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Accessibility of mental health care for adults with cerebral palsy

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Accessibility of mental health care for adults with cerebral palsy

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Laurea University of Applied Sciences **Abstract**
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Accessibility of mental health care for adults with cerebral palsy

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The purpose of this thesis is to describe the accessibility in mental health care from the point of view of an adult with cerebral palsy.

The theoretical framework of this thesis is constructed from the related literature and previous studies closely linked to the topic. Research was done to clarify the concepts of disability, cerebral palsy, and mental health. The research showed cerebral palsy as a multidimensional physical disability which may include different types of accompanying impairments.

Qualitative research method was applied and semi-structured interviews were carried out. Two respondents (n=2) with cerebral palsy and a psychiatric diagnosis were interviewed, and an inductive data analysis was conducted.

Physical challenges, attitudes in health care towards clients with CP, communication with clients with CP and the overall quality of life were the four main categories found based on the interviews. Discussed topics were divided into these categories and they were interpreted to have an effect on their experiences in mental health care.

The findings of the thesis showed that mental health care is rather functional from the point of view of people with CP, but few adjusments should be made in order to provide equal accessibility. The thesis also indicates a lack of knowledge on disabilities within the mental health care staff, but also disabeled people’s lack of knowledge regarding mental health support options.

Mental health nursing, accessibility, cerebral palsy

Laurea-ammattikorkeakoulu
Otaniemi
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Tiivistelmä

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Mielenterveyshoidon esteettömyys CP-vammaisille aikuisille

Vuosi 2014 Sivumäärä 41

Opinnäytetyön tarkoituksena on kuvata miten CP-vammaiset aikuiset kokevat mielenterveyshoidon ja sen esteettömyyden. Työn teoriatausta koottiin aiheiseen läheisesti liittyvästä kirjallisuudesta ja tutkimuksista. Vammaisuuden, CP-vamman, ja mielenterveyden käsitteitä tutkittiin yleisellä tasolla. Aiemmat tutkimukset osoittivat, että CP-vamma on monitahoinen fyysinen vamma, johon liittyy myös erilaisia liitännäisvammoja.

Empiriinen osuus toteutettiin laadullisena tukimuksena avointa teemahaastattelua käyttäen. Haastateltavina oli kaksi CP-vammaista henkilöä, joilla oli myös psykiatrinen diagnoosi (n=2). Tulokset tutkittiin induktiivisella sisällönanalyysilla.

Opinnäytetyön haastatteluista nousi esiin neljä laajempaa kategoriaa: fyysiset haasteet, terveydenhuollon asenteet CP-vammaisia kohtaan, kommunikointi CP-vammaisen mielenterveysasiakkaan kanssa ja elämän laatu. Keskusteluissa esiin nousseet aiheet luokiteltiin ja niiden tulkittiin vaikuttaneen kokemuksiin mielenterveyshoidosta.

Opinnäytetyön löydökset osoittivat, että mielenterveyspalvelut ovat melko toimivia CP-vammaisten henkilöiden näkökulmasta, vaikka joitakin päivityksiä olisikin tarpeellista tehdä esteettömyyden ja tasavertaisuuden turvaamiseksi. Opinnäytetyö myös osoitti, että hoitohenkilöstön vammaisuuteen liittyvissä tiedoissa on puutteita, ja että vammaiset henkilöt eivät välttämättä ole tietoisia erilaisista mielenterveystyön saatavilla olevista tukimuodoista.

Mielenterveyshoitotyö, esteettömyys, CP-vamma

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1 Introduction

This thesis aims to describe how adults with cerebral palsy (CP) experience mental health care and its accessibility. The term “accessibility” is understood in a broader context than just physical accessibility of the environment, instead it is used to also describe the social, structural, and attitudinal accessibility of mental health care.

The prevalence of psychiatric disorders among adults with CP is not vastly studied (Invalidiliitto 2009). However, the mental wellbeing of people with CP has been argued to be compromised due to several factors; decline in functionality and autonomy, chronic pain, and social isolation (Krigger 2006). This thesis explores the topic of accessibility in mental health care by examining previous studies on related topics, and by conducting semi-structured interviews and inductive data analysis based on the experiences of mental health clients with CP.

The idea of the thesis originates from working life. The other writer had worked with people who have CP and often got into informal conversations regarding mental wellbeing, as well as the accessibility of *any* health service. According to these conversations there were some problems with accessibility and attitudes in health care. It also seemed that this topic had not been studied much in the context of nursing.

In practice this thesis is thought to help mental health nurses to better understand their clients with CP, and to know how to pay attention to their possible special needs.

2 Disability

Historically the attitudes towards disabilities and disabled people have been negative, or at least dismissive. However, there has been a significant change in societal attitudes during time.

The ancient Greeks and Romans accepted filicide almost on any grounds, and it was even encouraged if it would be done in order to attain an ideal society (Vehmas 2005, 34-35). The philosophers of the time were in favor of slaying disabled children in order to keep the nation strong; Aristotle wrote "let there be law that no deformed child shall live" (Aristotle 330BCE). The ancient Greeks and Romans valued strength and health, and they thought that the only way for the society to thrive was to produce as many able-bodied individuals as possible.

When compared to the ancient Greeks and Romans, attitudes in The Bible are not as harsh on disabled people, but usually it still presented disability as a trial from God. This view on disabilities was dominant through the middle-ages, and it was not until the renaissance and the age of reason, when the more naturalistic explanations replaced the superstitious views. (Vehmas 2005, 24-25, 50-52).

Later, in the 19th century, when industrialization gave birth to medicalization the medical professionals took over the sphere of disability. However, the view on disabled people was more practical than caring; many of the disabled people were institutionalized mainly due to their inability to contribute to the society by physical labour. (Vehmas 2005, 53-59).

Nowadays, disability is usually viewed from two different aspects; the medical and the social aspect. The medical model is considered to be more traditional approach which has its roots in the 19th century, while the social model stems from the global human rights' movement of the mid 20th century (Vehmas 2005, 109).

Traditionally, the medical model sees disability as a personal tragedy affecting the individual, thus the response to disability has been through charity-, welfare-, and health systems (Richardson 1997). Within the medical view a disabled person is considered someone who needs to be cured, nursed, or otherwise treated by health care professionals. The medical model of disability identifies and tries to find solutions to the individual's problems, with an approach that is often called as the "restorative, rehabilitative or medical model of intervention." (Richardson 1997).

The framework for the medical view of disability is the "International Classification of Impairments, Disabilities and Handicaps" (ICDH), which is a manual published in 1976 by The World Health Organization (WHO). ICDH was similar to the standard diagnostic tool, the International Classification of Diseases (ICD), but rather than having a clinical diagnostic approach like ICD, the ICDH was described as a "manual for classification of consequences disease" (WHO 1980).

The ICDH describes disabilities in a rather limitation-focused way:

(a) Impairments (I code), concerned with abnormalities of body structure and appearance and with organ or system function resulting from any cause; in principle, impairments represent disturbances at the organ level.

(b) Disabilities (D code), reflecting the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person.

(c) Handicaps (H code), concerned with the disadvantages experienced by the individual as a result of impairments and disabilities; handicaps thus reflect interaction with and adaptation to the individual's surroundings. (WHO 1980)

The medical model of disability has been heavily criticized by disabled people, sociologists and different human rights' organizations (Vehmas 2005, 109-111). The medical model is often resented due to its underlining idea of disability being a personal tragedy, instead of it being a problem caused by the attitudes and structures within the society (Finkelstein 1993).

The social model suggests that disability is a social construct created by the physical and social barriers in a world that is primarily adapted for the non-disabled (Richardson 1997). Meaning that the world around us is not physically and socially fully accessible for disabled people; there are physical obstacles like inaccessible buildings, and social obstacles like employers who are reluctant to hire disabled people. Thus, the society and its attitudes and structures have made certain people disabled.

In common talk accessibility can often be understood as the physical accessibility of certain places, but in a larger context accessibility is defined as the "realization of the physical, psychological, and social environments in a way that every individual, regardless of their qualities, can equally function with others" (Laaksonen 2005).

The United Nations' (UN) Convention on the Rights of Persons with Disabilities seems to support the idea of the social model; they state that "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". (UN 2006)

Even though the social model of disability is more current and considered politically correct (Goodall 1995), there is also counter-criticism claiming that the social model alone is not enough to cover the sphere of disability, and that many disabled people still have an ongoing medical or nursing intervention in their lives and therefore the medical model cannot be totally disregarded (Goodall 1995).

Some sociologists working in the field of disability studies have criticized the social model for being "restrictive, simplistic, and insufficient framework for defining disability, as well as for the associated practical issues." The social model is also criticized for neglecting individual differences between disabled persons, although it has functioned well in the terms of promoting equal rights for the disabled. (Vehmas 2005, 140-141).

WHO has recently reacted to these ideological changes towards disabilities. The organization has replaced the old limitation-focused ICDH with a new more holistic classification system, the "International Classification of Functioning, Disability and Health" (ICF). The organization describes ICF as a "dynamic interaction between a person's health condition, environmental factors and personal factors", and it is thought to integrate the medical and social models of disability into a "bio-psycho-social synthesis".

In comparison to the clinical diagnostic tool, ICD, ICF "describes the associated functioning dimensions in multiple perspectives at body, person and social levels". (WHO 2013). However, the ICF does not cover the situations that are of solely based on socioeconomic or cultural factors, as its aim is to "conceptualize functioning and disability in the context of health." (WHO 2013).

3 Mental health

The historical views on mental health, and mental illnesses, are similar to the views on disabilities; the people who were suffering from different mental illnesses, or who were not behaving according to social norms, were considered possessed or somehow affected by supernatural powers (Pietikäinen 2013, 23-25).

Although Hippocrates already in 400 BCE classified two different types of mental illnesses, mania and melancholia, and suggested that mental illnesses result from physiological origins rather than demons, it was not until the age of reason in the mid 18th century that the doctors started to be more skeptical towards religious and supernatural explanations. (Pietikäinen 2013, 27-30, 55).

It was during this time when the first asylums for the mentally ill were established in Europe, and the “father of modern psychiatry” Dr. Philippine Pinel “freed the patients with his own hands despite the resistance of the staff.” (Pietikäinen 2013, 69-71). However, it was not until late 20th century when the modern Western mental health care started heading towards its current more humane and therapeutic approach. Though it is argued that even now the mental health care more is more focused on the disorders, illnesses, pathologies, shortcomings, diagnostics, and treating the symptoms, instead of making use of the clients’ resources and strengths (Koivisto, Janhonen, Kiikkala 2007).

According to a 2010 study by the professor of Social Policy Peter Beresford and his co-authors, mental health issues can be examined from a social point of view much like disability. The study claims that many of the interviewed mental health service users "experience barriers in the same way that disabled people have highlighted the barriers restricting them" (Beresford, Nettle, Perring 2010). The participants also considered the medical model of mental health playing a “powerful part in perpetuating the stigma associated with madness and distress” (Beresford et al. 2010). Also the language used when talking about mental health issues has been heavily criticized for promoting labeling of people who use mental health services (Oaks 2014). For example, some of the suggested alternative terms for “mentally ill” are “mental health client”, “person with a psychiatric history”, and even “psychiatrized” or “psychiatric survivor” (Oaks 2014).

Even if the terms “mentally ill” and “mental illness” can be considered stigmatizing, it would be beneficial to have an open dialogue and in a way demystify mental illnesses, much like Susan Sontag aimed to demystify cancer in her 1978 treatise Illness As Metaphor. In her work she suggests that cancer, and tuberculosis prior to it, has been considered something so tragic and utterly unthinkable that they have been shrouded in romantic metaphors and not called for what it is, resulting in that the people who have cancer live in silence and shame (Sontag 1978, 48). This reasoning can easily be applied to mental illnesses.

When defining mental health, and mental health care, in more psychological and philosophical terms, the psychologist and doctor of philosophy Lauri Rauhala’s holistic idea of man becomes relevant. In his theory Rauhala suggests that the human experience constitutes from three different aspects; consciousness, physicality, and situationality (Rauhala 2005, 32).

The consciousness equals to “psycho-spiritual existence”, which means that the human consciousness is constantly experiencing something; feelings, ideas, dreams, and memories. Consciousness steers the existence through meanings; certain experiences formulate meanings, and meanings then constitute a worldview. (Rauhala 2005, 32).

The physicality, as he puts it, is simply a “material-organic event” which represents all the bio-chemical, anatomic, and physiological aspects of the human body (Rauhala 2005, 39).

The situationality is explained as the “existence in relation to reality and situations.” Situationality encompasses all human interaction between other living beings, cultures, and even inanimate objects. Rauhala also describes situationality as a “type of a game arena in which the consciousness and physicality are located in.” (Suominen 1995).

Any kind of work within health care is done in the context of the client’s situationality. The work does not only constitute from the tangible measures and interventions, but it also includes the way the work is done; the approach should be sympathetic and discreet. The situationality can be affected through physical channels and through the channel of consciousness; for example psychotherapy is directly affecting the situationality through consciousness and surgery is affecting the situationality through physical channels (Rauhala 2005, 151).

In current mental health care the client is considered as an actor who interprets his or her own experiences and actions, and by doing so he or she can affect his or her actions and environment according to his or her abilities and tendencies. However, this requires that the client is accepted as a holistic being capable of self-reflection and that the development of his or hers unique consciousness is trusted in (Koivisto et al. 2007).

4 Cerebral palsy

Cerebral palsy (CP) is a well-recognized neuro-developmental condition that causes permanent damage to the parts of the developing brain which regulate motor functions. CP describes groups of permanent disorders of development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. (Eliasson, Krumlinde-Sundholm, Rösblad, Beckung, Arner, Ohrvall, Rosenbaum 2007.) It is a permanent but not a progressive condition.

CP is primarily a physical disability but there are various accompanying impairments. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behavior, by epilepsy, and by secondary musculo-skeletal problems (Eliasson et al. 2007).

The etiological reasons for CP can be divided into three different categories: 1) during pregnancy, 2) during or after the birth of the child, or 3) during infancy or early childhood. The location of the damage and the possible functional difficulties depend on the developmental stage of the central nervous system. For example, the lack of oxygen with premature babies creates different symptoms than with babies born full-term (Mäenpää).

CP is divided into three main types: 1) spastic, 2) ataxic and 3) athetotic or dyskinetic type. Spastic hypertonia, stiffness of muscles, which can vary in severity between children, makes movement in the affected body parts slow and difficult. It is caused by damage to the motor cortex of the brain, the part that controls movement.

Ataxia usually involves damage to the cerebellum which results in difficulties with balance and planning of movement. Individuals with ataxia often have difficulty with the fine control of movement and may have a tremor which increases on activity. Their muscle tone is usually low.

Atheotic/dyskinetic CP results in uncontrolled involuntary movements which produce fluctuations in muscle tone – muscles can sometimes be too stiff or too floppy and this can change suddenly. Movement is disorganized which makes it difficult for individuals with athetosis to stay still in one position or controlling limb movements precisely. It arises from damage to the basal ganglia (Bobath Centre).

CP varies in the parts of the body it affects. Hemiplegia predominantly only affects one side of the body. Diplegia affects the whole body with the lower limbs being more involved than the upper limbs. Quadriplegia affects the whole body with the upper limbs usually being as affected or more affected than the lower limbs (Bobath Centre).

Different scales are used when classifying cerebral palsy and its severity. The Gross Motor Function Classification Scale (GMFCS) for cerebral palsy is based on self-initiated movement. Distinctions between levels of motor function are based on functional limitations, the need for assistive technology, including mobility devices (such as walkers, crutches, and canes) and wheeled mobility, and to much lesser extent quality of movement. (Palisano, Rosenbaum, Walter, Russell, Wood, Galuppi 1997)

Another classification system, Manual Ability Classification Scale (MACS), defines the functioning ability of the upper limbs (Eliasson et al. 2007). It is used for children over the age of four, and it classifies how well the child is able to handle everyday objects in daily functioning.

The researchers at the Department of Developmental Neuroscience in Stella Maris Scientific Institute, Italy, state that "the incidence of mental retardation in CP is higher than that observed in the normal population.” They base their statement on several recent epidemiological data reports which indicate that 30-60% of people with CP suffer from cognitive disorders (Brizzolara, Brovedani, Ferretti 2010). Other factors which contribute to the cognitive functioning and the “psychological outcome” in CP include epilepsy, visual function disorders, factors related to the brain lesion, and different psychiatric conditions (Brizzolara et al. 2010).

5 Factors affecting the mental wellbeing of people with CP

When reviewing literature relevant to the mental wellbeing of people with CP, there were some reoccurring themes which are discussed in this chapter. The themes partly coincide with the research findings.

The cognitive and neurological factors, such as epilepsy and intellectual disability, are not discussed in greater detail as they are not that relevant to this thesis as it can be seen in chapter 7.2.1, “Interviews and informants.”

5.1 Psychiatric conditions associated with CP

There are very few studies on the prevalence of psychiatric illnesses and disorders among adults with CP (Invalidiliitto 2009). The medical studies on CP tend to focus on the physical attributes of the disability, and there is a lack of attention towards treatable psychiatric syndromes that may co-occur with CP (Foster, Rai, Weller, Dixon, Weller 2010).

On the other hand, there are several studies indicating that children with CP, or some other type of central nervous system affecting disability, are at a higher risk of developing behavioral and emotional symptoms than non-disabled children, or children with other types of disabilities (Masi & Brovedani 2010; Blackman & Cobbs 1989; Parkes, J., White-Koning, Dickinson, Thyen, Arnaud, Beckung, Fauconnier, Marcelli, McManus, Michelsen, Parkinson, Colver 2008; Sigurdardottir, Eiriksdottir, Gunnarsdottir, Meintema, Arnadottir, Vik; Foster et al. 2010; Harris 1995). The range of these symptoms is wide; adjustment and personality disorders, depressive symptoms, parent-child relationship issues, temperament difficulties, emotional lability, impulsiveness, attention deficits, limited problem-solving skills, and mood disorders. Also, children with CP are more liable to have separation anxiety, oppositional defiance disorder, and attention deficit (Foster et al. 2010; Harris 1995).

The reason why children with CP are at a higher risk of developing these psychiatric conditions can be either biological or non-biological. Biologically the brain lesions' size, location, and timing can contribute in developing psychiatric conditions, while other biological reasons include comorbid disorders (e.g. epilepsy and sensory deficits) and associated cognitive impairments, like intellectual disabilities and other different neuro-psychological deficits. (Masi & Brovedani 2010)

The non-biological reasons are more varied; impaired sensori-motor and speech skills, decreased functionality, stigmatizing effect of the disorder, and other psychosocial issues like problems in the family relationships and environment. Also, the neurological and psychosocial variables interact with each other, thus the development of the psychiatric condition may remain unclear. (Masi & Brovedani 2010). Foster et al. suggest in their study that children and adolescents with CP should be regularly screened for mental health issues, especially focusing on emotional, behavioral, academic, and social problems (Foster et al. 2010).

If the children with CP are more liable to develop psychiatric conditions than their non-disabled peers, it would be reasonable to assume that there is also a large group of adults with CP with similar conditions.

5.2 Loneliness and social isolation

The issue of loneliness and social isolation among adults with CP has been studied more than the prevalence of psychiatric illnesses, and the results of the studies show that many of the adults with CP feel more lonely and isolated than their non-disabled counterparts. The negative experiences of loneliness and social isolation seems to apply to all age groups of people with CP (Balandin, Berg, Waller 2006; Horsman, Suto, Dudgeon, Harris 2010; Cooper, Balandin, Trembath 2009). Especially, the older people with CP are more lonely than the non-disabled elderly (Balandin et al. 2006), but this does not seem to affect the prevalence of clinical depression among the older people with CP (McDermott, Moran, Platt, Issac, Wood, Dasari 2005).

It seems that people with CP start experiencing the negative attributes of aging sooner than the non-disabled (Balandin & Morgan 1997), and many of them also conceive life "less manageable, less meaningful, and especially unpredictable and incomprehensible" (Horsman et al 2010). These negative experiences affect their overall sense of loneliness and isolation.

The reasons for higher level of loneliness are mostly due to issues with mobility and accessibility; they were not able to access their communities well, they were not employed, and their independence was compromised due to living in different types of assisted living facilities. Also, the interaction between their peers was not often satisfying due to cognitive problems, and often there were no other common denominators between the peers besides CP. (Balandin et al. 2006)

An interesting detail in the research regarding loneliness and social isolation was that using alternative and augmentative communication (AAC) instead of natural speech did not add to the experienced loneliness; in fact the people using AAC were less lonely than their counterparts using natural speech. This was thought to be a result of the AAC itself; the person using AAC will always have an assistant closely working with him or her, and transcribing what the AAC user is communicating. (Cooper et al. 2009)

5.3 Chronic pain

Chronic pain is one of the most common co-morbid issues associated with CP, and it can have an effect on the physical, social, and psychological aspects of one's life. Approximately 28% of adults with CP experience chronic pain, and it has been also reported that the prevalence of chronic pain increases with age (Rosqvist, Harri-Lehtonen, Airaksinen, Ylinen, Kallinen 2009). Studies have also shown that adults with CP who suffer from chronic pain experience long-term fatigue, lowered contentment with life, and psychological distress (Jahnsen, Villien, Aamodt, Stanghelle, Holm 2004; Ehde, Jensen, Engel, Turner, Hoffman, Cardenas 2003).

The correlation between chronic pain and psychiatric illnesses and disorders has been studied to a great extent, and there is evidence that “psychiatric and medical pathologies interface prominently in pain disorders.” Conditions like depression, panic disorder, and anxiety disorders are fairly common among people who experience chronic pain. (Gatchel 2004)

5.4 Attitudes in health care

Within the health care system there have been reports of negative attitudes towards people with CP (Balandin, Hemsley, Sigafoos, Green 2007; Poulos, Balandin, Llewellyn, Dew 2006). The reason behind the negative attitudes has been considered to be lack of knowledge and misconceptions regarding the disability (Poulos et al. 2006).

The 2007 study by Balandin et al. describes how a group of adults with CP, and a related speech disorder, experienced the attitudes of nurses towards them as negative. They felt that the nurses behaved in a patronizing way, assumed them to be intellectually disabled, avoided eye contact, ended the patient/nurse situation prematurely, and they also thought that nurses did not spend as much time with them as with the non-disabled clients. (Balandin et al. 2007). In addition, there are reports of negative attitudes towards disabilities among medical students (Martin, Rowell, Reid, Marks, Reddinhough 2005).

The negative atmosphere in health care may affect the willingness of people with CP to acquire healthcare services (Poulos et al. 2006). This might especially affect the motivation to acquire help for mental health problems, since they might already feel stigmatized, or think that they will not be taken seriously.

6 Research question and the aim of the thesis

The research question of this thesis is “how do adults with cerebral palsy experience mental health care and its accessibility?”

The purpose of the thesis is to describe how mental health care is experienced by individuals with CP, and to discuss the physical, social, and psychological accessibility of mental health care. The thesis is thought to provide mental health nurses with tools how to encounter and care for a client with CP.

7 Methodology

7.1 Qualitative research

Qualitative research is a form of social inquiry used by researchers to explore the behavior, feelings and experiences of people with the aim to understand, describe and interpret social phenomena as perceived by individuals, groups and cultures (Holloway & Wheeler 2010, 3). As the thesis deals with individuals’ experiences and perceptions, and with social phenomenas, qualitative research was chosen as the research method.

Research area, topic and question need to be selected first, as a first step in the qualitative research process. Research question should be more precisely styled, whereas the research area and topic can be more general. Research question is a question about an issue that researchers examine to gain new information, and it should be explicit, meaningful and coherent. In the conclusions of any study research question should be answered (Holloway & Wheeler 2010, 31).

In qualitative research theory and literature search are used to set a framework for the topic and help to understand the phenomena under the study. Literature search and review often take place prior to the study but also proceed throughout. Researchers use literature to compare or contrast their own findings with the results reported in the literature. (Holloway & Wheeler 2010, 11/37). A vast literature search was carried out prior to engaging in the empirical part of this thesis, but since there were not many prior studies on the mental wellbeing of adults with CP, the searched literature covered several different areas related to topic such as neurology, sociology, psychology, pediatrics, and history.

As qualitative research is based in interviews, participants need to sign a consent form, in which they are fully informed about the research and give their voluntary agreement to take part in it without any implicit or explicit pressure from the researchers (Holloway & Wheeler

2010, 59). Researchers must respect the autonomy of the participants, and inform the participants about the benefits and risks of participating the study.

7.2 Semi-structured interview

As the aim of this thesis is to describe how those with CP experience mental health care, the qualitative research method and a semi-structured interview were chosen as research methods.

The semi-structured is considered the most common interview method in qualitative research (Payne 2000, 89). In semi-structured interviews the focus on the issues or topic areas are covered but the sequencing of questions are not necessarily the same for every participant. Questions may vary, depending on the process of the interview and the individual responses of the participants. When identifying a research question, researchers should ensure that the topic is relevant and researchable, and also feasible within the time span and resources (Holloway & Wheeler 2010, 32).

Interview guide for the questions is normally used, but with new ideas arising during the interviews, researchers may alter or add questions (Holloway & Wheeler 2010, 89-90). The rich and in-depth data collected from the interviews of the participants become the basis for theorizing (Holloway & Wheeler 2010, 4), and is then used when contrasting the research data to the framework literature. When interviewing the informants for this thesis the information guide was used very loosely as it was thought that the conversations should be able to flow freely in order to attain diverse information.

The interviewer is thought to aim to establish a relationship with the respondent in which he or she is comfortable enough to share feelings and thoughts (Payne 2000, 90). Holloway and Wheeler (2010, 57) take into account that especially interviews may affect participants by bringing up memories, emotions or hidden feelings for the first time when revealing their personal experiences and deep thoughts. It is not enough that the interviewer elicits these feelings, but he or she needs to also acknowledge them and support the respondent through the interview process (Payne 2000, 93).Careful listening is also a key factor in conducting a successful interview, because giving people undivided attention will probably enhance the quality of the relationship (Payne 2000, 93).

A possible source for bias, and a problem with interview validity, is that the qualitative interview is a social situation which can be influenced by interpersonal dynamics which then reflect on the outcome of the interview. As a method of “surviving as an interviewer” is to present oneself as interested but naïve about the topic in order to justify probing questions. (Payne 2000, 97-98).

Reflexivity and ethical sensitivity are highlighted as the main qualities of the interviewer in qualitative interview, but they also need to be concerned about the validity, truthfulness, and aim to minimize bias (Payne 2000, 100).

7.2.1 Interviews and informants

When acquiring informants for the thesis there were two qualifications which the informant was required to meet: 1) he or she needs to be of legal age, and must be able to give his or her informed consent to participate, and 2) the informant is diagnosed with cerebral palsy and some psychiatric diagnosis.

The idea behind interviewing people with a disability like CP was that the informants had lived and grown with the disability, and not been suddenly disabled by an illness or an accident. This was thought to provide the writers with a view of their whole lifespan living with the disability, and how it could have been affecting their mental wellbeing and/or how it has affected the accessibility of mental health care.

Coincidentally, both of the informants are males (30 and 50 years old), they share the psychiatric diagnosis of bipolar affective disorder, and both are also wheelchair users. The effect of these coincidences on the thesis, and the amount of informants, are discussed in chapter 9.3, “Trustworthiness” . The older informant is known as “Informant A” and the younger as “Informant B.”

Informants were searched using social media, personal contacts, and by visiting a day center for people with CP. The interviews were conducted by both of the writers in a very informal manner and in good co-operation with the informants. The first interview took place at the day center in a private room, and the second one took place at the informant’s home. The interviews were recorded and later transcribed.

The themes of the semi-structured interviews were modeled after the theoretical background of the thesis; physical aspects, attitudes within health care, how the informant ended up using mental health services, did they have mental health issues in childhood or adolescence, and would they like some more services or support now.

The answers and initial situations of the informants were very similar:

1. Both had a crisis event leading to a treatment at a closed ward.
2. Both have been admitted to a psychiatric ward several times.

3. Both have had manic and depressive periods.
4. Both said that the treatment helped in the acute situation.
5. Neither reported having cognitive problems, intellectual disability, or epilepsy
6. Neither one wants or needs more support at the moment.
7. Both had rather positive experiences of the overall care.

Besides their similarities they had totally different outlooks on life; Informant A was completely hopeless and did not consider his life worth living, while Informant B was very content with his life and looking forward to the future.

Another difference among the informants was that Informant A started using mental health services when he was approximately 30 years-old and did not experience any problems prior to that age. The informant B was around 20 years-old when he had his first psychosis, but he said that “things had gone downhill for some time” before the psychosis.

Also, Informant A has more severe physical symptoms related to CP: dyskinesia in all of his limbs and a dysarthric speech disorder, so their overall physical and mental realities differ substantially from each other.

7.3 Inductive data analysis

The function of inductive data analysis is to condense raw textual data into a compact form, establish links between the research objectives and the summary findings, and to develop a framework for the underlying structures in the raw data (Thomas 2006).

Inductive data analysis is a popular analysis method in qualitative nursing research; it is especially convenient when there is not a lot of theoretical background available on the subject of the thesis. When conducting an inductive data analysis, the interview material is searched for words and sentences that answer or relate to the research questions, while in deductive analysis the method is more based on the theory (Hannila & Kyngäs 2008).

Holloway and Wheeler (2010, 281) describe the process of qualitative data analysis, as “a complex, non-linear process but also systematic, orderly and structured”. They emphasize that there is no certain approach on how to analyze, but the research account must have its roots directly in the data generated by the interviewees. Most often researchers collect and analyze the data simultaneously. It is also stated that the research is initially inductive since the collected data has priority over theories and hypotheses (Holloway & Wheeler 2010, 17). The process of data analysis fluctuates from transcribing interviews and organizing and viewing the collected material to building themes and describing a phenomenon (Holloway & Wheeler 2010, 282).

The acquired data of this thesis was analyzed using the inductive data analysis method, but there are also elements of deductive analysis present; when collecting the theoretical framework some relevant topics were formed as themes for the interviews. However, the actual data analysis was carried out in the same inductive manner as suggested in figure 1:

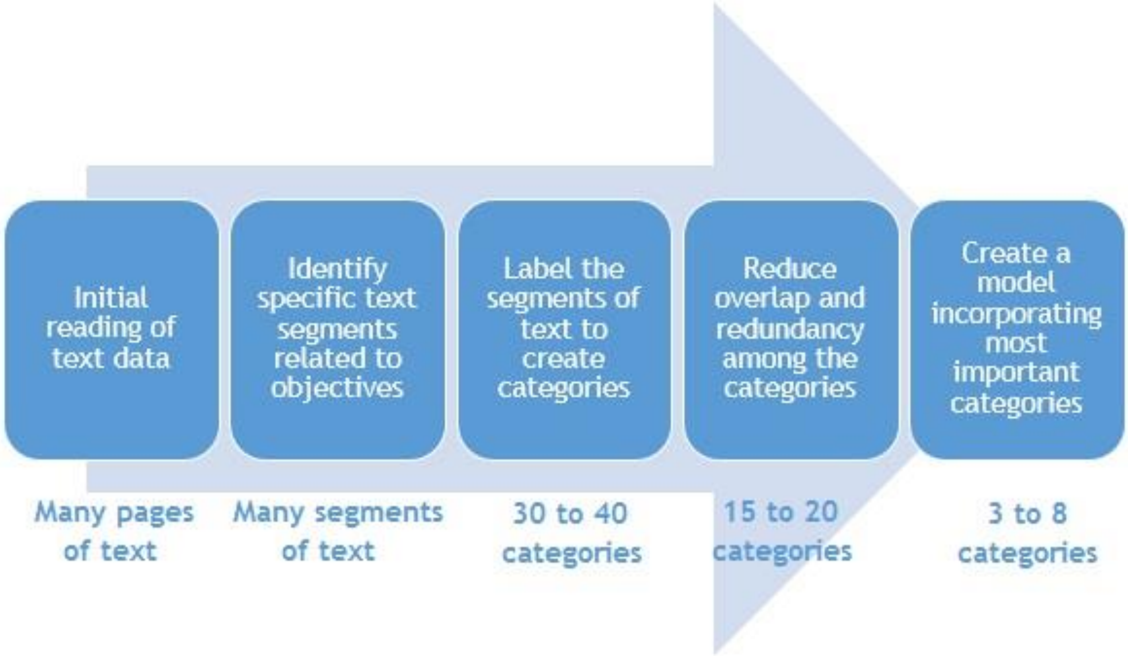

Figure 1: The Coding Process in Inductive Analysis (Thomas 2006)

After the text data was read, the segments were examined in relation to the themes and theoretical framework. For example, the text segments mentioning physical issues were identified, and then labeled as “physical challenges.” After indetifying the themes and labeling them with appropriate categories, they were checked for overlapping and four main categories were formed. These categories were then analyzed and discussed.

8 Findings

When executing the inductive data analysis there were four main categories found: 1) physical challenges, 2) attitudes towards people with CP, 3) communication with mental health clients with CP, and 4) quality of life.

8.1 Physical challenges

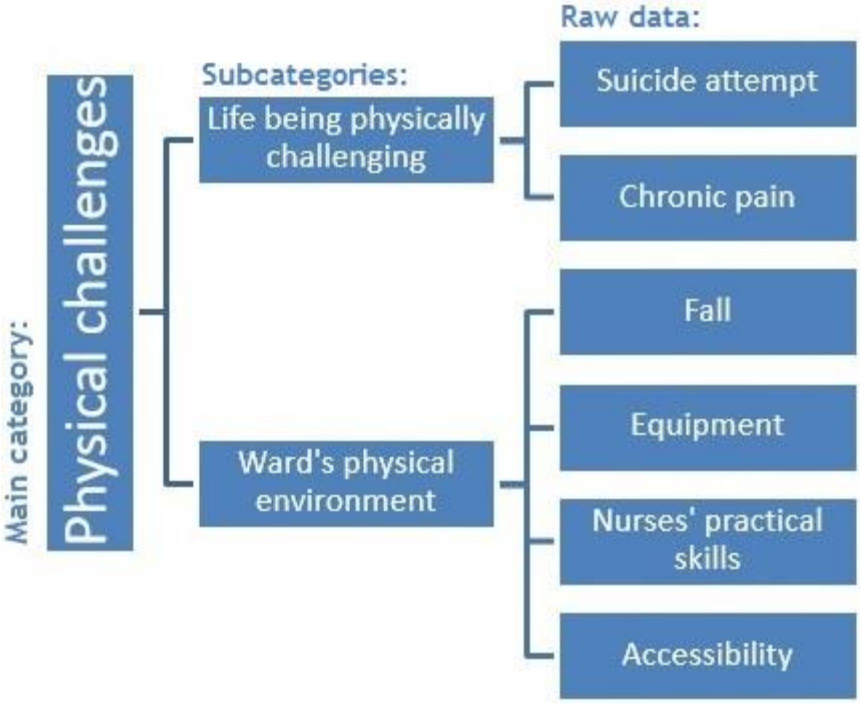

Figure 2: Process of forming the main category of “Physical challenges”

The raw data in figure 2 refers to the quotes given by the informants. The quotes were identified and labeled as two different subcategories; “Life being physically challenging” and “Ward’s physical environment” which then lead to the main category of “Physical challenges.”

Physical challenges were emphasized in several answers by Informant A. When asked if there has been some physical obstacles on the ward where he had been treated he replied:

“On, esimerkiksi huonekaveri on huutanut apua silloin kun mä olin lattialla, niin se ei ymmärtänyt.”

”Yes, for example my roommate had called for help when I was on the floor, so he didn’t understand.”

In this situation he had fallen on the ground and could not get up himself, and could not call for help either. He asked his roommate to call for help, but the roommate at first did not understand what to do. Besides this event there has not been any physical problems regarding the wards’ equipment or the nurses’ skills to help him.

When asked if the equipment and nursing staff were sufficient in aiding him physically, he briefly replied that there were no problems in those aspects and that he did not have to wait long for assistance, but later he said that it would be good that if the nurses would know more about CP.

He answered “yes” when asked if he is experiencing chronic pain, and later when he was asked are there some other reasons, like social issues, affecting his mental wellbeing, he said:

“Ehkä ei. Fyysiset ongelmat isompi syy.”

”Maybe not. Physical problems [are the] bigger reason.”

The physical aspects became again the focus when he was asked if he would like to receive some additional discussion support or therapy:

“Haluaisin, mutta luulen että se ei auta, koska tää vamma. Esimerkiksi kädet on koko ajan tossa.”

”I would, but I think it wouldn’t help, because of this disability. For example, my hands are always there.”

By saying this he was referring to the spasticity of his upper limbs; they were most of the time in an upward position and he was experiencing a lot of dyskinetic movement during the interview.

Informant B did not suffer from dyskinesia or other kind of physical problems, even though he is wheelchair-bound. His answers were not as physically oriented, but he told that there was only one wheelchair accessible psychiatric ward in the hospital where he was treated:

“Mä joudun aina tietylle osastolle, joka on suljettu osasto, koska se on ainut jossa pystyy liikkumaan pyörätuolilla. Mä oon aina päätynyt sinne suljetulle osastolle, vaikka mulla olis jotain muuta vikaa... johtuen siitä, että ne paikat ei oo todellakaan esteettömiä.”

”I always end up to a certain ward, which is a closed ward, [it’s] because it’s the only ward that is accessible by wheelchair. I’ve always ended up in a closed ward even though I had something else wrong… due to the inaccessibility of the other places really not being accessible.”

Even if he did not require care on a closed ward during his milder crises, he was always admitted to one due to the inaccessibility of other wards. When asked if he thought this was unfair or if it affected his recovery, he replied:

“Kyllä se siinä mielessä oli jännittävä seurata, kun oli ite paljon paremmassa kunnossa kuin ne muut siellä. Ei tuntunut pelottavalta, oli tottunut siihen.”

”In that sense it was interesting to see, when you yourself were in a better condition than the other ones there. It wasn’t scary, [I] was used to it.”

Later the informant B also added that physical challenges have never been a big issue to him since even in a psychosis he has been able to move around with his wheelchair. He also stated that the chronic pain associated to CP is not in his opinion linked to mental health at all.

8.2 Attitudes in health care towards clients with CP

Figure 3: Process of forming the main category of “Attitudes in health care towards clients with CP”

As seen in figure 3, the quotes from the transcribed interviews form the raw data. The quotes were again identified and labeled into subcategories; “Assumption of intellectual disability”, “Education”, and “Overall professionality of the staff.” The raw data and subcategories fell under the main category of “Attitudes in health care towards clients with CP.”

Neither of the informants had negative experiences regarding the ward staff; both said that the nurses, doctors, and other staff members had been friendly and professional. They also said that the disability has not affected the availability of mental health care.

Informant B told that he was very happy with the staff of his ward, and he even felt privileged there:

“Ne oli hyvin kiinnostuneita ja avualiaita, ja sosiaalisia ja tosi ammattimaisia silleen että koin ainakin koko ajan olevani turvassa siellä siinä mielessä, että muhun suhtauduttiin tosi hyvin.”

”They were very interested and helpful, and social and very professional in a way that at least I felt all the time safe there in the sense that I was concerned very well.”

“Varattiin jopa enemmän aikaa, koska mä puhuin niin paljon. Että sellaisia pieniä lisämyönnytyksiä, että esim. ei oo saman verran aikaa ku jollain toisella.”

”They even reserved more time because I talked so much. Like certain small concessions, like for example that I didn’t have the same amount of time as someone else.”

He also said that he still has an ongoing care contact in the smaller city where he used to live, and that he values it since he believes that it is easier to deal with a smaller organization.

Both were also asked if they have had problems regarding attitudes within bureaucracy, like Kela or municipal services, but they were content with them as well. Informant A said that he does not deal with bureaucracy himself since his brother takes care of it, and Informant B said he is used to dealing with all kinds of offices and knows how they function.

However, Informant B told that after his first psychosis at around 20 years of age, the doctor who first treated him interpreted the event as a pubertal fight between the informant and his parents, claiming that he does not need any psychiatric help after being found outside by the police on a neighbour’s yard naked and disoriented:

“Ensimmäinen lääkäri oli alun perin sitä mieltä, että tää oli jotain murrosikäisen riitoja, että mä oon vaan lähteny kotoa ovet paukkuen. Niinku mä lähdinki ovet paukkuen kotoa, mutta en varmaan siitä syystä että me oltais riidelty, vaan siitä syystä että mä voin muuten huonosti.”

”The first doctor initially thought that these are some adolescent fights, that I’ve just left home with doors banging. Like I did leave with the doors banging, but probably not because of fighting, but that I was otherwise feeling bad.”

After telling this story the informant was asked if has he has ever felt like the doctor or the nurse talks to him like he does not understand what is being said, meaning that has he been mistaken for an intellectually disabled person:

“Joskus jossain, mutta ei loppujen lopuksi mun terävyyttä ole epäilty ainakaan siellä sairaalan puolella. Joskus terveyskeskuksessa moneen kertaan, mutta sairaalan puolella ei ole.”

”Sometimes somewhere, but at the end my sharpness hasn’t been questioned at least there at the hospital side. Sometimes in the health center several times, but not on the hospital side.”

8.3 Communication with mental health clients with CP

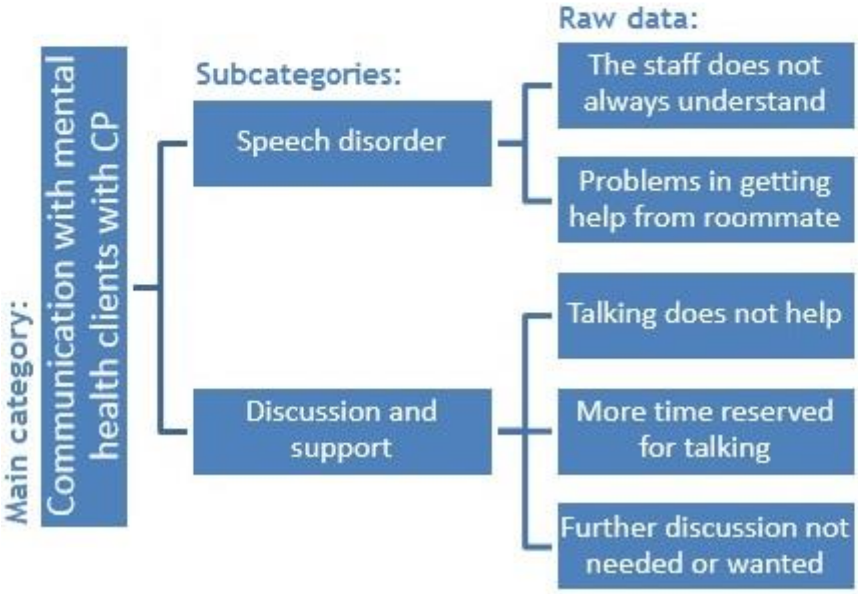

Figure 4: Process of forming the main category of “Communication with mental health clients with CP”

Figure 4 illustrates how the raw data identified from the interviews forms two subcategories, “Speech disorder” and “Discussion and support”, that are relevant in terms of the main category of “Communication with mental health clients with CP.”

Informant A and B had very different views and experiences on the communication aspect of their care. Informant A has a speech disorder as an accompanying impairment to his CP, whereas informant B does not have any difficulties with his speech and is rather talkative. When asked if informant A's speech disorder had affected the availability of care and whether there had there been problems with it:

"On. Kaikki ei saa mun puheesta selvää."

"Yes. Some cannot understand my speech."

Informant A also added that he has not always been understood properly by the health care professionals because of his speech.

"En aina [ole tullut ymmärretyksi]."

"Not always [been understood]."

As an example of a communication problem he told about the previously mentioned fall when he was struggling to get his roommate to call for help:

"On, esimerkiksi huonekaveri on huutanut apua silloin kun mä olin lattialla, niin se ei ymmärtänyt."

"Yes, for example my roommate had called for help when I was on the floor, so he didn't understand."

Informant B did not feel he had had any problems with the communication aspect of the care, and emphasized that his intelligence was rarely questioned by the health care professionals. He mentioned that because he is so talkative, they even reserved him more time for discussion at the hospital.

"Varattiin jopa enemmän aikaa, koska mä puhuin niin paljon. Että sellaisia pieniä lisämyönnytyksiä, että esim. ei oo saman verran aikaa ku jollain toisella."

"They even reserved more time because I talked so much. Like certain small concessions, like for example that I didn't have the same amount of time as someone else."

When asked if either of the participants would at the moment need more therapy or someone to talk to, informant A had a straightforward answer:

"Ei auta juttelut."

"Talking won't help."

Informant A does not think more therapy or support would help with his situation. He sees a therapist regularly, but does not find it helpful. Informant B on the other hand has policlinic visits once year, and for him those visits are enough. He appreciates the conversations, but considering his stable condition at the moment, does not feel the need for additional support.

"Käyn psykiatrian polilla kerran vuodessa. Ei tunnu siltä, että tarvitsisin lisää mitään keskusteluapua. Keskustelu on ihan hyvää, mutta oon pärjännyt ihan hyvin näin."

"I visit psychiatric policlinic once a year. It doesn't feel like I would need more support. Therapy is quite good, but I have gotten along just fine like this."

8.4 Quality of life

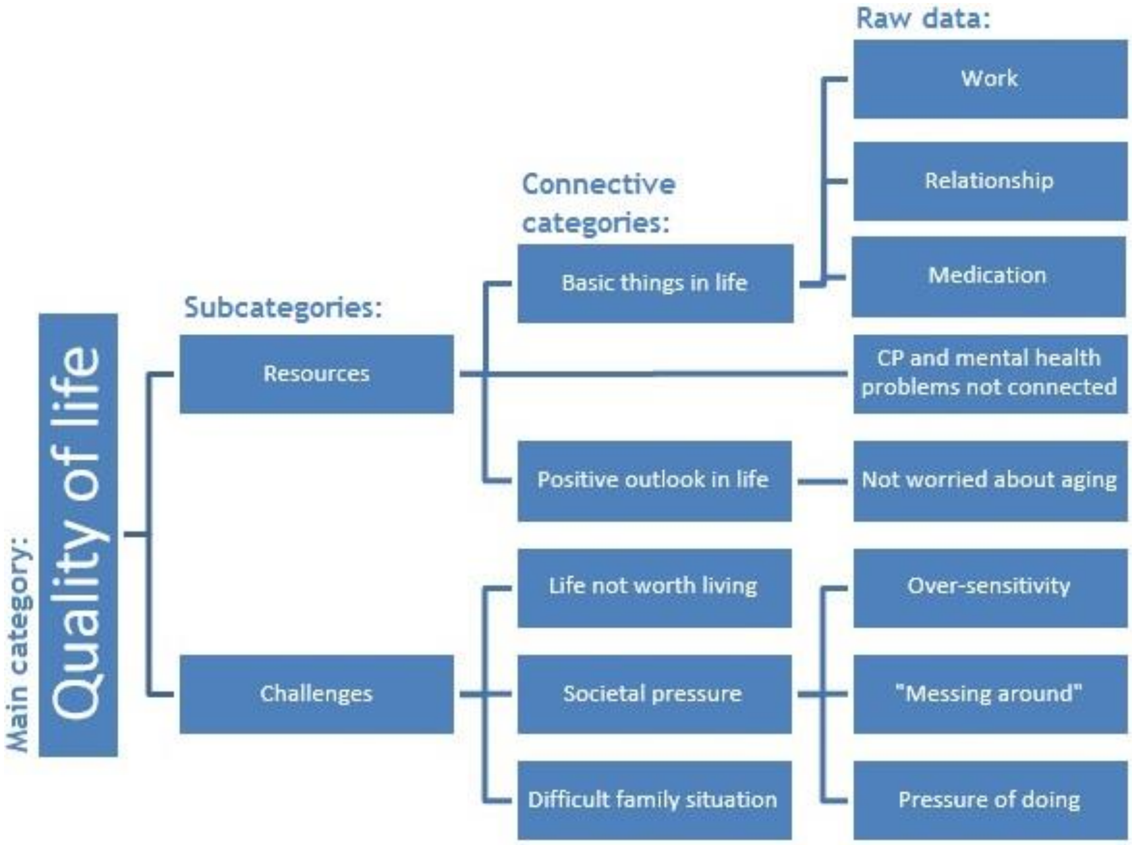

Figure 5: Process of forming the main category of "Quality of life"

The raw data visible in figure 5 was collected from the text segments that were relevant in terms of the overall mental wellbeing of the informants. After labeling the segments, the different connective categories were formed. The two subcategories of “Resources” and “Challenges” are seen as the positive and negative aspects affecting the overall “Quality of life.”

Informant A is constantly depressed and considers his life not worth living, and shared his hopeless view on life:

“Haluaisin mainita, että nyt tänä päivänä haluaisin kuolla pois. On niin vaikeeta elää.”

”I want to mention that even today I would want to die. It’s so hard to live.”

Informant B did not mention many negative factors affecting his mental wellbeing, but when asked what he thinks could cause disabled people to experience mental distress, he said:

“Voi olla jotkut sosiaaliset syyt, tai sit siinä voi olla se, että suorittamisen paine yhteiskunnassa tällä hetkellä rasittaa ja joutuu tekemään vähän enemmän kuin normaalisti.”

”It could be social reasons, or it could be that the pressure to achieve in the society at the moment is straining and you have to do a little more than normally.”

He also mentioned the pressure to achieve when told about the onset of his first psychosis:

“Tavallaan niin kuin yliherkkyys siitä, ja semmonen sählläämisen meininki, että yritti tehdä hirveesti asioita ja mikään ei onnistunut. Niin on käynyt useamman kerran vuosien varrella. Paineet tekemisestä on olleet kovat jossain vaiheessa. Semmonen fiilis, että kaikki kaatuu niskaan.”

”Sort of over-sensitivity of it, and a feeling of messing around, and trying to do a lot of different things and nothing was working out. It has happened several times over the years. The preussure of doing has been hard at some point. A feeling that everything is falling apart.”

He mentioned personal struggles with sexuality as one of the stress factors that could have contributed to the onset of the psychosis, and he also brought up his family relationships when discussing the first psychosis:

“Jälkeen päin ajateltuna uskon, että se kuormitti että kotiolot ei ollut kaikista helpoimmat. On aina ollut alkoholia ja muuta sellaista taustalla, mikä sitten taas kuormittaa ja rasittaa tavallaan sitä olemassaoloa siellä kotona.”

”When thinking back I believe that it was straining that the situation at home was not the easiest. There’s always been alcohol and other such things on the background, which then in a way burdens and strains being there at home.”

“Mä uskon, että meidän suvussa on mielenterveysongelmia. Ja ne asiat jotka oli heikosti kotona edesauttoi sitä, että se puhkes mulle.”

”I believe that there’s mental health problem in my family. And the things that were not well at home contributed to the fact of it appearing.”

The positive aspects affecting the quality of life are fewer in numbers than the negative ones, but there were some that came up during the interview; work, relationship, medication, and a generally positive outlook on life:

“Mä oon aina ollut suhteellisen positiivisella asenteella varustettu, että mä en osaa suhtautua siihenkään asiaan [CP] negatiivisesti. En mä koe, että se häiritsee mun elämää juuri millään tapaa”

”I’ve always been equipped with a fairly positive attitude, so that I can’t take it [CP] negatively either. I don’t feel that it disturbs my life hardly any way.”

“Periaatteessa muuton jälkeen 2006 on mennyt koko ajan noususuhdanteisesti ylöspäin vain. Oon työllistynytkin sen jälkeen. Pääpalikat on kunnossa, eli jaksaa pikkasen paremmin. Parisuhteet ja muut vaikuttaa siihen asiaan, kaikki tukee sitä ettei toivottavasti tarvii mennä hoitoon. Pysyvä lääkitys on koko ajan, jotka hoitaa.”

”Basically after moving in 2006 everything has gone only uphill. I even got employed after it. The main blocks are in order, so it’s a little bit easier to carry on. Romantic relationship and other things affect that thing, everything supports that I hopefully won’t have to go to the hospital. Permanent medication which helps.”

He also said that he is not particularly worried about getting older, and that CP and mental health problems are not interlinked:

“Tiedän, että monella CP-vammaisella on mielenterveysongelmia, mutten sitten tiedä miten ne niiden kanssa pärjää. Mun mielestä sitä ei voi littää siihen sairauteen [CP] mitenkään, mutta siinä on käynyt vain huono tuuri.”

”I know that many persons with CP have mental health problems, but then I don’t know how they manage with them. I think that it can’t be linked to the illness [CP] in any way, but it’s just a matter of bad luck.”

9 Discussion of the findings

9.1 Analysis of the categories

PHYSICAL CHALLENGES

Physical challenges, and physicality in general, were very present in the answers of Informant A. Even his background story of how he got admitted to a closed ward was physically oriented; he had tried to commit a suicide by drowning but due to his physical limitations a bystander was able to save him from the water. He also strongly emphasized that his life was not worth living due to physical problems, and that no amount of therapy or discussion will remove these problems.

When comparing his answers to the previously mentioned studies on chronic pain, it could be interpreted that he is now experiencing the negative sides of getting older and perceives his life “less manageable and meaningful” as well as “unpredictable and incomprehensible" (Horsman et al. 2010). Within this framework it could be seen that Informant B did not experience the same challenges because he is younger and has not been subjected to the problems related to aging are not yet relevant in his case.

Together the topics of suicide attempt and chronic pain formed the subcategory of “life being physically challenging.” These were the issues that were directly connected with the Informant A’s hardships caused by the disability. The second subcategory, “ward’s physical environment”, dealt with the more typical accessibility issues that could be fixed by altering the environment of the wards.

According to both of the informants it seems that the physical environment of psychiatric wards could be improved to better facilitate people using wheelchairs but the issues were not considered that essential, or that they did not come to think how the physical environment of the wards could be better. However, at least when Informant A fell in his room it would have proved beneficial for the room to have a call button.

In case of Informant B always ending up in a closed ward wheter he needs it or not, is a problem of equality. This problem did not seem to bother him, but he mentioned that he has sometimes felt out of place among other patients who were acutely more psychotic than him. It would be important to provide equal physical accessibility to all psychiatric wards, so that all patients would get the exact care they need.

THE ATTITUDES IN HEALTH CARE TOWARDS CLIENTS WITH CP

The discussed topics related to the attitudinal aspects formed three rather distinct subcategories; “Assumption of intellectual disability”, “Overall professionality of the staff”, and “Education.” The assumption of intellectual disability can be seen as a challenge for the staff and the clients, while the overall friendliness of the staff is an important resrource. In this context education could be seen as a bridge between the two.

The attitudes within health care towards people with CP were generally considered positive, but the examples told by Informant B hints to certain attitudinal issues. The story of the doctor interpreting his first psychosis a “pubertal fight” could be a sign of attitudinal issues since it should be clear that a 20 year-old is no longer in puberty. It could have been that the doctor assumed him to be mentally still in puberty and therefore initially dismissing the possibility of an actual mental health crisis.

He also told that he has felt several times like he might be mistaken for an intellectually disabled person when dealing with municipal health care, but never in specialized health care. It could be argued that perhaps the specialized health care is more focused on their speciality areas (e.g. psychiatry) than additional factors. The issue of assuming that people with CP are also intellectually disabled was also highlighted in the previously mentioned research by Balandin et al. (2007).

However, the informants were mostly happy with the professionality of the mental health care staff; they considered most nurses and doctors to have been friendly and helpful, and the other informant even felt that he was treated a bit better than other patients on the ward. Even if it the informants have not encountered a lot of negative attitudes in mental health care, it seems that there are still some issues in presuming that the client with CP might also have cognitive problems, or intellectual disabilities. This type presumptions could perhaps be solved with education, especially considering that both informants said that the health care staff would perhaps need more information regarding disabilities.

COMMUNICATION WITH MENTAL HEALTH CLIENTS WITH CP

Informant A reported having problems in communicating with the nurses and with other patients, even the interview was occasionally challenging due to his speech disorder. It is possible that problems in communicating efficiently will affect the accessibility of mental health care.

Understanding dysarthric speech can be difficult; for example, a person with spastic dysarthria has problems in pronouncing phonemes making the speech sound strained-harsh, slow rate, and lacking in pitch variety (Duffy 2005). For the listener this means that he or she must listen carefully in a quiet environment, and to be patient. In addition, the mental state of the client can make understanding even more challenging. In such cases the nurse should show particular patience and professionality by doing his or her best by listening carefully.

It is also possible that a person with CP has such a severe speech disorder that he or she is completely unable to communicate by using natural speech. In such cases he or she might use augmentative and alternative communication (AAC) methods, and maybe an interpreter. Under these circumstances it can prove very difficult to provide the client with sufficient support and understanding, or to maintain confidentiality.

The subcategory of “speech disorders” was formed from the reported communication problems, and the subcategory of “discussion and support” mainly constitutes from aspects related to ongoing mental health care contact.

It is interesting that neither of the informants desired for more discussion support, or they did not know what kind of support they could have. Their reasons for not wanting more communication with the nurses, doctors, or therapists were rather different; the other was doing well without any and the other one felt that it would not help anyway. The reasons could be that they had not been informed of the different options of attending peer support groups, or that after the acute mental health crises were over they did not have the need for additional support.

QUALITY OF LIFE

A recent nursing science study defines quality of life as “an intangible, subjective perception of one’s lived experience” (Plummer & Molzahn 2009.) In this thesis the concept is interpreted exatly in this context; as an overall perception of the informant’s lived lives. It includes events, thoughts, and emotions that have occurred in the past, and what the person feels in the present and what he expects from the future.

Forming the main category of “Quality of life” was more complex than the other main categories. These aspects did not directly fall under other categories, but were considered pivotal in terms of the overall mental wellbeing of the informants. The topics dealing with the quality of life are divided into two main subcategories; resources and challenges. The resources are the positive aspects enhancing the quality of life, and challenges are the negative aspects that might lower it. The resources and challenges constitute from further subcategories that are the practical and mental factors affecting the quality of life. In Rauhala’s (2005) terms all of the challenges and resources affecting the quality of life could be labeled as situationality; factors which are constantly changing and interacting with the consciousness and the physical reality.

The resources were “Positive outlook in life” and “Basic things in life.” The positive “basic thing in life” were work, relationship, and ongoing medication. The more philosophical comment about having a positive attitude in life and not being afraid of aging were also considered very important resources. The statement that CP and mental health problems are not in any way connected was categorized as a resource as well; clearly life quality would be lower if CP would cause mental health problems. The amount of resources seemed smaller than the amount of challenges, but at least in Informant B’s case the the resources outweighed the challenges.

Informant A’s statement that he would even now like to die is a direct statement on the quality of his life; he considers it so low quality that he would rather not live. The despair associated with the struggles of living with CP had a huge impact on his life, and he feels the quality cannot be enhanced and he did not actually mention anything that could be categorized as a resource.

Informant B did not experience challenges as severe as Informant A, but he seemed to think that there is an additional pressure for disabled people to achieve in the society, and that the pressure might get too overwhelming. He did not elaborate whether the pressure is external or internal, but in any case it can lead to dire consequences. As an external pressure it could be that the world around is not accessible enough for disabled people causing them to feel pressured. As an internal pressure it could be seen as a pressure that comes from the within when a disabled person has the need to prove that he and she can also achieve the same things in life as his or hers non-disabled peers. In either case, the feeling of pressure is closely knit to the social factors.

Informant B also brought up difficult family relationships, substance abuse, and struggles with sexuality as issues leading to his first psychosis. However, these aspects are not directly connected to disability as they can be considered as universal challenges which anyone can face at some point of their life.

9.2 Trustworthiness

Holloway and Wheeler (2010) suggest that conventional criteria of validity and reliability, or alternatives such as trustworthiness and authenticity, are used in qualitative research. In qualitative research trustworthiness implies methodological soundness and adequacy. Judgements of trustworthiness are made through developing credibility, transferability, dependability and confirmability. (Holloway & Wheeler 2010, 304). In this light, there are certain issues with the trustworthiness of this thesis; the limited amount of informants, their shared psychiatric diagnosis, and some liability issues regarding communication.

Even though the writers had prior contacts to disability organizations and individuals with CP, there were difficulties in finding informants for the interviews. The search through organizations and social media proved unfruitful, and it was not until a personal visit to The Finnish CP Association's day center when the informants were found. At first there were five individuals who were interested in participating in the thesis, but gradually they got reduced to two people who actually got interviewed.

Dr. Rola Ajjawi of Dundee Centre for Medical Education claims in her article concerning sample size in qualitative research claims that "the phenomenon that is more difficult to grasp and is below the surface would require more participants" and "the more usable data you have the less participants are needed." (Ajjawi 2013). In this context the small sample of informants interviewed presents an issue with trustworthiness.

The case of five prospective informants diminishing to two who got interviewed could result from the fact that one of thesis writers had connections to the organization. The writers had agreed that the one who does not have any connections to the organization does the interviewing to gain professional distance, but for practical reasons both of the writers ended up interviewing the informants together. There is no prior connection between the writers and informant A, but informant B and the other writer are acquaintances through the organization.

Having a contact with the organization, and one of the informants, may be beneficial in terms of networking, but in the context the thesis this type of connections can compromise the trustworthiness of the thesis. A 2009 study by McConnell-Henry, Ainsley, Chapman, and Francis mentions some problematic aspects that need to be considered when the qualitative researcher is interviewing someone he or she already knows; it is possible that the informant might feel obligated to volunteer for the interview, he or she might consider the interview as method for venting or debriefing, or he or she might feel exploited after the interview (McConnell-Henry et al. 2009) In turn, the researcher can feel “apprehension, anxiety and fear of the unknown” when interviewing persons they already know (McConnell-Henry et al. 2009).

When dealing with secrets and sensitive data it is possible that the researcher feels “upset, frustrated, fearful, angry or helpless.” It is also possible that the respondent might assume that the researcher is also in a position to help him or her regardless if the roles had been discussed prior to the interview. The study suggests that the key in avoiding such problems with the familiarity and roles in interviewing is good preparation and a disengagement of the interview; the researcher needs to have a plan laid out for the interview and at the end a mutual point of closure must be negotiated with the respondent. (McConnell-Henry et al. 2009).

The trustworthiness issue of the shared diagnosis means that the findings can only be applied to people who have CP and bipolar affective disorder. The findings could have been drastically different if the variety of mental illnesses would have been wider, now the thesis is only from the perspective of one mental illness and it gives a one-sided view from the psychiatric standpoint. Also, the reliability of the thesis would be compromised if the informants would be going through manic or depressive periods during the interviews. During manic episodes the person can be grandiotic, sporadic, and even psychotic, and even during depressive periods there is chance of psychotic symptoms (Huttunen 2013).

Another trustworthiness issue arises when considering that informant A had a rather severe speech disorder. For the most part his speech was understandable when listened carefully, but he replied in short answers because speaking seemed rather arduous for him. Due to his short answers the interviewers had to ask several clarifying questions, which could mean that the interviewers were unwillingly leading the conversation on to certain directions.

The fact that neither of the informants did not report experiencing any cognitive problems, and that neither were intellectually disabled, made the thesis less complex. In case of intellectual disability there would have been issues with informed consent, and a much deeper research on learning disabilities, and the specialized psychiatry associated with it, would have been required. For example, when it comes to intellectually disabled people more than half of the behavioural problems are not caused by mental illnesses and it can prove very difficult to diagnose intellectually disabled people with bipolar disorder or psychosis (Koskentausta 2014; Seppälä 2013).

The field of the thesis was very specific from the beginning, but during the process it became even narrower, which may affect the trustworthiness of the overall thesis. It would have been beneficial to have more informants and variety to attain a broader view of the subject.

9.3 Conclusion and suggested future studies

According to this thesis it seems that there are no major issues in the accessibility of mental health care, but there seems to be lack of knowledge on two different levels; the health care staff could have been better educated regarding disabilities and the disabled mental health users could have been better informed regarding the possibilities of further support and discussion.

This reflects the claim presented in the study by Foster et al. (2010); since medical disability studies are usually more concerned with physical attributes, the mental health issues remain largely unexplored. Hence, overall larger focus on the mental wellbeing of disabled people would be needed, as well as education for the mental health care staff.

The psychiatric wards should be improved to better facilitate wheelchair users and other people with physical accessibility issues; there could be some rooms equipped with call buttons and lifts in case of disabled patients being admitted to the ward.

There is an indication that a large scale nationwide study on the mental wellbeing of disabled adults is needed; such study would work as a valuable stepping point for further more specialized studies. Also, a study on the Finnish registered nurses’ knowledge and attitudes regarding disabilities and disabled people would offer valuable data for nursing sciences and sociological disability studies.

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Appendices

Appendix 1: Informed consent

Opinnäytetyö: “Accessibility in mental health care”

Kimmo Pihlaja & Paula Päivärinta
Laurea-AMK, Degree Program in Nursing

Teemme hoitotyön koulutusohjelman opinnäytetyönämme laadullisen tutkimuksen mielenterveyspalveluiden esteettömyydestä. Haastattelemme CP-vammaisia henkilöitä mielenterveyshoidon esteettömyyteen ja yleiseen henkiseen hyvinvointiin liittyvistä asioista.

Keskustelu on luottamuksellinen, eikä haastateltavista henkilöistä julkaista minkäänlaisia tietoja, joista heidät voisi tunnistaa. Keskustelu nauhoitetaan, mutta työn valmistuttua äänitteet ja litterointi hävitetään.

Annan suostumukseni haastattelun nauhoittamiseen, sekä materiaalin käyttämiseen opinnäytetyön empiirisen osuuden pohjana.

- -
Paikka, aika, allekirjoitus

Appendix 2: Frame for the semi-structured interview questions

1) Minkä ikäinen olet?
2) Mikä psykiatrinen diagnoosi sinulla on?
3) Onko sinulla jotain diagnooseja cp-vamman ja psykiatrisen diagnoosin lisäksi?
4) Missä sinua on hoidettu? Kauanko hoito kesti?
5) Milloin olet ensimmäisen kerran käyttänyt mielenterveyspalveluja?
6) Miten pääsit avun piiriin?
7) Onko sinusta cp-vamma vaikuttanut avun saatavuuteen?
8) Onko sinusta cp-vamma vaikuttanut henkiseen hyvinvointiisi?
9) Oletko tullut ymmärretyksi?
10) Millaista kohtelua olet saanut erityisesti hoitajilta?