutes. This form of interviewing fits second person AR because we had an interpersonal dialogue, from which we hopefully learned both. Besides, through this method, I came closer to a representation of reality. Combined with observations, this gave much insight (Anderson & Kirkpatrick, 2016). This made it possible to ‘show’ rather than ‘tell’ (Marshall, 2016). For good analysis, I recorded and transcribed the interviews.

Observations

After the interviews, I scheduled two moments for observation with three hcps. These observations aimed to see how hcps deal with their role in practice. The observations also gave me insight into the care process's daily life complexity, which was something I wanted to understand. I could observe (the context of) the PG-residents and therefore experience a bit how their life in a nursing home looks like.

I did the observations through the method of ‘shadowing’. This makes it possible to ‘give voice’ to people who are less capable of telling their experiences and feelings themselves. Besides, it gave insight in the context of these experiences (Van der Mijde, Leget & Olthuis, 2012). It, therefore, was of significant contribution to the open narrative interviews.

'Shadowing' is done through making detailed descriptions about everything I noticed during the observation: the interactions and sensory perceptions in the environment—all this information I put together in a personally told story (thick description). Therefore, the reader of this story could *experience* what is going one (Van der Mijde, et al., 2012) because I *showed* it (Marshall, 2016). The three hcps were curious about the things I wrote and were happy that they were observed. They could learn from it, because I made them 'more aware of the choices they made'. The observation format can be found in appendix 6.

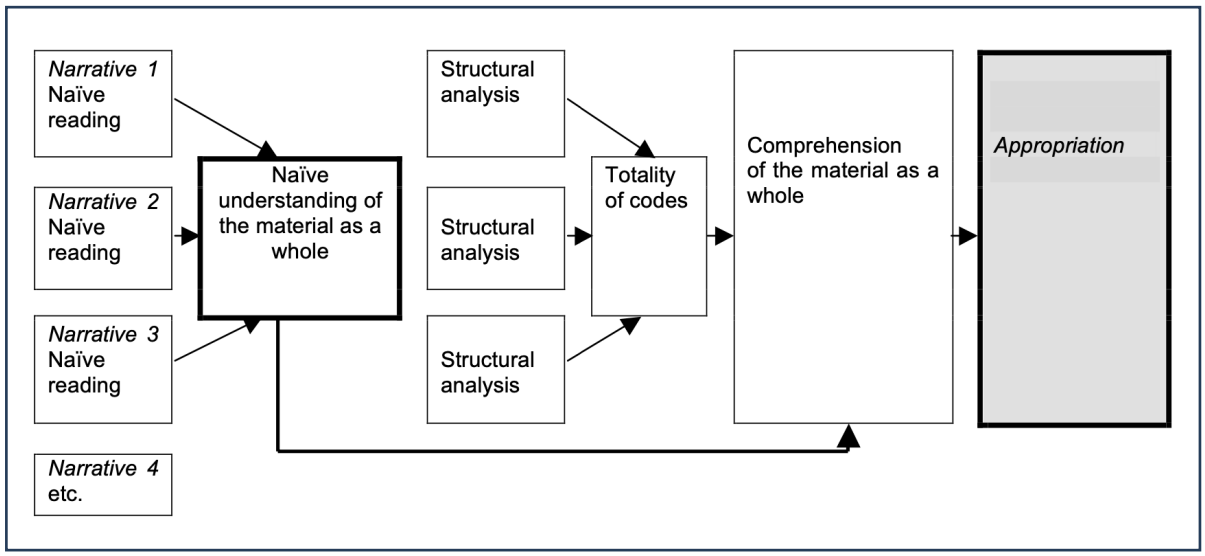
Why these methods?

Through these interviews and observations, I gained insights in what is going on in practice. Through the interviews, I got to know these hcps in person, which made it possible for me to understand their perception of IQL and empathize with their work. However, also, to give 'a voice' to the hcps and the complexity of their work. The observations were meant to be 'shown' the reader (Marshall, 2016) how the practice looks; how the interaction between the hcp and PG-resident occurs. Through these methods, the social construction (perceptions and actions) of IQL by hcps was investigated.

Data analyzes

The open narrative interviews were analyzed through a combination of 'thematic analysis' (Anderson & Kirkpatrick, 2016) and 'narrative analyses' (Blom & Nygren, 2010). For this, I used model 3 from Blom & Nygren (2010) (figure 7).

Figure 7: The third model for analyzing narrative material (Blom & Nygren, 2010)



First, I read/heard every interview naïvely; this means 'open, without prejudice' (p.29), so I understand the material as a whole. From this, I summarized every interview to come back to the core of the story told. After that, I transcribed the interviews, which I analyzed structurally through the 'thematic analysis' method (Anderson & Kirkpatrick, 2016), by

highlighting predefined and during defined topics in every transcription (open coding) and then grouped them (axial coding) (Verhoeven, 2014). This process I repeated one time to make sure I was rigor. With these topics, I draw a mind-map. Through this, I could find interrelatedness between the topics, which resulted in a totality of codes. This was the basis of the theory. However, I was also interested in the meaning of these concepts (comprehension). I defined what this concept meant to the interviewee for every interview and compared that between the interviews. To do this properly, I used an example from Blom & Nygren (2010). Through this, I could build an appropriation (interpretation based on the structural analysis and comprehension (Ricoeur, 1976 in Blom & Nygren, 2010)) of all interviews and answer the sub-questions. This whole process can be found in appendix 8. After that, I coded the observations with the same codes as the interviews. Through this I could easily find the 'action' that followed from the 'perception'. Therefore, I could understand the action in practice better than by 'hearing' it from them. This triangulation improved the validity and reliability of the research.
The data *from* practice I compared with the theories *about* practice and the interview with the Director. This was an integrative and inductive process. From there I theorized practice (chapter 4), changing both perceptions and theories (Cordeiro, Baldini Soares & Rittenmeyer, 2017).

3.3 First Person Action Research

What is First Person AR?

First-person AR is an approach that addresses the ability to reflect on my work as a researcher through the skill of reflexivity. This gave insight in how my own behavior, thoughts, and feelings have influenced the taken steps (Costley & Fulton, 2019; Symon & Cassell, 2012). Reflexivity made me more choiceful and aware of how the world around me influenced this research and, therefore the conclusions. I reflected on myself in action by acknowledging that I was part of the research process rather than an objective outsider (Reason & Bradbury, 2008). This made meta-reflection towards the relationship between theories *about* practice and data *from* practice possible. First-person AR is essential to move properly along the iterative AR cycle (Costley & Fulton, 2019; McDonnell & McNiff, 2017) (figure 5).

Why this approach?

Through reflexivity, I realized my deeper motivations and passions for this research, why I asked these questions, and why I used methods in the way I used them. This encouraged and motivated me. Curiosity about something that concerns me could have caused tunnel vision, but in this case, I delve deeper into the material than I would have done otherwise. This contributed to the research quality.

Method

During the whole research process, I kept up a journal in which I reflected on the process, ideas, behavior, thoughts, and feelings regarding the things I discovered. First on paper, then digitally. This made me aware of my line of thought and helped me decide next steps. Because of this awareness, I can better 'justify' my choices regarding the validity and reliability of the research.

Data analyzes

All this information is intertwined in the research, in every sentence, in every idea. It is not something that I analyzed in a specific section, but something spread all over the work.

3.4 Validity, Reliability, and Ethical considerations

The persons gave informed consent. The direct and indirect data about people, was anonymized. I investigated from different points of view (theory, documents, Director, hcps, and myself) to ensure the validity through different methods (literature study, document study, interviews, observations, and journaling). In this, I was as rigorous as possible to ensure the reliability of the results and the conclusions. This took shape through reflexivity. I reflected on questions such as: why did I make this choice? How did I influence the research process?

In addition, during the process, I showed the draft report to a peer and the policymaker (also my mentor) at Zinzia and asked for feedback. Through this, I got new insights, which made me more aware of my choices and possible 'unconscious' and 'unintended' assumptions in the report. I described these, or either I explained these assumptions, tested them, or replaced them with a more objective view. This increased the validity and reliability of the research.

Chapter 4 Results

The question of this research is: “How do these healthcare professionals who work for Zinzia, give meaning (through perception and action) to Integral Quality of Life of psychogeriatric residents, and what can these healthcare professionals and the policymakers of Zinzia learn from this and what does reflexivity teach me”?

In this Chapter, the most important results and answers towards the first four sub-questions are described in 4.1, concerning the perception of Zinzia and the theoretical framework (Chapter 2). In 4.2, these answers are theorized in figure 8. I also reflect on how my thoughts and feelings have influenced the research process (4.3).
This leads to the answer of sub-question five and six (5.1&5.2) and an answer to the research question (5.5).

4.1 Answers to sub-question one-four

Because of an inductive process, the answers to sub-questions one to four are theorized in 4.2. Therefore, in the text of 4.1 I refer to the areas in figure 8, by using the numbers 1-11.

Perceptions towards IQL

Sub-question one: Want kind of perception do healthcare professionals have on IQL?

A striking result was that according to several hcps the word Integral in IQL, does not need to be used. They believe that it adds nothing to the concept 'quality of life'. In the end, only your actions in practice count, instead of the 'word'. However, this did not influence the fact that their perception of quality of life was almost the same as the perception Zinzia has on IQL. The most striking difference is that the Spiritual Caregiver highlighted the importance of Spiritual Needs as well. Something Zinzia mentioned as part of a feeling of 'meaning', I think. However, because Zinzia mentioned IQL in their 'Mission, (care)Vision and Strategy' document, I will use IQL. Besides, 'Integral' represents the lack of neglect (1.2), making us aware of the complex and interconnected network of factors that influence someone's quality of life.

The perception of IQL by to hcps, holds seven core concepts: meaning, well-being, the individual, social-, psychological-, physical- and spiritual needs (1,2,3,4,5&6). It was constructed as Individual, because a hcp cannot decide what IQL is for a resident. That is why the interaction is essential (10&11) (Tonto, 1993). In this, making connection is crucial to understand someone's needs. Therefore, hcps try to look beyond physical diagnoses (as do Huber, at al., 2011) to see the person and his social-, psychological, and spiritual needs (2).

However, when people cannot tell what this means for themselves, the whole system must investigate this (7). For instance, family (network) provides much information about who someone was, and hcps observe. Teamwork is essential in this (7) because working multidisciplinarely broadens the view, ensuring a complete picture of a resident's needs (10). When there is only one hcp, there is a more significant risk of projecting their perception of IQL on the PG-resident. They see IQL as a joint responsibility towards the resident. Therefore, their role could be seen as glue (11): they bring the resident's story together to give meaning to IQL. *Care ethics* describes this as focusing on responsibility and responsiveness as a caregiver (table 1), by having an eye for the interconnected network of needs regarding the personal history and the prevention of harm towards someone who needs help (Beauchamp & Childress, 2019; Bolt, Verweij & Van Delden, 2010) (2.2). They see the PG-resident as a person instead of a patient (Tronto, 1993): 'We talk about a person with dementia, not about a dement person' (GZ-psychologist – Zinzia Zorggroep, personal communication, March 11, 2021). They also look beyond the condition of the PG-resident and try to find things this person still can do to contribute to a feeling of meaning (Frankl, 1983) and well-being through interaction (Tronto, 1993), to contribute to a feeling of 'health' despite physical illness (Huber & Jung, 2015). Then the resident can be seen and heard (Tronto, 1993). Hcps often say little things that make a difference. However, the balance between safety and autonomy is precarious in this. This requires constant tuning between care professionals mutually and the resident or his/her network (7,8,9&10), which occurs in *Reflexive Spaces* (4.1.4).

Actions towards IQL

Sub-question two: How subsequently influences this perspective of IQL how they give practical meaning to IQL?

Before this research started, I thought there would be a gap between the perceptions and the actions. However, I did not observe that. There was no ‘pretty talk’. With great dedication, they try to bring their perceptions into action, in which the PG-resident was central. However, their perceptions are ideal, and it is a utopia to think that they always exactly give what someone needs. Hcps themselves are very aware of this.

Nevertheless, they strive towards their ideal perceptions. I observed a strong relationship between the perceptions and actions. They looked for the best fitting solution concerning the circumstances, in which they had enough compassion to be hit. However, at the same time, they could take enough distance to make a sensible decision, in which the whole context of the PG-resident was considered (figure 8). What I saw during the observations was what the Director described as the essence of Zinzia’s work.

'This is the essence (…) to create as much value as possible in the last phase of life or to preserve the quality of life that is available, for as long as possible'

(Board of Directors – Zinzia Zorggroep, personal communication, February 24, 2021)

The quotes below give insights in how the theorization of figure 8 looks in practice. In appendix 7, you can find the whole stories, which gives more insights than the view-out-of-context quotes I have mentioned here—these stories 'show' rather than 'tell' what is going on.

Physical needs, Teamwork, Eye for individuality:

''How does it go with the general daily life activities towards this person?' the physical therapist asked the nurse. 'Interesting,' I thought for myself. During the interview, this physical therapist gave me a few examples about how she considers at general daily life activities, what she found necessary, and how she wants to support the caregiver s with this. I found it interesting that she indeed came back to this during this behavioural visit. (…) They talked together about a possible solution to make the care for this man as pleasant as possible.'

(Thick description observation Physical therapist and Psychologist during a behavioural visit – Zinzia Zorggroep, April 19, 2021)

Psychological needs, Teamwork and the Perception of the hcp:

'Mr. X has slept better, according to the nurse. 'Yes, I already thought, 'that is not bad,'' the psychologist responded. 'But this morning, he was very cranky', said the nurse. 'He constantly asked for his wife. However, their daughters still tell us that their mother does not want to visit him'. (…) 'Last Friday, I had a conversation about this with them', responded the physician. 'Their world collapsed last year. Their parents wanted to be together forever, but now that is not the case anymore (…)'. (…) The rest of the conversation was about possible solutions for this situation. Not only for Mr. X but also for his wife. (…) Maybe his wife also could live at Zinzia? (…) All the professionals listened carefully to each other (…). The atmosphere of mutual involvement was significant. (…) They brought their different perceptions about the situation together to get the best view possible.'

(Thick description observation Physical therapist and Psychologist during a behavioural visit – Zinzia Zorggroep, April 19, 2021)

Social needs, Spiritual needs and Connection:

'The spiritual caregiver had told me that it was a group session in which she talks to several residents who want this. She prepared the theme in advance. The purpose of this was to give everyone a sense of community. After all, it is quite difficult to get used to in a nursing home, where you live because of your condition. (…) 'It is time to light a candle in the middle of the statuette with all the people who hold each other's hands', said the spiritual caregiver. While she lighted the candle, she began to sing: 'light in the night, which drives away the dark. Light it, be it, you'. (…) The spiritual caregiver asked everyone if they had lived in the mountains. (…). She listened calmly while she sometimes summarized what was being said and continued asking. She was understanding and patient'.

(Thick description observation Spiritual Caregiver during a group session – Zinzia Zorggroep, March 30, 2021)

Spiritual needs:

''When you walk up in the mountains, it is so beautiful there, you will forget your tiredness when you are up there'. It touched me. This sentence was such a beautiful metaphor for life and the challenges you may encounter. The Spiritual Caregiver also agreed with this. 'Never measure the mountain until you have reached the top' and she clarified that comment'.

(Thick description observation Spiritual Caregiver during a group session – Zinzia Zorggroep, March 30, 2021)

Most important IQL themes

Sub-question three: Which themes concerning IQL are most important according to healthcare professionals looking at strengths and areas of improvement?

I noticed that the themes that were mentioned as most important towards IQL were not always concerning the perceptions towards IQL (1-6), but the factors involved in giving meaning to IQL (7-10). For instance, teamwork (10). Because every hcp has his perception, teamwork could contribute to a better insight in what the PG-resident needs, which could contribute to a feeling of more 'health' (6), because hcps contribute to meaning and well-being. However, the perception of the hcp could also cause paternalistic actions (Physician – Zinzia Zorggroep, Personal communication, March 12, 2021), which could result in power

tension (Tronto, 1993) (11). This is because the individual hcp sometimes found it difficult to only have an eye for the needs of the PG-resident without projecting or imposing their worldview. Teamwork probably keeps them on their toes. Also, the network was mentioned as necessary (7). They provide information about the PG-resident. I also saw this during the observations. However, in these actions towards IQL, they struggle with exhaustive resources, like time and money. They cannot do everything they want to do.

Besides this, they all mentioned the importance of reflecting on the question 'what is good care for this person?' Sometimes people think that PG-residents only have to 'sit down'. A very paternalistic approach. Besides, saying that to every resident does not contribute to a feeling of meaning for every individual.

In addition, the hcps sometimes struggle with the simplicity of the protocols: 'Good care is quality of life. This you reach not only by following the protocols because it is a very complicated process' (Physical therapist – Zinzia Zorggroep, Personal communication, March 12, 2021). 'Protocols are not always valid in a specific context, so you first have to look at what someone needs. Protocols could 'skip' these needs; that's not what we want. As a professional, I myself also have a perception on what good care contains' (Physical therapist – Zinzia Zorggroep, Personal communication, March 12, 2021).

Although the perception towards IQL of the different hcps holds overall the same topics, there was much difference in the topics they in-dept during the interview. For example, the Spiritual Caregiver highlighted culture, spiritual- and social needs and the connection between herself and the resident, whereas the other hcps focused more on individual needs and the importance of teamwork and the network of the resident. This difference I also saw during the observations. There were also differences between all the hcps. The Psychologist wants to know who someone was, to contribute to things that are still possible to reach that. The Physician mentioned the tricky balance between the autonomy and safety of the PG-resident. The Physical Therapist highlighted the shared responsibility of the different hcps, towards the needs of the PG-residents. The Occupational Therapist wants to be open and involved towards someone's needs because doing something extra (outside your 'function') is very important for IQL. Moreover, the Spiritual Caregiver mentioned that 'being there' and 'endure with someone' is essential, so someone feels seen and heard. In this, the cultural background of the resident is important to understand. In this case the Spiritual Caregiver needs to understand the Indian-Moluks background of the residents.

Reflection on Perceptions and Actions

Sub-question four: How do healthcare professionals reflect on their perceptions and actions in practice regarding IQL?

The interviews and observations helped define how reflexive spaces are shaped, how hcps reflect, and where they reflect. The results confirmed that Zinzia 'stimulates conversations constantly, to stimulate learning through reflection'. However, reflections are not always conscious actions, for which hcps 'sit down'. Instead, hcps constantly tune (9) between the needs of the PG-resident (2&3), their role as a hcp (11), the concerns of the network (7), and the fact that there are practical limitations (8). This they do by asking themselves questions like: 'am I doing this right?', by asking for feedback from their team- and discipline and reflecting on the whole care process (what could we changes, for instance, in the planning?). This they do both formally and informally, within *Reflexive spaces* (Wiig, Aase & Bal, 2019), such as behavioural visits, intervisions, moral deliberations, policy starting points, and quick conversations in the hallway. These are 'places' where they ask themselves questions to understand what 'good care' (4&5) is for this PG-resident. This was also shown through the observations. In particular, the observation of the *behavioural visit*. I felt that the dialogue between the hcps was open and that there was space to be vulnerable about 'how to act in practice'. This defines *Reflexive spaces*.
Although the reflections are happening 'between the lines' of their daily work activities, hcps are analyzing the situations metacognitively (Denton, 2019), and they are trying to understand how they *influence* the care process and *why* they think and do what they think and do (11) (appendix 7). My role as a researcher towards the research process (3.3), could be compared with the role of the hcp towards the care process: we do influence it. Being aware of that and considering it, is reflexivity rather than reflection (Coleman, 2019, in Costley & Fulton, 2019). They reflect with the skill of reflexivity in *Reflexive spaces*.

To illustrate this, I filtered a few questions towards IQL from on the dialogue during the interviews and observations. They could be seen as the embedded guideline or lead for reflexivity in the work of the hcps. The aim of IQL also became implicitly visible in these questions they asked or described (table 4).

Table 4: Imbedded guideline questions towards IQL

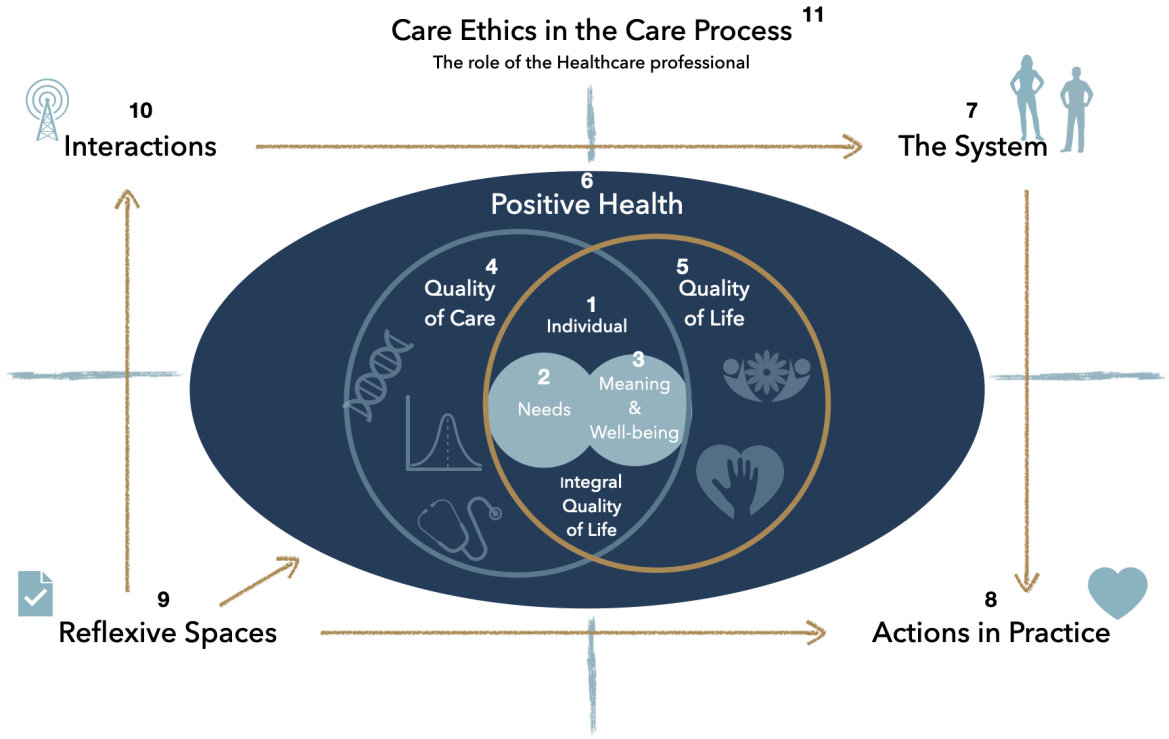
Topic towards IQL	*Question*
Meaning	'How could we continue your path of life, as best as possible in relation to who you have always been and what is important to you?'
Well-being	'How can we create the conditions in such a way that you can still do what you want, or so that you experience less 'burden' (pain, unrest or stress), which increases your well-being?'
Having eye for individuality	'Who are you? I want to know you, so I can help you. What do you still want with your life, so that you feel comfortable and so you are not a threat to yourself or others?'
Social needs	'How can we bring people (residents mutually or residents with family) together?'
Psychological needs	'What is the right balance between physical and psychological needs? And how can we support the network of the resident?'
Physical needs	'How do we look at someone's physical needs regarding his/her diagnoses, without forgetting the person, the individual, the life story, all other components of life?'
Spiritual needs	'How do I 'endure' with someone in relation to his/her questions about life and his religious background?'

All these reflexivities are about the question 'what is good care for this resident?' This is a highly complex question to answer universally. But even for an individual, it could be challenging to answer because PG-residents cannot tell themselves what they need. Hcps know a lot about certain aspects of good care, but they do not always know what 'good' is for a specific person. 'Sometimes we think very paternalistically: we know what you need' (Physician – Zinzia Zorggroep, Personal communication, March 12). However, they try to advise about what a 'good' choice could be.

4.2 Theorization

The answers to the first four sub-question (reflection) are theorized in figure 8. This model represents the role of the hcps (7-11) regarding the IQL experience of the PG-resident (1-6). It shows what factors influence how hcps give meaning to IQL. Besides, it shows what IQL means in practice and what Zinzia describes as 'it is a result of different services and activities, which lead to different IQL experiences for everyone' (Zinzia Zorggroep, 2021).

Figure 8: Theorization of factors that contribute to giving meaning to Integral Quality of Life



This model represents the role of the Healthcare Professional regarding the IQL experience of the PG-resident. Everything within the blue box represents the Individual IQL experience of a PG-resident (1-6). The four factors around the blue box can influence this experience (7-10).

In the middle of this figure (blue box), the construction of 'Integral Quality of Life' according to the healthcare professionals is visualized (1, 2 & 3). This relates to 'Positive Health' (6): which is a combination of Quality of Care (4) and Quality of Life (5) (figure 3). The construction of IQL shows that every Individual (1) has unique Social-, Physical-, Psychological- and Spiritual needs (2), which contribute to a feeling of Meaning and Well-being (3).

The four factors around the blue box are the System, Actions in Practice, Interactions, and Reflexive Spaces.
The System (7) plays a role in understanding the needs of the PG-resident. This could result in Actions in Practice (8).
There are many forms of Interactions (10) within the System. But also between the System and the PG-resident. This plays a role in understanding the needs of the PG-resident. Making a connection with the people involved and considering your perceptions as a Healthcare Professional towards the care process are the two most essential Interactions that influence the IQL experience of the PG-resident.
The Healthcare Professionals reflect on this in Reflexive Spaces (9). They reflect on their own perceptions and actions, on teamwork, and the whole care process. In this, they ask themselves the question, 'What is good care for this PG-resident in this situation?' Finally, the Healthcare Professional(s) consider all these factors to give meaning to the IQL experience of the PG-resident (11). This relates to Care Ethics.

4.3 Reflexivity: thoughts and feelings

These results gave me insights in the complexity of the care process and the role of the hcps in this. It moved me to see the compassion they have and the will to understand what a PG-resident needs. They want to know someone's story. They are not there to say what good care is in general; they investigate what good care is in a specific situation. So, their work is not based on a method or a tool, but it corresponds with what I call *emotionally driven logic* (appendix 4). Because it is about the actions that follow from a particular perception of human. Moreover, this perception is not only based on the biomedical discourse; they see the PG-resident not as a demented person. Although they have an eye for the challenges, the Dementia condition holds. There was much connection visible during the interviews and observations. They tried to bring the interconnected system of people who are involved closer together.

However, of course, their perceptions of IQL are idealistic. It is utopic to think that it is (always) reachable to give someone exactly what he/she needs. That is already a challenge among people who can tell. However, with this target group also in the end hcps do not know if they did the right thing, making it even more complex. Despite the chance that they understand someone completely wrong, or even though lack of resources prevents them from giving what someone needs, and even though specific existential questions and dilemmas of the family cannot be answered (why is this happening?), they try their best to do their jobs as good as possible. They also mentioned this complexity during the interview and are realistic about it while searching for solutions. It moved me to see this compassion within the brokenness of reality.

I think in the end, this is also one of the reasons to investigate this topic. Most things that are told in public hold tragedy and sadness. That is why I wanted to give a voice to the people who try to give meaning to an IQL experience of someone, despite all things that are not fixable anymore. That is why I wanted to tell the story of this complexity from a more insider and personal perspective.

Chapter 5 Discussion and Conclusion

In this chapter, I described the answers to sub-questions five and six (5.1&5.2). Besides, I discuss the validity, reliability, and other literature while providing an academic debate (5.3). I give recommendations for further research (5.4) and describe the conclusion of this research (5.5).

5.1 Recommendations for Zinzia

Sub-question five: What recommendations follow from this for further development and implementation of IQL in Zinzia for healthcare professionals and policymakers?

Zinzia wants to stimulate openness among hcps to increase learning through reflection. However, as discussed, reflection could be broadened by reflexivity. Instead of stimulating moments of reflection in which hcps are looking back on *how* they have done things concerning the things they try to do, Zinzia could stimulate reflexivity by reflecting on *why* they do things and how this *influences* the care process (table 4) (Coleman, 2019, in Costley & Fulton, 2019). The learning process is then also more personal, because most reflection happens 'between the lines'. Some hcps are already quite good at this, but they also mentioned that not all their colleagues are aware of how they influence the care process through their perceptions and actions. A recommendation therefore is to stimulate learning through reflection with the skill of reflexivity. Previously this got attention at Zinzia through presence training (based on the presence-theory, appendix 2). However, these trainings were stopped because the name of the training got more 'attention' than the skills, according to a policymaker. Nevertheless, based on the things I found I would recommend Zinzia to look for another way in which reflexivity by hcps could be stimulated. For instance, with focus on the elements of *care ethics* (table 1) and making hcps more receptive for the needs of 'the other' (table 4). How to act compassionately within *emotionally driven logic* (appendix 4)? The research of Allen (2018) and Mann (2005) about nurses as being the 'glue' in hospital care (like hcp are in long-term care) and the concept of *emotional labour*, which are also mentioned as recommendations for further research (5.4), could also be used to train the skill of reflexivity. From the role of Quality and Innovation Advisor, I would like to investigate how to design a learning program regarding this skill and regarding the creation of more *Reflexive spaces.* Learning this skill is essential for all different hcps, in every care context. It could make hcps aware of the power tension they are dealing with, because of the vulnerability of the care receiver.

Besides, Zinzia could train the understanding of someone's cultural background, in order to understand someone's needs. Culture can tell al lot about how someone experience IQL.

At last, as mentioned, most of the time, quality of life is measured by HRQoL (Banerjee, 2007). This research showed that it is also possible to show experiences regarding quality of

life qualitatively. A narrative way of storytelling could therefore be used as quality control. Not because it gives objective measurements (which is required by the inspection), but because it shows rather than tells what is going on in practice.

5.2 Personal Learning

Sub-question six: What does this research teach me (about how IQL is socially constructed)?

First of all, I learned that hcps construct IQL primarily based on their perception of human. Besides, the (im)possibilities play a role in this construction. For instance, the best would be if every PG-resident could have full attention for his/her needs. However, because of lack of time and money, they live in a group setting, in which the attention must be divided among eight or nine residents. Therefore, having an eye for individuality must be specially mentioned as an important theme of IQL; it is not self-evident. Regarding the limitations, 'assembly line' work would be much easier. However, because the individual is found significant, this is not how they construct IQL.

Second, this research gave me insights in the complexity of the care process and the dedication and compassion of the hcps. We must not think 'lightly' about the things they do. This work takes much patience, while they also have to deal with disappointments and loss. After all, they work with people who only deteriorate in their last phase of life. I found it admirable to see how hcps continue to work, even though the residents will not get better. Third, because of this dedication I saw, I now also look different at other hcps in other sectors. From my experience as a patient, it was depending on the hcp whether I felt seen or not (appendix 1). However, now I understand the difficulty of acting from *emotionally driven logic* in this job more (appendix 4). I can now understand why some hcps convey their biomedical logic to a patient without much attention to emotions. Because now I know that they are dedicated to helping me. Otherwise, they will not choose a profession in which the interactions between different people are complicated. This makes me more patient. However, this also teaches me that I, as a patient, may express my opinion because as dedicated as hcps are, only I know what IQL means to me. Hopefully, all hcps will stand as open towards that feedback and learn from this, as the hcps I interviewed and observed at Zinzia.

At last, the skill of reflexivity has broadened my perceptions, and it is a skill I can always use to learn from experiences and do things better in practice.

5.3 Discussion

In this paragraph, I will discuss how the research choices have influenced the quality of the research. Besides, I bring in an academic debate.

Concerning the Introduction

I used an interview with the Director as an introduction and as a guideline for the topic-lists. This has made it possible to align the research more closely with Zinzia's mission, (care) vision, and strategy.

In this research, I only indirectly considered the fact that the PG-residents are living in a group. This fact influences the care process of the individual, but I did not investigate this influence. This would have given insight in how hcps must divide their time between the PG-residents and this influence of giving meaning to IQL.

Besides, this research was done only among hcp who give 'treatment'. A comparison between the perceptions and action with the hcps of daily life activities would have given insights about both groups. Now I only heard from one group of hcps what the other group needs. I have an incomplete picture of the total complexity.

At last, in sub-question four, I asked about how hcps 'reflect', which I intend to describe. However, it turned out they use reflexivity instead of reflection. I had to use the word 'reflexivity' for this question. The answer could have made it possible to give target advice on what fronts this skill must be stimulated.

Concerning literature and theory

This research has a unique way of showing practice. Hcps try to understand the needs of a PG-resident because they are aware of the possible power tension (Tronto, 1993) when they project their perceptions on the PG-resident. It is not about how the hcps construct IQL, but about what the PG-resident needs. The difference in perception towards HRQoL between hcps and PG-residents which Nijsten, et al (2018) mentioned, is therefore indeed irrelevant. Nevertheless, this research showed that a PG-resident depends on the support of the hcp to experience IQL. This confirms the research of Custers, et al., 2012.

Care ethics and *positive health* help to understand the complexity of the care process, better. *Care ethics* gives insight in the importance of the role of the hcps, and *positive health* showed that every person has an individual 'health' experience depending on his/her ability to self-manage. However, as guideline, *care ethics* present rough generalizable elements (table 1), which cannot provide adequate guidance for all interactions and circumstances. What good care is for one PG-resident could be harmful to another (Beauchamp & Childress, 2019). That is why reflexivity in *Reflexive spaces* is essential. Through this, the hcps will be more aware of their influence on the care process, resulting in a better understanding of needs and better care for this PG-resident.

However, *positive health* is not fully applicable to the PG-resident. If these PG-residents were to be given complete self-management, this would lead to health damage (Van Staa,

Cardol & Van Dam, 2017). That is why they live in a nursing home. These people depend on help from the hcps because they lack sufficient self-management. Besides, the construct of *positive health* hardly gives any attention to environmental factors, such as helpful people, that influence a 'health' experience. It only mentions the personal experience (Van Staa, Cardol & Van Dam, 2017). That is why *care ethics* contribute to *positive health*. This discourse emphasizes the importance of other people -hcps- towards the PG-resident's personal 'health' experience. They strive for as much self-management as possible for the PG-resident.

Although I used *social construction* to investigate perceptions and action, this discourse is not necessarily approachable in an organizational culture, despite the fact I argued it could. It declared more about how society is shaped and how cultural perceptions develop over time (Barry & Yuill, 2016). Besides, I was interested in how the individual perception was framed, and from there have an 'overall' view, instead of looking at the cultural perception. I better could have used the concept *of Social Cognition*, which explains how people see themselves and the world around them and how they, therefore, select information, interpret, and use this (Vonk, 2013).

Concerning the methods

It was the first time I did AR. Although there is not one right way to do this, with more experience I could have better argued my choices and how this has influenced the research. During the research process, I learned how to do this. In the beginning, I was less aware of this than in the end. This could have influenced the quality of this research.

Besides, more experience with the field would mean, more knowledge about different methods of analysis. After I had already done the interviews, I decided to analyze them in a narrative and thematic way. Even though I think that this way of analysis fits the way I interviewed, I would have done the interviews slightly differently if I decided this beforehand. Then I focused more on the conversation itself and used the topic-list as back-up. Even though the conversations were spontaneous, I discussed every time almost the same topics. I am curious what I would have known if I had focused more on the stories instead of on the concepts. On the other hand, now I had more control of the interview content (Blom & Nygren, 2010). Nevertheless, in the end, I did ask about things they wanted to tell me about the topics we discussed or about what frustrated them or what they were enthusiastic about. Sometimes there came whole new stories, which made my data richer.

The hcp has very corresponding perceptions towards the topics. I had interviewed enough hcps, because of the consistency of the answers. However, five out of 150 hcps I defined for this research is not representative of the whole group. However, their perceptions fit the theories I used for the research. Nevertheless, this could also be caused by the fact that

Zinzia selects employees towards these perceptions, something a policymaker told me. So, if that is the case, these perceptions and actions are not generalizable to other hcps.
The observations were meant to show how actions in practice occur, so the reader would 'feel' what is happening. However, because I was the only person who observed and the only person who wrote a story about it, the story could be biased. I cannot know in what way. I asked the hcp themselves to read the stories I wrote. However, I got little to non feedback after asking twice. The most helpful feedback I got was that the spiritual caregiver had experienced little things differently from what I observed, which is obvious. To know if the stories showed what I tried to show, I asked my supervisor to read the stories and give feedback. She mainly agreed with what I had written, so I only changed a few things.
The stories represent my thoughts and feelings towards the things I observed, but they did not give a valid – like objective – view on reality. Nevertheless, this is not a problem because the goal was to theorize reality by showing my experiences.

I have analyzed the interviews and observations twice to increase my rigor, consistency, and reliability. Sometimes I changed things because deepening on the context; the same word must be coded differently. However, it would have been better if one or two other researchers would have coded them. Now I do not know what the inter-review-reliability is. Now I am the only person who can argue the validity of the codes.

Concerning the results

The occupational therapist and the spiritual caregiver worked more with somatic-residents than PG-resident. Their main perspective was therefore based on these experiences. However, they also had experiences with PG-residents, so I asked about that.
Besides the questions I formulated in table 4, I have filtered from the data myself. I did not validate these results by asking about it by the hcps.

However, I discussed the results with Zinzia's management (June 7, 2021). They were surprised and enthusiastic. They mentioned that Spiritual needs are intrinsically and naturally intertwined with other needs. So, even though this was not explicitly mentioned, it is indeed part of IQL. Especially the Spiritual Caregiver gives attention to these needs. Her role differs from the other hcps and is, therefore, in other ways important. They confirmed that I expressed IQL in figure 1 correctly.

I also discussed the theory of figure 8, which gives insights in the care process through a combination of discourses *about* practice and data *from* practice. This model is a new way of explaining practice because it is based on qualitative data. It does not tell 'averages' or 'standardizations'. However, it guides the explanation of experiences. To my knowledge, this is new in the literature about (I)QL. Zinzia could use these insights to explain to all employees what Zinzia aims: giving meaning to the IQL of the residents. Management considers whether this theory can be used strategically.

Besides, they told me that Zinzia starts with a project regarding reflexivity skills. My recommendations regarding this skill, confirmed the strategic choices they already made.

Concerning Reflexivity

I am aware that this research and the theories I used, fit my own opinion and the things I found important in life. This could have resulted in a bias of 'overconfidence barrier' (Vonk, 2013). This states that people are trusting the justice of their own decisions and opinions too much. On the other hand, personal motivation made me more motivated for this research, which could have led to deeper investigation. Besides, my hypothesis between perceptions and actions were different from the things I found. That result was not biased by the 'overconfidence barrier'.

Further, I am not sure how/if this research will contribute to social transformation at Zinzia (McDonnel &McNiff, 2017). Maybe the storytelling gives insight and could contribute to quality control. But it has already transformed me. It was confronting. I always looked at care from the perspective of a patient. My own experiences were my motivation for this study. Now I have learned to understand the perspective of the hcp. I think I have a better perception now, because my frame expanded.

5.4 Further research

I found making a reasonable research frame difficult. I wanted to bring into many theories, which made the research less readable and a little chaotic. I tried to narrow it down, but now I have the feeling I investigated not enough to understand the practice. Many questions are left to investigate in the future.

For instance, I would be interested in investigating the indirect actions on an organizational level that contribute to an IQL experience. This research has shown how there is given meaning to IQL directly around the PG-resident. However, there is a whole organization, there are laws and regulations, and a healthcare system that also influences this. It would be interesting to investigate how these indirect processes contribute to an IQL experience.

Besides, to increase the skill of reflexivity in practice, it could be helpful to investigate the translation mobilization theory of Allen (2018), in which the hcps could be seen as the 'glue' in the long-term care process because they play an essential role in the relationship between patient-, professional- and organizational needs (Allen, 2018). This also links to the first idea for investigation. Besides, to increases the skill of reflexivity, *emotional labour* could be helpful. This is the ability to express and suppresses empathy at the right moment in the right amount (Mann, 2015). This concept corresponds with how I view *emotionally driven logic.*

Another idea is to integrate *care ethics* and *positive health* even more deeply, which could be applied in other contexts such as education or police and justice. In these contexts, the relation between power tension and personal needs or experiences could also be a problem that these professionals need to be aware of.

5.5 Conclusion

The research question was: "*How do healthcare professionals who work for Zinzia, give meaning (through perception and action) to Integral Quality of Life of psychogeriatric residents, how do they reflect on this, and what can these healthcare professionals and the policymakers of Zinzia learn from this research and what does reflexivity teach me"?*

The answer to this question is multi-layered.
The hcps give meaning through perceptions and actions to Integral Quality of Life of psychogeriatric resident, **by having an eye for the individual** social-, psychological-, physical- and spiritual needs to contribute to a feeling of meaning and well-being. To know what these needs are, they use the skill of reflexivity to reflect in ***Reflexive spaces*** on the question '**what is good care for this PG-resident in this situation?**', towards themselves, with their team or discipline, and on the whole care process. Hcps and policymakers of Zinzia learn from this that **reflexivity in *Reflexive spaces* is essential to give meaning to Integral Quality of Life**. Besides, they learn that **storytelling could give valuable insight** to understand actions in practice regarding the PG-resident's Integral Quality of Life experience. Reflexivity, therefore, has taught me further to explore my influence on this research process, but it also gave me insight in **how healthcare professionals influence the care process**. It has broadened my perceptions. It is a skill they and I can always use to learn from experiences and do things better in practice.

Epilogue

In appendix 1 I told a personal story to explain the relevance I saw for this research. I hoped to understand how healthcare professionals try to understand the needs of someone who asks for help. That is what I saw.
I indeed say that the healthcare professionals had a personal interest in the needs of the PG-resident. They showed compassion through their dedication. They looked beyond the diagnoses and used treatment to contribute to a feeling of meaning and well-being for the PG-resident.

I think through these observations, I have seen the essence of life. Sometimes just because of the suffering and the knowledge that our life on earth is ending, people get more motivated to make the good out of it. Why should we do our best if we had endless opportunities to do so?
I saw the essence of life through the compassion that was expressed in the interaction between people. This interaction is essential for both the healthcare professional and the PG-resident; it contributes to a feeling of meaning and well-being. Because like Levinas has said, “The face of the other is a revelation” (Ten Kate & Poorthuis, 2018). We see the essence of life through the face of other human beings.

Therefore, I wrote a poem in which I express my hope for the PG-residents' feeling hopefully have deep inside, despite their condition and the lonely walk of it, towards the help they receive from the healthcare professionals.

Bij elke stap, heb ik de kans
die niet alleen te nemen.
De hand, die ik dan grijpen mag
is om de last wat te verdelen.
Eenzaam zwoegend tot de top
blijft de innerlijke pijn.
Toch weet ik dat elke stap
uiteindelijk niet alleen zal zijn.

"Language, consciousness, time and association are not comprehensible from an isolated human subject, as philosophy has long thought, but presuppose from the outset the relation of that subject to the other. It is this relationship that also provides access to transcendence, to an exteriority that does not destroy the integrity and freedom of the human being but founds it. Taking responsibility is at the heart of the revelation in the convergence of consciousness and conscience."

- *Immanuel Levinas (Ten Kate & Poorthuis, 2018)*

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Appendix

Reflection on giving meaning to Integral Quality of life

Master Thesis Appendix

"The face of the other is a revelation"

- Emmanuel Levinas

Content

Introduction

In this document, you can find all the appendix of this research, which will give further background. My motivation for this research will be in-depth, as will Zinzia's vision on IQL and the fruition of this construct. I also will explain what I mean with 'Emotionally driven logic,' as mentioned in chapter 3. Besides, the used topic list of the interviews will be explained, and the format used for the observations. Also, the whole observation stories are added to this document. Those will 'show' what is going on in practice and give therefore many insights into reality. After that, the analysis of the interviews and observations will be explained, in which you can find an abstract of the interviews.

1 Personal Motivation Story

There were several reasons why this thesis was relevant. Here I want to state my motivation. Therefore, I will tell an anecdote of personal experience, not a funny one, but a relevant one. One that hopefully makes clear why I feel connected with the PG-residents of Zinzia Zorggroep.

I have intestinal disease. I know this now for 12 years, but I think I have had it my whole life. Even though there is a good treatment for this disease, which makes that I do not have to worry about the quantity of life, this disease has a high impact on my quality of life. Every day I try to deal with this impact. However, that does not work out all the time. This is not because I cannot deal with the treatment but because of the emotional challenges compromised with it. Besides, I still have side effects of this disease like unexplained fatigue, pain in the abdomen and muscles, allergies and constant hunger, and low sugar levels. This results in much more side effects, which always makes me worry that there is something wrong with me.
Last years I went to different kinds of healthcare specialists. I hoped they could help me with these side effects, but almost none of them could. Their conclusion was always 'You have too much stress', making me feel it was all my own mistake. Because I'm the only one who can influence my stress, right? Nevertheless, isn't it logic I experience all this stress with all these side effects? However, towards that 'fact' they did not pay attention. So, I am alone in this process all over again. Nevertheless, despite this same conclusion repeatedly, I have difficulty with the existence of the fact that this might 'what it is' and that I cannot do anything about it.
So, I decided to go to a doctor for one last time to get some faith, which hopefully could contribute to dealing better with the unavoidable side effects of my disease. This was the same doctor who also discovered my intestinal disease 12 years ago. She then looked 'beyond the person', more to the context of life, instead of only her 'specialty' part of the body (like they do in regular hospitals). I had high hopes that she could give me advice that fits my needs and my ways of experiencing meaning and well-being. In short, that she would have an eye for my Integral Quality of Life experience. So, I made an appointment.

It was an appointment via the telephone, something that bothered me. I understand that this was necessary because of the Covid-19 pandemic, but try at least a video call… How can you give good advice to a patient without seeing them? Without reading the body language? Without having an eye for the contact? …
Before the appointment, I had to send in lots of information, so when I picked up the phone, the doctor directly asked me about my part-time study, and we talked a bit about it. Nice conversation. Then I also told her that I work two days a week. 'And you are tired? So, maybe that is too much for you? Maybe you should stop working?'

Within five minutes of our conversation, this was her conclusion. Without considering the context in which I work, without considering that I have to work to pay my bills, and without considering the fact that I like it to work, I want to work! She did not ask about my needs; she concludes the things I should need *based on a biomedical discourse. While my question was: can you give me advice that could help me peruse the essential things that give meaning to my life? Because I want to do something with the time and the abilities are given to me, and not only lie in bed if that is not necessarily necessary.*
Will the conversation continued, and I told her I always need to do things because I cannot sit still, she said: 'Maybe you have just some kind of the concentration disorder?' Without asking further, I was judged *(because that's how it felt) for my actions within five minutes of the conversation, while I was not seen for what I needed. I did not care about a possible diagnosis, I cared about her advice based on her attention towards my needs. But that was not there. My heart slinked into my shoes. This was not the conversation I hoped for. I had hoped to be seen, to be heard to, to be known for who I am because of actual interest. However, instead of that, I was judged for my decisions, which gave me the feeling it was my mistake all over again. The things I mentioned were directly diagnosed with some DSM sticker, making it impossible for this doctor to see me with 'other eyes'. She had done her judgment, and this was what it was.*
Despite that my feeling of being judged could have been not suited, this doctor showed too little interest in what was exactly going on. I came to her because I felt vulnerable and depending, not because I could not take care of myself (which I now doubted again), but because I just wanted to be seen with my problem, I think.

Even though this example does not correspond with the PG-residents' situation, I think I can relate to their situation because I know how it feels to be a patient. To feel vulnerable and depending. While I just want to live. Nothing more. I think in the end, every human being can relate to this feeling: to want to be seen and make your life worth it. To create meaning in just 'being there.
Therefore, for a healthcare professional, it is relevant to ask what meaning creates in the life of the person who asked them for help. 'What kind of help do you need?' Because people are not 'just' asking for help for nothing. In my opinion, healthcare professionals are not there to give good treatment because of your illness; they are there to give good treatment and pay attention because this treatment could contribute to a feeling of meaning. Treating the illness is not the first goal but contributing to meaning is. That why I was, and I am interested in how healthcare professionals try to do that? What is needed to do that? And how they give meaning to IQL, because a person asked for this?

Through this, I hope to learn from their dedication and compassion.
Through this, I hope to see how people can be good and do good to other people.
Through this, I hope to know how I can be a good person myself.

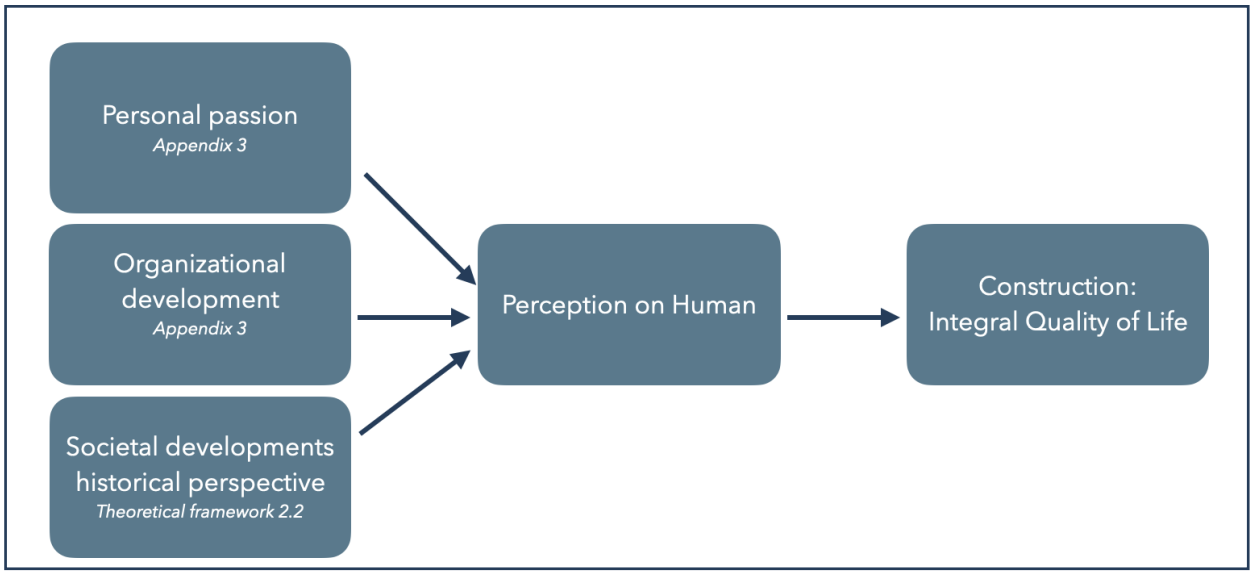
2 Zinzia's activities towards IQL

Zinzia's vision of IQL is based on their perception of human. They try to have eye for individual needs and how an individual experiences meaning and well-being. With this strive to IQL, Zinzia tries to contribute to a *Colourful life* for their residents (Zinzia Zorggroep, 2021), which they try to accomplish in several ways.
First of all, through connection with other people.
Second of all, through *Colour* (in Dutch KLEUR) which defines; Knowledge and Changes (Kennis en Kans), Lovingly (Liefdevol), Honesty (Eerlijk), Uniqe (Uniek) and Result (Resultaat). These 'key-values are expected from all the employees at Zinzia, because "It defines (…) what we found important in the interaction with each other" (Zinzia Zorggroep, 2020, p. 2). In this sentence, Zinzia confirmed that people's actions are influenced by their perception of how they have framed something.
Third of all, those key values of *Colour* result in a basic attitude of *hospitality*, *presence*, and *openness* for the residents, guests, and employees. *Hospitality* is about how care, comfort, and a feeling of welcome are experienced. This experience could be achieved through servitude, empathy, and knowledge within an inviting atmosphere with a sense of freedom, which leads to being comfortable and relax. *Presence* is related to the present-theory. This theory aims for connection with the world of 'the other'; you are opening up attentively to the other and his or her life, which requires constant tuning (Zinzia Zorggroep, 2020). This constant tuning is necessary because it can hardly be prevented that the perceptions of hcps about what IQL must look like for an individual influences how they act on it.
Nevertheless, for Zinzia this is the most essential basic attitude for a *Colourful life* for the residents (Zinzia Zorggroep, 2020). Because of that, *openness* is essential for Zinzia. Through openness, they can learn with and from each other, which could improve being present. Being reflective plays an essential role in this. Therefore, they stimulate conversation constantly to stimulate learning through reflection.
Besides these 'key values and this 'basic attitude', they try to reach IQL with practical activities such as: bringing the world inside, use modern technologies to improve care, have an eye for employees, volunteers, and family volunteers (mantelzorgers), and facilitate quality of care daily from a more biomedical perspective. So, according to Zinzia, this combination of different things contributes to an IQL experience (Zinzia Zorggroep, 2020) instead of only a biomedical discourse.

3 The Fruition of IQL

The construction of IQL came to fruition through roughly three factors, which were initial mentioned during an interview with the Director and was based on their perception on human: personal passion, organizational- and social (historical) developments. During this interview, I asked questions about what IQL means within Zinzia, how it came to fruition inclusive the history of this construct. Besides, I used Zinzia documents to investigate this vision and fruition (Zinzia Zorggroep, 2019; Zinzia Zorggroep, 2021; Zinzia Zorggroep, 2020; Breed, Baur & Visse, 2017; Zinzia Zorggroep, 2015; the Quality plan). These documents gave an overview of the fundamental starting points of 'good care' is according to Zinzia. I analyzed these documents from the same questions I asked the Director. However, this is a simplification, I mentioned the results towards fruition in figure 1. I also used this investigation to highlight a topic list for the open narrative interviews.

Figure 1: Factors towards the 'perception of human' and the construction of 'Integral Quality of Life' by Zinzia *(self-made based on interview with board of directors and document study)*



The interview showed the personal passion of the director and other employees at Zinzia, towards good care for their residents and other clients: "How can you add as much well-being as possible to people who have been entrusted to you in their last phase of life, who are very vulnerable and dependent?" (Board of Directors - Zinzia Zorggroep, personal communication, February 24, 2021). However, he mentioned that it is not about the term 'IQL', but about the action that follows from this perception, "because a term is always an appliance, not an end in itself" (Board of Directors – Zinzia Zorggroep, personal communication, February 24, 2021). So, the actions that follow from this perception are much more important than the perception itself. "It is about the elderly (…) so that he thinks 'nice to be surrounded by people who look after me and take care of me, who let me do nice things'" (Board of Directors - Zinzia Zorggroep, personal communication, February 24, 2021). So, in this context, the director mentioned that he kind of dislikes' throwing around with all

kinds of terms, (…) because a term is always an appliance, not an end in itself. When creating IQL, Zinzia used the idea of:

> *"Eclectics, this says that you try to use the good things of all kinds of stuff and ideas, and you try to optimize this in a new concept. With that in mind, also, I'm not too fond of the concept Integral Quality of Life, because this is also a term. So, language is something beautiful, but also somewhat limiting."*
>
> *(Board or Directors - Zinzia Zorggroep, personal communication, February 24, 2021)*

The organizational developmental factor that contributes is also influenced by the (short-term) history of the organization. From before 2015 they focus on the 'golden triangle', in which the care receiver, hcp & volunteer, but also a family caregiver (mantelzorger) played an essential role in creating quality of care for the residents (Breed, Baur & Visse, 2017; Zinzia Zorggroep, 2015b). They are aware of the influence of different perspectives from all actors in this triangle. The resident's perspective is seen as a need for well-being and living. This assumed safety and trust, which was encouraged with the ideas of LEAN. Besides, a few teams were trained and tried to work with the theory of 'presence'. In 2015 they combined 'presence' with LEAN management to encourage value optimization (well-being) for the resident, in which reflection on the role as a healthcare professional was the central starting point. Through this, a climate of continual improvement was encouraged (Zinzia Zorggroep, 2015a). This resulted in a 'radically human-oriented organization based on presence', according to research done at Zinzia in 2017 (Breed, Baur & Visse, 2017). Still, presence is an essential part of Zinzia's basic attitude and vision of good care (Zinzia Zorggroep, 2020; Zinzia Zorggroep, 2021). But, instead of seeing presence as thé goal, it is now a theory that contributes to IQL (Zinzia Zorggroep, 2021). LEAN disappeared from their vision document. Instead of using this term, Zinzia tries to create *Reflexive spaces* for learning through reflection to improve quality (Ziniza Zorggroep, 2020).

The societal developmental factors are theoretically from a historical perspective in-dept in the theoretical framework. However, the Director mentioned the extreme aging in the Netherlands, which increased indication before someone is allowed to go to a nursing home, as one of the most critical societal influences towards their construction of IQL. It gets more and more focus on palliative care.

> *"This all means that the throughput speed, this sounds very instrumental, but these are facts which we have seen in past years, of people who live in a nursing home and eventually passing away here, continues to rise. This is already gone from multiple years to three years. Moreover, now we see an average stay of 9 months due to how old people get and how bad they are. I expect that this will further decrease to three to six months. (…) What does this imply? They will live here shorter, that they can do and have less*

in this period (physically) and that these people are already palliative or will be very soon. All nursing homes then become palliative care programs. (…) this could mean two things. First, we want to add as much as possible emotional, psychological, and physical value for these people. Alternatively, second, that you will hold what they have left for as long as possible. (…) In this way, we want to support people to demise in the most valuable way possible. This we do by adding things to physical care, medical care, bus in particular psychological support and well-being. Well-being in this way, that we try to create every day one or more festive moments, nice moments. If we can do that, then we are on the right track. All these things together form Integral Quality of Life because it is a combination of things. There has to be good care and good medication, and we try to increase well-being to an optimum or maximum. This vision has to do with 'how we look a people'. This is a perception of human. Because a person is not only a patient, a washing object, or a person you could talk to, it is also about the integral human. The essence. (…) It is about how you look at people philosophically. And that is what we try to do over here."

(Board or Directors - Zinzia Zorggroep, personal communication, February 24, 2021)

These developments all result in the need for informal care, like family caregivers (mantelzorgers) and volunteers. Zinzia already had much focus on this, as mentioned through the 'golden triangle'. However, the Director mentioned that this need would further increase the future for all nursing homes.

"In elderly care, we can now, but even more in the future, not without the corporation with informal care. As formal caregivers from the nursing home institutions, we try to make every euro the highest amount of efficiency, so we could make our aims come true. However, we cannot do this without volunteers, relatives, and family who also give attention to their family members and help during afternoons, evenings, and holidays and support the formal care because we are not paid for an individual nurse who can go on a walk in the afternoon or who can go on a trip to the marked with one individual client. (…) If one employee does this, then there is no money left for the other members of the group."

(Board of Directors – Zinzia Zorggroep, personal communication, February 24, 2021)

4 Emotionally driven logic

I see emotions as momentary violent sensations from within in response to an experience and your perception of that experience.
A feeling is a long-term state of being concerning the world around you and your perceptions about that: based on emotions or thoughts. In practice, a feeling could be confusing if it highlights the separation or even a contradiction between emotions and thought. However, a feeling could also give insight into the relationship between emotions that you feel and thoughts you have about that. Therefore, feelings could give insight into the interpersonal 'foundations' of your perceptions about the world.
For instance: I have a feeling of hopelessness and impotence towards the COVID-19 situation. My emotions dictate deep sorrow for the brokenness of the world, which results in unsolvable existential questions. This prevents me from taking action: 'what is the point'. While my logic dictates that a pandemic results from certain environmental, social, and biological factors, which makes me sort of 'understand' what is happening. This understanding makes me look at it from a distance and respond to it through logic: 'right, so if holding distance from other people makes sense to reduce the contamination rate, then I will do that.
In this example of my emotions and logic towards the COVID-19 situation, you can see separation and contradiction. But also, contribution. Because of my logic, I'm still able to take action, and because of my emotion, I'm still able to be compassioned towards others. At the same time, this gives me a feeling of confusion, as I see the great value towards the contradiction of logic and emotion: What is the right balance? However,
through *emotionally driven logic*, I see my interpersonal perception towards the world; we have to be compassionate and consider the emotions of others in order to make justified and logical choices towards this very complex problem. When only consider emotions or only consider logic, I neglect the importance of the other factor.

5 Interview topic list Healthcare Professionals

Zinzia's perception of human, resulted in perception on IQL. Having an eye for individuality could contribute to experience meaning and well-being.
I did not ask all these questions exactly. Most of the time, all the themes got attention when I only asked question one: how does IQL mean to you?

Date:
Manner (face-to-face or online):
Function:

Questions towards the content of IQL:

- What is your perception of IQL?
- How do you try to give meaning to the social, emotional, and physical quality of life by adding *meaning*?
- How do you try to give meaning to the social, emotional, and physical quality of life by adding *well-being*?
- How do you try to give meaning to the social, emotional, and physical quality of life by *having aye for individuality*?
- Which themes concerning IQL are the most important, according to you?
- Strengths or areas of improvement?

Questions towards reflection and *Reflexive spaces:*

- How was this for you? Did these questions help you? How do you reflect on this interview?
- Where did we not yet talked about that is relevant in your opinion?
- What have you learned from this interview?
- How do you reflect on your work? Do you feel there is room for that?

6 Observation format

For the observations, I used a format to make sure I looked at all the relevant things. It holds the sensory-, and emotional perceptions plus the factual sensations that happened in the room and the interaction I observed.

Date:
Manner (face-to-face or online):
Function:

- Time or arrival and duration of the observation:
- Colours:
- Smells:
- Description of the room:
- Amount of people present:
- What kind of people:
- Ambiance:
- Temperature:
- What is being said?
- What are people doing?
- How does this influence you?
- What do I think?

7 Observation Stories

"The face of the other is a revelation" - Emmanuel Levinas

I did two observations. The first one was on the Spiritual Caregiver during a Group Session. The second one was on the Physical Therapist and the Psychologist during a Behavioural Visit. These observations were done through shadowing (Van der Mijde, Leget & Olthuis, 2012). Through this I hope to 'show' rather than tell (Marshall, 2016), what is going on in practice. They give many insights into how healthcare professionals give meaning to IQL.

Spiritual Caregiver (SC)
March 30, 2021

Thick Description
We had agreed to meet each other on location at 2:15 pm. I was quite nervous beforehand because this was my first observation for this research. Even though it turned out afterwards that the situation looked like what I had imagined, I had the idea in advance that I did not know what to expect. Perhaps not meant for the setting, but especially for the attitude I had to give myself because I needed something from "them". Then I felt a bit insecure and a layman quickly.
On the other hand, I was also curious about how the session that I would observe would go. The SC had told in advance that it was a group session. The SC then begins a conversation with several residents who are willing to participate about a theme that she has prepared in advance. The purpose of this is to give everyone a sense of community. After all, it is pretty challenging to get used to in a nursing home where you live because there is something the matters to you.
Besides this, this SC works in a nursing home for Dutch people with an Indian or Malukan background. Many of them were forced to come to the Netherlands after the formation of the state of Indonesia shortly after WWII, having experienced the devastation of the war and liberation in Indonesia. Therefore, the SC usually focuses in the group meetings on this cultural background and the experiences of many residents.

I was present on the location at a quarter to three. I had to wait a while for the SC to collect her material. This meant that I could "get used" to the environment and absorb many things. This location has aligned its design with the culture of the residents. Information about Indonesia can be found everywhere and photos of the country and works of art from the country. The atmosphere is also very warm and open. Residents sit together in the hall drinking coffee, and everyone greets each other when they enter or when they are on a walk. Every time I come to this location, I get a warm and open feeling. For some reason, I feel connected with these people, without knowing them or their culture well. I like to come there.

We walked to the living room of the ward, where the group meeting would take place. There was also a volunteer who would assist with the practical matters of the meeting. Two residents were already waiting at a large, long table in a sort of kitchen dinner. They smiled at us when we entered. The SC and the volunteer kindly greeted the residents. It was warm, although the curtains were drawn to block the sun. This department on the ground floor was directly in the sun. However, that was no problem for the residents. Since I was wearing a face mask, the smells I smelled were even more mixed together and, at the same time, softened. Here and there, a perfume scent from a resident 'came along', combined with food that had previously been prepared in the kitchen. The nurses picked up three more residents who wanted to participate in the meeting, which was entirely voluntary, while the other residents at the table chatted a bit. They were all women who were addressed as 'aunt', or their first name was mentioned. This alone already gave an open feeling of being together. Not so distant, but rather cozy. As if they had known each other for years. I was sitting in a large armchair at a short distance, watching. The care had already set up tea water. Every resident was given a cup of tea or juice while the women chatted. I also got a cup of tea from the volunteer. Coffee was no longer served in the afternoon, but chocolates were distributed. Not everyone needed one, but the gesture was nice. The sun continued to shine through the curtains all this time, which made the atmosphere in the room appear kind and accessible. In the meantime, people walked in and out. Several more residents were brought in, and everyone sat around the table in a circle. We were now with five residents, one volunteer, and one SC, and I observed the situation from a distance of about 2.5 meters.

'Good afternoon', these people were greeted by the SC. Some chatted about the sunny weather and their morning activities. Others sat quietly in their seats and listened to what was said if they could still follow or understand it. 'Here we are, cheers', said the SC as the official opening for this meeting. She had brought a large mountain boot, which immediately caught everyone's attention. 'Shoes on the table are bad luck', shouted one of the carers before she just left the room, while all the women chuckled at her comment. 'It has been a long time since I was there', this was because of the COVID-19 pandemic, but fortunately, all the people present had been vaccinated now, and they were glad to be back together here and that this meeting was possible again. That is for sure. So, the SC was luckily able to take off her mouth cap.
The SC continued her program: 'It is time to light the candle in the center of the statue with all the puppets holding hands.' As she lit the candle, she began to sing: 'light in the night, which drives away the dark, light it, be it, you'. Two residents began to sing along softly. They looked at the candle, partook of their chocolate, or choked on it. 'It is great that the light can light up the room, and us too'.
The SC began to tell what she wanted to talk about with the women. *'Mountains and valleys'* was the theme. 'Did anybody of you live in the mountains?' was the question. One of

the residents said yes, somewhere in Europe. The SC started a conversation about this with this resident. Another resident had only looked at the mountains. She could not go up because the weather had turned sour, and the cable car had stopped working. She had found the mountains interesting to see. The SC went all the way and asked everyone if they had lived in the mountains or had ever been there. Some did not remember, could not understand the question very well, or found the question difficult to answer. As she went through the list, the other women listened to what was told by everyone. Although it was indicated afterwards by the SC and the volunteer that we are, of course, not sure whether everyone could have followed the meeting correctly and whether they could have come along. That is always difficult to determine with this target group. Almost all women had lived in the Indies in their early years. The question about living in the mountains, therefore, evokes childhood memories in some women. The SC joked about marbles they played with as a kid that would have rolled down. 'Then we would flatten the bottom', one of the women replied. However, the memories were not always pleasant. Several women had lived through the war and had to live in a camp in the mountains for a while. In WWII, they were allowed to roam freely, but once the Japanese had left and Indian nationalism emerged, they were put in a camp with their families because they had (partly) a Dutch background. The memory and the emotion surfaced in these people. The SC continued to listen quietly, sometimes summarizing what was said, and continued asking questions. She was understanding and patient. One lady became a talking waterfall of memories; another lady could hardly express what it had been like for her. She nodded when asked if she recognized the stories but did not want to elaborate. The depth of their grief came to the fore, while at the same time, it was so intertwined with their life story that a certain distance from the situation was noticeable in the way of telling. At least, that was how I experienced it. Nevertheless, it seemed beneficial for all women to speak about this topic or listen to what other women were saying about it. Again, if they were able to follow the conversation at all. For some women, being together and feeling someone else's presence may have been a greater motivation to come to the meeting than the content of the conversations that took place. I thought it was nice to see that a little bit of the need for connection and being seen was achieved for everyone.

The SC indicated that she sometimes found it difficult that she had never been to the Indies and that she did not always understand everything about what it was like there. For example, the weather was so different from the Netherlands that these women should have gotten used to it. The Dutch perceive the Indies as a very warm country, but it is freezing up in the mountains even there. 'I recommend that you bring gloves. 'The Netherlands has no mountains', said the SC. 'Except the Wageningse berg, but it is only 30 / 35m high'. The women began to laugh among themselves. That was of course nothing compared to the Indies.

Despite the fact that the mountains were so high there, one of the women said, ' When you walk up in the mountains, it is so beautiful there that you will forget your tiredness when you are up there'. It touched me. This sentence was such a beautiful metaphor for life and

the challenges you may encounter. The SC also agreed with this. *'Never measure the mountain until you have reached the top,'* and she clarified that comment and then asked the question 'is this also the case in your life?' Do you sometimes see something like a mountain?' Again, she gave all women the opportunity to answer. Some people gave an example of what was difficult; others found it difficult to put it into words or indicated that they had never experienced it. Immediately after this, the Japanese era came up again. That they were no longer allowed to go to school and were no longer allowed to learn Dutch. 'My mother did not want us to speak it any longer because of safety'. 'I have also been in prison', said a lady. 'After the war we had to go there, because my father was Dutch". "I did things that shouldn't be done, but when you're hungry.' she gave a few examples: 'I hope my children won't ever experience war'. 'I just adore weeds from the garden.' 'I've been so hungry.' These ladies spoke very openly about their trauma because that is what they have got! The SC responded understandingly. 'I get so annoyed that people say they want to eat more and then don't eat it, I can't stand that,' one of the women said next. She elaborated on a story about what she shouldn't have done when she was hungry in the past. But yes, she was so hungry! They told how they took care of each other and the prisoners. A heated conversation, to which the SC and the volunteer contributed by asking questions. And politely the lady says: 'We were going to bury someone, and as soon as that was done the Indians came to steal his clothes to sell, because they were also hungry. They were also just people'. 'But we made it', said another woman, 'I should be grateful for that'.

I could sense the attention that several other women paid to this story. The SC and the volunteer also gave the story extra attention. Not all women received the story correctly, so the SC checked this with these women and asked if they could follow it. 'I had to take care of my mother, who had survived the war. She came to me for support, 'was the answer she got.' 'Everyone has worn his or her cross', said the SC. And the women nodded in agreement. 'But it always seems worse with someone else'. 'We are talking about mountains and valleys, and these are mainly valleys, yet you got out again, how?' said the SC. 'I pray a lot', almost all women agreed. Almost all of them were deeply religious, and praying helped them to recover, to get back to a mountain top. 'A beautiful song goes with that' the GV continued and began to sing. God is always there in life, whether you are standing on a mountain or sitting in a valley. Slowly, almost all the women began to sing along. A soft song echoed through the living room as everyone searched for the right words. I tasted a kind of unity because of the openness and vulnerability that sounded through this. Nice to be able to witness.

The SC continued, 'Have you had any high points?' was the next question. A lady tried to express what she thought 'we are better off than before', which they discussed. That is undoubtedly a highlight. 'What else made you so happy?' 'That I came to the Netherlands'. Although this lady indicated that the Netherlands was a high point for her, this had been a low point for another lady. She had not wanted to leave the Indies. She had a hard time

talking about it, too, so she kept quiet and listened to the other women. One started to say: 'we got food in the guesthouse when we arrived in the Netherlands, which we did not know: 'herring'

Who likes that? Later I asked if I could cook myself in the guesthouse. That was much better'. 'My mother was also so good at Indian cooking,' one of the other women continued. 'While I was born and raised in the Netherlands. But I didn't learn very well myself, because I had to take care of a lot for my father who was still afraid of the war'. For all women, the differences between the Netherlands and the Indies were great, which was sometimes quite confusing. The Dutch knew so little about their life in the Indies. "We were thought to be a little bit 'stupid"'. I could sense the frustration and irritation and misunderstanding of this lady when she said this. No doubt she would not have liked it. 'In addition, we had to pay back everything we had ever received when we came here in the Netherlands. And I don't want to say bad things about other immigrants, but…' She felt unjustly treated. The SC responded calmly to this. 'I understand', she said. 'Even if those other immigrants came later, and the times were different then, you had already experienced this, and it was not fun for you'. 'I don't tell everyone this everything either', said the lady. 'That's the beauty of this meeting', the SC agreed. 'Do you recognize this too?' A silent lady was asked, who found it difficult to say something about these things. Finally, she turned her head and nodded. There is still so much frustration about the differences in which other immigrants are treated compared to the Indians in the Netherlands. And there is a lot of frustration and pain because of what they had gone through. The pain about the past is still deep. The conversation went on a bit of a chopper. Everyone said something and the SC tried to make the conversation a bit more streamlined. She asked the question: 'And how do you feel about being here?' 'I'm having a good time. But I also have a lot of comments; much less interesting food, one of the women at the table responded. The SC went round and round, asking many how they like it in the nursing home: is it a mountain or a valley?' 'I am happy to say that I am satisfied'. 'My family is nice to me'. 'The people are nice here'. Fortunately, because there had been very few visitors lately, which was difficult, that is why life in the nursing home is a bit of both a mountain and a valley. 'You don't always live on top of a mountain'.

At the end of the meeting, the SC summarized: 'We have talked about the mountains and valleys of life. Don't worry about tomorrow and that trust and prayer are important to you.' Then she told another story to the women, who listened to her quietly. The story was about an echo in the mountains. She tells the story vividly and actively. The women had to laugh in between because the SC told it so vividly. It's like they can imagine it. 'The ultrasound is real life; you get back what you give. Life is a mirror of your actions. If you want more love, then give love. If you want people to be understanding and respectful, point that out to others. This applies to all aspects of life. What you give is reflected in what you get back from the other'. 'Very nice'. There was an affirmative response!

Finally, the SC sang *a wish for peace* for the women. The women quietly hummed along. It gave a mystical atmosphere to the meeting. 'Peace I wish you. Bless you'. There was a clap for the song. They could have shared something this afternoon. The women thanked the SC for this, while the candle was blown out. There was still some chatter, and some memories were recalled of previous times that the SC was there with the volunteer. And everyone was wished a nice afternoon. Some women stayed at the table; others went back to do their own thing while we left the living room again. The volunteer told me afterwards that there was so much more feedback than last time. So that I had been lucky with this session. The SC had been amazed at the speed with which the conversation had gone about deep dips and about things that were difficult in life. It was an art for her to get them out of that depth again. 'Sometimes it is difficult for these people to mention highlights in their lives because sometimes they are mainly concerned with the moment'.
We said goodbye, and I thanked her for this afternoon. I had learned a lot. Not only historically but also about how people deal with their trauma and challenging things in life. In addition, it had touched me that some women spoke so openly, as a result of which this also created openness for other women, formed an entrance to talking about their difficulties, even if they could not or no longer express it at that time. It was special to witness this form of connection between people who probably did not know each other before they lived here. However, the vulnerability they had did not prevent them from seeing each other. As far as I could tell, these women had had a pleasant afternoon, even though the conversation was often about difficult things that these people suffered as a child. And they still remember this exactly. Those stories moved me. It was great how the SC gave everyone attention and asked for everyone, even if people did not dare to say something of their own accord or could not speak or think so well at all.

Psychologist and Physical Therapist
April 14, 2021

Thick description
On Monday afternoon, April 14, 2021, I was allowed to observe the Physical therapist and the GZ psychologist that I had the opportunity to interview during a behavioural vision. A behavioural visit is a consultation between different care professionals, both from the expertise center (treatment) and from the care at home, who jointly discuss the observed behaviour of the residents of a particular department.
This visit was about a house with intensive PG-residents. This means that these demented residents have behaviour, such as aggression and anger, which require extra attention. All employees involved in caring for these residents, therefore, have expertise in this. From different disciplines and thus different perceptions, during such a conversation, each resident's behavior is examined. Together they investigate the cause of this behaviour and if they notice that a resident exhibits specific behaviour because he or she is not feeling well, for example, because of pain, they jointly look for a solution. This can be done in different ways: a different approach, additional medication, or a change in the daily schedule.

So, I was allowed to be present at such a meeting. At half-past one we had met in the meeting room of the managers. Or well, hall; it was a small room with a low ceiling and fluorescent lighting. These were not on when I entered because the sun let in enough light from the outside through the window. There was a long table in the center, already surrounded by five health care professionals. The six of us could only just get around it at 1.5m distance. More people were also not allowed to be present in the room due to the COVID-19 measures. I was able to sit close to the door between the nurse and GZ psychologist. Diagonally across from me, about 5m away the Physical Therapist, I had spoken to, sat. Next to her sat another doctor and a quality nurse. All of these people played a role in caring for the residents they talked about. They all had a laptop or a tablet with them, on which they searched or made notes. I think this is how the care file was immediately updated. Due to the tightness of the space and the need/obligation for ventilation, the tilt window was half-open. However, this caused so much noise from the lawn mower, which was mowing outside the lawn surrounding the old mansion (the main site of Zinzia), that the window was pulled shut. It quickly became hot and stuffy. But nobody seemed to care. The purpose of the meeting was clear, and they started working on it.

They had already started a bit before I got in. Apparently a little earlier than I knew. But that didn't matter. The GZ psychologist had extensively explained that I would come, and everyone was open to that. We did a short introduction round, so that I knew who was who and so that they knew what I was going to do. The atmosphere was open and pleasant. There was a laugh when someone made a joke and I immediately felt at ease. ‘We just act normal’ they immediately said. Something I agreed; because that was of course also what I

wanted to see: a meeting as usual. If I would deal discreetly with information about residents and describe everything I heard only as a case example, I was allowed to write down everything I observed. I wondered what I would see and hear!
One by one the team spoke about the residents. I didn't even keep track of how many were discussed as I initially thought there would be about three of them. But that became more than 10, I think.

The team picked up the conversation where they left off. This case was about a male who stood still in the shower for a long time. In the middle of the night. With clothes on. Without the shower being on. The nurse explained his behaviour and attitude. 'He has a bit of a blank look in his eyes. But I don't see any fear or panic'. 'Maybe it is a side effect of the medication', said the doctor. 'He can get Parkinson's-like symptoms'. 'How's the ADL going?' asked the Physical Therapist. ADL is an abbreviation for -general daily activities- (Algemene Dagelijkse Levensverrichtingen). You can think of washing, dressing and eating, for example, shortly after the resident has woken up. 'Interesting' I thought to myself, during the interview a few weeks ago, this Physical therapist gave me all kinds of examples about how she views ADL care, what she finds important in it and how she tries to support care workers in the home. I therefore found it striking to notice that the aspects mentioned are indeed here during this behavioural visit. The nurse replied: 'That is going pretty well. I just adapt to what he wants. He did not want to take a shower this morning, then I did a standing wash. So, you really have to move with him. He can also be looked after, though'. That the doctor responds to this: 'aah, so really give space, leave him with him and wait for the right moment', she noted with interest. Suddenly a question popped up at the psychologist as a result of the remark about the male staying in the shower: 'I was told that he was always rigid in the past. Is that why you can't lure him with food? The night shift keeps talking to him to escort him out of the shower. But perhaps baiting with food works better for him?' The nurse thought this was a good tip, after all, he told her everything with a smile, but without losing respect for the resident. 'Yes, he even eats Styrofoam and glass, absolutely everything'… There was more chuckling; funny that this male like that. The conversation continued. I noticed that everyone in the room was really interested in this client. They wanted to understand the cause his behaviour and help him feel the best he could. Family also plays an important role in this. For that reason, not only the behaviour of the resident is discussed during such a behavioral visit, but also the relationship and interaction that this resident may or may not have with his family or other loved ones. Also, around this male who stayed in the shower. 'Does his wife want to come over yet?' Asked the psychologist. 'No, not yet', said the nurse. That was because of COVID-19. 'I have talked about it with his daughter, because there is of course guidance for such a situation. However, he himself is not always tempted to do something', she continued. 'Sometimes we go and play football together or something'. 'Yes, talking doesn't work for this male', the psychologist added. 'That's right, that's why I often repeat the same word. Or I'll prompt it', the nurse responded. 'Then I say a few times, 'sit down, sit down''. 'Yes, some people don't get different words that mean the same thing anymore. They

cannot process that so quickly. Sometimes repeating the same word does indeed work better', the psychologist explains. It seemed like a good idea to include this tip in the care plan.

The doctor suggested to talk about the next resident. Apparently enough information and tips had been shared and notes made about this male. Mr. X slept better, according to the nurse. 'Yes, I thought so; 'That's not bad'', replied the psychologist. 'But he was very irritated this morning', the nurse continued. 'He kept asking for his wife. But his daughters keep saying that their mother does not want to visit him'. I had no idea what this situation was about. But gradually it became more and more clear to me that this is a complex relationship between husband and wife who had promised each other never to be separated from each other. But this had happened now. 'I had a talk about this with their daughters on Friday', the doctor said. 'Their world has really collapsed last year. The parents always wanted to stay together, but now this is not the case anymore. However, mother does not want to say anything, but no one knows why. They think she is angry about the whole situation. She never wanted to talk about her husband having dementia before'. 'Yes, that's right', the psychologist continued, 'she used to keep her mouth shut when something was difficult'. 'Yes, so those children find this very difficult', the doctor replied. 'Their father keeps asking for their mother, but she doesn't want to come'. 'She may be afraid that he will hit her again', said the nurse. I realized that this is a really complicated case. There is a lot of aggression in this target group, and that is often also very difficult for the family. The conversation continued on possible solutions to this situation. Not only for the man, but also for his wife. Supervision could be done when madam comes by, so that it can be done safely. In addition, the idea of a video message came along. Then the lady would not have to come by, but the male would have seen his wife anyway. But this would be difficult, because the lady does not say anything. As a last option, it might have been possible that the lady also came to live with Zinzia. 'It could be, given her limitations', the psychologist said. 'Then they are at least closer to each other'. But before such a decision would be made, the first visit must be awaited. And the lady was not ready for that yet. The doctor raised another tricky point in this complex case. 'He accepts more from men than from women. This has always been the case'. At that moment a male nurse just happened to join the conversation via an online route. He was greeted, and there was laughter. 'Well, I was just talking about you', the doctor said. 'So, he hears less from women, he doesn't take them that seriously'. In addition, some minor observations of the male were discussed by the Physical therapist and things that the daughters had indicated. He may have been cold at night. He used to have much thicker blankets at home, so the daughters would arrange extra blankets for their father. Perhaps that would also help him sleep better, as it would make him feel more nurtured. If that did not work well enough, the Physical therapist would see whether applying a weight blanket could be an option. The conversation about this resident ended with a nice remark of the doctor: 'Yes, I had a really good conversation with his daughters last Friday. They are very happy with you too', and she nodded to the nurse. 'Well, he really needs it, that intensive

PG', the nurse said. 'Sometimes he reminds me of a heavily pregnant woman who is completely covered with hormones'. They all had to chuckle at this description, imagining the situation.

Volunteers also play a major role in giving attention to the needs of every resident in this department. Both for this male's case, and for other residents, 'preventive walking' with volunteers would actually be very good. It would also offer a lot of room to give attention to the residents who stay behind in the house. A kind of win-win situation. Everyone responded enthusiastically to the psychologist's idea. 'Yes, or a cycle volunteer', the quality nurse came up with another idea. 'Yes, we are already arranging volunteers', the nurse continued. They continued to discuss this with each other. Everyone needs a volunteer for something. But those volunteers must then be aware of the target group they work with. Ow, and that they are going to do something physical with the residents. And they would have to come every day to move together. Then the residents who are a bit quieter can get some extra attention from the care staff.

In the meantime, the nurse who was connected online was briefly approached by the doctor. Some time for personal contact, between the residents' cases. 'Are you at home?' 'Yes, my youngest is in quarantine. So that is difficult'. 'Well, fortunately you could connect like this. What nice stained-glass windows you have, super nice' Everyone laughed. It remains strange to be able to look into someone's living room without being physically present together. At the same time, it creates a kind of connection. Sometimes you learn things about each other that you would never have known otherwise, such as having 'stained-glass' windows.

The next resident was discussed. 'I can't find the resident yet', the nurse said, tapping her iPad. 'No, I see it', the doctor said in surprise. 'Apparently I haven't pressed 'okay' yet'. Nevertheless, the conversation about this resident also started. 'He doesn't always want to be looked after', the nurse said. 'But is that bad?' the psychologist asks. What strikes me is that many of her questions or comments are really based on how the resident experiences something. She wants to make others aware of their actions in relation to their own norms and values, so that they focus more on the resident. 'If he's not dirty, it doesn't matter, does it?' the psychologist continued. The nurse explains the situation. This male suffers from incontinence, so now and then he really needs to be cared for. But he often does not want to cooperate. They just don't know why. Perhaps he has experienced something in the past, he was a dancer, so that grooming evokes aversion? However, once his clothes are off, it is no longer a problem. It's really about that first step. 'But why is he on medication?' the psychologist asks the nurse. 'Yes, that really works to keep him in his room; otherwise, he will keep walking down the hall and we will not be able to take care of him at all'. They jointly discuss possible solutions to make the care for this male as pleasant as possible. Sometimes it helps to turn on music, but not always. 'He's so blocked sometimes'. The nurse demonstrates how the male acts. When the clothes have to be taken off, he pulls it up.

‘Sometimes it is accessible, sometimes much less. You really have to arrange it at the right time, otherwise you cannot wash him’, the nurse explains. ‘I would like him to do it on his own, that he is ready for it himself’, the psychologist responds. ‘But he's not going to do that of his own accord’, the nurse continues, while there is a silence. ‘But does he understand what happens then?’ the doctor continues. The nurse does not know, ‘he is feeling ashamed. If he thinks it's his fault that he's wet, then he sometimes gets angry too if you want to help him. But if you say, ‘your pants got wet by someone or something’, he doesn't mind as much’. ‘But he might counteract by pulling up his pants when they need to be taken off. Maybe you should just pull up your pants?’, the psychologist says questionably to the nurse. I found this an interesting solution, a really different view of the problem. They talk a little bit further about this male. They don't know if he has a trauma, which makes washing so difficult for him. They can no longer ask this male. So, it really seems to be a process of trial and error, in which they try everything to make the process of washing and changing easier for this male: helping him in pairs, distracting in between, etc. etc. his response is the only way to find out if something works or not. All healthcare professionals are involved in the process and actively contribute ideas.
Suddenly the Physical therapist says: ‘These conversations don't always go that way, Merijne’, everyone started to laugh, a little uncomfortable. How would I respond? It is of course a fierce and complicated subject that I suddenly witness. What if he indeed has a trauma? But on the other hand, this is the reality, and I would like to map it. Unfortunately, these difficulties are part of that. That makes it even more inspiring to see how these people try to deal with this as well as possible. As the description of this observation has already shown, COVID-19 is still something that Zinzia has a lot to do with. Despite the fact that all residents who wanted to have been vaccinated, it remains difficult to deal with the entire situation. ‘So his sister has corona," the nurse says and she pauses for a moment. Everyone agrees. "But fortunately, she didn't come by’. ‘How lucky’ the doctor responds relieved. ‘Because it is not entirely clear whether we do not have to do anything else, even if everyone is vaccinated. The department will probably still have to be quarantined’. Fortunately, that was not necessary now, it would entail a lot of hassle.

They went further down the list of residents. The pace was good. Sometimes so good that I could hardly follow it. Of course, I don't know the residents, and typing is a lot slower than talking. Especially when 6 people are talking.

I think they were almost finished with this department, then a second department. Easy and more difficult cases came along. Some residents were doing better. 'A male can go to the toilet more easily, even during the night’. There was not always much to talk about other residents. ‘Except that I had a really nice conversation with this man’, said the doctor. ‘He was chatting during last Thursday's family meeting, feeling good about himself and had long stories’. Then the next case was complicated again. ‘This male probably has mood problems’, the doctor concluded from a conversation she had with the psychiatrist. ‘It's not acute PTSD,

but it is after-effects'. For that reason, the psychiatrist recommended increasing the medication anyway. 'Yes, he has always had that tearfulness', the psychologist went on to elaborate. 'But now he is withdrawing'. 'No, he hangs on to my arm all day', the nurse explains. 'He is just not withdrawing'. 'Oh, that's not too bad for me', the online nurse continued. 'He always lies down for dinner. Then it is a bit more accessible again. He does sleep a lot'. 'I just see him awake all day long', the nurse continues. So, you see that the perceptions and experiences also differ greatly between healthcare professionals. While they can all be 'true'. That sometimes makes finding the right approach extra difficult. Of course, a person is not black and white. 'Maybe he needs more balance, between rest and activity', the quality nurse continued. 'Yes, or perhaps just meaning', the psychologist responds. 'Something for which he is on earth'. The nurse explains how she tries to comply with this. 'But he doesn't like everything. The other day he even said, 'nice try girl''. And then he is crying all the time. We do have moments of fun, but if that is 2x 15 minutes on 24 hours, then that is a lot. His wife is there once a week for 2 hours'. 'Does she have to do that?' The psychologist asks. 'Well, that goes very well at that moment itself, but also afterwards. She often also takes someone along', the nurse responds. 'What do they do then?' The Physical therapist asks. 'Yes, sit in the room. Walking did not go well. But it's not like he cries more than usual. He's glad she's here; he keeps from her. And then they say goodbye and then it's all right again'. 'I hope she can keep that up', the psychologist continues. 'Because she finds his behaviour very difficult! So, I wonder if she can. We can also say to her, 'it's also okay if one time doesn't work'. She also has to watch herself a lot; it is a lot of giving, what good is that visit to her'. With this remark, the psychologist is able to identify and bring to the attention the different interests of the various parties involved, after which they discuss this together for a while. All residents of this department have now been discussed.

We now move on to the next residence. Here too people live who need 'intensive-PG' care. We have 10 minutes left of the scheduled hour. 'That should be easy', they say. But it soon became apparent that more time was needed to review these residents as well. I would like to specifically explain one case of this house. This again shows the complexity of the care process. It is difficult that the resident can no longer indicate how he feels, while you want to give good care and attention. In addition, they have to do with the interests of relatives, but also of employees. That makes it extra complicated to sometimes indicate what is 'right' to do. The online nurse went to the dentist with a resident. A very sad story, to which everyone involved responded: 'oh hey, how annoying for him'. In addition, however, this male also showed special behaviour. Sexual Behaviour. They had discussed this behaviour extensively with his wife last week. This male may have experienced something in the past that brought behaviour to the fore now, but they weren't sure. How they should interpret it and how they should deal with it, that was what the further discussion was about. An explanation for this behaviour could be that he was still in pain from the procedure at the dentist, although the visit had gone well. However, a MIC report (incident report) was generated because of his aggression. His intention would not have been sexually charged, but he does express this

kind of behaviour. He had approached a residential care worker with his hands ahead, after which he had grabbed her from the front. According to his wife, this had not had any ulterior motive. ‘But yes, everyone will say that about your husband, right?’ the quality nurse said. Because according to the psychologist this behaviour could possibly be due to the pain in his teeth, she did not want to make it very big in that sense. ‘It may be because, just like before, he will squeeze when he is in pain or not feeling well’. For that reason, they would see if pain relief would change the behaviour. ‘But we have to do something with the team about this’, the quality nurse responded. ‘Because this has had an impact on that residential care counselor’. None of the team really dared to go out alone with him and his wife tells everyone something different, which caused the concern among themselves to start arguing about what is or is not true. The team is used to forms of aggression, but this was a more personal incident, which could trigger all kinds of things for this employee. ‘We will ask the cluster manager how this residential care counselor is doing now, and whether we can do anything for her’. ‘Yes, and we have to take it seriously’, the quality nurse continued. ‘And don't just believe his wife that her husband wouldn't do that’, which everyone spent the night on. In addition, this male's wife made it very difficult for the team around the corona rules. She could find fault with every letter with an explanation she received. Logical too; because the rules have been drawn up universally, but each building is decorated differently. So, she was right to a degree, but she was so hard about it. ‘She always reproaches’, it was said. ‘She can't discuss it in a normal way’, something that really got in the way of healthcare workers. In this case you see that the reality of the care process is very complex. Different perceptions, experiences and interests emerge clearly. It remains important to look carefully and see how such a situation can best be tackled. For example, they discuss even more residents: What is already being done? What could they do against, for example, the pain someone is experiencing? How could they give the residents the right and appropriate form and amount of closeness?

Meanwhile it was getting warm in the room, while outside it was getting a little dim from the rain clouds hanging in the air. I then turned on the lights, which woke everyone up a bit. In between jokes are made, and every now and then something personal is said. This made the atmosphere open and pleasant, despite the fact that complicated cases were presented. They made appointments and put on ‘episodes’ to take care of the rest of the team. But also, are aware of what has been discussed; what these healthcare professionals now think is good for a resident. Almost everything in this is based on observation. Should you be on the right or left of someone, should you be fast or slow, should you repeat something or not. This so that everyone is aware of the needs and behaviour of a resident; this is how people are prepared, so that they can at the same time provide personal care that is ‘generally’ determined. I have deliberately chosen not to describe all of these cases in more detail. During this part of my observation, I wanted to focus more on the interaction between the different healthcare professionals. What are they actually doing now? What do they think is important? What is the focus on? All healthcare professionals listened carefully to each

other, while in the meantime they typed in their documentation for each resident. When they have their say, they tell with their whole body what happened to a specific resident. This emphasized the essence of their story. I thought it was very interesting and worth to be listened to. The atmosphere and mutual involvement was great. They kept asking each other and many examples were given. Together they tried to clarify different views of the situation. They then explained something from their own profession, and then tried to bring these different perceptions together in order to get the best possible picture of the resident. I find it special to see that this cooperation seems to be so strong. There is respect for each other's vision; they really need each other, and you find themselves embracing that fact. I often found the situations they describe harrowing. If you don't know that you can expect this, you would be shocked. In addition, the subjects were very intimate, complicated behaviour, complicated continence, etc. What strikes me is that they speak very normally about it, the dignity of the resident was never lost because of this! This is their job, this is reality, and they deal with that. The most normal thing in the world. I think that 'embracing' of the situation is necessary in order to give the right attention. They are not surprised; but sympathize and look for the right solution. While these are so dire situations, they do not let them distract and deter them. They focus on what they can do, within the complex interactions between all those involved in caring for a resident! The rest for the resident forms the starting point in this: do you have to change someone at night when he is very dirty, but also becomes very restless as a result? Or is it better to wait until morning? It is also common for them to have to choose the best option from only bad options. I think that is a strong observation. The conversation ended almost an hour later than planned. The laptop on which the online nurse was present was returned to the owner, and everyone chatted for a while. They were asked if someone could do something for someone else, they agreed on all the tasks again and I got the impression that everyone knew where he / she stood. A special experience to witness.

I have often talked about the complexity of the care process, but it is even more complex for this target group. I have therefore listed as many components as possible with which they are involved and which I have heard passing by during this observation.

- Intensive PG (where behavioral problems play a major role).
- The Care and Coercion Act (the law specifies under which circumstances you may provide someone with involuntary care and which you must constantly evaluate; for example, you may not just place someone in a time-out room).
- Medication (what suits someone, what is less convenient; what does someone need to feel as comfortable as possible.) You do not want someone to become too apathetic, but neither do you want someone to be very restless or in a lot of pain. Sometimes it is also difficult to give that medication, if someone has to swallow it, then it does not always work, or someone has a lot of resistance.
- Family/relatives (they often have a lot of trouble with someone's situation, and they are right next to it; they are in pain and sadness. Sometimes they don't know how to

deal with it either).

- The interaction between different professions (everyone takes his or her own profession and personal perception into account in the question "what is good and appropriate care for this person?").
- The fact that this is 24/7 care and not everyone is always there (as a result you have to communicate very well, which means that you sometimes neglect each other).
- The complexity of the care (in which they want to do the best for the resident, within the possibilities available. There is also often a difficult relationship between being present and absence. Too close is often a threat to a client, causing them to become aggressive. While they often need that close proximity to feel good).
- It is often also fierce for the employees (sexual excesses, aggression. This is fierce for those who give care to deal with).

In short, I have a deep respect for the work that is being done here, that they are doing and committed to it. They are themselves ‘in danger’, while at the same time they want to give someone ‘peace’ because of the care they provide.

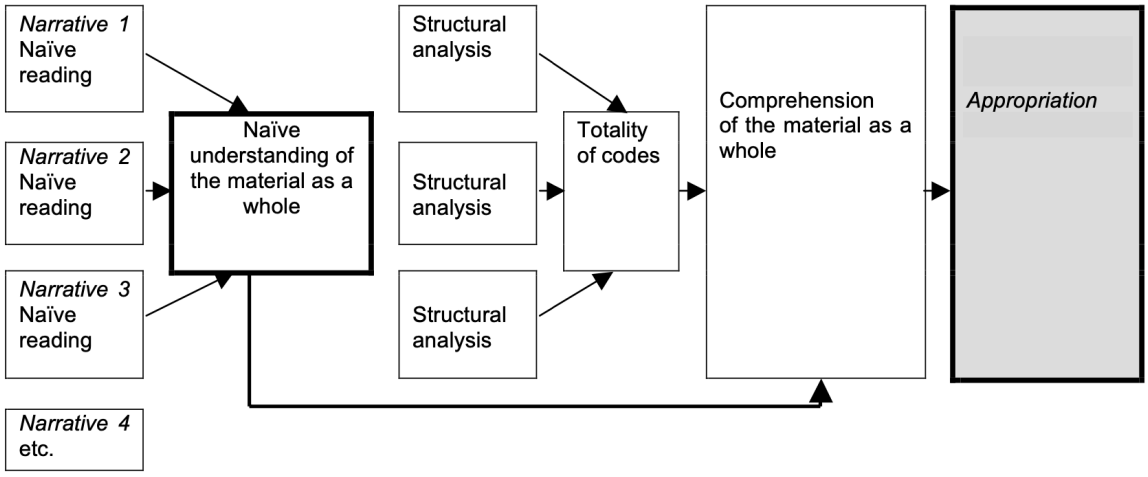
Reflection

The practice fitted in beautifully with how Zinzia as an organization wants to provide good care. Sometimes from a different perspective, depending on their profession. It is and often remains the question of what integral quality of life exactly is for a particular resident. Even for a specific resident, this cannot always be determined unambiguously, and it can often differ per moment. That is precisely why behavioural visits are necessary! However, I may also write down what confirms Zinzia's vision. So there could be an observation bias. But that is also logical; you will never know exactly what it is really like. It is virtually impossible to set out your own frame of reference, no matter how openly you step into something. On the other hand, I also expect that if the practice were not at all in line with Zinzia's vision, I would have noticed that too. When I analyze this observation, I must remain aware of the fact that I wrote the observation myself, in my own words my frame of reference. Even when I quote someone else, I give the meaning of those words my own content. I have not filmed the situation, so I do not have the opportunity to review the behavioural visit. Because of this, I will never find out "oh, that was different from what I thought". It is really my ad hoc interpretation. And that is where a piece of information and reliability is lost. But I try to name as honestly as possible. Aware of my own thoughts and limitations and share in this and the possible conclusions I draw from this.

8 Analysis and abstracts of the Interviews

This appendix shows how I came to my results. It answers the question of how I analyzed my interviews (and observations). I described this as detailed as possible to be rigor, which increases the reliability of the interpretations of the data and, therefore the conclusion of this research. For this analysis, I used a method Blom & Nygren (2010) described in figure 2.

Figure 2: The third model for analyzing narrative material (Blom & Nygren, 2010).



Interviews structural/open coding

Before I started to code, I first read the summaries I made of the interviews again. In this way, I knew what I could expect and knew better where I had to look. Through this, I had a 'Naïve understanding of the material as a whole'.

Then I analyzed all interviews separately. For this, I defined the following topics myself (table 1) to ensure the consistency of the coding process across different interviews; through the different days, I was buzzy with this. Those topics are related to the sub-question and the theoretical foundation of this research. I asked about these topics (indirectly) during the interviews (appendix 4), so they were easy to find. I gave every topic a colour. This colour I also used to cite the transcriptions when I read something about this topic.

Per topic, I described why this topic was relevant to look for. Then, after analyzing every interview, I 'checked' my topic coding for consistency. For example, did I still agree with the color I gave a particular sentence? During this process, I wrote down 'where and in which interview' I found a sentence related to the specific topic colour. So, during the phase of comprehension, I could find different meanings back and compare them. However, also to be rigor. In this way, other people could find my decisions of colour coding too.

Table 1: Open coding, Predefined topics

Topic	**Why?**	**Where in which interview?** ≈Time in minutes (page number)
IQL	Theme of the research	*GZ-psychologist* 5 (1, 2), 11 (4), 13 (4), 16 (5) *Physician* 4 (1), 5 (1), 6 (1), 9 (2) *Physical therapist* 4 (1), 7 (1), 7 (2), 8 (1), 16 (5), 21 (7), 22 (8), 29 (10), 31 (11), 32 (11), 46 (17), 47 (17), 51 (19) *Occupational therapist* 6 (2), 8 (3), 9 (4), 10 (4), 11 (4), 11 (5), 18 (8), 25 (11) *Spiritual caregiver* 5 (2), 7/8/9 (3), 10 (3), 10/11 (4), 34 (15), 44 (19), 48 (20), 51 (22)
Meaning	Part of IQL according to Zinzia	*GZ-psychologist* 5 (2), 8 (2), 9 (3), 10 (3), 13 (4), 30 (10), 36 (12) *Physician* 7 (2), 11 (3), 17 (5), 23 (6), 23 (7) *Physical therapist* 16 (5), 22 (8) *Occupational therapist* 13 (5), 14 (5), 25 (10) *Spiritual caregiver* 29 (12), 30 (12), 31/32 (13)
Well-being	Part of IQL according to Zinzia	*GZ-psychologist* 26 (2), 13 (4), 20 (7) *Physician* 17 (5) *Physical therapist* 16 (5), 18 (6) *Occupational therapist* 12 (5), 33 (14), *Spiritual caregiver*

		More integrated in the text towards 'connection'
Having aye for individuality	Part of IQL according to Zinzia	*GZ-psychologist* 5 (2), 9 (3), 16 (5), 19 (6), 20 (6), 22 (7), 26 (8) *Physician* 6 (1), 10 (2), 17 (5), 20 (6), 40 (13) *Physical therapist* 10 (3), 11 (3), 14 (5), 22 (8), 23 (8), 28 (10), 32 (11), 37 (13), 43 (15), 47 (17), 48 (18) *Occupational therapist* 9 (4), 10 (4), 13 (5), 21 (9), 21 (10), 26 (11) *Spiritual caregiver* 5 (2), 17 (7), 43 (18), 51 (22)
Social needs	Part of IQL according to director	*Physical therapist* 27 (9), *Spiritual caregiver* 17 (7), 19 (8), 51 (22)
Physical needs (or biomedical needs)	Part of IQL according to director	*GZ-psychologist* 5 (2), 10 (3), 11 (3), 11 (4) *Physician* 17 (5) *Physical therapist* 12 (4), 13 (4), 16 (5) *Occupational therapist* 9 (4)
Psychological needs	Part of IQL according to director	*GZ-psychologist* 34 (12), 35 (12) *Physician* 14 (4), 17 (5), 20 (6) *Physical therapist* 25 (9), 27 (9) *Occupational therapist* 9 (4), 24 (10)
Practical examples	To compare with the observations	*GZ-psychologist* 8 (2), 9 (3)

	and understand practice	*Physician* 7 (2), 10 (2), 13 (3), 14 (4), 17 (5), 25 (7) *Physical therapist* 8 (2), 9 (2), 10 (2), 16 (5), 18 (6), 29 (10), 32 (11), 34 (12), 42 (15), 45 (16/17), *Occupational therapist* 13 (5), 15 (6), 21 (9), 21 (10), 28 (11), 29 (11), 37 (16) *Spiritual caregiver* 17 (7), 25/26 (10), 37 (16), 39 (16/17), 51 (23), 52 (24)
Most important theme towards IQL	To give recommendations (Sub-question 5)	*GZ-psychologist* 5 (2), 8 (2), 14 (5) *Physician* 23 (6), 25 (7) *Physical therapist* 48 (18), 49 (18), 50 (19) *Occupational therapist* 18 (8)
Strengths of IQL	To give recommendations (Sub-question 5)	*GZ-psychologist* 5 (2), 22 (7), 33 (11), 35 (12), 36 (12) *Physical therapist* 48 (18)
Improvements of IQL or limits in practice	To give recommendations (Sub-question 5)	*GZ-psychologist* 9 (3), 11 (4), 26 (9), 28 (9), 28 (9), 30 (9), 37 (13) *Physician* 32 (10), 33 (10), 35 (10), 35 (11), 36 (11), 38 (12), 39 (12), 44 (14), 46 (15), 47 (15) *Physical therapist* 23 (8), 24 (8), 25 (9), 49 (18), 50 (19), 51 (19) *Occupational therapist* 15 (6), 16 (7), 42 (20), 43 (20), 43 (21), 46 (23) 47 (24) 48 (24), 49 (24), 49 (25), 15 (6)
Reflection (ways to reflect and things they reflect on)	To understand reflection towards the social construct IQL	*GZ-psychologist* 5 (2), 20 (6), 20 (7), 23 (7), 23 (8), 25 (8), 28 (9), 24 (12) *Physician*

	42 (13), 42 (14), 43 (14) *Physical therapist* 37 (13), 39 (14), 41 (15), 42 (15), 43 (15), 43 (16), 44 (16), 45 (16), 49 (18), 52 (19) *Occupational therapist* 15 (6), 33 (14), 34 (15), 35 (15), 35 (16), 40 (18) *Spiritual caregiver* 34 (14), 34 (15), 37 (16), 38 (16), 39 (17), 40 (17), 41-43 (18), 44 (19), 47/48 (20), 48 (21), 49 (21), 50 (22), 51 (23), 54 (24)

During the coding process, I found more topics in the interviews, which were helpful in answer the sub-question, but from which I had not thought beforehand. These topics I analyzed in the same way as I analyzed the topics of table 1 to make the totality of codes more complete.

Table 2: Open coding, During defined topics

Topic	**Why?**	**In which interview?** ≈Time in minutes (page number)
What is good care?	Healthcare professionals could not define this one way and asked themselves this question, or questions related to this question	*GZ-psychologist* 9 (3), 10 (3), 36 (12) *Physician* 11 (3), 15 (4), 21 (6), 23 (6), 23 (7), 44 (14) *Physical therapist* 29 (10), 31 (10), 32 (10), 43 (12), 35 (12), 36 (13), 37 (13), 39 (14), 49 (18), 50 (19) *Spiritual caregiver* 45 (19), 45-47 (20)
Teamwork	Came back as core point towards IQL in every interview	*GZ-psychologist* 17 (6), 20 (7), 37 (13) *Physician* 16 (4), 23 (7) *Physical therapist* 9 (2), 10 (3), 12 (4), 17 (6), 24 (8), 25 (9), 41 (15), 42 (15), 43 (15), 44 (16), 48 (15), 50 (19), 51 (19), 52 (19)

		Occupational therapist 14 (6), 25 (11), 26 (11), 30 (13), 33 (14), 33 (14), 34 (15) *Spiritual caregiver* 32 (13/14), 41 (18)
Culture	Influences how care receiver define IQL	*Spiritual caregiver* 24 (9), 24/25 (10), 26 (11), 29 (12), 30 (12), 31/32 (13)
Target groups	IQL experience and needs differ per target group	*GZ-psychologist* 9 (3), 19 (6), 20 (6) *Physician* 6 (2), 7 (2), 11 (3), 12 (3), 15 (4), 17 (5) *Physical therapist* 9 (2), 11 (3), 13 (4), 14 (4), 14 (5), 16 (5), 17 (6) *Occupational therapist* 8 (3), 9 (4), 10 (4), 31 (13), 32 (14) *Spiritual caregiver* 19/20 (8), 21 (8), 21 (9), 30 (12, 35 (15), 37 (16), 42 (18)
Network, those who are involved	Plays an important role in the experience of IQL of the residence: This could hold the different healthcare professionals, Family (caregivers), volunteers or other residents.	*GZ-psychologist* 16 (5), 17 (6), 20 (6), 20 (7), 22 (7) *Physician* 7 (2), 12 (3), 16 (4) *Physical therapist* 8 (2), 10 (3), 18 (6), 23 (8), 25 (9), 27 (9), 28 (10), 48 (18) *Occupational therapist* 25 (10), 25 (11) *Spiritual caregiver* 21 (8), 21/22 (9), 42 (18)
Profession specific	Some important points are only relevant for a specific profession	*Physical therapist* 17 (6), 20 (7), 37 (13/14) *Occupational therapist* 10 (4), 28 (11), 29 (11), 29 (12), 30 (13), 33 (14) *Spiritual caregiver*

		10 (3), 11/12 (4), 22 (9), 32 (13)
Communication	This plays an important role in the actions towards an IQL experience for the resident	*GZ-psychologist* 20 (7), 22 (7) *Physician* 20 (6) *Physical therapist* 10 (3), 11 (3), 12 (3), 14 (4), 15 (5), 25 (9), 28 (10), 46 (17) *Spiritual caregiver* 32 (13)
Observation resident/ Experience care process	The only way to understand the needs of a PG-resident, or to understand the care process of daily life activities	*Physician* 7 (2), 16 (5), 17 (5) *Physical therapist* 9 (2), 10 (3), 14 (5), 18 (6), 20 (6), 10 (7), 21 (7), 48 (18), 50 (19), 51 (19), 52 (19) *Occupational therapist* 10 (4) *Spiritual caregiver* 21 (9)
Connection	Connection between needs of the residents and abilities of the healthcare professionals, is part of IQL	*Physician* 13 (3), 15 (4), 16 (4), 21 (6), 21 (7), 25 (9), 49 (18), 52 (19) *Physical therapist* 11 (3), 12 (3), 12 (4), 14 (4), 14 (5), *Occupational therapist* 21 (9), 21(1), 26 (11) *Spiritual caregiver* 6 (2), 7/8/9/10(3), 11/12 (4), 17 (7), 19 (8), 21 (8), 24 (9), 26 (11), 34 (15), 39 (17), 42/43 (18), 45-48 (20), 50 (22), 51 (22)
The perception of the caregiver	Plays a role in the care process. Awareness towards contribution of care giver is important.	*GZ-psychologist* 5 (2), 9 (2), 10 (2), 14 (5), 23 (8), 26 (9), 28 (9), 36 (12), 37 (13) *Physician* 7 (2), 23 (7), 32 (10), 44 (14)

	+ personal opinions.	*Physical therapist* 34 (12), 35 (12), 36 (13), 43 (15), 49 (19), 50 (19) *Occupational therapist* 10 (4), 14 (6), 16 (7), 17 (7), 18 (8), 26 (11), 27 (11), 28 (11), 32 (13), (32 (14), 37 (16), 43 (21), 51 (23) *Spiritual caregiver* 45 (19), 47/48 (20)
Spiritual needs	The connection with the personal story	*Spiritual caregiver* 9 (3), 10/11 (4), 17 (7), 24 (9), 39 (17), 51 (23)

Axial coding

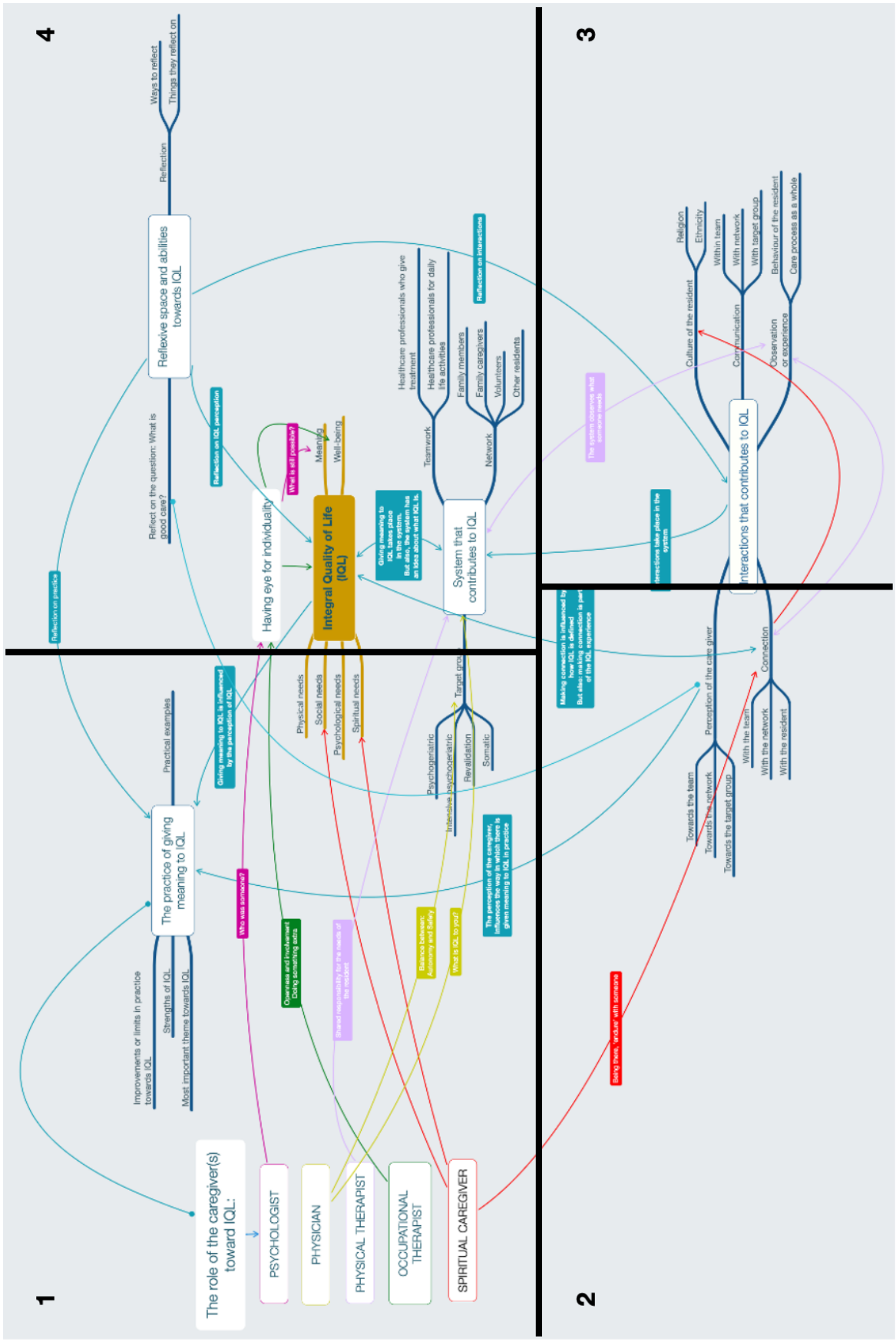
Now the open coding phase was ready. So, I started to code axial with all the topics of all the interviews together. This made it possible to see and understand the interrelatedness between topics and interviews because this axial coding was based on the meaning healthcare professionals gave to specific topics in the interviews. So first, I made group codes, in which you can see the direct relationship between different topics. But I also made 'diagonal' codes between the different open topics concerning each other. This I showed in a mind map (figure 3). You can also see the 'profession specific' topics and some 'practical examples' are integrated. However, overall, I did not show every relationship there, only the most essential thing to hold it straightforward.

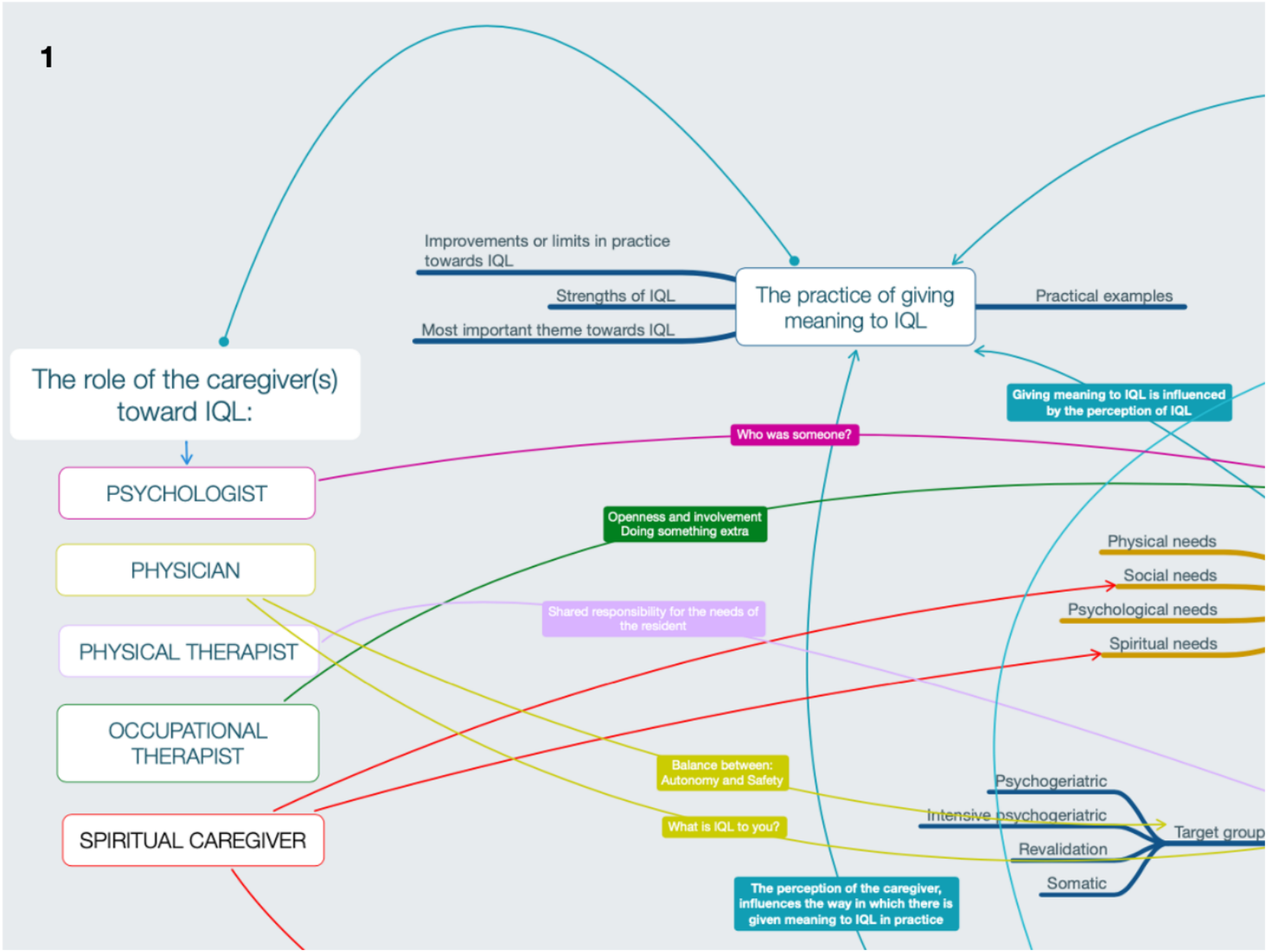
Table 3: Axial coding, Grouping all the topics

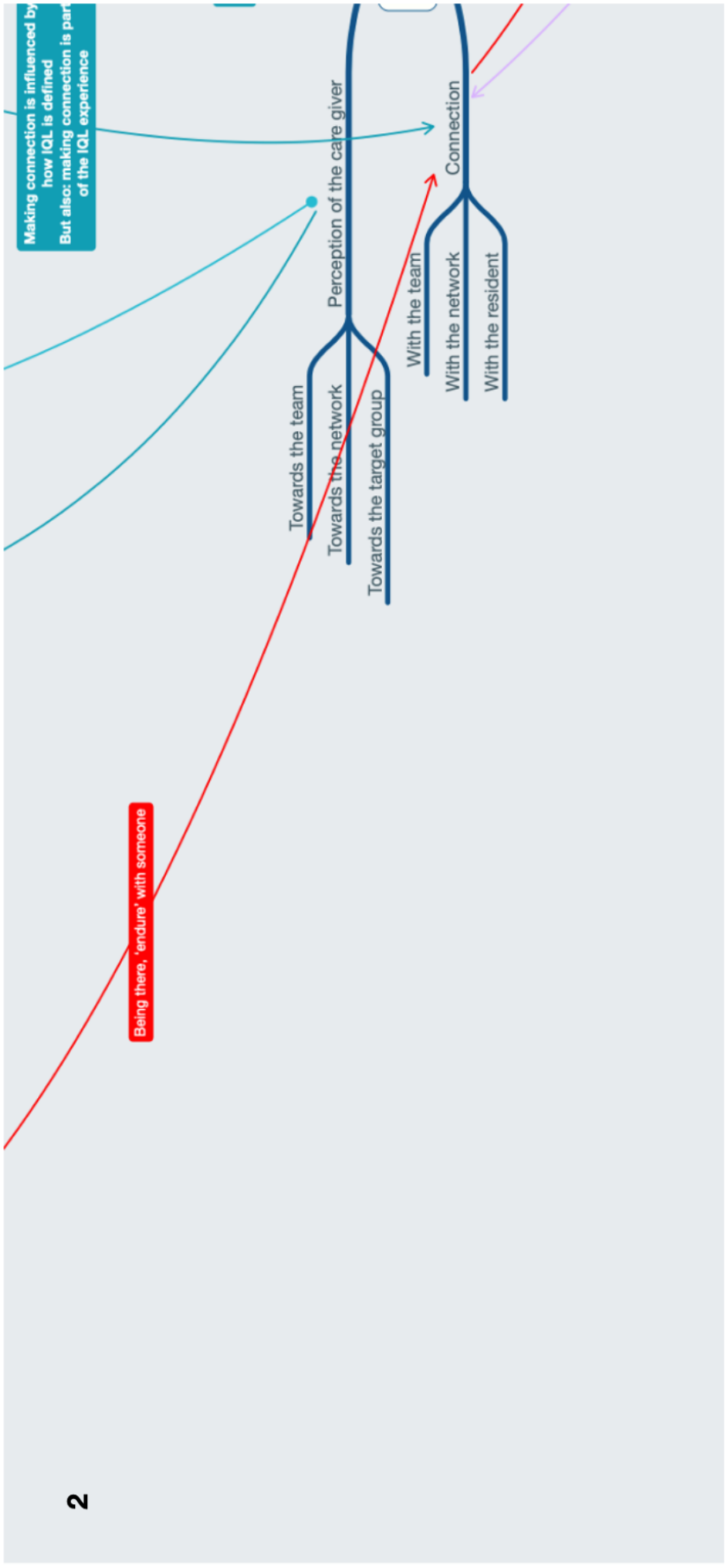
Topic group	Why can this together?	Topics part of this group
Integral Quality of Life	These topics relate to the perception of IQL these healthcare professionals have.	Integral Quality of life Meaning Well-being Having aye for Individuality Social needs Physical needs Psychological needs Spiritual needs

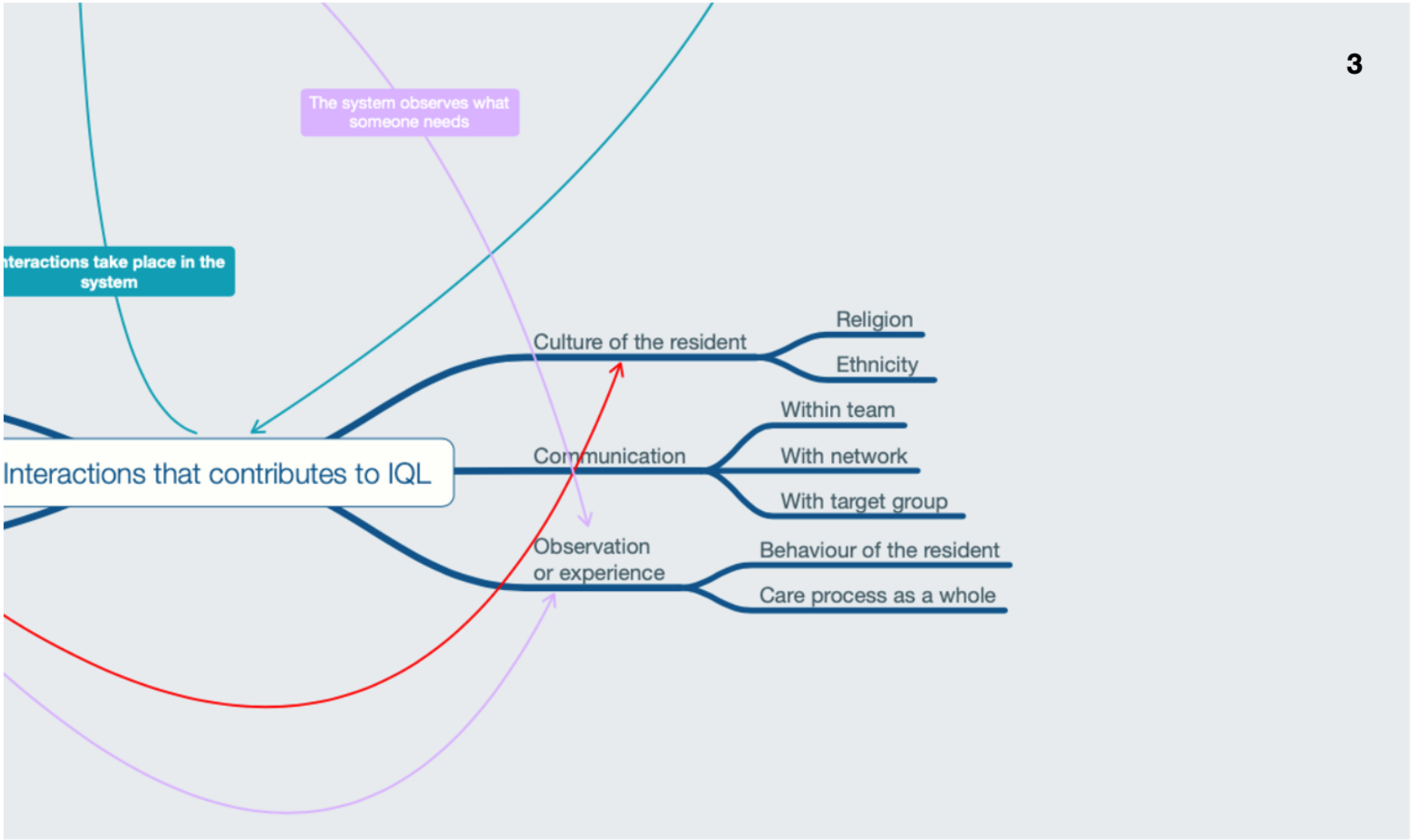
System that contributes to IQL	These topics concern the people involved in the care process, and who could help to contribute to a giving meaning to IQL.	Teamwork: Healthcare professionals who give treatment, Healthcare professionals for daily life activities Network: family member, family caregiver's, volunteers, other residents Target group
Interactions that contribute to IQL	These topics play a role in the interactions between the different people involved in the care process. They highlight what the healthcare professionals found important in interactions.	Communication Observation resident/ experience care process Connection The perception of the care giver Culture
Practice of giving meaning to IQL	These topics give examples of the practice of giving meaning to IQL.	Practical examples Most important theme towards IQL Strengths of IQL Improvements of IQL or limits in practice
Reflexive space and capabilities towards IQL	These topics relate to the *Reflective spaces* that are use and which questions they ask?	Reflection: Ways to reflect and things they reflect on? What is good care?

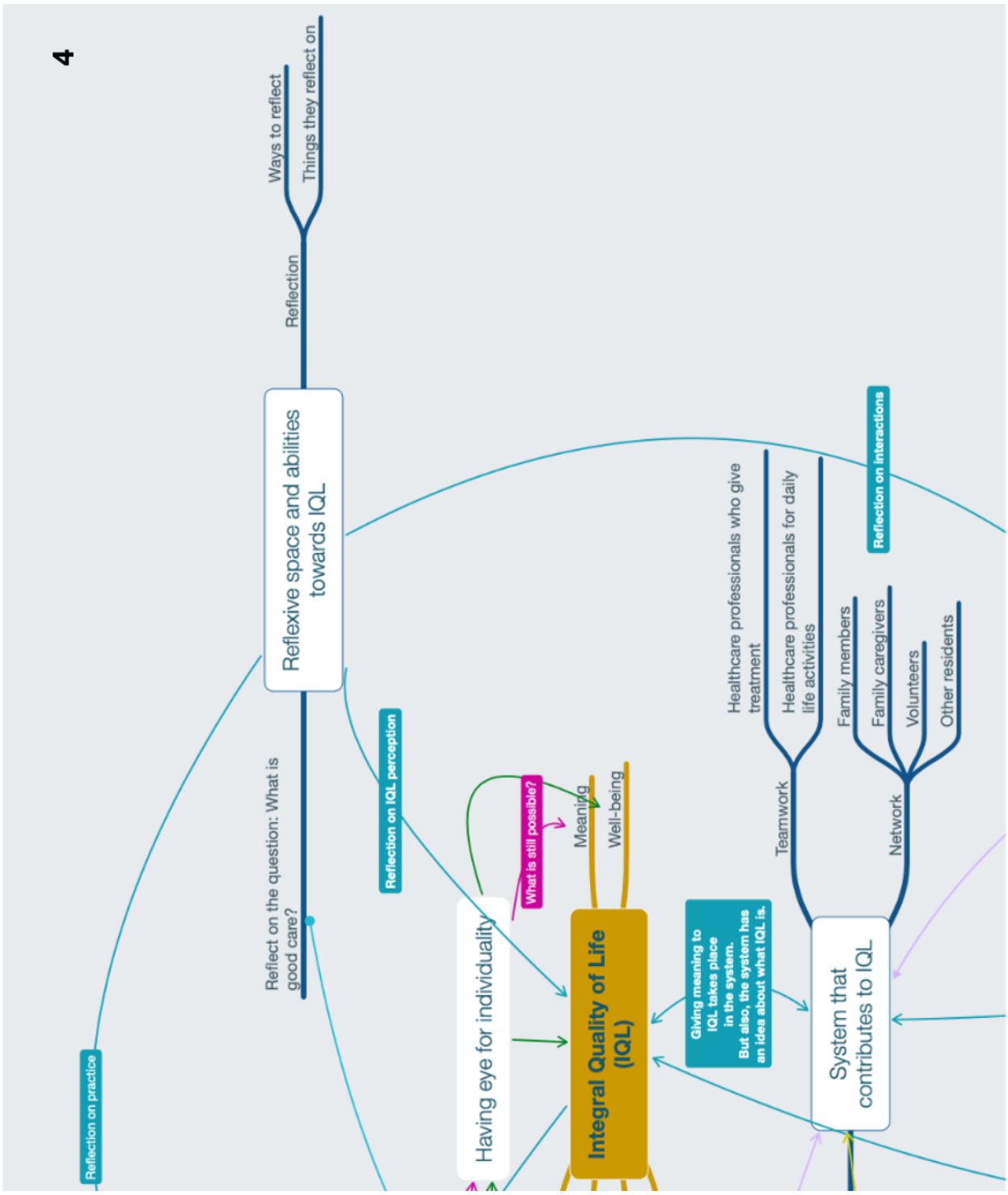
Figure 3: Mind-map of diagonal coding




1
The role of the caregiver(s) toward IQL:
PSYCHOLOGIST
PHYSICIAN
PHYSICAL THERAPIST
OCCUPATIONAL THERAPIST
SPIRITUAL CAREGIVER
Improvements or limits in practice towards IQL
Strengths of IQL
Most important theme towards IQL
The practice of giving meaning to IQL
Practical examples
Giving meaning to IQL is influenced by the perception of IQL
Who was someone?
Openness and involvement Doing something extra
Shared responsibility for the needs of the resident
Balance between: Autonomy and Safety
What is IQL to you?
Physical needs
Social needs
Psychological needs
Spiritual needs
Psychogeriatric
Intensive psychogeriatric
Revalidation
Somatic
Target group
The perception of the caregiver, influences the way in which there is given meaning to IQL in practice


Making connection is influenced by
how IQL is defined
But also: making connection is par
of the IQL experience
Perception of the care giver
Towards the team
Towards the network
Towards the target group
Connection
With the team
With the network
With the resident
Being there, 'endure' with someone
2


3
The system observes what someone needs
nteractions take place in the system
Interactions that contributes to IQL
Culture of the resident
Religion
Ethnicity
Communication
Within team
With network
With target group
Observation or experience
Behaviour of the resident
Care process as a whole


4
Ways to reflect
Things they reflect on
Reflection
Reflexive space and abilities towards IQL
Reflect on the question: What is good care?
Reflection on practice
Reflection on IQL perception
What is still possible?
Meaning
Well-being
Having eye for individuality
Integral Quality of Life (IQL)
Giving meaning to IQL takes place in the system. But also, the system has an idea about what IQL is.
Healthcare professionals who give treatment
Healthcare professionals for daily life activities
Teamwork
Family members
Family caregivers
Volunteers
Other residents
Network
Reflection on interactions
System that contributes to IQL

Comprehension and Appropriation

This axial coding resulted in a totality of codes (table 3). But besides this knowledge of the codes inside the interviews and their interrelatedness, I was also interested in the meaning of these codes (the comprehensions: (Ricoeur, 1976 in Blom & Nygren, 2010)). To unravel this, I used an example from Blom & Nygren (2010). In this example, they defined the 'preliminary units of meaning' (comprehension according to the interviewee) by citing or highlighting meaning from the text concerning a particular topic they code. So, they showed the *reason* why they emphasize the topic in the first place.

I also described the 'preliminary units of meaning' or 'comprehension' of the topic according to all interviews towards the different topics. For example, concerning 'having an eye for individuality', one of the interviews said: 'By us, they can be their wondrous self. So very much is accepted as long as that person feels comfortable and isn't a threat for another resident'. This quote shows 'the meaning' of having an eye for individuality by telling why and under which conditions it is possible, according to one of the interviewees. Through this, I understood what for instance, 'having an eye for individuality' mend to all healthcare professionals. After that I gave an appropriation (the researchers' interpretation from structural analysis and comprehension (Ricoeur, 1976 in Blom & Nygren, 2010)) of the essence of comprehending all topics in a topic group. This I did by comparing and combining all healthcare professionals' topics and reconstructing this in my own words concerning the topic group (table 4). So, become the meaning of 'having eye for individuality' part of the perception of healthcare professionals towards 'Integral Quality of Life' which contribute to answering sub-question one. Through this I made an overall appropriation per topic group and highlighted some essence with questions the healthcare professionals have to ask during their work. This has helped me answer the first four sub-questions: 1) what kind of perception healthcare professionals have on IQL? 2) How this perception subsequently influences how they give practical meaning to IQL? 3) Which themes concerning IQL are most important to them? 4) How healthcare professional reflects on their perceptions and actions in practice, regarding IQL? From this, I made a visual model to 'show' the results and writhe recommendations for further development of IQL at Zinzia (figure 7, 4.1). Besides, this appropriation I have used to relate the observations to the interviews, to relate perception to action. This together made figure 7.

Table 4: Comprehension which led to appropriation

Essence of the 'preliminary units of meaning' per topic from all interviews	**Topic**	**Overall appropriation of the essence per topic group**
Integral quality of life		
Psychologist You always have to look at IQL. Because it is dangerous to only look at someone's physical condition. There are much more problems than health problems. It is all about 'what can you still	Integral quality of life	According to several healthcare professionals, the word integral does not need to be used. They believe that it adds nothing to the concept of 'quality of life'. In the end, only your actions in practice count, instead of the 'word'.

do with your life'. We do not talk anymore about dementia persons, but about persons with dementia. That's an essential difference. Because now we look at who someone is and was, and what gave meaning to someone's life. How could we 'design' life, within the possibilities? So, we look at possibilities, not only at the diagnoses. People and their network can define that, so we can help design it. 'How could you continue your path of life, as best as possible, with who you have always been and what is important to you?' **Physician** I cannot figure what you think is integral to quality of life. Do we also have not integral quality of life? I should say, use easy words. Quality is something personal, which is influenced by different facets. But how do you know what this is, especially in the phase of life in which we see them; then it became little things that make the difference. So IQL is individual, but also within the individual, it changes during life. **Physical therapist** It is the 'new' word for things we already try to achieve. Colour to life, the unique human. For me, it is essential to look at the needs of a person. I do not want to send people from the 'closet to the wall'; we all have a joint responsibility that a person gets what he needs. For this, contiguous tuning is necessary. Don't always 'slide' it to another discipline but do it together: a binding factor. Everybody around the residents has a role in this. As physical therapist focusses on provision creation. So, someone can still/again do what he/she needs. But beware of the fact that you 'bring your own person' into the care process. But what it is, is determined by the resident himself. So, it is different for everyone. Nobody is 'black-white'. **Occupational therapist** It is an 'expensive' word for so many things. The term integral I found a little difficult because quality of life is already so meaningful. But it is not about the word, but about what I do in practice. Every person is unique. So, it is not unambiguous. It could differ for everyone. What it is for you does not have to be it for me. Satisfaction/content and a feeling of safety. Openness and involvement or connection. But also well-being. But this also depends on the target group. Ask the question, 'what can I do for you?' **Spiritual caregiver** There are lots of terms to think about. The total human, not only the biomedical aspects. Life story		Quality of life is a very personal experience. No one else can decide what this is for a resident. When people cannot tell what this means for themselves anymore, the network plays an important role. They provide a lot of information about who someone was and what was necessary for this person. Healthcare professionals see it as their task to investigate what someone needs. They do this mainly through observation, conversations with the network, and showing genuine interest in the resident. After all, the resident wants to be seen and heard. Besides, what they all mentioned is that it is not just about a person's physical needs. It concerns the whole person. So, they try to look beyond a diagnosis to see the person, also the social-, psychological-, and spiritual needs of being human. What does still give meaning? What is still possible? What increases a person's well-being? Often it are the little things that make a difference. Teamwork plays a very important in this. Working multidisciplinary (a collaboration between different disciplines) broadens the view, ensuring a more complete picture of the resident and his/her needs. So, they have a joint responsibility to the resident. However, they mentioned that you must be aware that you always bring your personality into the situation as a caregiver. You view the world from your standards and values and from what you think is normal. In the end, for many residents, it is the balance between safety and to maintain as much autonomy as possible so the well-being increases. This is a precarious balance that requires constant tuning between care professionals mutually, but certainly also with the resident or his/her network. The central question to them is: what is good care for this person? And how do I know if I give that? So, the perception of IQL by healthcare professionals holds seven core concepts: meaning, well-being, the individual, social, - psychological, - physical - and spiritual needs. Be aware, concerning the construction of IQL, according to Zinzia; the spiritual need was not mentioned explicitly. Per concept, I will highlight the essence by asking a question about it. These questions are (based on) examples from the healthcare professionals. Meaning: 'How could we continue your path of life, as best as possible, concerning who you have always been and what important is to you?'

That you are seen and heard I do not want to know which diagnoses someone has before I come in Show real interest I come when someone asks me Just being there, there is no other purpose for improvement. We do not work towards something; we 'endure' with someone.		Well-being: 'How can we create the conditions in such a way that you can still do what you want, or so that you experience less 'burden' (pain, unrest or stress), which increases your well-being?' Having an eye for individuality: 'Who are you? I want to know you, so I can help you. What do you still want with your life, so you feel comfortable and so you are not a threat to yourself or others?' Social needs: 'How can we bring people (residents mutually or residents with family) together?' Psychological needs: 'What is the right balance between physical and psychological needs? And how can we support the network of the resident?' Physical needs: 'How do we look at someone's physical needs regarding his/her diagnoses, without forgetting the person, the individual, the life story, all other components of life?' Spiritual needs: 'How do I 'endure' with someone concerning his/her questions about life and his religious background?'
Psychologist We try to understand what gave and gives meaning to someone's life, in which we look at possibilities in designing a meaningful life. 'How could you continue your path of life, as best as possible, with who you have always been and what is important to you?' For example, if there is someone who always liked to help others, we have to create a situation where we give this person the chance to still do that. **Physician** Little things make the difference. For people who found autonomy very important, it is more difficult to hear they have dementia because they eventually have to give away their autonomy. We always look to what is of meaning for someone. But sometimes that isn't possible anymore or too dangerous. So then we have to compromise. **Physical therapist** As physical therapist focusses on provision creation. So, someone can still/again do what he/she like. Like for instance, go to 'the song'. **Occupational therapist** Helping someone, is of much meaning to someone also, because we look at the whole picture: client, network, residence. But it is also vital that my work gives meaning to my life too. **Spiritual caregiver** I think to be seen and heard gives meaning to someone's life. Some people need it to tell their life stories, but not everyone is capable of this anymore. Knowledge of the culture by the healthcare professionals could eventually give meaning to the lives of the residents.	Meaning	
Psychologist Well-being is very interrelated with meaning. People experience more well-being when they can still do things that gave meaning to their lives, when they do something that 'fit' them. **Physical therapist**	Well-being	

As physical therapist focusses on provision creation. So, someone can still/again do what he/she needs. Or prevent that someone gets decubitus or other conditions. But also understanding defensive behaviour for, for instance, daily life activities, and change the way we give care, could improve the well-being of the resident. **Occupational therapist** We try to help so someone can still do what he wants to do.		
Psychologist We look at who someone was and what important was for someone. Besides, what do you still want with your life? How people deal with their condition is very different between people. **Physician** By us, they can be their wondrous self. So very much is accepted as long as that person feels comfortable with it and isn't a threat (for another resident). **Physical therapist** I get to know a resident to understand his story, background, and current situation. In this way, I can better understand what someone needs and how I can deal with him/her. Only in this way can I connect. **Occupational therapist** I want to help the individual, sometimes I think; what would I need in this situation. But it is also a lot of observing. **Spiritual caregiver** Who are you? I want to know you and hear your story.	Having eye for individual	
Psychologist Because of someone's diagnosis, they are not always capable anymore of thinking about giving attention to family. So, we help remember them. **Spiritual caregiver** I also do group meetings to reach community building, so everyone can get to know each other.	Social needs	
Psychologist Because of someone's diagnosis, they are not always capable anymore of thinking about giving attention to family. So, we help remember them. We educate ourselves with new theories and methods, like solution-oriented therapy, ACT (acceptance commitment therapy), or positive psychology. Nice to see that the focus of geriatric psychology on disorders is changing to a focus on positive treatment possibilities. And if you cannot reach the resident, you can help the system. **Physician**	Psychological needs	

In some cases, there is a thigh balance between physical and psychological needs—for instance, a person who has autism but also gets ill. We have to treat him, but this change in life is also disturbing for this person. **Physical therapist** We look at a resident's behaviour (aggression, flight or stress reactions) to understand what he/she needs to feel better. For this you also need psychological skills. **Occupational therapist** Sometimes because I can help people with self-sustainability in daily life activities, this also helps keep the psyche in order.		
Psychologist We do not talk anymore about dementia persons, but about persons with dementia. In this way, we look 'beyond' the diagnoses to someone's possibilities. Many nurses have a 'care heart'. That's nice and necessary, but physical care is not the only important thing. **Physical therapist** For this target group, it is not only about physical well-being. It is the core focus, but we try to look more holistic. So behaviour is constantly moving, which is influenced by senses. But when you are just from school, your view is different than when you have some experience with this (intensive PG) target group. But we are also focusing on avoiding things like decubitus. **Occupational therapist** I focus on lying and sitting positions to avoid problems.	Physical needs	
Spiritual caregiver A spiritual caregiver does not treat someone, but something is happening. You can drop your sorrows somewhere, for instance, about the which do die. Then I 'endure' this process with someone. During the group meetings, I sing a song and burn a candle. These are rituals I want to negatable things which truly reach life with each other. Church, commemorative events, or praying are other examples of this. Sometimes they sing or pray with me.	Spiritual needs	
System that contributes to IQL		
Psychologist With every discipline (also the nurses), we try to understand how someone feels and what someone needs. We try to make nurses aware of this. **Physician**	Teamwork: Healthcare professionals who give treatment, Healthcare	The system has a vital role in reaching IQL for these PG-residents. Within the system, there are roughly three groups: the teams of different healthcare professionals (teamwork), the network of the resident (like family and

Together with the team, we try to understand what someone needs. What could we give or do so someone's condition or feelings improve? **Physical therapist** It would help if you had the whole team because every profession sees something else. Alone you can never wholly indicate what someone needs. Also, the PG-resident self cannot say this. We are strongly connected with the nurses. So often, I look with them and coach them to improve, for instance, lifting positions. But also, help them understand the resident's behaviour and adapt their way of giving care to make the resident feel more comfortable. But we also cannot do everything. We have to work interdisciplinary instead of multidisciplinary. **Occupational therapist** We try to get the whole picture: client, network, residence. In this, working multidisciplinary is very nice. Everybody could use his point of view; in this way, your picture gets more complete. We share experiences and ideas about residents during conversations and sometimes ask if another discipline can look at it when I'm not sure about myself. We work very multidisciplinary. But we also cannot do everything; sometimes, someone has behavioural problems. Sometimes I also won't do everything for hospitalized residents. I work with the physical therapist on things a lying and sitting positions. I like it the most to discuss everything face-to-face, not via e-mail. We also decided that 'there is no such thing as stupid questions'. **Spiritual caregiver** Sometimes family or 'the care' asks me to talk with a resident when they think someone needs it. We do need other disciplines as well. There is much overlap with, for instance, psychology. Sometimes we refer a resident. We also give attention to the nurses. For example, we could coach them in dealing with complex ethical situations, such as about the meaning of life or questions about the end of life.	professionals for daily life activities	volunteers), but how these people contribute to the IQL of the resident also depends on the resident condition itself. For example, different forms of dementia ask for different approaches. Also, other forms of elderly care ask for different approaches. Teamwork is essential, according to healthcare professionals. Quotes like: 'Together whit every discipline (also the nurses), we try to understand how someone feels and what someone needs' & 'You need the whole team because every profession sees something else. Alone you can never completely indicate what someone needs', highlight the essence of this. The healthcare professionals see it as a shared responsibility to take care of the needs of every individual resident. Also, the network plays an essential role in this. They are still there to be part of the life of the resident. But they also can tell very much about the needs of a resident to the team, so the team can adjust their way of giving meaning to IQL to this information. Besides, also the network (especially family) has needs and wishes. For example, 'I just want to do this one last time with my wife', which leads to 'We always try to understand the point of sorrow behind a question; the condition of a resident is also challenging for the family. So the team tries as much as possible to consider these needs as well.
Psychologist Together with the network, we try to unravel the question 'what is still possible in someone's life?' most of the time, the network could give lots of information about who someone was and what gave meaning to his/her life. How the network deals with the condition of the resident is very different. 'Grant' they someone still a place or not? However, it is not only about the resident but about the whole system. Someone's condition influences loved others. So, we try to involve the entire system in the care process.	Network: family member, family caregivers, volunteers, other residents	

Physician The network can tell us a lot about what has been essential to someone/what someone needs. But sometimes, our residents change, so then we are entirely dependent on observation. **Physical therapist** Everybody around the resident has a role in his/her care process. Family can give lots of information about a resident, which cannot tell it himself. Besides, there are interactions between the network and the resident, which could result in specific behaviour. But also, the network has needs we try to understand and to adhere to. For example, 'I just want to do this or that one more time with my wife'. **Occupational therapist** I'm always buzzy with the client, the network, and the residence. **Spiritual Caregiver** Sometimes family, neighbors, or volunteers ask me to talk with a resident when they think someone needs it.		
Psychologist People can still tell how they feel at this specific moment. Maybe not in the full context, but this still gives us lots of information. So we must not 'skip' asking these questions to someone and only rely on the input of the network. We only act on things that bother residents themselves. **Physical therapist** What someone needs also depends on his/her diagnosis. **Occupational therapist** Working with PG is difficult because people cannot say what they need. Sometimes other people ask us to do something for a PG resident, through which we try to give some meaning to life. Then we see that someone is happy when there is some structure back. **Spiritual caregiver** Community building is difficult with PG-residents, because of their degenerating cognitive functions. So, most of the time, I do this with somatic residents, who are only at the beginning of dementia. What someone needs or still can do in terms of meaning depends on the person is his/her conditions. Not everyone is interested in the spiritual caregiver. Some people don't want it.	Target group	
Interactions that contribute to IQL		
Physical therapist	Communication	There are interactions between a IQL experience and the system (also with

When I'm trying to connect with a resident, I need to know what the 'background' is of this person to make sure I do not disturb things. Good communication with the whole system is necessary for this. Besides, I also do not just send a colleague because he/she doesn't know the 'background'. Reading this from paper is not enough. You have to know someone. New colleagues have to learn to work with this specific target group.		institutions, but that point goes beyond this thesis). The healthcare professionals need information about the resident because they are responsible for the care. For this, good communication is important. They communicate via the care file, but this is not enough if you want to give good care. Especially when you do not know the resident, only 'talking' via the file is insufficient. That's why they communicate much with each other, so they understand someone's 'background' and situation of the day. But talking with the resident him-/herself is often quite hard. At that moment, observation is the primary tool. Sometimes they also video-record someone to discuss and understand his/her reaction to specific stimulation (for instance, daily life activities). In this way, they try to understand what someone needs and how they can give 'better care'. Through communication and observation, the main goal is to connect with the resident, so they feel safe, and the healthcare professionals understand them better. For example, 'What do you mean with this or with that?', 'Especially 'this' moment is important to understand the needs of this moment, next time it can be completely different what someone needs', 'Is someone cold when they say, 'I'm cold', or is this loneliness?' Every healthcare professional uses her tool to make a connection. For instance, the spiritual caregiver sings or prays with the residents to become closer to each other. Besides connection with the resident, it is also essential to have a connection with the network. Also, for family, it is essential to feel safe enough to tell what they need. Again, it is essential to realize that the healthcare professional always brings his/her person into the situation. The healthcare professionals I interviewed also see it as their task to make nurses aware of that. They help them reflect on the question: 'How do you know you did it right?' They all work together, and all have a different view, which is seen as 'added value'. Together the picture is more complete. 'This is the only way to do it righter?' A unique contribution to this interaction gave the spiritual caregiver. She highlighted the importance of understanding the resident's culture to connect with him/her more deeply and therefore interact better. Understanding the culture contributes to understanding someone's needs. 'If you are a 100-years old and born in Indonesia, you have probably been
Physician In giving meaning to IQL, our target group depends on our translation of their behaviour: does someone make content and relaxed impression? Or is someone stressed out? The network can tell us a lot about what has been essential to someone. But sometimes, our residents change, so then we are entirely dependent on observation. Sometimes we use camera's to 'look back' at the moment someone's behaviour changes. When there is a signal of changes, we know we do something right, or we have to do something different next time. **Physical therapist** It is hard that someone cannot tell what he/she needs for himself anymore. We look with the whole team to the behavior of a resident, to understand what someone needs. Think of aggression, flight, or stress reactions, which could change every moment. What is happening here? What are the underlying causes? What can we do to make someone more comfortable? Often, I observe and work with the nurses to experience the care process myself and therefore give better advice. **Occupational therapist** I do a lot of observation to understand what someone needs.	Observation resident/ experience care process	
Physician When I talk with people with dementia (early stage) about the future of their condition and if they want to 'sit it out' or not, it is essential to understand each other. When someone says, 'I never want that', I have to ask what 'that' means. I many examples' people have a shocking image about severe stage of dementia. So, it could be helpful to come and visit our nursing home, so they can see for themselves that in history, it was different than it is now. We always ask the question, 'what means this behaviour?', to understand what someone needs. It is all about standing beside someone, taking the time, and making them feel seen and heard. **Physical therapist**	Connection	

I get to know a resident to understand his story, background, and current situation. In this way, I can better understand what someone needs and how I can deal with him/her. Only in this way, can I connect with the resident. You have to know that connecting with a resident is always for just 'this' moment, because of their condition, the next moment, someone needs completely different things. Therefore, we have to observe constantly. And mutually, we also constantly have to tune. Not only the connection with the resident is important, but also with the network. They also have needs we try to understand. **Occupational therapist** With one resident, I have more connection than with another because some are more open than others. In the beginning, I try to know the resident and what someone needs by asking questions. And because I'm buzzy with someone's own story, I can connect more easily. **Spiritual Caregiver** Who are you? I want to connect with the resident. What is your story of life? Just being there, taking time for someone. A spiritual caregiver does not treat someone, but something is happening. Little steps in the thinking process, helping to order. I try to build a relationship based on trust. I try to reach community building among the residents so that they could find support with each other. Is someone cold when they say, 'I'm cold', or is this loneliness? 'We are all so vulnerable. We have nothing to give, and we need each other so much'.		in the camps, so there is probably some trauma there'.
Psychologist Many times, nurses say: 'just go sit down'. Do they understand what this means? How does your day look when there is always someone who says, 'just go sit down'? It is essential to talk about this. They mean well, but it is essential to let them still do what they can. As psychologists, we always looked at the whole person and the whole life of someone. Seeing the things that someone still can do, everyone is open to that. But in practice, most of the time, they act according to the issues of the day. How would you feel to sit all day long with eight other residents around the table? And then think that these people have senses filtering problems… **Physician** Sometimes we think very paternalistically: we know what you need.	The perception of the care giver	

When we have to interpret the needs of others, we bring in our norms and values. So we have to be aware of this. **Physical therapist** But beware of the fact that you 'bring your own person' into the care process. So, also what happens between the nurse and the resident is unique and individual. Unfortunately, not everyone is aware of that and say, 'I do it right because I followed the protocol'. But I think it is good that there are many persons involved in the care process, together you come to the best way of doing it. As a professional, I also have a perception of what good care contains. **Occupational therapist** Sometimes I think, 'what would I need in this situation?' So, I work from that 'feeling' Working multidisciplinary is very nice. Everybody uses his point of view. In this way, your picture gets more complete. Ow and I'd like to show you can do 'something extra' for someone. **Spiritual caregiver** We also coach nurses to be vulnerable to make a connection with the living world of the resident. Sometimes people just 'pop-in' in the resident's room while they only have a few square meters to themselves.		
Spiritual caregiver People at this location (Indian-Moluks) are very modest to ask for help, so sometimes I need the network to do that. Everyone has a different religious background. So even though it looks the same, there are many differences in Christianity. Understanding the cultural background of someone is very important to make a good connection and understand what gives meaning to someone's life. So, I studied the history of Indonesia and the Molokan Islands. This information I cannot just 'give' to someone else.	Culture	
Practice of giving meaning to IQL		
Psychologist To look beyond the diagnoses and try to understand what still gives meaning to someone's life. We (multidisciplinary) help to understand and design that. **Physician** It is all about standing beside someone, taking the time, and making them feel seen and heard. We have to look at this for the balance between freedom/autonomy and safety. **Physical therapist**	Most important theme towards IQL	In practice, giving meaning to IQL can be challenging and beautiful at the same time. According to the healthcare professionals, essential things in this are: 'to look beyond the diagnoses', 'to stand beside someone, take the time and make them feel seen and heard', 'to share responsibility for a resident, but also to be transparent about the fact that we cannot do everything', 'to look to what someone needs' and 'endure with someone'. These things are important because the beauty of the

Shared responsibility for the needs of the resident. We have to be transparent about the fact that we cannot do everything. **Occupational therapist** It is not about the word and the concepts or theories we use; it's about what I do in practice. By looking at what someone needs. That's what my work is all about. **Spiritual caregiver** Being there and 'endure' with someone.		construction of IQL is that they try to look at the things that are still possible for someone, in which they involve the whole system (teamwork and network). While the construction of IQL has beautiful components, in practice, it isn't easy to always give meaning to it in the way you wanted. For instance, there has to be more awareness of the influence of your own norms and values towards the residents' condition. 'Coaching them is what we want, but we do not have the time'. 'Have people with dementia always go and 'sit' down?' Because not only physical care is essential. However, the nurses have much focus on that. So sometimes they forget that these people can still do things, despite their condition. Besides, the nurses are always buzzy. Now they try to order the care process better, so important things concerning the resident come first. 'Miss X has a pleasant day'. But what these are, essential things is complicated to track down when people cannot tell it for themselves anymore. 'When we have to interpret the needs of others.' Also, there is high work pressure, resulting in an intervention in someone's autonomy, while that is not necessarily necessary. It is also challenging in practice that there is always less and less money while giving the same or more care. 'It's like changing the roles while playing'. Besides, temporary workers are a problem; they do not know the residents. It would also be nice if people are letting more go of steadfastness because you can make better connections with someone in this way. Other healthcare professionals have difficulty with the (validity of) protocols. 'Does this make you a better professional?'. This stands next to the administration 'I have not chosen this profession because I wanted to be a secretary'. And doing moral deliberation with every team, one's a year is still a goal we haven't reached.
Psychologist We look at the things that are still possible for someone! We try to involve the whole system in the care process. Nice to see that the focus of geriatric psychology on disorders is changing to a focus on positive treatment possibilities. And if you cannot reach the resident, you can help the system. **Physician** When we open a new residence for eight people, which closes early because of CODIV and therefore there are just four people, these residents are feeling much better. They are relaxed and have less stress even though the movement is most of the time very traumatic. **Physical therapist** Working together is essential: this also means giving individual care. Information comes from that person and his network. They decide what IQL is for them.	Strengths of IQL	
Psychologist Many times, nurses say: 'just go sit down'. Do they understand what this means? How does your day look when there is always someone who says, 'just go sit down'? It is essential to talk about this. They mean well, but it is important to still let them do what they can because there is too little attention for this. Not only physical care is necessary; there has to be attention to the whole life of the residents. Seeing the things that someone still can do, everyone is open to that. But in practice, most of the time, they act according to the issues of the day. Nurses feel tightness. So, we work on ordering the care process better, so they first do what is essential for the resident. **Physician** It isn't very easy when someone himself is not competent (wilsbekwaam). Then we have to interpret the needs of this person. When we have to interpret the needs of others, we bring in our own norms and values. So we have to be aware of this.	Improvements of IQL or limits in practice	

It happens many time's that we have to give the same care with less money. That almost impossible. There is much too little time for nurses to give good care. So many times, I wrote advice in the dossier, but they don't have the time to read it, so… Temporary workers are also a problem; they don't know the residents. We also cannot see all the time what is happening in residence. So, how can we supervise them well? **Physical therapist** It would be nice if people let more go of steadfastness because you can make better connections with someone in this way. Within my discipline, I would create a space where people feel safe to ask questions. Also, there is high work pressure, resulting in an intervention in someone's autonomy, while that is not necessarily necessary. I also think that the nurses often go home with the feeling that they didn't think right. Everything must be done fast, while, when there had been more time, many nurses are capable of giving real attention. **Occupational therapist** I always have limited time, zo on your own you cannot solve every problem of a resident, so, sometimes you are significantly dependent on the rest of the team. This could be an obstacle. Because sometimes when I ask something of someone, they don't do it. While I thought it was essential for a resident. Besides, sometimes I have issues with the protocols and also the administration. It is essential, but it asks so much of my time, while I just want to help someone. I work for the contact with people, not as a secretary. Sometimes caregivers at the residence give me a feeling that I come inconveniently when I want to discuss something. While we just need each other. Also, coaching on the job is something that we have to give attention to as the core point of our improvement plan. But the 'floor' doesn't have to feel this as an 'assignment', but I understand if they do. But that's not the point. We just give advice. **Spiritual caregiver** Doing moral deliberation with every team one's a year, is still a goal we haven't reached. Coaching nurses is not as much possible as we which. But we can do it. And we want to.		
Reflexive space and capabilities towards IQL		
Psychologist We have to help people to still do what they can despite their diagnoses.	Reflection	Healthcare professionals reflect in different ways towards themselves in the care process or the care processes they observe.

One's a week, we have work supervision; these are moments we talk about work content and how you can deal with that. Four times a year, we have intervision with our discipline, then we talk about themes we want to know about more. But we also have intervision with each other. Besides, we have department consultations every four weeks. And two times a year, we have policy consultations, in which we decide our core themes for the year or reflect on them. It is the little things that matter. **Physician** We have three types of physicians. I'm a specialist, so I'm also the person who gets many questions for complex behaviour cases. For this, we have a mobile behaviour team; based on different disciplines depending on the case. Besides, we are sparring many times a week, just informal or formal. We also have a 'heidag' to discuss our functioning as physicians and if we are still satisfied with our work. **Physical therapist** For our registration, we have to do clinometry. So then you should be a good professional…. But I ask the question: am I better for the resident when I do this? I think it is some sort of 'false quality'. I think I add more quality when I look at the individual context. Besides, I think interdisciplinary is a better word than multidisciplinary. We are a self-organizing discipline with a coordinator per discipline. Within this, we reflect on each other because this makes us better professionals. But also, how do we divide the work between different disciplines. And as a physical therapist, do we have to do everything the same? Or may there be differences between locations? **Occupational therapist** Our discipline is often sparring informal when we have questions because we are uncertain of something. I like this informal way of communicating and reflection: I'm a team player. From this, I learn the most. But we also do this formal: like intervision or discussing the quality points which we formulate SMART. But also, case discussing with other disciplines. I would like to have a stagiaire because then I have to explain why I do things the way I do it. However, this would make me more critical. I know I do nothing without reason, but most of the time, it is so automatic and uncancerous that I'm not aware of it anymore. Besides, you only see the reality of practice when you are at work, not when you are still educated.	Ways to reflect and things they reflect on	Towards themselves, they reflect with questions from the concepts of IQL (as mentioned earlier). These reflections are done individually and with their discipline or even the whole team (of different disciplines). The effectiveness of these reflections depends on the amount of time and people they have availably to do actuality something with it. There are different types of structural reflection moments or reflexive spaces in their work: Consultation meetings, behavioural visits, mobile behavioural team, sparring moments every week, clinometry, intervision four times a year, and weekly supervision, every year they define their starting points as a team, and they evaluate on that. But also discipline meetings and moral deliberation towards care experiences and the care process. Besides, informal sparring when this is necessary happens often. All these reflections are about the question 'what is good care for this person?' This is a highly complex question to answer universally. But even for an individual, it could be challenging to answer because PG-residents cannot tell themselves what they need. They struggle with the protocols sometimes: 'Good care is quality of life. This you reach not only by following the protocols because it is a very complicated process'. 'Protocols are not always valid in a specific context, so you first have to look at what someone needs. Protocols could 'skip' these needs; that's not what we want. As a professional, I also have a perception of what good care contains'. Besides the protocols, they struggle with how to 'show' their profession in the right way. They know a lot about certain aspects of good care, but they do not always know what is 'good' for a specific person. 'Sometimes we think very paternalistically: we know what you need. At the same time, we have to involve the resident and the network in this. On the other hand, the balance between freedom/autonomy and safety is precarious.' Nevertheless, they can give good advice about what a 'good' choice could be.

Spiritual caregiver How do I know if I do things right? Well, that's a feeling. There is not much result of my work, but I feel that when I have talked with someone; they are thankful that I was there. Sometimes, the next time I see that someone is 'further' in his process, we can continue where we went off. This could improve the quality of life. We reflect every four weeks with all the spiritual caregivers of Zinzia. That is necessary; we can help each other a lot with difficulties. Every year we define our starting point as a team, and we evaluate that. We also have moral deliberations with the teams about difficult questions. I come and talk to the nursing teams, in which I explain what a spiritual caregiver is, and we also give attention to the reflection on ethics.		
Psychologist Last years we worked more on distance, because of lack of time and team members. But I'm glad we now can go more often to the residents themselves, to see and experience for ourselves how they feel. But also talk to the nurses more often. It is not enough to only 'hear' stories from the nurses and the network. This is something we want to improve! We have consultation meetings, behavioural visits, and we write episodes—all to improve the care process with the nurses and decide what has to have focus. But education is also essential: how do nurses look at illness and health? \ Dement person or person with dementia…? So, not focus on what isn't possible, but on what is. **Physician** When someone's personality changes because of their condition, how do you then translate this to the norms and values someone gave meaning to in life? From vegetarian to meat-eater. Good care is also the balance between what is essential to someone and what is possible. So, safety and freedom. For this, we have to tune constantly between the team, the network, and the resident. Sometimes we think very paternalistically: we know what you need. At the same time, we have to involve the resident and the network in this. On the other hand, the balance between freedom/autonomy and safety is precarious. **Physical therapist** Good care is quality of life. This you reach not only by following the protocols because it is a highly complex process. Protocols are not always valid in a specific context, so you must first look at what someone needs. Protocols could 'skip' these	What is good care?	

needs; that's not what we want. As a professional, I also have a perception of what good care contains. Look, the inspection found decubitus very bad. So, according to them, it could be a sign of inadequate care. But we think; we only do something about it if it bothers the resident. We don't do it to be 'more beautiful'. So, good care is influenced by looking at the individual. Sometimes people think, 'I do it just right when I follow the protocol. I don't have to ask if this was true for the resident'. But are you a good caregiver if you follow the protocol, or why should you not? It is difficult to say what the best way is of giving care. So, I try to be aware that I bring my 'person' into the process. But I think it is good that there are many persons involved in the care process, together you come to the best way of doing it.		

Observations and structural coding

In table 4 you can find the topics of the observations. These are examples from practice. This answers the sub-question 2: 'how do healthcare professionals give meaning to IQL in practice?' The described observations according to the shadowing method, you can find in appending 6—the coding of the observations I did on paper.

Table 4: Topic group of the observations

Topic group	Topic
Integral quality of life	IQL
	Meaning
	Well-being
	Having eye for individuality
	Social needs
	Physical (biomedical) needs
	Psychological needs
	Spiritual needs
System that contributes to IQL	Teamwork
	Network, those who are involved
	Target groups
Interactions that contribute to IQL	Communication
	Observation resident/ Experience care process
	Connection
	The perception of the caregiver
	Culture
Practice of giving meaning to IQL	Most important theme towards IQL
	Strengths of IQL

Reflexive space and capabilities towards IQL	Improvements of IQL
	Reflection
	What is good care?

Theorization

From this analysis, I formulated the answers to the sub-questions. The answers to the first four sub-questions are described in 4.1. Through this I could inductively theorize practice (4.2). Based on the topic list I made (appendix, table 3/4), I built a theoretical model which represents the role of the hcps regarding the IQL experience of the PG-resident. This model is visible in figure 8 (4.2). Finally, in 5.1 and 5.2, I answered sub-question five and six. I choice to put these answers in the Discussion chapter, because they hold advice and reflection.

Reflection

It is not always easy to code a sentence to a specific topic. Depending on the context, a sentence could better be code with another topic than the important words suggest. For example, when I saw 'system' in the text, you probably would think that this has to be coded with 'network' because healthcare professionals refer to this in many cases. But, when I read the sentence, I concluded that in this case, 'system' referred more to the 'social needs' of both the resident and the family members of that specific system. This has happened many times with different codes in different contexts. Most of the time, I gave the sentence two colour codes, which gave me insight into the codes' interrelatedness. But sometimes I chose only to use one colour. I try to make with this; I cannot guarantee that my way of coding was always this right or only way. It all depends on how I interpreted things, so I clearly see my influence as a researcher. I do not know how problematic this 'coding bias' is for the results. The only way I could have decreased this bias was when other persons code the exact text and disuse the 'inter-review-reliability' until the percentage was high enough to guarantee more validity than when I have done it on my own. However, that was not an option.