recess for families with chronically ill and/or disabled children

research plan

Jil Weber
5609526

Designing for Care in an Inclusive Environment
Dwelling Graduation Studio_AR3AD110
research Tutor: Ir. Frederique van Andel
design Tutors: Dr.-Ing. Birgit Jürgenhake &
Elke Miedema PhD
external Tutor: Prof.dr.ir. Klaske M. Havik

Table of contents

i. preliminary comments

a. keywords and abbreviations

recess, retreat, vacation, holiday, trip
regenerate, relax, take a break, rejuvenate
family, parents,children, siblings, relatives [care givers]
quality of life (QoL), well-being
chronically ill and/or diabled (CID) & chronic illnesses and/or disabilities
diagnosis, mental/physical health, disease, condition, burden

b. declaration

In this thesis, all survey or interview participants are kept anonymous and untraceable. Therefore, their names have all been changed. This is for the protection of all participants and their families.

I. introduction

a. general topic introduction

In recent years, the number of diagnoses of chronic illnesses and disabilities in paediatric care has risen steadily (Jansen & Illy, 2022). Therefore, late research started to focus on the long-term impact on the health related quality of life (QoL) of families with chronically ill and/or disabled (CID) children (Vonneilich et al., 2015).

According to Murray Bowen's Family system theory (1966) families are one emotional unit, where all the members are deeply connected on an emotional level. This connection is fundamentally based on the interdependence of family members. The moment one person within the system starts to malfunction, for example after receiving a diagnosis of a severe condition, the functioning of the whole system collapses and needs to be reorganised (zu Solms, 2022).

How the family unit changes in the wake of such a diagnosis and what can be done to generate positive effects are the questions that need to be answered. The focus of this research report lies on how families with CID children can recess in order to strengthen the connection between the various family members and maintain the functioning of their overall system.

A trip to a generic hotel will most likely fall short of reaching these goals. The families would confront numerous accessibility concerns, and unnecessary complications. Furthermore, caring for disabled or chronically ill children is a full-time job that never ceases. How then can those families have a trip that will genuinely be enjoyable and where all of the family's needs will be met?

In the past, people dealt with the issue by sending their sick children to camps for people with special needs. The documentary Crip Camp (Lebrecht & Newnham, 2020) draws a picture of how grateful and jubilant the children were to spend some time among fellow patients. As several of the participants described later, Camp Janet was a utopia where their handicap didn't matter because there, they were all simply kids (Lebrecht & Newnham, 2020). At the same time, the parents got time to themselves to regenerate and retreat.

However, as mentioned before, the centre point of this problem has broadened. The realisation of how relevant the bond between every member of the family unit is, changes the view on those camps and raises a different question. We therefore need to focus on how the family unit recesses together.

b. problem statement

Chronic illnesses and disabilities of a child does not only affect the health and well-being of the child, but also of their parents. They are constantly looking after their child and barely ever get a moment to themselves, which in many cases can lead to psychological problems. The caregivers often feel isolated and they suffer from a lack of social contact (Vonneilich et al., 2015). Recent studies have shown that it has several advantages when care is supplied by a third party, allowing the parents to spend time with the siblings, take care of other necessities, or simply take short pauses (Shelton, 2009).

The QoL of CID children is often lower than it could be. Since they hardly ever have peers with similar issues, they can only compare their situation to that of children in good health. They usually only get labelled as disabled or sick in their everyday life and they never just feel like a child. They are burdened by their condition and are unable to enjoy a carefree childhood (Lebrecht & Newnham, 2020). Bringing those children together and creating the opportunity for them to meet others with comparable issues, is therefore crucial for their mental health. This has been verified by analysing CID children that visited therapeutic camps. Allowing those children to participate in activities at their convenience, gave them the feeling of being like every other healthy child (Shelton, 2009).

c. personal fascination

Stories of seriously ill children have always deeply moved me. Not only did they have to go through so much trouble in their young age, but they often never got to experience a carefree life, because they were born with the condition.

A friend recently told me about her weekly support for a family with a severely disabled girl. According to her, they really struggle to go on vacation for various reasons.To be able to unwind a little, the family needs to bring along someone else, whether it be a paid caregiver or a relative. However, they also need to purchase additional gear, such as a special folding dining chair or a travel bed that can accommodate a six-year-old. Moreover, they have to cope with the eminent psychological strain. While travelling with such a severely disabled child, they unfortunately attract unwanted attention while staying in a nice environment.

Figure 1

d. research aim & contribution

The overall goal is to give relief by creating an opportunity of real recess and break from ongoing care for the child for parents and caregivers through architectural solutions, resulting in general improvement of their mental and physical well-being.

The true moment of regeneration and retreat coupled with the obtained time to meet and connect with other families and patients will lead to a higher health related QoL for all family members. This research also aims to ameliorate the families social contacts through connecting them with other families that are facing similar troubles. This will contribute to an alleviated well-being of families with CID children.

Long-term and consistent visit of a centre, where this situation would be provided, will result in a more functional family system. Furthermore, the advantageous situation in which all relatives can spend a relaxing holiday together also leads to a strengthening of the bond between the siblings and their parents. The deep connection that often falters due to everyday life with a CID child is thus further stabilised. In more extreme cases, it can even be completely restored.

e. research question

How can the **architectural environment** of a retreat for **families with disabled and/or chronically ill (CID) children** provide relaxing time together while supplying a potential **benefit for the child**?

Sub-questions

What kind of similar typologies or solutions have there been in the past and what design concepts can be integrated in such a retreat?

> IIt is necessary to determine the drawbacks of and the solutions provided by those typologies. Furthermore, understanding how multiple typologies can be merged together is crucial to develop the desired outcome.

What are the specific needs for the different family members and how can they be addressed through design choices?

> The visiting families should have all their needs covered. Therefore,infrastructure for both the parents and the CID children needs to be provided.

What design concepts would need to be integrated to create relief for CID children?

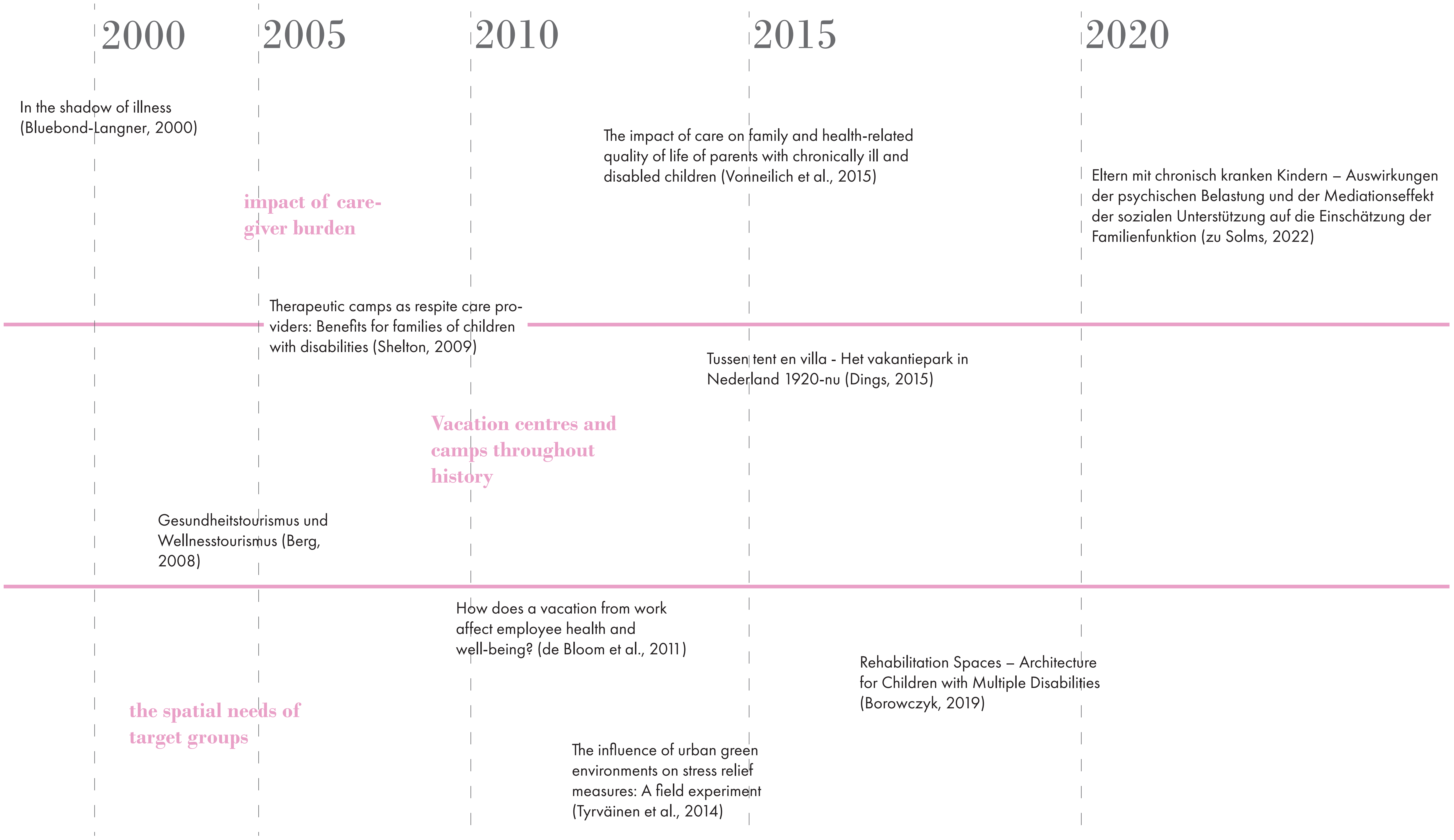
> Attaining a useful design, necessitates understanding about salutogenic design and getting a sense of how architecture may benefit people. Understanding the most common concepts for CID children is essential to a design that fosters a positive environment for these children.

f. hypothesis

A place where families with CID children can go for recess on a regular basis results in a significant increase in the health-related QoL of all family members.
It is valuable to develop a recess centre, where families can take a break from everyday life together without having to neglect the needs of the sick child. In the long run, this leads to a decrease in psychological strain and an overall increase in parents' or caregivers' health, as they feel included and can interact with other families in comparable situations. In addition, the siblings of CID children also benefit from this, since they frequently feel left out when their parents are caring for a sick child for a prolonged period of time. In such a centre, the siblings get the opportunity to spend some alone time with their parents, while the sick child is being taken care of, which will result in a stronger and more stable bond between the siblings.

II. theoretical framework

a. scheme



2000

2005

2010

2015

2020

In the shadow of illness (Bluebond-Langner, 2000)

impact of caregiver burden

Therapeutic camps as respite care providers: Benefits for families of children with disabilities (Shelton, 2009)

The impact of care on family and health-related quality of life of parents with chronically ill and disabled children (Vonneilich et al., 2015)

Eltern mit chronisch kranken Kindern – Auswirkungen der psychischen Belastung und der Mediationseffekt der sozialen Unterstützung auf die Einschätzung der Familienfunktion (zu Solms, 2022)

Tussen tent en villa - Het vakantiepark in Nederland 1920-nu (Dings, 2015)

Vacation centres and camps throughout history

Gesundheitstourismus und Wellnesstourismus (Berg, 2008)

How does a vacation from work affect employee health and well-being? (de Bloom et al., 2011)

Rehabilitation Spaces – Architecture for Children with Multiple Disabilities (Borowczyk, 2019)

the spatial needs of target groups

The influence of urban green environments on stress relief measures: A field experiment (Tyrväinen et al., 2014)

Figure 2

b. positioning

Interesting studies that have already been conducted on the subject of this inquiry are described in this theoretical framework. We can highlight three related streams of studies: impact of caregiver burden, vacation centres and camps throughout history, and the spatial needs of target groups.

impact of caregiver burden

Vonneilich et al (2015) studied the care related effects on parents of CID children. In their research paper, the authors used data analysis to identify a relationship between caring and the parents' health-related QoL. The results of their study show that a lower health related QoL is the direct consequence of a higher care need of the child. The medical sociologists concluded that future interventions need to target the whole family and not just the child in question. Their study clearly states the different causes of caregiver burden and even tries to link the severity of the child's diagnosis to the severity of the parent's load. This then helps to determine stress creating factors and deduce factors that create a moment of relief for the whole family.

The work by Bluebond-Langner (2000) also highlights the influence of a sick child on the entire family. In her book, Bluebond-Lagner draws portraits of nine different families that have a child with high care needs. Similar to the research by Vonneilich at al. (2015), this work helps to understand the load and impact of care on these families, which gives a better insight on the families' internal functioning and what might provide them with alleviation.

The study, which is positioned between two topics, by Shelton (2009) covers the needs and daily hurdles of a family with a CID child, as well as the extent to which camps for children with disabilities bring relief for the family. The author highlights moments of respite for the children during such camps and explains why these moments of relaxation, where the parents can regenerate, are crucial. That is why his work is so valuable for this thesis, as it already combines two of the topics to be dealt with. Nevertheless, the aspect of how an architectural environment or specific design elements allow families to relax together, has not yet been analysed therein.

Vacation centres and camps throughout history

The book by Berg, 2008) provides a detailed and in-depth overview of the health and wellness tourism market and a listing of different structures from this sector. It allows to determine both case studies that are worth analysing and to extract helpful data concerning people's demand of relaxing and regenerating. It also creates a better understanding of how people spent their health trips in the past and how that changed over time. It enables us to make a prediction for future needs and especially what those families would look for in an architectural environment providing retreat.

Another element of the theoretical framework is the PhD dissertation by Mieke Dings (2015), which draws a complete overview of tourism and vacation habits in the Netherlands over time. This research provides necessary knowledge on how Dutch people have spent their free time to relax and regenerate in the past. Similar to Berg's work this dissertation contributes to the learning of how the travel behaviour of the dutch population changed and how it might develop in the future.

the spatial needs of target groups

The paper by de Bloom et al. (2011) analyses if everyone experiences a beneficial effect on their health and well-being while taking a break from work and going on vacation. The authors investigate six factors such as health status, mood or energy level, in employees before, during and after their vacations.Their goal is to learn more about how vacations can enhance health and well-being and what factors affect how someone perceives their vacation. The needs for parents of CID children, who frequently shoulder the double burden of caregiving and working a full-time job, can be related to this paper's discussion of employees.

The research conducted by Tyrväinen et al. (2014), investigates the psychological and physiological influence of weekend getaways in a rural or suburban setting. Their results show that even a brief trip to nature can have major benefits on the overall well-being of a person and reduces their perceived stress significantly. This allows us to determine a set of criteria for the chosen site in order for it to be beneficial to its visitors. Moreover it helps to understand how and why these stays away are urgently needed by families with CID children.

Lastly, the recent work by Borowczyk (2019) describes the required conditions for spaces designed to rehabilitate CID children and how a carefully designed environment can be beneficial for those children. It gives the required input that helps determine design tools and criteria for the architectural response developed in this thesis. It especially provides information about the spatial needs for CID children and how spaces can be designed accessible to the broadest spectrum of disabilities and conditions possible.

III. methodology

A A diverse set of research techniques, such as case study analysis, in depth interviewing, and anthropological fieldwork, as well as literature reviews and documentaries will be utilised to complete this thesis. Those approaches will offer the necessary design guidelines to create a research catalogue of the target groups' spatial needs.

The first sub-question, dedicated to determining past and current infrastructure, will be reviewed through literature and existing case studies. First, we will study different children's hospitals, Ronald McDonald houses and daycare facilities for children with special needs, by analysing their floor plans and highlighting their spatial sequences. Then we will read about the evolution of these typologies and to understand their evolution over time. Moreover we will inspect how environments that allowed the family to stay over were established.
To gain an insight on what holiday resorts and organised trips nowadays have to offer to families with CID children, we will review literature and investigate documentations. Additional information can be gained by contacting organisations that offer either organised holidays for this target group or that coordinate camps for CID children.
To conclude, it is important to determine what crucial elements are found in health care typologies, but are missing in vacation/retreat resorts and vice versa. Trying to figure out if and how they can be combined and what each typology is missing on their own will lead to the conclusions necessary for determining first design parameters.

For the second sub-question, concerning the specific needs of every family member, are mainly going to be addressed through in-depth interviews with parents and siblings as well as interviews with staff of a daycare facility like therapists and nurses.
Additionally, the fieldwork that will be carried out at a daycare facility in Luxembourg for children with special needs will provide a deeper understanding. Not only will it provide the possibility to observe and interact with the children as they go about their daily lives, but it also gives an insight to the therapy and treatment rooms. This will allow us to gather information about their spatial requirements and how design may assist in supplying the required spaces and amenities. Furthermore, I will be spending a day with a family in Luxembourg, where I will do a semi-structured interview with the mother and study the living environment of a family with a CID child.
We will carry out a survey on- and offline, which will supply answers to the posed questions from the broadest audience possible. That will allow us to compare and extract wide-ranging wishes from families coming from different backgrounds. Additionally, reviewing literature that analyses health care facilities or vacation centres and provides further information on those typologies.
All of these findings will be necessary to identify the spatial needs that are specific to every family member, which will subsequently help to create an architectural environment fit to everyone's requirements.

The last sub-question regarding design concepts to create benefit for the child will primarily be investigated through literature reviews and case study analyses on both children's hospitals and holiday resorts. Reading about salutogenic or healing designs gives an insight on how architectural spaces can influence people's minds and therefore their mental well-being.
Additionally, the readings and analyses offer an understanding of therapy and treatment rooms as well as clues on the surroundings of the buildings which might be necessary to include in a design proposal. This might also be granted through insights gained through the field work.
This information will provide the proficiency and design guidelines that are necessary to design a space that will benefit its users both physically and mentally.

literature review	what? how? →	literature of the topics: causes of caregiver burden, vacation centres and camps throughout history and the spatial needs of target groups	outcome? →	understanding of factors for creating caregiver burden, learning about general needs of target groups and about how people regenerate
documentaries	what? how? →	mainly through *crip camp* which is a documentary of the summer camp for disabled children called "camp Jened"	outcome? →	understand why it is important for CID children to connect and be amongst other children facing similar disorders
case study analysis	what? how? →	analysis of children's hospitals & hospices, vacation centres and Ronald McDonald homes and livingrooms	outcome? →	get more knowledge about the spatial needs of CID children, parents/caregivers, siblings and staff members
surveys	what? how? →	for parents of CID children asking questions about travelling with and caring for sick children	outcome? →	get more reach and get answers & feedback from people with different backrouds and from various cultures
in-depth interviews	what? how? →	with parents, therapists and architects that design health(care) related buidlings	outcome? →	get a deeper understanding of the problem and what is important while designing for families with a CID child
fieldwork	what? how? →	in a daycare centre for disabled and chronically ill children	outcome? →	learn how the ervey day life of a CID child looks like; get insights to their care needs, and spatial requirements

Figure 3

IV. workplan

a. time planning

After the first five weeks of working together in the studio group on the topic of designing for health and care, I defined my specific research topic. This then led to formulating the problem statement and hypothesis that contributed to the research question. With the P1, the fieldwork will be completed, where I get to interact with the target population in person while accompanying and observing CID children in their everyday life.
Afterwards, the research will start. Through interviews with affected parents and staff of the daycare centre and the mentioned fieldwork, I will gather the first data. Then the writing of the thesis will slowly start. However, the writing phase, as well as the design phase, cannot yet be clearly defined. As new chapters are composed and new insights are gained, the written parts will be revised and reflected upon. In this way, the two aspects of writing and designing are repeatedly taken up or paused in time, which is represented in the diagram by the curved lines. It is clear that through the conclusion of the written thesis, a design toolkit can be transferred to develop a design proposal in response to the research question.

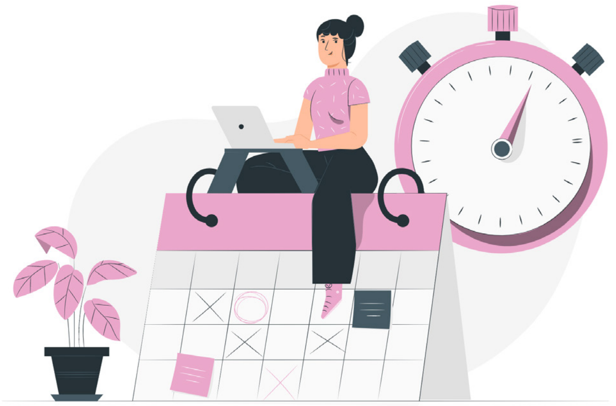


Figure 4

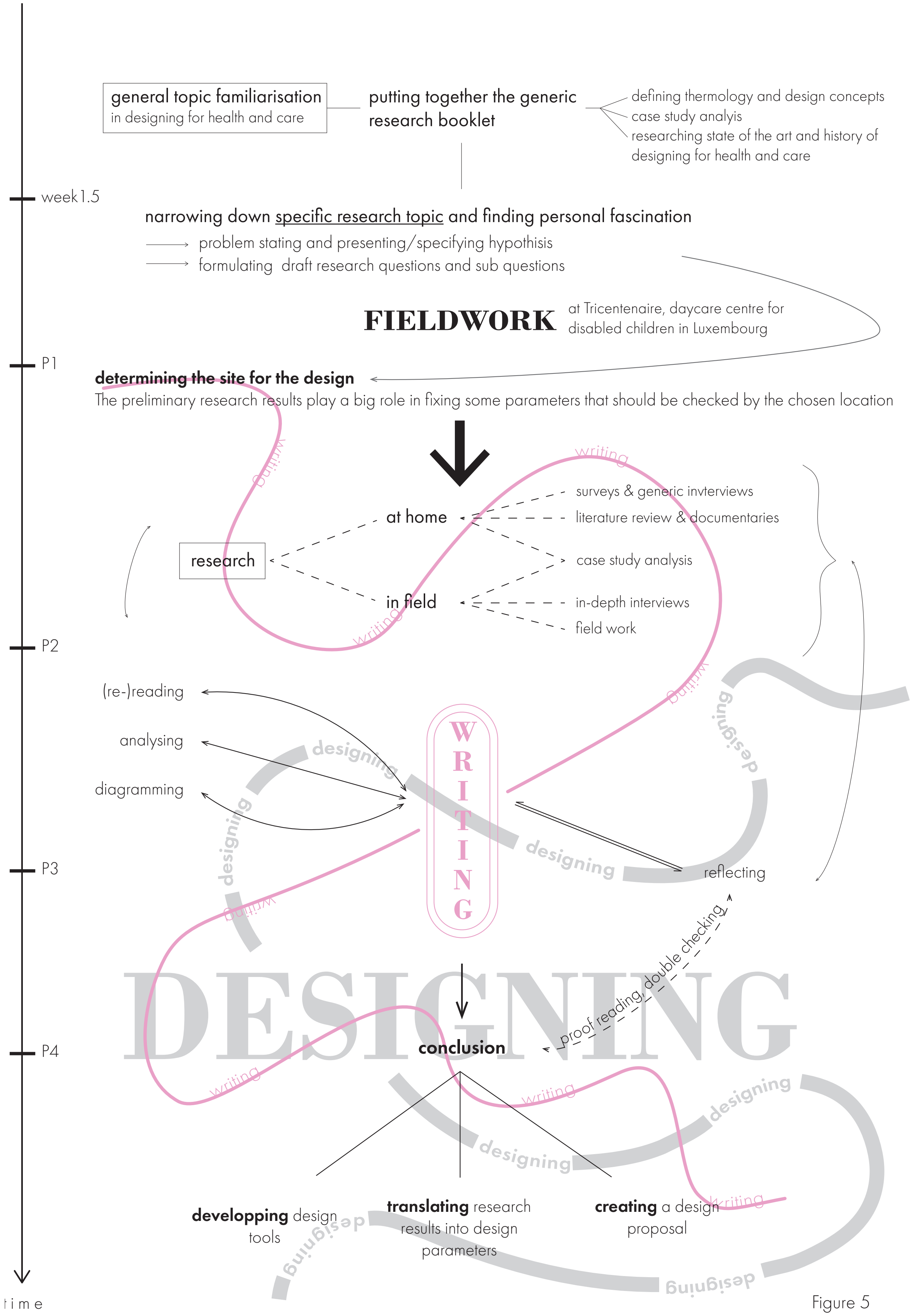


Figure 5

b. research plan diagram

WHY?

Problem:
Chronic illness and/or disability of a child affects the health and wellbeing of the children as well as their parents and caregivers. The families often feel isolated which in many cases leads to caregiver burden, depression or other psychological problems and lowers the health related QoL of all the family members.

Hypothesis:
The possibility to have a place where families with CID children will go for recess on a regular basis will result in a significant increase in the QoL of all family members as well as their physical and mental health.

Aim:
Create an opportunity of real recess and break from ongoing care for the child for parents, resulting in the general improvement of their mental and physical well-being.

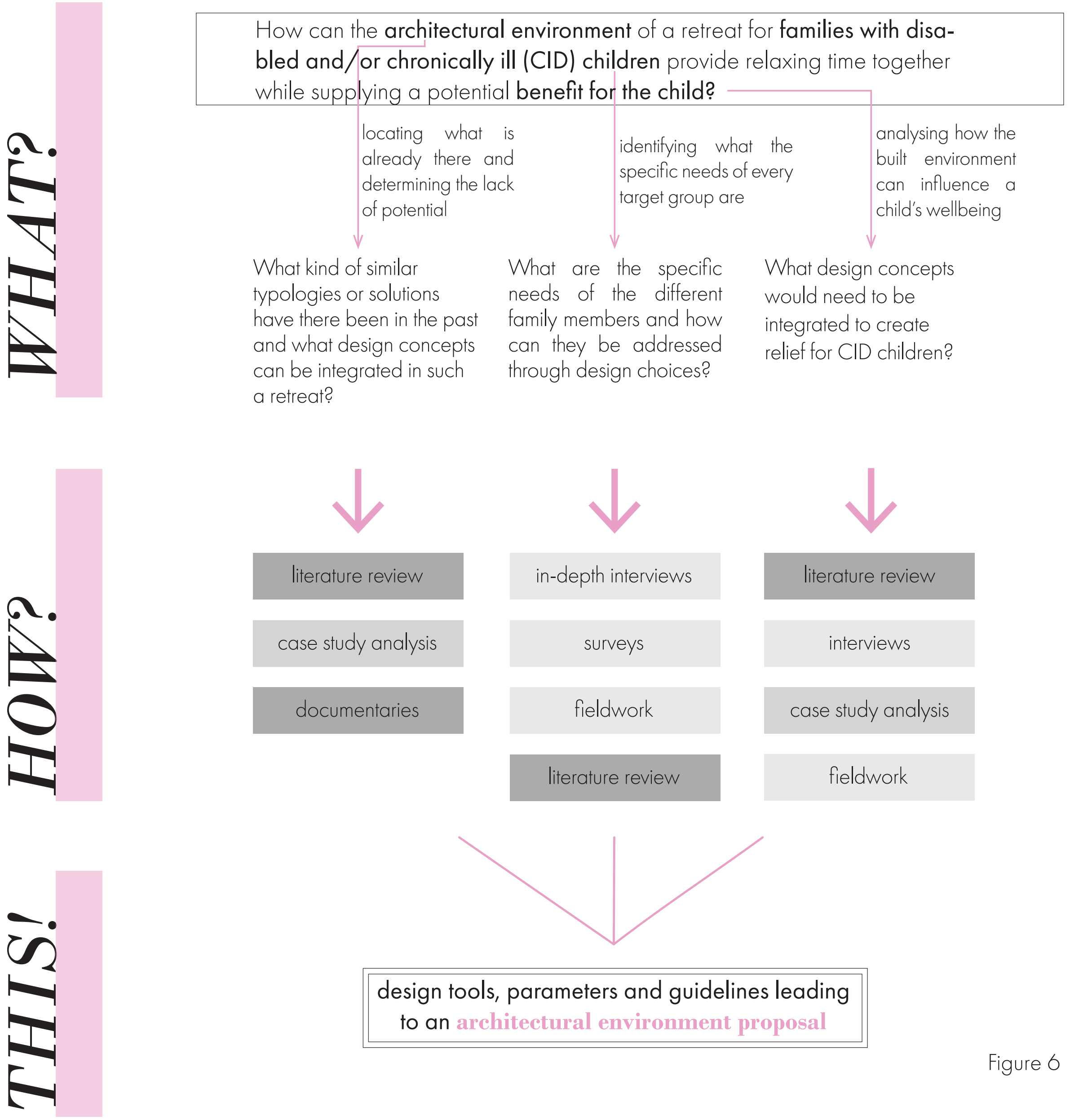


Figure 6

V. definitions

In the following, we give some terminology used in this thesis.

Quality of Life
"Quality of Life [is] an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." (WHO, 2012)

Caregiver burden
Caregiver burden defines "the stress and other psychological symptoms experienced by family members and other nonprofessional caregivers in response to looking after individuals with mental or physical disabilities, disorders, or diseases" (APA, n.d.)

Disabled and/or chronically ill child
Childhood chronic illness refers to conditions in pediatric patients that are usually prolonged in duration, do not resolve on their own, and are associated with impairment or disability.[1] (Stanton et al., 2007)

Recess
Recess describes "a suspension of business or procedure often for rest or relaxation" (Merriam Webster, n.d.)

Retreat
A retreat is "a quiet or secluded place in which one can rest and relax" (OED, n.d.)

Shelter
A shelter is "a building where people or animals that have nowhere to live or that are in danger can stay and receive help." (Longman Dictionary, n.d.)

---

[1] the used formulation can be found on Wikipedia,under the following link. They cite the source of Stanton et al. (2007) to definie disabled and/or chronically ill child (*https://en.wikipedia.org/wiki/Childhood_chronic_illness*, retrieved on 07.10.22)

VI. reference list

APA. (n.d.). *caregiver burden.* APA Dictionary of Psychology. Retrieved October 7, 2022, from https://dictionary.apa.org/caregiver-burden

Berg, W. (2008). *Gesundheitstourismus und Wellnesstourismus.* Oldenbourg. https://doi.org/10.1524/9783486711141

Bluebond-Langner, M. (2000, May 30). *In the Shadow of Illness.* Princeton University Press.

Borowczyk, J. (2019, February 23). Rehabilitation Spaces – Architecture for Children with Multiple Disabilities. *IOP Conference Series: Materials Science and Engineering*, 471, 072017. https://doi.org/10.1088/1757-899x/471/7/072017

Bowen, M. (1966). The use of family theory in clinical practice. *Comprehensive Psychiatry*, *7*(5), 345–374. https://doi.org/10.1016/s0010-440x(66)80065-2

de Bloom, J., Geurts, S. A., Sonnentag, S., Taris, T., de Weerth, C., & Kompier, M. A. (2011, December). How does a vacation from work affect employee health and well-being? *Psychology &Amp; Health, 26(12)*, 1606–1622. https://doi.org/10.1080/08870446.2010.546860

Dings, M. (2015). *Tussen tent en villa Het vakantiepark in Nederland 1920-nu* [PhD dissertation]. Technische Universiteit Delft.

Jansen, D., & Illy, K. (2022, January 18). Paediatric Care in The Netherlands: State of Affairs, Challenges and Prospects. *International Journal of Environmental Research and Public Health, 19(3)*, 1037. https://doi.org/10.3390/ijerph19031037

Kourkoutas, E., Georgiadi, M., & Plexousakis, S. (2010). Quality of life of children with chronic illnesses: A Review of the Literature. *Procedia - Social and Behavioral Sciences, 2(2)*, 4763–4767. https://doi.org/10.1016/j.sbspro.2010.03.765

Lebrecht, J., & Newnham, N. (Directors). (2020, January 23). *Crip Camp* [Netflix]. Higher Ground Productions, Little Punk, Ford Foundation, Just Films, Rusted Spoke Productions. https://www.youtube.com/watch?v=OFS8SpwioZ4

Longman Dictionary. (n.d.). *shelter.* Retrieved October 7, 2022, from https://www.ldoceonline.com/dictionary/shelter

Merriam Webster. (n.d.). *Recess.* Retrieved October 7, 2022, from https://www.merriam-webster.com/dictionary/recess

OED. (n.d.). Retreat. In *Oxford Languages.*

Shelton, K. J. (2009). *Therapeutic camps as respite care providers: Benefits for families of children with disabilities* [Master Thesis]. Texas A&M University.

Stanton, A. L., Revenson, T. A., & Tennen, H. (2007, January 1). Health Psychology: Psychological Adjustment to Chronic Disease. *Annual Review of Psychology, 58(1), 565–592.* https://doi.org/10.1146/annurev.psych.58.110405.085615

Tyrväinen, L., Ojala, A., Korpela, K., Lanki, T., Tsunetsugu, Y., & Kagawa, T. (2014, June). The influence of urban green environments on stress relief measures: A field experiment. *Journal of Environmental Psychology, 38, 1–9.* https://doi.org/10.1016/j.jenvp.2013.12.005

Vonneilich, N., Lüdecke, D., & Kofahl, C. (2015, June 23). The impact of care on family and health-related quality of life of parents with chronically ill and disabled children. *Disability and Rehabilitation, 38(8), 761–767.* https://doi.org/10.3109/09638288.2015.1060267

WHO. (2012, March 1). *WHOQOL.* Measuring Quality of Life| the World Health Organization. Retrieved October 7, 2022, from https://www.who.int/tools/whoqol

zu Solms, M. (2022). *Eltern mit chronisch kranken Kindern – Auswirkungen der psychischen Belastung und der Mediationseffekt der sozialen Unterstützung auf die Einschätzung der Familienfunktion* [Master Thesis]. Medical School Hamburg University of Applied Sciences and Medical University.

VII. list of figures