The Home-(*un*)making of parents with a child with Acquired Brain Injury

A research into the experience of parents with a child with Acquired Brain Injury (ABI) their home-making process.

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Summary

Every year about 19.000 children and young adults between the ages 0 and 24 acquire brain injury (ABI) in the Netherlands. This has severe consequences for these persons, their families and their friends. This study focuses on the parents of these young ABI patients. Most brain injuries in this age group are classified as traumatic brain injury, which can be caused by a traffic accident or a fall. Just as the patient, the parents experience a traumatic event in their lives and have to adjust to that. This study tries to find how parents adjust to such an event at the home. As such, the research question this research tries to answer is the following:

> *"How is the experience of home-making for the parents of a*
>
> *Son/Daughter With Acquired Brain Injury in the Netherlands?*

It was decided that the method would be the analysis of Dutch online blogs. These blogs were analysed in Atlas-ti, a software package for qualitative data analysis. The used code tree was based upon the theoretical framework. This yielded some useful data. From the analysis it appeared that there is no consciously conceived *self* for the child before acquiring brain injury, whereas the parents do consciously conceive a pre-ABI identity of the child and can thus compare it to after-ABI. To a certain extent, this makes it more difficult for the parents to accept the ABI than it is for the children. The analysis showed that the home-making process is mostly affected by the changed identity of the child, which results as a consequence in altered daily routines and more intensive caregiving, which puts some sort of strain on some parents.

It is paramount to acknowledge that the consequences of Acquired Brain Injury are highly individual, and it manifests itself in various ways. Taking this into consideration, it seems that in the current literature parents' home-making process is disregarded. However, this research shows there is need for further investigation, since the caregiving capabilities are potentially threatened by a worse wellbeing, resulting from difficulties in the home-making process.

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1. Introduction

1.1 Background & Research problem

In the Netherlands, approximately 19,000 people in the ages 0-24 years acquire brain injury every year (see figure 1), which in 15% of the cases is classified moderate or severe. The cause is usually a blow against the head in traffic accidents, by a fall or assault. One in four cases has a non-traumatic cause, those are the result of a brain disease, e.g. meningitis, brain tumour or a stroke (Kloet, 2015). These patients experience to varying extents reduced physical, cognitive and behavioural functionality (Vos & Diaz-Arrastia, 2015). The treatments are highly individualised since the disabilities differ per case (ABI Rehabilitation Specialists, 2016). After the acute rehabilitation phase, rehabilitation either continues at a rehabilitation unit or at home. Eventually some patients have to move into long-term care while others are able to move back to their parental home. In the latter case, physical changes to the home may have to be made for the safety and independence of the patient.

Evidently, acquiring a brain injury has a significant impact on a person's life as well as on their family members' (DeMatteo et al., 2008). Previous research has focused mainly on the patient, but the role of relatives is often neglected, while their influence on recovery is significant (Hersenstichting, 2013; Lefebvre et al., 2005). Some research has looked into the needs expressed by family members (Jordan & Linden, 2013; Keenan & Joseph, 2010), but little research has considered changes to the *home* that may be experienced by family members, be it physical or emotional, while such changes could influence the ability to support recovery. Meijering et al. (2016) did show the challenges stroke survivors as well as their partners experienced in the home-making process. However, no such research has been conducted to address challenges the parents of a child with Acquired Brain Injury (ABI) face, in spite of the fact that it has been shown that the hospital-to-home transition has a psychological impact on them too (Turner et al., 2011). This study therefore aims to identify how parents engage in the home-making process after a son/daughter acquires brain injury and moves back into the family home. Key questions to devise how these parents engage in home-making are: "How do the parents shape their identity in relation to their son/daughter with ABI in the home-making process? How do the parents shape their routines in relation to their son/daughter with ABI in the home-making process? How do the parents take the caregiving upon themselves in relation to their son/daughter with ABI in the home-making process?"

Figure 1. Number of ABI patients ages 0-24 per Municipality in the Netherlands in 2014.
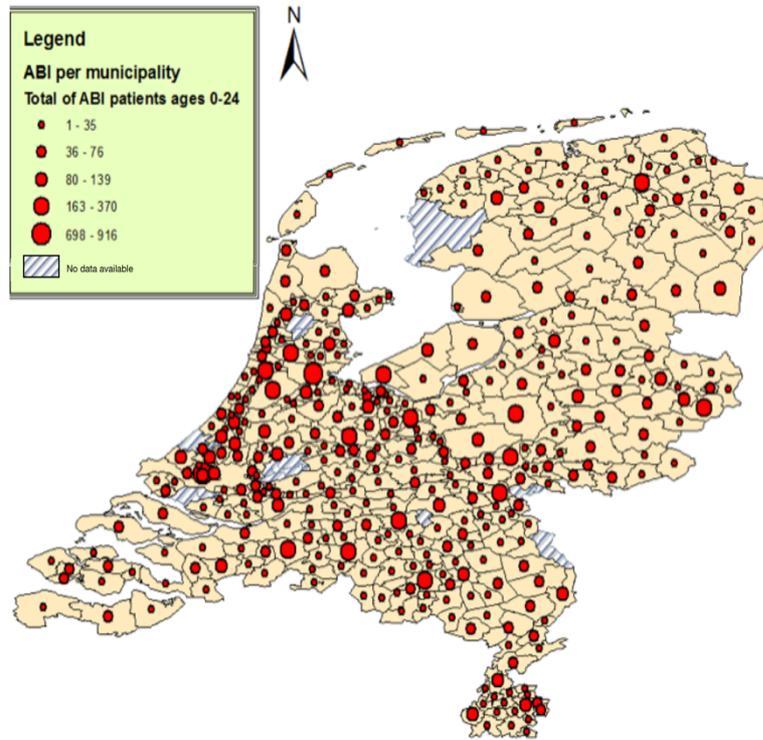
Data source: http://www.haweel.nl/hersenz/
Author: S. Grootemarsink
Sources: Esri, Garmin, USGS, NPS

1.2 Structure

In the following part of the thesis, chapter 2, I will outline the theoretical framework on which this research is based. On the basis of the framework a conceptual model has been created in chapter 3, which will be clarified. Then the methodology used to answer the research question will be explained in chapter 4 and discussed extensively. In the fifth chapter, I will discuss and analyse the results in reference to the theoretical framework. Finally, I will draw conclusions from this research in chapter 6 and make recommendations for future research and policy. In this chapter I also shortly reflect on the research limitations and put the findings in the context of the broader theoretical framework.

2. Theoretical framework

2.1 The home

The research on the home within cultural geography and beyond took off since Mona Domosh published her 1998 review on 'house and home, the household, and the domestic world' (Blunt, 2005; Domosh, 1998). Since then, many aspects of the home have been explored and discussed. The home has been conceptualised as a material and an affective space, shaped by everyday practices, lived experiences, social relations, memories and emotions (Blunt, 2005). The influence of the material space on mental and physical health has been extensively researched (Evans et al., 2003; Marsh et al., 2000), the affective space, however, has not received as much attention in research in relation to health effects. Evans et al. (2003) found that good (i.e. quality physical) housing offers protection from negative social conditions, while Marsh et al. (2000) similarly found that poor housing is significantly associated with greater likelihood of ill health. It is to be expected that the affective space also impacts mental health and to a certain extent physical health as well. Domestic violence for example contributes negatively to the home as a place of security and safety, as shown by Warrington (2001).

2.2 Home-making

Within the frame of the affective home, this study will focus on the process of home-making. The notion of home-making is understood as the intertwining of social relationships, identities, and materiality into a place called home (Douglas, 1991). There are a few specific aspects of home-making which are particularly interesting in light of this research.

The first aspect is routines. The outcomes of the social relations, identities and materiality of the home are the habits situated in places, or routines, such as getting the children to school in the morning or cooking dinner (Seamon, 1980). The routines and habits are important to find stability and support when something unexpected happens. In a study by Wilder and Granlund (2015) on sustainability of daily routines among families with a child with profound intellectual and multiple disabilities, it was found the sustainability was linked to fathers' involvement, couples' connectedness and emotional support. When a son/daughter acquires brain injury, the routines may have to change dramatically, which might be experienced in the home in various ways.

Another aspect is identity. Turner et al. (2011) found the ABI patients go through a process of change and acknowledgement of their different identity once returning home, which eventually becomes a challenge for the parents too; they have to intertwine the changed relationship and identity of the patient into their home. There is more to the aspect of identity however, for also the identity of either of the parents might evolve. Next to that, in a lot of ABI cases it is likely that the parents become caregivers (Gan, et al., 2010). The consequent effects were studied, among others, in Canada. A study among employed adults showed that the more time spent on care-giving, the lower well-being ratings were. Enhanced well-being was, of all researched factors, most strongly associated with sense of community (Hilbrecht et al., 2017). Putting this in the light of another study which found that the negative effect of caregiver strain on wellbeing is attenuated by active participation in online health forums (Tanis et al., 2011), it is interesting to research if the parents make use of such forums to enhance their community feelings and, as such, enhance their wellbeing.

Whether parents of an ABI patient face such caregiving challenges and how it affects their identity in the home-making process is of importance to this research.

2.3 Home-*un*making

Within this framework of the home, the proposed theory of home *un*making by Baxter and Brickell (2014) is to be considered. Because the hospitalisation of the son/daughter, and thus moving out of the house, after acquiring brain injury is often a painful moment, possibly inducing alienation and fear to be associated with the home. Such a change in the experience of the home is likely to affect the parents, perhaps even more so than when the son/daughter moves back in. It is important to examine whether there may be negative changes to the parents, because in general, the family members usually perform a significant role in the recovery of the patients (Estrada, 2016; Reupert et al., 2015). This is especially true in the case of ABI among youth, who were already under their parents' care before acquiring brain injury. A previous studies on the process of recovery among ABI patients explored the transition of hospital to home and found that initially the move back into the home was a relief for the patient, but after a few months that feeling faded and was replaced by frustration and despondency over the limitations of their capabilities (Fleming et al., 2012; Nalder et al., 2013; Turner et al., 2011). When the parents may not feel comfortable and have feelings of alienation and fear associated with the home, this may limit their capability to effectively contribute to the child's recovery.

3. Conceptual model
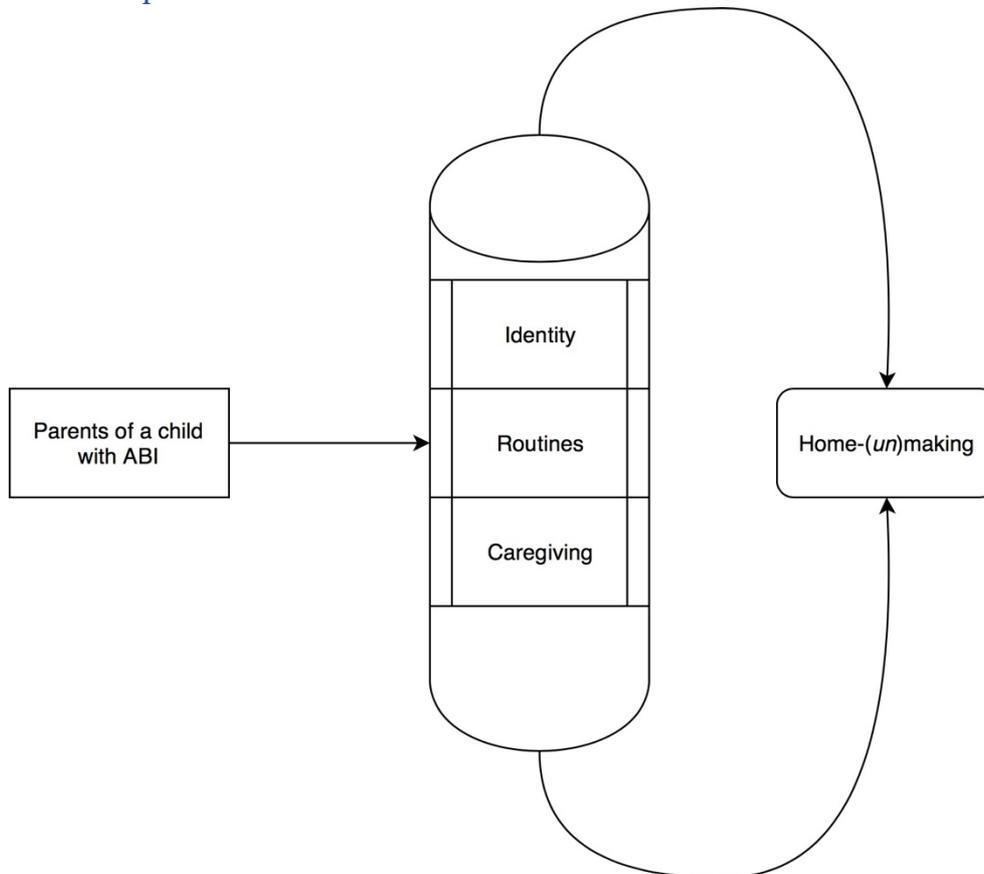
Figure 2. Conceptual model following from the theoretical framework

The conceptual model seen in figure 2 is described by the following: the parents have a child who acquired brain injury, which affects both them and the child (Vos & Diaz-Arrastia, 2015). As a consequence, the three main aspects are affected, being identity (Fleming et al., 2012; Hilbrecht et al., 2017; Nalder et al., 2013; Turner et al., 2011), Routines (Seamon, 1980; Wilder & Granlund, 2015) and Caregiving (Estrada, 2016; Reupert et al., 2015). Finally, the overall interactions of the parents have an effect on the parents' home-(un)making processes. The interaction of all these concepts contribute at least partially to either a home-making process or a home-unmaking process (Baxter & Brickell, 2014; Douglas, 1991).

4. Methodology

4.1 Semi-structured interviews

To study how a son/daughter with ABI affects parents' experiences in home-making, I initially wished to apply a qualitative research methodology by conducting semi-structured interviews with the parent(s) of moderate and severe ABI patients. The choice for semi-structured interviews had several reasons. First of all semi-structured interviews make a significant contribution to geographic research, especially to the discussions on, among others, meaning and identity (Longhurst, 2010). Secondly, semi-structured interviews are useful for investigating complex behaviours, opinions and emotions and for collecting a diversity of experiences (Longhurst, 2010). Finally, it is not the goal of qualitative research to be representative and to be able to replicate data, but to understand how individual people experience and make sense of their own lives (Valentine, 2005 in Longhurst, 2010). These qualities of semi-structured interviews made it the logical method for researching home-(un)making.

The families were to be selected by the *University Medical Centre Groningen* (UMCG), specialist care provider to ABI patients *Noorderbrug* and *Rehabilitation Centre Friesland*. However, I have not been able to recruit any participants through the three organisations listed above. I have tried to find participants through Facebook groups on ABI, but this was unsuccessful as well. Only in the final weeks of this research I learned about Mytylscholen, these are schools which deliver special education to those who do not fit into the regular schools in the Netherlands. They might have been able to help me with finding participants, unfortunately though, at that point in time it was too late.

4.2 Blogs

Halfway during the process of recruiting participants my supervisor and I looked into different possibilities of data gathering. She advised me to look into blogs by parents of a child with ABI. As time moved on and while I got rejected by the organisations, the focus shifted completely towards blogs. Through a google search on 'Blog kind met nah', a couple of Dutch blogs on the experiences of parents with a child with ABI were found. The blog with the most entries is written on the website Nahkindenjeugd. Other blogs were found on the website Hersenletseluitleg. In total I came upon 7 blogs which discussed a child with ABI and was written by a parent. Inspired by another student who used a documentary as a source, I looked for documentaries about children with ABI and found one called 'De eenzame Fietser', made by the mother of a child with ABI. After viewing I found that there were interesting passages, which were then transcribed and analysed in Atlas-ti. All links to the blogs can be found in appendix 1.

Blog collection 1 spans from January 2005 up until August 2014, with a total of 66 posts, 50 in 2005, 6 in 2006, 1 in 2009 and 10 in 2014. It is foremost a diary on the events that have happened to the mother and the child with ABI. The perspective of the texts is from the mother talking to the child. As a result, most of the information concerns itself with how the child is progressing through life and recovery. First, I read through everything and only after that started analysing the blogs posted on March 13, 2005, when the author started writing on the transition to the home and afterwards. I continued the analysis through to the end of 2014 and only analysed the posts regarding the home, caregiving, daily routines and identity, which is a total of 18 posts.

For all the other blogs a selection was not required for they consist of only one post. The blogs and transcript are all written in Dutch, whereas this research is conducted in English, as a consequence, the quotes in the findings are all translations.

4.2.1 Blogs in academic research

Blogs fall into the category of pre-existent documents, as Cope (2010) calls it in her chapter in Key methods in Geography. Coding such documents tends to be an even more inductive process than using the interviews would have been. In such cases 'the researcher's initial approach must be one of broad evaluation to see what trends come out of the material. In this approach the research questions must be flexible and open to change, depending on what is contained in the documents' (Cope 2010, p. 443). As this data was immediately available, analysis started forthwith. The gathered data has been analysed with Atlas-ti, a software package for qualitative data analysis. Within Atlas-ti I was able to make use of coding to generate themes and elicit meanings, and to evaluate and organize data in order to understand meanings in the texts. Coding was done on the basis of the conceptual model and added insights from the blogs and will be discussed further in the text to give openness on the practice of coding and interpretation (Cope, 2010).

4.2.2 Data analysis

Five main themes were used in the analysis. These themes are groupings of codes and all of the codes within these themes are deductive. These codes are more specific which makes it easier to analyse and distinguish meanings in the texts. Within the themes Caregiving and Routines there is a distinction in before, during and after hospitalisation. For the theme Identity I distinguished the identity of the son/daughter with ABI and the identity of the parents from one another and made a distinction in before ABI and after ABI. Finally, the themes of Home-making and Home-*un*making are divided into the codes Affected by: 1. Caregiving 2. Routines 3. Identity. While analysing, I repeatedly encountered mentions of annoyance by the parents towards a lack of understanding by their community and the professional caregivers. This prompted a new code called 'annoyance', which is the only inductive code. It was sufficient to use this code and those drawn in concurrence with the theoretical framework.

The coding of the blogs proved rather difficult. As already mentioned, when analysing pre-existing texts, the researcher should approach it with broad evaluation. However, a code tree was already created during the preparations for conducting the interviews. If taking Cope's (2010) advice to heart, this is the wrong approach. Because the codes had been established beforehand, I felt restrained by fitting the blogs within this same scheme, since this did not sufficiently offer the possibility of broad evaluation and possible changes to the research questions. As a result, though, I can solidly build on existing theoretical concepts of home and home-(*un*)making. Since the texts are fully on the initiative of the writer and not guided by any research questions, it was even more difficult to perceive useful information in relation to the research questions. Home-(*un*)making is not explicitly mentioned in any text, so it had to be deduced from related passages. The parts that do relate to Home-(*un*)making are not clear on whether it was positive or negative, therefore almost all the interesting passages were coded within both the themes home-making and home-*un*making. Daily routines and

changed identities are discussed most extensively in the blogs. There were no clear before/after passages in the blogs and no sufficient reports on the home situation during hospitalisation which has lead me to drop the research questions: 'How did the parents experience the home before he/she acquired brain injury? How is the hospitalisation of the ABI patient experienced in the home by his/her parents?'

4.3 Ethical considerations

The use of blogs as a research method is relatively new, compared to conventional qualitative methods (Hookway, 2008). Through blogs a confessional quality can be achieved, since there is no face-to-face audience, which gives the writer of the blog the opportunity to explain less polished and portray an even uglier self which might be difficult to tell as we 'enter the presence of others' (Goffman, 1959). In academia, there is no consensus on whether the usage of blogs for analysis is infringing a person's identity and privacy. In the document Ethical Decision-Making and Internet Research: Version 2.0 Markham and Buchanan explain this: "[some] users have described their blogs as a part of their identity, not to be treated as simply publicly accessible data" (2012, p. 11). However, there is also the camp who claims that all archived material on the internet is publicly available and therefore participant consent is not necessary (Walther, 2002). Hookway (2008) concludes there is a strong case to waive the necessity of consent, which is adopted for this research. Because all the blogs that are used are on freely accessible websites and no copyright infringements and disclaimers were stated on the websites which are relevant to this research. In this research, all used names are pseudonyms. I do not intend to share this research with the blog writers.

It is important to be aware of some of the characteristics of the data. Before, I mentioned that blogs give the writer of the blog the opportunity to explain less polished and portray an even uglier self, which is hard to get face to face conversations, however, a few things should be considered. First of all, the blogs are an interpretation of reality by the writer. A different person could have written a very different blog about the same situation. This is crucial in the blogs on children with ABI. As the parent, they are very involved and loving for their child, which limits them in critically reviewing the situation. On the other hand, there is also the researcher his bias which has to be considered. I have tried to be as objective as possible and put emotions aside, which, in my own opinion, has been successful. Secondly, the writers of blogs are apparently the people who feel the need to share their experiences and feelings. In light of this research and the theoretical notion of need for community among relatives of ABI patients, these people may fit the profile better than is really the case among the community.

5. Findings

I begin my findings by discussing how the identity of the son/daughter is affected by ABI and how this affects the parents' experience of the home and their own identity. Next, the routines of the ABI patients and their families is discussed in relation to the home-making process. Finally, the caregiving aspect is discussed and again put in the context of home-making.

5.1 Identities affected by ABI

The identity of both the parents and the child is the most coded theme in the blogs and the documentary. It is evident that with ABI, changes to the identity of the patient occur. Barbara called her daughter: *'unrestrained and restless'* while Alice said her son is now continuously overstimulated, which results in him being *'angry, not open to reason and unrestrained'*. Barbara also makes the comparison with the situation before ABI saying: *"(...) However, you {Mother towards child} are tired at the end of the day and you have little need to play outside or to play with other children, unlike before the accident."* To the parents, this is a confronting realisation, best exemplified by Abby in the documentary: *"Sometimes I think about how Yannick's life would have been if that accident hadn't happened. The friends he [would've] had, his hopes and his expectations..."* While in another scene in the documentary, Yannick tells his side of the story [edited]:

> *Abby: Suppose you had not had that accident, do you ever think about what you could become, like a doctor or something?*
> *Yannick: I don't like that. And no, actually not.*
> *Abby: Because, if you think about it, you will get angry or get sad or ...?*
> *Yannick: No actually not.*
> *Abby: And why not?*
> *Yannick: Well, I just never think about it..*
> *Abby: So, it's just that simple... Yes, maybe that's a lot better...*

It is interesting that, to the parent, the limitations the ABI imposes on the child are much more apparent than they are to the child itself. This may be caused by the fact that in all of the analysed cases, the children acquired ABI at a young age. Judith explicitly mentions the fact that her child acquired brain injury at a young age in her blog and what this means: *"For James there is no pre-and after-accident story, because he only knows himself as a person with brain injury."* Turner et al. (2011) remarked that once the patient moves back home after hospitalisation, he/she has to acknowledge his or her new identity, which then, in theory, would affect the parents, however, with such young children who are not yet aware of their own identity, it is mostly the parents who undergo these changes to identity consciously. One clear example is an anecdote told by Abby: *"The drawings, what I still know very well is that I came to kindergarten once when he was just back with his old teacher and there were drawings that the children had made, so I asked Yannick 'which is yours?' And that was really one big scratchy drawing, then I just walked out of school because that was so confronting! yes compared to the drawings that he used to make and then this."* To Yannick, it was not comprehensible that his skills had deteriorated so dramatically, which made it easier for him to go on with life, whereas Abby did have a reference, which made it much harder for her to accept Yannick's limitations. This links

to the notion of biographical disruption by Bury (1982). However, he does not consider the life-stage of a disruptive event, while it seems evident from the findings that a distinction should be made, for the impact the disruptive event has on a child compared to an (young) adult is radically different. Previous research has shown that it is difficult for a person to develop an alternative planned life course that is satisfactory (Price et al., 2012), but as these young children have not seriously considered their projected life course, there is little to no struggle at young age. While the child does not consciously experience a different identity according to several parents, it appears that they do go through a process of accepting their limited capabilities: (Judith:) *"Ultimately, years later, a lot of good things have come, he is quite good at external stimuli and sudden changes and he finally has more insight into himself and what acquired brain injury entails for him."* Note that she talks about how this only happened years later. This can be argued to be a result of the different self-awareness stages a child goes through, as described by Erikson (1959).

Another returning theme related to identity was the feeling parents and some children had towards the understanding of other people about their situation. Celine explains this in these wordings: *"When you are in the supermarket together you hear: 'You look good, nice that you are almost the old [Cody] again'. And then that look from Cody to me. Saying without words: 'I am not the old, I [will] never become the old person again, but I do not want to tell anyone about that.' So, he says, 'yes, it is going well.'"* Barbara experiences something similar: *"The lonely struggle and the search for solutions. The feeling that many people do not understand you because you do not see anything [off about her]."* This links back to the strain of caregiving mentioned in the theoretical framework and the lack of understanding within community.

This struggle is also where the theme 'Annoyance' was partly deduced from. This annoyance is different from the caregiver strain, which will be discussed further in the findings, in that the strain caused in this situation does not yield any progression in, for example, the rehabilitation process. The annoyance towards some professionals is exemplified in this quote: "April 7th at the rehabilitation doctor: You had to come [with me] this time. Ridiculous, because she [the doctor] barely looked at you, [while] I have to get you from school. Well, I know for sure that it will not take long before we transfer to Heliomare (another care provider)".

Whereas parents in the previous paragraphs had a hard time with the lack of understanding, a statement by Abby shows that parents can also hide the ABI: *"Until the moment he went to that school [for children with a disability], I could actually hide it a little bit, um I do not know if I did that very deliberately, but I did not always tell what was going on with Yannick, because you did not see anything about him and hey, why would you always tell that, but the moment he went to that school, then I could not avoid it, of course, so I think that was a final step in my acceptance of the fact that Yannick has that brain injury and that he has some limitations."* Previous research on raising a child with a disability showed that the experience differs within different families, due to disability severity and family structure (Ferguson, 2002). It is not deducible from the data what distinguishes the separate cases in their experience of their community recognition and their own acceptance of the situation.

5.2 Routines affected by ABI

Daily routines are an important part of the situation within a home. In the blogs it becomes clear that children with ABI experience different daily routines compared to pre-ABI, just

as has been shown with older ABI patients (Meijering et al., 2016). For young children, this does not consist of work and caring for children, but mostly of playing and learning. Take for example this quote by Barbara: *"We start with 3 mornings a week at school, so that you also have time for the therapy and do not get tired too quickly."* Tiredness plays a large role for most of the children with ABI in the blogs, showed among others by this example: *"James followed a year of education there, half days and only the instruction lessons, because he could no longer manage [to go to school]."* This tiredness creates conflict in some cases which affects the home-making process, negatively in this case: *"Maybe you are able to imagine, [that] in a class with 24 students, there are days that [Cody] cannot manage. So, then I pick him up and what do I have in my house? Yes, my child who is thank, thank god still here and whom I care for with love ... but also a child who is heavily frustrated, full of impotence, angry at everything that does not work, though what he wants [to do] so badly, and [that frustration] is actually so normal!"* Celine then goes on to say: *"And that is difficult. In the first place for him. But for me as a mother as well. And for his sister. (...) I hope that we will find a little more peace as a family."* Tiredness is a reoccurring theme throughout all the blogs and will be further touched upon in the context of caregiving.

5.3 Caregiving affected by ABI

The findings concerning caregiving affected by ABI are few. It is clear that parents are required to provide the son/daughter with extra care, as described by Barbara who quit her job to be able to handle the caregiving: *"Mom stops working until your cannula is out. It is impossible to combine work and to be called every time for cannula suctioning"* The parents had to provide care before the ABI already, nevertheless the ABI seems to cause caregiver strain to parents anyhow, explained here by *Celine "So, making plans? I know better now. This injury has such an erratic picture and medical demands that you cannot plan your day without caution.".* This also seems to affect the home-(un)making practice in concurrence with the routine aspect of this research, as such that uncertainty plays a major role in the daily lives of the parents. This is in line with previous results found by Gan et al. (2010). It is, however, not viable to argue based on these data whether the theory that caregiver strain experienced by some parents limit their capability to provide sufficient support, hope and motivation in the recovery of a patient. The only shred of evidence supporting this expectation is the passage by Judith: *"Because James required so much structure and clarity, we occasionally worked with a 'James Service'. One of us gave him instructions, corrections".* This sentence shows to a certain extent how parents approach caregiving but does not indicate serious strain. Therefore, I will not argue the theory any further.

On another note, in the context of home-(un)making, the impact of caregiving the parents experience are less strong than exemplified in other studies where the patient acquires brain injury at a later stage in life and have a different biological relation (e.g. Fleming et al., 2012; Meijering et al., 2016). Specifically, Meijering et al. (2016, p. 39) found that 'many partners resented how their home had become a place of giving and receiving informal care', which is nothing like described in the blogs. The difference is partially in the position the caregiver has in the relation to the patient; as a parent you are in a whole different position compared to when you are a partner, which is something constructed compared to something biological.

6. Conclusion

This research has answered the question "How is the experience of home-making for the parents of a Son/Daughter With Acquired Brain Injury in the Netherlands?" by addressing the three main aspects related to home-making, namely caregiving, identity and routines. As is discussed in the findings, the identity aspect of home-making is experienced by parents differently than theorized in the theoretical framework. This is mainly a result of the gathered data, which only contains cases with children with ABI instead of the intended research group of young adults (15-24). This group would, as I argued and as was suggested by one of the parents, have experienced a pre- and after-incident *self*, which could in theory result in more of an inner struggle on accepting their brain injury. However, the parents do witness their child pre-ABI and after-ABI. This was hard to accept for some parents and caused them to ponder over how life could have been for the child and for themselves. This can be regarded in the same light as results found by Meijering et al. (2016), who acknowledged that it is hard to abandon the previously anticipated life course. In this case, that holds for the parents, who foresaw a different future for their child. There is an aspect of home-*un*making in that sense, since it can be argued that such a different life path induces alienation to a certain extent (Baxter & Brickell, 2014).

The aspect of routines in relation to home-making seems to demand a lot of energy from some parents. The decreased tension curve of the children requires the parents to offer a lot of regularity and planning in the schedule of the child. The ABI also requires more flexibility and caregiving from the parents, which can result in some frustration and the choice to quit working.

For the sake of this research I analysed routines separately from identity and caregiving and vice versa. The findings showed that they are all strongly intertwined and affect one another, which sometimes blurred the lines in the analysis. This is most evident in the findings on caregiving, where incorporating new routines and extra caregiving seems to cause some strain. Another interesting result when comparing the data to research by Meijering et al. (2016) is the fact that it seems to bother parents less when their child acquired brain injury and requires more care, than compared to partners who requires more care. This may be partly due to the anticipation of caring for a child.

The induced theme 'annoyance' appears to show that parents feel misunderstood by their community and some professionals. This seems to create tension for the parents on a different level than caregiver strain does. The difference may be in the fact that caregiving (usually) yield something like success and improvement, whereas tensions with friends and family or professionals is not yielding any benefits, causing some parents to be annoyed a lot.

6.1 Limitations

As discussed in the methodology chapter of this paper, the intended method of gathering data through semi-structured interviews with an older group of ABI patients may have yielded different results, for the self-awareness plays a large role in identity and conflict within the ABI patient resulting in conflict with the parents and eventually affecting home-making probably more than is the case with younger ABI patients. Also, the effect of caregiving is different with young children, for young adults would be more independent of parental care before ABI, which might have a different dynamic. The use of blogs can yield very useful data and insights, as I have argued. In this research into home-making,

however, it was hard to deduce home-making from the blogs, which probably limits the findings in comparison to interviews, which would be completely built around home-making. Therefore, this research has to hedge when making statements and suggestions on home-making.

6.2 Future research and Recommendations

In the future, the academic field of home-making research as well as the field of Acquired Brain Injury studies would hugely benefit from a well-executed research, with the initially desired group: young adult with ABI (ages 15-24) who lives at the parental home, in the context of home-making, as to unveil the home-making process of these people. But also, to find whether the proposed theory of caregiver strain limiting parents' capability to provide sufficient support, hope and motivation in the recovery of the patient holds true. Based on the conducted research, more community-building would benefit the parents in their struggle for caregiving and maintaining their personal life, how this should be done is up for further research.

7. References

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