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Everyone is a variation of normal

Adolescents' experiences of having impaired arm function because of a birth injury

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Abstrakt

Syftet med studien var att studera ungdomars erfarenheter av att leva med en plexusskada, det vill säga nedsatt armfunktion på grund av en förlossningsskada, ur ett psykosocialt perspektiv med fokus på hur ungdomarna upplever sina liv beträffande studier, fritid och relationer, upplevelser av begränsningar i jämförelse med generationskamrater på grund av skadan, samt erfarenheter av sjukvården. Åtta ungdomar som opererats för skadan intervjuades. Genom kvalitativ fenomenologisk analys kunde följande meningsbärande enheter urskiljas: *'Jag och andra'*; *'Professionella kontakter och erfarenheter'* och *'Anpassningar och strategier till lösningar och hinder'* där *'Funktionshindrad eller ha funktionshinder'*; *'Då och nu'* samt *'Brist på referenser'* var gemensamma samtalsämnen. Resultatet visade att ungdomarna inte betraktade sig som handikappade, de fokuserade inte på sin arm i sin vardag, och önskade klara av mer fysiska aktiviteter. De upplevde gott stöd från sjukvården, men önskade uppföljningar och mer riktad information. De hade anpassat sig till skadan, men upplevde att de inte kunde jämföra med andra eftersom de haft skadan sedan födseln. Att kunna förstå ungdomars erfarenheter av att leva med en plexusskada, är nödvändigt för att förbättra vården och bemötandet för dessa individer.

183 ord.

Nyckelord:

Plexus Brachialisskada, Ungdom, Kvalitativ, Upplevelse, Förbättring av sjukvård, Psykosocialt perspektiv

Abstract

The aim of the study was to examine adolescents' experiences of having brachial plexus birth palsy, which is impaired arm function due to a birth injury. Psychosocial focal points were how the adolescent's experience their lives concerning studies, spare time activities and relationships, experiences of limitations in comparison to their peers, and how they experience health care. Eight adolescents who had surgery of the injury were interviewed. Through qualitative phenomenological analysis the following meaning units were identified: '*Me and others*'; '*Professional medical contacts and experiences*'; and '*Adjustment and strategies to solutions and obstacles*' with essences '*Disabled or have a disability*'; '*Then and now*' and '*Lack of references*'. The result showed that the adolescents did not identify themselves as disabled, and did not focus on their arm, but wished for improved physical function. They had good support from health care, although wanted more follow-ups and more aimed information. They had adjusted well to their injury, but did not have any comparisons as they had their injury since birth. Understanding the experiences adolescents with BPBP have is essential for advancing the care of these individuals. Further research is necessary regarding the experience people with this injury have.

Words: 195

Keywords:

Brachial Plexus Birth Palsy, Adolescent, Qualitative, Experience, Health Care Improvement, Psychosocial perspective

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1. Presentation of topic and aim of the study

Traumatic injuries to the nerves of the upper extremity are relatively common and often lead to significant disabilities with palsy/weakness, pain, psychological suffering and long periods of sick leave with subsequent economic and social consequences. A special situation is a tear injury of the nerves in the brachial plexus, which is in the neck and shoulder area. It is a rather uncommon injury, but in its most serious form has devastating effects on the injured extremity. The largest patient group with this injury is children who are injured during a difficult birth. This injury, often called *obstetric plexus injury* or *brachial plexus birth palsy* (BPBP), occurs in 2-3/1000 births in countries with good birth care. This corresponds to approximately 250 children a year in Sweden, 50-60 of whom get lasting problems such as disability of motion, weakness and misalignment in joints (Hultgren, 2013). Surgery on these patients has been done since 1902 (Kennedy, 1903).

The BPBP is often partial and will often heal in a benign way, but residual significant functional disabilities are common, particularly in the shoulder joint. The most common disability; approximately fifteen persons a year in Sweden, is a rotation deformity in the shoulder joint where surgical correction is necessary – this is the target group for this study. The rotation deformity places the shoulder, and hence the arm, in an inwardly twisted position. Statistics from the department of Hand surgery at Södersjukhuset, Stockholm shows that up to forty percent of the children with this deformity also have a dislocation (luxation) of the shoulder joint.

Based on the viewed literature in the field, one can conclude that there is a lack of references regarding the psychosocial focus of this patient group and hence, it is valuable to perform a study about the experiences that adolescents with BPBP have. To perform a study with focus on the experiences of adolescents with this injury would have many advantages. It would aid medical professionals, habilitation personnel, rehabilitation therapists, social workers, patients and their families throughout the process of planning the surgery, and may help to modify the existing support supplied - based on the individual patients' concerns and needs. The health care can integrate the experiences from previous patients, to achieve a greater understanding of what is requested in surgeries to come. A study of this character will be a means to

provide knowledge about the perspective of the individuals in this rather small patient group. This study focuses on when individuals are in the end of their teenage years and the main object is to understand the experiences of the individuals with body impairment after a brachial plexus birth palsy. When reaching their adolescent years, faced with limitations in body function while in the transition from a child to becoming an adult, what are the issues related to having an injury, during this process.

The British dictionary defines adolescence as the transitional period between puberty and adulthood in human development, extending mainly over the teen years and terminating legally when the age of majority is reached. The words ‘adolescent’, ‘youth’ and ‘teenager’ will be used synonymously throughout the text for variation. Youth is considered to be a generational category with its own cultures, identities and agencies (Priestley, 2003). The concept of youthfulness is identified as a significant cultural marker in disabling constructions of the perfectible body. Youth is a significant age category that lies somewhere between childhood and adulthood. However, young people take on the responsibilities of adulthood at different ages in different societies, so age does not merely describe youth. It is the timing, duration and social organization of these transitions that characterize much of what we understand as youth. In the adolescence years, much of the identity is formed (Priestley, 2003). Identity is defined as condition or character as to who a person or what a thing is; the qualities, beliefs, etc., that distinguish or identify a person or thing, according to the British Dictionary.

Aim and research questions

As this study focuses on the following experiences; the adolescents’ experiences of function, ability and disability, how the adolescents experience the injury’s consequence on everyday life and social interactions, the adolescents’ psychological- and body image, as well as the experience that the adolescents have of the healthcare input they have received, it has an explicit user perspective (Bergmark and Lundström, 2006).

In social work, there is an interest in different populations and how different factors affect the wellbeing of these people. For social workers at a somatic hospital, it is of importance to see how the somatic symptoms and care have an impact on the person, their health and their psychosocial situation

(National Association of Social Workers, 2016). A social worker often comes in contact with adolescents, and it is during this age much of the person's identity is made, even though the identity process does not start nor ends at adolescence (Marcia, 1980). The researcher is employed at the clinic where the research is taking place, as a social worker and counselor, and thus getting access to the material of previous research, medical records and respondents. However, the researcher never met the respondents prior to or after the study in the role of a social worker. So far, we have limited knowledge about this patient group with a psychosocial focus. Research with a user perspective where patients with BPBP are listened to as informants and regarded as to hold valuable information in relation to medical health care is necessary and important.

The specific aim of this study is to get improved knowledge about the life situation of these persons and their experiences of and due to their BPBP injury. Thereby, it may be possible to improve the medical caretaking and increase the participation of the patients in the healthcare. For example, the healthcare can focus on interventions based on what the patients prioritize, avoid or adjust treatment situations that are thought of as negative, efficiently support the individuals and their families psychologically and socially, and plan follow-ups and rehabilitation programs which encourage participation and motivation. The following questions are expected to help provide answers to the study:

1. How do the adolescents experience their lives with respect to studies, spare time activities, relationships – with peers and others, and quality of life?
2. Do they experience any limitations compared to their peers due to the BPBP injury? If so, how?
3. How do the adolescents experience their health care, is there something that could have been done differently?

After this introduction, a presentation of the field of knowledge will be followed. Following, theoretical considerations and the conceptual framework will be addressed. Method, ethical considerations, results, analysis, and discussion will thereafter be presented in separate chapters. The thesis will end with a chapter of conclusion; involving a summary of the text and suggestions for further praxis and research.

2. The field of knowledge

Introduction

Brachial plexus birth palsy can have a significant impact on the function of the arm. The main reason for the injury is that the shoulders of the infant are stuck in the birth canal at delivery. This can cause partial or total rupture of the nerves in the plexus area, which is in the neck and shoulder region. Normally, this rupture is restricted to some of the spinal nerves, and these injuries tend to heal spontaneously. The most serious injuries involve all spinal nerves, which lead to paralysis of the whole limb, including the hand. A majority of the birth related plexus injuries recover spontaneously, but if the recovery is not complete within two to three months, there will generally be a palsy and weakness to some extent in the arm (Hultgren, 2013). Some of these children undergo surgical interventions to improve their arm function. Having a psychosocial focus on patients in healthcare is in line of holding a holistic view of the person treated for different somatic injuries, illnesses or conditions (McEvoy and Duffy, 2008). Aligned with modern view on medical healthcare, as well as legislative demands (Hälso- och sjukvårdslagen, 1982:763), it is important to focus on the perspective of the patient (Frampton and Guastello, 2014, Campbell et al., 2002) and consider one's demands, requests, wishes and opinions regarding their situation related to the specific issues as why they are patients at a hospital. The following introductory review of knowledge is based on research with psychosocial perspectives on disability, ableness and, normality in relation to adolescence and on what is known in medical research about surgery on brachial plexus birth palsy.

Ability and disability

Disability is described as the condition of being unable to perform a task or function because of a physical or mental impairment, and consequence of an injury or a disease which leads to a handicap, only if changes in the surrounding environment cannot compensate for it, according to the British Dictionary. Youth groups are well represented in research from a psychosocial point of view and much research have been made regarding youth's specific social problems and terms (i.e Stone et al., 2012, Reijntjes et al., 2010, Metzger et al., 2011) where we can see that different challenges have an impact on the psychological

and social wellbeing. In conclusion, there have been several studies published regarding illness experience and the effect of a specific illness, but very few articles focus on the 'health experience' and have a focus on insider's orientation dealing with the perspective of the people directly concerned, chronic illness and the material, affective and subjective consequences of the illness on how people organize their lives and interpret what is happening to them (Pierret, 2003). Furthermore, youths with impairments have in various studies been shown to feel a sense of belonging with their peers with the same condition (i.e Magen, 1990). Many studies regarding disability and normality have been made, for example Hansen and Philo (2007), which showed that people with disabilities experience pressure to pass as normal, to perform in a manner corresponding to as closely as possible to an able-bodied way of doing things, all of which perpetuate a great disjunction for them between their actual bodies and the bodies that they feel others think they should have, in order to pass as normal. However, it is important to shift the emphasis from (aiding disabled people in) *doing things 'normally'* to (underlining for all of 'us'), the *normality of doing things differently* (Hansen and Philo, 2007).

Previous research has shown that the dominant notions about the abled body are embedded in discourses concerning sports and physicality (van Amsterdam et al., 2015). Ableism is the attitudes and views of able-bodied people toward disabled people and is based on the (often implicit) assumption that the world should be tailored to those without disabilities (Duncan, 2001, Wendell, 1996). Adolescents with disabilities position themselves in alternative discourses, for example stating 'everyone is different, everyone is normal' and hence positioning one's disabled self as different and normal simultaneously. By resisting the norm of ableness, this person could accept her disability as part of oneself. Other participants normalized their disabled bodies by trying to pass as able-bodied. They tried to minimize and/or hide their disability. By doing this they reproduced ableist discourses about sport and physicality, according to the authors. Mainstreaming disabled students into ordinary school system and thus to mainstream sports, enhances the visibility and participation of physically disabled students. Nevertheless, mainstreaming also draws attention to the marginal position these students commonly occupy in their educational environment because they are few in number and often have difficulty

participating in physical activities available in schools, which are created as normal and important for youth in general (van Amsterdam et al., 2015).

Psychosocial aspects on physical injuries and chronic illnesses

The social context of chronic illness relates to health policy and the roles played by patients' associations, consumerism, charities and the media. There is a clear distinction between different concepts when discussing illness and disability; 'coping' refers to cognitive processes, 'strategy' to the actions people take, and 'style' to the way people respond (Bury et al., 1991). Adolescents with cerebral palsy (CP) are reported to have decreased quality of life as well as health related quality of life compared with a normative population without impairments. However, variations in physical condition do not necessarily correlate with psychosocial wellbeing (Livingston et al., 2007).

Though, in adjacent fields, there are some studies with valuable information about how young patients experience different body impairments in daily life (i.e Erosa et al., 2014, Metzger et al., 2011, Pakenham, 1999, Shikako-Thomas et al., 2009, Stiffman et al., 1999, Tsao et al., 2007, Wolke et al., 2013) and further studies of how the influence of support groups is important for young women with physical impairments and their sense of belonging (Mejias et al., 2014). Supplementary studies with focus on disability and adolescents studied health and quality of life in children with ventilator dependency (Noyes, 2006). Social and leisure provision supported young people with language impairment (Myers et al., 2011). Neuro-developmental outcome, psychological adjustment, and quality of life in adolescents with congenital heart disease have also been studied (Schaefer et al., 2013), as well as the quality of life of adolescents and young adults born at high risk (Dahan-Oliel et al., 2011) and how patients with a locked-in syndrome integrate bodily changes in experienced identity (Nizzi et al., 2012).

The treatment of brachial plexus injuries

Research has been done on the set clinic regarding surgical treatment of brachial plexus injuries (Hultgren et al., 2014, Hultgren et al., 2013, Hultgren, 2013, Westin et al., 2012, Hultgren et al., 2010, Carlstedt et al., 2009, Einarsson et al., 2008, Carlstedt et al., 1991). These studies have not primarily been made with qualitative objectives; but rather with quantitative methods regarding the hand

and arm function of these patients and the effects of surgical treatment. Previous clinical studies at the set clinic (Hultgren et al., 2014) have shown that the rotation deformity of the shoulder can be treated surgically. A significant increase in both movement and function can be seen, both in the short term and in the long term. However, to date we know very little about how these individuals experience their life situation regarding the functional disability and social interactions, or how they perceive the contact with the healthcare. Hitherto, to our knowledge, not much is published regarding these concerns in scientific literature.

A few international studies regarding BPBP with a qualitative approach have been made; i.e. the impact of peer relations with chronic illnesses (Helgeson and Holmbeck, 2015); the impact of BPBP on families (Louden et al., 2015); how classmate support was associated with a higher self-concept and fewer social difficulties regarding youths with BPBP (Mentrikoski et al., 2015); social impact of peripheral nerve injury (Wojtkiewicz et al., 2015); psychometric properties of outcome measures for children and adolescents with BPBP (Bialocerkowski et al., 2013). Comparisons between adolescents with and without BPBP showing that self-esteem in youths with the most severe form of BPBP was lower than the control group (Strombeck and Fernell, 2003); and youths with BPBP show higher problem scores in both internalizing and externalizing behavior domains compared to a control group (Alyanak et al., 2013); showing that adolescents with BPBP are at risk for psychological difficulties. Other studies focused on concepts of functioning and health importance to children with a BPBP using focus groups (Sarac et al., 2013); medical decision-making among adolescents with BPBP and their families (Squitieri et al., 2013); evaluation of an education day for families of children with BPBP (Ho and Ulster, 2011); inclusion understood from the perspectives of children with disability (Spencer-Cavaliere and Watkinson, 2010); risk and resistance factors associated with paternal adjustment to BPBP (McLean et al., 2014); and mothers' experience of having a child with BPBP (Beck, 2009). Additionally, there are some international studies regarding the psychosocial impacts of traumatic plexus brachial injury, in contrast to the obstetrical (i.e. Gray, 2016, Franzblau and Chung, 2015, McDonald and Pettigrew, 2014). Hence, research on the patient group focuses in the perspectives of health care

personnel or parents, and studies with another focus than the medical are rare, and relatively scarce, and little is known about the perspectives of the youth themselves.

In this chapter, a presentation of the field of knowledge has been made. Ability and disability have been explained; the psychosocial aspects on physical injuries and chronic illnesses and the treatment of brachial plexus injuries have also been clarified to give the reader a background to the chosen phenomenon which is the focus of this master thesis; adolescents' experience of living with an impairment in the arm due to a birth injury.

3. Theoretical considerations

Introduction

In the following chapter, descriptions of phenomenology and phenomenology of the body will occur. These are the theoretical perspectives on which part of the analysis will be built on, together with previous research and the conceptual framework which will follow.

Phenomenology

The aim of this study is to focus on the experience of adolescents with BPBP. A lot of studies interested in the experience of certain phenomena use a theoretical frame of phenomenology. Some research is of interpretative and phenomenological viewpoint; they seek to discover naturally arising meaning among members of the study populations (Berg, 2006). This study will also have a theoretical framework of phenomenology as it is well affiliated to the aim of the study.

Phenomenology is about how the world is described and perceived by humans. In other words, it is about humans perceiving the world differently depending on the perspective of the single person, where the derivation of the investigation lies within the different experiences affected by context and circumstances, such as perspective of the person, context, mental focus, hope and purpose (Willig, 2013). Phenomenology hence includes how phenomenon occurs in human consciousness in interaction with the world.

The meaning of the phenomenon, its progression and its possibility to be revealed is not of weight if it is not viewed and interpreted by someone from the outside, for example; the scientist. The weight of the

phenomenon lies therefore between the object as a whole in relation to the subject's attention and understanding. Fundamental is hence that the same environment and same phenomenon can be understood differently depending on the viewer (Bengtsson, 1999, Willig, 2013). The aim within phenomenology is to get a rich and full understanding of the phenomenon studied, hence, it is of value that the attention is not drawn only to moments where the adolescents have negative experiences of their injury, but also to capture the instances of joy and fulfillment in order for the researcher to achieve a better understanding of factors involved in the experience of having and living with a brachial plexus injury.

Phenomenology initiated the term *essence*, which is to be explained as the invariant of the phenomenon. The phenomenon consist of various important parts, where the essence is its most essential part and without the essences the meaning of the phenomenon fails (Szklański, 2015). Another term which clarifies the intension and understanding of phenomenology is *lifeworld* and its reflection, which aims to describe how it is possible to familiarize other people's experiences and life, and understand how their perspective of the world is (Bengtsson, 1999). All people have their own lifeworld which is non-questionable. However, it is challenged by other people's perspective, culture and function, which enables the person to think and view differently about the phenomenon (Karlsson, 1993, Bengtsson, 1999). The reason why the lifeworld can be dispersed lies in its combination and complexity between people's perceptions, physical traits, perspectives, experiences, feelings and intellectual activity. A lifeworld is the reality in which humanity cannot ignore it and completely understand it (Bengtsson, 1999). The specific world of experiences and values every individual has is the formation of scientific knowledge – the lifeworld. This is further explained as the world as each of us knows it in the practical managing of everyday tasks, in our daily and interpersonal activities. The subjective experience of meaningful phenomenon is the immediate entry to the world we exist in. The lifeworld is described as it emerges from a subjective perspective. However, a subjective perspective does not necessarily mean an individual or private perspective. Other human beings are a part of our immediate experience of our lifeworld, and participants in it. Through the experience of the perspective of other people, our own perspective

can be clarified and complemented. The world can be viewed from different perspectives, although at the same time a common ground for mutual experiences, beliefs and patterns of understanding (Thomassen and Retzlaff, 2007). The term lifeworld can be useful in this master thesis as the researcher has the intention to understand the lifeworld and the experiences of the respondents.

Phenomenology can further be explained as when one is observing something one is also anticipating other characteristics and qualities of the object. Our experiences of the surroundings are always beyond what we can observe with our eyes. The focus of phenomenology is to describe how the phenomenon in front of us emerges and thus how it is experienced; it is at all times subjective. Consequently, description and analysis of the phenomena can then be done through different scientific perspectives. However, scientific perspectives do not state anything about the phenomenon as it is experienced. Rather, human experiences carry meaning primarily and this is what phenomenology is set to describe. The purpose of the study is hence to attain the distinctive features of the phenomenon: what is constant through all variations - the essence of the phenomenon. All experiences are comprehensions of something; an awareness of something. Experiences are structured as an inseparable unit of understandings and understood objects. It is accordingly not possible to draw a line between the reality and the human experience of this reality. The world appears as phenomena of our experiences. Phenomenology as a methodological approach demands an unbiased study. The researcher is obliged to disregard all theories, assumptions and expectations which normally are included when encounter new experiences. The purpose of the study is hence to attain the distinctive features of the phenomenon; what is constant through all variations – the essence of the phenomenon (Thomassen and Retzlaff, 2007).

In order to understand a phenomenon it is necessary not to divide it by its part, but to understand and look at it to its' fully content. When one systematically ignore prejudices naturally coexisting with a certain phenomenon, one can then reach a full understanding of the phenomenon as it is given; its core without external determinations. However, the human lives in a world full of meaningful phenomenon; in a historical, cultural and social context. If all prejudices have to be ignored in order to get access to the core of

the phenomenon, it is also critical that we then neglect the whole context in which where the phenomenon is experienced, something that is strongly criticized. Nonetheless, it is the prejudices that allow the possibility to understand something. It is through this understanding one can bring meaning to a phenomenon (Thomassen and Retzlaff, 2007).

The Phenomenology of the Body

Insofar as one has ‘sensational organs’, a ‘body’, and ‘psychological functions’ that can be compared to other people, every moment in one’s experience cease to exist of being an integrated, strict unique entirety where the parts only exist in relation to the entirety, and one becomes a place where diversity of causalities intersect with each other. Insofar as one inhabits a ‘physical world’ where constant ‘stimuli’ and typical situations reoccurs, one’s life contains of rhythms that do not have its’ foundation in what one chooses it to be, but in its’ conditions in the surroundings. The body is not just a tool and an object, it is the subject of the personality and it is through the body the consciousness takes place – one’s existence. It is with the body that we exist in the world, and are in contact with the things and life itself. It is as a body we speak, feel and become the soul which thinks it is something by itself (Merleau-Ponty, 1999).

Merleau-Ponty (1999) further describes how the existence is between the body and consciousness. His views regarding the body can be summarized as ‘I am my own body’ and the body can only exist here and now, it can never be in the past. One does not simply stand in front of one’s own body and can visualize it from the outside; a person is their own body. The consciousness of me is the one thing that controls my own body. The phenomenology of the body is about how to relate to one’s body as one experiences it now, hence one can only understand the function of the living body by moving and using it oneself, and to the extent where one is a body that reaches out to the world (Merleau-Ponty, 1999).

A person that is healthy and nondisabled cannot preserve the living memory of a disease, or as adults preserve the living memory of the bodies we had when we were children. These blackouts are only an expression for our bodies’ time structure. Insofar as one possesses a body and acts in the world through it, the space and time are not a sum of things that are on the same level within the same system, but differs in function, and is not an eternity of relations

which my consciousness does the synthesis of which involves my body; I am not in space or in time; I do not think of space and time, I am to space and time, my body takes them to it and includes them. The inclusion is a guidance of the inclusiveness of my existence, but it can never be total, the space and time which I inhabit are always surrounded by undefined horizons, which include other perspectives. The motor experience of our bodies gives us an access to the world and the objects. There is an experience of my body, but there is also an experience of my body in the outer world, though my body only has its' world and only understand its' world, without any images, ideas or representations. Our perception of the world is based on our own bodies' perspective. If, in the process of perception of the own body, we talk about interpretation, one has to conclude that the body interprets itself. To be a body means to be bound to a certain world (Merleau-Ponty, 1999).

A subject has learnt certain skills and hence, do not think about how they are performed, the skills are then incorporated into their body schemas, meaning that they are incorporated in their systems of sensory-motor abilities. The skill is then a part of our bodily know-how, and the body can then disappear from our attention when executing the skill. One's lived body is the here from which a person sees the world of far and near distances, and the now in which a person interprets its' past and stretch to the future (Zeiler, 2010).

Our bodies play a significant role in shaping our experiences of the world. Hence, human experiences are always embodied (Leder, 1990). When engaging in interactions with others, one seldom think of their bodies, it dys-appears from one's attention. There is a difference between dis-apperance and dys-apperance, where the first concerns when the body disappears from one's attention, and the latter is when the body appears to be 'ill' or 'bad'. Medical therapies and surgery seek to soften bodily dys-apperance and facilitates bodily dis-apperance for patients. Regarding the perspective of the lived body, the body is what makes relations to others possible. The body is made meaningful to me in interactions with others and the world, and it is never only an object to oneself. It is a lived reality. The lived body is a mind-body unity that experiences and functions in specific situations. However, the body can appear to oneself in different ways (Zeiler, 2010).

How the brain feels and thinks is confirmed by the way it is connected to the rest of the body (Damasio, 1999). Thoughts are made meaningful by the feelings that come first and feed into them in a variety of bodily ways. The self then comes adjusted through its bodily being, and such adjustment is essential for all human understanding. Different organs seem to have different significance to the identity of a person. The identity-forming processes of the self consist of processes of the body, processes of the mind, and processes of social and cultural foundations. The process of selfhood starts with meaning configuration that takes place on preconscious embodied stage, but the processes attain another quality in the conscious level of self-reflection. This is what happens when one understands, and not only feels, that one is something, which is encountering other things (Svenaeus, 2012).

In this chapter, the characteristics of phenomenology, with the terms lifeworld and essence; and phenomenology of the body, have been presented and how this affects the reality of a person.

4. Conceptual framework

Introduction

In the following chapter; a description of concepts concerning disability and normality, disability and self-image, and finally body and status will be explained. These concepts, together with the previous chapter of theoretical considerations and previous research will form the foundation of the analysis.

Disability and normality

It is with difficulties one has to decide what is included in the concept of normality. It is also problematical to determine what is integrated in the idea of everyone having their own responsibility of their own lives. It is known that two different individuals with the same disability view their situations, hindrances and disability differently. However, it is a dangerous trap to try to compare the life situation of a person with physical disabilities to a life situation of a person without physical disabilities (Peterson et al., 2006). Often this viewpoint is in the eye of the beholder. The beholder is assuming that the person is comparing their own life with a person without disabilities. This is rather common in the adolescent years when it is natural to dream and hope for a different life where

they are beautiful, happy, successful and not tormented by feelings of shortcomings and deficiencies (Peterson et al., 2006).

Hansen and Philo (2007) argues that we should not use terms as disability and normality to categorize individuals, but that we rather should shift focus from aiding disabled people in by doing things normally, to underlining from all of 'us' and see the normality of doing things differently. Society fails to accommodate the impairments of individuals, demanding a critical stance on the underlying 'ableism' of a nondisabled society that forms a world in its own able-bodied image, which could lead to discrimination of individuals with disabilities to participate in activities available to everyone else. However, they argue that the specificities of individual impairment matters and must be centered, but always in relation to the kinds of spaces that non-disabled individuals have created. The categorization of people with disabilities can be linked to stigmatizing, patronizing and demeaning of disabled people. Further, Hansen and Philo (2007) state how someone with a disability repeatedly needs to explain their disability, so that her bodily difference can be accepted, by the non-disabled majority.

It is important to state the difference between active and passive tense; where 'active' is defined as asserting that the person or thing represented by the grammatical subjects performs the action represented by the verb, and 'passive' is defined as asserting that the grammatical subject to a verb is subjected to or affected by the action represented by that verb. This is important when describing someone being and someone doing. Following, it is important to state the differences in connotations and pervasiveness in the verbs 'be' and 'have' and referring to Webster's dictionary saying;

be = to equal in meaning

to have same connotation as

to have identity with

to constitute the same class as

have = to hold in possession

to hold in one's use

to consist of

to stand in relationship to

to be marked or characterized by

to experience

SYN – to keep, control, retain or experience (Zola, 1993)

Disability and self-image

Self-image is usually the description the individual gives herself in different circumstances. It is the result of the individual's own way of understanding herself (Peterson et al., 2006) A child who is born with a disability does not view herself as abnormal or deviant until someone else tells them that it is the case. Nor does a child put any values to a disability. The sense of self-worth is an un-reflected experience which occurs together with the primary care persons. As time passes, the attitudes of other people also reflect in the self-image (Peterson et al., 2006). People with disabilities have introvert behavior, low self-esteem and resignation, which could be consequences of lack of confirmation and forced negative special status in society, rather than the disability itself. Exclusion from society becomes critical during the teenage years when the individual creates her own life outside the family and the time together with friends becomes more important (Harper and Richman, 1978, Anderson et al., 1982, Goldberger and Breznitz, 1982).

However, studies by Peterson et al. (2006) show that it is not only negative consequences the person experience of having a disability. It could also be positive consequences such inner strength, personal maturity, and empathy. Some people also say that their disability is accepted by themselves and a natural part of life; an incorporated reality – something that is existing but not evident and always in focus and hence emotionally neutral. The individual adjusts, accepts and gets used to the disability. The results in the studies by Peterson et al. (2006) show that the individuals do not necessarily view their disability as a personality trait, but as something that limits their life in different ways.

From a disability perspective, not everyone is able to make the transition from childhood to adulthood in all the various aspects. There are many barriers to full adult status for young disabled people (Priestley, 2003). Understanding of young disabled people's collective biography requires both structural and cultural explanations. A similar conclusion about youth and disability is that they are both social categories (Priestley, 2003).

Body and status

Sweden is in the forefront in the process of granting people with disabilities civil status. There are, however, still weaknesses in the progress of granting them the same rights and obligations as people without disabilities. In society today, it is a dominating focus on the healthy and strong body, and at the same time a moralization around the deviation from this archetype (Peterson et al., 2006). Hence, the flipside of this admiration for the healthy, beautiful and strong is a disdain towards the people who cannot correspond to this ideal. This could lead to a person with a disability being stigmatized, an outcast and is consigned to a social borderland. Also, the myth of bodily perfection is a significant, long-standing component in the construction of people with visible impairments as inferior and disabled (Priestley, 2003). Although young people themselves may not consciously articulate the structural context of their life choices, their accounts provide a richly situated lens through which to view structural barriers and social changes (Priestley, 2003).

To bring order in a complex world we categorize people into groups based on for example; characteristics, appearances, or function. Problem occurs when we try to simplify the reality by exaggerating the similarities between the individuals in a category, or assume that they are similar to each other in aspects we have little knowledge about. However, more serious is how one often categorizes people in in-groups; where we ourselves are included, respectively out-groups, where other people belong, and especially where the ones with less valuable characteristics belong to. These categorizations are made by the values that dominate society about what is normal and the norm (Peterson et al., 2006). The beholder categorizes people with disabilities into a homogenous group, where one assumes they would share characteristics that have little to do with the disability.

Clearly, people with a disability do not have a collective understanding of people without disabilities, and are not a certain type of humans. Just like everyone else, people with disabilities, is a heterogeneous group where perhaps the only thing in common is the biological or medical experience they share. There is a cognitive component in viewing which means that by visual perception we make a complex reality understandable by organizing people in categories. These categories could be stereotypical – a set

ideas of a certain group of people. The set of ideas could also be true or false, and are usually labeled prejudices when a specific value is set to the group of individuals. Discrimination happens when negative special treatment occurs. Violation can also happen when one's individuality is taken away. If the social model of disability has taught us anything, it is not to ignore the strength of structure in producing disability and disabling environments (Priestley, 2003).

Previous research (i.e Peterson et al., 2006) shows that a lot of people with disabilities experience others treating them *as* their disabilities, not as individuals *with* a disability. Their body hence becomes their personality, which could be very difficult and demanding, and rarely these persons are viewed as individuals with traits, manners and beliefs.

This chapter included explanations and clarifications of disability and normality, disability and self-image and body and status as conceptual framework which will form the foundation of the analysis, together with previous research and the theoretical considerations.

5. Method

The frame of understanding

The collection of material within phenomenology is primary through interviews and observations, as the method gives the researcher access to the talk and expressions of the respondents' experiences of people, phenomena and lifeworlds. Phenomenological interviews are often unstructured or semi-structured where the researcher interacts with the respondent through open questions and active listening, which is also important in qualitative research through the close relationship the researcher has to the chosen field of investigation (Ahrne and Svensson, 2015, Szklarski, 2015).

Since scientific knowledge is theories and statements about different parts of reality, the theories have to be compared to the reality they speak of. A consequence of this is that the theories have to be subjected to empirical material and data from the reality that is studied. The data has to be accessible to other researchers and generally accepted – intersubjectivity. (Thomassen and Retzlaff, 2007).

According to Popper (in Thomassen and Retzlaff, 2007), when one is observing the surrounding reality, it is always through a certain perspective,

something that occupies a mindset, something one wants to solve and explain, or a task that has to be done. When we are observing – looking – we are always looking at something, and looking away from something else. This observation is always based on assumptions and certain expectations; however these references can be both conscious and unconscious. Observing is hence an active process. In the scientific world theories and hypothesis are both a part of this reference frame which precedes all observations. Hence, collecting data and observations are restricted to theories and interpretations. Data becomes meaningful once one puts perspectives to it. If observations are regulated, restricted and structured by a preceding reference frame stating certain expectations, the data which is registered as evidence for scientific theories are in fact themselves imprinted by theoretical framework. Hence, no data is neutral and data is always theory based (Thomassen and Retzlaff, 2007).

Clients and patients as objects or subjects

Within health- and medical care it is common to respond to and treat individuals from different perspectives; as subjects, as objects or as both. Viewing the human as a subject means that the person is active, autonomous, independent, and carries with her resources for growth and development, that she can take responsibility for her own maturity and self-realization that she is free to create the life she wants. The stance of the person as an object would then mean that the person is dependent on her own biology and inner mechanisms which she has little control of (Eliasson-Lappalainen, 1995). Nevertheless, while some argue that humans are subjects in relation to our reality; humans are also objects in the regards of being formed in interaction with the surroundings, other people and the circumstances of one's life. This point of view includes a respect for the individual being and her autonomy, and at the same time admits her dependence of others and the responsibility everyone has for our fellow human beings; it is a holistic view of the human (Eliasson-Lappalainen, 1995). Individuals with disabilities are often met with a paternalistic perspective, where it is not unusual to be viewed as objects rather than subjects without their own free will; and focus for actions decided by others. Literature within the field states that an individual with disability has to have strong motivation and drive in their demands and desires to live a life based on the same terms and conditions as others (Peterson et al., 2006).

The non-disabled body is subjectively established as the 'natural' way to act, to be and to be seen, and everyday places are effectively 'naturalized' as ones to be inhabited and used by non-disabled people. Many kinds of bodies have questionably yet to 'belong' in such spaces (Hansen and Philo, 2007). The power and prejudices of the beholder of what a person with a disability reacts to, is also a consequence of the thought of the patient as an object, rather than a subject (Peterson et al., 2006).

It is a common experience amongst people who are in contact with medical healthcare, that the person with a disability is risking to lose one's role as an expert of their own life (Riddersporre, 2003); to be the one who has firsthand knowledge and information about one's situation, how it is to live with the existing disability 24 hours a day. The term 'client perspective' consists of a labeling of people from an action-, therapeutic-, or governmental perspective. Hence, it is not a perspective which belongs to the client. The person has a lot of other identities and roles rather than just client, and perhaps the person adapts this role to one's only role. A risk with this is that the perspective is tightened to consist of the person's experience in the client perspective – and missing the whole human perspective (Eliasson-Lappalainen, 1995). However, the client or patient is often limited to the constructions of an organization; hence have small chances to affect their situation. They are often viewed by their shortcomings and limitations and eventual progresses are categorized by staff members. Researchers trust staff members' definitions of problem situations and aims of the organization, rather than listening to the patient/client's definition of their own situation and their goals with their lives. Another perspective is the treatment perspective, which focuses on the knowledge that the staff sets up and proclaims as fundamental is missing the client's own stories and experiences. As a researcher it is valid to challenge these frames of knowledge (Eliasson-Lappalainen, 1995).

Selection of data

The study group was accessed via medical records at the clinic where they had been treated. The aim was to get approximately ten interviewees in the age group 16-19 years and to conduct the interviews with them. An exclusion criterion was patients who have met the researcher in the role as a social worker at the set clinic. The population within this study was all patients who had

undergone surgical correction for rotational deformity of the shoulder. The individuals that are operated on with this method have a mild level of plexus injury. Out of the 19 individuals in the population, twelve were female and seven were male. Of the 19 individuals, eight responded that they wanted to participate in the study. The mean age of when the respondents had their surgery was eleven years and at the interview the mean age was 17 years.

Table I. The respondents gender, age at surgery, and age at interview.

Identity Code	Gender	Age at surgery	Age at interview
Anna	Female	8	16
Bente	Female	14	19
Cecilia	Female	12	17
Diana	Female	10	17
Emma	Female	11	17
Fanny	Female	11	17
Gilberte	Female	13	17
Henry	Male	10	18

As the surgery does not differ based on where geographically in Sweden these individuals live, it was not necessary for the aim of the study to collect individuals from only the geographical vicinity of the set clinic, as the results of the surgery were most likely to be the same. However, having this in mind, the after-treatment and habilitation and rehabilitation could vary as it is dependent on the local conditions; for example supply of habilitation centers and limited knowledge and experience of the injury. Since the injury is comparatively rare and it is a small patient group, none of the individuals had had any other contact with persons with the same injury.

Empirical data

The empirical data of the study is found in the voices of the adolescents with a brachial plexus birth injury. By listening to their stories, reflections and thoughts a holistic perspective of their experiences comes to life. Through carefully chosen questions the purpose, is to guide them and support the respondents so they will give a broad and wide image of how life is, and how they view themselves and their bodies, with the impairment they got at birth. Through this

method, the individuals leave remarks and thoughts meaningful and valuable to others in the same situation. The researcher worked carefully on a semi structured interview guide before conducting the interviews with possibilities for the respondents to elaborate and develop their answers so they would fit the aim of this study; to reach a greater understanding through their experiences (Berg, 2006).

To collect qualitative data – words – is said to be an open method where the researcher influence the collected information as little as possible. It is of importance that the interviewees are allowed to express their opinion and experiences in their own words. Hence, the researcher only controls to little extent what can be brought up in an interview and how it is dealt with. During the analyze phase, eventual structuring of the information is done. In this way one can be more certain that the information gathered are the interviewees' opinions and interpretations. Thus, it is not the questions of the researcher, and thereby her prejudices, which determines what information is gathered. Within research methodology, the process of collecting qualitative data has an inductive approach, which means that the researcher tries to collect the data in an open way and tries to influence the data as little as possible. This openness makes qualitative data suitable for explorative studies (Jacobsen and Järvå, 2007). Openness can also mean that the data collected is much nuanced. It is a single respondent which gives ones interpretation and opinion of a specific situation. The data is hence valuable in order to describe a certain situation in a set context.

Qualitative research methods are also known to focus on the closeness in relationship between the researcher and the respondent. Qualitative methods are also known to be flexible. In qualitative research methods the research questions can be altered and modified as more information is gathered during the process. The process is interactive which means that the researcher can change the research question and the data gathering method as the research continues (Jacobsen and Järvå, 2007). Qualitative methods are argued for having a respect for the individual, a subject-subject relationship, empathy and solidarity with the ones the research is focused on. A risk with this is to exaggerate the importance of the case description and life stories. The researcher may lose the scientific critical potential. Quantifying data and statistical methods

only, cannot be enough to produce understanding and explanations, and a hazard is to produce questionnaires based on knowledge the researcher decides in beforehand is important to know (Eliason, 1995). A combination of the two different methods is valuable to receive valuable information and knowledge about the whole problem.

The choice of method is crucial to the structure of the research and determines what part of the material which will answer the questions and aim of the study. The purpose of the choice of method is to use the approach where the empirical material will be gathered, which will focus on the questions of the study as well as to be trustworthy to the public eye (Ahrne and Svensson, 2015).

Focus of the study is patients in their late teenage years. Teenagers in the age of 16 to 19 years of age also go through different transits during this time; physically, socially, emotionally and psychologically. During this period of life social contacts with peers are important. The teenagers compare themselves to others, and it is important to fit in and have a sense of normality, see previous research listed above. Initially in the research process, questions reflecting the injury, differences and normality, considering to be as everyone and not give the injury attention as the adolescents always have had it and hence cannot compare their lives to a time where they did not have the injury, were considered. Further, questions that emerged were if their parents chose to give the injury attention, or if the parents were looking at the injury as something different compared to other children. Was the arm viewed as an impairment, and if so, in what ways?

Studying these patients with this focus can also produce valuable information if, and how, they have a forum to exchange experiences with individuals in the same situation, or if this is something that would be of any interest. After the empirical data had been gathered the researcher analyzed it based on a theoretical framework of phenomenology to draw conclusions and produce new knowledge.

The interviews

Interviews are a method form which focuses on the participants' experiences and attitudes, and gives the researcher a picture of social aspects within a chosen environment or issue. By using qualitative interviews the researcher is allowed to follow the narratives of the participant, ask developing questions and it allows

her to affect the interview as a whole (Ahrne and Svensson, 2015). This method allows the researcher to get a description of the experiences the adolescents' have of their birth injury. Although, the interviewer has to be aware that the statements could possibly not be entirely true, and that the researcher sometimes have to interpret the meaning of the statements (Ahrne and Svensson, 2015).

The interviews were held in a location selected by the respondent and the researcher; at the hospital where the surgery had taken place, at a local coffeehouse, and through Skype, as that person was currently abroad. The respondent had the right to choose where the interview would take place as their personal experience was the aim of the study. Hence, public environments and the home of the respondent could be possible locations for the interview, whereas professional experiences would preferably take place at the respondents work unit (Ahrne and Svensson, 2015).

The researcher has a position as a social worker at the set clinic. Through searches in medical records, the researcher found 19 individuals which met the inclusion- and exclusion criteria, and hence consist of the population of the study. Based on their year of birth, they were classified and sent a letter of information of the study, starting with the individuals that were born in the beginning of the year. They were also classified by gender. 19 individuals were included in the population, twelve female and seven male individuals. After considerations regarding quantity of interviews, and keeping in mind that saturation of participants would occur when no new information arose, we aimed at having eight to ten interviews as a start, to get richness and nuances in the experiences, also keeping in mind that the population as such was rather small to begin with. Letters were first sent out to ten of these individuals and three weeks later a reminder letter was sent out. At the same time as the first letters were sent out to the adolescents, a letter to their parents or guardians was also sent out for information. Hereafter, one by one letter was sent until wanted quantity was filled (8-10 ten interviews). All 19 individuals ended up being informed and asked to participate in the study, and only one individual sent a reply with a negative response. Eight interviews were conducted. All other individuals declined to respond completely.

Most of the semi structured interviews were performed at the set clinic in a neutral room where the interviews were recorded. However, the

respondents were given the chance to choose the location of the interview, whereas some were held at different locations and contexts. During the interviews, the researcher had civil outfits, and not the hospital uniform. Following, the interviews were transcribed and then coded to draw conclusions based on the empirical data in the interviews.

With the letter of information to the participants, a letter of informed consent was sent out and signed by all (appendix I, and appendix II). The signed informed consent was sent back to the researcher before the interview was conducted. At the time of the interview, the respondents were also informed orally about the purpose of the study. Further, their possibility to ask questions during the interview if they did not fully understand the question was implied. They were also reminded about their rights, the confidentiality and anonymity. Information about the interviews would be recorded, in accordance to the rules of ethics. Through both written and oral information the respondents had the possibility to prepare mentally for the interview as well as have the possibility to ask questions, which enabled safety and honesty in the statements of the interview. All interviews also ended with the possibility for the respondents to clarify or add something that was said during the interview. All participants were also e-mailed the written transcripts of the interviews and hence having an opportunity to affect, further explain or explicate their answers. The interviews consisted of questions concerning the four different themes of the study; reduced functional ability, social interaction, interaction with health care, and self-image. Each theme consisted of various suggestions of questions (appendix II) and the questions were discussed with a varying order together with situation based follow-up questions. The interviews lasted between 40 minutes to 110 minutes, which generated a large material of 185 computer written transcription pages. This resulted in something, referred by Ahrne and Svensson (2015) as a chaotic problem within transcription and sorting out the material, which was viewed upon as a whole, throughout the chosen method of analyze. A further explanation of the analyze method will follow later on in the thesis.

Transcription

After conducting and recording the interviews, they were transcribed by the researcher. The transcriptions were done close in the time of the interview, so

the researcher could remember non-verbal expression done by the respondents, and body language was written down where the respondents showed something, for example with their arm gestures. During the interviews, no notes were taken in order for the researcher to have full focus on the respondent. As the interviewer and interviewee were solely alone in the room, the interviewer could be fully present mentally. The relevance of the transcribed material, in relation with the aim of the study, was almost solely quotes or descriptions of situations, and where pauses or hesitations were thought of as of less importance, they were only marked with three dots in a row (Ahrne and Svensson, 2015, Fejes and Thornberg, 2015, Willig, 2013).

As the transcription should be easy organized before the analyze phase (Fejes and Thornberg, 2015), the researcher chose to organize and order the questions of the interview based on the research questions. This simplified the analyze phase of expressions, experiences and interpretations, as they easily could be connected with the present context. In the presentation of the results, rather extensive quotations are chosen in order to improve reliability according to the interpretation of the interviews. Advantages when the researcher herself is transcribing the material are that there is a frequent contact with the material, which is good when analyzing it.

Method of analysis

After the transcription had taken place the researcher read through all the written transcription material to get an overview of the data. As a starting point, the interviews were then manually coded based on the research questions of the study under a number of headings and key words: how the adolescents experienced their lives and quality of life, psychological and physical self-image, interaction with others, physical function and limitation, and experiences of and suggestions to develop the health care.

The researcher looked if there were specific themes, and particular attention was also paid to emerging commonalities and points of disagreement. To find the different themes, the researcher looked at all the transcriptions as an entity to see how the keywords could belong to each other. The researcher also systematically went through every interview question one by one, as the respondents sometimes answered the questions in different contexts. Following, the researcher identified specific quotes that are thought of as describing certain

meanings. Within phenomenological analyzing method, these are called *meaning units*. All of the texts are not meaning units. Next in the analysis process, the researcher developed the meaning units to meaning categories, or *clusters*. Finally, in the analysis process, the clusters describe the variation of the material. Something that is found in all of the clusters is called *essence*. The essence is the invariable; something that does not vary despite of the different data. The essence is the new entirety. The matters of the interviews were: the impact of the injury on family life, peer networks, studies and potential employment, its effect on personal identities, the use of health system and medical regimens.

After conducting eight interviews the following meaning units, clusters and essences were identified during the analysis. The three prominent meaning units were '*Me and others*', '*Professional medical contacts and experiences*', and '*Adjustment and strategies regarding solutions and obstacles*'. Thereafter; the clusters under each meaning unit were interpreted as '*Physical and psychological self-image*', '*Function of the arm*', '*Exercise*', '*Social relations*' and '*Disability and normality*' under the meaning unit '*Me and others*', and the essence thereof is '*Disabled or have a disability*'. Under the meaning unit '*Professional medical contacts and experiences*', the clusters '*Satisfaction and Requests*', '*Hospital and surgery*' and '*Habilitation*' can be found. The essence of this cluster is '*Then and now*'. The third meaning unit; '*Adjustment and strategies regarding solutions and obstacles*' have the clusters '*Personality traits*' and '*Social network*', with the essence of '*Lack of reference*'.

Table II. The results in meaning units, clusters and essence of the themes the respondents have talked about during the interview.

Meaning units	<i>Me and others</i>	<i>Professional medical contacts and experiences</i>	<i>Adjustment and strategies regarding solutions and obstacles</i>
Clusters	<i>Physical and psychological self-image Function of the arm Exercise Social relations Disability and normality</i>	<i>Satisfaction Requests Hospital and surgery Habilitation</i>	<i>Personality traits Social network</i>
Essence	<i>Disabled or have a disability</i>	<i>Then and now</i>	<i>Lack of reference</i>

After the coding had taken place, the researcher analyzed the empirical data with the help of different themes, such as the theoretical framework of phenomenology, with the terms lifeworld, meaning units, and essence, and phenomenology of the body. The analysis also consisted of previous research within the field. The researcher was then able to draw conclusions based on the empirical data, together with previous research, as well as the theoretical framework used. Qualitative research often has high internal validity regarding openness, richness in nuances and flexibility. Qualitative research brings out the real understanding of a phenomenon or a situation; the respondents' construction of reality (Jacobsen and Järvå, 2007). However, it can be problems with the external validity and problems with generalizations. Qualitative research method is preferably used when there is little knowledge about the phenomenon to be study; an explorative study, when one wants to find out what a phenomenon involves; a depth and detailed understanding, and understanding as a whole of the phenomenon/situation/individual (Jacobsen and Järvå, 2007). This study aimed at having an explorative character as well as to reach an understanding of the phenomenon as a whole, and these individuals.

Ethical considerations

When conducting research with children and adolescents one has to take into consideration special issues and regards. Within the research field of social work little research has been made where minors are used as informants. However, minors have the right to participate in research based on UNs Children convention. The information minors can contribute with is valuable and necessary. To not include minors in research is not ethically motivated, and could also be filled with problems. To include minors in a qualitative study is hence motivated so their voices can be heard, and in this study where the aim is to study the experience adolescents have, it is valid and appropriate. Nevertheless, the researcher has great responsibility towards the adolescents so they will not come to any harm during the research process. According to Swedish Research Council (2011), the researcher has to weigh this aspect towards the beneficial terms which can be deducted from the study. Special adherence to the concept of rights is a significant component of respect; such as respect for the dignity of persons, rights to privacy, self-determination, and personal liberty. It is important that the researcher respect the rights of the participants. It is also important that there is mutual respect and trust between researcher and informants. Underlying, is the four codes of ethics which the researcher has to respect; consent of information where the participation is voluntary, valid consent, confidentiality and anonymity demands, and the demands of valid use of the information. Furthermore, disclosure of informant data will require informed written consent. They will be anonymous such that people other than the informants themselves are unlikely to recognize them (Swedish Research Council, 2011). Written consent was sent out to the adolescents as they are able to grant an independent consent based on their age and hence their maturity. However, a letter of information was sent to parents of the adolescents, in order for them to get knowledge about the study, the aim of it and the participation of the adolescents. It is essential that the parents are aware of what kind of information will be shared by their adolescents.

Due to the fact that the researcher had to look through medical records in order to get access and collect the respondents; prior to the research begun, a written consent and approval of the study was gathered from the head at the Department of Hand surgery at the set hospital, to conduct the study with

its design. The author of this study is formally employed as a social worker at the set clinic. An exclusion criterion for participating in the study was if the adolescents would have met the researcher in the role as a social worker prior to the research. Being employed at the set clinic enabled the researcher to get access to and recruit the respondents. However, this is not solely without any ethical concerns; the researcher had to be aware of her original role as a social worker and try to look beyond it and become a researcher; which sometimes was slightly confusing.

Nonetheless, in phenomenological aspects, the prior knowledge and understanding she had of the patient group was an important factor. Thus, an approach free from previous knowledge and bias could not be a reality, as the critics of phenomenology point out – this can never be a reality as one always have previous understandings of a phenomenon (Thomassen and Retzlaff, 2007). We cannot put our pre-understanding within parenthesis. However, there is an advantage if the researcher is involved in the context studied – she knows the subject, can make decisions and know which sources of information are worth focusing upon. The respondents were aware of the researcher's double role, which could have limited their answers as they might believe that there were double loyalties. It could also affect the credibility of the result, if the respondents felt as if they had to please the researcher as she was a part of and involved in the organization studied. However, the respondents were informed that their participation of the study would not affect their treatment in any way, and if issues and concerns would arise during the interviews, they received information that they would be referred to a suitable health care provider.

Prior to the start of the research, a formal application of ethical vetting of research on humans was filled in and approved by the Ethics review board in Stockholm (Dnr: 2015/1219-31, appendix IV), where the requirements of the ethical review act had to be fulfilled. The letter of information to the respondents followed the set standard of the Ethics review board. The application form consisted of nine different topics which were all taken into consideration and presented carefully and thoroughly. No exceptions or changes from the form were done during the research process.

7. Results and Analysis

Introduction

In this chapter, the results of the study are presented. Keeping in mind the aim of the study: to examine the experiences adolescents with BPBP have, through the research questions: How they experience their lives regarding studies, spare time activities, relationships and quality of life, if they experiences any limitations due to their injury, and how they experience the health care and if they have suggestions for improvements. After the presentation of the results, categorized in the different meaning units, clusters and essences for the sake of logic and to get an easier overview, an analysis is presented under the essences where connections of the results to the chosen theoretical considerations, conceptual framework together with previous research are made. The different sections are ‘Me and others’, ‘Professional and medical contacts and experiences’, ‘Adjustment and strategies regarding solutions and obstacles’

Me and others

During the interviews the adolescents talked about themselves and their social network. They described their physical and psychological self-image in relation to their injury, the function of the arm, exercises, social relations and disability and normality. A common theme of the interviews was whether they viewed themselves as disabled or to have a disability. Hence, one meaning unit that was noted was ‘*Me and others*’.

Physical and psychological self-image

The cluster ‘*Physical and psychological self-image*’ consisted of expressions of good self-esteem and one person said that when classmates were to choose team mates for physical education classes, that person was always chosen first based on both physical and psychological reasons.

I have always been one of those people who demands space, I have always gone in and really been involved and been a part of, so I’ve... I have never had any problems with being allowed to participate, or something like that, because of the injury. (Henry)

One person felt very comfortable and integrated with the arm, and said that the arm was never hidden nor denied, and could even have a sense of pride regarding it: ‘*I think I am a bit proud of it [the injury]. You know, it’s a part of*

me.' (Diana) and someone else explained how he never viewed himself as handicapped:

I've never seen it as an injury, like, I always knew I had it, but I haven't thought about it. So I haven't seen myself as handicapped, or so. And I've never felt handicapped really. It's just something I can joke around with my friends, like, you know I'm injured, so I'm like handicapped, but I've never FELT like it. And it's not like I've been treated like it from you know doctors and stuff, everything's been very normal. (Henry)

Another person was open with having a disability to other peers and wanted to show that disabilities and handicaps can be of various kinds, but it is alright and everyone still has an equal value:

I don't think about it [the injury] anymore, as I have had it for all my life. But of course it has affected me quite much, since it's... I have a handicap. And it's a functional disability (...) But people need to understand that one can have handicaps in different levels. And because one has a smaller handicap, but have an understanding for those who have a bigger handicap, I think it's good to be able to talk about it in a light manner, and to be able to explain it to other people. (Diana)

A few of the respondents talked about the aesthetics of the arm and how they view themselves:

It's one little thing that I think of. But it becomes more annoying, just to be able to look at oneself in the mirror and to see that the other shoulder is a bit... It's a bit annoying when you see it all the time (...) I didn't notice it before, I've just started to see it now, I think that's changed. It's a bit hard, but I don't feel bad about it, it's more that it's annoying. I think I have a complex that the shoulder is smaller than the other one. That's what I think is the hardest. Often I, I have some, although I don't really like tank tops without sleeves, I don't want to have any questions, or notice it all the time. Even though, no one else might not notice it, I think it's difficult. I don't want anybody to point it out either, because, you know... I know it. But everything else is okay, but it's just that it is smaller, I'm not very pleased about it, but everything else is like fine, it's okay. (Emma)

The scar did not seem to be a big problem for most of the respondents, they neither hid it in long sleeved tops nor did they have an issue with it. Although the adolescents pointed out that the scar was a bigger problem when they were younger:

I don't really care. I don't really care about the scar now, I really don't. I look at other people, and see that they also got scars, so that doesn't make you less of a person, not a scar at least. (Bente)

A common denominator was humor which the adolescents used in different situations to interact with others, to think about their scar and injury. One participant described to others that the reason for the scar was a tiger attack, and another participant reflected on one's possibility to qualify and participate in the Paralympics based on the injury. A common topic most of the respondents talked about was how they did not want anyone else feel sorry for them:

I don't really like the idea of someone feeling sorry for me because of it [the injury], I have never thought about it like that myself. (...) I have never tried to overstate my injury, I have more tried to reduce it, like, I know it exists, but like... Of course I think about it, but I don't want to go around saying like Do you know how difficult it is, it's more like... you know.... (Diana)

Some of the teenagers said '*I never think about the injury*' (Anna) whereas others said '*I think about it every day*' (Gilberte), where someone else said '*I am used to it, I don't know anything else*' (Henry) and yet another said '*I accept how I look, with a shorter arm*' (Emma) and another said she is becoming more aware of the arm the older she gets:

I recently noticed that, in pictures and such, you can really tell that the arm is shorter if it is bent, so what I try to do is... I try to hide it a bit. I try to tighten my muscles, I try to make it look as straight as possible... It feels like I've become more and more aware of it. I guess it's because I see pictures of myself. And I take more pictures of myself, and I've become older. And with social media and everything, it's like... You put out more pictures of yourself, and then you try to look as good as possible, and if one of the arms is five centimeters shorter than the other one, you can see it, so that's what I've been trying to... It hasn't affected me that much, but it's still something I have thought about if I take pictures. (...) And when I was younger I didn't care that much. I maybe care about those things a little bit more now. I don't think anyone else but me thinks about it though. But if I say it like this, if a friend and I are taking a picture together, then maybe I want to stand, like with my arm around her, so it doesn't show... Or I try to stretch my arm so it looks straighter'. (Fanny)

However, most of the participants were of the opinion that they did not think of the injury or hardly notice it in everyday life. The respondents would sum up during the interviews that they do not perceive that they think about it every day as they are used to it and do not have anything else to compare with, but going deeper they realized that they think about it every day, but they adjust their actions around their injury and their functional capability:

I don't think about it that much I would say, I can basically do everything I guess. Despite of the injury. Of course, there are some things that I can't do... Well, it's a little bit difficult to do certain things, of course, but other than that, it hasn't been any problems at all. (Henry)

The adolescents were aware of how and why they got their injury and many also knew that another possible outcome would have been a more severe injury due to oxygen shortage when they got stuck in the birth canal as infants:

I'd rather take this little injury than have a CP injury [cerebral palsy] or die at birth, as they [midwives] had to do something very fast when I was born. (Anna)

Function of the arm

Under the cluster '*Function of the arm*' the adolescents described various experiences, both in past and present terms. Many of them stated that they had little limitations in present days with their arm:

I have gone to a few spare time activities in my days, like swimming and rock hill climbing, and during them I didn't think of my injury. No, I wouldn't say that. Like, there are of course certain things I can't do, like certain parts of the activity, but then I just don't do that part, I don't stay out of the activity because of it. (Cecilia)

Someone explained how she experienced the physical limitations and how she compared herself to others who did not have these limitations:

Well, how is it living with this? I'm so used to it, it's kind of hard to explain, but... It has always been a little bit hard, not being able to do everything else that others do, like horseback riding, and like, to put up a pony tail in the back of my neck, without it having a stop and such... It has always been a bit hard not being able to do everything in physical education class. Even if it's small things it's not like... In the end it's hard, and sometimes when I stretch it, it hurts a bit. But I can live with that. Like, I don't know anything else. (Emma)

However, although they might not experience bigger limitations due to the injury, a few of the participants explained how they used their injury as an excuse not to participate in the physical education classes. Despite that this had nothing to do with their arm, they were just too tired in general or knew that they were going to do for example pushups in class. Due to their injury they cannot do any pushups, or not as many as their peers, which led to them sitting the class out. The arm had to take the blame, or the adolescents said that they did not have any exercise clothes with them just so that the peers or the physical education teacher would not notice their limitations in the arm or how they would do pushups differently.

They experienced that their affected arm was weaker than the other, and has less movement, even though this has improved after surgery:

The arm was very weak and I couldn't do much with it. I did the surgery so I could rotate the elbow like out from my body, and now I can do it much more. (Cecilia)

One thing they all agreed on was that their physical limitations did not hinder or prevent them from doing activities. One of the respondents is an elite athlete and can manage very well physically, despite the injury:

There's really nothing that I notice that much that I can't do. It's just that it's a bit harder to do some things, but I don't have any problems with that. I don't have any problems taking part of my peers activities, I find my way around the small obstacles that I have. (Henry)

Furthermore, the respondent stated that their injured arm was smaller and shorter compared to their other arm. Someone stated they had a decreased movement in present days compared to how they remembered the arm before the surgery.

Exercise

As they have grown older they are more aware of the purpose of *exercise*. The adolescents strongly felt by doing exercises, it would stop them from getting worse at a later stage in life. As one of the respondents explained how she stopped doing her exercises and the reason for it was due to lack of interest:

I have been very careless lately with my exercise. In the beginning after the surgery I went to the physiotherapist maybe twice a week, but then I stopped. I just stopped going, you get uninterested in it and stuff. And now I haven't been in a while. I haven't even done my exercises, and it's like, now you regret it, and you know like, I should have done it. Because they [the medical personnel] told me that I have to exercise the arm for my entire life, otherwise it will go back to where it was before the surgery. (Bente)

Many of the adolescents stated the difficulties to find motivation to exercise and stretch the arm, something they thought had to do with the state of life they are currently in. They are instead occupied with other activities; i.e. school work and friends:

I think about every day, that I have to do the exercises. And I had it as a routine, you know since I had the normal routines of going to school and stuff. So I did my exercise every night. And then, every summer I stop, because all of my routines are then gone, and then it's really hard to come in to it after summer, and then I always feel bad about it, because I think of it every night, and then I'm like Oh well, it's been too long now, and like I haven't done it in a while, and it's hard to start again. Aarrh, Gosh, I really sound lazy, I don't know what's wrong with me. (Anna)

A common opinion was that they have a lot of own responsibility for their exercise and where some found it easy to find motivation to train and exercise, others had a hard time finding this motivation and were troubled with guilty conscience everyday they did not perform any exercises or stretching:

Of course, I always know that I have to do my exercises. It's always in my head. And you just, like... I can feel it [the arm] become more stiff, I feel it. It's very hard. I have a really bad conscious about it. And I've told myself, I really need to go to a physiotherapist, I have to do it, but then I never do. But now, I have to do it! Because, it feels so bad that I have gone through with the whole surgery, and now I can't just be bothered. Not all are so lucky that they get a surgery and have the possibility to make it better. But I want to know, now when I haven't done anything, if it really does gets worse. (Bente)

They all believed that it was important to do stretching and exercise every day not to be worse or to get pain - '*When I do my exercises I can use my arm better, the function and the movement is better*' (Fanny) where someone else said she could always improve the function and strength of the arm with exercise.

Social relations

The cluster '*Social relations*' was a dominant and recurrent topic the adolescents talked about. Almost all of them experienced good supportive social network,

both when it came to families, peers, staff from school and from spare time activities. They expressed that their parents supported them and pushed them to do exercises, but the adolescents were aware of the responsibility of their own body and did the exercises (or the lack of it) without their parents' involvement. As the adolescents had grown older, the parents' role as reminding them to do the exercise decreased. All of the respondents said that their families helped with a lot of practical chores in the beginning after surgery:

My brother's girlfriend and my mom had to help me with everything. I couldn't do almost anything by myself. (Gilberte)

Throughout the years, their friends and peers had treated them like anyone else, and not special because of the birth injury. The adolescents expressed that their peers did not fully understand the whole meaning and consequences of the injury and someone explained that the friends cannot see or understand when the respondent had pain in the arm, and did not want to talk about it openly, the person wanted to fit in and not be different, and thus never told its peers about the pain that would come in some situations, but once the person told the peers they respected and accepted this. Additionally, they felt that their peers showed them respect if they could not do all activities, get pain, or have to stretch in the middle of an activity. All of them expressed that they had good, supportive, curious friends, despite how they felt about the experience:

When I had my surgery, I was just going to start 7th grade and a new class, and I had to have the brace for several weeks, that was kind of hard. But everyone was very nice to me, so I didn't mind. Maybe I was lucky, I think it could have been worse, but I came to a very nice and kind class, so it was like, well people called me The Plank for some weeks, but then they forgot I had it [the brace](...) But I had to sit at the end of the table at school, so I didn't bump in to anyone (...) I thought it was a little bit embarrassing to have it [the brace]and I thought it looked a little bit weird. Especially when you are like thirteen, in a new class. It's not the best impression on people you want to make. (Cecilia)

They did not feel excluded from social activities and relations, no one had experienced any bullying except for some minor events where their peers had interfered, and almost all of the respondents did not experience worse school results than peers, due to their injury. Some of the respondents had important roles as role models within their school and community based on their injury and some were presently active in school organizations against bullying:

It's such a super cliché, but I think everyone is different, and it's like I have one of those things that people don't really know and see at a first glimpse. (Diana)

Some of the teenagers had told their closest peers and teachers about their injury with a purpose of prevention; however a lot of their peers did not know they had an injury:

I don't think that people notice my injury. I told a friend today, because she was wondering what I was supposed to do today, and when I told her I was going to this thing [the interview] she was like "What, you have an injury? What is it?" and I've known her for many years and she hadn't noticed anything. And I was like, well I can't move my arm and stuff. (Cecilia)

Some of the teenagers explained how they had used the injury when they were younger to get sympathies from an older relative and thus a gain from having the injury:

I remember when I was young, I got a lot of attention, and I sometimes used the arm to get it. I could say to my grandmother like 'Oh no, my arm is stuck' or something, and my grandmother was like 'Oh no!' And I was like, 'it hurts so much, it hurts'. But I wasn't in pain. And then I got her attention. So, it's been like that. Really. I have taken advantage of the situation. But once I had the surgery, it was no more fun. And not when you get older either, just when you are younger. (Bente)

Disability and normality

The cluster of '*disability and normality*' included sayings as '*I am like everyone else, but special*' (Emma), referring to her injury as a special part of her, but in all other aspects they were like their peers. All adolescents referred themselves as normal teenagers; doing what everyone else in their age would do: go to school, spend time with friends and attend physical spare time activities. A common view was that they participants did not feel that they are handicapped or disabled – being handicapped was someone's own experience of thinking something is difficult or hard:

I think being handicapped is something you feel yourself, if you feel like, something is hard with the way life is for you, well, then you might see yourself as handicapped. If you feel that you are handicapped, then I think you are handicapped. And if you feel like, there's no problem, I'm fine, like, I don't have any problems, and then it's not a handicap. Then there's nothing that bothers you, so you're like, okay. (Henry)

Some of the teenagers also had associations of the need for help if one was handicapped, and placed themselves away from that term:

Being handicapped to me is when you can't, like, do the everyday things in life, when you have to have help. So, I wouldn't say I'm handicapped. (Fanny)

Essence: Disabled or have disability

The essence of '*Disabled or have a disability*' consisted of the adolescents defining themselves not to be disabled, but to have a disability. In their experience, *being* disabled was something that would define them as a person,

which this injury did not, and *having* a disability or an injury, which they all considered themselves having, was only one part of their whole life situation:

I think of it as an injury. Not as something I am. It's not like I'm sick, and it's not my identity. I think I've always said that I HAVE an injury. The injury doesn't define me. I wouldn't mention it if I have to tell anyone about myself. I don't see myself as a plexus injured person. Even if that's what I am... I don't identify myself with it. I just see it like something I HAVE. I AM a person. I AM injured sounds more severe. Maybe it is because I don't think about it every day that I say that I HAVE it... (Emma)

Their injury was one thing among other things and experiences, and not something that defined them or made up their persona or said something about them as persons:

Well, if I would to think that I AM disabled or AM plexus injured, it would be more as if it would define me. Like, I AM blonde, I AM injured. But to say I HAVE a plexus injury, well, it's more like, it would be something of less importance. Otherwise it would sound more like a handicap. It would sound more serious, and it's not me. (Cecilia)

They also believed that being disabled had more severe consequences than their own injury, and thus would not relate to it:

Disabled... For me it is when you can't walk. You're in a wheelchair. You can't do anything by you self. And I can. Most of it anyways. So, I wouldn't say I'm handicapped or disabled. (Emma)

Something the adolescents talked about during the interviews whether they consider themselves to have an identity as disabled. They did not want to see themselves as disabled or handicapped, but normal teenagers with life situations similar to their peers without an injury:

I have a handicap. Before, I used to identify myself like being handicapped, but now it feels like I have one. But it's not something that identifies me, it's just a small part of me. (Diana)

Professional medical contacts and experiences

All respondents had their surgery at the set hospital, but had different experiences in the rehabilitation phase. Some of the adolescents were dependent on the habilitation centers at their home municipality, whereas some used the set clinic for rehabilitation. All respondents were given a brace and had medical follow-ups at the set clinic. Their experiences of the professional medical contact varied between them. Hence, this is the second meaning unit; '*Professional medical contacts and experiences*'.

Satisfaction

In general, most of the informants were *satisfied* with the surgery, the result of it, and the contact with medical staff at the set hospital where the surgery had taken place:

Every time I went to the hospital, they were very friendly and nice to me. The doctor, the nurses. I remember thinking of them as very sweet. I now think that it is funny that I thought about them like that. I've always been greeted very friendly by them. (Emma)

They expressed feelings of being seen and taken seriously. They remembered the satisfaction of choosing the colors of the brace, and thought of it as well adapted to children. They felt encouraged by the doctors and health care personnel; validating them and motivating them to further exercise the arm:

I've never felt like it was difficult and hard to be there [the hospital] or been afraid or anything. I've felt very comfortable all the time with them. (Emma)

Another respondent had embraced the experience by naming one of its' teddy bears after one of the operation room nurses. The brace however, was difficult and annoying:

Walking around with the brace was so hard. My grandma had to redo my jackets and sweaters so I could wear something. I couldn't have a normal jacket, because the brace went from my belly out to my elbow, so there was no chance I could have a normal jacket on. I couldn't even carry my own tray at school at lunch time. It was very hard. It's worth it [the surgery], but the hard part was the brace. (Emma)

Some questioned the efficiency and necessity of the surgery, but many experienced themselves being well-informed about the surgery, and told the researcher that the rotation of the arm would have been worse without the surgery and they were very aware that the surgery made their rotation of the arm better. They were descriptive when they explained to what extent they could move their arm prior to the surgery and after. All experienced increased movement in their arm and that they could do more with it after surgery:

I didn't really think about the limitations my arm had before the surgery, but afterwards I could feel the difference and it was very positive. (Henry)

Many of the teenagers presented thoughts of how it would be if they had the surgery at an earlier age, and questioned why this did not happen to them. They reflected on that the later on in life they had the surgery, the worse it would be. They would rather have had the surgery as early in life as possible; preferably when they were toddlers:

I can now think that it would have been good to do it as early as possible, so it was just over and done. Because the thought of the brace, it just gets harder and

harder the older you get. If I would have done it today I don't think I would have gone to school! (Bente)

The individuals that perceived that they had gotten information about the surgery, expectations and rehabilitation were the ones who also were satisfied with the surgery and the result of it. The ones that felt they were lacking information were somewhat dissatisfied with the surgery and the result. However, all adolescents asked for more aimed information, both written and oral. Someone stated that they prior to the surgery did not get enough information, that the information had been aimed mostly to the parents:

I remember thinking that I didn't really understand why I had to have the operation, I told my mom that I didn't want to do it, because I was afraid of the anesthesia, and I had never been anesthetized, and I thought that was a little bit scary (...) I wish now, that someone had explained to me what the surgery was about. Like, in a child friendly way. What's the reason? (Emma)

Requests

Under the cluster of '*requests*'; a recurrent subject the informants talked about was their requests and desire to have more information in this stage of their lives; medical information about the injury, tips and pointers of how to train and exercise the arm now, and share information and experiences with others with the same disability and how they experience their own impairment, as they have not met others with the same disability. They also request information about how common the injury is, motivational tips, and how others have coped with it.

The adolescents also asked for a systematical follow-up with doctors and physiotherapists to their adult years regarding how the arm is functioning, as well as guidelines of what to think of to maintain and improve function and mobility. They expressed insecurity about the function of the arm and wanted check-ups regularly to validate and confirm the progress, or if something needed to be adjusted or added to their exercise regime.

All the informants wanted the health care to initialize contact with other adolescents with the same injury, to exchange experiences and learn from another, as they had not met and talked to anyone else with the same injury. Something that was apparent was that none of the respondents had met any other individual with the same injury; although two had met another child with the same injury very briefly. This was something most of them were interested in doing as they wanted to know how they had experienced the injury, how they had coped with it and what solutions and adjustments others had made and used.

Hospital and surgery

The adolescents stated that they were pleased with the '*hospital and surgery*':

It was fun coming to Stockholm and the hospital. I came there once a year, but lately it's been once every other year. And I've always been interested in everything there, and to learn more about my injury. But I haven't had that much habilitation and hospital visits close to my hometown. I had some when I was little, but nothing as I grew older. I've missed that since I want to know more things, like what I can do to strengthen my arm (...) it really felt like the personnel knew what they were doing. And they could explain everything to me. (Fanny)

Most of the adolescents would recommend other children to do the surgery, as they thought that the benefits were bigger than the problems regarding surgery and after-care.

Habilitation

Almost all of the adolescents experienced that their *habilitation* was not adjusted for their needs, and that the habilitation staff lacked knowledge about their specific situation and disability. The adolescents expressed their dissatisfaction with the habilitation centers outside the hospital as they did not receive satisfying help and support. The adolescents reported that the habilitation staff lacked understanding about the specific injury and the needs for habilitation and individual demands and requirements when it came to habilitation programs and activities:

'My physiotherapist at home didn't know anything about my injury, but she knew different exercises, and she helped me with them (...) I've actually asked for more help now, and I just met with a physiotherapist three times and she helped me with exercises that I could do now, because I really felt like that was important'. (Fanny)

Individuals that only went to the set hospital for rehabilitation and not to a habilitation center were pleased with the contact; someone said: '*They had adjusted the exercises for me, maybe because I was younger, and it was fun things to do*'. (Emma)

Essence: Then and now

The essence of '*then and now*' refers to how the adolescents experienced the professional contact in past and in present time, where most of the experienced good contacts around the time of the operation, both prior, during and right after, whereas they experience almost non-existent support and contact today, and feel as they are somewhat on their own without present regularly contact, neither with the hospital, nor the habilitation. All the adolescents spoke and reflected on

the concept of time, and how their view of themselves and their body and injury had changed over time. They were aware that they had great responsibility for their arm and they were more mature now regarding the function and necessity of exercise so the arm would not get worse.

Adjustment and strategies regarding solutions and obstacles

The adolescents had their injury since birth and they were all competent and autonomous teenagers. Due to their palsy they did certain activities in a different manner than their peers and family members. None of the adolescents were dependent on their surroundings to lead a life which they desired; they did not use any professional assistance or medical means of assistance. However, when they compared themselves to others they could see that they did things slightly different, they analyzed the reasons for this and stated that they did not have anything else to compare to as they got their injury at birth, leading to the third meaning unit; *'Adjustment and strategies regarding solutions and obstacles'*.

Personality traits

Most of the adolescents had themselves thought of solutions of how to face and encounter problems and how to solve them. The cluster of *'personality traits'* describes how the adolescents used their own personality traits to come up with adjustments to the obstacles faced. Some of the adolescents had however thought of new strategies as they grew older to adjust for the disability. Many of them had become more aware of their limitations as the years passed and were now more conscious about limitations and deviant appearances of the arm: *'I hide my arms in photos, or try to stretch it out. I use long sleeved shirts all the time'*. (Gilberte)

The adolescents used their healthy arm to compensate for the lacking function and movement from the affected arm:

I try to carry things with both hands, like treys and bags, and I try do a lot with my left hand [affected side], but I'm much stronger in the right hand. (Anna)

Another participant said that when doing exercises at the local gym, they positioned their whole body in a manner which would ease the burden on the affected arm. With information from physicians and physiotherapists some of the adolescents expressed how this compensated the fear of doing certain activities, because they would then know that for example building muscles and

strength in the arm would decrease the risk of getting a new injury in the already affected arm.

Others explained thoroughly in the interview how they had supported their injured arm on a bookshelf in order to put their hair in a ponytail, or how they used different furniture in their homes as a tool to be able to perform certain daily activities.

Social network

Another cluster is '*social network*' which the adolescents used for some practical chores and tasks, and to compensate for their limitations, mainly in the first period after surgery. As time went by they mostly managed to do everything they wanted by themselves, they had learnt to adjust based on their ability and they used their network as a additional source of coming up with new ideas of how to perform activities and adjust to their specific condition and function:

The arm locks itself in a certain position, it can't go the whole way. So I can't do the last bit when I exercise, it's things like that. But I meet with different personal trainers, so we come up with different exercises, we solve the problem. Together we find other solutions, but there are certain exercises that I can't do'.
(Henry)

All participants received good social support from friends and family, they received help without asking for it, and sometimes without thinking of it:

There are things, like heavy lifting, which I can't do. I can find alternative solutions to most of the things, but there are some things which I can't do. I have to ask someone to help me then, which they do. (Gilberte)

Essence: Lack of references

Many of the adolescents '*lacked references*', which is the essence of this meaning unit, and stated that they do not have anything else to compare to as they have had this injury since birth - and have not had an unimpaired body, and hence not reflected too much on activities which they could not perform.

The essence: The experiences taken together

Based on the interview results, the previous research and field of knowledge, together with the theoretical considerations and conceptual framework, an analysis was made on these eight adolescents' experiences of having and living with an arm impairment due to a birth injury. The essences from the results and the different meaning units '*Me and others*', '*Professional medical contacts and experiences*' and '*Adjustment and strategies regarding solutions and obstacles*'

are respectively '*Disabled or have a disability*', where the adolescents defined themselves not as disabled, but they considered themselves having a disability; '*Then and now*' of how the adolescents experienced the professional contact in past and in present time, which they were pleased with in the past but wanted more information and follow-ups at present days, and '*Lack of reference*' where the adolescents stated that they do not have anything else to compare to as they have had this injury since birth. Important tools for analyzing were also in terms of lifeworld, and phenomenology of the body, which will follow after the essences.

Disabled or have a disability

Zola (1993) described the differences of the verbs 'be' and 'have' which also the adolescents describe regarding being disabled or having a disability. They do not want to 'be' disabled, to 'be' injured, or to 'be' handicapped as they do not want it to define them, but feel more comfortable describing themselves as to 'have' an injury or to 'have' a disability. This description of themselves are very important as this says a lot about their identity and their self-image.

The adolescents in this study talked about how they could participate in sports and leisure activities; they went to the gym, did yoga, danced and played handball to name a few. Although they stated that they did parts of the exercises differently or not at all, they still participated in the whole activity. Referring to van Amsterdam et al. (2015) they challenged the discourse of only abled bodies participating in these activities and did not accept to be left out on sports activities which they wanted to do. They were all in mainstream school and sport activities, and were able to perform the task, even though they did not participate in certain physical activities due to their limitation.

Regarding identity the adolescents in this study showed how they incorporated their injury in their own identity, letting it not define themselves as being disabled or handicapped but having the sense of being like everyone else and being normal. This form of 'normalization' entails either acting as if the injury has no impact on life, and thus putting it in parentheses or else integrating it into one's life. A disability which is highly visible can cause tension between the person's private self and public social identity (Beaty, 1992), which is not something that these adolescents experience, they can be who they want to be. People with different disabilities constantly negotiates and reverses the meaning

of their injury, and the social context decides how to use the language (Zola, 1993); where in the private circles the affected individual can make jokes and refer themselves as something which they not normally do; as does some of the respondents when they are with their friends and then describing themselves as handicapped, which they normally do not. Something that is evident though, in the interviews is that the adolescents themselves choose how and what to describe themselves as, and are not dependent on the surrounding environment to describe them or falls into what others believe about them. They state and choose their own description of their injury, they tell the ones they want to about it, and they define themselves with appellations they feel comfortable with.

The term bodily difference (Hansen and Philo, 2007) in normal populations may be a valid thought regarding these adolescents as they do not personate themselves with terms as neither being handicapped or disabled, nor having a handicap, but by being normal and being like everyone else. By naming it bodily difference, it creates a society built on acceptance and differences within the normality term are more tolerable. Hence, by purposely viewing it as the 'normality of doing things differently' a greater acceptance and tolerance can be built. These adolescents acted in accordance to this, they knew they did things slightly different, but still considered themselves being normal teenagers.

Biology may not determine our destiny, and that we must seek a transformation in the connotations and the generality of the names we add to ourselves, without denying the essential reality of the conditions we might have (Zola, 1993), which is something very important to learn from these adolescents; they do not let their injury define them, although they are aware of the consequences and results of having it. Variations in physical condition do not necessarily correlate with psychosocial wellbeing (Livingston et al., 2007), which is also implied in this study. These adolescents were satisfied with their lives, and their physical obstacles were not of great importance to their general wellbeing and quality of life.

Regarding family and peer support, conclusions can be drawn that the impact of peer relations for people with chronic illnesses, as Helgeson and Holmbeck (2015) describes, is well in sync with the adolescents of this study. They experience similar classmate support to the study of Mentrikoski et al.

(2015), which in this study also was associated with a higher self-concept and fewer social difficulties regarding youths with this injury. The individual and the immediate family was affected by the injury, especially early after surgery which correlates to the social impact Wojtkiewicz et al. (2015) mentions and the impact of the injury on families which Loudon et al. (2015) describes. Family represents the first line of affective and material support, and they are essential in helping the individual in the first stages after the surgery, but also to cope with having the injury and the consequences of it. The adolescents were homogenous in this part, as they experienced very good support from their immediate family, as well as other family members and relatives.

The narratives in qualitative studies can be referred to as reconstructing a life story and a sense of self, and can also be used to explain a collective experience via the accounts provided by the individuals (Pierret, 2003) and in this study the experience of living with a BPBP is being seen from a holistic perspective and focuses on the diversity of experiences of living with this.

Then and now

A self-help group is something that is asked for by all adolescents in the study, which can be used as an additional resource for them. They want the health care to initiate such contacts. These groups can provide an alternative to the medical viewpoint (Pierret, 2003), and information regarding the specifics of the adolescents. Youths with impairments have been shown to feel a sense of belonging with their peers with the same condition (Magen, 1990), and this is something that is evident here as the adolescents request such contacts to exchange experience with each other and establish a feeling of belonging. Most of the participants in this study are female, this correlates well to the influence of support groups is important for young women with physical impairments and their sense of belonging (Mejias et al., 2014). The result of the study enables the health care in different levels to improve the care, needs and wishes for these patients and families that will be in need for the surgery in the future. The individuals who have participated in this study acts as informants to the health care and provide it with important information.

Lack of references

As a result of having an injury, everyday activities are threatened, and thus the individual risks being stigmatized. Managing the stigma involves working out strategies as a function of social circumstances and situations (Pierret, 2003). The occurrence of stigmatizing or demeaning of disabled people (Hansen and Philo, 2007) would not fit in with the adolescents of this study, as they consider themselves to be well treated both by their peers, teachers and employers: they do not experience any pressure to perform beyond their limits by yoga teachers or physical education class teachers, they have not received a lower grade in school due to their injury. In these aspects, the adolescents have not been forced to fit in to a non disabled society, but have been accepted as they are, with their limitations. Contrary to how Hansen and Philo (2007) describes as only the non-disabled bodies have a natural way of appearing in everyday places, the adolescents of this study experience that they do not have limited accessibility to public spaces and activities; they express that they fit in to non-disabled arenas, although they adjust their activities, and to some extent can show that disabilities can look differently and that a disability should not hinder them from participating in activities they are interested in. Their lack of references, as having the palsy since birth, perhaps helped them in these contexts, as they do not have anything else to compare themselves to, and thought of themselves similar to their peers.

The adolescents did not experience their injury as a limitation and expressing having a stable and good life; in other words, their quality of life was high, which can be compared to studies made with adolescents with other physical impairments and their experienced quality of life (i.e Dahan-Oliel et al., 2011, Noyes, 2006, Schaefer et al., 2013). Nizzi et al. (2012) focused on how bodily changes in experienced identity affected their adolescents, and conclusions can here be made that although the body of the adolescents in this study is different than to their peers, their body does not define their identity.

Youth with BPBP might encounter circumstances that negatively affect their psychosocial adjustment owing to the nature or severity of their injuries, i.e. difficulties in performing everyday tasks (Alyanak et al., 2013, Mentrikoski et al., 2015, Strombeck and Fernell, 2003), but these adolescents seem to cope very well despite their injury. Protective factors against these

circumstances seem to be well functioning and adequate social support networks, and frequent use of positive coping skills.

Hansen and Philo (2007) states that the disabled person always needs to voice their disability which is also prominent in the adolescents of this study. The respondents here state how they tell different school teachers and friends with a preventive purpose about their injury, so they do not have to see this when an activity arises which the adolescents cannot physically do. Something that occurs is how and why a non-disabled person do not have to express their ability, but somehow this is needed for a person with a disability. It is common to negate or deny one's disability (Zola, 1993); this is integrated in statements as the adolescents say: 'I never think of myself as handicapped', whereas the meaning of the adolescents was more that they are so used to their injury and do not have anything else to compare with.

Lifeworld

The lifeworld describes how it is possible to know other people's experiences and life, and understand how their perspective of the world is (Bengtsson, 1999), The lifeworld of the adolescents was that they had a meaningful participation in life and considered themselves being normal teenagers and human beings. Their lifeworld is their subjective reality, how they view themselves in the context they are in (Thomassen and Retzlaff, 2007). The focal points of their reality and lifeworld were not their injured arm – this was something which in periods they would give much consideration, especially around physical activities which they could not participate in, but most of the time did not reflect upon. They did not experience big limitations due to their arm, and were able to take part in social activities, had good social support systems. Their injury was not something that identified them, it was only one detail about them – something they did not neither think nor talk a lot about with their surroundings. However, they believed in the power of exercise and wanted to keep doing this in order to keep the arms physical ability. Their lifeworld was that they were normal, abled individuals, just as everyone else.

Phenomenology of the body

When analyzing through the phenomenology of the body, one can conclude that the adolescents only have their body. They have not gained their injury

traumatically, but at birth, and hence have nothing else to compare with. They have no recollection of having a “non-injured” or abled body. They view themselves through their body – they are their bodies. The body is the subject of the personality and it is through the body the consciousness takes place. It is with our bodies that we exist in the world, and though it we are connected with things and life itself (Merleau-Ponty, 1999). The adolescents of this study used and integrated their bodies in various ways, some were more open than others that they had an injury, and some tried to hide their arm more than others. In various ways they formed their personalities and identities based on their injury and the experiences thereof. They used their body as examples of showing different categorizations of bodies, and could use their bodies in social contacts with others. They experienced some physical limitations of what their body could do and perform, but would not let these limitations decide how they would lead their lives. They were in general grateful for this injury and not having a more severe injury with more consequences for their consciousness, mind and soul. Our perception of the world is based on our own bodies’ perspective (Merleau-Ponty, 1999) and this corresponds well to these adolescents.

Conclusions

One research questions of this study was how the adolescents experience their lives with respect to studies, spare time activities, relationships – with peers and others, and quality of life. Another research question was if they experience any limitations compared to their peers due to the injury, and if so, how. Finally, the last research question was how the adolescents experience their health care, and if there is something that could have been done differently. Looking at the information from the adolescents and analyzing it together with previous research, one can tell that the adolescents are enjoying their lives regarding studies, spare time activities and relations, and have a high quality of life. They can participate in all activities, and are not excluded from anything. They accept their injury and are well integrated in society, and do not feel as this injury defines them as disabled, but having a physical disability. They experience a high quality of life, and can do activities, both in school and in their spare time as their peers. They experience a rich social network with good support. However, there are certain physical activities that they cannot perform, and want to become better at this. They find personal solutions to the physical obstacles

and use their social network for mental and practical support if there are certain things they cannot do. They consider their health care contact positively, regarding the hospital and the care around the surgery. However, they want more information regarding their injury and suggestions for exercises, they want more regular follow-ups, and want the health care to initiate contacts with other adolescents with the same injury to exchange experiences. These adolescents seem to cope very well despite their BPBP. Protective factors against negative circumstances seem to be adequate social support systems, and frequent use of positive coping skills.

8. Discussion

After conducting interviews with eight adolescents with brachial plexus birth palsy, and analyzing the results together with the theories and previous research, conclusions could be made of the impact of the results. Data was analyzed through a phenomenological approach. Three meaning units emerged from the data: *'Me and others'*, *'Professional medical contacts and experiences'* and *'Adjustment and strategies regarding solutions and obstacles'*. The essence of this study are *'Disabled or have a disability'*, *'Then and now'*, and *'Lack of references'*. The answers to the research questions are that the adolescents are well-adapted to their injury, are well-functioning regarding both activities and relationships. They experience certain physical limitations and want more information, follow-ups from the health care. They want to come in contact with others with the same injury.

As stated in this thesis there had been limited research prior to this one, regarding the chosen perspective of the patient group, both nationally and internationally. The result of this study showed that the adolescents had good function and self-esteem similar to research in close fields (i.e Erosa et al., 2014, Metzger et al., 2011, Pakenham, 1999, Shikako-Thomas et al., 2009, Stiffman et al., 1999, Tsao et al., 2007, Wolke et al., 2013), but better quality of life than other studies (Harper and Richman, 1978, Anderson et al., 1982, Goldberger and Breznitz, 1982). They experienced capability and ability to do almost all activities they wished and did not think of the injury at a regular basis, except the need for exercise throughout their lives. They are adolescents of their generation; trying to find information online and researching about their situation on their own. As it is such a small patient group they had little

experience in meeting others in the same age with the same injury. The result of the study shows that these adolescents are well-functioning in different parts of their lives; social networks, personal self confident, and ability to perform different physical activities. The adolescents reported satisfaction psychosocially, had some aesthetic concerns of the arm and the scar from surgery, had good social network and support, experienced good support in the beginning after surgery from health care, although wanting more follow-ups and more aimed information, and were satisfied with physical results, even though they expressed wishes of improved physical function in activities where they experienced limitations. They experienced a good quality of life, despite or because of the injury. Surprisingly enough, these individuals showed a higher quality of life, and experiences of wellbeing and bodily function than the researcher had assumed, based on her previous experiences in meeting individuals with a BPBP injury in her role as a social worker at the clinic.

There are some limitations to consider in this study. Firstly, the sample size is small. Information letters and written formal consents were sent out to 19 adolescents and their parents, and only nine adolescents replied, eight wanting to participate in the study and one declining to participate. Something that is of valid thought is who of the whole population of 19 individuals accepted to be a part of the study and wanted to be interviewed; was it the individuals that were the most satisfied with the result, the ones who thought it was fun, or did not have any difficulties to talk about their experiences, was it the ones who felt as they had to give something back to the health care? And who were the ones choosing not to participate, and not responding to the letters of information. Secondly, there was only one interview for each participant, which means that they only gave information once, and there were no follow-ups. Thirdly, no control group was used, neither was there any comparisons over time, nor a before- and after examination. In studies with a distinct user perspective, and with this study design, no conclusions about causality can be made, as the researcher cannot control for other aspects in the person's life affecting the answers and results given in the interview.

There are difficulties to draw conclusions of generalizability to other adolescents with the same injury, or adolescents with other disabilities based on the results of this study, which is not the aim with phenomenological

studies as this: the aim is to examine the phenomenon being how it is living with this specific injury for these individual given their context. The results of this study are only applicable for these adolescents. As the aim of the study is to reach a greater understanding through collecting these individuals' experience of the injury the researcher took into account their different opinions, thoughts and reflections. Naturally, the researcher had ethical considerations to make during the process of the thesis and they were dealt with an ongoing concern.

Due to the various character, results and focuses of the studies the researcher found through searches in scientific databases, it is difficult to compare and contrast them with each other regarding theory and methods. However, many of the studies use semi structured or structured interviews to collect their empirical data. Mejias et al. (2014) used qualitative semi structured interviews to get their empirical material. Pakenham (1999) used semi structured interview schemes and questionnaires where both the patient and the caregiver answered these. Stiffman et al. (1999) used structured interviews. Ho and Ulster (2011) used questionnaires which the families replied to after participating on an information day about obstetrical plexus injury.

Qualitative research, which this study is consists of, is known for interviews and through it lies possibilities to focus on an event or a certain phenomenon. Qualitative studies are founded on the ascertainment of existence; phenomena which are difficult to grasp such as experiences, feelings and intentions (Ahrne and Svensson, 2015). The aim of the study is to look at adolescent's experiences of having a birth injury in the shoulder/arm and therefore a qualitative approach is chosen, as it increases the possibilities to a flexible research process and closer relationship to the participant adolescents (Ahrne and Svensson, 2015).

Interviews with a theoretical framework within phenomenology are structured mostly as a permissive approach towards the participant, with easier questions as well as the possibility to collaboration and active listening (Ahrne and Svensson, 2015, Szklarski, 2015). This type of method is usually referred to as semi-structured qualitative interviews, where the interviewer have the possibility to use recurring, set questions which are complimented by more situation based questions to reach a more descriptive image of the experiences the adolescents have. Even the order of the questions during the interview is not

set in semi-structured interviews (Ahrne and Svensson, 2015). The balance of starting the interview with a concrete set of questions and meeting the respondent's answers with open situation bound questions decreases the risk of letting the participant talk about more general issues (Ahrne and Svensson, 2015). How we chose to formulate the interview questions could have affected the response we got from the respondents, which affects the credibility of the material. During the interview it is hence important how the interview questions are put, and what answers these generates. Through qualitative, semi-structured interviews there are several occasions where the interviewer can explain the questions with different words so the person has the possibility to reformulate answers to create a deeper understanding. If the interviewer in the follow-up questions uses words used by the respondent, it creates a sense of safe environment and a collective interest towards the subject (Ahrne and Svensson, 2015).

However, there are certain negative features of interviewing that should be mentioned, as it deals with qualitative aspects. An interview can only give a limited version of the situation. Interviews may not conclude all that is essential for the given situation, as well as there could be a possibility that the statements given will not be entirely true. Another difficulty is interpretation of what is said, as experiences can be built by assumptions, as well as how the researcher chooses to interpret the meaning of the statement (Ahrne and Svensson, 2015). Positive aspects of interviews are to get an insight about experiences and important factors. The aim of the study was to look at the experiences adolescents with a BPBP have. By using interviews as a method it enabled these adolescents' experiences to be focused on, as another person's perspective can only be interpreted if the person oneself describes it's perspective (Ahrne and Svensson, 2015).

The interviews are comprehensive and postulate both commitment to the task, endurance and the ability to formulate ones experiences verbally. Hence, it is likely to assume that participants, who have agreed to the interviews, are the ones who find it easy to express themselves, are reflective, and have the most prominent opinions, both positive and negative. Also, something to take into account when analyzing the interviews can also be the whole interview session with its purpose and how it is conducted; it would maybe have been

different answers and results if the aim of the study was different. The lack of responses in the population could depend on that those individuals do not want to talk about their injury, and thus have no intention of participating in studies of this character as this would lead to admitting that they have an injury which creates a disability, and the information letter and the fact that they are asked to participate leads to feelings of enlarging their disability and hence reducing their feelings of being normal.

Even though the theoretical framework is phenomenology, a weakness in the study and method could be that there are few set questions in the interview guide and this could possibly hinder the participants in expressing their full opinion and experience. This is, however, combined with interview questions with an open questions method where the participants can respond freely and openly. By using open questions the answers can more easily relate to the theoretical framework of phenomenology. The researcher has to formulate the questions with an open, unbiased and unprejudiced approach (Peterson et al., 2006). The interview guide was constructed based on the four research questions. It is crucial that the researcher is aware that the participant of the research - in the role of respondent as well as patient, is in a power relation with the researcher and medical staff where the researcher/medical staff has the advantage. The researcher is asking the participant to expose details about one's personal life and at the same time has the advantage to interpret the data. The researcher worked carefully with the study guide before conducting the interviews. During and after the interviews the respondents had the possibility to affect the material through further questions and explanations. The respondents were sent the written transcriptions for comments and verifications, but none was sent back to the researcher.

An important purpose of the study was to get an improved knowledge about these individuals' life situation based on their injury/functional disability, and their experiences of the healthcare input. There are some implications for the medical care. Thereby, the possibility to improve the medical caretaking and increase the participation of the patients in the healthcare can be provided. For example, the healthcare can avoid or improve treatment situations that are thought of as negative, efficiently support the individuals and their families psychologically and socially, and plan follow-ups and

rehabilitation programs so they are helpful when it comes to participation and motivation.

Medical caregivers are in need of greater and deeper knowledge of the patients' own perspective. Based on the experiences of youths, the medical staff can purposely and meaningfully create and design treatment which better would fit the needs of the individuals. Having a wider focus than the purely medical aspects may also give the adolescents a chance to influence the treatment and increase the knowledge necessary to improve an already well-functioning medical treatment. Through better understanding of the needs and experiences of the adolescents, medical staff will be better equipped to provide support for these persons in a broader sense than with merely medical aspects. Greater knowledge would be useful as it could be paid forward in for example a specific and aimed day of information where medical staff could inform about medical options, rehabilitation treatments as well as it would be a forum for the adolescents to share their experiences of having a plexus injury with and to each other. It would also empower the adolescents in the given situation.

Assumptions can be made and transitioned to the specific hospital department based on the empirical data about how it is living and coping with an injury such as this one. This knowledge will be valuable to medical staff when they design treatment program for new patients in order to give them the best support and treatment there is. As the patient always have to be in focus, and with a child perspective as it is in this study as the respondents are minors, it will influence medical staff and guide them to take into consideration a perspective which is rare, yet very important, to focus upon. This study will give medical caregivers firsthand information and knowledge about these patients, and will be a means to affect treatment and support for this patient group.

As it is a rather small patient group the health care can probably provide a forum for these patients where they could meet each other and at the same time get more information about the disability and exercise programs, coping strategies, learn from each other, and also meet peers in the same situation and exchange experiences; something which might be difficult as these patients are spread across the country and perhaps do not encounter each other in daily life.

Lastly, some remarks about further research. This study has focused on a group with relatively mild injuries, all of whom had undergone a specific operation to correct a shoulder deformity. Similar studies need to be conducted for other groups with plexus injuries; e.g. those who have been operated on with nerve repairs, in particular persons with the most severe injuries which affect the hand function. Another group of interest would be adults with un-operated injuries, i.e. persons who sustained their injury at a time when surgical treatment was not available. Comparisons over time would also be interesting, following this and other cohorts over several years and seeing how for example social, individual and medical changes affect them.

Finally, based on the results in the study the adolescents with brachial plexus birth palsy define themselves as normal teenagers like everyone else in their age group, with a special experience of having this injury. They do not view themselves as disabled, but due to their functional disability they adjust and find solutions so they can manage and cope in their everyday life. They are interested in their injury and want more current information as they have experienced a lack of knowledge from the habilitation staff they have met. Keeping in mind that these adolescents have had this disability since birth and hence have nothing else to compare with in their own life, they will have this injury all of their lives and it will affect them in different ways in different parts of life. They are physically active and enjoying it, although they do not like to be pointed out at activities where they are not able to participate fully. They are satisfied with the surgery. Social relations are very important for children and adolescents with disabilities. The health care can learn a lot from listening to the perspective of these patients and their history and experiences. A study like this emphasizes the necessity in understanding and inclusion of people with different disabilities. Considering the statements the adolescents had regarding normality one can conclude that everyone is different and hence everyone is a variation of normal.

9. References

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Appendices

Appendix I

Informerat samtycke

Ja, jag har erhållit och läst informationen angående studien om ungdomars upplevelser av en plexusskada från förlossningen.

Jag har läst och förstått studiens syfte och genomförande och vill delta i studien.

.....
Namn

.....
Telefonnummer

Appendix II

Forskningspersonsinformation Studie angående upplevelser av plexusskada

Namn:

Adress:

Hej,

Vi är en grupp vid Handkirurgiska kliniken på Södersjukhuset som planerar att göra en forskningsstudie för att få mer kunskap om hur det är att leva med en förlossningsskada i armens nervfläta (s.k. plexusskada). Vi har i tidigare studier visat att rotationsfelställning i axelleden efter förlossningsskada i plexus med framgång kan behandlas kirurgiskt. Vi vet dock mycket lite om hur den som har en sådan skada själv upplever sin livssituation; hur armen fungerar, om skadan på något sätt påverkar kontakten med andra människor, och hur kontakten med sjukvården har varit. Väldigt lite forskning har tidigare gjorts kring sådana frågor.

Syftet med studien är att ge en förbättrad kunskap om hur speciellt tonåringar som opererats för en plexusskada upplever sin vardag och livssituation till följd av skadan och om deras upplevelse av sjukvårdande insatser. På det sättet kan vi förbättra det medicinska omhändertagandet och öka patienters delaktighet i vården: exempelvis att fokusera kirurgiska insatser på de funktioner som patienterna prioriterar, att undvika behandlingssituationer som kan upplevas negativt, att stötta psykologiskt och socialt på ett ändamålsenligt sätt och att planera uppföljnings- och träningsprogram så att de ger hög grad av medverkan och motivation.

Vi skickar denna förfrågan till Dig därför att Du är född mellan 1996 - 1999 och har genomgått operation vid Södersjukhuset. Vi har alltså fått Ditt namn genom att söka i vårt journalsystem. Vi önskar nu att få kontakt 10-tal personer, lika många pojkar och flickor, och hoppas att Du vill vara med i den här studien.

Om Du Väljer att vara med i studien kommer Du att intervjuas under ca en timme av Linda Häger som är kurator vid vår klinik, på en plats som vi kommer överens om. Tanken är att Du ska träffa en person som inte varit direkt inblandad i Din behandling, för att lättare kunna berätta fritt om Dina upplevelser. Intervjuerna kommer att bandas in för att Linda Häger sedan noggrant skall kunna gå igenom allt som Du berättar under intervjun. Banden kommer att förvaras i ett låst skåp som bara Linda Häger har tillgång till. Den här studien är en så kallad pilotstudie (förstudie), vilket betyder att det kan bli en annan, lite större, uppföljande studie med flera tonåringar som har samma skada och där Du också kan bli tillfrågad om att delta. Intervjuerna är halvstrukturerade med några teman som utgångspunkt, vilket betyder att Du kommer att uppmuntras att tala fritt inom varje frågeområde. Intervjuerna spelas in på band samt skrivs ut i text. Alla data (bandinspelningar samt pappersutskrifter) bearbetas och redovisas kodat (dvs. inga personuppgifter kommer att redovisas). Endast Linda Häger, som utför intervjuerna kommer ha en så kallad kodnyckel, alltså kunna se hur olika personer har svarat .

Vi bedömer att det inte innebär några risker för Dig att vill medverka i studien. Om Du vill avstå, så kommer det naturligtvis inte att påverka en eventuell behandling om du skulle behöva någon ny sådan i framtiden. Studien medför inga särskilda vinster eller fördelar för Dig men kan hjälpa andra i framtiden, som behandlas för samma skada. Om Du väljer att delta i studien kommer Du att ha en möjlighet påverka den vård och behandling som andra personer får, med liknande situation som Din. Din röst är därför mycket värdefull och dina åsikter och synpunkter är mycket viktiga. Om något kommer fram under intervjun, som kan föranleda en ny bedömning och ev. behandling av dig personligen, så kommer vi förstås också att kunna hänvisa dig till en sådan.

Svaren kommer att behandlas konfidentiellt, vilket betyder att Dina svar och Dina resultat kommer att behandlas så att inga obehöriga kan ta del av dem, inte heller kommer man att kunna identifiera Dig i studien då resultaten presenteras. Alla personuppgifter kommer att sparas i ett låst skåp som endast Linda Häger kommer att ha tillgång till. All uppgifter bearbetas, och beskrivs i en text, men ingenting kommer inte att kunna härledas till Dig eller någon annan av studiepersonerna. Dina personuppgifter kommer inte att föras vidare på något sätt till någon annan som inte är ansvarig i studien, eller på något sätt spridas till någon obehörig på kliniken, sjukhuset eller utanför sjukhuset. Ansvarig för Dina personuppgifter är Karolinska Institutet. Syftet med studien är att redovisa vad personer i din åldersgrupp upplever kring skadan. De personuppgifter vi är intresserade av är Din ålder, Din skadediagnos, personnummer, namn och kontaktuppgifter. Vi kommer att hämta dessa uppgifter från sjukhusets journalsystem. Personuppgifterna kommer att hanteras enligt Personuppgiftslagen (PUL 1998:204). Som forskningsperson har Du rätt att få ett registerutdrag och rätt att få rättelse av eventuellt felaktiga uppgifter. Uppgifterna kommer att behållas så länge vi behöver för att kunna genomföra den nu planerade studien. Om du önskar kommer du få ta del av den transkriberade utskriften av intervjun och läsa igenom den så att du inte blivit missförstådd. Studiens resultat kommer att presenteras i en vetenskaplig artikel i en tidsskrift, samt presenteras på internationella kongresser av dem som är ansvariga för studien. Ingen kommer att kunna veta att det handlar om just Dig.

När studien är klar och publicerad i en tidsskrift kan Du förstås få information om resultaten eller hänvisning till var Du kan läsa artikeln. Meddela någon av oss forskningsansvariga, så kommer vi kontakta Dig när studien är publicerad. Vill Du inte ta del av studien när den är klar så behöver Du naturligtvis inte göra det.

Väljer Du att delta i studien kommer Du att vid intervjutillfället formellt att registreras som öppenvårdspatient vid Handkirurgiska kliniken, Södersjukhuset. Därmed har Du samma försäkringsskydd om något skulle hända, som gäller för all vård i landstinget. Studien kan inte ge Dig ersättning för förlorad arbetsinkomst, men vi kan ersätta resekostnader om Du lämnar in kvitto eller reseräkning.

Att delta i den här studien är helt frivilligt. Om Du väljer att vara med kan Du ändå avbryta när som helst under studiens gång, trots att Du har svarat ja till att vara med i början och behöver inte ge någon förklaring till varför Du vill

avbryta. Detta kommer i så fall naturligtvis inte heller att påverka eventuell ny behandling, om sådan blir aktuell.

Om Du går med i studien och sedan vill avbryta, så kommer hela den insamlade informationen från studien om dig att destrueras och den kommer inte att användas i studien. Om du vill avbryta din medverkan ska du kontakta Linda Häger, se kontaktuppgifter längre ner i brevet.

Ansvarig för studien är Karolinska Institutet, som är forskningshuvudman och ytterst personuppgiftsansvarig.

Forskningsansvarig är överläkare Tomas Hultgren vid handkirurgiska kliniken.

Forskare, personuppgiftsombud, utförare av studien och den som kommer att intervjua Dig, är Linda Häger, kurator vid Handkirurgiska kliniken, Södersjukhuset.

Övrig forskare, som kommer att ha en mer handledande funktion är Katarina Piuva, docent vid Socialhögskolan i Stockholm.

Har du några frågor kring studien, kontakta ansvariga forskare.

Linda Häger: linda.hager@sll.se /08-6161526.

Tomas Hultgren: tomas.hultgren@sll.se /08-6162034

Katarina Piuva; katarina.piuva@socarb.su.se /08-6747381

Om du vill vara med i studien ber vi dig att skicka in den bifogade samtyckesblanketten, senast DATUM till

Linda Häger
Handkirurgiska kliniken
Hiss I, Plan 1
Södersjukhuset
Sjukhusbacken 10
118 83 Stockholm

Appendix III

Intervjuguide

Intervjuguiden är baserad på de fyra områden som vi fokuserar på i studiens syfte. Intervjuerna kommer att anpassas till hur respondenterna svarar.

- Berätta kort om din plexusskada och hur du upplever eller tänker kring den

Nedsatt funktion – Exempel och förslag på frågor:

Klarar allt som behövs hemma, i skola, på fritid? Avstå från aktiviteter pga skadan? Funderar de på om det påverkar yrkesval? Skadan inneburit något i positiv mening? Skadan inneburit något i negativ mening? Hur förhåller sig till skadan? Strategier/förhållningssätt?

Social interaktion – Exempel och förslag på frågor:

Kosmetik? Behov av extern hjälp? Fattas någon extern hjälp? Behov att förklara nedsatt funktion? Avstår från aktiviteter pga detta? Vill ha kontakt med andra i samma situation och i så fall under vilka premisser (enskilt, i grupp, via intresseförening, tillsammans med sjukvårdsrepresentanter som temadag)? Annan ansett att de är handikappade? Sagt nåt om det? Upplevt stigma? Utanförskap? Förnekat skada (eller nån annan)? Mobbning? Homogen grupp med plexusskadade? Stöttande nätverk? Reaktionen på skadan? Hur berättar du om skadan? Hur har omgivningen varit? Någon som tyckt synd om dig?

Interaktion med sjukvården och vårdinsatser - Exempel och förslag på frågor:

Är det över lag positivt? Förstärker sjukvårdskontakt känslan av att vara handikappad eller det ett stöd? Minns perioden före operation(er) och kan jämföra om det var skillnad före och efter? Kirurgin förbättrat funktion/livssituation/utseende? Skulle du rekommendera operation?

Hur upplevdes kirurgin och eftervården (sövning, smärta, ortosbehandling, sjukgymnastik, egen träning)? Mer från sjukvården (information, stöd, förmedling av kontakter)?

Självbild – Exempel och förslag på frågor:

Påverkas självbilden av nedsatt funktion (oavsett omgivningens inverkan)? Gömmer hand/arm? Nöjd med utseendet på armen/handen? Självförtroende? Hämmat beteende? När förstod hade en skada? Var det någon särskild händelse? Kroppsuppfattning? Tänker de att de har en funktionsnedsättning, eller är de "som vem som helst"? Begrepp som normalitet och handikapp, hur känner de sig? Påverkas av hur andra ser på din skada och vad de säger om den? Hopp om bättring? Existentiella frågor? Ödesbestämt? Ofrånkomligt? Känslor förr och nu till skadan och kroppen? Om du normalt skulle beskriva dig själv, tar du med att du har opererats? Har plexusskada/är plexusskadad. Funktionsnedsättning/handikapp?

- Något ytterligare vi borde tagit upp? Något som missats?
- Vad hade de förväntat sig att vi skulle prata om?

Appendix IV

A brief medical background to the different BPBP injuries:

“Most frequently, the injury is limited to the upper spinal nerves and these patients have a considerable potential for spontaneous healing. The designation ‘Erb-Duchenne palsy’ or ‘Erb’s palsy’ refers to a C5-C6 injury, with subsequent paralysis of the shoulder and of elbow flexion. If the wrist and finger extensors are also paralysed this may indicate that C7 is also involved. The majority of these partial plexus injuries are benign in nature and probably 70–80% recover spontaneously. If the palsy does not resolve completely within 2–3 months, there will usually be residual weakness to a lesser or greater extent. Plexus injuries involving the upper as well as the lower parts of the plexus constitute a very different situation. Not only is the whole limb including the hand affected, the tearing of the nerves is usually more complete and the prognosis is much poorer. Most of these patients benefit from nerve reconstruction. Fortunately, this type of injury is rare; it represents approximately 10% of the children with a persistent palsy. Breech deliveries can cause plexus injuries with a slightly different pattern. They are usually limited to C5 and C6, but they are often bilateral, and the spinal nerves are injured at a more proximal level, even torn right out of the spinal cord (root avulsion). The clinical picture in these children is characterised by extremely atrophic and atonic shoulder muscles and elbow flexors. Considering that the forces of the birth trauma are strong enough to rupture or avulse several spinal nerves, and occasionally also fracture bones in the limb, it is reasonable to assume that there may also be substantial injuries to other surrounding tissues, such as tendons, muscles and joints. Not much is known about the associated soft tissue injuries, however.” (Hultgren, 2013)

Appendix V



BESLUT

Dnr: 2015/1219-31
Sökande: Karolinska Institutet
Behörig företrädare: Per Tornvall
Projekt: Att leva med en förlossningsskada i armens nervfläta - En pilotstudie om ungdomars erfarenhet kring funktionsnedsättning, sociala relationer och sjukvårdskontakter.
Forskare som genomför projektet: Tomas Hultgren

Nämnden har vid sammanträdet den 19 augusti 2015 lämnat över till den vetenskaplige sekreteraren att avgöra ärendet sedan kompletteringar gjorts.

Sedan sökanden kommit in med begärda kompletteringar fattar den vetenskaplige sekreteraren följande

BESLUT 2015-09-16

Nämnden godkänner forskningen.

På nämndens vägnar

Hans Glaumann
vetenskaplig sekreterare

Beslut expedierat till behörig företrädare
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