

Edging forward: using sailing holidays to change dependence, self-esteem and body image in people with acquired brain injuries



SASKIA PETERS (940108649090)

WAGENINGEN UNIVERSITY

BSC THESIS TOURISM: XTO-80818

SUPERVISORS: MEGHANN ORMOND AND PIETERNEL CREMERS

DATE OF SUBMISSION: AUGUST 17TH, 2017

AUTHOR STATEMENT

Full thesis title: Edging forward: using sailing holidays to change dependence, self-esteem and body image in people with acquired brain injuries

Author's name: Saskia Peters

Bachelor degree programme: BSc Tourism

Educational Institutes: NHTV Breda University of Applied Science and Wageningen University, NL

Authorship statement

I hereby declare that this thesis is wholly the work of Saskia Peters. Any other contributors have either been referenced in the prescribed manner or are listed in the acknowledgements together with the nature and the scope of their contribution.

Where I have consulted the published work of others this is always clearly attributed. Where I have quoted from the work of others the source is always given. A list of the references used, is included. An appropriate referencing style is used throughout. With the exception of such quotations this thesis is entirely my own work. I have read and understand the penalties associated with plagiarism as stated in the Student Charter.

Declaration of Partial Copyright

I hereby grant to NHTV Breda University of Applied Science ("NHTV") and Wageningen University ("WU") the non-exclusive, royalty-free right to include a digital copy of my thesis and associated supplemental files ("Work") in the Library Catalogue at NHTV. NHTV and WU may use, reproduce, display, convert, sublicense and distribute the Work for purposes of a scholarly or research nature, in any format and any medium, without prior permission or charge, provided that the Work is not altered in any way and is properly acknowledged, including citing the author, title and full bibliographic details. (Note: this corresponds to the Attribution-NonCommercial-NoDerivatives, or CC BY-NC-ND Creative Commons license)

I further agree that NHTV and WU may keep more than one copy of the Work for purposes of back-up and security; and that NHTV and WU may, without changing the content, translate, if technically possible, the Work to any medium or format for the purpose of preserving the Work and facilitating the exercise of NHTV and WU's rights under this license. I understand that work deposited in the NHTV Library Catalogue will be accessible to a wide variety of people and institutions - including automated agents - via the World Wide Web. Copying, publication, or public performance of the Work for commercial purposes shall not be allowed without my written permission.

While granting the above uses to NHTV and WU, I retain copyright ownership and moral rights in the Work, and may deal with the copyright in the Work in any way consistent with the terms of this license, including the right to change the Work for subsequent purposes, including editing and publishing the Work in whole or in part, and licensing the content to other parties as I may desire.

I represent and warrant that I have the right to grant the rights contained in this license and that the Work does not, to the best of my knowledge, infringe upon anyone's copyright. I have obtained written copyright permission, where required, for the use of any third-party copyrighted material contained in the Work. I represent and warrant that the Work is my original work and that I have not previously assigned or relinquished the rights conferred in this license.

Date: August 17th,2017

Abstract

Despite the several barriers people with a disability face in tourism, the number of active tourists is increasing. Studies have shown that active tourism participation can reinforce confidence, social interaction and well-being. In collaboration with the WUR Science Shop project and SailWise, this qualitative exploratory study focused on participants with an acquired brain injury (ABI), who went sailing with the Lutgerdina. ABI has several bodily and psychological effects, of which growing dependence and a less-positive body image are examples. This study tries to explore the connection between independence, self-esteem and body image, in relation to a sailing holiday. Interviews were conducted before, during and after the holiday using relational maps, visual elicitation and observations. This study argues that independence, self-esteem and body image are connected, and that the effects of the holiday on dependence and body image are rather short-term than long-term. In addition, the effects have a bigger influence on first-time visitors compared to repeat-visitors. To generalise the results of this study, further research must be undertaken that focuses on the concepts of dependence and body image in relation to different disabilities or different types of tourism.

“It is not the ship so much as the skillful sailing that assures the prosperous voyage”
- George William Curtis

Table of contents

AUTHOR STATEMENT	2
Abstract	3
1. Introduction	6
1.1. <i>SailWise</i>	6
1.2. <i>Abbreviations</i>	6
2. Literature review	7
2.1. <i>Participation in tourism and leisure</i>	7
2.2. <i>Outdoors and blue space</i>	7
2.3. <i>Acquired Brain Injury (ABI)</i>	8
2.4. <i>Dependence</i>	8
2.5. <i>Body image</i>	10
2.6. <i>Connecting dependence, body image and self-esteem</i>	11
2.7. <i>Research gap and scholarly relevance</i>	12
3. Methodology	13
3.1. <i>Research question</i>	13
3.2. <i>Sampling</i>	13
3.3. <i>Data collection</i>	14
3.4. <i>Ethical considerations</i>	16
3.5. <i>Data analysis</i>	16
4. Results	18
4.1. <i>Hendrik</i>	18
4.2. <i>Willem</i>	20
4.3. <i>Piet</i>	22
4.4. <i>First-time visitors</i>	25
5. Discussion	26
5.1. <i>Discussion of results per theme</i>	26
5.2. <i>Answers to secondary research questions</i>	31
5.3. <i>Limitations</i>	33
5.4. <i>Recommendations</i>	34
5.4.1. <i>SailWise</i>	34
5.4.2. <i>Future research</i>	35
6. Conclusion	37
7. Acknowledgements	39
8. References	40
Appendix 1: Inquiry letter	44
Appendix 2: Translated quotes from transcripts	45
Appendix 3: Elaboration on methods	47
3.1 <i>Relational map</i>	47
3.2 <i>Visual elicitation</i>	47
Appendix 4: Inquiry mail first-time visitors SailWise	48

Appendix 5: Information letter	49
Appendix 6: Consent form	51
Appendix 7: Decoded visuals	53
7.1.1 <i>Dependencies Hendrik</i>	53
7.1.2 <i>Body image Hendrik</i>	53
7.2.1 <i>Dependencies Willem</i>	53
7.2.2 <i>Body image Willem</i>	53
7.3.1 <i>Dependencies Piet</i>	54
7.3.2 <i>Body image Piet</i>	54

Table of tables, figures and images

Table 1: General information participants	14
Figure I: Drawing of person standing up	15
Figure II: Drawing of person in wheelchair	15
Figure III: Relational map Hendrik	18
Figure IV: Relational map Willem	21
Figure V: Relational map Piet, according to Piet	22
Figure VI: Relational map Piet, according to his wife	23
Image 1: Body image Hendrik	19
Image 2: Body image Willem	21
Image 3: Body image Piet	23

Introduction

Participation in leisure activities for people with a disability can be influenced by different challenges they are facing, including affected social, physical and mental capabilities (Yau, McKercher, & Packer, 2004). Especially for physically disabled people, accessibility issues are often a barrier to participate in (sports) tourism (Hua, Ibrahim, & Chiu, 2013; Yau, McKercher, & Packer, 2004). Does this mean that people with a disability should stay at home, and not face these barriers? Or can holidays be an escape to an “at times a restricted and routinized life”, just as with doing leisure activities in the outdoors (Burns, Watson, & Paterson, 2013, p. 1068)? This question is the focus of the Wageningen University and Research Science Shop project on sailing holidays. Together with SailWise – an organisation that accommodates sailing holidays and water sports for people with a disability – different studies are being conducted to look at the effects of such a holiday on people with a disability. And with SailWise being a foundation, most people that assist during these holidays are volunteers. This thesis explores what effects the holidays can have on the concepts of independence, body image, and self-esteem, while focusing on people with an acquired brain injury (ABI). To get an insight into the holiday, I joined as a volunteer myself on one of the Lutgerdina-travels. Thus, this thesis will be a contribution to the WUR Science Shop project, as well as a contribution to the (so-far limited) existing literature on ‘acquired brain injuries’ & tourism. What the facilitating organisation SailWise entails will be explained in the next paragraph. Chapter two of this report will highlight the main literature on disability tourism, dependence, body image and self-esteem. The research gap will lead to the formulation of a research question in chapter three. Here, an explanation of the visual elicitation and relational maps that were used in this study, as well as why they were used, is given as well. The results from the semi-structured interviews will be presented per participant per theme in chapter four, followed by discussing these in relation to the academic literature in chapter five; in this chapter the research questions will also be answered. Chapter six will entail a conclusion on the study.

1.1. SailWise

SailWise offers holidays for people with physical, sensory, intellectual, multiple disabilities or acquired brain injuries. The facilities are adapted to the needs of the participants (i.e. special beds) to assure that they can enjoy their holiday to the fullest. There are three different accommodations to choose from: ‘Robinson Crusoe’, an island for water sports; ‘It Sailhûs’, from where a catamaran will operate several sailing trips; and finally, the Lutgerdina, a double-masted clipper on which you undertake an adventurous sailing trip. These activities all take place in Dutch waters. As mentioned before, this study will focus on people with acquired brain injuries, and the Lutgerdina-accommodation.

1.2. Abbreviations

Throughout this thesis, several abbreviations will be used for repetitive words. Here is an overview:

ABI = Acquired Brain Injury

TBI = Traumatic Brain Injury

CVA = Cerebrovascular Accident/Attack

MS = Multiple Sclerosis

P1/P2/P3 = Phase 1, 2, 3

2. Literature review

2.1. Participation in tourism and leisure

Only a limited amount of research has yet focused specifically on tourism participation of people with ABI. Because the body of work on tourism and ABI is limited, the focus of this literature review was broadened to include leisure activities. Adding the field of leisure activities in relation to ABI is not strange, since sailing as a one-day activity can be seen as a leisure activity. In a previous study by Wise et al. it has been concluded that people who have suffered from a traumatic brain injury (the difference between ABI and traumatic brain injury (TBI) will be further explained in one of the following sections) are less participative in leisure activities to their own disliking, “with a resulting negative impact on life satisfaction” (Wise, et al., 2010, p. 1359), even though participation in leisure can “enhance people’s perceptions of autonomy and independence” (Trainor, Delfabbro, Anderson, & Winefield, 2010, p. 174). The existing barriers as mentioned in the introduction seem to limit people’s participation. But, several scholars studied the positive effects of participation in leisure activities by people with ABI. Especially for those who acquire their injury at a young age, leisure activities can help in forming friendships, developing new skills and contribute to forming an identity (Majnemer, et al., 2008). According to Wise et al., the effect leisure participation has on the participant’s physical and emotional health is a big contributor to the reason behind participation: “for those with disabilities, leisure activities appear to have even greater importance” (Wise, et al., 2010, p. 1357). In the same article, Wise et al. argue that for people after TBI, it might be safer to undertake physical activities in a ‘controlled, predictable environment’. Creating these controlled environments can be the base to participate with like-minded people, and at the same time “build confidence along with social and communication skills” (Wise, et al., 2010, p. 1361).

The active physical activities that Wise et al. talked about can be translated into sports- or active tourism. Sports tourism is gaining more popularity, inspired by the sport attractions it includes (Hua, Ibrahim, & Chiu, 2013). Several scholars studied the positive effects of participation in sport on people with a disability. These effects can differ from increasing self-confidence, social mobility and “to handle the stigma of a disabled body” (Hua, Ibrahim, & Chiu, 2013, p. 258; Blichfeldt & Nicolaisen, 2011; Martin, Adams-Mushett, & Smith, 1995). It is recognized by Hua et al. that volunteers, as well as technological improvements, are the key in making sports tourism more accessible and available for people with a disability.

2.2. Outdoors and blue space

Activities that take place in the nature, such as water sports, are one of the reasons to participate in sports tourism (Hua, Ibrahim, & Chiu, 2013). For people with a disability this may be riskier, as they must face their inabilities and overcome barriers. However, in the controlled environment Wise et al. talked about, participating in these nature-based activities can have positive effects. First of all, the outdoor setting has been shown to stimulate self-improvement, as well as the feeling of control over the body. In addition, for people who have acquired their disability at a later point in their lives, it is a perfect opportunity to participate in things they had previously done (Burns, Watson, & Paterson, 2013). Besides the outdoor experience, water also seems to have positive effects. According to Prideaux, Timothy & Cooper, being near water benefits the person (Prideaux, Timothy, & Cooper, 2009). Foley & Kistemann (2015) add that water spaces are beneficial for one’s health: so-called blue spaces are “health-enabling

places and spaces, where water is at the centre of a range of environments with identifiable potential for the promotion of human wellbeing” (Foley & Kistemann, 2015, p. 158).

2.3. Acquired Brain Injury (ABI)

According to the Hersenstichting – the Dutch institute that focuses on education and research about brain injuries – around 650.000 people living in the Netherlands suffer from an acquired brain injury (Hersenstichting, sd). An acquired brain injury can be divided over two sub-groups: traumatic brain injuries and non-traumatic injuries. TBI is caused by effects that are external from the body, such as accidents, hitting the head in a fall, or violence. The non-traumatic injuries follow internal causes, such as cerebrovascular accidents (CVA; better known as a stroke), meningitis, a tumour or a lack of oxygen. The severity of the injury can differ per person; some people recover almost fully after successful treatment of meningitis, where others might be paralysed after their stroke and thus gain both mental and physical disabilities. These different effects of ABI have been studied by several scholars; the field of neuroscience plays an important factor in research on these effects, as they deal with ‘how the brain and nervous system work’. Main effects of ABI can be a change in personality (Leonhardt, Schmukle, & Exner, 2016; Yeates, Gracey, & Mcgrath, 2008), changing social roles (Jumisko, Lexell, & Söderberg, 2005), decreased life satisfaction (Jacobsson, Westerberg, & Lexell, 2010) and changes in motor- and cognitive abilities (Doris, Lee, Hong, Lau, & Leung, 2008; Filiatrault, Arsenault, Dutil, & Bourbonnais, 1991; Söderback & Ekholm, 1992, as cited in (Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001)).

Two concepts that arose in the literature on effects of acquired brain injuries – but have not been extensively studied yet in relation to this specific disability – are changed dependence and body image. Changing dependence is part of changing social roles; the changing body image deals with trust-issues, as will be explained later on. Instead of the brain injury creating a barrier for participation in tourism, it would be interesting to see how tourism could decrease the negative effects of ABI. Because the link between effects of ABI and tourism has not been made often, this study will focus on the effect tourism has on dependence and body image.

2.4. Dependence

Studies focusing on people with ABI concluded a change in dependence on family, friends or caregivers which can be in a physical way (i.e. when paralysed and in a wheelchair; someone needs to help with personal care) or emotionally (i.e. helping with finances) (Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001; Jumisko, Lexell, & Söderberg, 2005). Deficits in cognitive and emotional functions are the main reason for the increasing dependence on others (Corrigan, Smith-Knapp, & Granger, 1997). This dependence can be defined in different ways, depending on the type of dependency one refers to.

Three types of dependency

The European Council defined dependency as “a condition related to the loss of autonomy and the need of support by a third person, related to an impairment of activities of daily living, specially self-care” (Salvador-Carulla & Gasca, 2010, p. 70). People who are dependent on others in order to maintain an autonomous life can thus be seen as part of the dependent population (Salvador-Carulla & Gasca, 2010). But even though people with a disability often encounter barriers that affect their daily living, not everyone is in need for this third person’s

help; most people observe themselves not as totally dependent nor independent, but somewhere in between, depending on each situation (Rabiee, 2012; Zunzunegui, 2011).

The previous definitions of dependency focused on physical dependency, lacking to include the emotional side. Several scholars acknowledge the emotional dependency, and define independence as not only being able to do things physically yourself, but also exert control over decisions that are made i.e. about whatever assistance is necessary or emotional support (Rabiee, 2012; Salvador-Carulla & Gasca, 2010). So, as Barnes defined, independence is “a thought process not contingent upon physical abilities” (Barnes C. , 1991, p. 129). In addition to physical and emotional dependency, there also is an economic dependency for people with a disability. This mostly deals with welfare provision (Kittay, 2011; Saugeres, 2011).

Determinants of dependence

Several factors can influence the degree of dependence between people: from physical context to social factors such as age, gender and background (Saugeres, 2011; Zunzunegui, 2011). Young and Lloyd mentioned that marginalisation of disability also plays a role in dependence which “involves the exclusion from meaningful participation in society” (Lloyd, 2001; Saugeres, 2011; Young, 2000). Furthermore, the way people perceive dependence is subject to the view towards disability. As Zunzunegui discussed, the scientific paradigm has an influence on the meaning of dependence: in example, recent paradigms consider changing social and physical environment in order to let a person with a disability maintain their autonomy (Zunzunegui, 2011).

The approach to care also influences the way one looks at dependency-relations. An example is the ‘Ethics of Care’, to which Tronto is a main contributor (Tronto, 1993). Ethics of care is “based on the principle that there is something ‘good’ in every form of care” (Klaver & Baart, 2011). In Tronto’s book ‘Moral boundaries: a political argument for an ethic of care’, she proposes a framework which includes four ethical elements of care: attentiveness, responsibility, competence and responsiveness. To be able to provide good care, one must start with being attentive: attentiveness refers to the recognition that care is necessary. Not recognizing the need for care is not the same as ignoring it Tronto mentions: inattentive refers to not paying attention, while with ignorance, one does notice the need for care but fails to consider it. The second ethical element is responsibility. Here, the dichotomy is between responsibility and obligation. The care-giver should not feel obliged because of societal norms (i.e. a woman takes care of the children), but instead wants to take the responsibility of taking care of someone. The third ethical element is competency: meeting the needs of the care, often including physical work. This element is important for good care, as care should be executed adequately. The final element is responsiveness, which focuses on care-receiving. It is not about putting yourself in the shoes of the care-receiver, but rather how the receiver responds to it (Klaver & Baart, 2011; Tronto, 1993).

Finally, several scholars argued that dependence can also be seen as a two-way stream between people where both parties have responsibilities, rather than one person only being dependent on third persons or the State (Reindal, 1999). Rabiee, Sevenhuijsen and Tronto are also in favour of acknowledging interdependency, as mutual dependence is the essence for everyone, not just the ‘dependent population’ (Rabiee, 2012; Sevenhuijsen, 1998; Tronto, 1993). This refers to the reciprocity of relations: in the case of disabled people, one can be a

care-giver (i.e. to a child) and care-receiver (i.e. from spouse) at the same time (Barnes M. , 2005).

Social pressure

So far it is mentioned that disabled people can be dependent on family/friends ('familial network') and care-takers ('therapeutic network'). In a study by Saugeres a decrease in social relations occurred, which decreased these networks in size (Saugeres, 2011). But besides these familial and therapeutic dependence, people with a disability are also dependent on welfare systems for payment or finding appropriate housing (Kittay, 2011; Saugeres, 2011). This dependence on the welfare system increases social pressure and creates a 'demonisation of dependency'. Valentine & Harris argued that this demonisation causes a negative image on people with a disability and their dependence, and might cause non-disabled people to lose social responsibility. An example of a negative discourse is mentioned in the same article: middle- and working-class express their ideas on "the importance of disabled people taking responsibility for their own lives rather than deserving 'special treatment' from the State" (Valentine & Harris, 2014, p. 89). Others are less negative towards disabled people, but do address the importance for disabled people to gain autonomy in order to achieve equal citizenship rights as any other person (Rabiee, 2012; Saugeres, 2011). Young concluded that the negativity is not focused on the concept of dependence itself, as everyone is dependent at one point or another in their lives; instead, it is 'the social construction of dependency and disability' that makes it more difficult for people with a disability (Saugeres, 2011; Young, 2000). Finally, the growing dependence of people after acquiring a disability also has its downsides on social relations. Being dependent on parents while being an adult yourself can make one feel like a child (Saugeres, 2011). The growing dependence on family members can affect power dynamics within a relationship, or be "at the cost of carers' own independence" (Rabiee, 2012, p. 882).

2.5. Body image

As Holzer et al. mentioned in their paper, previous studies concluded that body image and self-esteem are affected by several physical diseases (Holzer, et al., 2014). Body image can be seen as "the subjective view a person has of his or her body in terms of physical appearance" (Keppel & Crowe, 2000, p. 17). People who acknowledge the influence of media and how these portray a certain image of how a body should look like, but are satisfied with their appearance despite the flaws, are seen to have a positive body image, according to Bailey et al (2017). The definition of Keppel & Crowe focuses on appearance as the determinant of body image, which is mostly present with adolescent females (Bailey, Gammage, van Ingen, & Ditor, 2017; Holzer, et al., 2014; Keppel & Crowe, 2000). However, these definitions fail to include ability as a determinant for body image. The ability or inability to perform physical activities and perceptions of one's abilities and health greatly influences body image as well (Clarke, Liu-Ambrose, Zyla, McKay, & Khan, 2005; Liechty & Yarnal, 2010). Inabilities can negatively affect the body image of those with a disability, but acceptance of these inabilities can make a difference in how people with a disability perceive their body image (Taleporos & McCabe, 2002). Thus, the definition of Keppel & Crowe focused on physical appearance while defining body image, and lacked to address the influence of ability. Neither narrowing body image as solely one's appearance nor abilities seems more fitting, as Cash used: "a person's attitude toward and evaluations of his or her body" (Cash, 2004; as cited in (Liechty & Yarnal, 2010, p. 444)).

Factors influencing body image

The literature focused on appearance and ability as main indicators for body image, but these are still comprehensive concepts that contain many influencing aspects. For appearance, main factors have shown to be the weight and shape of one's body and facial features (Cash, 2004; McLaren & Wardle, 2002), Body Mass Index (Kaminsky & Dewey, 2014; Meltzer, et al., 2001) and the loss of body parts (Holzer, et al., 2014). At the same time, athletic ability and physical health are contributing to the perception of one's abilities (Cash, 2004; McLaren & Wardle, 2002). Bailey et al. discussed that body image is subjective, as social determinants also play a role in forming one's body image. An example of this is the media: social images of being fit and vital, and not fitting into that image can influence one's body image (Bailey, Gammage, van Ingen, & Ditor, 2017; Holzer, et al., 2014). Other social determinants are relationships and social support (Bailey, Gammage, van Ingen, & Ditor, 2017; Barker & Galambos, 2003). Due to the nature of these social influences, interactions can help in changing one's body image (Bailey, Gammage, van Ingen, & Ditor, 2017). It is important to make sure one's body image does not become too negative, as Brausch and Muehlenkamp found that for young adults, a negative body image was a predictor for suicidal thoughts (2007).

2.6. Connecting dependence, body image and self-esteem

From Keppel & Crowe's study it can be concluded that body image and self-esteem of a person with ABI are interrelated; the failures in functioning of the body have shown to contribute to a lower self-esteem (Corbin, 2003; Howes, Edwards, & Benton, 2005; Jumisko, Lexell, & Söderberg, 2005; Keppel & Crowe, 2000; Sohlberg & Mateer, 2001). Self-esteem can be defined as "a reflection of someone's worth or value" (Holzer, et al., 2014, p. 7). Emotions can influence self-esteem positively or negatively: examples of these emotions are "triumph, despair, pride and shame" (Holzer, et al., 2014, p. 1). Furthermore, physical activity can benefit one's self-esteem (Kaminsky & Dewey, 2014). There are also factors that can influence a negative self-esteem: based on previous studies, Chalk mentioned that "individuals with physical, learning, and psychiatric disabilities experience lower self-esteem than peers" (Chalk, 2016, p. 201). Especially young adults can be sensitive to a lower self-esteem, based on the combination of certain psychosocial factors and one's disability (Chalk, 2016).

For people with a disability, body image can both be a barrier and opportunity for tourism & leisure participation. A negative body image can constrain leisure participation because of one's self-consciousness about the body, but also stimulate leisure participation for those wanting to work on their bodies to become more confident (Liechty & Yarnal, 2010). Since studies on body image showed that the confidence people have in their body following ABI has been changed after increasing inability, leisure and tourism activities could improve one's self-esteem. Brausch & Decker also addressed one's view of 'competence' and 'acceptance' in their definition of self-esteem (Brausch & Decker, 2014). Including acceptance of the disability in the definition of self-esteem fits the results of Chalk's study, where self-esteem and acceptance of one's disability turned out to be correlated (Chalk, 2016). As discussed before, acceptance of the disability also affected the perception one has about their body image (Taleporos & McCabe, 2002). Acceptance thus plays an important factor in both body image and self-esteem. In the study of Saugeres, participants mentioned how there was an increase in staring at and gossiping about them, after people acquired their disability (Saugeres, 2011). Being judged on their appearance might elicit feelings of shame and thus stimulate a negative body image and lower self-esteem.

Coming back to physical dependence, this concept focused on what someone can do autonomously in terms of physical abilities. And as mentioned before, body image is mostly determined by ability and appearance. It can be hypothesised that an increase in physical abilities reinforces a positive body image as well as create more independence. Being less dependent on third persons for physical help might decrease feeling like a burden on others, which seemed to reinforce a positive self-esteem (Brausch & Decker, 2014).

2.7. Research gap and scholarly relevance

Looking at the present literature on ABI, dependence and body image, several research gaps remain. The effects of a brain injury on 'the patient' have been studied multiple times, and mostly in a quantitative way (Azulay & Mott, 2016; Cattran, Oddy, Wood, & Moir, 2011; Ilmer, et al., 2016). A change in dependency and body image were two examples of this. With regards to dependence, it can be concluded that independence is a multidimensional concept, and not fixed (Rabiee, 2012). The cause of the change in dependence has been studied, and there are different opinions towards the dependency of disabled people on third persons and society. Little scientific research is present on how independence and autonomy can be gained by participating in leisure or tourism activities.

According to their 8 core values, SailWise focuses on possibilities rather than inabilities, and tries to stimulate independence. The vision of the facilitating tourism organisation SailWise expresses the believe that more independence can be gained through tourism: "Active and independent participation in water sports contributes to physical and emotional independence of people with a disability" (SailWise, sd). They want to give the participants of the holiday the opportunity to explore what is still possible despite their disability, and aim to increase these possibilities. Provided with a safe environment with qualified sailers and dedicated volunteers, participants have the chance to discover their boundaries. Because SailWise wishes to increase physical and emotional independence, this study aims to see if and how this physical and emotional independence is achieved. Because SailWise is used as a case, this study will have both academic as well as a professional contribution.

Furthermore, existing literature on dependence distinguished physical, emotional and economic dependence of a person with a disability. A different approach, which focuses on the other actor in the dependency-stream (i.e. family, care-taker, doctor) is not popular in the literature yet. This study hopes to find differences between this familial network and therapeutic network that people with a disability depend on, in terms of the degree of dependence.

Studies on the relation between disability tourism and body image is also still limited. Being able to perform an activity generates a positive body image. But how does this work with disability tourism, where tourists often experience barriers? Also the note from Bailey et al. that social interactions can change one's body image is interesting to look at more thoroughly (Bailey, Gammage, van Ingen, & Ditor, 2017). During the SailWise holiday, participants will be surrounded by peers with ABI, does this affect one's body image? This study will look into active, adapted holidays, to see if being able to perform daily activities without someone's help will influence independence and body image.

3. Methodology

3.1. Research question

Changes in independence and body image have shown to be results of brain injuries. The neurological damage can be a cause for the 'just feeling different now' of people following ABI (Yeates, Gracey, & Mcgrath, 2008). At the same time, disability tourism stimulates the life satisfaction of the participant (Pagán, 2015). Can tourism also be a moderating factor in changing the self-perception of people with ABI? Since little to no research has yet focused on this, the research question is:

What influence does active participation in sailing tourism have on self-esteem and body image, and what effect does this have on independence?

In order to answer this main research question, three secondary research questions have been formulated:

SRQ1: How does a person with ABI perceive their independence before, during and after participating in the holiday?

SRQ2: What body image does a person with ABI have before, during and after participating in the holiday?

SRQ3: Is there a correlation between body image, self-esteem and dependency?

After initial data collection, an extra secondary research question was formulated to distinguish first-time visitors from repeat visitors:

SRQ4: Does the effect of active participation in the holiday differ between first-time visitors and repeat visitors?

3.2. Sampling

The participants for this study were chosen based on targeted sampling, as the people that booked a sailing holiday from SailWise on the Lutgerdina during a specific date were requested to participate. This has led to all participants being Dutch. Inclusion is for participants that could verbally express themselves independently, through spoken word and visual drawings. To ensure confidentiality of the participants' personal information, SailWise sent out a first inquiry letter (appendix 1) to the participants of the specific holiday, to ask if they were willing to participate. Only once they confirmed, contact details were shared with me and a second e-mail was sent out with more specific details about the study, as well as discussing dates of conducting the interviews.

In the end, three participants of the specific sailing week agreed to participate in this study. In table 1 some basic information on the participants is given: the pseudonym that will be used in this study, age, the living arrangement of the participant and additional information on their disability.

Pseudonym	Age	Living arrangement	Disability
Hendrik	53	Assisted living facility	ABI + MS
Willem	60	Assisted living facility	ABI + Epilepsy
Piet	61	At home with wife	CVA + Aphasia

Table 1: General information participants

3.3. Data collection

Timing

To collect sufficient data for analysing the effects of the holiday, interviews were conducted during three moments; three to two weeks before the holiday (phase 1, P1), during the trip (phase 2, P2) and two to three weeks after returning home (phase 3, P3).

Location

The pre- and post-holiday data collection occurred in a home setting to create a safe environment for the participants, and limit barriers. The type of home setting per participant can be found in table I. To have the best possible comparison between P1 and P3, it was attempted to have the same location for these two research moments to replicate the conditions as much as possible. However, in the case of one participant, this was logistically not possible; instead, the final interview took place at the activity centre where he spends 4 days a week.

Methods

So far, much research on people with ABI has focused on quantitative methods, where either participants or their close contacts are asked to fill in questionnaires. These questionnaires were then analysed with a model or scale. Less focus has been on qualitative methods that emphasize the detailed experience of the person with ABI themselves, even though “qualitative methods provide the most appropriate form of evidence on ‘experiences and processes’ – especially as understood by respondents themselves” (Becker & Bryman, 2004, p. 57). Since the experiences of the participants during the sailing holiday – and how this might change independence and body image – are the main priority, qualitative methods were selected.

To encourage participants to share their thoughts, which might be difficult to express due to the disability, a creative method of data gathering was used to elicit information. As mentioned by Bagnoli (2009), “an arts-based method or graphic elicitation tool may encourage a holistic narration of self, and also help overcoming silences, including those aspects of one’s life that might for some reason be sensitive and difficult to be related in words” (p. 566). In the same article, Bagnoli mentioned the fact that including non-linguistic aspects in a study can be the key to accessing other insights into people’s experiences (Bagnoli, 2009). For this study, two different methods (related to creative elicitation) were used as a base for qualitative interviews: visual elicitation and making relational maps. To lower barriers and create the possibility for the participants to express themselves easily, the study was executed in the native language of the participants. Since all participants were Dutch, the interviews were conducted in Dutch. In appendix 2, the quotes that are used throughout the report are translated into English. A third method that was used mainly during P2, is observations. Here, the focus was on the attitude of the participant in both sailing and non-sailing activities (i.e. do they show independent action, or are they ‘hiding’ behind their disability). Furthermore, conversations outside the non-recording moments were also written down as observations and personal

communication. Below will be an elaboration on how these three methods have been used in practice.

Relational maps

To get an insight into the dependence of the participant on others, they were asked to make a relational map. As discussed in the literature, dependence has different definitions. In this study, the participants could decide for themselves how they interpreted the word 'dependence'. People in their lives should be placed on a map; the closer the person is drawn to the participant's name in the middle, the more important the person is in the life of the participant. The participants were also asked to provide a short fact about what kind of relationship there is between the person and the participant, in written or spoken word; this could help in distinguishing what kind of dependence it was (physical, emotional and/or economic). The visualisation was used to elicit information for an interview. A question that was asked during the first interview was: 'Do you only depend on these people, or is it an equal relation?'. The direction of the dependence was expressed on the map in colours, with green meaning mutual dependence and orange being a one-way stream with the participant as the 'dependent person' (see appendix 3.1 for elaboration). The same relational map was used as a base for the interviews in all three phases of the study: rather than drawing a new map, people were asked to change things on the original map to see if the vision of SailWise (more independence by active participation) was achieved. Before the first interview, it was inquired if a family member or care-taker could be present during this first interview. The aim of this was to get another perspective on the dependence of the participant, and see what differences could be found (and why). With the third interview, these people were asked if they noticed any changes in behaviour in the participant after the holiday. During the second and third phase of the data collection, questions for the participants focused on if they emotionally and/or physically missed an actor in the network, or if they felt less dependent than initially drawn.



Figure I: Drawing of person standing up

Visual elicitation

To get an insight in how participants perceived their own bodies, they were asked to colour a drawing of a human body, which reflected how they see themselves and how satisfied they were. Just as with dependence, participants could decide for themselves how to interpret the concept of 'body image'. Two drawings of human bodies could be chosen from: one of a standing body and one of a body in a wheelchair (see figure I and II). A proposed guideline was provided on the meaning of the colours (from most negative to most positive: red, orange, brown, blue, green; see appendix 3.2 for elaboration) Comments could be added to the paper as well, if desired. This drawing was the inspiration for an interview about body image, and why the participant gave certain body parts certain colours. During P2 and P3, participants were asked to have a look at their previous drawings. If they wanted, they could change colours in the drawing, or add additional comments. Questions that followed were concerned with why certain changes were made, what effects influenced the change



Figure III: Drawing of person in wheelchair

(i.e. ability vs. appearance). The goal of this method was to not only observe the changes, but also to try to understand why.

Observations

As mentioned before, the observations were mainly used to observe changes in behaviour during the holiday itself. Were the participants more assertive and independent than before the sailing week, or is there a change within the time span of the sailing week itself? Interesting observations were written down in notes and coded after returning home. Conversations with other volunteers about participants and/or general things were also noted down as observations.

Conversations

After the interviews conducted during P2, the sailing trip, it was concluded that there might be a difference in effect between first-time visitors and return visitors. Therefore, more respondents – who visited SailWise for the first time in 2016 or 2017 – were gathered through the database of SailWise, to have a short conversation via Skype/Facetime or e-mail. During this conversation, respondents were asked to tell about their first experience with the specially-adapted holiday. Questions that were asked focused on the things they learned, and possible changes in body image and/or dependence. It was also asked to give a short description of their first SailWise experience. In the end, 3 people responded to the inquiry letter (appendix 4) that was sent out.

3.4. Ethical considerations

To make sure the study would be executed ethically, and participants were protected, an information letter was set up and a written consent form was formulated for the initial sample (see appendices 5, 6). In the consent form, responsibilities of the researcher were explained, as well as the rights of the participant. In case of under-aged participants, or participants that were assigned a legal guardian, extra consent was required from the parents and/or legal guardians. This did not apply to any of the participants; however, one participant was unable to use his hand for signing the consent form. Therefore, his personal mentor signed the consent form on his behalf. The written consent was given by the participants before the first day of data collection. Before the start of each interview, verbal consent was required and was given in all cases as well, to make sure the participant was feeling comfortable and answered in voluntary will. Anonymity and confidentiality were guaranteed, and results will only be used for this thesis. For the researcher to still quote the participants in the report, pseudonyms are used.

3.5. Data analysis

To transform all the data into results, both the visuals and transcriptions of interviews were analysed. Visuals were also decoded into a table: for body image, the corresponding numbers are presented and for the relational map an order of importance is provided (see appendix 7). The interviews were transcribed after the interview and before the next phase of data collection. After all interviews were done, transcripts were coded and a few themes occurred: 'general participant information', 'dependencies', 'body image', 'decision process', 'experience with SailWise', 'learning processes' and finally 'differences between boat- and home setting'. Not all themes occurred during every phase of data collection: to clarify this, the abbreviations of P1, P2 and P3 are used within the text. An analysis of the visuals, accompanied with the

interviews of P1, will give an indication of the (in)dependence and body image of a person with ABI, before participating on the specific sailing holiday. Results from the interviews and observations during P2 were compared to P1 to demonstrate what effects the holiday had on the (in)dependence and body image. The results of P3 were compared to both P1 and P2, to see if changes remained after returning to the home-setting, or if new changes had occurred since the holiday.

4. Results

An interesting saying that was heard during the volunteer evaluation was that none with ABI are the same. This also became clear after looking at the P2-interviews, conducted during the sailing trip. All three participants experienced their holiday differently, influenced by being a first-time visitor or not, as well as other diseases and/or facilitating materials. Therefore, this result section will be divided into four sections: one for each initial participant, and the fourth sections elaborates on general first-time visitors' experiences. Here, the most striking results will be explained.

4.1. Hendrik

General participant information

The youngest participant was Hendrik, a 52-year old male. He lives in an assisted living facility with his own room, bathroom and kitchenette, but with 24/7 care when needed and a shared living room and big kitchen. In addition to ABI he has also been suffering from MS (multiple sclerosis), since he was 27. As reflected in the visual elicitation drawing (image I), the right side of his body is affected mostly by the disease so far. After spending some time with the participant, it is still not exactly clear what effects come from the MS and which from ABI; his answers were confusing on that topic. However, according to the SailWise subscription forms he indeed has an acquired brain injury, but due to sensitive information more details were not asked for. At home, Hendrik moves around in an electric wheelchair; he uses the joystick to drive. However, he was told by SailWise that this wheelchair was not fitting for the boat, thus he had to bring a non-electrical wheelchair and be pushed around by others; driving with his arms and feet is not feasible anymore. Also walking is not possible as he does not have a good balance and would fall. He said there are still many things he can do himself, even though he knows it can only get worse. He would love to feel better but it will not happen, which was confirmed by the neurologist; this is something "I have to deal with", he said (H01).

Dependencies

P1: Looking at the relational map (figure III), it seemed like his sister is the most important person in his life; this was confirmed during the interviews. He referred to her importance 18 times during the interviews, whether this was asked or not. Several times Hendrik indicated that his sister "is like a second mom" (H02). In addition to his sister, his aunt plays a role in his life as well, as he is having dinner with her once a week. With both these family members there is mutual dependence. On the contrary, his other two sisters are not as involved with his life anymore: this is a shame according to Hendrik. During the interviews, it became clear that Hendrik is quite a straightforward guy; "No, I'm not a difficult person. If everyone just talks to me, then everyone is my friend" (H03). Next to his family members, three others were included in the relational map, all with a one-way dependence line. These are two of his caretakers, and the taxi driver. He indicated

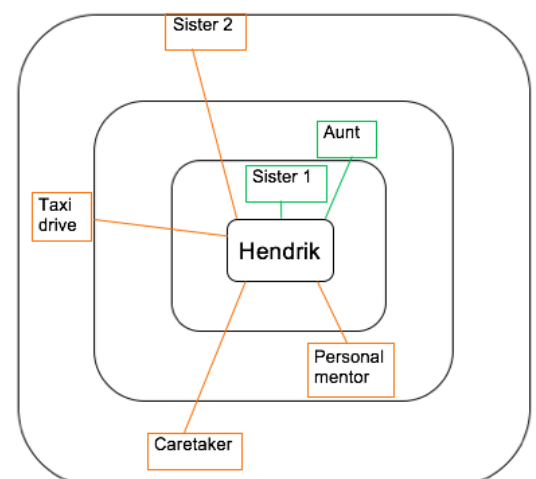


Figure III: Relational map Hendrik

to always have a chat with them and is both emotionally and logistically dependent on them, but since they have their own lives it is not mutual.

P2: During the trip, Hendrik missed his family members emotionally once, when there was some miscommunication with a volunteer. After sharing his thoughts and talking about it, everything was solved and since then he had been happy about the trip and the help he got. The importance of aids was shown during the trip, when Hendrik indicated feeling more dependent due to the different wheelchair: *“Yes, I feel more dependent. Because in the other chair I would drive myself. Then, for example, I could go to Stavoren where we went today. Then I could have driven myself. But now I am required to let someone push me. I admire the guys (volunteers, red.) for that, because I am not one of the thinnest due to all the medicines I have been taking”* (H04).

Body image

P1: Because of limited hand function and difficulties in sight, the body image was asked in numbers, instead of colours. Numbers (1-5) were written down on the drawing, and before transcribing the interview they were converted into colours on the drawing by me (image 1). Hendrik indicated that he used to be more negative in the beginning, when he felt he could not do anything. But after remarks from his personal mentor he stopped doing that, and now realises he can still do quite much. When asked about how he views his head, he is quite positive (a four), because his thinking is still good. However, later that interview, he indicated that his thinking has become less, his memory is not good and when people talk fast it is also difficult for him to follow. But despite that he seems to be positive about it. Due to his MS, his right side has failed. However, his left side is compensating for this: *“(my left foot) has only become stronger. Because I do not use the other one anymore. Yes, I can still stand on it for a short while but I cannot bike with it or something like that. Then it stays the same way. So I do everything with left. Basically, I turned fully left”* (H05). This malfunctioning of the right side also made him quit his job as a carpenter. However, his motivation to make the best of his situation was also shown when talking about his physical therapy: *“once I start with something I want to get the most out of it. Even if this means water is running down my head”* (H06).



Image 1: Body image Hendrik

P2: When asked – during the second interview – what should happen for him to feel more positive about his body, he mentioned walking. However, he is accepting the fact that that will not happen.

P3: After returning home, Hendrik shared that he knows his stronger points (i.e. his left arm and hand) and his weaker points (thinking capacity). And, he appreciates his body parts as long as they are still working.

Decision process

P1: The main reason for Hendrik to specifically choose a SailWise holiday again was because he used to have a boat, and because he feels at home on the water: *“I really like it. Then I really have holidays. I do not need to go to Spain: if you put me on the water and the weather is nice I already feel at home (H07)”*. In addition, he finds it difficult to just sit somewhere and

not do anything; he likes to be busy. He also likes to be around other people, and have a chat with others.

Experience with SailWise

P2/P3: The highlight of the trip was all the sailing, especially when there was a strong wind and waves. The sailing through Friesland and steering the wheel were most memorable for him. Describing the holiday, he mentioned it was excellent, and all arranged well. Especially doing things like the barbecue and bonfire, which do not happen at home, were fun.

Learning processes

P2: During the trip, Hendrik realised that there are more things that he cannot do anymore due to the MS. But he acknowledged and accepts this; instead, he also focused on the things that still did go well. Besides that, he also learned new things about the sailing; he has learned this on previous trips as well, but due to the bad memory he had forgotten some of it. In addition to this, Hendrik has learned to ask more for help, instead of spending a long time trying to do it himself.

P3: When asked about leisure activities at home that might have helped him in learning about his body, he mentioned painting and other kinds of crafts, which go well with only his left side.

Difference between boat- and home setting

P3: The main difference for Hendrik was his wheelchair: a non-electrical one instead of his own joystick-driven wheelchair. This limited his experience, in a way that he was dependent on people pushing him around. This made him less calm because he likes to do things himself and can be a bit impatient. And since he is used to be able to drive himself around, asking for help is still something he is learning. He also indicated that he felt bad for the people having to help him with pushing around, but accepted that that is the way it is. Furthermore, Hendrik indicated that on the boat, he could physically do more with his 'bad' arm. But despite this, he was more negative about it during the interview. This was partly influenced by the other people. Seeing they were still able to i.e. use both arms, or walk, made him feel a bit sorry for himself, thinking 'why can I not do that'. A final big difference for Hendrik was that compared to his home-setting, SailWise provides a real holiday-setting where you can genuinely celebrate your holiday.

4.2. Willem

General participant information

The second participant is Willem, 60 years old with a brain injury since his 20s. In addition to the brain injury, Willem has epilepsy. Just as Hendrik he lives in an assisted living facility with his own room. Looking at the holiday and at the interviews, it became clear that Willem is a quieter person, that is not very talkative. In his daily life, he spends most of his time listening to (classical) music, or at the activity centre where they do crafts and use the computer for leisure. Everyone has access to this place, and according to Willem it is not intentionally adapted to people with a disability.

Dependencies

P1: Looking at the map (figure IV), there are only three people that seemed to be important to Willem. However, the people that are present are very important to him. His dad, with whom

he plays cards and who visits him every week (and vice versa); his sister, who lives a bit further away so there is less visiting but she arranges things like the holiday; and his brother-in-law, who looks after his tax-declaration. According to Willem, there is mutual dependence between him and all actors, as they could not live without him emotionally. He is fine with only having these three people this important. The dependence and importance has increased since the brain injury.

P2: During the sailing trip, Willem mentioned not to miss his family members (neither emotionally nor physically) because he feels independent. Despite his 'independence', he would still locate the family members as close as before the trip.

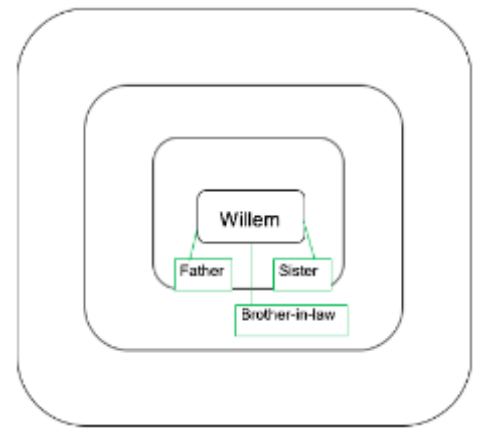


Figure IV: Relational map Willem

Body image

P1: From Willem's drawing (image 2) it was clear that there are not as many physical effects from the brain injury as with the other participants. Both arms, hands, legs and feet were perceived as very positive according to the respondent. In general he was content with his body; a 4 out of 5. He ("obviously!") chose the drawing of a standing person as he is not in a wheelchair. His head got a 3 because of the epilepsy. He claimed to not have many attacks (but, as was later found out, they happen more often than he remembers). His eyes were a 3 because he does not have 100% vision anymore. The mouth got a 3 because he would not consider himself to be a talkative person; he did not know whether this was due to the brain injury or not. When asked what should be improved for him to feel more positive, he said he would not want to improve anything.

P2: Reflecting on the first four days of the sailing trip, Willem claimed to not have noticed any attacks or absences due to his epilepsy. However, from the observations, the volunteers and I did notice a few absences and two attacks over the time span of the whole sailing week. There were no clear differences in physical behaviour (things that went better compared to at home). His satisfaction with his mouth and head was better than at home; the eyes and heart stay the same. He acknowledged that the sailing holiday did something good for him.



Image 2: Body image Willem

Decision process

P1: Willem had joined SailWise already multiple times before. He was most looking forward to sailing and the 'being busy' during these holidays. When asked if he would prefer sailing by himself or with others, he mentioned to rather sail together with other people. It is interesting that, despite portraying himself as a non-talkative person, his main reason for choosing the Lutgerdina was the social environment of being with other people 24/7.

Experience with SailWise

P2: When describing the atmosphere on the boat, Willem thought it was really 'gezellig' with everyone else. His highlight was sailing from Den Oever to Leeuwarden (day two), when all participants and volunteers were spending most of the time outside and together. He really enjoyed himself and would love to return.

P3: During the final interview Willem was asked to recollect some previous SailWise memories, but he remembered little to nothing. But from this current edition, the most memorable thing was going off the boat; especially Leeuwarden was a highlight. Furthermore, he did not mind the fact that during SailWise holidays, you are asked to actively participate with both sailing and the household-tasks because “*you sign up for it*” (W01). Summarizing the holiday in three words Willem chose for ‘fun’ and ‘relaxing’ (“*I’ll leave it at that*” (W02)).

Learning processes

P2: Willem said that there were no tricks he learned during this specific trip: neither things from sailing, nor about himself. He did learn to sail on a SailWise trip (and how his handicap fits into this), but that was during the previous editions he joined. Furthermore, all activities went as good as at home, he claims. He did not get influenced by the other participants; it did not affect his self-perceived body image. During the final interview, he again confirmed these statements.

Difference between boat- and home setting

P3: It was difficult for Willem to express what the main difference was between the sailing during the trip, and his activities at home. Finally, he mentioned that the ‘being away from home’ and ‘holiday-feeling’ were the main differences. The difference appeared not to be in the physical sphere but more towards the emotional state. Because, despite being busy the whole day and helping with ‘household-tasks’, he claimed to still have the ‘holiday-feeling’. He did not notice a difference with how it is going back home versus the trip. There were also no differences in behaviour, as he also helps with things like dishes at home.

4.3. Piet

General participant information

The third participant is Piet, a 61-year old male who lives at home with his wife. Around four years ago he obtained a cerebrovascular attack (CVA; a stroke); following this, part of his right side is not functioning properly anymore. In addition to this, he has aphasia (impaired ability to understand or produce speech), which limits his speech and vocabulary at times. Despite some bodily malfunctions, he can still drive his car (which can even be adapted to the driver – Piet or his wife).

Dependencies

P1: During the first and third interview Piet’s wife was also present to answer some questions. Both from the relational map (figure V) and the conversations with Piet during the whole data collection period, it is obvious that his wife is the central point in his life. Piet even felt that ‘green’ for mutual dependence was not enough to show the importance of his relationship with his wife. In addition to his wife and their two sons, Piet also added ‘professionals’ to his map. According to him, these therapists have a mutual dependence-line between them and Piet, because of the contract (as he financially compensates them for their expertise). There is a division between emotional dependence (family) and physical dependence (professionals). He also indicated that a year after the CVA the relational map looked different and included many

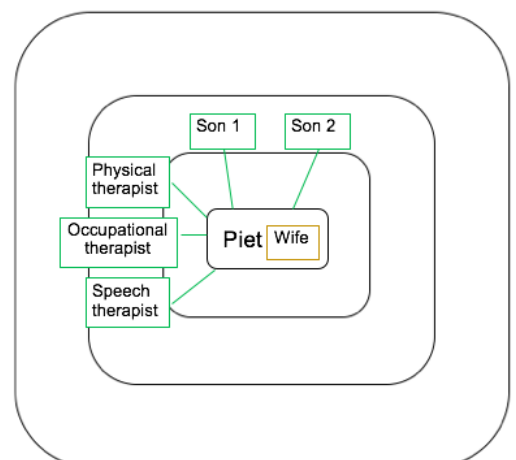


Figure V: Relational map Piet, according to Piet

more people. He would love to see his sons a bit closer on the map, but it depends on how you interpret the concept: do you look at it therapeutically, or emotionally? Compared to Piet, his wife looked at the relational map less therapeutically (figure VI), but was sure Piet felt the same way: (talking about the distance on the maps between them and the sons) *“I think you feel it the same way, that is the way it is. One person fills it in, and you can feel the other things but that might just be a more formal person, that also depends on who you are as a person. Because they are not less important to you than to me”* (WP01). With this she also acknowledged the importance of their sons, who might not always be present but are important people in their lives. They agreed that they are more dependent on their sons than vice versa, because they raised them to be able to live without them when necessary. The professionals were still included but with more distance; however, it is important that there are more perspectives on the rehabilitation process than just from family.

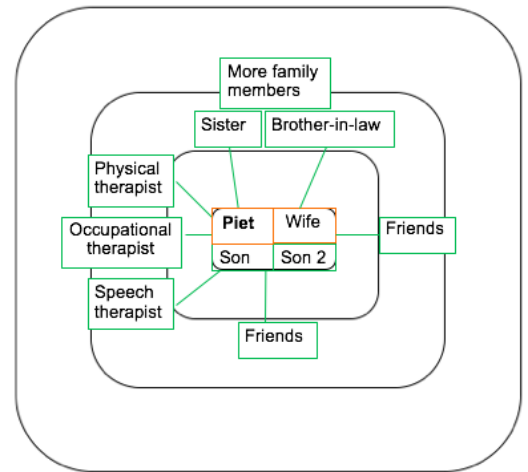


Figure VI: Relational map Piet, according to his wife

P2: During the trip, Piet physically did not miss any of the people on his map. He was not sure before joining the trip if all would go well, but he was surprised to notice that he did not miss them that much, admitting he would even feel confident enough to spend 2 or 3 weeks without his wife nearby. He would not change a thing about the map despite this.

Body image

P1: Since his CVA a lot of improvement had occurred already. However, his speech – due to the aphasia – was still not satisfying him (image 3; added to the drawing in words: 'spraak'). Furthermore, the body parts that show malfunction were also seen negatively, while working body parts were indicated as very positive. His opinion on sitting in a wheelchair was clear: *“No-one wants that. Yes, maybe in the long-term. But not in the near future”* (P01). His negativity on the affected body parts is, according to Piet, all because of the malfunctioning it has caused: *“I am not affected by other people’s opinions. They can think whatever they want”* (P02). Overall, the attitude of Piet towards his own body has two sides; looking at how the brain injury affected his professional career, he would give it a 3 or 4 out of 10 on average, as he lost his job which was quite difficult for him to accept. At the same time, there are many other possibilities for him to do now and in general he would give his body an 8 out of 10.



Image 3: Body image Piet

P2: During the holiday, no changes in positivity were mentioned. A goal for him to feel more positive would be to get some more response in his right hand: being able to hold and grab things would make life easier. That Piet was still in the process of accepting his disability was also noticed by one of the volunteers during the trip: when saying goodbye to the crew, Piet got a bit emotional. He told one of the volunteers that he is still in the process of grieving and accepting what has happened to him, and how his life has changed. Confidence in his own body is something that

still lacks sometimes: during the trip, Piet was mostly on deck, helping with the sailing. When asked if he wanted to help with cooking and/or dishes, he always laughed and politely declined.

P3: With the last interview, Piet explained that not helping out with household tasks was not only because 'he had holiday', but mostly due to a lack of confidence: "*At home I help out with things (...), but that all happens really calmly, and I have enough time to use my knife to grab a potato. But on the boat everything was moving, so I was not feeling that. Besides that, when I have only one arm to both hold something and hold my balance when walking...*" (P03). This lack of confidence in his body also resulted in Piet not going into the ropes of the 'jib' (the sail at the front of the boat). Despite not changing anything on his drawing, Piet did observe some improvements during the week: "*In the beginning I still needed some help, but in the end I could walk from the back to the front of the deck in one go. Well, that gave me confidence*" (P04). This confidence showed at home when – despite his wife's asking to wait until she was home from her own holiday – he lifted his bag from the car and unpacked it.

Decision process

P1: During all interviews, it became clear that the main reason for Piet to join a SailWise holiday, was because of his love for sailing. He used to sail a lot before, both in The Netherlands but also on the Dutch Antilles. After his CVA this was the first test for Piet, to see how the sailing would go with his acquired disability. Furthermore, the holiday was a way for Piet to get in contact with other people; due to his aphasia, it is sometimes difficult for people to have a conversation with Piet. Being on the boat would break his current social circle a bit. The approach towards participation was not for Piet to improve physically from this holiday, but to challenge him a bit emotionally.

Experience with SailWise

P2: The best sailing day according to Piet was the first one, from Enkhuizen to Den Oever: clouds that covered up the sun but with enough wind to conquer the created waves and get water onto the boat. In addition, steering the wheel was a highlight for him. The off-boat activities such as canoeing and walking around in the cities were also fun.

P3: At the third interview Piet concluded that all in all, the sailing trip itself was real fun, so there was nothing to comment negatively on that. The social environment however, which was also indicated as a motivation during P1, was a bit disappointing as only two out of seven other participants were talkative. He had hoped to get in touch with the others afterwards, but the effort was not put in from both sides. The contact with the volunteers was better, and Piet had some good conversations there. The inactive social environment would not be a deal breaker for next time, but if it could be different then Piet would prefer that. He described the week as 'just amazing!'.

Learning processes

P2/P3: As indicated as a motivation for joining SailWise, the main goal for Piet was to see how well the sailing would go with his disability. He learned that it was all still possible; perhaps not with the same strength, but in a setting such as the Lutgerdina, there are enough people around to help out and work together with. Next to learning about his body, he did learn one thing about sailing: how to easily 'bundle' a rope when you can only use one arm. This was also the most memorable thing for Piet about the sailing. All in all, learning he could do more than expected was a highlight of the holiday.

Difference boat- and home setting

P3: Piet said that being in an environment with more disabled people made him realise he is not doing that bad – he is not in a wheelchair and his posture and pace of walking was average or better. Another difference is that at home, his kitchen utilities are adapted to his wishing so he can help out more easily with cooking; also the different amount of people to feed played a big role in this. Other than that, little differences between the boat- and home setting were noticed.

4.4. First-time visitors

The three first-time visitors are on average younger than the original sample. The youngest participant – Billy, who also joined the sailing week of Piet, Hendrik and Willem – was affected by meningitis at age 1, which means he has already spent 33 years living with the consequences. The other two participants had a CVA a few years ago; this resulted for both in hemiplegia (one-side paralysis), epilepsy and being more tired. With regards to the dependence, the participants complimented the volunteers for creating a safe space to try things themselves, and only help where and when necessary. This helped in building confidence, for example when riding the electrical wheelchair on deck. As one of the participants explained: *“I get a lot more support and confidence from the volunteers, than at the assisted living facility where I live”* (FT01). Also walking on deck was easier for those with balancing issues, after getting used to the boat. The longer the trip lasted, the better it went to walk around without needing help. This taught the participants that they could still do things such as sailing, despite their disability. Whether it was helping with the sailing or with cooking, the active participation in all these activities made the holiday memorable for them. Not only to give them a smile on their faces, but also to reload energy for the ones at home taking care of them. There was one remark about the social environment, though. Billy, who joined in the same week as my data collection, indicated both during the trip and afterwards that he felt a bit misplaced in the group. This had more to do with the age difference than with the inabilities of everyone. He indicated that he missed some excitement and silliness within the group, but some of the volunteers did compensate this. His final remark on the holiday: *“The differences between the participants were too big to call it a group, however everyone individually did enjoy the trip very much!”* (FT02).

5. Discussion

5.1. Discussion of results per theme

What common grounds can be discovered between the respondents? And how does the data from this study relate to the existing literature on ABI? In this section a more thorough interpretation of the results will be given, in the light of existing literature and the goals of SailWise. This will be done using the themes that came forward during the analysis. An additional paragraph is added to discuss the most outstanding differences and similarities between the first-time visitors and the repeat visitors. After the discussion of the findings, the research questions will be answered. This chapter ends with an explanation of the limitations to the study and some academic as well as professional recommendations towards SailWise.

General participant information

During the specific sailing week, 7 males and 1 female participated in the trip. Except for one participant, who was in his thirties, the age-group was 50+. The initial sample of Hendrik, Willem and Piet thus represented the image of the average participant's age and gender. The participants all had a different backstory in terms of their disability, which shows that no acquired brain injury is the same. Out of the three, only one participant obtained his disability through a CVA at a later age: the other two have been dealing with their brain injuries for most of their lives. The sample of the first-time interviews is a bit different: here, one third was female. The average age was lower: 45 here versus 58 in the original sample. Out of the three participants, only one has had his disability for as long as he can remember (due to meningitis at age 1). The others obtained their injuries four to six years ago, and are living partially paralysed and with epilepsy.

Dependencies

Between the three maps there were some noticeable similarities and differences. The definition of dependence was left open for own interpretation which resulted in both physical and emotional dependence being described with the relational map. Whereas the literature provided three types of dependence, none of the participants mentioned an economic dependence. Because people with ABI are in need for both physical and emotional support, the definition of Barnes ("a thought process not contingent upon physical abilities" (Barnes C. , 1991, p. 129)) seems fitting for describing independence.

Looking at the kind of actors in the network, a distinction could be made between therapeutic and familial importance, where the therapeutic network mostly dealt with physical dependence, and the familial network with emotional dependence. Only for Piet, who still lives at home, the familial network involved some physical dependencies. Whereas all participants have included this familial side (i.e. (close) family members), Willem was the only one that left it at that. An explanation for this could be that he experienced less physical inabilities than the others – which was observed in the body image drawing as well – and therefore needed less care-taking. This is in line with the arguments of Rabiee and Zunzunegui, that people might be more dependent in one aspect (i.e. emotional support) than other aspects (i.e. physical support) (Rabiee, 2012; Zunzunegui, 2011). In addition to the family members, Piet and Hendrik both added people that were involved in their rehabilitation or medical care (therapeutic environment). There was a difference in the dependencies they linked to it, though: Hendrik saw the relation with his caretakers as a one-way dependence (as they "have their own lives"

and are not emotionally dependent on Hendrik (H08)), whereas Piet indicated mutual dependence because of the contract-based relation (therapy in exchange for salary). In general, most relations were indicated as mutual because both parties had responsibilities towards the other (Reindal, 1999).

Looking at the four ethical elements of Tronto, it can be discussed that 'good care' is not always perceived as such, by the participants. The familial network might stop at step two, because they do not have the competency to perform the care-activities. but, the most striking element is responsibility. Tronto argued that the care-taking should not feel as an obligation (Tronto, 1993). In the case of Piet, the therapeutic network would then not perform 'good care' as their mutual dependence is based on a contract. From this study, it is not clear if familial actors would perceive their relations with the participant as a moral obligation or not, as only Piet's wife could be present at the interviews. So, participants might be physically dependent on family members, but it can be discussed if 'good care' can be achieved within this familial network.

During the interviews, it was mentioned by all participants that the dependence on others had increased since the ABI, while their network grew smaller. This decrease in network actors was also found in the study by Saugeres (Saugeres, 2011). During the data collection, it also became clear which influence (mobility) aids can have on the dependence of the participants. Hendrik indicated several times during the interviews that he felt less at ease on the boat, because compared to home he was dependent on other people pushing him around in a wheelchair. Not only did this limit his freedom of movement on the boat, but it was noticed that he was talking and laughing less on the boat than when I met him during the first and last interview. From all the participants, only Piet indicated that the power dynamics of the relation with his wife and children had changed a bit as Rabiee mentioned (Rabiee, 2012). Because he lives at home, his family-members are the main care-takers when necessary. This has led to some occasional frustrations but in the end, everything was fine again.

So how does this relate to the vision and core values of SailWise? The vision of SailWise was: "Active and independent participation in water sports contributes to physical and emotional independence of people with a disability" (SailWise, sd), with one of the core values referring to stimulating autonomy and independence. In general, the respondents indeed felt less dependent on others and they were motivated by the volunteers to try things themselves. Also their familial network at home was not as much missed, which could indicate the emotional independence is also achieved. Considering this, I could agree with Trainor et al., that leisure activities can "enhance people's perception of autonomy and independence" (Trainor, Delfabbro, Anderson, & Winefield, 2010, p. 174). However, during and after the sailing week, none of the participants would change their relational maps. During the third interview, there was not even enough mentioned about the relational maps to occur as a theme. It could thus be argued that the sailing week only has a strong short-term effect which lasts for the time being on the boat, but two or more weeks after return, the effect on physical and/or mental independence has slowly faded away. Here lies a challenging but interesting opportunity for SailWise: to create an optional take-home message about gaining more autonomy (i.e. tricks for household activities), while still maintaining the holiday-feeling.

Body image

With regards to the body image, it was interesting to see that in general, the participants were optimistic when colouring the image: much of the body-parts got a neutral or positive colour. During the first interview, it was asked what factors influenced their negative perceptions of certain body parts the most. The participants indicated that it was the malfunctioning and lack of confidence in their body, rather than other people's opinions. This is in line with the findings of Keppel & Crowe (2000) that body image and self-esteem are related; a lower self-esteem and body-trust, can affect the body image. Because the participants focused on ability over appearance, it was clear from the image which body-parts were not working anymore due to the disability. So why did many studies find appearance to be an important indicator of body image, while no-one mentioned it in this study? As Bailey et al. discussed, media can affect one's body image when someone is not fitting to the 'ideal image' that media portray (Bailey, Gammage, van Ingen, & Ditor, 2017; Holzer, et al., 2014). Looking at the sample, this study consisted of males that were 50+ years old, where the other studies were more focused on adolescent girls who might be more easily affected by the media.

One of the aims of this study was to find changes in body image after participation in the sailing holiday; however, these were almost non-existent. Cash et al. mentioned that athletic ability and physical health were contributing to a better body image (Cash, 2004; McLaren & Wardle, 2002). From the results, the athletic ability was the main influence to body image: the active participation in steering the wheel and helping with the sails elicited feelings of surprise, pride and confidence. The participants did indicate that they could do more during this week compared to at home, which contributed to a higher self-esteem, but it did not affect how content they were about their bodies enough to adapt their initial drawings. This is also shown in the themes, where body image only appeared during the first and second interview meaning there were no noticeable things mentioned during the last interview with regards to body image. So the 'voluntary risk-taking was an intrinsic part of the outdoor leisure experience and it elicited feelings of self-improvement' (2013, p. 1070), as found by Burns et al. in their study, was only partially applicable to the sailing week. One participant, Hendrik, did indicate some changes, but only for the worse: this could be explained by his additional disability MS – which means his body is slowly getting worse, or the fact that due to his higher dependence his mind-set was not as positive as usual.

The role of acceptance in body image and self-esteem was not necessarily obvious through the interviews; however, the participants who had their injury for longer (and accepted it) showed less emotional boundaries and seemed to know their body better. This resulted in more confidence in their body and more active participation in the household-activities (Taleporos & McCabe, 2002). However, for Hendrik this was contradicting. As his MS was getting worse, his body image was more negative than during the first interview. The fact that he accepted that his body slowly weakens did not have an influence on this. It can thus be discussed that acceptance of a disability can contribute to a better body image – as one accepts that this is their new body – but the type of disability plays a role in this.

In the end, I can partially agree with Liechty & Yarnal that body image (and perhaps self-esteem even more so) can be both a barrier and an opportunity for tourism participation (Liechty & Yarnal, 2010). In this study, only Piet mentioned that he had experienced his disability as being both. Before joining the holiday this year, he had spent a few years looking at the SailWise folders, but did not feel confident enough in his body to actually subscribe

(barrier). After different types of therapy and rehabilitation, this year he felt confident enough with his body, and the holiday was used to get him out of his usual social circle. Here, his disability is used as a reason to join the holiday and have new social interactions.

Decision process

Burns et al. concluded in their study that participation in an outdoor activity such as sailing created a nice opportunity for people to experience the same leisure activities as before the injury was acquired (2013). This was also one of the reasons for participation that was discovered during the study. For Hendrik, who had a motor boat when he was younger, this water-environment seemed to be an important factor. During all three interviews, he mentioned the boat he used to have 5 times. Also Piet, who had been sailing for most of his life, chose the holiday to be on the water again. Next to the participants' history with water and sailing, two other motivations were repeatedly mentioned during the interviews: the 'being busy', and the social environment. Both Hendrik and Willem mentioned that a reason to choose this holiday was 'to be busy'. Helping with household-tasks such as cooking or doing dishes seemed to be a non-issue, as they gladly participated in all. Finally, the social environment and interaction with others was preferred by all participants: they liked the idea that they could interact with different people, and share experiences.

The statement of Wise et al. (2010) about choosing leisure activities for "the positive impact on their physical and emotional health" (p. 1357), can – just as the vision of SailWise about physical and emotional independence – be partially agreed with in the way that during this particular study, only emotional health seems to have improved. The participants indicated that they very much enjoyed the holiday, and went back home with new memories and happy faces. Of course, the actual physical and emotional health is not specifically studied with the current methods, but only the self-perception of the participants on how they felt. From this self-perception, the physical health did not seem to be improved much, as especially the repeat visitors already knew what they would be able to do on the boat and what not, from previous experience. They did indicate that they returned to the Lutgerdina because of the nice experience.

Experience with SailWise

As mentioned in the previous paragraph, all participants left the boat with a smile after five days. The key words that they used to describe the sailing week make a good representation of the holiday: 'Just amazing', 'fun', 'relaxing', 'excellent' and 'all arranged well'. Conquering the waves at IJsselmeer but also visiting cities like Leeuwarden and Hoorn were mentioned as highlights: it was the variation between actively sailing and having the holiday-feeling on shore that made these participants want to come back. Both the crew and the volunteers were mentioned to be big contributors to the experience as well: "*Look, you have a well-qualified crew, good volunteers who you can talk to and you can work according as you can, well, I think that is already incredibly good*" (P05). These volunteers – who are at the heart of SailWise – have been previously highlighted by Hua, Ibrahim and Chiu on their important contribution to making sport events more accessible for people with a disability (2013). I agree with this statement: volunteers are the key to keeping these sailing holidays accessible and with a relaxed feeling, because they are partially on (working-)holiday themselves as well.

One thing that was limiting the experience of some participants was mentioned by Piet and another first-time visitor (Billy, who joined in the same week). Both are (still) active and

talkative, and chose this sailing week partly because of the social interaction with fellow ABI'ers. The current group existed of mostly 50+ males of which only three were always in for a chat, the two participants included. The idea of Bailey et al. that social interactions can affect body image was slightly present in this study; self-esteem seemed to be more affected by the interactions with peers. However, these effects were both positive and negative. For some, the interaction with peers helped in realising they were not doing that bad (i.e. no wheelchair). But, at the same time, for one of the participants it was the opposite: seeing his peers being able to walk everywhere, made him feel sorry for himself. On top of that, Billy felt like the age difference between him (34 years old) and the other participants and volunteers was noticeable as they were more serious. Luckily a few volunteers could release their inner kids and give him the active and playful atmosphere that he had hoped for. Looking back on the sailing week, these two participants indicated that they would not stop joining SailWise because of this lacking social environment; however, if it could be different they would prefer that. Thus, instead of 'labelling' a participant in the category of ABI, more attention should be paid to what someone can still do, or wants to do during the holiday. But in the end this is proof of how complicated and diverse brain injuries can be.

Learning processes

One of the aims of this study was to find out to what extent the participants learned about themselves, their dependence and about how to use their bodies after the ABI. During the interviews, it became clear that all participants learned something about sailing, whether this was basic information about sailing-terms or tying knots. Even Piet, who had a lot of experience with sailing, learned some new tricks on how to coil up a rope with only one arm. Not everyone learned as much about their body as others: there is a noticeable difference between first-time visitors and repeat-visitors. These latter men went sailing before with SailWise, so they had already experienced how everything works on the boat. Whether they remembered everything is not relevant here; the basics about sailing were already learned during previous trips. For them, the main contribution of the holiday was that they had a great time, that left them with a smile on their faces. For Piet, this trip was the first trip independently from his family, after his CVA. More things were learned about his body, partially because he could still do surprisingly many things with regards to the sailing. This difference in learning processes will be further elaborated on in the last paragraph of this section.

Based on several studies it was hypothesised in section 2.6 that an increase in physical abilities reinforces a positive body image as well as create more independence. Accepting or rejecting this hypothesis is difficult, as it can be discussed that no real increase in physical abilities has occurred during the study: instead, it was the atmosphere of the holiday that made people realise they were capable of performing certain tasks. So rather than an increase in abilities leading to more independence and a better body image, it was an increase in self-esteem that made people less dependent on help and feel more positive towards their body. This shows that self-esteem is related to dependence and body image. However, the direct relation between dependence and body image seems a bit contradicting. As acceptance of the disability played an important role in improving one's body image, the dependence seems to be affected negatively: accepting the disability meant giving into asking for help. It thus depends on what factor is influencing dependence and body image if these are positively or negatively related.

Differences between boat- and home setting

In this theme the focus was on the difference in behaviour between the boat- and home setting, as well as differences in dependence and body image between the different interview-moments. In terms of behaviour, the participants did not notice any big differences between the holiday, and how they are at home. On the boat, Hendrik and Willem had the opportunity to be more involved in the cooking and grocery shopping than at home, where they live in an assisted living facility where things are arranged on a broader scale. This added to their feeling of being away from home on a holiday. Because the participants were given more space to try and do things themselves, their feeling of independence increased a bit when things went successfully. Especially Piet – whose first experience with going on holiday by himself after the CVA showed him that he did not need his family as much as expected – took this home by trying more himself. It was not enough to make changes in the relational map, but the confidence in his body did increase. However, as discussed in the paragraph about body image, there were some moments where the participants felt like they could do more than expected, but they would not change their drawings.

First-time visitors versus repeat visitors

The first-time visitors were excited to join SailWise, as (one of) the first holidays independently after their acquired brain injury; the participants were not used to using their ‘new’ bodies in an environment like this. They appreciated the freedom that the professionals and volunteers gave them to act independently, knowing they were there to help when and where necessary. This can be considered the ‘controlled’ environment Wise et al. talked about (2010). It seemed indeed that a holiday in such a controlled setting is a nice start to discovering what is still possible after an ABI. The biggest difference between the group first-time visitors and the repeat visitors lied in the new experience: where repeat visitors were used to the boat and already knew what was possible and what was not, the ‘newbies’ recognized the motivation of becoming independent and learned more about this, per their responses.

5.2. Answers to secondary research questions

Now that the findings of all participants are compared and it is discussed how the results relate to the existing literature, it is time to use the findings to answer the research questions; the secondary research questions will be answered first, before looking at the main research question. While answering the questions, limitations to the study will become clear and recommendations can be derived: these will be discussed in the sections following this one.

- *SRQ1: How does a person with ABI perceive their independence before, during and after participating in the holiday?*

During the interviews, two types of dependence were revealed: emotional dependence and physical dependence. Participants indicated they do not only depend on others when it comes to care-taking, but also for emotional support, finances and logistics. This was translated into an emotional and therapeutic network on the relational maps, with the therapeutic network dealing more with the physical dependence and the familial network with the emotional support. For most actors, mutual dependence was acknowledged as the recipients are either emotionally or financially dependent on the participants. The perspective of the participant did influence the type of dependence with the therapeutic network and the distance there was on the relational map: a person with a more business-like view might see less of a difference

between the emotional and therapeutic network than a more emotionally-invested person, and sees the therapeutic network as being financially dependent on him/her instead of emotionally independent. The dependence network changed after acquiring the brain injury, where friends (and family) made way for the therapeutic actors. During the holiday, the participants indicated a few changes in dependence. Because of the stimulating atmosphere participants could perform activities more independently. On the contrary, Hendrik was more dependent and therefore less happy during the holiday because of the 'wheelchair-incident', showing how important accessibility and use of aids are. Overall these circumstances made a slight change in the participant's independence, nonetheless, the differences were not enough to change something in the drawings at the end of the data collection period: effects seemed to be more short-term for now.

- *SRQ2: What body image does a person with ABI have before, during and after participating in the holiday?*

For this question, body image was left open for own interpretation. Coding the colours into numbers (1-5, with 1 being the most negative and 5 being most positive), an average of 3,85 indicates that the participants were overall leaning more towards being 'positive but with room for improvement' about their bodies, despite their brain injuries and additional inabilities. For the reasoning behind these numbers, the participants shared the view that how they perceived their body-parts was mostly based on the (mal)functioning of the body: the opinion of others did not influence the self-perception. The body image during the holiday was influenced by being around peers: comparing oneself to other participants of the holiday would either reinforce or balance the body image one had. After participating in the holiday, participants indicated to have enjoyed the holiday, however the effects on their body image were not sufficient to change the drawing. Just as with dependence, the effects of the holiday seemed to be more short-term for this group.

- *SRQ3: Is there a correlation between body image, self-esteem and dependency?*

No, there is not. Being able to perform activities independently created more self-esteem, which made people more positive about their body. However, an increase in body image does not automatically lead to an increase in independence. Accepting the disability made people see the positive side of their bodies, but could also make people more dependent because they do not try to do everything themselves anymore, but rather ask for support. This uneven relation means there is no correlation (mutual relation) between body image, self-esteem and dependence, but they are in fact connected.

- *SRQ4: Does the effect of active participation in the holiday differ between first-time visitors and repeat visitors?*

The learning processes have a bigger influence on first-time visitors. Participating in the sailing holiday is one of the first big activities these people undertake after acquiring their brain injury, and thus they are newly exposed to getting out of their comforting network and into a holiday-setting. The attitude of SailWise to have more independence for the participants reinforces the learning process and boosts confidence in people's body; the biggest difference is the effect in self-esteem that is gained. For repeat visitors, the learning processes have a more limited

effect, as they have experienced before during previous trips that their body can still participate in sailing.

These answers lead to the main research question, which was:

“What influence does active participation in sailing tourism have on self-esteem and body image, and what effect does this have on independence?”

Participation in tourism can have many barriers for people with a disability. However, through active participation in this adapted sailing holiday, they realise that barriers can be overcome and with that the self-esteem of participants increases. Because of this increase in confidence, and being around peers, the body image can be slightly affected. This effect is bigger on first-time visitors because of the new experience. But, there are additional elements that influence body image besides the ability of the body and social environment, such as additional aids. With regards to independence, participants perceive themselves to be more independent during the holiday because of the ‘laissez-faire’ attitude of the volunteers. However, only small changes in dependence are indicated after the holiday. And where less dependence seemed to positively influence self-esteem and body image, a better body image did not automatically lead to more independence. So, although people felt less dependent during the trip, the longer-term effect is minimal. In the end, it can be concluded that the improvements on dependence and body image are limited, but the participants seem to have a great time anyway and do not mind as the longer-term effects are not their reason for joining the holiday.

5.3. Limitations

Just as in any other study there are limitations to be found in this thesis study. Could these limitations be avoided – and if so, how? And why did I choose not to do so? These questions will be answered per limitation.

- *Experimental methods.* The drawing was an experimental instrument, which led to some struggles. It was difficult to find big changes in body image because of the small scale (1-5). This scale was also confusing when giving an average grade for their bodies, as people tend to use the 1-10 scale. This would be something to improve next time.
- *Yes/no answers.* The intention for the data collection was to do semi-structured interviews. It was difficult to find appropriate questions that were not to be easily answered with a simple yes or no. Preparing all questions in detail could have avoided this; however, structured interviews would limit the personal touch to the interviews. Not being able to respond with sub-questions to the responses would be unnatural, and interesting anecdotes could have been missed otherwise.
- *Influences of the disability.* Due to the brain injury, the memory of the participants was sometimes limited, which was difficult when asked about previous experiences or when creating the relational map: important people in their lives can be forgotten. Also additional inabilities, such as the aphasia and MS might have limited the participation. In the case of aphasia, Piet sometimes struggled to find an appropriate word, and thus might have used different phrases opposed to what he really meant. The MS influenced

the study in a way that Hendrik could not hold a pen or pencil himself: instead, I had to draw his relational map and colour his drawing. During and after this process the drawings were double-checked for correctness by Hendrik, but there is still a possibility that something was missing, or wrong.

- *Repeated testing.* During the 2nd and 3rd interview the participants were familiar with the questions asked about the map/drawing, and nothing was changed; perhaps the results would have differed if all drawings were asked to be done from scratch every time. However, I chose not to do this because it would take too much time (especially during the boat trip – do not want to keep them away from sailing too long), and to avoid participants not wanting to do it anymore in the third phase, or not thinking it through.
- *Bias of researcher.* The topic of this thesis study was influenced by experiences from my aunt, who has ABI since November 2014. During the interviews, it was easy to make a link between the responses of the participants and my own experiences with my aunt's life. However, this could sometimes lead to a bias, and too much focusing on what I already knew instead of what was actually said by my sample. At the same time, this bias made the study closer to my heart and boosted my motivation.
- *Small and specific sample.* The study only existed out of three participants (with an additional three participants for the first-time group); this could not be changed, as the study focused on a specific disability and location that did not offer more trips within the time span of the thesis process. It is not possible to generalise these results to other kinds of trips, as characteristics of SailWise are used. But, this could also be translated into an opportunity for future research, to see if different kinds of trips might have bigger effect on dependence and/or body image.

5.4. Recommendations

As discussed before, this thesis has both a professional value for SailWise as well as an academic relevance. To start with the professional value, I would like to make some recommendations towards SailWise, based on my results and things I have heard during the trip. After that, some recommendations for future research will be mentioned.

5.4.1. SailWise

- *Good communication about accessibility.* Look carefully at what you communicate to the participants. Something as small as a wheelchair can be important in the life of the participant. During the field work, this different wheelchair and thus the changing dependence influenced the experience of the participant.
- *Think outside the box.* By multiple participants the feedback was given that ABI is a big and diverse group, differing from very social people to non-talkative people. For some participants, this holiday might be chosen to enjoy the sailing, but for others the social environment is almost as important. A wish from these latter participants is to have either more distinctive groups within ABI, or more possibilities to join other groups and not be judged solely on their disability indication.

- *Stimulate longer-term dependence.* This recommendation is somewhat idealistic on my behalf, but nonetheless interesting to mention. There is no doubt that the SailWise holidays have a positive influence on the participants (and volunteers) in some way, as everyone leaves with a smile. And most first-time visitors also leave the boat knowing they are still able to participate in activities such as sailing after their brain injury. However, with regards to the dependence, the post-holiday effects are still limited. Of course, the holiday should stay a holiday and not a rehabilitation camp, but maybe considering options for increasing longer-term dependence might not only fit their vision, but also contribute to the daily lives of the participants.

5.4.2. Future research

- *Happiness and holidays for people with ABI.* Even though the effects on dependence and body image were limited to short-term effects, the happiness when people left was unmistakably present. Unfortunately, ABI is still an under-studied disability in relation to holidays. Therefore, there is never enough research done on happiness and holidays for people with ABI.
- *Concepts of dependence and body image.* Prior feelings of dependence and body image have an influence on how people experience the holiday. Because there is still limited research done on these topics, it would be interesting to look more into the concepts of body image/dependence, either in combination with other disabilities & SailWise, or in combination with ABI but other types of holiday/leisure activities.
- *Correlation between dependency and body image.* Elaborating on the previous recommendation, I would suggest to look more into the relation between dependency and body image. Self-esteem seems to affect both concepts positively, while acceptance creates opposing results. It would be useful to see if this contradicting finding is due to the sample of the study, or if there are external factors that affect the relation between the two concepts.
- *External influences on body image.* The participants concluded that their body image was influenced by ability rather than appearance. However, one of the participants indicated during the trip that he felt less positive about certain body-parts, even though they were functioning better than at home. This seems a bit contradicting at first, but suggests there must be other factors playing a role in body image. It would be interesting to know what these possible factors are.
- *Include more perspectives on the dependence network.* During the first and third interview, the wife of Piet was present to share some of her opinions on her husband's independence. She had mentioned to have a more emotional view towards the network of people than Piet. Here it became clear that there is a difference between one's self-perceived dependence compared to how a third person perceives it. Unfortunately, it was not possible for the other participants to have a family member present. This would be a suggestion for future research, to see if people with ABI have a different perspective on dependence than their family members, and where this difference comes from (is it the person, or a result from the brain damage?). A current study from Tilburg University (Giesbergs, Hendriks, Jahoda, Hastings, Embregts) is using the

perspectives of both people with a mild intellectual disability and an equal number of family members and professional care-takers, on the topic of familial network and emotional support. As this study is not published yet, the framework could not be used in this thesis.

6. Conclusion

The aim of this study was to provide an academic contribution to the existing literature on sailing holidays and ABI, but also to contribute to the Science Shop project of Wageningen University and SailWise. Data collection took place during one of the sailing weeks of SailWise, on the accommodation 'Lutgerdina'. The participants were gathered using the database of SailWise and consisted of three males with acquired brain injuries. Using elicitation methods as a base for semi-structured interviews the concepts of dependence and body image were studied. These creative methods were used to gain a deeper insight into the experiences of the participants themselves, rather than hearing the views of close family or caretakers. In addition to this, three extra first-time visitors of SailWise that fitted into the category of ABI participated in an interview via e-mail. This created the opportunity to look at differences in learning processes and effects of the holiday between first-time visitors and repeat visitors. From the results, some main conclusions can be drawn: these will be further explained in a few sub-sections.

- *ABI is complicated and diverse.* After hearing all the backstories from the participants of the sailing trip and the additional first-time visitors, it became clear that people with ABI are very different from each other. This already starts at the wide scale of causes of ABI: from traumatic accidents to strokes or meningitis. Also the inabilities that follow these brain injuries can differ from paralysation to aphasia and to epilepsy. Some people end up in a wheelchair, some just have trouble talking. The differences can be big and therefore make it difficult to find common ground when you do not have a deep understanding of the medical and/or neurological field.
- *Short term independence.* Participants feel more independent during the trip, mainly because of the freedom the volunteers give them. This boosts the confidence of the participants in their body, and increases the feeling that they do not need help from others. However, only small changes in dependence are mentioned after the holiday. Thus, it can be concluded that the holiday does have a short-term effect on the independence of the participant, but the longer-term effect is minimal.
- *Body image can be influenced by several factors.* The (mal)functioning of the body was indicated as the main influence on body image. However, during the interviews it became clear that also additional aids, such as a wheelchair, can be of great importance to one's self-perception. Being around peers with the same disability can positively or negatively affect the body image, depending on the abilities of both the participant and the peers.
- *Active participation boosts self-esteem.* Participants that joined in the sailing activities realised they were still able to perform such activities, which boosted the confidence in their body and self-esteem.
- *Body image, self-esteem and independence are connected, but not correlated.* A change in dependence influences self-esteem and body image, but vice versa this is not always the case. The concepts are therefore connected to each other, but as this connection is not mutual they are not correlated.

- *The effects are bigger on first-time visitors.* Using the additional first-time visitors to compare their experiences with the repeat-visitors, it revealed that there are more things learnt, which leads to a bigger effect on dependence and body image. Because the holiday is a new experience for the first-timers, there is still more to learn about themselves after they acquired their brain injury. Realising that they could do more than expected, or that they were still able to perform certain activities (i.e. sailing) like they did pre-injury, increased the confidence in their bodies. Repeat visitors had already experienced these learning processes on previous trips, and were thus less affected by this current trip.
- *Happy faces.* Even though only limited changes were noticed after the sailing holiday, which indicates that the positive effects of the sailing holiday are only for the short-term, the participants seemed to not mind. In the end, they all went back home with a smile on their faces. It can be concluded that despite not having longer-term effects on dependence and/or body image, the holiday does bring happiness and satisfaction to the participants.

7. Acknowledgements

It would be a lie if I said these past few months have been 'easy peasy', and that I did it all by myself (before you are checking for plagiarism; I am referring to emotional support). So consider this a reference list 2.0 where I share my gratitude. First of all, I would like to send a massive thank you to Pieterneel Cremers & Meghann Ormond for guiding me through this at times stressing process with their constructive feedback (and also the many cups of tea that have been drunk during the meetings). Secondly, my fellow classmates for helping me with brainstorm sessions, drawing of the visual elicitation images (told you I was going to mention you, Linda!), and motivating me when my brain was buzzing with all but concentration. I would also like to show my gratitude towards my sister, who was my extra spelling- and grammar check when my brain could not read any more words. And finally, the organization that made my data collection possible. I chose the topic because of personal interests for disability tourism – and not because of my hidden sailing talent – but I appreciate how helpful SailWise was: especially the ladies from the administration. Thanks for helping me get in touch with the participants, and sending reminding e-mails on my behalf so that I could remain the good 'guy'. And finally: the crew, volunteers and participants of the Lutgerdina for asking questions about my study, helping me by telling your experiences, and introducing me to the lovely world of sailing.

8. References

- Azulay, J., & Mott, T. (2016). Using Mindfulness Attention Meditation (MAP) with a Mixed Brain injury Population to Enhance Awareness and Improve Emotional Regulation. *Journal of Psychology and Clinical Psychiatry*(6(5)).
- Bagnoli, A. (2009). Beyond the standard interview: the use of graphic elicitation and arts-based methods. *Qualitative Research*(9(5)), 547-570.
- Bailey, K. A., Gammage, K. L., van Ingen, C., & Ditor, D. S. (2017). "My body was my temple": a narrative revealing body image experiences following treatment of a spinal cord injury. *Disability and rehabilitation*(39(18)), 1886-1892.
- Barker, E. T., & Galambos, N. L. (2003). Body dissatisfaction of adolescent girls and boys: risk and resource factors. *The Journal of Early Adolescence*(23(2)), 141-165.
- Barnes, C. (1991). *Disabled People in Britain: A Case for Anti-Discrimination Legislation for Disabled People*. London: British Council of Organisations of Disabled People.
- Barnes, M. (2005). *Caring and social justice*. Palgrave Macmillan.
- Becker, S., & Bryman, A. (2004). Understanding research for social policy and practice: themes, methods and approaches. In S. Becker, & A. Bryman, *Understanding research for social policy and practice: themes, methods and approaches*. Bristol, UK: The Policy Press.
- Blichfeldt, B. S., & Nicolaisen, J. (2011). Disabled travel: not easy, but doable. *Current Issues in Tourism*(14(1)), 79-102.
- Brausch, A. M., & Decker, K. M. (2014). Self-Esteem and Social Support as Moderators of Depression, Body Image, and Disordered Eating for Suicidal Ideation in Adolescents. *Journal of abnormal child psychology*(42(5)), 779-789.
- Brausch, A. M., & Muehlenkamp, J. J. (2007). Body image and suicidal ideation in adolescents. *Body image*(4(2)), 207-212.
- Burns, N., Watson, N., & Paterson, K. (2013). Risky bodies in risky spaces: disabled people's pursuit of outdoor leisure. *Disability & Society*(28(8)), 1059-1073.
- Cash, T. F. (2004). Body image: Past, present, and future. *Body image*(1(1)), 1-5.
- Catran, C. J., Oddy, M., Wood, R. L., & Moir, J. F. (2011). Post-injury personality in the prediction of outcome following severe acquired brain injury. *Brain Injury*(25(11)), 1035-1046.
- Chalk, H. M. (2016). Disability Self-Categorization in Emerging Adults: Relationship With Self-Esteem, Perceived Esteem, Mindfulness, and Markers of Adulthood. *Emerging Adulthood*(4(3)), 200-206.
- Clarke, L. H., Liu-Ambrose, T., Zyla, J. A., McKay, H., & Khan, K. (2005). Being able to do the things that I want to do: Older women with osteoporosis define health, quality of life, and well-being. *Activities, Adaptation & Aging*(29(4)), 41-59.

- Corbin, J. M. (2003). The Body in Health and Illness. *Qualitative Health Research*(13(2)), 256-267.
- Corrigan, J. D., Bogner, J. A., Mysiw, W. J., Clinchot, D., & Fugate, L. (2001). Life Satisfaction After Traumatic Brain Injury. *The Journal of Head Trauma Rehabilitation*(16(6)), 543-555.
- Corrigan, J. D., Smith-Knapp, K., & Granger, C. V. (1997). Validity of the functional independence measure for persons with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation* (78(8)), 828-834.
- Doris, S. F., Lee, D. T., Hong, A. W., Lau, T. Y., & Leung, E. M. (2008). Impact of oral health status on oral health-related quality of life in Chinese hospitalised geriatric patients. *Quality of Life Research*(17(3)), 397-405.
- Filiatrault, J., Arsenault, A. B., Dutil, E., & Bourbonnais, D. (1991). Motor function and activities of daily living assessments: a study of three tests for persons with hemiplegia. *American Journal of Occupational Therapy*(45(9)), 806-810.
- Foley, R., & Kistemann, T. (2015). Blue space geographies: Enabling health in place. *Health & place*(35), 157-166.
- Hersenstichting. (n.d.). *Cijfers over patienten*. Retrieved April 6, 2017, from Hersenstichting: <https://www.hersenstichting.nl/alles-over-hersenen/hersenaandoeningen/cijfers-over-patienten>
- Holzer, L. A., Sevelde, F., Fraberger, G., Bluder, O., Kicking, W., & Holzer, G. (2014). Body Image and Self-Esteem in Lower-Limb Amputees. *PLoS ONE*(9(3)), 1-8.
- Howes, H., Edwards, S., & Benton, D. (2005). Male body image following acquired brain injury. *Brain Injury*(19(2)), 135-147.
- Hua, K. P., Ibrahim, I., & Chiu, L. K. (2013). Sport Tourism: Physically-Disabled Sport Tourists' Orientation. *Procedia-Social and Behavioral Sciences*(91), 257-269.
- Ilmer, E. C., Lambregts, S. A., Berger, M. A., de Kloet, A. J., Hilberink, S. R., & Roebroek, M. E. (2016). Health-related quality of life in children and youth with acquired brain injury: Two years after injury. (20(1)), 131-139.
- Jacobsson, L. J., Westerberg, M., & Lexell, J. (2010). Health-related quality-of-life and life satisfaction 6–15 years after traumatic brain injuries in northern Sweden. *Brain injury*(24(9)), 1075-1086.
- Jumisko, E., Lexell, J., & Söderberg, S. (2005, February). The Meaning of Living with Traumatic Brain Injury in People with Moderate or Severe Traumatic Brain Injury. *Journal of Neuroscience Nursing*(37(1)), 42-50.
- Kaminsky, L. A., & Dewey, D. (2014). The association between body mass index and physical activity, and body image, self esteem and social support in adolescents with type 1 diabetes. *Canadian journal of diabetes*(38(4)), 244-249.
- Keppel, C. C., & Crowe, S. F. (2000). Changes to body image and self- esteem following stroke in young adults. *Neuropsychological Rehabilitation*(10(1)), 15-31.

- Kittay, E. F. (2011). The Ethics of Care, Dependence, and Disability. *Ratio Juris*(24(1)), 49-58.
- Klaver, K., & Baart, A. (2011). Attentiveness in care: Towards a theoretical framework. *Nursing ethics*(18(5)), 686-693.
- Leonhardt, A., Schmukle, S. C., & Exner, C. (2016). Evidence of Big-Five personality changes following acquired brain injury from a prospective longitudinal investigation. *Journal of psychosomatic research*(82), 17-23.
- Liechty, T., & Yarnal, C. M. (2010). The role of body image in older women's leisure. *Journal of leisure research*(42(3)), 443-467.
- Lloyd, M. (2001). The politics of disability and feminism: Discord or synthesis. *Sociology*(35(3)), 715-728.
- Majnemer, A., Shevell, M., Law, M., Birnbaum, R., Chilingaryan, G., Rosenbaum, P., & Poulin, C. (2008). Participation and enjoyment of leisure activities in school-aged children with cerebral palsy. *Developmental Medicine & Child Neurology*(50(10)), 751-758.
- Martin, J. J., Adams-Mushett, C., & Smith, K. L. (1995). Athletic identity and sport orientation of adolescent swimmers with disabilities. *Adapted Physical Activity Quarterly*(12(2)), 113-123.
- McLaren, L., & Wardle, J. (2002). Body image: A life course perspective. *A life course approach to women's health*, 177-194.
- Meltzer, L. J., Johnson, S. B., Prine, J. M., Banks, R. A., Desrosiers, P. M., & Silverstein, J. H. (2001). Disordered Eating, Body Mass, and Glycemic Control in Adolescents With Type 1 Diabetes. *Diabetes care*(24(4)), 678-682.
- Pagán, R. (2015). The contribution of holiday trips to life satisfaction: the case of people with disabilities. *Current Issues in Tourism*(18(6)), 524-538.
- Prideaux, B., Timothy, D. J., & Cooper, M. (2009). Introducing river tourism: physical, ecological and human aspects. In B. Prideaux, & M. Cooper, *River Tourism* (pp. 1-22). CABI.
- Rabiee, P. (2012). Exploring the relationships between choice and independence: experiences of disabled and older people. *British Journal of Social Work*(43(5)), 872-888.
- Reindal, S. M. (1999). Independence, dependence, interdependence: Some reflections on the subject and personal autonomy. *Disability & Society*(14(3)), 353-367.
- Söderback, I., & Ekholm, J. (1992). Medical and social factors affecting behaviour patterns in patients with acquired brain damage: a study of patients living at home three years after the incident. *Disability and rehabilitation*(14(1)), 30-35.
- SailWise. (n.d.). *Waar wij voor staan*. Retrieved April 8, 2017, from Sailwise: <https://sailwise.nl/nl/over-sailwise/visie-missie>

- Salvador-Carulla, L., & Gasca, V. I. (2010). Defining disability, functioning, autonomy and dependency in person-centered medicine and integrated care. *International Journal of integrated care*(10(5)), 69-72.
- Saugeres, L. (2011). (Un)accommodating disabilities: housing, marginalization and dependency in Australia. *Journal of Housing and the Built Environment*(26(1)), 1-15.
- Sevenhuijsen, S. (1998). Citizenship and the ethics of care: Feminist considerations on justice, morality, and politics. Psychology Press.
- Sohlberg, M. M., & Mateer, C. A. (2001). Cognitive rehabilitation: An integrative neuro psychological approach. In M. M. Sohlberg, & C. A. Mateer, *Cognitive rehabilitation: An integrative neuro psychological approach* (pp. 25-59). New York: Guilford Press.
- Taleporos, G., & McCabe, M. P. (2002). Body image and physical disability—personal perspectives. *Social science & medicine*(54(6)), 971-980.
- Trainor, S., Delfabbro, P., Anderson, S., & Winefield, A. (2010). Leisure activities and adolescent psychological well-being. *Journal of Adolescence*(33(1)), 173-186.
- Tronto, J. C. (1993). Moral boundaries: A political argument for an ethic of care. Psychology Press.
- Valentine, G., & Harris, C. (2014). Strivers vs skivers: Class prejudice and the demonisation of dependency in everyday life. *Geoforum*(53), 84-92.
- Wise, E. K., Mathews-Dalton, C., Dikmen, S., Temkin, N., Machamer, J., Bell, K., & Powell, J. M. (2010). Impact of traumatic brain injury on participation in leisure activities. *Archives of physical medicine and rehabilitation*(91(9)), 1357-1362.
- Yau, M. K., McKercher, B., & Packer, T. L. (2004). TRAVELING WITH A DISABILITY More than an Access Issue. *Annals of Tourism Research*(31(4)), 946-960.
- Yeates, G. N., Gracey, F., & Mcgrath, J. C. (2008). A biopsychosocial deconstruction of “personality change” following acquired brain injury. *Neuropsychological Rehabilitation*(18(5-6)), 566-589.
- Young, I. M. (2000). Five faces of oppression. In M. Adams, W. J. Blumenfeld, R. Castaneda, H. W. Hackman, M. L. Peters, & Z. X., *Readings for diversity and social justice: An anthology on racism, sexism, anti-semitism, heterosexism, classism, and ableism* (pp. 35-49). London: Routledge.
- Zunzunegui, M. V. (2011). Evolución de la discapacidad y la dependencia. Una mirada internacional . *Gaceta Sanitaria*(25), 12-20.

Appendix 1: Inquiry letter

Beste (toekomstige) zeiler!

Mijn naam is Saskia, ik ben 23 jaar en kom uit Arnhem. Ik studeer toerisme in Wageningen en zit nu in mijn laatste jaar. Verder hou ik van volleybal, voetbal kijken en gezellig met mijn vrienden kletsen.

Voor mijn studie ga ik onderzoek doen tijdens een SailWise vakantie op de Lutgerdina. Ik ben nu druk bezig met informatie lezen om mij hier op voor te bereiden,



maar voor dit onderzoek heb ik ook jullie hulp nodig! Het onderwerp van mijn onderzoek zal namelijk gaan over hoe mensen met niet-aangeboren hersenletsel een zeilvakantie ervaren. Super interessant dus! Om dit tot een goed einde te brengen, en genoeg informatie te krijgen, wil ik graag met je afspreken. Eenmaal voor de vakantie, tijdens de vakantie en eenmaal na afloop van de vakantie; precieze data hiervoor doen we uiteraard in overleg. Mocht je nu denken: kan ik wel vakantie vieren als ik hier aan mee doe, dan zal ik je gerust stellen: de vakantie staat voorop, we zullen voornamelijk een super gezellige vakantie week hebben samen met heel veel zeil- en ontdekkingsplezier en zo nu en dan even samen zitten voor een gesprekje. Maar als je daar even geen zin in hebt, kun je dat gewoon aangeven en doen we het op een moment dat jij er wel weer zin in hebt. Het is geheel vrijblijvend, maar uit eerdere ervaringen blijkt dat deelnemers het ook vaak erg leuk vinden om mee te werken en een bijdrage te leveren aan de toekomst van deze belangrijke soort vakanties. Mocht je na het lezen van bovenstaande informatie nog steeds denken dat je geen interesse hebt om mee te doen met het onderzoek dan is dat ook prima, dan zien we elkaar als medereizigers tijdens de reis en maken we er op die manier een mooie tijd van.

Ik zou het fijn vinden als je iets van je kunt laten horen, zodat ik mij goed kan voorbereiden. Wil je uit de onderstaande opties kiezen, en dit in een reactie terugsturen naar dit e-mail adres? Alvast bedankt, en tot ziens ☺

Groetjes, Saskia

(voor vragen kun je me een mailtje sturen op saskia.peters@wur.nl)

*** Dit formulier is nog niet het officiële toestemmingsformulier, deze zal je krijgen voor de eerste afspraak! ***

- Ik wil liever niet deelnemen met het onderzoek
- Ik wil misschien deelnemen met het onderzoek, maar heb eerst nog een paar vragen voordat ik een besluit maak
- Ik wil deelnemen met het onderzoek en wacht vol spanning af op meer informatie!

Appendix 2: Translated quotes from transcripts

R = Respondent, FT = First Time participant

Resp.	#reference:	Dutch:	English:
R01: H	H01	En daar moet ik het mee doen	It is something I have to deal with
	H02	M'n zus is onderhand een 2 ^e moeder voor me	My sister is like a second mom
	H03	Nee, ik ben nou geen moeilijk persoon. Als iedereen gewoon naar me praat, is iedereen m'n vriend.	No, I'm not a difficult person. If everyone just talks to me, then everyone is my friend.
	H04	Ja dat heb ik wel, veel meer afhankelijk. Want in de andere stoel deed ik altijd zelf. Dan kon ik bij wijze van spreken naar Stavoren, waar we vanmiddag geweest zijn. Dan kon ik altijd zelf naar toe rijden. Maar nu ben ik verplicht om te laten duwen. Dat vind ik wel knap van die mannen want ik ben niet een van de lichtste door alle medicijnen-troep die ik slik	Yes, I feel more dependent. Because in the other chair I would drive myself. Then, for example, I could go to Stavoren where we went today. Then I could have driven myself. But now I am required to let someone push me. I admire the guys (volunteers) for that, because I am not one of the thinnest due to all the medicines I have been taking
	H05	Die is alleen maar sterker geworden, omdat ik die ander niet meer gebruik. Ja, ik kan er nog wel even op staan maar ik kan er niet mee fietsen ofzo. Dan blijft ie rechttuit staan. Dus ik doe alles met links. Ik ben eigenlijk optimaal links geworden.	(my left foot) has only become stronger. Because I do not use the other one anymore. Yes, I can still stand on it for a short while but I cannot bike with it or something like that. Then it stays the same way. So I do everything with left. Basically, I turned fully left.
	H06	Ja, maar als ik iets mee begin, wil ik het uiterste eruit hebben. Ook al loopt het water over m'n hoofd heen...	Once I start with something I want to get the most out of it. Even if this means water is running down my head
	H07	Dat bevalt me prima. Dan heb ik echt vakantie. Dan hoef ik niet naar Spanje; als je me op water kan zetten en het is mooi weer dan voel ik mij al thuis.	I really like it. Then I really have holidays. I don't need to go to Spain: if you put me on the water and the weather is nice I already feel at home
	H08	Want zij heeft d'r eigen leven	They have their own lives
R02: W	W01	Ja dat weet ik van tevoren he.	You sign up for it
	W02	Daar houd ik het maar op.	I'll leave it at that

R03: P	P01	Dat wil een mens gewoon niet. Ja, op termijn misschien. Maar voorlopig niet.	No-one wants that. Yes, maybe in the long-term. But not in the near future
	P02	Ja dat moeten ze maar vooral denken, ze zoeken het maar uit	I am not affected by other people's opinions. They can think whatever they want
	P03	Maar ik werk weleens in de keuken, vaatwasser inpakken en aardappels schillen. Maar dat gebeurt allemaal heel rustig, en dan kan ik ook heel rustig met m'n zakmes de aardappel beetpakken. En op die boot is alles in beweging dus dat zag ik niet zitten. Bovendien, als ik 1 hand heb om de vaat vast te houden dan heb ik de ander maar dat wil niet.	At home I help out with things (...), but that all happens really calmly, and I have enough time to use my knife to grab a potato. But on the boat everything was moving, so I was not feeling that. Besides that, when I have only one arm to both hold something and hold my balance when walking...
	P04	In het begin moest ik nog een beetje geholpen worden, maar uiteindelijk kon ik zo in 1 streep over het scheepsdek lopen. Nee, dat gaf mij wel vertrouwen hoor.	In the beginning I still needed some help, but in the end I could walk from the back to the front of the deck in one go. Well, that gave me confidence
	P05	Ja en kijk je hebt nu goeie bemanning, goeie begeleiders tegen wie je wat kan aanpraten en kan werken naarmate je kan, nou ik vind dat al vreselijk goed.	Look, you have a well-qualified crew, good volunteers who you can talk to and you can work according as you can, well, I think that is already incredibly good
Wife R03	WP01	Maar ik denk dat jij het wel net zo hard voelt, maar dat is gewoon zo. De ene persoon vult het in, maar die kan dat andere wel voelen, maar dat is dan gewoon een wat zakelijker persoon, dat heeft ook wel met je persoon te maken of met je werk wat je hebt gedaan. Want voor jou zijn hun niks minder belangrijk dan voor mij.	I think you feel it the same way, that is the way it is. One person fills it in, and you can feel the other things but that might just be a more formal person, that also depends on who you are as a person. Because they are not less important to you than to me
FT01:	FT01	Ik kreeg veel meer steun en vertrouwen van de vrijwilligers dan ik gewend ben bij de instelling waar ik woon	I get a lot more support and confidence from the volunteers, than at the assisted living facility where I live
FT02:	FT02	De onderlinge verschillen waren zo groot dat erg geen sprake was van een groep, daarentegen heeft iedereen individueel wel erg genoten!!	The differences between the participants were too big to call it a group, however everyone individually did enjoy the trip very much!

Appendix 3: Elaboration on methods

3.1 Relational map

Colours used:

Red = I am only dependent on the other person (one-way dependency);

Blue = the other person is only dependent on me (one-way dependency);

Green = the other person and me are both dependent on each other (mutual dependency)

3.2 Visual elicitation

Colours used:

1 = red: Very unsatisfied (in my opinion, it is useless);

2 = orange: Slightly unsatisfied (it could be worse, but I would love to see improvement);

3 = brown: Neither unsatisfied nor satisfied (I feel neutral about it);

4 = blue: Slightly satisfied (It could be better, but it is sufficient)

5 = green: Very satisfied (I would not change anything)

Body parts that are asked to be coloured in

- Head
- Eyes
- Mouth
- Heart
- Right arm
- Right hand
- Left arm
- Left hand
- Right leg
- Right foot
- Left leg
- Left foot

Appendix 4: Inquiry mail first-time visitors SailWise

Hallo (oud-) zeilers van SailWise!

Mijn naam is Saskia Peters, ik ben 23 jaar en studeer momenteel Toerisme in Wageningen. Voor mijn afstudeer-onderzoek kijk ik naar de effecten van een zeilvakantie van SailWise. Zelf ben ik recentelijk als vrijwilliger mee geweest tijdens een NAH-week op de Lutgerdina; dit was zeer gezellig, maar bovenal interessant voor mijn studie! Ik zou graag iets meer verhalen horen van mensen over hun eerste deelname, en vroeg mij af of jij mij hier misschien mee wilt helpen. Dit kan door binnenkort een keer kort te Skypen/Facetimen, of door een mailtje te sturen naar SailWise of mijn eigen adres (zie onderaan); het liefst vóór 17 juli. Je kunt dus zelf bepalen hoe anoniem je wilt blijven; namen zullen altijd aangepast worden. Je gaat wel akkoord dat ik je ervaring mag gebruiken en beschrijven in mijn verslag.

“Dus, wat wil je precies weten?”

Wat uit mijn onderzoek tot nu toe is gebleken, is dat de zeilvakantie aan de deelnemers laat zien hoe goed hun lichaam nog werkt, en wat er nog allemaal wél kan. Ook is het voor mensen die recentelijk hun hersenletsel hebben opgelopen, soms nog een stukje verwerking en acceptatie. Ik ben daarom erg benieuwd hoe jij dit alles hebt ervaren!

Daarnaast is het fijn om te weten
wat je huidige leeftijd is
op welke leeftijd je het hersenletsel hebt gekregen (of hoelang je het hersenletsel al ongeveer hebt)
of er nog verdere beperkingen zijn die meespelen (vb. Epilepsie, MS).

Mochten er vragen tussen zitten die je liever niet beantwoord, dan is dit uiteraard geen probleem.

Ik hoop dat deze uitleg duidelijk is en dat je mee wilt helpen; mocht je vragen hebben, stel deze gerust!

Groetjes,

Saskia Peters

(saskia.peters@wur.nl)

Appendix 5: Information letter

Hallo medereizigers en/of ouders/verzorgers,

Wat leuk om te horen dat je interesse hebt om mij te helpen met mijn onderzoek! In de vorige brief heb ik al kort iets over mijzelf vertelt; in deze brief zal ik iets specifieker ingaan op het onderzoek zelf. Het is belangrijk dat je dit goed leest, en daarna het toestemmingsformulier ondertekent; zowel jijzelf als je ouder/verzorger, waar nodig. Mocht je nog vragen of opmerkingen hebben na het lezen van deze brief, stuur me gerust een mailtje!

Saskia Peters

Saskia.peters@wur.nl

Het onderwerp

Het project is in samenwerking met SailWise en mijn universiteit, in Wageningen. Ze willen graag weten wat de waarde is van een vakantie van SailWise. Daarom ga ik, net als drie klasgenoten, SailWise hierbij helpen door allemaal een specifiek onderzoek uit te voeren.

Mijn onderzoek zal gaan over de effecten van een zeilvakantie op de manier waarop je naar jezelf kijkt, met de focus op mensen met niet-aangeboren hersenletsel. Maakt een vakantie je onafhankelijker, en stijgt het vertrouwen in je eigen lichaam met zo'n vakantie? Door het meedoen aan dit onderzoek help je niet alleen mij met afstuderen, maar kun je ook SailWise helpen doordat zij met mijn resultaten hun vakanties nóg beter kunnen maken ☺.

Wat kun je verwachten?

Om goed te kunnen zien wat het effect is van het deelnemen aan de vakantie, wil ik graag meerdere keren afspreken. 2-4 weken voor start van de vakantie, tijdens de vakantie op de Lutgerdina (12-16 Juni), en zo'n 2 weken na afloop. Het eerste onderzoek zal iets langer duren dan de andere keren, aangezien we hier de basis maken voor de andere twee momenten. Ik wil je graag vragen om van tevoren een tekening, die ik zal opsturen, in te kleuren. Het gebruik van kleurtjes zal gaan op basis van hoe jij je voelt ten opzichte van dat deel van je lichaam. Ook wil ik, samen met jou, een tekening maken van jou en je sociale netwerk. Op basis van de ingekleurde tekening en de tekening van het sociale netwerk, gaan we een gesprek voeren.

Tijdens en na de vakantie zal ik je niet opnieuw vragen om beide tekeningen te maken; wel zullen we weer een gesprek voeren over dingen die je zou aanpassen. Dit om er voor te zorgen dat je niet de hele vakantie bezig bent met het onderzoek, maar vooral van je vakantie geniet!

Rechten als deelnemer

Nu je weet wat ik van jou verwacht, is het belangrijk om te weten wat jij van mij kunt verwachten. Het belangrijkste is dat je deelname op vrijwillige basis is. Dus als je even geen zin hebt om te kletsen, dan is dat helemaal oke! Ook als je tijdens het gesprek een pauze wilt, ergens geen antwoord op wilt geven, of een ander probleem ziet, dan is het belangrijk dat je het mij vertelt. Dan kunnen we namelijk samen kijken hoe we het oplossen! Het plezier van de vakantie staat namelijk voorop! Mocht je besluiten om te willen stoppen tijdens het onderzoek, dan is dat geen probleem. Hier zullen geen consequenties aan zitten.

Vertrouwelijke informatie

Het onderzoek is geen geheim, dus vertel vooral aan je familie en vrienden waar je mee bezig bent! Ik doe namelijk hetzelfde ☺. Aangezien er persoonlijke informatie gedeeld wordt met mij, zal ik je naam aanpassen in het verslag. Als je wilt, mag je mij helpen met het verzinnen van een naam! Ook in het geval van foto's of tekeningen die gebruikt worden in het verslag, zal ik herkenbare details zoals namen aanpassen.

Het fijnste is om tijdens het gesprek op te nemen, zodat ik dit later kan terugluisteren en makkelijker uit kan schrijven. Hiervoor vraag ik altijd eerst toestemming! Naast mijzelf zullen alleen mijn begeleiders toegang hebben tot deze gesprekken.

De informatie die ik vanuit de gesprekken krijg, zal alleen gebruikt worden voor mijn eindverslag. Dit eindverslag zal beschikbaar komen voor (de bibliotheek van) Wageningen Universiteit, SailWise, jijzelf en waar toepasbaar de ouders/verzorgers.

Ik hoop dat het allemaal een beetje duidelijk is, en dat jullie zin hebben in de vakantie. Ik in ieder geval wel! Mochten er na het lezen van deze brief nog steeds vragen zijn dan hoor ik dat graag.

Groetjes,
Saskia Peters

Appendix 6: Consent form

Toestemmingsformulier onderzoek Lutgerdina

Voordat we van start kunnen gaan met het onderzoek, is het verplicht om mondeling en schriftelijk toestemming te geven voor deelname. Hiermee geef je aan te snappen welke rechten jij als deelnemer hebt, en dat je genoeg informatie hebt ontvangen van mij. Zou je dit formulier goed willen lezen en ondertekenen? En vergeet niet, stoppen mag altijd!

Jonger dan 18 jaar, of heb je een verzorger? Zorg dan dat zij ook hun toestemming geven door middel van een handtekening!

Titel onderzoek: Het effect van een zeilvakantie op hoe mensen met niet-aangeboren hersenletsel naar hun (on)afhankelijkheid en lichaam kijken

Verantwoordelijke onderzoeker: Saskia Peters
Student
Bsc Tourism
Wageningen Universiteit

Door het ondertekenen van dit formulier ga ik, de deelnemer, akkoord dat ik...

- ✓ begrijp dat het meehelpen aan dit onderzoek op vrijwillige basis is;
- ✓ begrijp dat ik op ieder moment vragen mag stellen aan Saskia als ik iets niet snap, of meer wil weten;
- ✓ begrijp dat ik op ieder moment mag stoppen met deelname aan het onderzoek, zonder dat dit consequenties heeft;
- ✓ begrijp dat informatie die ik tijdens het onderzoek tegen Saskia vertel, door haar gebruikt kan worden in het verslag dat door haar geschreven wordt;
- ✓ begrijp dat namen niet genoemd zullen worden in het verslag;
- ✓ begrijp dat tekeningen en/of andere visuele afbeeldingen gebruikt kunnen worden in het verslag. Ook hier zullen kenmerken worden aangepast waar nodig;
- ✓ begrijp dat er eerst om toestemming moet worden gevraagd voordat een afbeelding kan worden gebruikt voor andere redenen dan het verslag;
- ✓ genoeg informatie heb ontvangen van Saskia over het doel van het onderzoek en de onderzoeksmethoden;

Naam deelnemer: _____

Handtekening deelnemer: _____ **Datum:** _____

Handtekening ouder/verzorger (waar nodig): _____ **Datum:** _____

In te vullen door de verantwoordelijke onderzoeker

Ik heb de deelnemer – en waar nodig de ouder/verzorger – geïnformeerd over het doel, methoden en resultaat van het onderzoek, en de rechten van de deelnemer tot het weigeren van deelname, zonder dat dat enige consequenties zal hebben. Ik stem in dat ik ten alle tijden vragen zo goed mogelijk zal beantwoorden, zowel voor, tijdens als na het onderzoek.

Naam onderzoeker: Saskia Peters

Handtekening onderzoeker: _____ **Datum:** _____

Appendix 7: Decoded visuals

7.1.1 Dependencies Hendrik (in order of importance)

<i>Person</i>	<i>Dependency</i>	<i>Characteristic</i>
1: Sister 1	Mutual	Arranges finances, eating together, visiting
2: Aunt	Mutual	Eating together, visiting
3: Personal mentor living facility	One-way	Good conversations
4: Caretaker living facility	One-way	Good conversations
4: Sister 2	One-way	Talking on FB but not visiting
4: Taxi driver	One-way	Talking while driving to the activity centre

7.1.2 Body image Hendrik

Head	4
Eyes	3
Mouth	4
Heart	5
Right arm	4
Right hand	4
Left arm	2
Left hand	2
Right leg	4
Right foot	4
Left leg	2
Left foot	3
Total:	3
Average:	3,42

7.2.1 Dependencies Willem (in order of importance)

<i>Person</i>	<i>Dependency</i>	<i>Characteristic</i>
1: Sister	Mutual	Arranging things like holiday
1: Father	Mutual	Visiting each other every week and playing cards
2: Brother-in-law	Mutual	Taking care of taxes

7.2.2 Body image Willem

Head	3
Eyes	3
Mouth	3
Heart	3

Right arm	5
Right hand	5
Left arm	5
Left hand	5
Right leg	5
Right foot	5
Left leg	5
Left foot	5
Total:	4
Average:	4,33

7.3.1 Dependencies Piet (as viewed by Piet, in order of importance)

<i>Person</i>	<i>Dependency</i>	<i>Characteristic</i>
1: Wife	Mutual	She is everything
2: Son 1	Mutual	Family-relation
2: Son 2	Mutual	Family-relation
2: Physical therapist	Mutual	Contract
2: Speech therapist	Mutual	Contract
2: Occupational therapist	No judgement yet	Contract

Dependencies Piet (as viewed by Piet's wife, in order of importance)

<i>Person</i>	<i>Dependency</i>	<i>Characteristic</i>
1: Wife	Mutual	Everything
1: Son 1	Mutual (but more towards orange than towards blue)	Son is less dependent on parents than vice versa
1: Son 2	Mutual (but more towards orange than towards blue)	Son is less dependent on parents than vice versa
2: Cluster of therapists	Mutual	Medical importance
2: Cluster of friends	Mutual	Emotional support
2: Cluster of other second-degree family members	Mutual	Emotional support

7.3.2 Body image Piet

Head	5
Eyes	5/2 (left-eye)
Mouth	5/2 (right-corner)
Heart	5
Right arm	5
Right hand	5
Left arm	1
Left hand	1
Right leg	5
Right foot	5
Left leg	2/3 (getting better)

Left foot	2
Speech	2
Total:	4
Average:	4,07 – 3,54