Creating Meaning - Understanding the Experiences of People Living with Mental Illness in Switzerland

A Qualitative Study

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Photo on title page:
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Abstract

Mental illnesses have a large impact on individuals, their families and friends and communities. People living with mental illness often face discrimination and not the least within the health-care system. However, there is an ongoing shift from a paternalistic to a person-centred approach in the treatment of people living with mental illness. User involvement in the development of care has become common practice and personal recovery rather than cure is at the core of treatment. However, to further improve professional practice, there is a need to understand more about the experiences of people living with mental illness.

The aim of this research is to explore and evaluate the personal experiences of people living with mental illness in Switzerland and to identify aspects that are most relevant to this population in living with and adapting to mental illness. Therefore, the study aims to create an understanding of the adaptation process to mental illness from a patient perspective.

A constructivist and reflexive Grounded Theory approach was chosen for the main study. Ten participants, people living with mental illness in Switzerland, were interviewed. However, the project also includes a preliminary study, comprising a focus group with mental health professionals, that used qualitative thematic analysis.

Three categories were generated from the data of the main study: *Constructing explanations* refers to the process of participants trying to understand what is going on in their lives. *Defining self-identity* points out that people living with mental illness provide themselves with an understanding of who they are*. Making sense-of-life* refers to the aspect, that the participants give situations meaning and take control over them. The three categories form the theoretical framework of the *Creating Meaning Theory*, which summarises the experiences of the people interviewed for this study. The findings support existing theories but add a new and unique understanding of people's experiences in living with mental illness that will help to further improve concepts such as empowerment and recovery.

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Preface

It has been due to my dear friend and mentor the late Prof Dr Francis C. Biley that I have started the PhD programme at Bournemouth University (BU). Prof Biley and I share a common understanding of the art and science of nursing that brought us together as close friends ever since I first met him as my first lecturer in the Master of Science in Nursing (MScN) Germany outreach programme at Cardiff University. Our long and challenging, at times even contentious debates were part of my professional and personal development over several years and helped me to consolidate my own views and values not only in nursing but in other aspects of life as well. Therefore, when asked to join Prof Biley and his international team that has been establishing a series of research projects around the broad topic area of adaptation to illness, I did not hesitate to apply for the doctoral programme at BU.

I am very grateful to Bournemouth University that they accepted my application for the Vice Chancellor Doctoral Scholarship programme and offered me to undertake the Doctoral Research Degree (PhD) programme at the Faculty of Health and Social Sciences in part time mode under supervision of Prof Biley. Sadly, Prof Biley passed away unexpectedly before I started the programme and with him gone, as the leader of the international collaboration around his research topic, the original idea of my contribution to his project ended. However, under the encouraging supervision of Dr Sarah Thomas, Dr Zoe Sheppard and Prof Dr Edwin van Teijlingen, I could develop a new and my very own project that lead to this thesis. Their effortless support helped me throughout the whole process and many difficult times. A huge thankyou to you all, including staff and colleagues at the Faculty of Health and Social Sciences, the Graduate School, now the Doctoral College, and other allies and affiliates at Bournemouth University!

Another profound thankyou pertains to Prof Dr Sabine Hahn, who, as a wonderful friend and mentor, became my external supervisor. This was especially important because the project was carried out in Switzerland and all the data collected is in German. Prof Hahn also guaranteed the approval from the Swiss ethics authorities in appearing as primary investigator in the study, a procedure which is demanded with the Swiss authorities. Without her support and patience this project could not have been finished.

In addition to the academic team who supported my work, there are several other people who helped me making this dream come true. First and foremost, my long-time partner, best friend and husband Peter Kyburz. Without his love and patience, his tremendous emotional and not to forget his lasting financial support, I could not have accomplished what I did over the last couple of years. This is also in large part true for my family and friends, employers, co-workers and many more. It has been my private social and my professional network that has helped me to gain access to relevant resources including my niece Cornelia Stutz who did most of the transcriptions of the interviews or friends and colleagues who distributed study leaflets to potential participants or kept the discussion going on with me.

However, in fact, it is the participants who made this study happen. A very big thankyou to all my wonderful participants of this study, even the ones who were not directly participating but still contributed to it through conversations at conferences or elsewhere. It is the people with their lived experiences who made this possible. Without them the study could not have been conducted. Their willingness and openness to share their stories empowered me to keep going with the project, even when I struggled to move on.

I am sure that I have forgotten to acknowledge many more here. They all know who they are and I am deeply grateful to all of them. I know I am very privileged in having had such great support on so many different levels. It all helped to keep a good balance for myself and not getting lost in despair. Living in a beautiful and save country, having the opportunity to go walking in lovely surroundings whenever I feel like it, spending time with our precious dog Ginger, meeting friends, and so much more, all this helped tremendously and could not have been taken for granted.

Thank you!

Dedication

This thesis is dedicated to my late friend Prof Dr Francis C. Biley and his loving wife Anna with their sons Matthew-Jack and James. Over time I realised that Fran would have wanted me to have my own project and not his or anybody else's. In holding on to a research topic related to people I work with and care for and carry on aspects of Fran's work, this whole project became much more than just 'a thesis submitted in partial fulfilment of the requirements for the Doctor of Philosophy (PhD) degree', it really became a part of my ongoing journey as a human being and a professional.

Author's Declaration

I certify that this thesis has not already been accepted, nor is it currently being submitted for any other degree and / or publication.

The work is a result of my own investigation and all quotations and sources from other authors have been acknowledged.

Signature: P. Wolfensberger

Peter Wolfensberger

Date: 30. August 2019

Sternenberg, Switzerland

1 INTRODUCTION

Wägital, Switzerland 2017

“Human caring science must be lived
in walking alongside in caring healing love
and light,
there is sad peace”
(Biley 2017a, p.1)

1.1 An Ongoing Journey

Even though this chapter marks the beginning of a thesis that will also have a final page, the whole project is an ongoing journey that most likely will continue after the defence of the thesis. On this journey, I continuously try to keep my own work-life balance in going for long walks and hikes, enjoying music, literature and the arts among other things. Therefore, I choose to add photos and quotes that symbolise or emphasise aspects that are written or discussed in the thesis and, at the same time, are directly linked to my own contemplation and well-being, hoping it may have a similar effect on the reader.

This first chapter opens with a picture of a hiking trail signpost that has been installed directly on the ground behind a solid rock because the area is at risk of rock fall. It seems an appropriate symbol for the content of this chapter which provides insights into the development of the study and explains the choices that have been made in taking certain directions. Additionally, the quote by Anna Biley (2017a) stemming from an artistic excerpt of her doctoral thesis (Biley 2017b) that she wrote in remembrance of her beloved husband Fran Biley, creates an atmospheric opening into this thesis. The quote indirectly refers to my own personal and professional experiences in life and my relationship to Professor Biley and points out several concepts and ideas that are of upmost relevance to me: ‘caring’ as a central aspect of nursing, ‘science that must be lived’ which indicates that knowledge needs to become useful in life and the combination of ‘love, light and sad peace’ that mirrors a non-dualistic, holistic view of life. All of these aspects are part of my own story, the story behind the project, which I will outline in this chapter in more detail. Due to these deeply personal accounts and the largely reflective character of the methodology underlying the main study of this research (see 3.2) first person is used throughout the thesis. First person is considered consistent with interpretive qualitative research (Webb 1992). However, writing in first person can be challenging (Davies 2012) and the distinction between the personal and the impersonal is not a given. Therefore, in order to better differentiate between personal opinion, interpretation and reflection and simple, even academic description, indirect language in passive voice is often used for the latter.

Starting with the original research idea and its adaptation for the current study, this opening chapter also contains the aims and objectives of the main study and a description of the research context. Following my personal story, it concludes with an exploration of my understanding of nursing and a note regarding translations in this thesis.

1.2 Original Research Idea

Based on previous work by Perrett and Biley (2013) the underlying idea of this project was to adapt the Perrett and Biley Negotiating Uncertainty Theory (PBNUT) to new populations with chronic illnesses and potentially also to people living with mental illness. The latter was taken into consideration as it is my own field of practice and expertise. Perrett and Biley (2013) generated their theory of negotiating uncertainty out of an investigation of the process of adaptation to illness for those living with the human immunodeficiency virus (HIV). Glaser's grounded-theory method (Glaser 1978) was used for their original study (Perrett 2009). Negotiating uncertainty emerged as the core concept within the process of adapting to a life with HIV (Perrett 2009). Seven subcategories were defined that represented movements between the two opposing categories 'anticipating hopelessness' and 'regaining optimism' (Perrett and Biley 2013). Based on the assumption that these findings could be adapted to other populations, the guiding research question for the proposed study would have consisted of establishing how health-care practitioners can promote an improved quality of life and increased well-being by recognising and responding to an inability to successfully negotiate uncertainty in those who experience long term conditions (Wolfensberger 2012). The initial stages of the project would have been the development and testing of an assessment tool that is based on the PBNUT.

However, before I even started my PhD programme my mentor and close friend Professor Biley passed away unexpectedly. With the loss of Professor Biley who was leading the overarching project and conceptualisation around the PBNUT, the direction of the proposed PhD thesis had to be reflected upon and needed to be renegotiated and adjusted.

Additionally, an early search of the literature around adaptation to illness and related assessment tools resulted in finding several existing instruments that assess stages of adaptation to illness (Mishel 1981; Derogatis 1986; Hilton 1994) or illness perception (Weinman et al. 1996; Moss-Morris et al. 2002; Witteman et al. 2011). Mishel's Uncertainty in Illness Scale (MUIS) (Mishel 1981) and the Illness Perception Questionnaire (Weinman et al. 1996) have been tested and adapted continuously since their original development. The MUIS (Mishel 1981) is also the instrument that seemed to be closest to the theoretical framework of the PBNUT (Perrett and Biley 2013). Considering this initial review of the literature along with the loss of Professor Biley, the further development of the PBNUT (Perrett and Biley 2013) and the idea of a tool development based on the theory became unfeasible. Therefore, together with my supervisory team, I decided to dismiss the original research idea permanently. However, some aspects of the original idea remained relevant in the further development of the project and helped me finding a new focus.

1.3 Adapting the Project

Within the original idea of the project, the study population was not conclusively defined but left open to a wide range of people living with chronic illnesses. However, with the foundational repositioning of the project, I defined the target population of this study conclusively to people living with mental illness. The decision was made on the basis of my main interests, my primary professional background and my current area of practice in mental health nursing.

Coming from a nursing background, quality of life and well-being are key domains in my professional and personal career. Therefore, the underlying research question of the original project "how can health-care providers such as nurses promote an improved quality of life and increased well-being by recognising and responding to the needs of those who experience illness" (Wolfensberger 2012, p.4) remains a guiding interest. However, what are the needs of those who experience illness, in this project of people living with mental illness? And is this the right question to ask? What needs to be the focus of the investigation in this research project?

Perrett and Biley (2013) based their development of the PBNUT on an exploration of Roy's adaptation model (Roy 1970) and the process of adapting to life with HIV (Perrett 2009). Roy's model served as guidance for the research and was tested by comparing it to the research results. However, in this present research project focusing on people living with mental illness and their process of adapting to life with mental illness, I chose not to use a specific model as a guiding framework through the research process. Nevertheless, in focusing on people living with mental illness, the philosophical assumptions of personal recovery (Slade 2009) need to be taken into consideration at some point of the project, at latest when discussing the results of this study. Personal recovery could be seen as an adaptation model to mental illness. It is an important focus in current perspectives in mental health nursing (Trenoweth 2016) and therefore, needs to be reflected upon. However, within this research project, various concepts are taken into account and personal recovery is only one of them along with the PBNUT (Perrett and Biley 2013), Mishel's (1988, 1990) uncertainty in illness theory and potentially others as well.

Stemming from the previous findings of Perrett (2009) and Perrett & Biley (2013), who describe negotiating uncertainty as the core concept within the process of adapting to a life with HIV, uncertainty in illness as an important topic or concept came up early in the process of adapting the original research idea. Therefore, uncertainty in illness (Mishel 1988, 1990) was further explored and is part of the background of this study. However, the search for literature around uncertainty among people living with mental illness was difficult and did not provide sufficient information or results. It seems that the term 'uncertainty' is almost non-existent in current literature about experiences of people living with mental illness and personal recovery. Therefore, in addition to the literature search, I conducted a small preliminary study previous to the main study of this research project (Wolfensberger et al. 2019). The findings of that small study are also part of the background of this project and its methodology is described in the methodology chapter of the thesis (see 3.4).

All of these aspects, the newly defined target population, the original underlying research question, the initial literature search, the small preliminary study, various discussions with my supervisors and others, helped me framing the present research project and its aims and objectives, focusing on personal experiences of people living with mental illness.

1.4 Aims and Objectives

The aim of the main study in this PhD project is to explore and evaluate the personal experiences of people living with mental illness in relation to their adaptation process to illness. The findings will help to create a unique understanding of the adaptation process to mental illness from a patient's perspective. This understanding may help health-care providers such as nurses to promote an improved quality of life and increased well-being by recognising and responding to the needs of those who experience mental illness.

The objectives are to:

- identify aspects and issues that are most relevant and meaningful to people living with mental illness as part of their adaptation process to illness;
- outline the process of dealing with these aspects and issues within a conceptual model or theory.

The guiding research questions are:

1. What are the issues people living with mental illness experience in the context of their adaptation process to illness?
2. How do they experience such issues and aspects?
3. How are they dealing or coping with those issues?

1.5 Research Context

The research context was extensively discussed with my supervisors. There were ideas to collect data in England and Switzerland to be able to compare results and potentially explore variances. However, as it soon became clear, that the project will be primarily of qualitative content, and resources are limited, we decided to limit data collection to Switzerland. Therefore, the main study has been carried out in the German-speaking part of Switzerland, as this is the region I am working in and where I am closely affiliated with the psychiatric and mental health-care system. However, participants were recruited through affiliates that are not directly linked with my employer, a psychiatric institution in the canton of

Zurich. This was to avoid potential professional role conflicts or confidentiality issues when participants formerly have been or currently were patients of the institution I am working for. Further details about the recruiting process and ethical considerations are listed in the methodology chapter (see 3.3).

In Switzerland, federal laws on illness insurance and accident insurance build the general foundation for the national health-care system. However, the cantons, the states within the country, are responsible for the provision of health care and the partial financing of hospital and other health-care costs (OECD 2011). This leads to 26 different health-care systems in Switzerland, as not every canton provides the same services. Additionally, the financing of health expenditure in Switzerland is a mixture of state finances (mainly cantons and municipalities), social insurances (mandatory health insurance, accident insurance, old age and disability insurance and military insurance), private insurances, cost-sharing and out-of-pocket expenditure from households (OECD 2011).

People living with a long-term mental illness who are unable to work get mainly funded through disability insurance and social security. However, their health-care costs are covered by health insurance, state finances and cost-sharing as for anyone else. The complexity of the health-care and social system in Switzerland can make it challenging and difficult to get what one needs for someone who needs specialised support in social and health related issues.

Nonetheless, the Swiss health-care system is often considered to be one of the best in Europe or even the world, especially when talking about accessibility and quality of services (Björnberg 2017; GBD 2017). This means that even though financing is fragmented, and often various authorities are involved, health-care services, even specialised ones, are in general available, accessible and mostly covered by one of the insurances. However, in complex situations, it might be difficult for individuals to find the most appropriate service that suits their needs. This not only depends on the knowledge of the primary health-care provider or other health and social-care professionals involved, but also on the available specialised services in the region or the canton. Integrated care approaches in a sense of good networks and collaborations between care providers are not yet available everywhere and exist predominantly in urban areas or major cities.

A national evaluation of the situation of psychiatric care services in Switzerland (Guggenbühl et al. 2012) showed that arrangements for psychiatric service provision vary from one canton to another. The report concludes that the majority of the cantons provided insufficient outpatient services such as psychiatric day care, psychiatric practices, outpatient clinics or home visits and home treatments. One key factor that leads to the lack of these services is the existing financing system that favours inpatient treatment (Guggenbühl et al. 2012; BAG 2016). Stocker et al. (2016) argue that mental health services are especially insufficient for children and young adults and that there is also a major gap between rural and urban areas in relation to available specialist services.

Despite potential limitations because of insufficient services in certain areas, people living with mental illness in Switzerland normally have access to a variety of services. These include home visiting general and psychiatric nursing services, often called Spitex, general practitioners, psychotherapy through consultant psychiatrists and clinical psychologists, which are available almost everywhere in Switzerland with the exception of very remote regions such as some alpine areas. In addition to those widespread services there exist various occupational therapy services, psychiatric day care clinics, specialised psychiatric hospital services, acute psychiatric clinics and crises intervention centres. These services are completed by rehabilitative facilities such as occupational rehabilitation and vocational reintegration through sheltered workshops or job coaching in the primary labour market (BAG 2016).

1.6 My Own Story

This section is about my personal background and motives and the language chosen is much more informal and narrative than expected in academic writing. However, I do want the reader to clearly distinguish between my story and the more formal content of the thesis. Adding personal details in a research project can be irritating at first. When I wrote some details of my personal story in the transfer document of my studies, one of my supervisors questioned its purpose. I was perplexed, but it made me realise that I had to explain and defend my intentions. So, why am I doing it? For me, there are two main reasons: First, I have chosen a methodology that, in my opinion, demands more insights into the motives and background of the researcher as it would be necessary within other approaches. Second, doing a PhD for me has a lot to do with my own life journey, my experiences, values and beliefs. It is not just another step in my professional career but an opportunity to reflect on my own life experiences in the context of my research.

The methodology is explained in chapter three. However, as it is my main argument to write about myself, here is what I think: Within the chosen reflective interpretive qualitative approach, the researcher is anything but a neutral data analyst. He is part of the investigation and interaction (Charmaz 2014; Breuer et al. 2017). Therefore, I believe it is most relevant to know where the researcher is coming from, what has influenced his perceptions and what his values and beliefs are. I am going to share these details of my own life story. In doing so, I do want to help the reader to understand what might have influenced my interaction with participants and potentially my interpretation of the data. It also serves as an explanation of why and how I approach the project in certain ways.

1.6.1 Experiencing Stigma

The first linkage between my own life and the project I find important to describe is the one about experiencing stigma. People living with mental illness are potentially facing various types of public and/or self-stigma such as stereotypes, prejudice and discrimination (Corrigan et al. 2005; Rüsch et al. 2005; Casados 2017; Sheehan et al. 2017). These are all aspects that I have experienced myself for different reasons: Born and raised in rural Switzerland back in the Seventies and Eighties I realised early in my life that I might be different from the others around me. And even though I tried hard to fit in and did quite well in doing so, I asked myself, what is wrong with me? When it became clearer that those feelings were because I am more attracted to boys than girls, it did not really help or get better but worse. I had no role models to look up to and everything I heard or read about was not very supportive or empowering at all. So being gay for me basically meant hiding and denying who I really was for quite a long time. I fought a long battle to come to terms with myself, something that many LGBTIQ+ (lesbian, gay, bisexual, trans, intersex, queer or questioning) people are going through: In my case, I doubted my own identity, was looking for answers I did not get or with conflicting results. After years of ups and downs and even after my first coming out to some friends, which was rather well received, I decided to overcome these feelings by begging Jesus to deliver me from them. It did not work, but I told the few people who knew I was gay, that I was not gay anymore due to my faith and being reborn in Christ. I will talk a little bit more about that religious aspect of my life in the next subsection. Anyway, it took several years to finally accept myself. In all those years, I had only a few people I could talk to. For a very long time it was only the correspondence with a pen pal, an older catholic priest, where I could address my struggles. However, this one thread of hope might have saved my life as a teenager when I was going through suicidal thoughts and more. Years later, along with accepting myself and my sexuality, came the desire to tell people who I am and being open about it. However, coming out is a difficult task, especially because sexual orientation alone does not define who you are and puts a focus upon something that is usually considered being a private affair. And still, because it differs LGBTIQ+ people from others and from what is called the norm, coming out serves a purpose. Corrigan and Matthews (2003) argue that the benefits of coming out are an increased self-esteem, decreased distress, psychological well-being and enhanced relatedness to key institutions like work as well as that it facilitates interpersonal relations. All of this has been and still is undoubtedly true for me. However, coming out may also come with the costs of physical harm, social avoidance and disapproval by others (Corrigan and Matthews 2003) which can lead to more stigma and discrimination. Luckily, I never experienced physical abuse or assault due to my sexual orientation, but I did get avoided and disapproved by others. Experiences that repeated themselves again, when I decided to come out once more as being HIV positive. In relation to my homosexuality, maybe the most difficult experience was the disapproval by my own brother and the church where I was an active member for many years. However, having 'lost' a family member and friends that way did not break my newly found inner freedom but made me stronger instead. The gay community offered me comfort and a new place where I belong. Corrigan and Matthews (2003) argue that the experiences of stigma are similar for gays/lesbians and people with mental illness and therefore, “what the gay community has learned about coming out may inform a similar movement in the community of people who identify themselves as mentally ill” (p.244). My experiences of stigma, homophobia, discrimination and prejudice in various facets are my own, but they can help me to better understand and relate to what similar experiences could mean for others. Stigma, consisting of the elements of prejudice, stereotypes and discrimination (Sheehan et al. 2017) are not always visible at first glance but may have an extremely damaging effect on people in many ways (Wolfensberger 2011). For me, fortunately, that has not come true. Instead, being openly gay in a hetero-normative world, has helped me to become highly sensitive and attentive to human rights issues, such as equality, social justice and freedom. Also, it made me realise that it is important to always look beyond what I see of people first, their face, expression or a certain behaviour, and to search for the individual human being behind it. Because with only first impressions in mind, stigma, prejudice and discrimination may start in my own head. Rüsch et al. (2005) argue that public stigma starts as a selection of human qualities and distinguishing between different groups in society that then leads to labelling differences. Labelling always requires an oversimplification of attributes, such as skin-colour, gender, sexual orientation, income or health. Labelling often implies a separation between ‘them’ and ‘us’, even if there is no clear demarcation line between the groups (Rüsch et al. 2005). So, here I am as a gay man and mental health professional and have probably more in common with people living with mental illness than I would have considered before. There is more to each one of us than just our sexual orientation, our mental or any other illness, our ethnicity or whatever. We are all unitary human beings after all. What I understand of unitary human beings brings me to my worldview and belief system.

1.6.2 Worldview and Belief System

Faith and religion have always been part of my personal journey that shaped who I am today and what I believe in. I have been brought up in the Western Christian tradition but without a strong connection to church. My parents were moderately religious and belonged to the reformed church like the majority of the Swiss population back then. In those days, it was custom for children and teenagers to attend religious education classes after school once a week and also go to church on Sundays. Over the years, my siblings and I became more religious than our parents ever were. We engaged in Christian youth groups and later in Bible study groups and other activities with a clear evangelical background. To me, these activities provided a sense of belonging that I very much enjoyed and probably needed. Struggling with all kinds of insecurities that come along with growing up made me amenable to religious faith and its practices. However, it also became one of my biggest burdens and challenges ever. When I realised that I am gay, I could not find anything positive about it. Even more so, it was a mere contradiction to everything I read or heard about it. Believing in the power of redemption, I handed over my life into Jesus' hands, hoping He would change my sexual orientation. I became a born-again Christian (no, I would not call myself that anymore), or so I believed. However, fact is, it did not change my sexuality and my sexual desires and therefore, the struggles intensified and became even more internalised than ever before. Reflecting on those years, I thought that I was fighting with God when I was actually fighting myself, society and the stigma the church has always and still been holding up around issues of sexuality. The day I gave up on this fight, I prayed to God, telling Her, that if I would not get a clear answer for my struggles with my sexuality, I would simply and completely give up on faith. I clearly remember that there was this immediate inner peace and freedom that filled every vein in my body and a tremendous sense of knowing who I am. I never ever doubted my sexuality or my faith anymore. Both aspects are intrinsic factors of who I am today. This whole process made me stronger and much more confident. It also completely changed my perception of faith, God and religion. Did I previously come from a clearly dualistic way of thinking, like there is right and wrong, good and bad, sin and forgiveness, I found peace and reconciliation in an inclusive, accepting and loving approach to life and all its facets including faith and spirituality. It became my worldview. My church however, did not share my enthusiasm for my new life and so I had to leave it behind.

Today, my faith is stronger than ever, but completely non-exclusive and non-judgemental and I do not belong to a certain congregation or church anymore. It is no longer important to me if or what someone believes in, but that we all have a responsibility for the world we live in, for each other and ourselves in a loving, caring and accepting way. I do not see God as an external force or power anymore, some mysterious deity who rules everything, but I see God, if one wants to call Her that way, as the essence of life within everyone and everything. Therefore, I believe in a source within all of us that shares our weaknesses and strengths, that has the potential to build bridges, to care for one other, to love and to forgive, to learn and to teach but also to fail. John Dun Scotus (1266-1308), philosopher and theologian, and Thomas Aquinas (1224-1274), priest and philosopher, both taught that God is Being and not a Being as it is often heard or understood (Rohr and Feister 2001). It is this kind of a belief system that helps me to keep an open mind, a loving heart and a solid foundation of hope and a belief in the good that goes beyond the mere evidence of current sciences. It is also what I understand of unitary human beings: with all our uniqueness and individuality, our different backgrounds, ethnicities, faiths and everything else one could think of that may separate us from each other; we are all connected with each other. I call this universal connection God or unconditional love. However, it does not matter how one explains that connection, as long as we seek it within us.

The linkage between my project and my worldview and belief system is, that these aspects essentially influence the way I approach and interact with people, how I value and interpret life and being. It is also relevant for the analysis and the interpretation of the data of this study which I will further explain in the methodology chapter. However, it is the open heart and mind that is helping me to relate to others. Also, with my positive attitude on life, I truly believe in the good in every one of us and that there is always hope, even if we cannot see it. For many people living with mental illness, hope is considered the starting point in their personal recovery (Slade 2009) and in carrying hope with me all the time, I do hope others can sense it and use it for their own strengthening. Nevertheless, towards the end of this thesis I will critically discuss the issues around hope and optimism in life (see 5.3.7).

1.6.3 The Journey to Nursing

As most young people do, I had to make decisions for my professional career at an early point in my life, when I actually had other things that seemed more important to deal with such as my faith and my sexuality. Therefore, instead of going to college and university, which my teachers and parents suggested and my grades indicated, I chose an apprenticeship, as most young people do in Switzerland (EDK 2017). It seemed the easier and quicker way to become more independent and get away from home and my social environment. The Swiss National Railways company offered a great opportunity to work in different places over the course of the three-year vocational training. As a trainee railway station manager, I worked all kinds of shifts and had a great variety of duties such as selling tickets and arranging journeys, operating the signal box and switching the points, organising rail cargo and much more. I loved my job, especially due to the fact that I had to work with a lot of different people as co-workers and clients. These experiences built the foundation of my professional career. However, over the years and having grown into a more matured, self-reflected life, partially due to my spiritual and coming-out journey, I started thinking about changing my career. I did want to move away from a mainly commercial job into a more caring profession where I could work with people on a more interpersonal and humanistic level. Nursing seemed to be this kind of profession.

However, still in my early twenties, I felt that I needed to break away from more than just my profession, but other aspects of my past as well. Having lost the connection to the church I used to belong to and to some of my friends there, I decided to try a new start somewhere else. Luckily, through a good friend of mine, I have met the leader of the Episcopalian chaplaincy at the San Francisco General Hospital during a previous visit in California. We became friends and he invited me to participate in their non-denominational AIDS (Acquired Immune Deficiency Syndrome) ministry programme, an intensive three-months training programme and internship. I was convinced that this would help me to get into nursing as well and therefore, I emigrated from Switzerland to the USA. To start my new life, I could stay and live with this friend, but soon found many more friends as I became a member of the San Francisco Gay Men’s Chorus and built my own lifeworld in the city by the bay. It was in the early years of the HIV and AIDS crises and San Francisco seemed to be one of the main centres in the USA where the treatment of patients with HIV and AIDS was developing fast and in various facets. AIDS was still considered being a gay disease and therefore, I was willing to do my part to fight against stigma and to try to help those affected by the disease in doing what I did as a chaplain, but also in hopefully becoming a health-care professional. I was very happy and maybe for the first time in my life, I felt that I fully belonged: I was living openly gay, volunteered at a hospital I was hoping to work one day, and I even attended church again. Indeed, I could reconcile my faith in experiencing and participating in various religious groups where being gay was not only accepted but fully included. For about a year I volunteered as a chaplain intern for AIDS patients at San Francisco General Hospital. I learnt a lot about the lives of the people living with HIV/AIDS. Dealing with the struggles of the patients, as well as with helpless and sometimes angry relatives was an immense challenge, but also tremendously rewarding. The programme I was involved in offered one to one supervision and additionally I experienced support through personal psychotherapy and through my good friend I lived with. At the same time, throughout the year I have met many nurses and other health-care professionals, some of whom became good friends, and I was even more convinced than ever before that I did want to get into nursing. However, my efforts to enrol in a nursing education programme failed due to lack of financial resources and my residence status. Because of the latter I could not work legally either. Therefore, after my attempts to find legal work or payments failed, I decided to return to Switzerland to get my nursing degree there. I was hoping to return to San Francisco with a finished degree.

In Switzerland, I studied in a nursing school that was connected to a psychiatric hospital. It turned out to be the right choice as the programme had a humanistic and holistic approach to nursing that pretty much matched my own worldview and interests in the profession (see also Section 1.7). Nursing truly became my passion. My basic nursing education and the experiences at San Francisco General Hospital, remain a main source in my professional and personal development ever since. This is also true for my experiences as an active member of the gay community in San Francisco where I could not only restore my faith but also learn about the gay movement and its relation to other liberation and human rights movements. I never returned to the USA for living and working there though, but that is another story which has little to do with what I want to share here in relation to my PhD project.

Now, what is the connection between my career decisions in the past, my professional journey into nursing and the current project? First of all, it shows my always existing interest in people. Over the course of my life, I have met and worked with people from various professional and personal backgrounds. It has and still does enrich my life and I do not want to miss a single one of these encounters, even though not all of them but most were positive. During my years working for the Swiss National Railways for example, I often used to have lunch with colleagues that were track workers and craftsmen. Some of their lives were very different to mine, and some faced challenges I was not even aware of. This brought me closer to ideas, interests and worldviews that I did not even consider looking at before. I also had several friends working in gastronomy as we had similar working hours and we often sat together after our shifts in the middle of the night sharing stories. I strongly value these connections and experiences as they made me appreciating diversity and personalities rather than social class and scholastically acquired intelligence. In mental health nursing, it helps me to this day, to always try to see the whole person and the human potential and resources within that person and his social environment.

Therefore, my interest in people, my radical openness to diversity, deviance, differences combined with my willingness to try or accept varying and individual approaches to problem solving or in dealing with life situation, became my driving force into nursing. I do think that this is one important aspect of nursing care that distinguishes it from other health-care professions: Focusing on the person in need, his or her background, life situation and resources and trying to help to (re)activate self-help-mechanisms and support systems within the person’s environment, as much as possible. Empowerment on a truly personal or at least person-centred level rather than trying to enforce evidence-based knowledge onto someone that does not suit the individual situation of that person. Which brings me to my understanding of nursing.

1.7 The Nursing Paradigm

The title of this section might be misleading as there is not one nursing paradigm. In the context of nursing research, Weaver and Olson (2006) distinguish between four different research paradigms, positivist, postpositivist, interpretive and critical social theory, and argue that they all have their limitations. All those research paradigms are…

> “…patterns of beliefs and practices that regulate inquiry within a discipline by providing lenses, frames and processes through which investigation is accomplished” (Weaver and Olson 2006, p.460).

However, even though patterns of beliefs and practices are important to consider when looking at one’s own understanding of nursing, this section is not about research paradigms, but about an even broader and more overarching understanding of nursing as a profession and science that cannot be explained within one of these research paradigms.

Nursing cannot be easily described or defined, even though the first recognised attempt to conceptualise nursing practice goes all the way back to the mid nineteenth century (Nightingale 1860). There are different schools of thought, theories and conceptual models that build a heterogeneous foundation of the discipline of nursing. Barrett (2002) calls the attempt to define nursing an “age-old dilemma” and continues:

> “I define nursing as a basic science and the practice of nursing as the scientific art of using knowledge of unitary human beings who are in mutual process with their environments for the well-being of people” (Barrett 2002, p.51).

This definition already includes all the relevant aspects of nursing: it combines science and practice into a scientific artform for the well-being of human beings living in an environment, which is the focus of the profession. The focus is not on a person only, it is on a person or people in an environment, in a mutual process with the environment, meaning it needs both and both are affecting the other. Also, there is no mentioning of curing, as this is not the primary focus of nursing, the focus of nursing is well-being or healing in a sense of becoming whole. Therefore, the definition is in line with the four fundamental patterns of knowing (Carper 1978), that are described as:

1) Empirics, the science of nursing

2) Aesthetics, the art of nursing

3) The component of personal knowledge in nursing

4) Ethics, the component of moral knowledge in nursing

Where empirics and aesthetics build the foundation for science and practice, it is personal and moral knowledge that allows the professional to interact as a unitary human being with another unitary human being for their well-being. All four patterns of knowledge are essential and cannot be separated from nursing.

Barrett (2002) argues that personal definitions of nursing reflect personal professional identities and philosophies of nursing. This is certainly true for myself and I do share Barrett’s definition, knowing that it reflects my own perspective on nursing only and not a generalisable one. However, this understanding is based on a particular nursing paradigm, the simultaneity paradigm.

> “In the simultaneity paradigm whole means unitary, and the unitary human has characteristics that are different from the parts and cannot be understood by a knowledge of the parts. Moreover, the human cannot be separated from the entirety of the universe, as both change continuously

> in innovative, unpredictable ways, and together create health, a value defined by people for themselves” (Barrett 2002, p.52).

The term ‘unitary human beings’, as used by Barrett (2002) and in this thesis, stems from Martha Rogers’ Science of Unitary Human Beings (SUHB) (1994). Rogers (1990) argues that the uniqueness of nursing lies in the focus on people and the world they live in, the integrality of people and environment and “the irreducible nature of individuals that is different from the sum of the parts” (Rogers 1990, p.6). Rogers’ theory clearly reflects the underlying simultaneity paradigm, where health rather is a value or a co-created process of becoming than a status of well-being defined by specific norms (Parse 1992; Barrett 2002). Other nursing theories that refer to the simultaneity paradigm are Parse’s Human Becoming Theory (Parse 1992; 1998), Newman’s Theory of Expanding Consciousness (Newman 1990) or Watson’s Caring Science Theory (1999). The paradigm also kind of reflects and matches my own understanding of ‘God is Being’ (Rohr and Feister 2001), as it is briefly outlined in the previous section. It is a view on life as a whole, completely non-dualistic, that cannot be separated into parts and therefore, always needs a holistic view. Also, it is an understanding of the world that does not easily accept cause and effect which may lead to a dualistic understanding of processes that favours contrasts such as positive and negative or even antagonism instead of simultaneity.

The totality paradigm, in contrast to the simultaneity paradigm, borrows from a positivistic understanding of well-defined concepts and variables and cause and effect (Parse 1992; Weaver and Olson 2006). Totality theories in nursing recognise human beings as bio-psycho-social, sometimes including spiritual, organisms that interact with the environment in rather linear ways (Barrett 2002). Barrett (2002) argues that although the two paradigms of nursing are different, neither one is better or superior.

> “The purpose of identifying and delineating paradigms is to organise the knowledge in a discipline into like and unlike schools of thought and to consider the differences” (Cody 1995, p.145).

We need different worldviews and paradigms as this diversity opens opportunities for varying methodological approaches in research and practice and helps to encompass all disciplinary and interprofessional activities in health care. This is also consistent with real life nursing practice, where different opinions and worldviews have the potential to open the discussion and may facilitate shared decision-making. Shared decision-making needs to be at the core of person-centred care in all health-care settings including mental health (Drake and Deegan 2009; Drake et al. 2010b). However, from my personal experience in nursing, and especially in mental health nursing, shared decision-making and person-centeredness often tends to be more professionally influenced and guided than being a mutual process among equal partners. One reason why this might be true is the widely accepted understanding of evidence-based practice which is based on evidence-based medicine (Sackett et al. 1996). In evidence-based practice there are four aspects that should be valued and integrated mutually: 1) the individual knowledge and expertise of the nurse, that was acquired through extensive clinical experience and practice, 2) the best external evidence, which refers to the knowledge generated through research, preferably systematic reviews that include at least one randomised controlled trial, as they are considered to be the gold standard, 3) context factors, such as available resources or setting limitations and 4) patient's choice. In reality of mental health practice this often means that with all the arguments professionals bring in, the patient might willingly accept a 'shared decision' but was actually simply overruled three to one by arguments and by the fact that his or her choice does not count as evidence. But who decides what evidence is and does nursing really rely on an understanding of evidence that is influenced by a bio-medical or totality paradigm? Rose et al. (2006) argue that a new paradigm in mental health care should be implemented that includes a multiple perspective approach that integrates varied sources of evidence, such as the ones from a service users perspective, which are often qualitative. In writing a doctoral thesis stemming from data about patients' experiences, I will contribute to a broader evidence in mental health care, where user involvement in practice and research still needs to be much improved. However, to me it is not so much a question of what kind of evidence should be used in nursing practice than that nurses, especially mental health nurses, should see themselves as advocates for their patients and work towards, with all the knowledge they have, the well-being of their patients.

1.8 A Note on Translations

Some of the materials and references in this thesis are in German. Where no official translations were available and direct quotes were used, all translations were done by myself. This includes the quotations of the participants of the main study which were mostly in Swiss German. To distinguish these translated quotations from other quotes, *italics* are used in addition with the double quotation marks that are used for all quotations in accordance with Bournemouth University's code of practice for research degrees (Version no. 14). Additionally, where direct quotes from participants are used, the line spacing will be left unchanged in distinction to other quotations. An exploration and explanation of the language issue in relation to data analysis can be found in the methodology chapter (see Section 3.3.6)

2 BACKGROUND

Monastery Fischingen, Switzerland 2016

2.1 Chapter Introduction

The photo shows an old archive of a monastery. It is the place where important papers and files were stored; contracts and knowledge relevant to maintain the operation of the monastery. This refers to what this chapter is all about: It contains background information and knowledge that is relevant for this research project. It complements the introduction chapter of the thesis and includes the initial literature review of this research project and the findings of a preliminary study that both were conducted before data collection and analysis of the main study of this thesis. However, within Grounded Theory, the methodological approach that is used in the main study of this research project, it is argued that the literature review is an ongoing process that goes beyond an initial search of the literature (Charmaz 2014). Therefore, this chapter does not contain an extensive or highly structured literature review. It is an exploration of the literature that led to the formation of this research project and other relevant background information. Based on the original research idea and its adaptation to the current project (see Section 1.2*ff*), the background information presented in this chapter focuses on issues around mental health and mental illness including personal recovery, but also on uncertainty in illness and adaptation to illness. This is also congruent with the aims and objectives of this study.

The concept of uncertainty in illness first appeared when reflecting on Perrett & Biley's (2013) Negotiating Uncertainty Theory (PBNUT). Uncertainty is seen as a key component in experiencing illness. Therefore, the concept of uncertainty in illness was further explored (see 2.4). However, the concept could hardly be found in relation to people living with mental illness. This gap in the literature initiated a small preliminary study of this research project focusing on uncertainty in illness among people living with mental illness (see 2.5). Uncertainty in illness (Mishel 1988, 1990) and negotiating uncertainty (Perrett 2009; Perrett and Biley 2013) are both models of adaptation to illness. In contemporary mental health nursing, the concept most often referred to when talking about adaptation to illness and the process of living with mental illness is recovery (Amering and Schmolke 2012) or personal recovery (Slade 2009). Therefore, all three concepts are highlighted in this chapter.

2.2 Mental Health & Mental Illness

Starting with a brief exploration of mental health and mental illness opens up a whole debate on the meaning of these concepts and it seems important to point out some of the divergent views and different perspectives. Additionally, it is my intention to provide an understanding of my own use of the terminology.

2.2.1 Mental Health

Mental health is an inseparable aspect and integral part of health and contributes to the overall well-being of human beings (WHO 2001, 2016). Therefore, from a global public health perspective, mental health is as important as physical health and needs our full attention. The World Health Organization (WHO) defines mental health as…

> "…a state of well-being in which every individual realizes his or her own potential, can cope with normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community" (WHO 2014).

However, this definition cannot withstand fundamental criticism: Who is going to judge what a person's potential is, what one considers normal stress of life or what productive and fruitful work might be? The stance of an employer or a health-care professional is likely to be different from someone who is living with a mental illness or from someone who simply has a different conviction due to his or her specific life situation, character or personality. Galderisi et al. (2015) argue that well-being as a key aspect of mental health could be misleading, as people in good mental health are often not well, which is seen as part of living a normal human life. Additionally, the definition of the WHO implies positive functioning, which…

> "…may lead to the wrong conclusion that an individual at an age or in a physical condition preventing her/him from working productively is not by definition in good mental health" (Galderisi et al. 2015, p.231).

Therefore, Galderisi et al. (2015) suggest a new definition of mental health using 'inner equilibrium' rather than 'well-being' and refer to values such as respect and care for oneself, other living beings and the environment and respect for one's own and others' freedom. However, in appreciation of the effort to find a better definition, this only shows how difficult it is to find a definition of mental health that fits all expectations. Even the WHO admits that "it is nearly impossible to define mental health comprehensively” (WHO 2001, p.5) but that it is important to conceptualise mental health more broadly than only the absence of mental illness, which is congruent with the WHO’s own definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO 1948, p.1).

With the simultaneity paradigm in mind (see Section 1.7), there is no clear demarcation between health and illness, or mental health and mental illness, hence I agree with Parse (1992) who sees health as a process of becoming rather than a defined status. Therefore, to distinguish between conditions of conceivable complete health and complete illness on a continuum one cannot but ask the person about their subjective appraisal of well-being and their own interpretation and understanding of health and mental health. However, as much as personal value systems might influence the definition of health and mental health, it is also influenced by socioeconomic culture (Galderisi et al. 2015). Therefore, in recent definitions of health and well-being, they are not seen on the same continuum as illness anymore, but viewed as separate dimensions or continua where recovery is the bridge between them (Manderscheid et al. 2010). This seems reasonable as someone who is diagnosed with an illness can still feel very well and healthy. Overall, this brief excursion on the definitions of mental health and health underlines the notion that definitions are not exact science and may change over time.

2.2.2 Mental Illness

The lack of exact science and changing definitions over time are certainly true in relation to the understanding of mental illness. How do we understand mental illness today? What is it really? Or is ‘mental illness’ even the correct term for it? To anticipate the outcome, there is not an exact answer to this.

However, to begin with, I would like to explain why I am using the term ‘mental illness’: It is not that I favour a medical understanding of the concept. The simple reason behind it is that term is one of the most frequently used terms in topic related publications and scientific articles. Additionally, in German the word ‘illness’ (Krankheit) is a relatively non-judgmental term that legitimises professional care and support, whereas the words ‘disorder’ (Störung) or ‘disability’ (Behinderung) seem much more stigmatizing, especially in the field of mental health. I am fully aware that the use of words can make a difference in the assessment of the content and that therefore, some people would probably prefer terms like ‘mental ill health’, ‘mental health condition’ or ‘mental health problem’. The list of possible terms is long and varies according to personal preferences and attitude towards the topic. However, even after many discussions with service users, I could not discern a clear consensus on what term should be used. Some service users use ‘mental illness’ and others even prefer the term ‘madness’. That term has also been used by historians in the field (Porter 2002; Scull 2011) when considering the wider cultural response to mental illness over the centuries (Beveridge 2012). I will briefly explore the use of the term madness in the next section (see 2.2.3). However, as pointed out in the previous section, I see mental health and mental illness on a continuum and as a process, an aspect of life rather than a medical diagnosis. We all are dealing with issues around our mental health. The problems range from minor worries and uncertainties we all experience as part of everyday life to serious and sometimes long-term conditions.

Nevertheless, without having to go back to ancient theories in ancient times, in the last seventy years alone we have seen many changes and adjustments in the understanding of mental illness. In 1948 the 6th edition of the International Statistical Classification of Diseases and Related Health Problems (ICD) of the WHO was published. For the first time it contained a chapter about mental disorders which the American Psychiatric Association (APA) further developed into the first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1952. It contained a glossary of descriptions of the diagnostic categories and therefore, it was the first manual of mental disorders that focused on clinical use (APA 2018). With classification systems and theoretical frameworks in place, the development of new treatment approaches and the study of mental illness began to increase significantly (Jutras 2017). However, in the 1960s and 70s people with mental illnesses were still commonly stigmatised and institutionalised, where at the same time deinstitutionalisation had begun (Manderscheid et al. 2010). It took another couple of decades until new concepts and understandings, such as person-centeredness and recovery approaches, were incorporated into mental health services. And this process is still ongoing.

However, sociocultural changes and new knowledge or evidence have repeatedly led to adjustments in the diagnosis and treatment of mental illnesses. These sometimes-far-reaching adjustments are reflected in each new version of the ICD and the DSM. One example of a precedent-setting amendment of the classification of mental illnesses was the removal of homosexuality which appeared as a mental disorder in both manuals for many decades. The APA was the first organisation that erased it from its list of mental illnesses in 1987. It took another fifteen years for the WHO to do the same and up until these days many people all over the world, including health-care professionals, still think homosexuality is a mental disorder that can, and even should be treated and cured (Wolfensberger 2011). This indicates that labelling can have a long-lasting effect on the stigmatisation of an entire population. Therefore, a psychiatric diagnosis should only be made with the utmost caution and should always be considered very carefully. The damaging effect of a diagnosis such as schizophrenia can easily last much longer than the illness might have been present in someone's life. It is not without reason that the use of certain diagnostic labels is being questioned. The Japanese Society of Psychiatry and Neurology, for example, renamed schizophrenia to remove its harmful impact on patients and their families and to reduce the stigma attached to the diagnosis (Sato 2006).

Nonetheless, the benefits and the need for naming and defining illnesses including mental illnesses cannot and must not be called into question if socio-economic factors are considered. The WHO describes the ICD as:

> "…the bedrock for health statistics. It maps the human condition from birth to death: any injury or disease we encounter in life − and anything we might die of − is coded. *[…]* These health statistics form the basis for almost every decision made in health care today − understanding what people get sick from, and what eventually kills them, is at the core of mapping disease trends and epidemics, deciding how to programme health services, allocate health care spending, and invest in R&D" (WHO 2018, p.1).

In other words, this statement reads as there is a compelling need and an irrevocable legitimacy to name illnesses to be able to control and finance them, to teach and research them and to put them into public policy. It is exactly the same argument that is often cited to justify nursing classification systems (Clark and Lang 1992). However, fortunately, in nursing there is still no clear consensus on the use of a single terminology or classification. In mental health nursing, Barker and Buchanan-Barker (2005) argue that it is more helpful to use the language and descriptions of service users rather than professional terminology. It is an aspect that is also used in parts within person-centred integrative diagnosis (Mezzich et al. 2010), where the voice of the patient should be included in the diagnosis. However, global health care and policy making very much rely on health statistics based on the ICD and that will not change soon. Therefore, investigations into the further development of the ICD or the DSM in favour of the population it should serve are important. Hopefully, the nursing profession, and specifically mental health nurses and mental health nurse academics will contribute to that process as well.

Wittchen et al. (2011) argue, that mental and neurological disorders “must be considered to be Europe's foremost health-care challenge of the 21st century” (p.670) which corresponds with the Global Burden Disease report (WHO 2008) that projects a tremendous increase of noncommunicable diseases by 2030 with unipolar depressive disorders on top of the list of the leading causes of burden of diseases. That might sound surprising, however, according to different sources, between 25% and 50% of all people will be affected by a mental or behavioural disorder some time during their lives (WHO 2001; Wittchen and Jacobi 2005; Schuler et al. 2016). Wittchen et al. (2011) found that well over one third of the whole population in Europe suffer from a mental disorder during any given twelve months period. In Switzerland, 18% of the population mention moderate to severe psychological stress and approximately 30% show symptoms of depressive disorders (BAG 2015; Schuler et al. 2016). Therefore, mental disorders and mental illnesses are universal, very common and could affect anyone anywhere (WHO 2001).

Mental illness differs from physical illness in regard that the starting point for understanding the illness is primarily a subjective experience (Slade 2009). There are different ways to make sense of such experiences. Slade (2009) describes three broad ways of understanding mental illness (see Table 2.1) of which clinical models are the most used frameworks in mental health services. However, with more focus on person-centeredness in psychiatry (Mezzich et al. 2016b), there seems to be a clear shift towards the disability model in professional mental health services.

However, it seems important to include yet another view on mental health and illness, the one of the ‘antipsychiatrists’ and the growing ‘mad pride movement’, the liberation of mental patients.

Table 2.1: Understanding mental illness: Clinical, disability and diversity models

	Clinical model	Disability model	Diversity model
Source of problem	Illness in the person	The combination of mental illness and societal response	Society
Treatment	Necessary and appropriate	Necessary but insufficient	Only if wanted, never if not wanted
Expertise	In the professional	Shared	In the consumer
Central role of the mental health professional	Providing evidence-based treatment	Advocacy	Supporting consumer activism
Role of the mental health service user	Taking treatment	Developing inter-dependence – taking appropriate support and developing self-management skills	Accepting and valuing oneself, losing self-stigmatising beliefs
Strengths	Provides a clear explanatory model, and leads to well-developed treatments	De-emphasises illness encourages social inclusion, consistent with existing disability & discrimination legislation	Doesn’t pathologies, places power in the hands of the individual consumer
Weaknesses	Doesn’t fit for everyone, promises cure but doesn’t deliver	Retains paternalistic approach	How to gate-keep support resources if everyone is “normal”?

Adapted from Slade (2009, p.33)

2.2.3 Madness and Liberation

Madness existed long before psychiatry emerged as a medical discipline in the late 18th century. Foucault (1965) traces the evolution of the concept of madness back to the Middle Ages and forms of insanity or madness must have existed ever since the emergence of humankind, at the latest with the beginning of civilisation (Tuke 1878). It is inconceivable that there haven’t always been those among us who think, feel or act differently from the majority or the norm, which partially defines insanity. But who is it to judge or define what is right or wrong, sane or insane? The history of psychiatry and therefore also its interpretation of mental disturbances or abnormalities used to be written mainly by clinicians who legitimised their own practices and approaches (Beveridge 2012). However, in the 1960s, Szasz (1961) “launched an intellectual revolution with his argument that the idea of mental illness is a myth” (Farber 2012, p.118). Not least with this provocative stance the controversies about the interpretational sovereignty of the meaning of mental illness were launched.

Although Szasz’s work was essential for rethinking mental illness, his beliefs were too radical for many people living with mental health problems, because their problems were real and madness existed. Farber (2012) who writes about the rise of the mad pride movement, clearly favours the work of Laing (Laing 1960; Laing and Esterson 1964; Laing 1967) as basis for the movement, even though he admits that Laing’s work was long ignored by the psychiatric survivors’ movement and the mental patients’ liberation movement.

> “It was Laing, more than any other figure, whose writings provided a basis for the mad to affirm their madness, to assert it as a spiritual gift and to question the sanity of normal society. *[…]* Laing startled the world with the claim that the mad were mystics and that schizophrenics were saner than normal people, including psychiatrists. Here was a basis for Mad Pride” (Farber 2012, p.120).

However, these are just two examples of radical, different thinking about mental illness: Szasz who denied the existence of mental illness and Laing who believed that it is an altered state of consciousness or a journey in the inner world (Farber 2012). More important than the content of these two approaches is that they showed those with a history of mental health issues that a different view and one’s own interpretation of mental illness is possible. It is part of the liberation from a medically dominated and professional led approach to mental disorders.

> “Mad Pride wants to give the mad the freedom to be themselves, to be maladjusted to an insane world. *[…]* For many mad people, adjustment to the status quo may not be feasible. It may well be that the only way they can achieve a state of emotional equilibrium is to become the prophets, activists, and spiritual leaders who will endeavour to bring the world closer to the visions they have had and to attempt to help humanity to make the transition to a higher stage of consciousness beyond the status quo” (Farber 2012, p.130).

It does not have to be as far-reaching as described in this quote, but it is about individuals regaining the freedom to decide for themselves what is good for them, how they understand and value their situation and what they wish to make of it. In my personal opinion this should be at the core of person-centredness as well where health professionals offer their support and their knowledge for a well-balanced and shared decision about treatment.

Returning to the different understandings of mental illness as outlined by Slade (2009), what has been described in this section best refers to the diversity model (see Table 2.1). In conclusion, openness to the strengths and weaknesses of each model, combined with a person-centred understanding of illness and suffering, may provide the best individual framework or approach to support people living with mental illness and their social environment.

2.3 Person-Centred Mental Health Care

Person-centredness in mental health care aims to promote the health and well-being of the whole person where the person is the centre and goal of health care (Mezzich et al. 2016a). It goes beyond individualisation of care and respect for patients' rights and includes…

> "dealing with the inner world of a patient in his particular situation of suffering and dependence caused by illness, […] crucial here is the commitment of the mental health professional to approach the patient's subjectivity in such singular vital situation" (Mezzich et al. 2016a, p.4).

Therefore, policymakers and funders should consider shifting contemporary mental health care away from a medical oriented perspective on disease and patient to a lifeworld perspective that focuses on the person. However, such a person-centred approach requires a differentiated understanding of what a 'whole person' is. McCormack and McCance (2017) argue that person-centredness requires attention to the being as a person and describe four "modes of being" (p.17) that relate to:

a) the importance of relationships ('being in relation')
b) interconnectedness with a social world ('being in a social world')
c) a connection with places and one's histories ('being in place')
d) the need to be recognised as a person and knowing of self ('being with self').

An even more comprehensive exploration of the person as the centre of health is provided by Cassell and Stoyanov (2016, p.33):

> "In summary a person is an embodied being, purposeful, thinking, feeling, emotional, capable of choosing, reflective, relational, responsible, very complex human individual of a certain personality and temperament, existing through time in a narrative sense, whose life in all spheres points both outward and inward and who does things. Each of these terms is a dynamic function, constantly changing, and requiring action on the part of the person to be maintained – although generally the maintenance is habitual and unmediated by thought."

Both descriptions draw a holistic picture of the person at the focus of person-centred care and also include a spiritual dimension (Cassell and Stoyanov 2016) or a dimension of beliefs and values (McCormack and McCance 2017). Therefore, it seems important to understand person-centredness as a truly holistic approach to care. This is also consistent with other person-centred models of care in nursing such as the Tidal Model (Barker 2001; Barker and Buchanan-Barker 2005), an approach to recovery within mental health nursing, and Kitwood's (1997) approach to dementia care.

The WHO focuses on a global perspective and outlined a global strategy on people-centred and integrated health services. It describes people-centred health services as:

> "…an approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways. It requires that people have the education and support they need to make decisions and participate in their own care. It is organized around the health needs and expectations of people rather than diseases" (WHO 2015, p.7).

This definition serves well as a definition of person-centred care as it covers all its relevant aspects: the inclusion of the patient (person) as a mutual partner and adopting his or her perspective, and a holistic treatment approach that responds to the needs and preferences of the patient (person). However, person-centred care is not a new concept and has historical roots in Eastern civilisations with the Traditional Chinese and the Ayurvedic Medicine; both are holistic care approaches that are still widely alive and practised (Mezzich et al. 2016a). Nevertheless, modern Western medicine, despite its important advances and developments in scientific understandings and much more, has mostly forgotten about a holistic and humane view on illness and the person with the illness and this has led to a health-care system and treatments that often focus on cure, healing and reducing symptoms of diseases only.

> "[Modern medicine] has led to a hyperbolic, impersonal, and dehumanising focus on disease and organs, over-specialisation of medical disciplines, fragmentation of health services, weakening of the clinician-patient relationship, and commoditisation of medicine" (Mezzich et al. 2016a, p.2).

However, Ladd and Churchill (2012) argue that in moving from the 20th-century Industrial Age into an Information Age of the 21st-century "there is an emerging paradigm shift" (p.15) away from rigid and rules-based structures, in medicine often symptom-based, into more participatory formats where patients get involved in problem-solving and decision-making processes. This paradigm shift is well described and captured by the WHO's definition of people-centred health-care services (see above). Person-centred and humanising approaches have become increasingly relevant in current developments of health-care systems around the world, but the process and progress are slow.

McCormack and McCance (2017) argue that despite all of these developments where person-centredness forms the basis of health-care reforms, the focus should remain "on 'care' and less on how organisations create person-centred cultures"(p.3). This seems congruent with Galvin and Todres' (2013) experience and understanding of what is still missing in health and social care; they call it the need for humanised care. Both indications show that the underlying attitude or philosophy of what constitutes person-centred care obviously does not necessarily mean that it will also be put into practice, or its understanding has not yet reached health-care workers and clinical practice.

> "Patients and service users are telling us in different ways that they do not feel fully met as human persons in the way that care is organised and practised. […] people are seen as categories and often respond with the heartfelt question: where am I in all of this?" (Galvin and Todres 2013, p.1).

This could certainly be said about some experiences in mental health care, where diagnosis and treatment planning for those living with mental illness often follow a traditional, symptom-based approach (Ladd and Churchill 2012). Nonetheless and fortunately, person-centredness is on the rise in mental health care and may be best reflected in the personal recovery movement (see Section 2.8). However, unlike the concept of Person-Centred Psychiatry (Mezzich 2007; Mezzich et al.

2016b), personal recovery has emerged from ex-patients and service users of mental health services themselves (Slade 2009; Schmolke et al. 2016) which makes it more person-centred than most other approaches. Personal recovery is a person's personal journey of transformation and adaptation to illness that may lead to a meaningful life and individual well-being (Anthony 1993; NAMI-Thurston-Mason 2019).

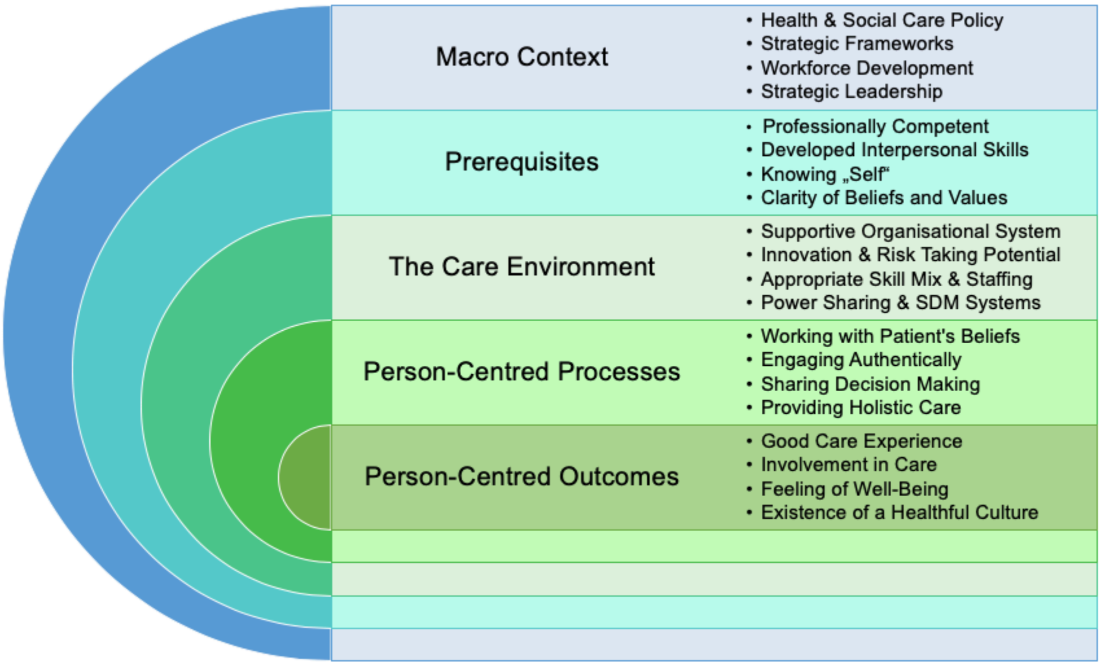

Figure 2.1: An adapted version of the Person-centred Practice Framework (McCormack and McCance 2017, p.42)

In contemporary mental health care personal recovery, a process rather than a specific outcome, is seen as the goal of all treatment approaches and professional support. However, specific recovery outcomes can include a variety of multidimensional variables such as regained valued social roles, increased physical health or well-being, reduced symptoms, but also increased self-worth and empowerment (Farkas et al. 2005; Farkas et al. 2016). According to McCormack and McCance (2017) who developed a person-centred practice framework (see Figure 2.1), the person-centred outcomes of their approach are good care experiences, involvement in care, feelings of well-being and the existence of a healthy culture. These are all outcomes that probably every person would appreciate in a situation of needing professional health-care support.

In conclusion, it is highly desirable that person-centred care as described in this section is or becomes the standard approach in mental health care everywhere.

2.4 Uncertainty in Illness

Uncertainty in illness is a concept that has been widely studied (Mishel 1988, 1990; Penrod 2001; McCormick 2002; Neville 2003; Hansen et al. 2012; Flaskerud 2015; Zhang 2017). Mishel (1988, p.225) originally defined uncertainty in illness as “the inability to determine the meaning of illness-related events” and later specified that uncertainty in illness “is viewed as a fluctuation that can either regress or cause no particular disruption” (Mishel 1990, p.259). The development of the original theory was influenced by social psychology and information processing models, personality theory and stress-coping-adaptation models (Flaskerud 2015).

Mishel’s (1988) theory explains how patients deal with illness-related events and symptoms and how they construct meaning in acute phases of illness or within a downward (as in deteriorating and dying) illness trajectory. Therefore, in the original theory, uncertainty as an opportunity is only appraised when the alternative is negative certainty which makes uncertainty a preferable state (Mishel 1990). However, this understanding was not congruent with the idea, that the theory could be generalised and adapted to different patient populations, especially the ones with long term conditions and chronic illnesses. For these individuals it is often unclear what the outcome of the illness or living with the illness might be and it does not have to be a negative experience or outcome. Therefore, in appreciating that uncertainty as an opportunity could also serve people living with long-term chronic illnesses, Mishel (1990) reconceptualised her theory focusing more on probabilistic thinking where uncertainty is seen as a natural phenomenon. This interpretation is congruent with the fact that uncertainty prevails in all human existence and is inherently neutral (Penrod 2001). However, Mishel (1988) argues, that the experience of uncertainty is neutral until it is appraised through a process of inference or illusion. Inference means that uncertainty is evaluated using situations a person can recall and relate to the present experience. Therefore, inference is based on previous experiences, knowledge of similar situations and contextual cues. Illusion refers to the construction of beliefs out of uncertainty, which may lead to an appraisal of uncertainty as an opportunity. Based on such an appraisal process, uncertainty is either viewed as danger or opportunity which influences the coping strategies one choses. If the coping strategies are effective, adaptation to illness will occur (Mishel 1988). Putting adaptation at the end of the whole process of dealing with uncertainty can be understood in the context of the original target population of the theory that focused on acute phases of illness or within downward illness trajectories only. However, within chronic conditions and long-term illnesses, I would argue that adaptation to illness is an ongoing process that includes rather than follows the process of dealing with uncertainties. Flaskerud (2015) argues that under the influence of ongoing uncertainty, an individual may move away from viewing uncertainty negatively and rather focuses on new perspectives in life that can result in change and growth.

Nonetheless, Mishel's theory (1988, 1990) has been cited almost a thousand times according to a recent search in Scopus and her model has helped outline illness uncertainty in various fields of nursing. According to Zhang (2017) the theory has been widely applied to patients with cancer and serves as a valuable "framework for clinicians to understand the generation and control of uncertainty" (p.648). However, even though Mishel's theory (1988, 1990) seems well known and accepted within the nursing discipline and beyond, it is not the only conceptualisation of uncertainty in illness.

The concept of uncertainty exists in various disciplines and therefore, Penrod (2001) proposed a definition of uncertainty that is valid across disciplines:

> "Uncertainty is a dynamic state in which there is a perception of being unable to assign probabilities for outcomes that prompts a discomforting, uneasy sensation that may be affected (reduced or escalated) through cognitive, emotive, or behavioural reactions, or by the passage of time and changes in the perception of circumstances. The experience of uncertainty is pervasive in human existence and is mediated by feelings of confidence and control that may be highly specific (event-focused) or more global (a world view)" (p.241).

This definition offers a multidimensional approach to the concept of uncertainty. However, if it can really serve all disciplines that were included in their concept analysis, must be questioned. Smithson (2008) mentions an ambiguity on the views of uncertainty within the discipline of psychology, where there are different views of human responses to uncertainty, as well as different constructs of uncertainty. This clearly shows, that finding a common understanding of uncertainty is difficult.

Within the discipline of nursing, there are other authors that promote the multidimensionality of the concept of uncertainty and the potential of positive responses to uncertainty in illness (McCormick 2002; Hansen et al. 2012). McCormick (2002) defines uncertainty in illness as a separate component of illness that has its own attributes: temporality, perception and probability. It is argued that all three attributes are present in every situation of uncertainty in illness. Temporality refers to the temporal conditions within an uncertain illness situation, for example: how long will the situation last, how fast will treatment prove to be effective, how often will symptoms reoccur?

> “When one does not know what the future holds, or how much time will be required until the ambiguity, unpredictability, or vagueness of a situation is clarified, then uncertainty prevails” (McCormick 2002, p.130).

Thinking about people living with mental illness, that seems exactly what most of them have to endure for a long time or repeatedly when dealing with mental illness. Perception, the second attribute of uncertainty in illness, refers to one’s understanding of something, it is an interpretation or impression of a situation: “For a situation to be uncertain, it must be perceived and recognised as uncertain” (McCormick 2002, p.130). With perception begins the search for answers and solutions, something that most people living with mental illness seek as this present study shows. Probability, as the third attribute of uncertainty in illness, can be defined as “the likelihood of something happening” (McCormick 2002, p.129). McCormick (2002) argues that probabilities are an important part of all uncertain illness situations underlying questions such as: What is going on? What caused the illness? Why me? Within the field of mental illnesses, it is likely that many situations present unclear probabilities and therefore are reinforcing uncertainty in illness.

Aiming to provide a synthesis of patient experiences of uncertainty in illness, Hansen et al. (2012) searched the literature between 2000 and 2011 and found 685 papers. However, only 88 research articles were appropriate in relation to the aim of their study and after preliminary reading, only 15 empirical papers were included. Not a single one of the research articles Hansen et al. (2012) included in their study was about people with mental illness. This lack of research focusing on uncertainty in illness among people living with mental illness, has been confirmed by my own search of the literature over the last couple of years (see Section 2.3). Hansen et al. (2012) describe several characteristics of patients' experiences of uncertainty and divide the uncertainty experience in three themes: explaining (what causes/generates uncertainty), feeling (how does uncertainty affect someone) and facing uncertainty (how can uncertainty be dealt with). A secondary analysis of qualitative data exploring how uncertainty shapes patient experiences in advanced illness (Etkind et al. 2017) reveals that patients' responses to uncertainty vary according to their level of engagement with the illness and their information preferences. Engagement with the illness refers to how much a patient wants to maintain independence and being in control rather than losing control or letting go. Information preferences refer to the patient's understanding of the illness, its complexity and if the patient wants a lot of information about the illness or no information at all. Etkind et al. (2017) argue that these aspects are key factors in determining how patients respond to uncertainty, how they are capable to focus on present and future, and what kind of priorities they might set. The findings are interesting because they were looking at a big sample within a range of different advanced illnesses. Therefore, similar conclusions could probably be found among people living with other challenging illnesses, such as severe mental illness.

In conclusion, after looking at the different conceptual approaches and constructs, it can be summarised that uncertainty in illness is a multidimensional concept and a major part of illness that in its purest form is a neutral cognitive state, meaning that it might be experienced negatively or positively. Feelings of uncertainty in illness are described as stressful and a burden, giving rise to fear and worry, unpredictability, ambiguity, inconsistency, vagueness and loneliness, whereas the process of facing uncertainty seems to encompass a continuum from stress through reorientation and adjustment, acceptance, hope and even optimism (McCormick 2002; Hansen et al. 2012). However, what uncertainty in illness means for people living with mental illness remains unclear and can only be guessed according to the literature in this section. Therefore, a preliminary study focusing on the concept of uncertainty among people living with mental illness was conducted within the PhD project. The results of this small study and the further exploration of the concept are outlined in the following section.

2.5 Uncertainty Among People Living with Mental Illness

As described in the previous section, uncertainty in illness among people living with mental illness is difficult to find in the literature. However, there are a few exceptions. Rapport et al. (2010) aimed to identify aspects of treatment uncertainty in mental health service users and providers by analysing narrative data from a large mental health data set. They found that patients would rather tell their own story of illness than directly outlining uncertainties related to their treatment. This might be one of the reasons why it is difficult to find accounts of experiences of uncertainty among people living with mental illness. However, Rapport et al. (2010) identified three main themes: medication and treatment options, objectification and marginalisation of patients and integrity of service delivery. Patients' main concerns about medication focused on the side effects and therefore, they were especially interested in alternative treatment options. However, patients find that health-care professionals focus far too strongly on medicating the mentally ill than considering other options. Therefore, patients often feel that they are not treated individually and see a strong sense of objectification and marginalisation in the health-care system. This is especially difficult, if there is lack of consistency and communication within and across mental health services, which not only patients but also carers strongly criticise. However, patients also reported several aspects that were not directly linked to treatment uncertainties: Their stories were also about loneliness, uncertainties about their future, feelings of being unsupported by health-care professionals and a lack of understanding of their illness (Rapport et al. 2010). This indicates that there is a vast range of possible uncertainties among people living with mental illness.

In a qualitative inquiry of the experiences of people recovering from psychosis, Forchuk et al. (2003) describe 'fears' and 'concerns' rather than uncertainties. However, according to Hansen et al. (2012) worries and fears are part of feeling uncertainty. Experiencing psychosis itself must be a tremendously troubling and worrying experience that leaves a person with a lot of uncertainty in illness. However, according to Forchuk et al. (2003), even though there is some literature that focuses on observations of symptoms, there is not much knowledge around personal experiences of people who have gone through psychotic episodes. Within their own findings the authors describe a range of issues that people recovering from psychosis are going through: Many of those issues are dealing with medication and its anticipated effectiveness but also the difficulties inherent in estimating side effects. Participants in the study were concerned that symptoms would reappear, maybe even stronger than before, that they would have to be readmitted to hospital and would remain ill for a long time or even lifelong. However, they also had hopes such as being able to live with the illness, achieving goals in life and living a ‘normal’ life (Forchuk et al. 2003). In an investigations of the perceptions of young psychosis patients Lam et al. (2011) reported subjective feelings of stigma related to the psychiatric diagnosis, even if no overt discrimination had been experienced. This was a major issue for these people. All these issues could easily be seen as aspects of uncertainty in illness among people living with mental illness.

However, due to the gap in literature about uncertainty in illness among people living with mental illness, a small preliminary study was conducted prior to the main study of this PhD research project (Wolfensberger et al. 2019). The findings of that qualitative study are based on mental health nurses’ expertise and their professional views on the topic. More information on setting, sample, data collection and analysis are outlined in Chapter 3.4. All participants of that study agreed that uncertainty in illness among people living with mental illness exists and that it is an important issue in the process of recovery. However, uncertainty is also seen as an integral part of all human experience and existence. Therefore, it is argued that uncertainty is normal for everyone, including people living with mental illness. Uncertainties can be experienced in various life situations and we all know, what this can feel like in our own lives, from moderate to severe. One of the study participants with a history of mental illness herself summed it up in saying:

> “Uncertainties [among people living with mental ill health] are the same as for anybody else, except maybe more extreme…” (P9) in (Wolfensberger et al. 2019, p.184).

Nevertheless, among people with mental illness, uncertainties are often seen in the context of loss. The risk of losing employment, hobbies and even friends is considered high among people living with mental illness. All of that might even lead to the loss of self and self-identity. Participants recalled numerous examples of people with mental illness they cared for or were related to, who must have experienced that kind of loss in their lives. The loss of self or identity “are often interwoven with experiencing stigmatisation” (Wolfensberger et al. 2019, p.185). Experiencing stigma is common among people living with mental illness (Rüsch et al. 2005) and needs to be addressed as much as the fear of or the realisation of concrete losses in a person’s life (Buck et al. 2013). Uncertainties in the context of real or potential losses may compromise a person’s ability to stay or feel safe (Wolfensberger et al. 2019). Therefore, supporting people with mental illness to regain a sense of safety and security is an important task for nurses and other health care professionals (Barker and Buchanan-Barker 2005; Slade 2009). However, uncertainty might also serve as stimulus for change, where action arises out of those feelings (Wolfensberger et al. 2019). Therefore, negotiating uncertainties is seen as a learning experience, a process of soul-searching and making sense of what is happening. In doing so “uncertainty could be overcome by hope and taking action” (Wolfensberger et al. 2019, p.184), a real stimulus for change and a driving force for a new outlook in life or even a new beginning.

All of these findings are congruent with the literature that describe uncertainty in illness from a perspective outside the population of the mentally ill. Therefore, it can be assumed that the concept of uncertainty in illness could also be adapted to those living with mental illness. Uncertainty seems to be an important aspect in dealing with illness and also mental illness.

2.6 Negotiating Uncertainty

Negotiating uncertainty is the core category and the name of the theory developed by Perrett & Biley (2013) based on a detailed exploration of the experiences of people living with the human immunodeficiency virus (HIV) (Perrett 2009). Similar to this present study, Perrett (2009) used a Grounded Theory approach to investigate the process of adapting to life with an illness. Aiming to identify stages of adaptation to having HIV and to outline the process of adapting to living with HIV within a conceptual model, eight men were interviewed. Negotiating uncertainty emerged as the action responsible for adaptation and was demonstrated by seven subcategories (Perrett and Biley 2013). The adaptation process to living with the illness is seen as a dynamic process shown through movement of negotiating uncertainty between categories and subcategories on a range between anticipating hopelessness and regaining optimism (see Table 2.2).

Table 2.2: Subcategories of the Negotiating Uncertainty Theory

	Movement of negotiating uncertainty	
Subcategory	**Anticipating hopelessness**	**Regaining optimism**
Considering risk	Denial of risk	Acceptance of risk
Seizing opportunity	Destroying life	Saving life
Planning for future	Escaping	Distracting
Assuming direction	Controlled by HIV	Controlling HIV
Strengthening through hope	Vulnerability	Empowerment
Broadening vision	Self-focusing	Self-comparing
Existing as-was	Changing everything	Staying the same

Adapted from Perrett (2009, p.177) and Perrett and Biley (2013, p.209)

With their work Perrett and Biley (2013) demonstrate that adaptation to illness is not an automatic process but needs thought and action and therefore is a dynamic and continual process within changing life situations. Negotiating uncertainties means adapting to uncertainties by trying to create certainties and regaining optimism and a positive outlook in a difficult situation to move forward in life. This is congruent with other research on dealing with chronic illness that refer to an active process of learning and self-management (Ambrosio et al. 2015).

In summary, Perrett's (2009) work provides a new and unique perspective of adapting to living with HIV that is explained through a constant process of negotiating uncertainties. It is argued that some of the aspects identified as being part of the adaptation process have not been previously researched and therefore, progresses the concept of adaptation, specifically in the field of experiencing HIV (Perrett 2009). One example of a new and not previously researched aspect of adaptation is the use of self-comparison. According to Perrett (2009) comparison seemed to be a method used by all her participants and “enabled a wider vision of their own illness, lessening the isolation sometimes described” (p.240).

Negotiating uncertainty as the core concept underlining the entire process of adapting to living with HIV stems also from the fact that “uncertainty was caused by the unpredictable nature of the virus” (Perrett 2009, p.256) and that this uncertainty remained unchanged and constant throughout the process. However, even though Perrett (2009) argues that her Grounded Theory stands “independent of any other work, in its own right, as a theory of negotiating uncertainty” (p.292), she also suggests further research with a broader and more diverse group of participants or in other areas of nursing to strengthen the theory.

2.7 The Concept of Adaptation to Illness

With Mishel’s (1988, 1990) uncertainty in illness and Perrett and Biley’s (2013) negotiating uncertainty theories, two models which were at the beginning of the conceptualisation of this research project, have been outlined (see Sections 2.4 and 2.6). Both theories could be seen as models of adaptation to illness, as much as the concept of personal recovery, which is described further below in this chapter. Therefore, this section provides a brief exploration of the concept of adaptation to illness.

2.7.1 Introducing Thoughts on Adaptation

Adaptation is a broad term. According to the Oxford English Dictionary (OED) (2019) the term ‘adaptation’ has multiple origins borrowing from French and Latin and is used to describe actions or processes of adapting, applying, adjusting and accommodating and therefore can be found not only in psychosocial but in various other contexts such as biology and physiology, the arts and music. Within the historical thesaurus of the OED, a taxonomic classification or kind of semantic index of the contents of the OED, adaptation is seen as a part of the relative properties of the world and belongs to the order of agreement, harmony or congruity. This leads to a potential understanding and meaning of the term adaptation as striving for unity and wholeness.

However, adaptation as a process can take multiple forms as suggested by the various contexts it is used in. As a concept adaptation has been studied by disciplines like psychology, medicine and nursing, but also in economics and other disciplines (Perrett 2009). Adaptation is seen as a process that all human beings and probably all living things experience within and in response to a constantly changing world and environment.

In nursing, adaptation has become a major concept focusing on how people can adapt to variances in their lives, including changes in their physical and mental health conditions or their environment (see 2.7.2). However, even though adaptation plays an important role in nursing theories and practice, there is no single or generally valid definition of the concept in the field of nursing.

2.7.2 Towards a Definition of Psychosocial Adaptation

Even though ‘adaptation to illness’ and ‘psychosocial adaptation’ are commonly used terms in healthcare and the psychological literature, it is not easy to find a clear definition or analysis of what is meant by adaptation to illness. This is unlike the concept of coping, where several concept analyses and reviews exist and most definitions, studies and models can be linked to the theoretical work of Lazarus (1966) (Audulv et al. 2016). However, there seems to be broad consensus that adaptation to illness involves coping efforts and therefore, coping might be an integral part of it. Monsen et al. (1992) even argue that adaptation is the consequence of coping efforts:

> “Adaptation results when the individual is able to effect a series of behaviours and mental processes to neutralise the stress experience and re-establish integrity of function” (p.28).

The authors seem to value adaptation as an outcome rather than a process. However, according to Audulv et al. (2016), even though the terms adaptation and adjustment are sometimes used interchangeably, adaptation actually describes a process and adjustment the potential outcome of that process.

In nursing, the concept of adaptation has a long tradition and is seen as a central aspect of an individual’s life (Londono and McMillan 2015). Adaptation can be found in many theoretical frameworks in nursing. Roy’s Adaptation Model, for example, was first published in 1970 (Roy 1970) and since then serves as a conceptual model that aims to assist nurses in their efforts to support patients in dealing with the changes and challenges in their lives (Perrett 2009). Roy (2008) defines adaptation as:

> “the process and outcome whereby thinking and feeling persons as individuals or in groups use conscious awareness and choice to create human and environmental integration” (p.29).

Murray and Zentner (1975), also nursing scholars, even equate adaptation with health and define health as “an adaptive response physically, mentally and emotionally to internal and external stimuli to maintain stability and comfort” (p.7).

However, the concept of adaptation to illness has several roots with its strongest influences from rehabilitation, psychology and nursing (Londono and McMillan 2015) and even though the literature on adaptation to illness is broad and “contains valuable theoretical discussions and the results of clinical studies with diverse populations” (Livneh and Antonak 1997, p.17), the concept still lacks agreement or common definition. Therefore, Londono and McMillan (2015) conducted an evolutionary concept analysis (Rodgers 2000) to provide more clarity about the concept of psychosocial adaptation. They describe causes and consequences as part of the conceptual basis of the concept. A new life situation or condition is the antecedent that exists before psychosocial adaptation starts. A new life situation can be almost anything; a physical or mental health condition such as injuries, diseases or mental illness, a change in roles like adulthood or becoming a caregiver of a relative, or various other life changes and events, such as migration or unemployment just to name a few. Where psychosocial adaptation occurs, there will be consequences or outcomes that can be good or poor, positive or negative and anywhere in between. These consequences are characterised by levels of functioning in daily life, sense of well-being or life satisfaction, quality of life, connectedness or, on the more negative side, frustration, hopelessness, uncertainty, loneliness or social avoidance (Londono and McMillan 2015). This means that psychosocial adaptation to illness does not have to be a process with a positive outcome.

> “The concept of psychosocial adaptation is characterised as a continuous process, where internal and external interactions reflect the changes that individuals undergo while adjusting to their situation. This process is influenced by characteristics of the individual or environment” (Londono and McMillan 2015, p.2508).

Suggesting change, process, continuity, interaction and influences as the main attributes of psychosocial adaptation, Londono and McMillan (2015) share an understanding of psychosocial adaptation that is rather fluent than stringent in its phases. This has to do with the identification of non-linear, ongoing or even lifelong processes, internal and external interactions with self and environment as well as the importance of positive and negative influences of adaptation on an individual and environmental level. Livneh and Antonak (1997) call scholars behind such arguments “opponents of a phase model in psychosocial adaptation” (p.18) and summarise their arguments as follows:

> “…reactions to chronic illness or disability are not universally experienced. […] a state of final adjustment (alternatively referred to as resolution, acceptance, assimilation, reorganisation, reintegration) is not always achieved by persons with chronic illness and disabilities. […] psychological recovery does not follow an orderly sequence of reaction phases” (p.18).

These arguments suggest a view on psychosocial adaptation as an individual process and “as just one of a set of independent and non-sequential patterns of human behaviour” (Livneh and Antonak 1997, p.27).

However, Livneh and Antonak (1997) favour a phase model and define various reaction phases to chronic illness and disability such as shock, anxiety, denial, depression, internalised anger, externalised hostility, acknowledgment and adjustment. It implies a series of phases and changes that happen over time. This is congruent with many articles on adaptation to illness where the process is sometimes called a trajectory or evolution (Londono and McMillan 2015). The phase model also shows similarities to the work of Kübler-Ross (1969) on death and dying and grief and grieving (Kübler-Ross and Kessler 2005) with different stages a person needs to be going through to find meaning and to adapt to a difficult situation.

Londono and McMillan (2015) argue that ‘process’ implies mainly the temporality of different changes that occur when someone endures imbalance in their life and not so much linearity. Changes manifest themselves in a series of actions without a definitive end and may be ongoing for a long time. Within a process of psychosocial adaptation to illness there are also always dynamic interactions an individual has with oneself, with others and the environment. These interactions may serve as factors influencing the adaptation process along with other ‘influences’ such as personality aspects, coping skills, but also socioeconomic status and discrimination (Londono and McMillan 2015).

In summary, even though there are attempts to clarify the concepts of psychosocial adaptation and adaptation to illness, they remain broad concepts stemming from a “broad term describing the response required when change occurs” (Perrett 2009, p.24). Therefore, the meaning of the concepts may vary in their details depending on the context they are used in or the original literature they rely on.

This leads to the next and last section of the background chapter focusing on personal recovery. Personal recovery, as stated before, could also be seen as a process of adaptation to illness and more specifically to living with mental illness.

2.8 Personal Recovery

According to the previous sections one could argue that mental illness is the antecedent that initiates psychosocial adaptation and that personal recovery is the consequence of it. However, this logic is not fully congruent as recovery or personal recovery, as it will be used in this thesis, is more than an outcome but a process in itself and even “a way of living” (Anthony 1993, p.13).

The term ‘recovery’ has several meanings and may be used and understood differently by health professionals in different fields and disciplines. Therefore, it is useful to distinguish between a more clinical understanding of recovery and one that is based on personal experiences of service users rather than clinical outcomes. Clinical recovery emerged from professional-led research and stems from a biomedical view of health and illness and refers to an observable, clinical outcome that is rated by expert clinicians and usually means full remission of symptoms (Slade 2009; Trenoweth 2016).

2.8.1 Finding a Definition of Personal Recovery

In mental health care Amering and Schmolke (2012) argue that recovery is the progression from the limitations of the role as a psychiatric patient into a self-determined and meaningful life as a human being with a mental illness. Therefore, an individual process and living as a whole person are in focus when talking about recovery in mental health care and not predominantly a predefined outcome or medical recovery. The National Alliance on Mental Illness (NAMI) defines mental health recovery as…

> "…a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her potential" (2019).

Achieving an individual's own aspirations and goals is also what the WHO refers to in their Mental Health Action Plan (WHO 2013) when addressing recovery-based approaches. Therefore, also the WHO sees recovery in mental health care from the perspective of people living with mental illness rather than from a clinical or medically oriented position. However, the WHO does not provide their own definition of recovery but rather refers to and adapts existing frameworks and positions (WHO 2012).

Among those sources of the WHO (2012) are Jacobson and Greenley (2001) who argue that recovery in mental health…

> "…refers to both internal conditions experienced by persons who describe themselves as being in recovery – hope, healing, empowerment, and connection – and external conditions that facilitate recovery – implementation of the principle of human rights, a positive culture of healing, and recovery-oriented services" (p.482).

Jacobson and Greenley's (2001) approach not only points out some of the key aspects of personal recovery such as hope and empowerment, but also the importance of external conditions that always influence, promote or hinder a personal recovery process. Therefore, the principles of recovery-oriented mental health practice (see Table 2.3) as published by the WHO (2012) contain not only individual aspects but focus on structural and attitudinal aspects as well.

Attitude is an important aspect of it and might be one of the reasons why there are still different interpretations of recovery in psychiatric and mental health care. An attitude stemming from a different understanding of mental health and mental illness that does not include a service user perspective, will most likely lead to a different understanding of recovery (see Section 2.2 and Table 2.1).

Table 2.3: Principles of recovery-oriented mental health practice

	Recovery oriented mental health practice:
1. Uniqueness of the individual	• recognises that recovery is not necessarily about cure but is about having opportunities for choices and living a meaningful, satisfying and purposeful life, and being a valued member of the community • accepts that recovery outcomes are personal and unique for each individual and go beyond an exclusive health focus to include an emphasis on social inclusion and quality of life • empowers individuals so they recognise that they are at the centre of the care they receive.
2. Real choices	• supports and empowers individuals to make their own choices about how they want to lead their lives and acknowledges choices need to be meaningful and creatively explored • supports individuals to build on their strengths and take as much responsibility for their lives as they can at any given time • ensures that there is a balance between duty of care and support for individuals to take positive risks and make the most of new opportunities
3. Attitudes and rights	• involves listening to, learning from and acting upon communications from the individual and their carers about what is important to each individual • promotes and protects individual’s legal, citizenship and human rights • supports individuals to maintain and develop social, recreational, occupational and vocational activities which are meaningful to the individual • instils hope in an individual’s future and ability to live a meaningful life
4. Dignity and respect	• consists of being courteous, respectful and honest in all interactions • involves sensitivity and respect for each individual, particularly for their values, beliefs and culture • challenges discrimination and stigma wherever it exists within our own services or the broader community
5. Partnership and communication	• acknowledges each individual is an expert on their own life and that recovery involves working in partnership with individuals and their carers to provide support in a way that makes sense to them • values the importance of sharing relevant information and the need to communicate clearly to enable effective engagement • involves working in positive and realistic ways with individuals and their carers to help them realise their own hopes, goals and aspirations
6. Evaluating recovery	• ensures and enables continuous evaluation of recovery-based practice at several levels • individuals and their carers can track their own progress • services demonstrate that they use the individual’s experiences of care to inform quality improvement activities • the mental health system reports on key outcomes that indicate recovery including (but not limited to) housing, employment, education and social and family relationships as well as health and well-being measures.

Adapted from World Health Organization (WHO 2012, pp.41-43)

There is an important difference between recovery from an illness and recovery within an illness experience. Therefore, in order to distinguish more clearly within this blending of meanings of ‘recovery’, Slade (2009) introduced ‘personal recovery’. The word ‘personal’ indicates the understanding of recovery as an individually defined and experienced process rather than a result. However, Slade (2009) does not provide his own or a new definition for personal recovery but uses the often cited definition by Anthony (1993) that refers to personal recovery as…

> “…a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness” (p.13).

Jacobson and Greenley (2001) argue that this notion of recovery from mental illness origins in the 1980s when personal accounts of service users on how they have survived mental illness and managed to recover in living with the illness have started influencing theoretical and practical models of recovery.

> “The recovery approach has developed from the growth of the service user movement which has carried an imperative for all mental health services to be human, meet the needs and demands of the person and honour their human rights” (Trenoweth 2016, p.6).

Up until today it is the most common conceptualisation of recovery or personal recovery in mental health care. However, Wallcraft (2012) points out that there is an often omitted second paragraph to Anthony’s well known definition that is also of “high importance to consumers and users of mental health services” (p.166):

> “Recovery from mental illness involves much more than recovery from the illness itself. People with mental illness may have to recover from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment setting; from lack of recent opportunities for self-determination; from the negative side effects of unemployment; and from crushed dreams. Recovery is often a complex, time-consuming process. Recovery is what people with disabilities do. Treatment, case-management and rehabilitation are what helpers do to facilitate recovery” (Anthony 1993, p.13).

The statement adds to a better understanding of what that process of personal recovery may include for people living with mental illness.

2.8.2 Key Elements, Components and Stages of Personal Recovery

Even though there is some kind of consensus on the overall definition of recovery or personal recovery in mental health care, the same cannot be easily said about the key elements or concepts, components, stages, tasks or whatever partition is described about recovery. It seems that almost every contemporary mental health-care provider or mental health charity have their own description of what recovery is all about. However, most of them have in common that they orient themselves on the individual process of the affected person and their dealing with the illness. One example of the many descriptions of aspects of recovery are the principles of recovery-oriented mental health practice by the WHO (2012) mentioned in the previous section (see Table 2.3). The National Alliance on Mental Illness (NAMI) describes ten fundamental components of recovery that include aspects such as self-direction, referring to personal choice and control, non-linearity, referring to continuality rather than a step-by step process, responsibilities, referring to service users own responsibility in the process, respect, referring to the elimination of stigma, and hope as the catalyst of the whole process (NAMI-Thurston-Mason 2019). Schmolke et al. (2016) refer to the Scottish Recovery Network (SRN) as an example for a consensus on key elements of recovery and describe nine elements from hope to creative risk-taking. The SRN has originally published a discussion paper on those elements of recovery that is “based on international learning around what people have identified as important elements…” (Bradstreet 2004, p.4) but has not followed up or updated it ever since.

A similar process based on “empirical research into the domains and stages of personal recovery” (Slade 2009, p.77) led to a personal recovery framework, containing four key domains of personal recovery (see Table 2.4), several potential stages and four tasks of recovery. The four recovery tasks identified by Slade (2009) are “developing a positive identity, framing the ‘mental illness’, self-managing the mental illness, and developing socially valued roles” (p.83). A summary of these task is presented in Table 2.5.

However, components of all of those aspects, the key domains, as well as some of the stages and the tasks of personal recovery are used in comparable but not completely identical or less detailed ways in other descriptions of recovery (Bonney and Stickley 2008; Leamy et al. 2011). In general, when talking about personal recovery, key is the attitude behind it, the attitude of those affected by mental illness, professionals and relatives alike. An attitude that focuses on recuperation and recovery from illness in the sense of well-being, self-determination and new meaning and purpose.

Table 2.4: Key domains of personal recovery

Domain	**Definition**	**The central question**	**Importance in mental illness**
1. Hope	A primary future-oriented expectation of attaining personally valued goals, relationships or spirituality which lead to meaning and are subjectively considered possible	What will happen to me?	Mental illness and its devaluing consequences can take away hope for a good future
2. Identity	Those persistent characteristics which make us unique and by which we are connected to the rest of the world	Who am I?	Mental illness undermines personal and social identity
3. Meaning			
Direct meaning	An understanding which makes adequate personal sense of the mental illness experience	What has happened?	Mental illness is a profound experience, which requires a personally satisfactory explanation
Indirect meaning	An integration of the direct meaning into personal and social identity	What does this mean for me?	Mental illness leads to re-evaluation of values and personally meaningful life goals
4. Personal responsibility	A constellation of values, cognitions, emotions and behaviours which lead to full engagement in life	What can I do?	The mental illness itself and responses from the person, mental health services and wider society can all undermine the ability to be responsible for one's own life

Adapted from Slade (2009, p.78)

Pro Mente Sana, a foundation that supports people with mental disabilities in Switzerland, even argues that the realisation of this kind of recovery approach in mental health care is only possible if a corresponding change in values and attitudes also takes place in society (Bening and Schläppi 2016).

Table 2.5: Four tasks of recovery

Recovery task	Summary description
1. Developing a positive identity	The goal for people with a mental illness is to move from an either-or stance to a both-and stance – I am a person in my own right *and* I have a mental illness (or whatever other frame of meaning is helpful). It is about moving towards an identity which contains the possibility of a better future.
2. Framing the 'mental illness'	Framing involves making sense of the experience and requires a level of acceptance or integration of the mental illness experience into broader identity.
3. Self-managing the mental illness	The key transition is from being clinically managed to taking personal responsibility through self-management. It means being responsible for your own well-being, including seeking help and support from others when necessary.
4. Developing valued social roles	It is about who I am to others and in the world by providing a rich and layered identity in which no one element is the only element that really matters.

Adapted from Slade (2009, pp.83-87)

A slightly different approach to personal recovery can be found in Barker and Buchanan-Barker's (2005) 'Tidal Model' that reflects a holistic model of care. Therefore, the key principles of the Tidal Model focus more on the therapeutic relationship rather than on tasks of recovery for people living with mental illness. Barker & Buchanan-Barker (2005) argue that their model is all about experience and learning from it, from our own and others' experience. The Tidal Model is an approach to value making, something they see as the "sole purpose of our existence" (p.xviii). Therefore, value making is seen as part of mental health recovery. Similar to other recovery approaches, the Tidal Model interprets psychiatric crisis or illness only as one aspect among others, that might threaten the natural or normal lives of people. And change, beyond the necessity of awareness, is seen as a constant and ongoing process in anybody's life.

Empowerment, one of the principles of the Tidal Model and other recovery approaches as well, builds the foundation of the caring process in a temporary therapeutic relationship and needs to involve an “act of unison” and “caring with people, rather than simply caring for them” (Barker and Buchanan-Barker 2005, p.23). Therefore, reflecting on the self, value making and learning are not only seen as aspects relevant for the person living with mental illness but for professionals and caretakers alike. Barker and Buchanan-Barker (2005) even go as far as to tell professionals that “the person who becomes the patient is always the teacher. We must learn how to become the pupil” (p.17). This understanding demands listening to the stories of the people and valuing their stories about who they are or how they see themselves. Therefore, it constructs a narrative-based form of practice (Barker and Kerr 2001).

In conclusion, the different approaches to personal recovery reveal that it cannot be conclusively described or defined. There is no conclusive scientific consensus or clear evidence on the definitions of stages, sub-processes, tasks or however one wants to call the subordinate aspects of the recovery process. Therefore, in this thesis as in most areas of contemporary mental health care, I focus on the greatest possible agreement that recovery or personal recovery is seen as a highly individual and profoundly personal process of a person living with mental illness.

2.9 Background Summary

The contents outlined in this chapter represent a larger part of the foundation of the discussion of my PhD project. Certainly, every topic or concept covered here could be explored in much more detail, but the aim is to provide an overview of the main aspects and contents that allow a good and consistent understanding of each topic area. As outlined at the beginning of the chapter (Section 2.1), it does not reflect an extensive or systematic literature review and therefore, there is no claim to completeness or conclusiveness.

Nevertheless, a critical reflection on mental health and mental illness, as well as on important approaches to mental health care, such as person-centredness and personal recovery are inevitable if one wants to deal with the point of view of those affected by mental illness. Also, the examination of the concepts of uncertainty in illness, negotiating uncertainty and uncertainty among people living with mental illness, that stand at the beginning of this research project (see Sections 1.2 and 1.3), are relevant as different approaches to adaptation to illness. This critical reflection will go on throughout the whole process of my PhD project and will culminate in the discussion chapter and the defence of this thesis.

3 METHODOLOGY

Toni Areal, Zurich, Switzerland 2016

“We can share the journey, but the adventure is yours.
[…]
At each phase of the research journey, your readings
of your work guide you to the next moves”
(Charmaz 2014, p.xiv)

3.1 Methodology in Plural

An impressive stairway in a new university building in Zurich and a quote from Kathy Charmaz introduce the methodology chapter. The methodology has different layers and it is like climbing and descending a staircase, entering one or another level, going back and forth and down again: an adventure indeed. The method in this research project is not a straightforward one but indeed methodology in plural. Plural methodology because there is the preliminary and the main study. Plural also because within the methodology of the main study, Grounded Theory, there is not a singular approach, but it has several schools of thought (see Section 3.2.1). However, even though within this chapter all elements are covered, the primary focus is on the main study which is at the core of my PhD research project.

Aiming to explore the personal experiences of people living with mental illness in relation to their adaptation process to illness, it seemed inevitable that this research must focus on people's stories. In academia stories are often called narratives. Through telling their stories people make sense of their lives (Basset and Stickley 2010). Narrative research approaches have been established in various disciplines including health care even though "historically, in health research, people's stories are considered to be the weakest kind of evidence" (Basset and Stickley 2010, p.3). Nonetheless, stories matter, and voices need to be heard. This is especially true for people living with mental illness, who face stigma from society, health professionals and self (Rüsch et al. 2005). My personal experiences also show, that narrative accounts and qualitative inquiries are becoming more important in the context of mental health practice and practice lead research.

Research approaches using stories and narratives as their primary source of data are primarily qualitative. However, quantitative narrative analyses exist and are considered useful if the amount of data is vast (Franzosi 2010). In this study, I have chosen a Grounded Theory approach to collect and analyse the mainly narrative data. Grounded theory methods build on fifty years of utilisation as "systematic, yet flexible guidelines for collecting and analysing qualitative data to construct theories from the data themselves" (Charmaz 2014, p.1).

It has been this combination of a systematic, yet flexible approach that appealed to me. At an early stage of the research project, I have also had the opportunity to attend a summer school with Charmaz which was very inspiring. To construct and find a new and unique theory from data became the main reason and motivation why I chose Grounded Theory for the main study of this research project. Charmaz's explanations and guidance were encouraging or, as one of the original founders of the method, Glaser, expresses its essential features:

> "How are you doing? I'm doing. Just do it. Let's do it. Do it because it is meant to be. Do it because it is there to be done. Do it because it WORKS" (Glaser 1998, p.1).

The methodology of the preliminary study that was conducted prior to the main study of this research project, is described in the last section of this chapter (see 3.4). Its findings are described in the background chapter (see 2.5).

3.2 The Main Study

Charmaz's Constructivist Grounded Theory (2009, 2014) approach in combination with Breuer et al.'s (2009; 2017) Reflexive Grounded Theory approach have been used for the main study of this research project. Each one is 'a' Grounded Theory approach with emphasis on 'an' approach rather than 'the' methodology, as there is no such thing as 'the' Grounded Theory methodology. Therefore, this section outlines not only the emergence of Grounded Theory but also some of its controversies. However, most importantly, it gives an insight into the chosen approach, or better the combination of approaches, for this study and its implications for the project.

3.2.1 The Emergence of Grounded Theory

The original research that led to the discovery of Grounded Theory was about dying in hospitals (Glaser and Strauss 1965) conducted by two sociologists; Barney G. Glaser (*1930) and Anselm L. Strauss (1916-1996). In their original work they outlined the use of a method that intends to develop an abstract theoretical understanding of social processes. Glaser and Strauss realised that there was a lack of research methods that would allow specification of the relationship between actions, conditions and meaning within a given situation. Therefore, they developed a method that allows the discovery of theories from the data collected in social science research (Glaser and Strauss 1967). Grounded Theory became a highly acclaimed research methodology in various fields of science (Mey and Mruck 2011). Glaser and Strauss's original work (1967) later became known as classic Grounded Theory or 'Glaserian' Grounded Theory, due to the strong influence of Glaser's scientific and methodological background and his own claim to have written "90% of the book" (Glaser 1998, p.22).

However, over the years Grounded Theory as a qualitative research methodology has been further developed by Glaser (1978, 1998), Strauss and Corbin and other scientists and now has several strands of varying similarity that are all called Grounded Theory methods (Strauss and Corbin 1990; Clarke 2005; Charmaz 2014; Breuer et al. 2017).

The emergence of Grounded Theory can be best understood in its historical context, particularly the tensions between differing social scientific inquiries in the United States in the early 1960s. Charmaz (2014) describes it as follows:

> "At that time, the divide between theory and research deepened […] and the gap between inductive qualitative and deductive quantitative research widened. Despite […] sharp critiques of quantification from critical theorists, the discipline [sociology] marched toward defining research in quantitative terms" (p.6).

It is in this context, that Glaser and Strauss merged their two divergent disciplinary traditions into Grounded Theory methodology: Glaser representing the Columbia University positivism and Strauss representing the Chicago school pragmatism and symbolic interactionism (Glaser 1998; Charmaz 2014). The influence of their contrasting backgrounds is evident in what they each bring to the formation of Grounded Theory (Perrett 2009).

Positivism emphasises a rigorous scientific method using reliable and verifiable instruments, that should lead to objective and value-free results for the development of abstract and generalisable concepts and theories (Abrutyn 2013). This emphasis has always been Glaser's stance on the methodology of Grounded Theory, strictly differentiating it from other forms of qualitative data analysis. It could be argued that the rigorous methodology in classic Grounded Theory and its clear demarcation from other forms of qualitative inquiries might have helped to keep qualitative research in line with the mostly quantitative approaches in sociology back in the 1960s and 70s in the USA. However, for Glaser, it seems that it has always been a question of how to do research rightly or wrongly, a thinking that is deeply rooted in a positivistic research paradigm. In an article defending the classic Grounded Theory method he states (Glaser and Holton 2004):

> "While grounded in data, the conceptual hypotheses of Grounded Theory (GT) do not entail the problems of accuracy that plague qualitative data analysis (QDA) methods. The mixing of QDA and GT methodologies has the effect of downgrading and eroding the GT goal of conceptual theory. The result is a default remodelling of classic GT into just another QDA method with all its descriptive baggage" (p.2).

This statement clearly shows Glaser's understanding of the superiority of rigorously built conceptual theory out of data (something usually conceived through huge amounts of quantitative data) over less generalisable outcomes of most other qualitative inquiries. Therefore, it is no surprise that in recent years, proponents of classic Grounded Theory consider Grounded Theory suitable for quantitative research as well (Walsh et al. 2015).

It is interesting that Glaser's position, based on positivism and Strauss's methodological background stemming from pragmatism and symbolic interactionism could be interwoven into one methodology. However, both Strauss and Glaser were members of a group called The Social Interactionist Society and were both interested in symbolic interactionism and nonpositivist thinking (Milliken and Schreiber 2012). Symbolic interactionism (Blumer 1969) emphasises how people construct meanings and identities and focuses on how symbols and interaction serve as a framework of social life. It encourages interpretive analysis and interactional processes (Fine and Sandstrom 2011). Interaction is a central aspect in Grounded Theory. Milliken and Schreiber (2012) argue that without attending to the philosophical origins of the methodology, that is symbolic interactionism, one cannot develop fully contextualised and grounded theories that explain human experience. However, this viewpoint is not shared by all Grounded Theory researchers (Charmaz 2009). Symbolic interactionism provides a set of concepts that help the researcher to understand the meanings people give to their experience and how behaviour has been shaped through social interaction (Aldiabat and Le Navenec 2011). Milliken and Schreiber (2012) refer to the self, the mind and society as the three key concepts. The self is composed of the 'I' as subject and 'Me' as object in relationship and interaction between the two (Mead 1934) and the mind develops concurrently with the self and “is socially derived, arising from communication and association with others” (Milliken and Schreiber 2012, p.688). Society is viewed as a process rather than a static condition that depends on constant interactions between people in a social context.

> “In conclusion, human beings [...] have a self that enables them to think and to interact with themselves in the form of internal conversation. [...] Based on this internal interaction, humans act in relation to others as well as toward themselves” (Aldiabat and Le Navenec 2011, p.1065).

These conceptual understandings do not only relate to the people investigated in research but also to the researcher him- or herself and therefore, are also part of the interaction between the two. However, Glaser (2012) continuously argues that researchers in Grounded Theory do not intrude the data and that rigorous constant comparison alone reveals everything. Therefore, even though it is argued that both Glaser and Strauss have incorporated symbolic interactionism into Grounded Theory methodology, it still seems that their underpinning philosophy differs widely. The divide in the further development of Grounded Theory seems inevitable.

Glaser’s monography ‘Theoretical Sensitivity: Advances in the Methodology of Grounded Theory’ (1978) further supports his positivistic approach to the methodology but added important concepts to the methodology such as open, selective and theoretical coding. According to Equit and Hohage (2016) Glaser’s book (1978) could be seen as the first Grounded Theory methodology book that provides detailed descriptions of coding procedures and explains concepts for the systematic inclusion of foreknowledge and existing theories into the methodology. Even though Strauss did partially rely on Glaser’s ideas and terminology in his own book on the methodology (1987), he added his own concepts and understandings. It is argued that the two publications (Glaser 1978; Strauss 1987) mark the beginning of the diverging development of the Grounded Theory methodology (Equit and Hohage 2016). Strauss further developed his own understanding in collaboration with Corbin (Strauss and Corbin 1990). Their approach to Grounded Theory is considered to be more pragmatic than Glaser’s and rejects a positivist position (Hallberg 2006).

3.2.2 Methodological Assumptions of Grounded Theory

Grounded theory is originally defined as a “general method of comparative analysis” with the intention of “the discovery of theory from data” (Glaser and Strauss 1967, p.1). Grounded theory is open to any type of data (Glaser and Strauss 1967; Walsh et al. 2015) or “all is data” as Glaser (2001, p.145) likes to say, meaning that data is everything that is going on in the research situation. That includes not only what is being said in an interview, but also how and why it has been said, the context around it, observations or documents and anything else in any possible combination (Glaser 2001). With that assumption about data in mind, Glaser and Strauss introduced the following defining components of the methodology (Charmaz 2014, pp.7-8):

- “Simultaneous involvement in data collection and analysis
- Constructing analytic codes and categories from data, not from preconceived logically deduced hypotheses
- Using the constant comparison method, which involves making comparisons during each stage of the analysis
- Advancing theory development during each step of data collection and analysis
- Memo-writing to elaborate categories, specify properties, define relationships between categories, and identify gaps
- Sampling aimed toward theory construction, not for population representativeness
- Conducting the literature review after developing an independent analysis.”

These components still form the foundation of most Grounded Theory methods and were also used in this research project including the components added by Charmaz (2014). Charmaz (2014) adopted and partially redefined the defining components of Grounded Theory and added the following components to the research strategies of grounded theorists (p.15):

- “Emphasise theory construction rather than description or application of current theories
- Search for variation in the studied categories or process
- Pursue developing a category rather than covering a specific empirical topic”

These strategies in the research process are transportable across philosophical, epistemological and ontological gulfs (Charmaz 2014). However, the underlying understanding of how to do Grounded Theory methodology, including the role of the researcher and what the exact stages of the analysis are, may vary depending on a researcher's philosophical and methodological background (see Sections 3.3.1 *ff*). Walsh et al. (2015) argue that because the original authors were from different philosophical backgrounds, Grounded Theory itself is philosophically neutral and could be seen more as a research paradigm than as a methodology or a research framework. To me, Grounded Theory is a rigorous methodology in comparative analysis aiming to develop theory from data; not more and not less.

3.2.3 Constructivist Grounded Theory

I have chosen a constructivist approach to Grounded Theory for this study as its underlying philosophical assumptions are consistent with my own philosophical understanding that is based on the simultaneity paradigm (see Section 1.7).

> "[Constructivist Grounded Theory] …assumes a relativist epistemology, sees knowledge as socially produced, acknowledges multiple standpoints of both the research participants and the grounded theorist, and takes a reflexive stance toward our actions, situations, and participants in the field setting – and our analytic construction of them" (Charmaz 2009, p.129).

It is the relativity and subjectivity aspect in the constructivist approach of Grounded Theory that appeals to me and why I favour it over other approaches. Charmaz (2014) uses the term 'constructivist' "to acknowledge subjectivity and the researcher's involvement in the construction and interpretation of data" (p.14). Therefore, constructivist grounded theorists acknowledge the existence of mutuality in a research relationship between participant and researcher and recognise the privilege of a connection between them that must be respected by the researcher (Gardner et al. 2012). Additionally, if all is data, as Glaser (2001) distinctly points out, there is no way of leaving the researcher's perspective, his or her background, understanding or belief system unnoticed or unreflected upon in the whole research process. I am convinced that there is no pure objectivity in qualitative data as it is always a matter of perspective and subject to various influences on the participant's as well as on the researcher's side. Therefore, to achieve theory development in Grounded Theory, it demands constant reflexivity in all stages and aspects of the research process.

Gardner et al. (2012) conceptualise their interpretation of the Constructivist Grounded Theory method in an illustration that points out most aspects relevant to this approach (Figure 3.1). Their recommendation to researchers in the field of mental health research is to consider the constructivist approach for their research as it is consistent with contemporary mental health nursing practice (Gardner et al. 2012). I appreciate this figurative conceptualisation and share it as part of my own understanding of the method.

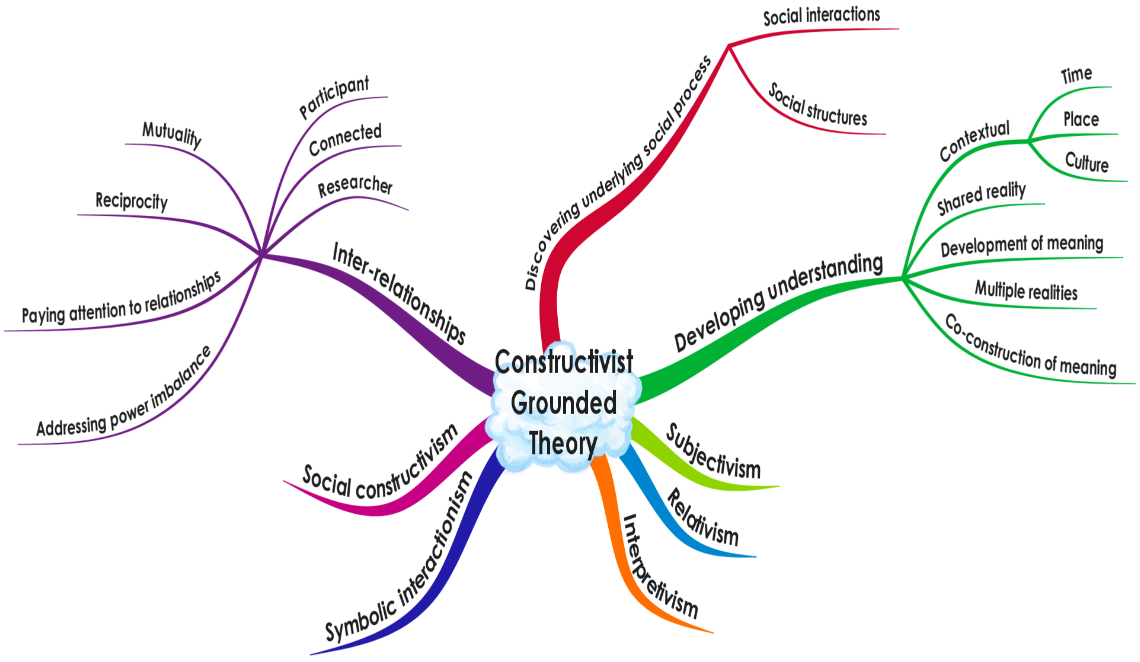

Figure 3.1: Constructivist Grounded Theory (Gardner et al. 2012, p.69)

However, Glaser (2012) critiques the constructivist approach calling it a “misnomer” (p.28) and concludes, after a lengthy dismantling of the constructivist orientation, that…

> “…the researcher impact on data is just one more variable to consider whenever it emerges as relevant. It is like all Grounded Theory categories and properties; it must earn its relevance. Thus it depends” (p.37).

I could not disagree with that conclusion besides the fact, that I see the relevance of the researcher’s background in the interpretation of data always as a given.

3.2.4 Reflexive Grounded Theory

Reflexive Grounded Theory cannot be found in English publications. Therefore, all direct quotes are translated by myself, as mentioned in the introduction of the thesis (see 1.8). Reflexive Grounded Theory originates from Germany where Grounded Theory methods, as probably in many countries, traditionally are used in sociology and related disciplines. However, the author and his co-authors of the first edition of 'Reflexive Grounded Theory' (Breuer 2009) all have a professional background in psychology, a discipline that is known, at least in German speaking countries, for its methodologically rigorous grounding in quantifiable data and its excessive orientation towards natural sciences such as medicine (Breuer et al. 2017). It is in this context that Breuer et al. (2009; 2017) realised the importance of guidance and support for their psychology students who were about to use Grounded Theory methodology in research projects. Therefore, Reflexive Grounded Theory has been developed for a better understanding and a meaningful use of Grounded Theory.

A key aspect of Reflexive Grounded Theory is the emphasis on the researcher and the interaction between the researcher and the participant and this is seen as *"central to gaining knowledge"* (Breuer et al. 2017, p.2). The reflexive stance, as well as the aspect of the researcher as a part of the investigation, analysis and interpretation can be found in corresponding ways in Constructivist Grounded Theory (Charmaz 2014). However, Breuer et al. (2017) describe Reflexive Grounded Theory as a specific research approach based on conceptual foundations such as:

> ***"The understanding of the researcher and his tasks:*** *The researcher is not (only) seen as a task-oriented agent serving the research project in validating or developing a conceived "gran theory" but has indeed his own creative potential. […] That potential provides "a licence to think", to explore new theories. […] Considering the anthropological characteristics of the researcher and the participant both have the same premises, and both have self-/reflexive capabilities. […] "* (p.4).

The researcher is not just an instrument in a scientific process but part of it as a person who shares many commonalities with the participants of the study. This creates an understanding of the researcher as part of the investigation who must use his self-/reflexive capabilities to distinguish between his own intentions and assumptions and what is presented from the participant and the context they participate in.

> ***"The self-/reflexive elaboration of thinking and functioning:*** *In doing research, the researcher creates his own positioning, value system, a unique "handwriting" or style that can be seen in the context of the field of the research and its methodology. We believe that it is the researcher-as-person that generates new scientific knowledge and that knowledge is always influenced by a certain perspective, a subject-perspective"* (Breuer et al. 2017, p.5).

This understanding of the researcher-as-person that generates new knowledge seems to clearly contrast with Glaser's position that theory (knowledge) emerges from data only (Glaser 1978). From my own experience in the research process of this study, it seems clear that within the constant comparative analysis, one's own understanding and background is part of that comparison and in the end, it is the researcher's decision, based on data, as to what is outlined and what theory is generated.

> ***"The context of the acquisition and the utilisation of the research method:*** *Research as well as the situation of the researcher always have a context that needs to be taken into account. Basically, it is relevant to consider the importance and impact of social, economic, historical and institutional aspects"* (Breuer et al. 2017, p.5).

Context is key to qualitative inquiry. Breuer et al. (2017) explicitly focus on the context of the researcher, considering it from two different levels, arguing that these two levels are always important to consider no matter what research or methods are in place:

- Who is the researcher as an individual person? Where is she or he coming from, how has she/he been socialised in her/his family and/or culturally, what is the 'zeitgeist' she/he is coming from, what is her/his personality, identity and self-conception, what are her/his aptitudes?
- What is the researcher's institutional, academic and methodological background, what are the expectations in his/her field of research?

This understanding within the Reflexive Grounded Theory approach reflects my natural readiness to write about myself and my own private and professional background (see 1.6). Therefore, that rather unusual part of the thesis can be understood as part of the extended methodology.

In addition to the conceptual foundations, Breuer et al. (2017) provide a clear structure with detailed descriptions of the different stages of the research process calling it a 'toolkit' of Reflexive Grounded Theory. Their methodology does not differ much from the original components provided by Glaser and Strauss (1967; Glaser 1978; Strauss 1987) even though they talk about a ‘first circulation’’ which includes open, axial and selective coding and a ‘second circulation’ that is all about categorising, theoretical sampling and theory building. However, in this study, mainly the process as outlined by Charmaz (2014) has been used (see 3.3), but additional information and insights were taken from the reflexive approach for a better understanding of the variations within Grounded Theory (Breuer et al. 2017).

3.3 Constructing Grounded Theory in This Research

The process of constructing Grounded Theory in this research has been difficult, challenging, sometimes confusing and even overwhelming. This is due to some organisational and structural aspects in the process as well as to the difficulty of learning a complex methodology by doing it.

Charmaz’s approach to Grounded Theory (2014) has advantages and disadvantages. The main advantage is that it suits my own understanding and philosophy (see Section 3.2.3). A disadvantage might be that the research steps seem rather fluid and open and sometimes difficult to demarcate from each other. The attempt to illustrate the process with curved bows and overlapping arrows in the visual representation of a grounded theory (Figure 3.2) shows how difficult such a process might be. Therefore, I decided to use ATLAS.ti, a computer-assisted qualitative data analysis software (CAQDAS) that is supposed to support the analytical process from initial coding to theory building. However, it did not make the task easier. Maybe, this is because I did not use the programme to its full extent and also used hand-written field notes, memos, post-it notes and mind-maps. Nevertheless, in this part of the methodology chapter and its sections I will highlight some of these challenges and provide an overview of the research processes that have been followed in this particular study.

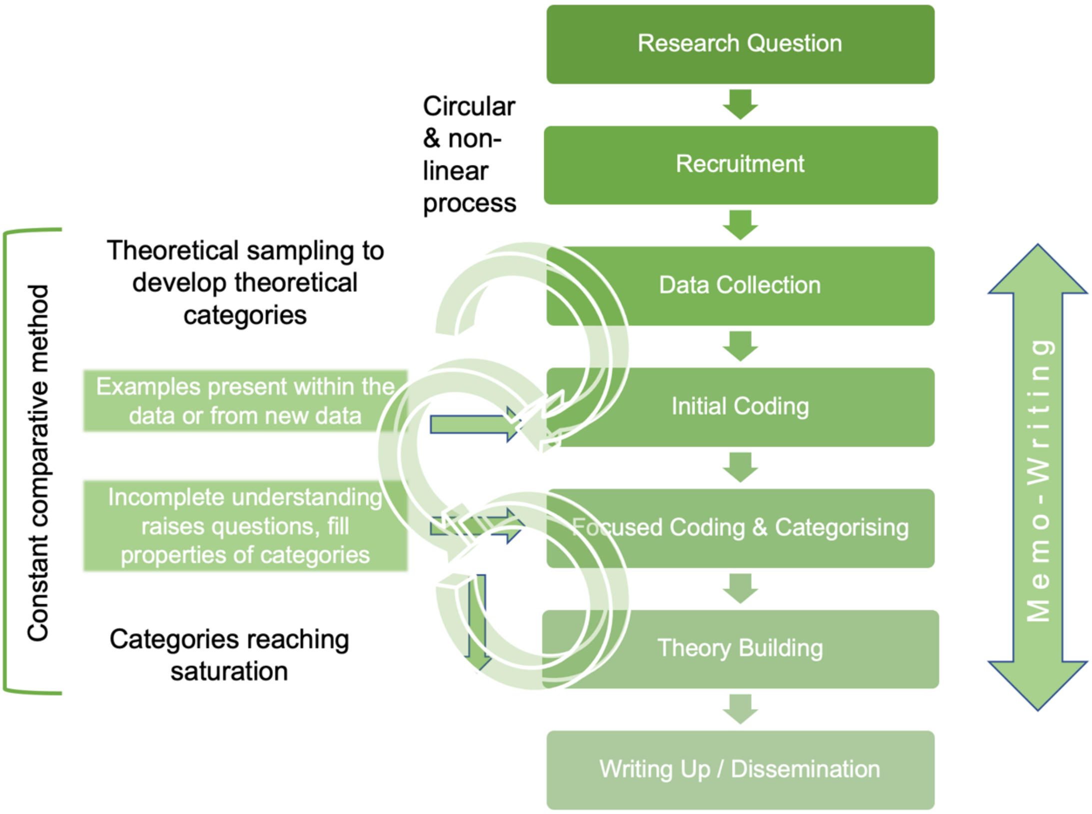

Figure 3.2: An adapted version of a visual representation of a grounded theory (Charmaz 2014, p.18) An earlier version of this figure originally appeared in Tweed & Charmaz (2011, p.133)

3.3.1 The Literature Review

The literature review in Grounded Theory is an ongoing process that extends beyond an initial search and continues throughout the whole analytical process including theorising (Charmaz 2014). In classic Grounded Theory (Glaser and Strauss 1967; Glaser 1978) it is even supported to delay the literature review until after completing the analysis. This is due to the idea, that the analysis should not be influenced or even biased by existing theories. However, to discover gaps in the subject area that a study is focusing on, a certain amount of background knowledge is needed. Additionally, a credible identification of the research area is normally needed for obtaining approval from an ethics committee (McGhee et al. 2007). Charmaz (2014) argues that the literature review provides a place to analyse relevant works in relation the newly developed Grounded Theory and the specific research problem it addresses and therefore, “to engage the ideas and research in the areas that your Grounded Theory addresses” (p.309).

In this study, the initial review (Chapter 2) I conducted was primarily by searching for literature on the topic of uncertainty among people living with mental illness. The search has since been ongoing through an electronic search subscription for ‘uncertainty in illness’ and ‘patient-uncertainty’ at PubMed, the search engine of the United States National Library of Medicine and the National Institutes of Health. However, as suggested by Smith and Biley (1997), the reading has not been too ‘extensive’. More literature has been added throughout the whole research process, but only part of it is described as background literature in the corresponding chapter. Most of the occurring literature within the development of the Grounded Theory of this project is used for further and extensive study of the topic area and in the discussion chapter.

Within Grounded Theory, the search for literature cannot be compared with a systematic literature review in other research approaches. It is less structured and less systematic, meaning that it rather follows the research processes of Grounded Theory than being a single and clearly definable part at the beginning of the project. Also, no thorough analysis or formal critique of the literature has been undertaken prior or alongside the analysis. The same can be said about any other literature that occurs within the whole research process. However, basic critical examination of the literature has always been carried out but is not systematically displayed.

The literature review in Grounded Theory should not interfere with the creative and reflexive research process to an extent that it hinders the emerging theory (Charmaz 2014). However, not only a previous or initial literature review might influence the research process, but also the researcher’s relationship with the research area (McGhee et al. 2007). Therefore, as I am very familiar with aspects of the field of my investigation, constant reflexivity is crucial (Charmaz 2014). Some of the literature added throughout the process helped in the analytical process of the research and could be considered as additional data (see 3.3.4).

3.3.2 Ethical Considerations

As this thesis and research project is part of my doctoral programme at Bournemouth University, the work is subject to strict regulations and review processes of the university. As part of that process, I developed a research protocol (Appendix 4: Research Protocol). A short and adapted version of this protocol served as the study information for participants (Appendix 3: Study Information). Additionally, the ethics committee in Bern, Switzerland, reviewed and approved the study (Appendix 5: Approval of the Ethics Committee). In preparation to submit to the ethics committee in Switzerland, I also had to attend a Good Clinical Practice course at the University of Bern, as Swiss regulations do not accept foreign ethics training such as Bournemouth University's online ethics modules that I successfully completed at the beginning of the project. In summary, there was rigorous preparation for the ethical approval process, which passed without any adjustments needed.

People living with mental illness need to be considered as a potentially highly vulnerable population, not least because of the stigma attached to mental illness (Rüsch et al. 2005). Therefore, it is not only highly important that the researcher maintains the anonymity of participants and that the data collected remain strictly confidential, it is also of great importance how a researcher or interviewer interacts and deals with respondents before, during and after the interview and that he or she is aware of the potential risk of distress (Holloway and Wheeler 2010; Thompson and Chambers 2011). As a clinical nurse specialist (CNS) in mental health nursing I am well aware of these issues and have particular expertise in interviewing and discussion techniques for sensitive issues, as well as in de-escalation management. Confidentiality and anonymity of the data are protected in using English pseudonyms when directly referring to participants. These pseudonyms do not correspond with the real names of the participants in any way. Additionally, details of their stories that are not relevant for the emerging theory have been left out or were changed accordingly.

Focusing on the experiences of people living with mental illness may bring forth issues respondents have forgotten about or suppressed (Thompson and Chambers 2011). Therefore, it is essential to negotiate with the participant before the interview who could be contacted for assistance if needed. Additionally, the researcher's own health and safety issues need to be taken into consideration (Holloway and Wheeler 2010): there is a potential risk of facing unexpected outburst of emotions or relapse in participants that may lead to difficult or, in the worst case, even violent situations. However, as mentioned above, as a trained mental health professional I have been well prepared for such incidents and was able to use my professional and personal skills during the interviews to avoid such situations.

Another important consideration is how to anonymise and securely store the data (WMA 1964 - 2013). Findings that are written up in publications and in the thesis are fully pseudonymised for maximum protection of participants and to fulfil highest standards of confidentiality (Holloway and Wheeler 2010). Therefore, the collected data were coded and pseudonymised from the beginning and securely stored in a password-protected file on my personal computer and on a separate secure external hard drive backup. Any handwritten documents have been stored in a private, key-locked archive. The code list is stored separately from the other data. All data will be permanently deleted after the legally regulated period of retention in Switzerland where the data have been collected (Swiss-Confederation 2011).

Withdrawals from participation in the study prior to publication of the thesis will result in completely anonymising the data after data analysis, meaning that all personal details, the details from the code list and the code itself will be deleted and no direct quotations from participants will be used in the thesis or publications. However, the data that have been collected until withdrawal will still be used for the data analysis and the overall research findings and interpretations.

3.3.3 Recruitment & Sampling

Theoretical sampling is the method used in Grounded Theory. It is crucial to Grounded Theory methodology and distinguishes it from other types of qualitative inquiry (Charmaz 2014). Theoretical sampling means seeking data to refine categories and develop theory. Therefore, it is driven by the emerging theory and not by the need to address initial research questions or population distributions (Cutcliffe 2000; Charmaz 2014). Within theoretical sampling the overall sample size is usually not known or given at the beginning of the research process. Glaser and Strauss (1967) argue that sample size should be decided by the individual researcher based on the emerging theory and the intended depth of the study and its aspired level of theory.

In this study, an initial sampling size of about five interviews was considered sufficient for getting a profound data base for the analytical process. An overall sampling size of up to 30 interviews was considered to reach data saturation through the process of theoretical sampling. Initial sampling in Grounded Theory is meant to get the research started, whereas theoretical sampling guides the direction of study (Charmaz 2014). In this thesis initial sampling and theoretical sampling partially overlapped, whereas theoretical sampling guided the whole analytical process throughout the study as Glaser (1998) suggests (see 3.3.4). However, data saturation was reached much earlier than expected because the interviews provided such extensive and extremely rich data (see 3.3.5.5).

For this study, people living with mental illness were sought. To participate in the study a person must have been aged 18 or over (no gender or ethnicity restrictions) and must have had an initial diagnosis of a mental illness (current or past) that was diagnosed by a psychiatrist. Apart from these minor restrictions the study has been designed to be as inclusive as possible and to include participants with a broad spectrum of mental health conditions. It is not of my primary interest what specific diagnosis they have but how they experience their own situation and life with the illness. However, participants had to be able to speak and understand German fluently and be cognitively capable to engage in and follow a conversation. This excludes people with limited cognitive abilities or persistent delusional disorders or people who are in an acute mental crisis or psychosis. While exclusion criteria were specified for the ethics approval, I personally used my clinical and professional judgement to decide whether it was appropriate or not to conduct an interview. Additionally, only participants who were not hospitalised at the time of recruitment or at the time of the interview have been included. To determine if potential participants fulfilled these criteria they were briefly interviewed about these aspects by telephone prior to enrolment into the study. This process usually took place during the phone call that I made to arrange the first meeting with the potential participant.

The recruitment process has been supported by the Swiss network of freelance mental health nurses in community care (Verein für Ambulante Psychiatrische Pflege – VAPP) and by affiliates of Bern University of Applied Sciences that are offering training programmes for peer-coaches. They acted as gatekeepers who granted access to potential participants (Holloway and Wheeler 2010). These organisations, e.g. the leaders whom I personally know, received a personal letter and were provided with leaflets (Appendix 2: Study Leaflet) about the project that they could distribute to potential participants. I do not know how many leaflets were finally distributed to potential participants but handed out approximately fifty to seventy-five of them. There has also been a snowball sampling effect where participants have told others about the project. Snowball sampling or chain referral sampling is useful with vulnerable populations or when potential participants are not easily accessible (Penrod et al. 2003).

People that heard of the study and were interested to participate could contact the research team by email, letter or phone. The research team was indicated on the leaflet and is composed of me, who was named as the contact person, and the respective representatives of Bournemouth University and Bern University of Applied Sciences. However, not all potential participants did use the contact information on the leaflet to get in touch with the research team. Some simply gave their visiting mental health nurse, from whom they got the information about the study, permission to forward their contact details. After this first contact by participants, they received a personal letter with the detailed study information (Appendix 3: Study Information) and an informed consent form (Appendix 6: Consent Form). The letter indicated an upcoming telephone contact and explained the next steps. The personal contact by phone was made by myself.

3.3.4 Data Collection

The main source of data for this thesis are interviews with people living with mental illness. I have conducted ten face-to-face in-depth, intensive narrative interviews. Charmaz (2014) argues that intensive interviews fit Grounded Theory methods particularly well:

> “Both Grounded Theory methods and intensive interviewing are open-ended yet directed, shaped yet emergent, and paced yet unrestricted. […] Intensive interviewing focuses the topic while providing the interactive space and time to enable the research participant’s views and insights to emerge” (p.85).

Although I developed a rough interview guide (Appendix 1: Interview Guide) to support the interview process, I left the interviews unfold naturally and completely narratively rather than using step-by-step questions or directing the discussion too much. Even the demographic questionnaire that was part of the interview guide I did not apply in a directive way but rather added respective questions in an appropriate context and completed the questionnaire after the interview. All interviews were undertaken by me and were digitally recorded. To maximise participants' comfort and ease they were free to choose their preferred place and location for the interview so long as it was manageable for me to get there and suitable in relation to the digital recording of the interview and privacy or confidentiality issues.

The length and number of interviews with each participant depended on their stories and the experiences they were willing to share. However, my intention was that individual interviews should not last longer than 90 minutes and that no more than one or two interviews would be undertaken with each participant. Ninety minutes was the average length of in-depth face-to-face interviews in a comparative exploration of telephone and face-to-face interviews (Irvine 2011). From my own experience in mental health it is also considered a manageable length of time for both interviewer and interviewee. Participants were informed of the approximate duration of the interview via the study leaflet (Appendix 2: Study Leaflet) and the study information (Appendix 3: Study Information) they received prior the interview.

Follow-up or second interviews, something considered useful in Constructivist Grounded Theory (Charmaz 2014), were not necessary as within the process of theoretical sampling, saturation for theorising could be reached without the need for further clarifications through participants (see 3.3.3). Among other things, this was possible because most interviews were already recorded and transcribed when I began the structured analytical process. Therefore, when I started the analysis of the first interview, the other interviews were already available for comparisons and for specifications or clarifications. I am fully aware that this is not exactly how the process of theoretical sampling and data saturation is described and suggested in Grounded Theory, but how the process actually worked in this study. The ten interviews were so rich in content that they provided sufficient data, also because there was more to them than just the verbatim transcriptions. Additional sources of data were available that can and must be considered within the analytical process and this is fully in line with Grounded Theory methodology (Glaser 1998). First of all, there were my observations and other contextual factors from within the interviews. Some of these I kept in written form as memos and others remained present through repeated listening of the interviews. Additionally, over a long period of time, throughout the whole analytical process, I have been in a state of constant reflection. In that process I had numerous discussions at conferences, in meetings and informally, with colleagues at work, other health-care professionals, and also with people living with mental illness who were not participants of the study. All of these, as well as narratives of people living with mental illness I came across in the literature (Basset and Stickley 2010; Grant et al. 2011; Schulz and Zuaboni 2014), are seen as additional sources of data and knowledge that I have taken into account for constant comparison of the original data and therefore, for theoretical sampling (see 3.3.3).

3.3.5 Data Analysis

Using some of the defining components of Grounded Theory as extended and redefined by Charmaz (2014), the data analysis in this study will be explained in this section. Overall, data analysis has followed the process as outlined by Charmaz (Figure 3.2).

3.3.5.1 Simultaneous involvement in data collection and analysis

The initial steps of data analysis during the interviews contained memo writing and critical reflections on interviews as a whole. That included paying attention to actions and reactions, as well as processes during the interviews in addition to the words that were spoken. However, no significant physical actions or reactions were observed in connection with the interviews apart from occasional eye contact avoidance. More frequent were small emotional reactions, changes in expression or varying modulation of the voice. It could also be called ‘reading between the lines’ of what has been said and reflecting on the context of self, the researcher, and the participant. These reflexive processes, including memo writing, have been continued throughout the whole analysis. However, due to the circumstances, the systematic analytical process did not start right away with the first interview and most interviews did not build upon pre-existing analytical codes and ideas. Therefore, the simultaneity of data collection and analysis could only be partially fulfilled.

3.3.5.2 Constructing analytic codes and categories from data

The construction of analytical codes and categories, from initial coding to focused coding and theoretical coding (Figure 3.2), experienced some delay due to my ongoing methodological training. However, the long duration of the coding process has had the advantage that the original data have been reviewed and compared over and over again and in various constellations. From early on in this process I also worked closely with my external supervisor, who is experienced in Grounded Theory. She analysed a part of the data in parallel with me, whereupon we could compare and discuss codes and categories. We continued that process over several months. In doing so, preconceived hypotheses were recognised and rejected, and categories covered a wide range of empirical observations. However, somewhere between initial, focused and theoretical coding, I ceased using the computer-assisted qualitative data analysis software and instead used a mix of mind-map like sketches and illustrations on paper, printouts from the programme and post-it notes. Also, as mentioned above (see 3.3.4), having been able to talk about the process and its emerging content with several other people over time and reading additional narrative accounts of people living with mental illness and their experiences, helped with the process of constructing codes and categories further. It was part of my constant reflection process and therefore, part of the constant comparison within the analytical process as well.

3.3.5.3 Using constant comparison methods during each stage of the analysis

Constant comparison methods (Glaser and Strauss 1967) are used to compare data with data, such as interviews with interviews or even words with words, but also to compare codes, categories or every other aspect relevant to the data, such as contextual factors. This constant comparison method is part of the constant reflexive approach to the methodology and adds a systematic analytical form to it. Constant comparison has been used throughout the whole analytical process in this study and helped identifying terms, codes and categories that fit the data (see 3.3.5.2). Constant comparison started even before I began the systematic analytical process when comparing the overall content and the impression of each interview. It provided a first glimpse of what each interview might add to the data. The process then continued with comparing the words that were used in initial codes to find more focused codes and so on. As mentioned above, the process of constant comparison during each stage of the analysis was also strongly supported by direct participation of my supervisors. Throughout the whole analysis we held several supervisory meetings in which we discussed aspects of the analytical process and compared the content of the data analysis.

The latter I did even more in depth with my external supervisor, who is also Swiss-German speaking. This certainly helped in analysing and comparing the original data, the spoken word and its transcription. However, because of my multilingual supervisory team, I used English early on in the analytical process (see 3.3.6).

3.3.5.4 Memo-writing

Memo-writing has been used from the beginning of the research process. However, not all stages in the research process are equally documented by written memos. Memo-writing indicates another aspect of constant reflexivity in the research process and is part of all stages of the research process, including the constant comparison and identifying gaps (Charmaz 2014). Memos can be provided in various forms such as free-writing texts, drawing mind-maps, field notes, poems and more. I also used notes taken at conferences when confronted with useful information. However, some memos were not written down, drawn or recorded in any particular form of presentation, but only stored in my thought memory.

3.3.5.5 Sampling aimed toward theory construction

The focus on people’s stories rather than their medical diagnoses or demographical aspects has helped to use sampling aimed toward theory construction. However, as described under 3.3.3 and 3.3.3, with an overlap of initial sampling and theoretical sampling, more interviews without an adapted or specific focus on the emerging theory have been conducted. Therefore, some of the data collected did not fulfil the criteria for theoretical sampling and were only used partially. Nevertheless, this also proves that the interviews conducted provided sufficient information to reach data saturation and were sufficient for theory construction. Even when considering the additional data from written accounts of people living with mental illness (see 3.3.3), no new or different insights were gained for theory construction.

3.3.5.6 Search for variation in the studied categories or process

The search for variations in the categories has been used to broaden and extend the understanding of the topic. Even opposing variations could be discovered but were needed for further refinements and in the process of theory construction. It is difficult to clearly outline this step of the analytical process. However, it might be best understood when referring to the discussions held with my supervisory team and others challenging and questioning emerging themes and categories in the process of theory construction. This process led to a conscious and well-reflected choice of words, concepts and categories.

3.3.5.7 Developing categories and emphasise theory construction

Seeking to develop new and unique categories instead of covering already known empirical topics and knowledge has been challenging due to my extensive background in clinical nursing practice in the field of mental health nursing. It is only by constantly challenging my own judgements or the use of preconceived terms that I could discover new categories. The same can be said about theory construction, where many existing concepts and theories came to mind and needed to be discarded in favour of developing theory out of the data from this study rather than out of existing concepts. However, it was also of great importance to reflect and critically discuss each stage of the analytical process with my supervisors who do not all come from a nursing background and of whom only one has a mental health background. Towards the end of the analysis we held a long workshop to critically compare the theory I had outlined and generated with the available data.

3.3.6 Language as an Issue

The use of language, in particular when to translate non-English data or findings into English, is a topic that cannot be addressed easily or clearly. Language differences in qualitative research and the potential of losing meaning when translation is involved is an important methodological issue (Esposito 2001; Smith et al. 2008; Squires 2009; van Nes et al. 2010). However, whereas van Nes et al. (2010) recommend staying in the original language as long and as much as possible, Smith et al. (2008) acknowledge various procedures and point out the advantage of having the coding system in English to be able to discuss it within a whole team.

Within this project most of the interviews were held and recorded in Swiss German, a language with a vast number of different dialects that is spoken only and not officially used in a written form. Therefore, the first translation issue arose at an early stage of the process when transcribing the interviews. However, as both the person who translated the interviews from Swiss German to high

German and I are native Swiss German speakers, we have considerable experience in translating Swiss German into High German as it is the first language taught and learnt at school. High German, as regular German is called in Switzerland, is also the official written language in the German speaking part of the country. Therefore, the translation of Swiss German into High German, if done by native Swiss German speakers, is unlikely to lose the original meaning. Additionally, all the transcripts that were translated by an external person were double-checked by me and the recordings were used throughout the whole analytical process to remain as close to the original data as possible.

However, for the analytical process, various options of language use were discussed and tried out. Asked about when to start using English in the process of Grounded Theory research, Breuer (2016) hesitated to give definitive advice. Concerning the use of the data he suggested to use the original language throughout the analytical process and translate everything at the end. However, he admitted that this might not always be the best way to do it and, in relation to resources, is probably the most demanding. Therefore, some initial coding was conducted in German and other coding in English. Some memo-writing was in German, other memo-writing in English. The process closest to the original data seemed to profit from the use of German, whereas during the continuing comparative analysis, English became more suitable to use. Tarozzi (2011), who translated "The Discovery of Grounded Theory" into Italian argues that English is a conceptualising language with propositional power and…

> "…therefore, it [English] seems more suitable for making propositional statements, binding concepts, expressing complex and tricky categories with synthetic nomenclature. Because of this, I prefer English for more advanced coding, where it is necessary to label concepts. […] The more the analysis proceeds into selective and theoretical coding, the more English becomes appropriate for sorting and conceptualisation" (p.171).

This has been my own experience in this study and therefore, English was used at an early stage of the analytical process. Additionally, the use of English made the comparison with existing published theories more accessible because these theories are often published in English. It also facilitated the writing process of the thesis and the discussion of the results within the supervisory team. The latter was especially important as I had no other regular and binding opportunities to discuss the data with others.

3.3.7 Ensuring Credibility and Validity

There is a need to differentiate between good and poor research in all scientific areas (Brink 1993). However, in qualitative research, ensuring credibility and validity is a controversial issue that lacks consensus (Morse et al. 2002; Sandelowski and Barroso 2002; Rolfe 2006). Rolfe (2006) argues that “the quality of the research cannot be assured by the rigorous application of a set of previously agreed strategies and procedures” (p.308) and should rather be judged by the reader than the writer, or the consumers of the research rather than the researchers themselves. Porter (2007) defends the need for quality measurement within qualitative research and argues, that rather than constructing a set of criteria for all qualitative methodologies, “it is possible to judge the methodological approaches themselves” (p.85). I personally agree with both stances, but still chose to follow a set of criteria to ensure credibility and validity of this research.

Frameworks for ensuring trustworthiness and rigour of qualitative research have been in existence for many years (Shenton 2004). However, validity and reliability are terms and concepts that are often avoided by qualitative researchers because they cannot be addressed in the same way as in quantitative research (Brink 1993; Shenton 2004). Therefore, the criteria for trustworthiness in qualitative research by Guba (1981) are in preference to the ones used in quantitative research (Shenton 2004): credibility is used in preference to internal validity, transferability in preference to external validity and generalisability, dependability in preference to reliability and confirmability in preference to objectivity. These constructs have been widely accepted in qualitative research.

However, some scientists have designed their own criteria, in partial adaptation of existing ones, to verify and justify their research approach. Charmaz (2014) argues, that within Grounded Theory methodology the criteria credibility, originality, resonance and usefulness should be met: Credibility is given when the methodology was applied correctly and congruently. Originality can be achieved by an analysis that offers new insights and a theory that extends or refines current ideas, concepts and practices. Resonance can be sought through categories that portray the fullness of the studied experiences or if the developed Grounded Theory makes sense to participants or people who share their circumstances. “A strong combination of originality and credibility increases resonance, usefulness, and the subsequent value of the contribution" (Charmaz 2014, p.338). I decided to apply the criteria of Charmaz (2017) to this project. Therefore, in the following subsections I describe how these criteria were met within this research project.

3.3.7.1 Credibility and Trustworthiness

The methodology has been followed rigorously as it is described in this chapter (see 3.3.1 *ff)*. However, auditability cannot be easily outlined within this long-lasting process due to the application of different working methods; for example, not using the computer-assisted qualitative data analysis software throughout, and various documentation techniques in the project. St John & Johnson (2000) argue that researchers should be critical when choosing software for qualitative data analysis and "consider its effects on their research" (p.397). For me Atlas.ti became more of a limitation in the process of data analysis than an advantage or supportive tool and therefore, I had to move on without it (see 3.3.5.2).

Nevertheless, as an expert in the field of mental health care, I am very familiar with the setting and spent a long time in data collection and analysis for this study. Therefore, there has been an intense engagement and constant reflexivity with the phenomena and the topic area that was not limited to data collection and analysis only. The process included comprehensive expert consultations with the supervisory team, sometimes in the form of a clear peer review process (Holloway and Wheeler 2010), and various health professionals in my extended working and study environment. Some of these consultations were actively sought through own conference presentations or participation in workshops, lectures and other professional platforms. Other consultations and discussions, not of lesser value, included people with lived experiences in mental health. For example, early in the process of the research project, in a workshop held at a recovery conference where initial thoughts and ideas of the study were presented and discussed, a service user questioned the representativeness of the study because of its sample. The service user's feedback led to an in-depth examination of possibly missing content and a higher sensitivity in the process of theoretical sampling. These kind of encounters served as a form of member checking (Guba 1981).

Talking to people living with mental illness and/or lived experiences has been an ongoing part of this research. Sometimes, when mentioning my research project, I received feedback from people who then opened up about their own struggles with mental health or who started talking about experiences of close relatives. Feedback of all kind is seen as a valuable contribution to the development of new knowledge, self-reflection and personal growth. It has been continuously incorporated and integrated into the research process and served not only for validation purposes but also to question the interpretation of data. Furthermore, findings were critically reflected within a wide range of literature. Existing theories and philosophies were taken into considerations as well as prose and narratives. All this is expressed in the following chapters by thick data description, a differentiated discussion of the findings, comprehensive conclusions and meaningful implications for practice.

3.3.7.2 Originality, Resonance and Usefulness

The theory developed in this study is original for several reasons: It has been established through original data of people living with mental illness and it is not based on existing theories. Therefore, categories are new and unique and offer new insights. Additionally, the terminology used for the theory is thoroughly explained and helps differentiating and refining of existing ideas and concepts. However, as data are about experiences of people living with mental illness, existing concepts such as adaptation to illness and personal recovery show similarities.

The extent of resonance and usefulness cannot be conclusively appraised at this time, e.g. before publication and presentation of final results among corresponding audiences and target groups. However, considering the multifaceted discussions with experts and service users over the whole course of this research project, it is likely that the study finds resonance and will be considered useful by practitioners as well as service users. Intermediate results, which were presented and discussed on various occasions, showed high agreement among professionals. Nonetheless, to prove resonance and usefulness, judgement of professionals and people living with mental illness is required and will be actively sought. Many people in my own personal and professional environment are waiting for it.

3.3.7.3 Focusing on Participants

Participants of the study were informed about the approximate schedule of the project. However, as the initial schedule was delayed due to various circumstances, participants were occasionally informed about these delays. To do so, I sent participants personalised seasonal greetings cards with original photography. The cards were well received, and most participants even responded to them. With some of the participants there have been additional informal encounters at conferences and events, all in a friendly and informal manner. These encounters, together with ongoing, often informal, feedback from participants about the progress of the study, encouraged me to keep my focus clearly on the participants' views and perspectives.

3.4 Preliminary Study

At the outset of the main study a preliminary study among health-care professionals was carried out. The study focused on the concept of uncertainty in illness among people living with mental illness. An initial review of the literature around the concept of uncertainty in illness (see Section 2.4) did not provide sufficient information of the concept in relation to people living with mental illness. Therefore, a small qualitative study comprising a focus group with mental health nurses was conducted. The findings of the preliminary study are summarised in chapter two as part of the background of the main study (see 2.5).

3.4.1 Setting

The preliminary study was carried out as a workshop within the setting of an international mental health nursing conference held in Istanbul, Turkey. The conference was organised by a local committee under the auspices of the Horatio – European Psychiatric Nurses organisation. The conference enabled to reach out to a broad group of mental health nurses, potentially representing different backgrounds, countries and settings.

3.4.2 Ethical Consideration

The use of a conference setting to collect data was discussed and agreed with my supervisors. Permission to conduct the study was granted by the scientific committee of the conference. The abstract submitted to the conference clearly emphasised the use of a workshop for data collection. Neither members of the scientific committee nor any of the participants of this preliminary study had any previous affiliation with the project.

3.4.3 Sample

Psychiatric and mental health nurses were chosen as participants. They are usually the ones who are seeing and interacting with patients 24 hours a day. In hospital settings, and even when they are working in outpatient or home treatment services, they are often the first ones who have to deal with crises and issues that their patients encounter. As the workshop was held at a nursing conference and was open to registered attendees of the conference only, the only criteria participants had to fulfil were voluntary attendance and participation in a focus group discussion and being able to speak and understand English. Participants did not have to sign up for the workshop in advance and therefore, the number of participants remained unknown until it started.

Eleven conference attendees participated in the workshop, representing six different European countries, eight were female and three were male. Most participants were nurses/mental health nurses or were otherwise affiliated with mental health care. All participants had university level education. The nurses had spent a median of 21 years (with a range of 6 – 32 years) in health care and were currently working in nursing management (n=2), nursing education (n=3), nursing practice (n=2) and nursing research (n=1).

3.4.4 Data Collection

The workshop was carried out as a focus group and lasted 90 minutes. Focus groups serve to explore participants' expertise, their knowledge, understanding and experiences about a predefined and limited topic (Kitzinger 1995; Robinson 1999). Additionally, the focus group method seems ideal to examine not only what the participants think but also how and why they think that way (Kitzinger 1995). Van Teijlingen and Pitchforth (2006) argue that the dynamic interactions within a focus group and the constant negotiation of meanings are key to the data gathered and distinguishes focus groups from other group methods.

Prior to the start of the group discussion, participants received an information sheet and consent form as well as a demographic questionnaire with some topic specific questions at the beginning of the workshop. Participants were also informed verbally about me, my intentions and the planned content of the focus group discussion. There was time for questions about the project including its methodology. The focus group discussion was led by me and was supported by a senior mental health nurse researcher who also participated in the discussion. A group discussion guide was used to remain focussed on the topic. The discussion was digitally recorded, transcribed and analysed using qualitative thematic analysis (Braun and Clarke 2006).

3.4.5 Data Analysis

Qualitative thematic analysis (Braun and Clarke 2006) involves several phases of the analysis that all have been performed in this preliminary study: In transcribing the data, mainly through paraphrasing, I familiarised myself anew with the data and noted down initial ideas (phase 1). Generating initial codes (phase 2) from what appeared to be most relevant to the analyst and searching for themes (phase 3) in analysing the initial codes, led to a variety of potential themes or outcomes. Those were reviewed (phase 4) with the initial ideas and codes and then defined and named as main themes (phase 5). The final stage of the analytical process, producing a study report (phase 6), helped relating back to the aim of the study and the literature. Vaismoradi et al. (2013) argue that thematic analysis provides researchers with a clear and user-friendly method for analysing qualitative data due to transparent structures and defined analytical stages.

3.4.6 Ensuring Credibility and Validity

To ensure credibility of the study, the findings were repeatedly discussed with experts in the field of mental health and psychiatric nursing and with service users. These discussions were held at two conferences following the initial focus group, where I presented the findings of the thematic analysis. Rolfe (2006) argues that there cannot be an overarching set of criteria by which one judges the validity of qualitative research but that individual judgments of individual studies should be favoured. The chosen validation process of discussing the results with experts and service users seems appropriate for this kind of preliminary study and supported the findings (see 2.5).

In addition to this validation process, the results of this preliminary study have been submitted to a peer reviewed journal (Wolfensberger et al. 2019 accepted for publication) and therefore, the study had to go through a review process that adds to its credibility and relevance.

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4 FINDINGS

Matterhorn, Zermatt, Switzerland 2014

4.1 Chapter Introduction

The photo of the Matterhorn in Zermatt illustrates all there is that it takes to achieve a doctoral degree: A beautiful mountain that seems far too high and steep and too magnificent that it could be climbed all the way up to its peak. And still, it has been done by many and many times. It takes endurance, courage, decision making, the right equipment and guidance. And at the top of the mountain, if the weather is clear, one can see more and wider than it could have been imagined before. It is the moment of identifying the findings, or in case of this study, the emerging theory. Therefore, up there on the mountain top, the main goal is reached but the journey is not at the end. There is a descent that needs to be mastered as well. The descent could be seen in the chapters following the findings; the discussion, the conclusions and the recommendations. Only the whole journey makes the experience, and the thesis, complete. However, what can be expected from the view at the top of the mountain, from the findings?

In this chapter the results of the long-lasting analytical process based on the constructivist and reflexive Grounded Theory approaches used in the main study of this PhD research project are outlined. This includes a detailed description of the emerging theory, the Creating Meaning Theory. The theory is presented as a theoretical model with three categories that describe the process of adaptation to life in living with mental illness.

The findings from the preliminary study are reported in the background chapter (see Section 2.5).

4.2 Background to the Data Collected

The main source of data for the principal investigation of this study were the participant interviews. The interviews provide the foundations for the analytical process. Along with focusing on transcriptions and memos, I repeatedly listened to the whole interviews throughout the analytical process to ensure that contextual factors such as voice modulations, emotional tone, the ‘reading between the lines’ were included in the analysis (see Section 3.3).

4.2.1 The Participants

Ten participants, six women and four men, have been interviewed for this study. Their stories are very personal and contain specific details and highly sensitive information. Therefore, in addition to the use of pseudonyms (see 3.3.2), extra measures were taken to further assure anonymity. These include changing certain contextual details related to people, places or events that are not relevant for the findings of this study. However, their stories remain real, some things have been left out, but no fictional content is added. All participants are currently living in Switzerland and have had at least one diagnosis of mental illness. Some participants had received several psychiatric diagnoses over their lifespan and not all of them could recall exactly when they were first diagnosed with a mental illness. Therefore, some information listed in Table 4.1 is based on estimates. The diagnoses listed are the ones participants mentioned first when asked about them.

All participants had been living with mental illness for several years. The one with briefest experience of living with a mental illness spoke about seven years whereas the one with the longest history of illness is looking back at 43 years! Interestingly, more than half of the participants had lived with mental illness for the majority of their lifetime. However, that seems to correlate with the age group of the participants ranging from 33 to 68 years with a median age of 44 years.

Most participants had experienced hospitalisation in a psychiatric institution, many more than once or on multiple occasions. All currently were still receiving some form of treatment for their mental illness. These forms of treatment and support included taking illness-related medications (such as anti-psychotics or anti-depressants), attending psychotherapy or other professional psychological sessions, visits from mental health nurses, using occupational or other specialised therapies, as well as participating in self-help groups or contributing to peer support networks. Often, participants described using a combination of several of these approaches in addition to countless personal strategies of self-care.

Table 4.1: Participants Demographics and Characteristics

Characteristics (self-declared)	**No. of Participants (n=10)**
Sex	
Female	6
Male	4
Age	
Median	44
Range	33 - 68
Ethnicity	
White European	10
Work, Income and Benefits (combinations are possible)	
Working	5
Basic income through work (part time or full time)	3
Disability insurance (full or partial pension)	7
Retirement pension	1
Jobseeker's allowance	1
Family Situation	
Married	4
Living in a committed relationship (not married)	3
Divorced or separated	1
Single	2
Have children	4
First Diagnosis of Mental Illness	
Age: < 18	4
Age: 18 - 25	1
Age: > 25	5
Living with Mental Illness (in years)	
Median	21
Range	7 - 43
Primary Mental Illness	
Borderline personality disorder	2
Depression	1
Bipolar disorder	3
Schizophrenia	3
Anxiety disorder	1

4.2.2 The Interviews

All participants were interviewed once but all gave permission to be contacted for additional information or feedback if needed. The ten initial interviews were conducted between October 2014 and May 2015. Four interviews lasted between one hour and one and a quarter hour. Four interviews were approximately one and a half hours long. One interview took one hour and forty-five minutes and the longest was over two hours. The duration of the interviews depended primarily on what the participants were willing to talk about and share. Only one interview was limited timewise as it was held in a consultation room that had to be vacated after one and a half hours. The participant of that particular interview, a repeatedly traumatised person, asked for a neutral interview space, so that it did not have any association with her private or illness-related experiences. Therefore, the office chosen was located in a different city from where she comes from. However, most participants felt that their private homes would be the most suitable and comfortable place to be interviewed. Therefore, seven out of ten interviews were held in participants' homes. For two participants it was more convenient to come to my office for different reasons: one participant felt that having young children at home would lead to interruptions and the other was working nearby and could incorporate the interview within her working day.

All interviews took place in a friendly and informal atmosphere on a one-to-one level between the participant and me. Participants' openness and willingness to share intimate details of their lives was striking. One participant summed it up at the end of her interview: *"You know, that was a very lovely conversation, and I even told you things I haven't told my therapist…"* (Louise). In Switzerland, even in health-care settings, it is unusual for people to be so open and disclose intimate details of their lives. It might have helped that no other people were around or in the same room during the interviews and that there were no pre-existing professional or other relational connections between me and the participants. These circumstances certainly provided an open space to talk about everything participants were willing to share.

4.3 Synopsis of the Emerging Grounded Theory

The ten extensive narrative interviews provided a vast amount of rich data. They covered topics such as self-management techniques and strategies for living, ways to fight discrimination and stigma, and much more. Participants revealed profound reflections on life, self and illness with rich examples of how mental illness was discovered, what symptoms had been experienced, what effects the illness has had on their lives, how they coped with it and what brought them to the point in life where they are now. Based on the detailed and rigorous data analysis the following theory finally emerged.

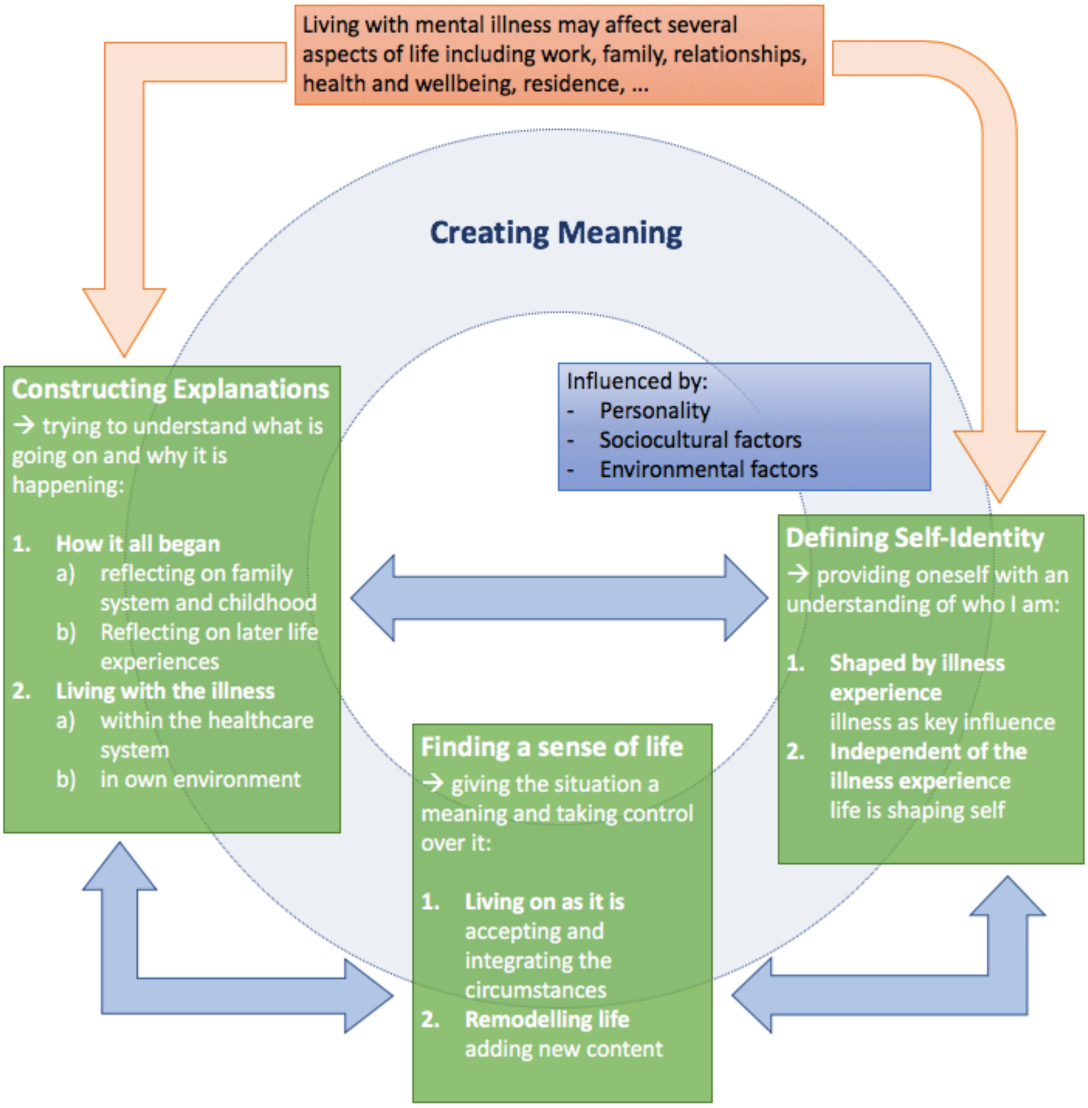


Figure 4.1: The Creating Meaning Theory of Experiences of Mental Illness

Living with mental illness means different things for different people. However, there is a common understanding that it affects the lives of these people in one way or the other. The Creating Meaning Theory (see Figure 4.1), generated by me out of the data, provides a framework to understand the process of adaptation to life in living with a mental illness. It is a theoretical model of the key processes in the lives of the studied population. These key processes are described as:

a) Trying to understand what is going on and why it is happening
b) Providing oneself with an understanding of who I am
c) Giving the situation a meaning and taking control over it

At the beginning of the analytical process individual life stories and participants' unique experiences and coping strategies were at the centre of my focus. However, gaining more insights through the analytical process (see Section 3.3.5), the key processes in participants' lives became more evident. They build the three categories within the Creating Meaning Theory (CMT).

In connection with the development of the three categories, the comprehensive theme of the theory also emerged. Creating meaning is the superordinate process and main theme of the theory that includes the three categories. It is seen as an active process by the person living with mental illness, even though it might not always be consciously experienced as such. Creating meaning is not a linear but rather a circular process without clear or constant sequence or structure (see Figure 4.1).

The model of the CMT contains the core process and main theme 'creating meaning' and three categories, derived from the three key processes. The three categories are focusing on:

a) Circumstances and the human urge to understand – this category is called 'constructing explanations',
b) self-concept and identity – this category is called 'defining self-identity', and
c) purpose and a meaning of life – this category is called 'finding a sense-of-life'.

All of these categories are interrelated. Each category builds on a wide range of experiences, actions and feelings of the participants and shows a broad spectrum of possibilities on a continuum. For example, within the category of defining self-identity, everything from not accepting self and railing against one's fate to fully embracing self with all experienced limitations can be found.

4.4 The Main Theme: Creating Meaning

Creating meaning is the main theme and core process that emerged from the data of this study. It combines creation and meaning into a new and unique understanding and builds the framework of the developed theory of this study. Creating meaning describes a process of actively dealing with fundamental questions about oneself and identity in circumstances of mental impairment or illness that can make it difficult and challenging to find a positive and meaningful sense-of-life.

Creating meaning demands action because it does not just accidentally happen. Therefore, there is a clear emphasis on actively doing something. Creation itself is an active and creative process of building or constructing something new. This new or renewed meaning could be applied to different aspects of life or life as a whole in the sense of meaning of life. Therefore, creating meaning covers all aspects of life including the big human question of the meaning of life. The process is creative, even when the person involved would not consider it that way or does not (always) realise it. This means, that the creational aspect of the concept can be implicit or explicit.

The process of creating meaning as it is described in this study according to the conceptual model of the Creating Meaning Theory (CMT) might not be something that is experienced by people living with mental illness only but other socially marginalised populations as well. Creating meaning could even be seen as a common and ongoing process in anybody's life. However, the CMT model stems solely from data of people living with mental illness. The participants of this study and, in my experience, most people living with mental illness experience a lot of difficulties in several aspects of their lives and these difficulties and challenges are quite unique. Often, relationships, work, hobbies and even physical health are affected by mental illness and therefore, creating meaning becomes compelling for people living with mental illness. For some participants in this study the problems and their effects were almost unbearable, for others they were less dramatic but still life changing. However, life changing does not mean that all aspects of life have to be visibly changing, but that the understanding of life or the point of view of things and the personal perspective is changing.

Interview data show that among those aspects of changing personal perspectives and experiences of people living with mental illness are stigmatisation, side-effects of psychotropic drugs, difficult illness symptoms, increased physical and emotional vulnerability, illness-related difficulties in the capability of work or in keeping up a social life with family and friends or building new relationships. The list is not exhaustive. Therefore, people living with mental illness are likely to be confronted with fundamental questions of life such as:

a) what is happening to me and why?
b) who am I – what have I become?
c) what can I expect from life – what does it hold in store for me?

All three questions lead to a process of creating meaning, as it is explained in this study and each one indicates one of the key processes and categories of the CMT (see Table 4.2). However, even though all three questions can be asked separately, they are as interconnected as the processes and categories of the CMT.

Creating meaning is a unique way of describing the adaptation process to illness, or even more specifically, the process of reclaiming life. Therefore, it can be compared with other models of adaptation to illness or personal recovery in mental health. This will be discussed in depth in the discussion chapter of this thesis.

Table 4.2: Relations between fundamental questions of life and creating meaning

Fundamental Question	**Key Process** (Action)	**Motivation**	**Category**	**Creating Meaning**
What is happening to me and why?	Trying to understand what is going on and why it is happening	Understanding	Constructing Explanations	
Who am I – what have I become?	Providing oneself with an understanding of who I am	Identity	Defining Self-Identity	
What can I expect from life – what does it hold in store for me?	Giving the situation a meaning and taking control over it	Meaning	Finding a Sense-of-Life	

For a better understanding of the core process or main theme it is necessary to focus on the different categories of the CMT. The three categories (see Figure 4.1) are an inseparable part of the whole model and contain its actual content, the key processes of the CMT (see Table 4.2). However, the three categories, respectively the key processes are subordinated to creating meaning, the core process of the CMT.

4.5 The Three Categories

The three categories, constructing explanations, defining self-identity and finding a sense-of-life describe the main motives and key processes of the Creating Meaning Theory (see Table 4.2). All categories are strongly interrelated (see Figure 4.1) and often, the data that lead to these categories are not clearly or exclusively assignable to one category. This is due to the fact that human wholeness, according to my own understanding of the simultaneity paradigm in nursing (see Section 1.7), cannot be easily separated into categories or into isolated concepts as everything is connected and many things happen simultaneously. This is also true for spoken words as they can contain more than one meaning, not only to the listener, but also to the person who is saying them.

Additionally, within the interviews that were conducted to collect the data, there were not only words and sentences, but also feelings and emotions, messages 'between the lines' and unspoken content that had to be considered. It is an advantage of a Grounded Theory approach to take all of that into account. Therefore, within the analytical process the concepts of the categories became clearer. The three categories are:

- Constructing explanations
- Defining self-identity
- Finding a sense-of-life

Participants richly described all kinds of aspects of their lives, from childhood experiences to family ties, from broken hearts to broken legs and provided holistic insights into their personalities and lives, as well as their experiences of living with mental illness. The three categories cover much of their stories but not everything. However, they are the essence of the emergent Grounded Theory, the Creating Meaning Theory (CMT). The next section outlines the first one of these three categories.

4.5.1 Constructing Explanations

Constructing explanations is the category that relates to the human need to understand what is going on and why things are happening. Therefore, the motivation behind this category is understanding (see Table 4.2). It covers the perception that all participants construct their own explanations around their illness and try to make sense of their experiences. 'I want to understand' or even 'I have to understand' is something often heard from those living with a mental illness and even when they say 'I don't understand it' they might indicate their longing to understand. However, there is also the explicit or internalised stance of 'there is nothing to understand'. Therefore, the spectrum or continuum within this category ranges from denying that there are influencing factors of mental health and mental illness to actively attributing a specific life situation to an influencing factor or constructing a factor out of the experiences. Denying influencing factors does not mean that these people do not construct explanations. Denial can be a very creative and active process and therefore, it is simply a different form of constructing explanations and creating meaning.

However, between these different poles lies an array of variations that are also influenced by knowledge and consciousness (see Table 4.3).

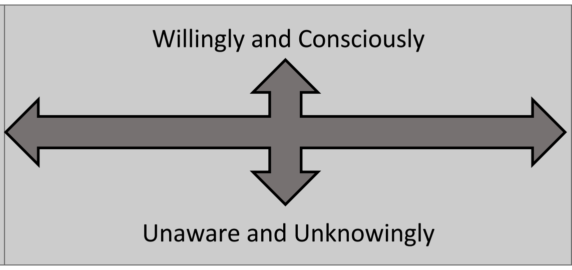
Knowledge refers to how much a person knows about influencing factors of health and illness and how they might be interrelated. Additionally, personal experiences in life probably have shaped that knowledge. For example, someone, who has experienced his or her family as a safe haven, will more likely construct an explanation for their illness that is not related to the family.

> *"I really had caring and loving parents […] but we were treated like foreigners and intruders in our village, which very much hurt me."* (Nancy)

The person from this quote is very conscious about everything going on around her. She sees herself as a highly sensitive person from early on in her life and therefore, it is life events like the one she mentions in this quote that she constructs her illness explanations from.

On the other side of the spectrum might be someone who does not want to reflect on such issues because they might be too hurtful or simply because the person is not aware of them. Here we have the aspect of willingly avoiding versus not knowing or seeing aspects that might have influenced one's health and illness.

Table 4.3: Continuum and Dimensions of Constructing Explanations

<table>
<tr><td colspan="3">Influencing Factors of Mental Health: Life events and biographical aspects including a person's individual characteristics and behaviours, sociocultural and environmental aspects (determinants of health).</td></tr>
<tr><td>Denying, avoiding or not perceiving influencing factors</td><td>
</td><td>Defining of or attributing influencing factors</td></tr>
<tr><td colspan="3">Determinants of Understanding and Making Sense: What is known about the influencing factors and their interrelatedness and how past experiences have shaped this knowledge. How open someone is to new insights (which in itself depends on a person's state of mind/mental health).</td></tr>
</table>

However, the category of constructing explanations stems from hearing most of the participants reflecting on their lives and experiences in a profound way. Participants seemed used to reflecting on aspects of their lives and were skilled in doing so. Many must have told others about aspects of their experiences many times over the course of their illness. This is certainly the case within the Swiss health-care system where patients usually have to tell their stories anew each time they see a different physician, psychiatrist or their place of treatment changes. Also, this aspect of having to repeat details of one's personal life over and over again, could be one of the reasons why sometimes, parts of participants' stories sound like plain, almost detached narration rather than reflections. For example, Graham, at one point of the interview, mentions his siblings by simply saying *"I have a brother and a sister, I am the middle one"*, which is a fairly trivial statement that sounds narrowly descriptive and as if he were asked about his family situation in a clinical assessment. However, later he mentions that "*I've always been sort of the animator of my family, building bridges between my siblings, myself and my parents…"* (Graham), which shows his understanding and reflection of his role in the family rather than just being the second born. He then continues with a more detailed description of what that meant to be the 'animator' of the family and how it shaped his life; he constructs explanations.

In all the interviews both kinds of narratives, some that sound almost superficial and other more truly in-depth accounts, can be found. However, comparing statements within interviews and across the whole sample, even facile statements often reveal a more profound meaning and underlying reflection than the statement itself would first suggest. Therefore, even though not all of the participants would say that they are looking for answers and explanations, when talking about their experiences and how they talk about it, they add their own interpretations and construct their own explanations. Even a statement like 'this has nothing to do with it' actually helps to understand how someone constructs an explanation, in this case denying or negating a relationship between events for whatever reason. However, the common motive is, explicit or not, an underlying human urge to understand of what is happening, why it happens and what it has to do with oneself. The people who participated in this study were willing to share their stories and it seems, that they all had previously reflected on their experiences in one way or another.

Looking at the rich data relating to the category of constructing explanations, it is useful to divide this category into two sub-categories which will further explain what it means to construct explanations:

a) Constructing explanations around how it all began or the cause of illness
b) Constructing explanations around living with and experiencing illness

Both sub-categories are described by examples of the participants of this study in the following sections.

4.5.1.1 Constructing explanations around how it all began

Constructing explanations around how it all began is mostly about people's reflections on the cause of illness and therefore, focusing on the past including childhood experiences, family systems, and everything that is potentially related to the development of the mental illness.

Early in the interviews for this study, I normally asked when and how participants recall first experiencing mental illness. Most mention a first episode of psychotic symptoms, severe depression, panic attacks or something else strongly related to their diagnosed mental illness. However, at the same time, they often say that it actually began much earlier and talk about experiences from times predating their diagnosis and even before the start of their symptoms. This indicates that participants construct their own explanations of how mental illness developed in their lives in reflecting on past experiences and life events. It seems that the fact that a mental illness occurred leads to more profound reflections of the past than another illness probably would, because of its impact on several functional levels in life. Some of the participants might have learnt to reflect on the past through psychotherapeutic interventions, however, none of them specifically recall such influences on their process of constructing explanations. Therefore, constructing explanations around how it all began is a deeply personal process of reflection that includes all the aspects a person considers relevant or is aware of.

Reflecting on family systems and childhood experiences

Most participants consider their childhood and teenage years, growing up in a unique family system, as highly relevant in their stories of their lives and therefore, inseparable from the development of the illness. However, family systems are a complex area when trying to make sense of what is happening to someone who has developed a mental illness. Some of the participants hold their childhood experiences exclusively responsible for their mental illness whereas for others it is just one aspect among others. However, even when participants explain the development of their mental illness through their childhood experiences, it is never attributed to a single cause or event only, not even when severe trauma is involved.

A story with multiple traumas is told by Louise. She describes several layers of family structures that she considers influential on her personal development. Her story includes an absent father and a stepfather who sexually abused her, a mother who did not care and only wanted another baby with her new partner, a much younger half-sibling she did not get along with and grandparents, who played an important role in her upbringing. She recalls that her problems started with experiencing the loss of her grandparents:

> *"It all started when my grandparents, who were looking after me, passed away when I was 7 respectively 8 years old. My grandpa, who was very religious, had cancer and denied treatment, so basically, he didn't die but decayed, it was a terrible experience for me…"* (Louise)

Louise is looking back at all the different relationships in her childhood that had an impact on her. And even though the sexual abuse by her stepfather stands out to the listener of her story, she does not judge this traumatic experience as the ultimate or only cause of her illness. The experience of seeing her grandfather slowly die and other aspects of her childhood left a lasting impression in her life as well. Therefore, Louise is a good example of how participants in this study are taking various aspects of their lives into consideration when constructing their explanations.

Sometimes those explanations contain explicit accusations. And sometimes the allegations are clearly directed at family members:

> *"…there were these subtle and tacit expectations of my parents, especially my mother, that I have to succeed as much as my siblings did, which created a lot of uncertainty and pressure on me […] it was a battle zone: winning or losing".* (Irene)

For Irene it is clear that the constant pressure she felt, led to her emotional struggles that later became a mental illness. However, she also states, that she cannot blame anyone but herself for the internalisation of that pressure and also reflects on the broader context of her situation in childhood.

Similar in some ways and yet different in others is the story of Katie, who was born and raised in a very religious and evangelical family in a rural area of Switzerland. Her parents would not allow her to go to high school because they did not approve of her, as a girl, being away from home. Also, she always had to be a good and humble person, a role-model of a young girl, as her parents were hosting evangelisation meetings at home and presented her as the perfect child. So, she always did what was asked of her. She voluntarily entered religious training and became involved in missionary work abroad, where she soon became the leader of a big project. Katie says that she very much liked her work. However, reflecting on those years between childhood and adulthood she recalls:

> *"Until I was 26 I have been functioning well in life, I had a [demanding and fulfilling…] job, but in fact, I wasn't really functioning, I already had suicidal thoughts when I was in school…"* (Katie)

Within one sentence, that starts with a positive affirmation of what she had experienced, she erases the positivity of it with a memory that relates to ongoing struggles over all those years. All the experiences build up to what Katie calls her own *"9/11"*, her first major episode of depression. From her current perspective, her childhood and her young adult life as a deeply religious person are part of the explanation why everything happened as it did in her life. However, in contrast to Irene, who holds her parents directly responsible, Katie harbours no ill feelings towards her parents and makes no direct accusations. She still shows humbleness and avoids making judgments.

Francis reckons that the starting point of his own illness trajectory was the moment in his teenage years when he witnessed how his much older sister being admitted to a psychiatric hospital. The day his sister came back from the hospital she was not even able to undress herself and therefore, Francis helped her doing that. Having difficulties in coming to terms with what had happened to his sister and how his parents had responded to all this, Francis was sent to a residential school where he soon started displaying behavioural problems. Looking back at these years, Francis recalls that he did not really know what his sister had, but that he just could not accept the way she was treated. His parents' response felt inappropriate and humiliating. Francis describes his father as *"outstandingly intelligent"* but his mother as *"pretty much the opposite"*. He uses these past experiences and appraisals to explain his own further development in life. He says that it had been the beginning of his artistic and rebellious side. Even though he was struggling in school and testing the boundaries, he did not develop a mental illness until much later in his life. Actually, to a certain extent, he even did what his parents expected from him and took over his father's business one day. However, he was not happy with these conventions but still went on with some of them for quite a while. Listening to Francis's story it becomes clear how much he was longing to become the artist he is today.

> *"If I were to write my biography, no one would be interested in that, but to me, it would be important to see how it always went into the direction of becoming an artist. But obviously, until, …I would say, the artist was definitely born 2007."* (Francis)

Later on, on that journey there were also the downsides of his existence with attempted suicides and episodes of deep despair. Reflecting on all the different aspects along the way, Francis was able to find his own explanations for almost everything that happened so far in his life, but his family still plays an important role in all of that.

Some participants do not consider their family system as highly relevant to their development of mental illness. However, they do recall other experiences from their early years, from childhood to adolescence, that had an impact on their lives or that they see as explanations for developing a mental illness.

Nancy, who describes her family as warm and loving, has been struggling with the environment of the village they lived in when she grew up. It was a small rural community where people seemed to be very conservative and hostile. She recalls that this made her sick and ill. Her whole family had been bullied, and it seemed, it had all happened just because they were newcomers in the village. Considering herself being highly sensitive, Nancy reports several illnesses that occurred or started during her childhood. She links them all with her inner suffering and vulnerability. She felt torn between a loving family and people around them who despised them. One example of how she describes her physical and emotional struggles is:

> *"I had to be treated for my tonsils several times including surgical removal. […] I got bullied so often, that I could not listen to them anymore and temporarily lost my hearing […] I simply could not take it in anymore, I literally lost my capability to swallow"* (Nancy)

The struggles went on, Nancy gained weight, developed diabetes and then became anorexic, which led to her first psychiatric hospitalisation at only 14 years of age. Nancy is an example of how clearly someone living with mental illness might draw a picture of what, how and why certain things in life happened. She has found a way of explaining most things that happened to her and making sense of them.

Reflecting on later life experiences

Not all participants made a clear connection between their childhood experiences and their mental illness though. Graham, for example, attributes the development of his mental problems largely to the way he lived his life as a teenager and young adult:

> *"I've always been a fleeing person, running away from things. I had no interest in thinking too much or thinking to the end of things. However, I've been thinking a lot though and had been involved in many things, but whenever it got too tight, demanding or too close, I told myself; well it's time to move on to something else."* (Graham)

Graham, who has an anxiety disorder, blames his lack or avoidance of emotional depth for the development of his anxieties. This explanation has helped Graham to find a new focus in life that includes searching for clarity and being open to spirituality. What sounds like a contradiction is actually Graham's understanding of allowing depth to the things in his life: He wants to understand things more clearly and fully than before, allowing himself to *"dive deeper"*.

Amy started hearing voices when working abroad for a charity organisation. She soon realised that the voices could not be real and that they were probably a symptom of a mental illness. However, as the voices were not threatening her and were not malevolent ones that demanded mean things from her, she decided not to panic but to stay calm and monitor closely how it will go on. Amy was afraid that, if she told her employer, she would not get an appropriate response from them and that she would not receive the treatment that she needed. However, Amy did share her experiences with some local women she was working with and they were not unsettled or overly concerned by these, instead were supportive and caring. Looking back at that time, when her illness begun, and trying to find answers why the voices started, Amy mentions, that she was under a lot of stress. She very much liked her work but was forced to leave due to administrative issues, not knowing if she could return to that place again:

> *"I lived in a family and felt very much as a part of it, integrated, and, yes, I have had really beautiful experiences there, especially in the women's world [referring to a different cultural background and the position of women in society]. Those women, I find, are very warm-hearted, caring and open, much more than people around here. And actually, I do think that this was the trigger [having to leave all that], finally, for my psychosis, that's how I can explain it to myself now."* (Amy)

This is how Amy constructs her explanations of getting ill: the emotional stress of not knowing what would happen and fear of losing a place that felt like home caused mental distortion. Suffering from a lot of stress and living under immense pressure is an explanation often heard in the interviews. Along with that often goes the insight that one should have taken better care of oneself earlier. Some participants considered this aspect at least partially responsible for having developed a mental illness. However, stress and burden were not always experienced negatively. Neither Kathie, Amy nor Alice complained about personal situations that they consider relevant for having developed serious mental health problems.

Alice gave birth to five children within ten years and was always working hard in a small community where they also took care of people living with mental illness. After her fourth child was born, Alice experienced an episode of postnatal depression. However, due to her workload in the community and her sense of feeling jointly responsible for the well-being of the others in her family and the community, she just kept going as best as she could without any time off or recreation. Even the family doctor, who was a member of the community as well, suggested that she should just take it a little easier but keep working.

> *“That was a big mistake that I did not handle the situation differently back then […] The workload, raising five children over the years and everything else, it was actually impossible to stem. […] But you know, looking back, that’s my predisposition, I always made sure that I had enough work and with any sign of boredom, I took on some more. So, it is my own fault that it ended in a massive overload.”* (Alice)

However, Alice did not break down, not then and not until many years later, when she completely overworked beyond limits and had to be admitted to a psychiatric hospital in a massive manic state of mind.

There is only one participant in this study who does not seem to construct explanations around how his mental illness might have begun or how it relates to other aspects of life. However, Norman’s story goes back to the seventies and his narratives from those early years with a mental illness are pretty vague. Nevertheless, he quite clearly recalls his different psychotic episodes that have left a lasting impression. From his perspective, these episodes just happened unexpectedly and were completely unrelated to anything else in his life.

4.5.1.2 Constructing explanations around living with the illness

As much as constructing explanations around how it all began and the cause of illness, the participants seek to understand what is and was happening to them beyond the origins of the illness. There is a wide range of implicit and explicit explanations of how and why certain things happened in participants’ lives. They all have in common that they are meant to help the person living with mental illness to understand what is happening to them and to help them to deal with experiences such as stigma. Constructing explanations around living with mental illness is often linked with experiences of stigma or situations that were not properly explained or dealt with when they happened. It is the outcome of reflecting on past experiences.

Participants and, on the basis of my own expertise, most people living with mental illness reflect on their experiences, compare situations with previous experiences and combine personal and external knowledge to understand what is going on. In doing so they often make their own interpretation and construct their own explanations within various life situations. Therefore, they create meaning.

Experiences in the health-care system

When Graham started experiencing severe symptoms such as pronounced dyspnoea, agitation, and sweating attacks, he first considered the symptoms as being related to working nightshifts. He says, that he never really adapted well to working at night. However, the symptoms remained the same and still occurred when he returned to work in day shifts. That was extremely worrisome, and his anxiety increased. Searching for an answer, Graham went to see his general practitioner, telling him about his breathing problems and was diagnosed with a lung disease. That did not reduce his anxiety however and the treatment he received did not change anything in his physical or emotional condition. "*The only advantage of that situation was that I quit smoking"* recalls Graham. Even though he was going through rough times, and still was unable to make sense of what was happening, Graham somehow managed to continue working. He argues that it kept him going. As much as Graham did not see a mental problem arising, his general practitioner, who only heard of his breathing problems, could not see it either. It was not before Graham encountered more difficulties physically and emotionally, and having a girlfriend, who questioned his diagnosis, that Graham consulted a lung specialist. His lung disease could not be confirmed. Only then Graham started to understand and accept that he was dealing with a mental problem. Therefore, he went to see a psychologist and recalls his experiences as follows:

> *"I couldn't open up at all. That made me realise; aha, I do have a problem to open up, twelve sessions, and the only thing I realised was that. I noticed that I was deluding myself. Then I slowly got into the real subject; all right, it is about my own psyche!"* (Graham)

With this insight he began to self-reflect more thoroughly. For Graham, the question was not so much about why the mental illness occurred, but more about what it revealed to him and what could be learnt from it. Graham's example also shows, that within the health-care system, even though he sought help, he had to actively participate in the process of finding the right answers. He had to realise that only by accepting that it was a mental problem could he start the process of dealing with it. In doing so, he constructed his own explanations that guided him further through the process of living with mental illness. Graham started to create new meaning in his life.

Nancy, who has a very long history of living with various physical and mental illnesses and complications, says that she does constantly try to understand what is happening to her and often sees connections between mental struggles and physical illnesses: *"Saying this is simply somatic, purely functional, I don't know, I don't believe it, it cannot be separated [from the mental]".* However, she also says that one cannot always explain everything: At a time when she actually felt completely healthy, and that is not something she felt often, she developed cancer! It was one of these situations that was difficult to explain or to make sense of. However, Nancy found a way to construct explanations that go beyond her own suffering.

Having had experiences as both a psychiatric and a physically ill patient, Nancy can clearly see where the differences lie. She recalls the vast support she felt from family and friends when she was admitted to the hospital for cancer treatment and the exact opposite experience on being admitted to a psychiatric care unit, where no one sent her get-well cards or flowers or came to visit. Additionally, when in psychiatric care she often experienced stigmatisation from professionals who saw her as "the borderline patient" rather than Nancy, a woman in need of help. All these experiences have led Nancy to become an advocate for the mentally ill and she says:

> *"with all my experiences, working towards antistigmatisation is a matter of the heart, even when I'm only able to make a small contribution, with my limited resources, it motivates me."* (Nancy)

This is Nancy's way of creating meaning. Sadly, Nancy's negative experiences in mental health care are not the only ones reported in the interviews. Louise reported several incidents that happened to her. She recalls that it started with being involuntarily transferred from a regular hospital into a psychiatric hospital when struggling with anorexia. Louise believes she was admitted to that psychiatric hospital shortly before her 18th birthday because her mother could not deal with her anymore. *"They always listened to my mom and not to me"* she says and tells how the nurses in the general hospital betrayed her in saying she would be transferred to a hospital nearer her mom when in fact it was a psychiatric hospital she was sent to. There she was forced to take medication and was threatened with coercive measures if she would not comply. It shows how Louise was trapped in a system and at the mercy of mental health professionals.

However, Louise constructs her own explanations and interpretations of the experience when she says that it happened just before she attained adult status when she was not permitted to make such decisions herself. Therefore, to her, her early experiences with mental health care were primarily an issue of authority and the abuse of power.

However, it is not the case that only negative experiences from within the mental health system were reported. All participants recall positive experiences, especially when there was a real connection, an interpersonal relation between a health-care professional and the participant.

> *"I've experienced [name of institution] very well. Also the doctors. And the psychologist, even though she was a beginner, lacking experience, but somehow, she was good for me. She was young but very present. And yes, the whole [nursing] team, they were very human, they didn't doubt what I said."* (Katie)

Talking about her experiences in a mental health hospital, Katie reflects on what was important to her and what she recalls has helped her in a very difficult situation. It was not so much a specific intervention or treatment but the freedom to express herself, be listened to and feeling validated in what she was going through. Katie describes a situation involving a powerful realisation about the past, some gloomy enlightenment, that caused a lot of pain and tears in her. Overwhelmed by emotions and grief, she locked herself up in a bathroom to cry and mourn. After a while she came to the realisation that, to overcome these strong emotions, she needed to perform some form of a ritual. Katie wanted to put the experiences from the past to sleep and die and therefore felt the urge to go to a nearby restaurant to somehow perform and experience a funeral reception. However, being on a locked psychiatric unit she needed permission from the nurse to go outside. With tears in her eyes and in a fairly agitated state she briefly explained what she wanted, and the nurse let her go despite the potential danger of self-harm the nurse must have considered. This was tremendously important to Katie and that specific moment of being trusted meant a lot to her. It was a moment full of meaning, that was supported by a mental health nurse who only learnt the details of her wish afterwards.

It is this kind of reflection process that helps participants to construct their own explanations, to understand what was going on and to create meaning. In this situation, Katie explained the importance of professionals being supportive and trusting rather than restrictive when it comes to unconventional handling of emotional distress.

Experiences in one's own environment

Constructing explanations and finding answers to experiences in life seems to be a constant in the lives of people living with a mental illness. Many of the participants seem to reflect constantly on issues of life or at least this seems to be the case when they were asked to talk about their experiences. The use of specific questions such as 'what was helpful in the process of living and dealing with the illness' could have led to the attribution of positive meanings to something or someone that they had not thought of before. However, within the interviews, most narratives came naturally and without specific questions. Therefore, the process of constructing explanations is not primarily indicated by questions asked by me, but by an existing desire to understand and to make sense of past and present events.

Reflecting on some of his crises in life, Francis sees a clear connection between his desire to be a free and independent spirit and human being and the liabilities that come with getting involved in relationships or having to earn money for a living. Francis had a wife and two children when he met another woman he loved which led to a complete separation from the family he loved and most of his social network because it was his wife who always had invested in this network before. This was a devastating experience for Francis and even though they tried to work through the issues in family therapy, the tensions could not be resolved. Another unresolved tension in Francis's life was his interest in working in the arts that did not cover his living expenses. Therefore, Francis repeatedly had to work in fields he had no real interest in. These are some of the circumstances Francis refers to when explaining his illness episodes. With these kinds of reflections, he constructs his own explanations around what was happening. It is his personal interpretation of life events, that creates meaning.

Keith was diagnosed with bipolar disorder early in his life and had his first major manic episode when he was only sixteen. However, even though Keith admits that receiving a medical diagnosis was helpful at the time, he now finds it limiting and he does not let it define him anymore. Part of that process of changing attitude towards the mental illness was also influenced by personal circumstances in Keith's life: With a parent who is a psychiatrist his experiences of living with a mental illness as a young adult were double-edged. On the one hand the illness was well understood and did not cause additional troubles and stresses during depressive episodes. Keith always was given time and space to recover from illness episodes by his parents. However, on the other hand, even the slightest sign of a possible manic episode drew warning attention.

> *"It [the illness] was still a difficult issue. If it was an issue, actually, most of the time it was not even an issue. It was just dealt with in a certain way, but we didn't really talk about it... Whenever I was a bit happier than usual or more enthusiastic, they sensed it. And then it was difficult."* (Keith)

This experience limited the effects and the potential of empowerment and personal responsibility due to the fact that Keith had no choice to find out where his own limits were or how he could deal with his illness on his own responsibility. Keith does not blame his parents but realises how that situation was hindering him from finding a good balance. In saying this, Keith provides insights into how he constructs his own explanations around the experience of having to live with a mental illness in a household with a mental health professional.

The stories of the participants in this study are full of examples of how they construct explanations to better understand what is going on or what happened to them. With this ongoing process of reflection of life situations and events, emotions and feelings, people living with mental illness confer meaning to them, they create meaning. The process of constructing explanations is also essential when it comes to the next category, defining self-identity. Constructing explanations helps defining self-identity. What it means to define self-identity is outlined in the following section.

4.5.2 Defining Self-Identity

In addition to the first category, ‘constructing explanations’, where the focus is primarily on what is happening and why, this category focuses on understanding of self. The underlying key process is providing oneself with an understanding of who I am, and the motivation is identity which is essential to adapting to a new or changing life situation.

> *“I do believe that I am simply different. Me, as a human being, I am somehow different. I am much more sensitive than others. I am concerned with questions that do not concern others so much. This is certainly one aspect [why I am struggling with mental illness]”.* (Nancy)

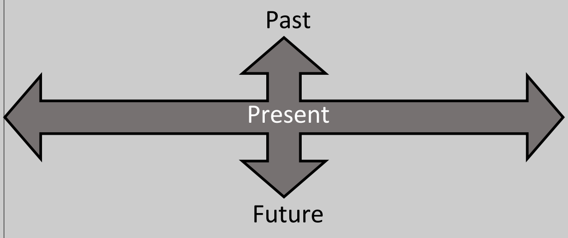
Nancy’s statement indicates how defining self-identity is often linked to the explanations people living with mental illness construct around their experiences of life and illness.

As with the other categories of the Creating Meaning Theory (CMT), defining or redefining self-identity is seen as an active process. Therefore, it is not just something that accidentally happens, but rather a process that is proactively sought by people living with mental illness or a process that they are forced into by the circumstances that their illness causes.

Defining self-identity requires an ongoing and profound reflection on life, often including past experiences but also focusing on the present and the future. The questions ‘who am I? – what have I become?’ encourage a person to focus on identities in the past ‘what defined me?’ and what might be in the future - ‘who do I want to be?’. The latter already builds the bridge to the third category of the CMT; ‘finding a sense-of-life’. This strong linkage is almost inseparable.

Self-identity, as used in the context of this thesis and in accordance with my own understanding, refers to a holistic understanding of who a person is and how that person sees themself. It includes self-awareness of one’s own body, mind and spirit but also of one’s identity in a personal and social context. Therefore, self-identity is a self-concept, the identity a person gives themself in a specific life situation. Within the category ‘defining self-identity’ of the CMT participants who are struggling with their self-identity can be found as much as those who fully embrace self and the situation they are living in (see Table 4.4).

Table 4.4: Continuum and Dimensions of Defining Self-Identity

<table>
<tr><td colspan="3">Aspects of Self-Identity: Personality attributes, knowledge of one’s skills and abilities, one’s occupation and hobbies, and awareness of one’s physical attributes and health.</td></tr>
<tr><td>Struggling with self / railing against one’s fate</td><td>
</td><td>Fully embracing self</td></tr>
<tr><td colspan="3">Factors Influencing Identity: Sociocultural and environmental aspects as well as personality.</td></tr>
</table>

In this study, participants were not asked specifically about their self-identity or how they would define themselves. And still, with telling their stories they all provide a lot of information about their own understanding of their self-identity and also their struggles with it. Also, their stories demonstrate how the understanding of self is not only influenced by illness experiences but also their personality and sociocultural and environmental factors. Participants talk about these issues and point out the importance of certain factors in becoming who they are or see themselves.

The two sub-categories of this category “Self-identity shaped by illness experience” and “Self-identity shaped independent of the illness experience” help to differentiate between participants who predominantly express the development of their self-identity through their experiences of living with mental illness from those who do not consider their mental illness of particular relevance in that process.

4.5.2.1 Shaped by illness experience

Almost all participants consider their experiences with mental illness an important aspect in relation to who and where they are in their lives today. Through the illness or rather by dealing with all the aspects of illness, they all have grown, learnt and been shaped. However, not all participants would consider their experiences in living with a mental illness as a main defining aspect of who they are as a person now.

Katie’s story, which has been partially outlined in the previous category, is an example of how difficult or even impossible it might be to separate illness experiences from other life events. Therefore, the question of what has shaped her self-identity, illness experiences or other aspects of life, becomes irrelevant. Katie struggled for many years to find out what is going on in her life and what has caused her illness. During that difficult and ongoing process, she had to face issues and life events that she was not aware of earlier in life and that were kept hidden in her subconsciousness, denied from people around her or simply unknown. Therefore, her illness experiences are inseparable from her experiences throughout her whole life, they are part of her existence. Within that process, Katie left her religious community and broke with her family ties. Both things she could not have imagined that they would ever happen when she was younger. However, all of her experiences are linked and related to each other. Her story provides a good example of how defining self-identity is connected to and shaped by all aspects of a person’s life and how it is influenced by various factors:

- The sociocultural context, in Katie’s situation her upbringing in a deeply religious family who lived in a rural and conservative community, affected many years of her life.
- Environmental aspects, such as the rural area, quite far away from the next high school and the fact of being the youngest in her family, limited her ability to attend the school and getting the education she wanted.
- The factor personality: Her strong personality helped her to deal with everything she was asked to do even though it was not what she desired. Katie learnt to use circumstances for her own good. However, her decision to enter religious training, might have been influenced by her environment and the religion she had adopted from her family.
- Factors leading to crisis: Increasing and overwhelming responsibilities let Katie’s stress level rise until the pressure became unbearable. This triggered her first illness episode.
- Processing illness and life: Within the process of having to deal with a mental illness, more and more issues surfaced that had to be faced and dealt with and therefore, originally stabilising factors such as faith, religious community and family collapsed like a house of cards.

Defining self-identity in Katie's situation meant that she had to go through severe episodes of mental illness, having to discover early childhood abuse, questioning everything that was of value and finding a new self to be able to move on:

> *"For years I could not tell what my family is and what is the church, everything was blurred. Today, I can let go of much of it. I found a relationship with myself and my body and I am proud of it. And yes, I could finally say that I am proud, and that brings me forward."* (Katie)

The process is not finished, and Katie's self-identity will further develop and unfold as she is still struggling. However, being proud about having rebuilt a relationship with self and body shows self-confidence, something that Katie had lost when she got ill. Still struggling with what she is or has become does also Nancy.

> *"Due to my illnesses I couldn't finish high school and therefore could not study. […] I very much regret this, I would have loved to study, learn something else, having a better job."* (Nancy)

Nancy had a different idea about her personal development when she was younger and still does, but she does realise her limitations now and has accepted them. However, even though she sees positive aspects in her situation, she cannot fully embrace it.

Defining self-identity shaped by illness experiences does not have to be as drastic and dramatic as it is described in the examples above. Amy's story, for example, provides a different view of how experiencing illness kind of "helped" her to become who she is today. It is an act of self-reflection, valuing and integrating experiences into a new understanding of self and identity. It demands a kind of acceptance of what happened and what is now. Amy argues that for her, the things she experienced within psychotic episodes were highly relevant to her. The voices she heard in those episodes were talking about issues that she considered important to work on and to deal with. She provides an example and talks about her body image she has not been confident with for many years. Initiated by some of the voices she heard during her psychotic episodes, she actually started working on the issue and gaining confidence. However, Amy does not deny that it was also overwhelming sometimes and caused a lot of problems:

> *"I am grateful for occasionally having become ill, because it really shook me up, it also caused uncertainty for a long time, when you can't trust your ears anymore […] but it also helped me to profoundly think and reflect on anything, I started to question things […] it has given me a positive impulse…"* (Amy)

Throughout the whole process of experiencing illness, Amy reflected a lot about her life, her strengths and weaknesses and also realised, that due to the side-effects of certain medication she had even lost interest in one of her favourite hobbies, reading. The interest came back when she could reduce and eventually stop the medication. Constantly reflecting on issues like that help Amy to understand what is important to her. Amy has goals in life, is very open about her illness experiences, and shares a tremendous drive for life. Her self-identity is shaped by illness but not marked by it and that is how she presents herself.

The same could be said about Graham. His experiences with mental illness helped him to refocus on what is most important to him in his life. However, he points out that his current position on what is important to him and how he sees himself in life is a *"snapshot in time"* and *"might change again"*. Nonetheless, he says that in experiencing illness:

> *"I realised that I had to become the captain of my own ship. […] It is an attitude and a demeanour which for me currently contains three aspects: clarity, security and openness to spirituality"* (Graham)

In explaining and reflecting on these aspects Graham creates an image of himself and of how he currently sees himself and how he is dealing with his issues and concerns. There are dichotomies in his explanations that he himself realises and tries to dismantle, for example when talking about securities:

> *"I've learnt in my childhood that it is important to always have some money, and I still kind of rely on that, I need financial security, having a place to live, food in the refrigerator, […] but then, I do not want to rely too much on money, it's not that important, it's about my inner security…"* (Graham)

However, it is these dichotomies that build the foundation for Graham's openness to spirituality, which he did not consider important or relevant in the past and before his mental problems appeared. He is still searching and does not have the answers yet to where it will lead him to.

Graham's story is just another example of how a person living with a mental illness is defining his self-identity, looking back and ahead in time and making perfect sense for the here and now. Graham has found his self-identity and some of its defining aspects for now, fully knowing those aspects might change again.

4.5.2.2 Independent of the illness experience

Sometimes, the self-identity that is revealed is not necessarily linked with having experienced mental illness. As for Norman, for example, his self-identity seems very much to rely on one important aspect of his life: music! He richly describes his passion for music and his past experiences as a musician. Even though he could never live from music alone, and does not play music anymore, music is still a defining aspect in his life:

> *"The last time I played an instrument was at a friend's birthday a couple of years ago. [The reason why I stopped playing is…] I just didn't feel like it anymore. Today, classical music is pure fulfilment […], the music captivates and liberates me, and I don't have to listen to it, if I don't want to, but I do want to […] it's the only activity I really enjoy, I quickly get bored by other repeating activities like shaving, washing or shopping…"* (Norman)

Norman reveals a lot about himself within these few sentences: He stopped playing music just because he did not feel like doing it anymore. What seems like randomly happening was a conscious decision that comes across like a liberation from the past or from conventions that had to be met. Norman was writing music, singing and playing different instruments. As a musician in a rock band and other musical formations, Norman played for audiences and as a multi-instrumentalist friends liked to hear him play. So, turning to mainly listening to classical music, the activity became primarily self-directed. This seems very much congruent with his detached life in the countryside with no phone, no computer or television. Norman avoids being interrupted or disturbed and in stopping actively playing music, he probably also got rid of the pressure of having to be productive or creative. What clearly could be interpreted as social withdrawal, something potentially related to his mental illness, becomes Norman's personal redefining of self-identity. Music which always was important to him, still is most important, but is simply lived differently. And music still connects Norman to the rest of the world when he leaves his little village to go to the city to buy CD’s or to attend a classical concert!

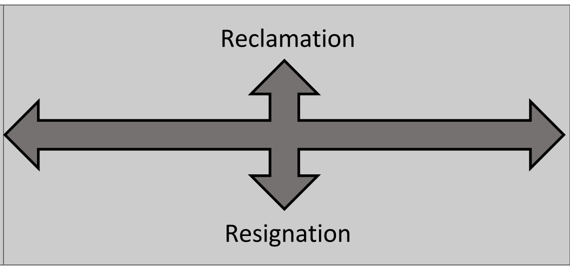
It could easily be argued that Norman’s story and his defining of self-identity is shaped by illness experience as much as the ones described before. Indeed, his change of behaviour and lifestyle could be interpreted as reducing illness-related stress. However, Norman does not refer to his illness when describing his way of life and his passion for music. He certainly knows that he has a mental illness, but he definitely does not define himself through it.

4.5.3 Finding a Sense-of-Life

Finding a sense-of-life is the third and last category of the Creating Meaning Theory (CMT). It could be understood as the category that summarises the efforts that were taken within the other two aspects of the creating meaning process. In constructing explanations and defining self-identity, participants describe what living with the illness means to them, what it made of them and where it might lead them to. Meaning is the motivation for this category. However, meaning is also the main theme of the core category and the whole theory. Giving life and its aspects a meaning is what finding a sense-of-life is all about, it is creating meaning in daily living. It is making life worth living and having a perspective in life.

However, the tension in this category is not so much the continuum from leaving things as they are to changing as much as possible, but the motivation behind the process (see Table 4.5). Meaning can be found in a forward oriented way or in a more static, surrendering way. ‘Forward oriented’ would mean that a person actively reclaims life, driven by hope, where ‘static’ relates to resignation and a sense of ‘nothing really matters’. One can live with either motivation. However, within resignation chances of losing hope and the will to live are much more likely. It takes much more effort to keep going than when hope and perspectives are the driving force.

Table 4.5: Continuum and Dimensions of Finding a Sense-of-Life

<table>
<tr><td colspan="3">Alterable Areas of Life: Relationships, working environment, recreational activities (incl. sports, arts, hobbies), intellectual abilities, spirituality, …</td></tr>
<tr><td>Leaving things as they are / as little change as possible</td><td> </td><td>Starting anew / changing as much as possible</td></tr>
<tr><td colspan="3">Importance of Vertical Dimension: Hope → reclaiming life, resignation → nothing matters</td></tr>
</table>

Within this category, the subcategories chosen to describe the process and concept of finding a sense-of-life are the two spaced points of the spectrum or continuum, ‘living on as it is’ and ‘remodelling life’. However, as a continuum is naturally not one or the other, for most participants it is also the whole spectrum, where there are aspects of life that stay as they are and some that might change. Therefore, the differentiation between the two subcategories can only be made in considering subtle distinctions such as:

a) What does the person currently more focus on: change or maintenance?
b) What is more prominent in the story of the person according to adaptation to illness: trying to keep things as they are or going for the big changes?
c) What is the ‘clustered feeling and impression’ of that person that I got from the interviews and throughout the analytical process?

With these distinctions in mind, it is clear that the subcategories are a theoretical interpretation of the data and not a well-defined construct in the lives of the people interviewed for this study.

4.5.3.1 Living on as it is

In addition to the previously made distinctions between the subcategories, there is another aspect that needs to be highlighted in this subcategory. ‘Living on as it is’ indicates the present tense. It is not ‘living on as it was’, but clearly focusing on the present, the here and now. No one of all the participants is at the same place in life as before the illness occurred and the understanding of their life situation has changed over time for everyone. It is a long way and a unique journey to the present for every human being and for people living with mental illness, this journey includes dealing with everything that the illness affected in their lives. This might include family and relationships, work, hobbies, physical and mental abilities and much more. Therefore, the present is never what it was a day or even years before.

It could easily be argued that ‘living on as it was’ is simply impossible for someone who has experienced mental illness. However, ‘living on as it is’ can also be seen as an attitude, where life is more or less unpredictable and happens anyway.

> *“My quality of life is really high right now, and I can live and be who I am. Everything I do, playing drums, writing a play, dancing, doing woodcraft, it’s like playing the notes of the music of my life.”* (Francis)

Francis found his inner peace. However, it took him a long time, several years and many struggles to get here. His sense-of-life is optimistic and hope driven even though he knows that the dark sides of his illness may always reappear.

> *“I know my armamentarium now, and if I sense it [suicidality] coming back, I won’t use my knife to cut bread but call out for help.”* (Francis)

‘Living on as it is’ suits Francis well as he is in a good position. However, in the past he had to adjust many things in his life including relationships and his working environment. He is divorced from his wife now and lives on a disability pension which allows him to be free from the pressure of having to earn money. This is certainly a very helpful aspect in his life. Receiving a disability pension and or other social insurance benefits is something many of the participants of this study had to accept. Only a minority are still in the primary labour market. However, that means, that they do not have the benefits of a regular working environment which for many people is an important aspect of having a purpose in life, being useful and contributing to the greater good. Therefore, some of the participants are currently involved in peer-support work that gives them a sense of being useful and helping others in similar situations.

> *“It really means a lot to me. When I see, that someone could be helped with my own story, my journey, all the suffering, was not in vain, […] it makes sense and gives me a feeling of meaningfulness.”* (Keith)

Sometimes, these meaningful interactions with others who are living with mental illness, serve as empowerment for their own journeys. Nancy, who does not see that many opportunities in her own life, considers this kind of work crucial to fight against injustice and the lack of recovery orientation in mental health care, as well as against the stigmatisation of people living with mental illness. Therefore, peer-support and anti-stigmatisation work are what Nancy is currently living for, it is what gives her a sense-of-life and where she puts most of her energy in. However, she is living on as it is, as with all of her experiences in the past, she hesitates to set too far reaching goals or to consider big changes. In contrast to other participants, her motivation seems more on the resigning side where hope is still there but relativised by experience and ongoing suffering under the limitations and effects of her illness.

The drive to fight for a good cause is also one of Louise's key motivations that gives her life meaning. Having suffered many losses in her life, even of her own children due to some unforeseen and immutable circumstances, her motivation is also not primarily hope driven and not much forward looking but rooted in the difficult realities and limitations of her own life. At the very end of the interview, and after telling too many sad stories, she says:

> *"What really keeps me going is my husband who has a life-threatening illness and, as a man of colour, he is already at the bottom of the social ladder, we do need each other's support."* (Louise)

A powerful statement of what gives her life meaning. A sense-of-life can be found in different aspects of one's life. For Graham, who's situation has been described in the section about defining self-identity, it certainly is music. It is the one aspect of his life that is the constant that stands out. Graham fits very well in this subcategory as someone who is living on as it is. There are no big changes, no major arguments, no doubts, or at least nothing that he showed or mentioned in the interview or that could have been interpreted into it. Graham seems to have found his sense-of-life in simply being, diving into music and taking everything slowly and with care. The underlying motivation is neither forward driven hopeful nor in any way resigned, it is living in the here and now. His example also shows how closely linked defining self-identity and finding a sense-of-life can be.

Living on as it is can also be very much forward driven and hopeful in a sense of reclaiming life that has been interrupted or irritated temporarily. For Amy, it is about integrating the experiences of her illness into her life without having to change much around it. Amy is among the few participants that are still in the primary labour market. She has finished a postgraduate degree despite her illness and has been able to deal with the illness without longer sick leaves. Therefore, she is confident to stay in a regular working process. However, she is currently considering a reorientation in relation to her work environment, but that process seems to be just a normal attempt in the course of a constantly reflected life.

> *"The fact that I currently don't have a job is actually accidental. I quit my job because I wanted to reorient myself anyway […] and then came this illness episode, stronger than the ones before."* (Amy)

However, Amy admits that there might be an inner connection between the two events. Nevertheless, her goal remains to find a new satisfying job and move on with her life as she has always done in the past. Amy did not have to find a new sense-of-life but continues to integrate her experiences into her present and future well-being.

4.5.3.2 Remodelling life

Many participants of this study were going through major changes in their lives due to their mental illnesses. Some were forced to, and others were empowered to remodelling their lives. Reasons to remodel or recreate life are manifold. In some cases, life might simply fall apart when illness occurs. This had been true for several of the participants in this study, even though it did not happen at once but over a longer period of time.

> *"The moment I said, now I'm going to take my life [double meaning] and live my life, […] a lot began to dismantle within myself, […] a heavy burden got off my shoulders, I could breathe and had to cry."* (Katie)

That moment in Katie's life occurred during a hospitalisation in a mental health hospital, quite some time after she started to realise that some of her dreams were actually uncovering issues of her past. Facing the traumata, she was forced to remodel her life. As described in the section of 'defining self-identity', Katie broke with her family and her religion. She is still trying to find the way of life that works best for her. However, her process is clearly driven by hope and a strong will to reclaim everything she can.

In Alice's life it also took many years to find the right answers for herself and her environment on how to move on with her illness and the limitations or effects that came along with it. Today she lives separated from her husband and her children are all adults and some have children of their own. Alice had to let go of a lot of her responsibilities to keep a better balance in her life and to regain mental health. Living on disability pension and insurance benefits, she does not have to work anymore and is now focusing on things that strengthen her well-being, such as looking after her grandchildren, caring for her old father, knitting and…

> *"I'm really looking after myself these days. [instead of one] I have four men now to cover my needs [laughs], one to go for walks, one to have dinner with, one to go out with…"* (Alice)

Alice has found her sense-of-life which is very much positively underpinned. However, remodelling life does not have to mean to separate from a partner or to brake with one's family. For Keith it just meant to adjust his working environment and job profile, reconsidering his occupational skills.

> *"Because of my illness everything took a bit longer […], the jobs that I have tried did not work out for me. They were too stressful […] But now I know that I would like to open my own business. I'm actually working on it, it's a project that I have thought of when I did my university degree a few years ago…"* (Keith)

With a loving wife and a young child, he has some important stability in his life and is open to try something new. His outlook in life is certainly positive today and he is willing to work for it. However, as for anyone else in this study, having found meaning and a sense-of-life has not always just been there, and it took an active process to get here.

Remodelling life to find a sense-of-life can also be working on a single aspect in life that has not or not as much been in focus before, such as spirituality. Dealing with non-scientific theories about health and well-being or alternative and complementary healing methods and spiritual teachings have been reported in some of the interviews.

> *"I did Reiki and became involved in Radiance Technique […] it helped me to refocus […] I think that without it I would not be alive today."* (Irene)

However, in summary it can be argued that finding a sense-of-life and give life meaning is as diverse as all the other processes are within the creating meaning categories. And even though, all of the participants in this study have found a meaning for themselves, they have experienced moments in life when they did not know who they are and what life might hold in store for them.

4.6 Contextual Factors

In addition to the key findings of the Creating Meaning Theory (CMT) explained in the previous sections, there are a few contextual factors that need to be outlined as they add to the overall understanding of the CMT. The factors chosen and presented here do not provide a comprehensive picture of all possible contextual factors. However, as the findings of this thesis also address mental health service providers such as nurses, the role of the professional and service users' experiences of treatment are of specific interest. The special focus within these contextual factors also contributes to the overall discussion in Chapter 5.

4.6.1 The Role of the Professional and Relationships

All participants of this study have encountered professionals in various situations and settings. The experiences behind those encounters are as varied and diverse as human interactions can be. Participants recall positive and encouraging experiences with professionals but also disheartening and frustrating ones. Positive experiences are the ones when participants felt understood or trusted and when professionals showed real interest in the individual and her or his situation and needs rather than mainly focusing on illness and symptoms. Participants construct explanations around these different experiences in the health-care system (see Section 4.5.1.2) and try to understand what is or was going on. One repeated example of trying to make sense of an experience most participants had at some point in their illness trajectory are coercive measures: "*Maybe I did need those coercive measures in the state I was in then"* (Louise).

However, even though this questioning realisation can be heard occasionally, for most participants in this study, experiences of coercion and other heteronomous measures clearly have a negative connotation. What often goes along with such memories are images of uncaring, unloving, emotionally detached and power exercising personnel. One participant even describes what she experienced as *“contempt for people”* (Irene); a really strong statement. Even though not everyone talks about similar experiences in the same way, it is interesting that not a single participant mentions caring and supportive professionals in the context of coercive measures. That does not mean that there were no caring people around at such moments but that the negative remains in the foreground of the memory.

Nevertheless, there are numerous accounts of positive encounters with health-care professionals, such as nurses, doctors and therapists. These stories talk about how important it is to feel accepted and non-stigmatised by the professional:

> *“Positive experiences have always been the ones when the professional was primarily a human being. […] Being human and seeing the human in me. That is most important. Therapy is relationship, whenever I felt that, even in acute crisis, it helped.“* (Nancy)

Such reports about caring professionals illustrate that some really try hard to gain trust and build on a supporting relationship with the person in need. All participants of this study, at one point or another in the interviews, refer to the importance of such humanistic and caring approaches of professionals. Katie, for example, describes a situation during one of her stays in a mental health facility as follows:

> *“I couldn’t even trust myself anymore, it was so bad, I had kind of lost myself […] and then to realise that the nurses trusted me, believed in me, that leap of faith was so important and rewarding.”* (Katie)

However, even though interactions with health-care professionals are always part of the stories of the people interviewed for this study and do play a role in their personal journeys of recovery and adaptation to illness, they are usually not the focus or the major aspect in that process.

> *“[Getting to the roots of my illness], it was mainly a personal effort. Primarily. Sure, there were professionals, because I needed support in this process from time to time…”* (Irene)

The personal process and effort stand out in all the stories of the participants. Some do not even mention health-care professionals unless asked about them. It shows that all participants experienced some sort of support and help from professionals, but in the context of their whole lifeworld experience, they are only one aspect among others.

However, supporting relationships, not only the ones with health professionals but even more so those with family and friends are important to all participants. One of the participants argues:

> *“If it weren't for my husband, I don't know where I'd be today. He gives me so much and I also want to take care of him. He has a chronic illness, but together we can do it.”* (Louise)

For Louise it is the relationship with her husband that gives her stability. She values it as mutually complementary where there are positive dependencies on both sides. However, relationships, or people to rely on outside of the health-care system do not have to be spouses, parents or children:

> *“I always had friends around me who really stood by me. I was never alone. […] and therefore, I had never lost hope, not even in the severest depression.”* (Alice)

Alice has been married and has children; however, it is not her husband or the children that she mentions as key helpers in dealing with the illness but good friends. Most participants describe such relationships and their importance and impact on their lives. They all vary considering intensity, frequency of contact or relationship level, one participant even mentions his landlord as an important relationship. Therefore, relationships are an important contextual factor in relation to creating meaning, but it seems that professionals are not the most crucial ones.

4.6.2 Information and Decision Making in the Treatment Process

Treatment experiences have already been mentioned in the previous section about the role of the professional and relationships (see 4.6.1). Both aspects are closely inter-linked. From a participants' point of view, treatment decisions and their own involvement in a decision-making process, depend on the relationship with the health professional. Some of the following examples of treatment experiences seem quite extreme. However, most participants view them not as the most dominant ones in the context of their illness experiences. Nevertheless, some descriptions show dehumanising practice in psychiatric care.

> *"Isolation or medication was my only choice and sometimes it was both. […] For more than 12 years I had to take several drugs and I had severe side effects. […] Actually, it was hardly voluntary, the pressure [within the institution] was usually the threat with compulsory medication and an exit ban."* (Louise)

Louise is off medication now, but still has some when she feels that she needs it. It was a long way for her to get to this kind of freedom and choice. The freedom of personal decision-making and getting off continuous treatment with medication is something other participants are working towards as well:

> *"I take antidepressants for my illness and I still depend on them. However, I want to slowly get away from them again. […] I managed it in the past and will get there again, I can feel it."* (Graham)

Medication is often used as part of psychiatric treatment. For some participants it does not seem to be an issue at all as it does not come up in their stories or is only mentioned as an aside, whereas for others, such as Graham and Louise, it is an aspect they wish to gain full control over or even live without it. The individual process behind it is part of the whole creating meaning process as described above. Therefore, there is no predominant stance on medication or any other treatment option within the heterogeneous group of participants.

However, those participants who reflect in a very differentiated and profound way on their experiences of different treatments within the health-care system agree to a large extent that at some point they felt helpless, often at the beginning of their psychiatric treatment, because they did not know enough about it yet. In such vulnerable phases of the illness, on the first appearance of the illness or its symptoms, but also in acute crisis, lacking, incomplete or unhelpful information is a devastating experience. Amy, for example, who was living with the illness for a long time and dealt with its symptoms (voices) very well on her own, was studying full time when she had to seek professional help for the first time due to an overwhelming increase of her voices. She describes it as follows:

> *"And when I finally agreed to take medication but raised my concerns about the side effects, the psychiatrist told me that they are not that bad and that she has a client who can even work 30% part-time. That was absolutely devastating for me!"* (Amy)

At least, Amy was not forced to take medication, but could not see any other alternatives due to her suffering. Therefore, it was not exactly a choice but the only available solution in her situation. However, the difficult part was the therapist's rash statement about the limited ability to work, information that was anything but helpful in that situation. Others were not involved in the decision-making process and were confronted with anticipated decisions by professionals instead:

> *"I was 15 years old when I was admitted to a psychiatric hospital for the first time. […] there was a bonus/malus system [that did not work for me] I was basically locked up in my room, no music, no TV, no hobbies, I have been denied everything […] that was very negative."* (Nancy)

The participants remember many examples and are willing to share how they have experienced their treatments in the mental health-care system. However, the examples are as diverse as the participants and their individual stories. Negative and positive experiences are often made almost simultaneously and are close together. Participants views of treatment range from it being a necessity that was willingly sought and appreciated to something forcefully and involuntarily enforced upon them. This personal assessment may shift over time and negative experiences may become less burdensome when viewed from a distance in time. However, between voluntariness and compulsion lie success and failure of treatment. The view and processing of it differs between service users and health-care professionals.

4.7 Summary

The brief exploration of contextual factors (see Section 4.6) is not exhaustive but adds to the overall understanding of the Creating Meaning Theory (CMT). It offers a focus on topics that played an important role in the participants' narratives. However, all the experiences are highly individual and are valued differently by each participant. For some, the struggles with and within the health-care system, with health-care professionals, treatments and medication, are an important or even inseparable part of the whole creating meaning process: They want to understand their experiences and what they can learn from them (constructing explanations and understanding). They use those struggles to find out what they want or do not want, and what they need and deserve (defining self-identity). This might lead to ideas about where to go from there in their lives and maybe even help to provide a new meaning (finding a sense-of-life and meaning). For others, the process of creating meaning is less dependent on experiences within the health-care system and they are just part of the whole process. It illustrates the broad range of how participants adapt to their lives with a mental illness and how they create meaning.

In summary, the CMT and its three categories offer a wide spectrum of insights into the personal stories of the participants. Within each one of the categories there is multidimensionality and potentially simultaneity with other categories. There is no linearity or clear starting point. And still, the CMT provides an understanding of the process people living with mental illness are going through.

In trying to understand what is going on or why certain things are happening in their lives, participants construct their own explanations about their situation. However, constructing explanations is a process within the CMT that does not always happen consciously or willingly (see 4.5.1). Mental illness often challenges one’s own understanding of self and self-identity and raises the question of ‘who am I and what have I become’. In the process of adaptation to living with mental illness, people define their self-identity anew and provide themselves with a potentially new understanding of who they are. Defining self-identity may change over time and ranges from struggling with self and railing against one’s fate to fully embracing self in the presence, past and potentially in the future (see 4.5.2). Lastly, people living with mental illness search for their potential in asking what they can expect from life, what it holds in store for them. In doing so, they are taking back control and finding a sense-of-life, motivated by the search for meaning. However, finding a sense-of-life needs a perspective to reclaim life as on the other side of that continuum is resignation that might shut down any motivation to move on (see 4.5.3).

Creating meaning includes all of these processes from constructing explanations to defining self-identity and finding a sense-of-life in no particular order. It is an overall process every single one of the participants is doing in his or her unique way. Experiences with professional services and relationships always play a role in all the aspects of the CMT. The findings are discussed in the following chapter.

5 DISCUSSION

Dalai Lama, Tibet Institute, Rikon, Switzerland, 2018

“Like all works of art –
whether masterpieces or not –
persons are definably greater than
the sum of their constituent parts.
They are work in progress, […]”
(Barker 2011, p.vii)

5.1 Beginning the Discussion

This chapter highlights and discusses some of the key findings as well as aspects of the whole research process of this study and combines them with findings from the existing literature and my personal reflections.

The photo of the Dalai Lama, taken at a monastic conversation (Dalai_Lama 2018) near my hometown has been chosen to introduce this chapter for a simple reason: In his lecture the Dalai Lama called on the Tibetan monks to share their knowledge, talk about it and discuss it. This is what this chapter is all about. Additionally, Barker's statement, metaphorically speaking, refers to the findings of this study that are discussed in this chapter. Indeed, the stories that led to these findings are ongoing, unfinished and work in progress. The same applies to the discussion of the findings of this study that will not be exhaustive, because it goes beyond the scope of the present thesis. Not only is the number of words limited, but also the possibilities for philosophical examination of the contents within a doctoral thesis. Therefore, it is important to say that this chapter can only mark the beginning of the discussion and hopefully inspires continuing conversation.

However, as an integral part of the PhD research project and thesis, the discussion chapter not only focuses on the findings but also includes critical reflections on methodology and strengths and limitations of the overall project. To begin with, the next section covers reflections on the original aims and objectives of the research project and how these have been achieved or not.

5.2 Reflections on Aims and Objectives

Aiming to explore and evaluate personal experiences of people living with mental illness (see Section 1.4) was at the forefront of this research project. It guided the whole research process, including the methodological choices that had to be made. A discussion and reflection on the methodology can be found later in this chapter (see 5.4). However, the overall aims and objectives of the study have been achieved by the extensive reports of the participants and the development and emergence of the Creating Meaning Theory (CMT). The narratives from people living with mental illness have helped to identify aspects and issues that seem most relevant and meaningful to the population studied and the process of dealing with these aspects has been outlined within a new model, the CMT.

Considering the original research questions (‘what are the issues people living with mental illness experience in the context of their adaptation process to illness?’ and ‘how do they experience such issues and aspects?’), the answers are well explored within the CMT and its broad descriptions of the categories and the contextual factors. The issues and aspects people living with mental illness are dealing with are summarised in the three categories of the model: (1) constructing explanations; (2) defining self-identity; and (3) finding a sense-of-life.

The individual experiences are well included in the categories and contextual factors of the CMT. A separate list of issues or aspects and detailed descriptions of individual phenomena are not effective as these are as diverse as the participants of this study. For example, for some, dealing with stigma within the health-care system is a big issue, for others it does not seem particularly relevant. Another example is the use of medication; even though it is often a controversial issue among people living with mental illness, it does not seem to be a defining topic in the lives of those who have been interviewed. Additionally, the evaluation and estimation of the importance of an issue someone is dealing with is highly personal. Therefore, instead of outlining and describing several issues, the intention was to cluster them into a broader understanding. Constructivist and Reflexive Grounded Theory emphasises theory construction rather than descriptions of phenomena and pursues developing categories rather than covering specific empirical topics (Charmaz 2014). Therefore, issues that the participants were dealing with, appear in the context of the descriptions of the CMT and are described on continua rather than in a phenomenological way.

This leads to the next section of this chapter that focuses on the main findings of the study, the CMT and its categories, the importance of contextual factors and the advantages of a new model or theory.

5.3 The Creating Meaning Theory

The rich findings of this thesis are described in detail in Chapter 4. They resulted in the emergence of the Creating Meaning Theory (CMT). Creating meaning is the core category of the CMT (see Figure 4.1). The CMT is uniquely developed in this study and presents a new model of adaptation to mental illness from a patient or service user perspective. It is this aspect, that the model was generated entirely from the participants' narratives, that makes the CMT authentic and not or hardly influenced by existing theories or models.

Therefore, in this section the focus is on those findings again, where they will be compared with existing theories or concepts and discussed in a broader context. However, the first issue raised here is about the advantages of a new model or theory in the body of knowledge around mental health and psychiatric nursing.

5.3.1 Advantages of a New Model or Theory

What are the advantages of a new model or theory like the Creating Meaning Theory (CMT)? Models and theories are meant to help practitioners, scholars, policymakers, managers and others alike, to better understand processes, to put them in perspective with their own experiences and to critically reflect on them.

> “[Theory] is a symbolic depiction of aspects of reality that are discovered or invented for describing, explaining, predicting, or prescribing responses, events, situations, conditions, or relationships.” (Meleis 2007, p.37)

However, what to call the findings of this research project, a theory, a model, or even something else, could be assessed in different ways. Fawcett (1984) distinguishes between conceptual models and theories and justifies this with the respective degree of abstraction. Conceptual models are relatively abstract and contain rather general concepts whereas theories are defined as…

> “…one or more relatively concrete and specific concepts that are derived from a conceptual model, the propositions that narrowly describe those concepts and the propositions that state relatively concrete and specific relations between two or more of the concepts.” (Fawcett 2005, p.18)

From that perspective I probably would consider the CMT somewhere in between a conceptual model and a theory, because the model itself (see Figure 4.1) is relatively abstract and broad. However, having rigorously used a Grounded Theory approach, it seems suitable to call the CMT a theory, a Grounded Theory

(GT), which justifies its name. Additionally, the categories of the CMT are well described and defined and provide a clear framework with specific relations between them.

Each story of the people who participated in this study could have served as a single case study or as an extensive narrative account. Basset and Stickley (2010) did the latter and collected stories of experiences into an impressive book. Those voices of experiences provide powerful insights in the lives of those who live with a mental illness.

> "In this book people with experience of living with mental health problems talk about how they cope, survive, manage, recover, discover, struggle, combat discrimination, thrive, become liberated and grow – in essence, how they live their lives. Their stories are about finding meaning and explanations. They are about their beliefs and their strategies for life…" (Basset and Stickley 2010, p.1)

The editors argue that the narratives inspire hope in readers with similar experiences. Their intention was not a further analysis of the stories or the development of a model or theory. However, as a researcher one has a variety of different methodological approaches to choose from. For me, as interesting and standing on their own as the participants' stories are, I was more interested in what might come out of those stories without a preconceived idea or concept in mind. I was interested in what the 'bigger picture' of those stories could be. It is an advantage of the chosen methodology that it culminates in a new model or theory that captures that 'bigger picture' into a more generalisable form, here the CMT.

However, reading the introduction to Basset and Stickley's (2010) book (see quote above) it surprisingly shows some congruency with this current research project, in that their statement could easily serve as part of the introduction to the findings of this thesis. With only the last two sentences of that quote being rephrased into 'Their stories are about creating meaning, a unique process that includes constructing explanations, finding a sense-of-life and defining their self-identity', it would perfectly fit this study. Interestingly, all three categories of the CMT could be found or incorporated into the original quote: Where the editors of the book talk about finding meaning and explanations, in the theoretical model of the CMT those aspects are reflected in the two categories 'Constructing Explanations' and 'Finding a Sense-of-Life' (see Figure 4.1). And the third category of the CMT ‘Defining Self-Identity’ can be found in the aspects of ‘their beliefs’ and ‘become liberated and grow’. However, I discovered these similarities by chance, after the emergence of the CMT, when I reconsidered previously searched literature for inclusion in the discussion of the thesis. On reflection, it is not that surprising, as both the editors of that book and I myself were focusing on people’s stories and narratives and were looking at them from a mental health nursing and social work perspective. However, unlike the findings of this current research project that emerged out of an extensive analytical process, Basset and Stickley (2010) simply made their statement based on their professional appraisal. Does this now call into question the results of this study? Not at all, because the analysis was conducted rigorously (see Section 3.3.5) and was as unbiased as possible. I constantly reflected upon the analysis and tried to be mindful throughout the process of my pre-existing knowledge and to ensure that it only appeared in the theory if grounded in the data. Therefore, I do argue that the visible connection between the CMT and a simple professional assessment and statement actually supports the value of the theory, because it shows a clear linkage between a theoretically developed model, stemming from patients’ accounts, and real-life professional expertise.

In summary, this small discourse on narratives versus research-based analysis demonstrates that models and theories developed through research have the potential to reinforce expert knowledge and common sense and provide new ways of understanding complex nexus and interrelations. In the next sub-sections the focus will be on the CMT and its categories in more detail.

5.3.2 What is New about the Concept of Creating Meaning?

Creating meaning is the core category or main theme of this research. It is the process that all the people interviewed for this study are going through in adapting to living with mental illness. According to the data of this study, people living with mental illness face various challenges in their lives which lead to three fundamental questions of life (see 4.4); what is happening to me, who am I and what can I expect from life? The actions or key processes that go along with these fundamental questions of life follow different motivations (see Table 4.2); understanding, identity and meaning. The need to understand leads to constructing explanations, defining self-identity provides an understanding of who I am, and taking control over one’s life and finding sense in it gives meaning.

The combination of them all, in no linear order or definitive pattern, is the process of creating meaning.

The Creating Meaning Theory (CMT) is in itself new and unique as it is based on personal experiences of people living with mental illness and not on preconceived theoretical models or knowledge. Creating meaning explicitly involves a creative and proactive process and therefore, it is always fully owned by the person concerned. This circumstance does not deny the fact that different influencing factors exist. However, creating meaning is always a deeply personal and individual process.

Even though creating meaning, as it is described within this research project, is a newly defined individual process in adapting to living with mental illness, meaning or searching for meaning are well-known concepts in the health-related literature. Skaggs and Barron (2006) list more than a dozen theories that add to definitions of meaning. In their concept analysis of searching for meaning in unexpected, negative life events, the authors conclude that "each individual is indeed unique and responds differently to *[such]* life events" (p.568). The uniqueness of the process and the individual personal experience is a critical attribute in searching for meaning (Frankl 1988; Park and Folkman 1997; Skaggs and Barron 2006). This is congruent with the findings of this study and also with other key literature on adaptation to illness (Strauss 1975; Benner and Wrubel 1989; Charmaz 1991; Livneh and Antonak 1997; Strauss 1997).

However, where some authors clearly refer to different phases in their model (Livneh and Antonak 1997) or describe a pathway in their concept analysis from antecedents to consequences (Skaggs and Barron 2006; Ambrosio et al. 2015), the CMT does not follow any linear rules or processes, because it could not be identified in the data of this study. Therefore, the results of this study are congruent with a simultaneity paradigm (see Section 1.7) that seeks to understand phenomena in a holistic, multidimensional, inseparable way rather than seeing them through an understanding of cause and effect.

It is one of the main features of the CMT that distinguishes it from other models of adaptation to illness or searching for meaning theories, that there is no clear, let alone compelling starting point or antecedent, no uniformity or linearity in the process and probably not even temporality but rather infinity. Therefore, it allows service users to find themselves in the model no matter where they are at in their process of adaptation to living with a mental illness. And it facilitates the understanding of that process for mental health professionals without having to categorise aspects of that process into narrow concepts. Creating meaning is a continuing process in the life of those interviewed for this study and includes more than just their illness experiences but living as a whole. In the next few sub-sections the three categories of the CMT will be examined in more detail, following and continuing the discussion suggested here.

5.3.3 Constructing Explanations and the Need to Understand

The title of this section might be misleading as it suggests that constructing explanations (see 4.5.1) must include a need to understand. However, even though understanding is the motivation behind this category of the Creating Meaning Theory (CMT) and the fundamental question leading to it is ‘what is happening to me and why?’ (see Table 4.2), the need to understand varies in this study sample. In parts this is also why the category is called ‘constructing explanations’ and not ‘the need to understand’. On the continuum of constructing explanations (see Table 4.3) influencing factors are as broad as general determinants of health, such as life events and biographical, sociocultural and environmental aspects or anything that someone defines as such. However, where trying to understand is normally a cognitively conscious process, constructing explanations and building one’s own reality could happen subconsciously. Therefore, all the people interviewed for this study construct their own explanations around the many issues they are facing in their lives. Most of them search for answers on why things are happening and what is going on, but one participant, for example, does not seem to question why mental illness occurred in his life and puts his psychotic experiences in an almost spiritual context of understanding life. Therefore, not questioning what is going on or why something is happening is also a way of constructing explanations. The explanation constructed here simply is ‘it is’, the conscious or unconscious acceptance of a reality; no more, no less. Therefore, constructing explanations goes beyond the simple need to understand and shows how participants profoundly deal with their life and illness, their fate and how they reflect on their experiences in various ways.

Reflection and engagement with one's own life situations are attributes found in all the interviews of this research project. Therefore, constructing explanations is an inseparable aspect of creating meaning. This seems congruent with the assumption that the search for meaning, the question of the meaning of life, is part of human existence (Frankl 2016, 2017; Längle 2018). Understanding why something is happening and constructing one's own explanation around it is part of that process. Nietzsche (1889) once argued that a person who has a 'why to live' can bear almost any 'how'; however, that 'why' refers to a reason to live and meaning rather than to an understanding of what and why certain things in life are happening or happened in the past. And still, for most people in this study, understanding what is and was going on in their lives is part of that meaning. Längle (2018) argues that behind all human actions, behind every form of engagement with life, there is the question of meaningfulness, an orientation, a 'why' - no matter whether the person is aware of it or whether it is spontaneous or unconscious. This is a good way to describe how all participants of this study construct explanations, it is part of their being and part of living. Also, they are free to choose how they value their experiences in any way and what they choose to take out of that experience. It is a personal decision what one wants to accept and integrate and what might be denied or left behind to move on in life. This is an active process, at least in the sense of devotion, openness and being able to allow change and or change of mind. All participants are capable of doing so, no matter how ill they were in the past. It could be argued though, that there might be a need for some stability in thinking and cognitive functions to construct explanations and therefore, acute crises with cognitive disruptions may hinder the process of constructing explanations. However, this is with no evidence from my data.

The underpinning question behind the process of constructing explanations, the 'what is happening to me and why' can also be found in Slade's four key domains of personal recovery (see Table 2.4) where it is called 'direct meaning'. Defining 'direct meaning' Slade (2009) argues, that because mental illness is such a profound experience, it requires:

> "a personally satisfactory explanation, […] an understanding which makes adequate personal sense of the 'mental illness' experience." (p.78)

Integrating such direct meaning of the mental illness into one's personal life is seen as a key step in the personal recovery process. The study data largely support the assumption of "the quest for direct meaning – making sense of what has been, and is, happening" (Slade 2009, p.146). However, with at least one participant not consciously trying to find explanations or making sense of what was happening, the construct of 'direct meaning' needs to be questioned. Constructing explanations, as defined in this study, includes a non-questioning stance on being and experiencing, where the simple acceptance of a reality is enough.

Mishel (1990) talks about encouraging people to use probabilistic thinking and to consider alternatives when faced with uncertainty in illness, helping them to view uncertainty as "leading to more possibilities and new patterns of contingencies" (p.261). Uncertainty in illness could be seen as a source behind the process of constructing explanations. However, constructing explanations goes beyond probabilistic thinking and searching for alternatives; it clearly includes free will and the ultimate freedom and power of decision over which situations, life events or uncertainties one attributes which meanings to. Therefore, constructing explanations is undeniably unique and individual and potentially outside anyone else's understanding.

All participants of this study were willing to share their stories, talk about their lives and experiences and how all of that had to be scrutinised, rethought and rediscovered. Frank (2013) argues that people with serious illness who may have lost their previous goals and outlook in life, not only need to learn to think differently but "to tell their stories, in order to construct new maps and new perceptions of their relationships to the world" (p.3). This matches my own experiences in listening to the participants' stories. In telling me about their lives they show self-reflection, new and different ways of thinking and how much they deal and sometimes struggle with their illness and themselves, which are all part of constructing explanations.

5.3.4 Defining Self-Identity: Identity as a Key Concept

Defining self-identity is the second category of the Creating Meaning Theory (CMT). 'Defining' refers to an active process of development, refinement or adjustment of a highly personal and therefore unique view of self. This view of self is what is meant by ‘self-identity’ and therefore it includes aspects that the person considers important or relevant for themselves. However, self and identity could also be seen as two separate but fully related concepts that are

> “…representing different dimensions of the same phenomenon, especially in terms of the process of identity change. Self-concept usually refers to the more private aspects of the phenomenon (a personal sense of self that often includes perspectives of a past, present, and future self); identity is considered to represent more of an integration of the public and private selves (how the self is known by others).” (Shea 2010, p.43)

Shea (2010) uses the term ‘self-identity’ to capture both aspects which is true in this study as well, even though the data show an emphasis on the personal sense of self. However, it is difficult to find a well-supported definition of ‘self-identity’ with a broad consensus in health-care literature. Self-identity and personal identity are often used interchangeably. Whereas self-identity “can be defined by role identities and personal traits, as well as by social structures” (McKendree 2010, p.547), personal identity is often distinguished from social identity (Layder 2004; Leary and Tangney 2012). Views and definitions of personal identity are diverse and depend on professional and philosophical background and are part of an ongoing scholarly debate (McKendree 2010). Therefore, in this study in addition to Shea’s (2010) understanding of self-identity (see above), self-identity simply refers to the way participants think about themselves and how they construct their own narratives of the self with which they emotionally identify (Barker 2004).

Nevertheless, the narratives of the participants of this study contain many aspects that form the process of defining self-identity within the CMT. Defining aspects of self-identity may encompass a range of dimensions from individual (*“I am simply different”* – Nancy) to interpersonal (“*I am the middle one of my siblings”* – Graham), from social (*“I am an artist”* – Francis) to cultural (*“I am very German in this”* – Graham), and from physical/sexual (*“I am not very attractive”* – Keith) to spiritual (*“I am a deeply spiritual person today”* – Irene). This list is not exhaustive, and the short quotes serve as examples only; the process is much more complex than these statements suggest.

The process of defining self-identity is closely linked to the previous category, that of constructing explanations. Therefore, it is not always easy to clearly distinguish between the two nor in relation to the third category, the process of finding a sense-of-life. The stories of the participants often contain aspects of all three categories in a single statement. It is all creating meaning as suggested in this study. And still, all three categories could be identified and all three are relevant. However, defining self-identity seems to be the basis to create a perspective for the here and now and the future. In defining self-identity participants are able to reflect on their situation and develop a sense for the future.

Therefore, identity or self-identity are key concepts in the context of illness and illness experiences. The influence of illness on self and identity has long and extensively been described in the context of chronic illness (Strauss 1975; Bury 1982; Charmaz 1991).

> “It should be obvious that a person’s changing views of his or her trajectory, and the shifting social relations that may occur as it progresses, can profoundly affect the sense of personal identity.” (Strauss 1975, p.73)

The quote illustrates that even though mental illnesses are not synonymous with chronic illnesses, some aspects within the illness experience are quite similar or at least comparable. Life trajectories change drastically for people living with mental illness as the data of this study suggest and therefore, there are shifting social roles that demand changes in one’s self-concept. Where “serious chronic illness undermines the unity between body and self and forces identity changes” (Charmaz 1995, p.657), in the context of mental illness it is one’s own knowing and understanding of self that is undermined and questioned. Therefore, it is the unsettling of and challenge to the self that demands identity changes and a process of defining self-identity.

This confrontation with one's own identity and its adaptation in a changing life-world is an important aspect and process in personal recovery of people with mental illness (Slade 2009; Leamy et al. 2011; van Weeghel et al. 2019).

> “The first task of recovery is developing a positive identity outside of being a person with a mental illness.” (Slade 2009, p.83)

The core of this rationale, developing an identity outside of being ill, is congruent with the findings of this study where participants are trying to get an understanding of themselves that goes beyond mental illness. It is part of the process of defining self-identity. However, even though the goal of that process might be a positive identity and a positive self-awareness, defining self-identity does not necessarily imply positivity (see Table 4.4).

In our preliminary study (Wolfensberger et al. 2019 accepted for publication) we found that fear of loss of self and self-identity could be one of the reasons for the experience of uncertainty in illness and Spaniol et al. (1999) describe the loss of a sense of self as one way people with mental illness are affected by the illness. Loss of former self has also been described in this study and is part of why participants had to define a new or adapted self-identity. Strauss (1997) talks about turning points in adult life that lead to transformations of identity, and experiences of loss of a sense of self, or simply the impact of an emerging mental illness are certainly turning points in one’s life.

There is broad consensus that any form of adaptation to life with mental illness demands a process of defining self-identity as it is called in this study. Other authors call it; “building a positive and multifaceted sense of self” (Hine et al. 2018, p.26), “the full development of self-awareness […] and incorporating both positive and negative aspects of self” (Shea 2010, p.48), “the development of a functional sense of self” (Davidson and Strauss 1992, p.141). The subjective experience of self may be an influencing factor on the course of mental illness (Roe 2005) and is a key factor in personal recovery and adaptation to illness.

5.3.5 Finding a Sense-of-Life: What Provides Meaning?

Finding a sense-of-life is the third category of the Creating Meaning Theory (CMT). What does it mean to find a sense-of-life, what provides meaning? As explored and discussed in the previous sections, this process is an extension of and strongly linked to constructing explanations and defining self-identity. It is all part of creating meaning. Barker and Buchanan-Barker (2005) call this process ‘value making’:

> “… *[it]* is the point of life: it is why we are here; it is the sole purpose of our existence. *[…]* Value making guides us through life. Value making is the compass that we use to steer the course of our lives.” (p.xviii)

Making something of value, something that matters to oneself seems a good way to describe the process of finding a sense-of-life as described in this study. The findings show (see Section 4.5.3) that the continuum of finding a sense-of-life ranges from leaving things as they are to completely starting anew; between the poles of reclamation, which could be seen as an aspect of hope, and resignation. Hope is often seen as one of the fundamental aspects of personal recovery (Slade 2009; Leamy et al. 2011; Ellison et al. 2018) that includes optimism about the future, beliefs in possibilities, dreams and aspirations, positive thinking and motivation to change. What if nothing of that exists or cannot be seen by the person in question? Is creating meaning or value making still possible? The data in this thesis suggest yes, because it does not take more than accepting one's own personal reality (see 5.3.3) and being able to live and believe in the moment.

Sometimes, looking back and trying to understand what happened or looking forward and trying to see a future is too much to ask of someone living with mental illness. Additionally, some people with serious mental illness "will choose not to manage their condition" (Davidson and Roe 2007, p.468) and can still live a fulfilling life. This is in fact their choice and their own way of dealing with the illness. Therefore, finding a sense-of-life and what provides meaning is not limited to a positive outlook and hope. However, what is it then that keeps someone going even when resignation is spreading? Frankl (2006) argues that it is 'tragic optimism' meaning that a person is and remains optimistic despite any tragic circumstances and Hayes et al. (2012) see it as the human potential because suffering is part of all human existence. Undoubtedly, most people, including those with mental illness, have a will to live and survive and that seems to include a will to meaning and making sense, causing a process of creating meaning or value making. However, people with a serious mental illness such as severe depression or in an acute crisis may not have a will to live and need support to find that again. This argument is not exhaustive and invites further discussion.

5.3.6 Professional Relationships and Shared Decision Making

Among the contextual factors of the Creating Meaning Theory (CMT) that have been outlined in the findings of this thesis are the roles of the professional and of decision-making processes (see Section 4.6). Borg and Kristiansen (2004) found that service users find it most helpful when mental health professionals demonstrate "empathy, respect, and a general person-to-person investment" (p.495), when they are "available for the large and small challenges in everyday life" (p.497) and when they are able to go beyond what usually can be expected as 'professional conduct'. These findings are consistent with those from this PhD study and underline the importance of carefully built relationships between health-care professionals and service users. However, aspects such as the lack of information from health-care professionals and missing shared decision-making processes as found in this study are not mentioned in the findings of Borg and Kristiansen (2004).

Most participants in my study want to decide for themselves what is good for them. However, their experiences in the health-care system often proved otherwise. Instead of receiving all the information needed to make a decision, they received no or insufficient information. Sometimes, decisions were even made without them.

> "In the traditional, paternalistic model, the caregiver assesses what is best for a particular individual, based on scientific evidence and clinical judgment, and makes the decision. *[…]* Real choice is predicated on having access to unbiased information about psychiatric treatment and alternatives to treatment." (Drake et al. 2010a, p.8)

A shared participatory decision-making approach falls somewhere between a paternalistic model of care and complete autonomy of the service user. The advantages of shared decision-making processes include person-centred communication and better acceptance of treatment (Adams and Drake 2006). Mental health nurses could play an active role in this process in providing the information needed and constantly involving service users at all stages of the treatment process (Stringer et al. 2008). However, as the stories of our participants show, this does not yet always happen.

> "As long as nurses are not adequately skilled to create this shared reality, patients will continue to be a passive counterpart in planning, implementing and evaluating the provision of health services." (Stringer et al. 2008, p.682)

Nevertheless, the findings show that 'good' professional relationships and attempts to share decision making exist and are well received and highly valued. Drake et al. (2010a) argue that they can enhance not only service users' satisfaction, but indeed the quality of care and its outcomes.

5.3.7 The Creating Meaning Theory in Context of Personal Recovery

The previous sections have outlined similarities and differences between the Creating Meaning Theory (CMT) and some of the key aspects of personal recovery such as hope, identity and meaning (Leamy et al. 2011; van Weeghel et al. 2019). Despite the perceived differences in these core concepts, the CMT could be seen as a particular description of a personal recovery process because it stems from a service users' perspective and shows how people living with mental illness adapt to their life situations. However, while the CMT can be defined as a new model of adaptation to mental illness (see 5.3.2) personal recovery, despite its proliferation, still has no clear consensus on its conceptualisation (Ellison et al. 2018; van Weeghel et al. 2019). Slade (2009) originally defined four key domains of personal recovery (see Table 2.4). On the basis of a systematic review the model was further developed into a conceptual framework for personal recovery known as CHIME (Leamy et al. 2011), an acronym comprising the five recovery processes 'Connectedness', 'Hope and optimism about the future', 'Identity', 'Meaning in life' and 'Empowerment'. Stuart et al. (2017) who carried out another literature review argue that more themes should be included in the CHIME framework and name 'difficulties', 'therapeutic input', 'acceptance and mindful awareness' and 'returning to, or desiring, normality'. Most of these themes and recovery processes are not further described in these two reviews but are referred to the corresponding literature only where detailed concept analyses on individual aspects are difficult to find. The same can be said about the seventeen recovery components and dimensions identified by Ellison et al. (2018) that are only partially identical to those in the CHIME-framework.

> "Personal recovery is an evolving, dynamic concept: Although most elements have remained constant over time, some have gained greater value and others appear to be losing relevance." (van Weeghel et al. 2019, p.10)

Therefore, there is no simple comparison between the CMT and its categories and personal recovery components. However, with the different dimensions within the three categories and the contextual factors, the CMT could be associated with many of the recovery processes and characteristics outlined by the authors cited above (Slade 2009; Leamy et al. 2011; Stuart et al. 2017; Ellison et al. 2018). Nevertheless, as the CMT has been developed as an independent model or theory it stands for itself. The differentiated analysis of creating meaning though may provide important information and a better understanding of at least two aspects of the personal recovery model; identity and meaning.

Even though personnel recovery is not defined in a generally valid consensus, one key component seems to be confirmed by most definitions and explanatory attempts; ‘hope’. Optimism about the future, beliefs that recovery is real and possible and positive thinking are among the reasons for hope (Leamy et al. 2011; Ellison et al. 2018). Within the CMT there is a notable difference to that: creating meaning does not automatically imply hope and optimism (see 5.3.5). It also includes a primarily existential attitude to life, where the here and now, the way things are can provide meaning. Creating meaning does not need to focus on the future and happens even when hope is a faraway dream or does not exist.

> “So what is it that people are doing when they appear not to be taking up ‘the work of recovery’, when they do not appear to be trying to cope with, manage, or have a life in the face of mental illness?” (Davidson and Roe 2007, p.466)

The answer to this question could be that they are still creating meaning. Davidson and Roe (2007) think about people who, due to the severity of illness, life experiences and personality traits are neither in clinical recovery from serious mental illness, nor in a process of personal recovery. Supporting people in their process of creating meaning, valuing and honouring the effort of those people in surviving, might be a first step to lead them into a process of personal recovery, or at least into a state of relative well-being. Therefore, creating meaning can be a process within personal recovery but also an independent one without or before the ‘work of recovery’ (Davidson and Strauss 1992). However, both, personal recovery and creating meaning are active, highly individual, non-linear and unique processes that people living with mental illness might be going through. They are ways of adaptation to illness or as I prefer to say ways of adaptation to life with illness.

Personal recovery and creating meaning are processes which service users do and experience themselves. Person-centredness is an approach to care and treatment that is the responsibility of health-care professionals. Person-centredness (see 2.3) is crucial to any care approach that focuses on personal recovery of service users or on their process of creating meaning. Person-centred care is not only the individualisation of care and respect for service users’ rights but includes the recognition of the whole person beyond his or her illness (Mezzich et al. 2016a). Therefore, person-centred care is humanising care.

> “The therapeutic relationship between the professional helper and the person involves a temporary act of unison. They are like dancers united in the dance. Effective nursing involves *caring with people*, rather than caring *for* them or caring *about* them.” (Barker and Buchanan-Barker 2005, p.23)

This is exactly what participants in this study describe when they are talking about positive and supportive experiences with mental health professionals. Person-centredness is an important component of recovery (Ellison et al. 2018) and the foundation of recovery-focussed mental health services. McCormack and McCance (2017) argue that working with service users’ beliefs and values, engaging authentically, being present and sharing decision-making are key aspects in a person-centred care process. These aspects mirror what our participants expect from good care experiences. However, providing person-centred and holistic care is a difficult task. The Tidal Model (Barker and Buchanan-Barker 2005) which is a model of person-centred care with, not for, people with mental illness, focuses on their needs for security, their capacities for adaptation and existing resources. However,

> “The Tidal Model acknowledges that we should aspire to do as *little* as necessary to help support the person in making personally meaningful and appropriate life choices.” (p.26)

As our data show, therapeutic relationships and professional services may be important in the lives of those living with mental illness, but they are not everything. Therefore, holistic and person-centred care could also mean withdrawing as a professional when self-responsibility or others become the supporting pillar in a service user’s life.

In conclusion personal recovery and creating meaning are two separate processes in the lives of those living with mental illness. Creating meaning can be part of or initiate a personal recovery journey but it stands as an independent process. Person-centred care is the way to support people in their processes of personal recovery and creating meaning.

5.4 Reflections on Methodology

Methodology is an important aspect in any PhD study. For the original research idea that included developing a questionnaire (see Section 1.2), methodological choices would have been quite different to the current project and most likely would have contained a combination of quantitative and qualitative research methods that are often used to enhance the validity of questionnaires (Parahoo 2006). However, I have serious questions when it comes to these research approaches, because I am extremely critical of the development of research to date in the health-care sector. The focus is still too much on measurable insights and empirical knowledge and does not take enough account of people's experiences, feelings and individual well-being. We construct explanations based on statistics, experiments, imaging techniques, systematic reviews, and more and forget that reality is not a fixed quantity or given, shifts between perceptions and perspectives and is constantly changing. However, from a less personal and more academic perspective, it is clear that different questions demand different research methodologies. Nevertheless, maybe because of my own experiences in life (see 1.6), dominant views, norms and standards in the sense of quantified normality or majority norms have never really appealed to me and therefore, I have always been interested in the ‘other perspective’ and a holistic view of life and being.

Such an underpinning philosophy of wholeness can be found in the Science on Unitary Human Beings (Rogers 1990; 1994). Therefore, I would have loved to conduct a Unitary Appreciative Inquiry (UAI) (Cowling 2001; Cowling and Repede 2010), a research approach based on Rogers’ theory that I critically reflected upon before (Wolfensberger 2008b, 2008a). UAI is a research method that tries to provide an understanding of the wholeness of life in creating a participatory context “that leads toward transformation and emancipation of those involved” (Cowling and Repede 2010, p.73). However, even though the present research project supports a qualitative approach, choosing a hardly known and not widely established methodology for a PhD research project would have become an almost unmanageable challenge. Therefore, I had to find another qualitative method. A method that first of all had to fit the aims and objectives of the study, before other criteria such as personal preferences could have been considered. Grounded Theory (GT) as widely used and accepted methodology with its multi-layered further developments proved to be a good choice. Why I chose a constructivist and reflexive approach to GT has been previously outlined (see 3.1).

Therefore, the next section provides only a brief critical reflection on the chosen methodology for this PhD research project. Additional critical reflections on specific aspects of the research process are outlined in the methodology chapter (see 3.3) and further below in limitations (see 5.5.2).

5.4.1 Grounded Theory

The constructivist and reflexive Grounded Theory approaches (Charmaz 2014; Breuer et al. 2017) have had good congruency with my own values and understanding of qualitative research and my own role in the research process. As outlined in Chapter 1, I see myself not only as a researcher in this process but also as a unitary human being who is in constant interaction with myself and others. The chosen methodology supports or even demands constant reflection. Additionally, the self as a researcher plays an important role in all Grounded Theory approaches (see 3.2.1*ff*). Within classic Grounded Theory (Glaser and Strauss 1967; Glaser 1978) the researcher's role is understood through the underpinning philosophy of symbolic interactionism, whereas Charmaz (2014) and Breuer et al. (2017) more explicitly describe the researcher as a part of the investigation, analysis and interpretation of data, rather than a neutral observer. It is this specific view of the role of the researcher that made Charmaz's (2014) constructivist and Breuer et al.'s (2017) reflexive approach to Grounded Theory more applicable to my PhD project.

Even though there was an initial focus on uncertainty in illness among people living with mental illness, it soon became clear that the focus of this research project should be on participants' experiences, with no preconceptions. Therefore, choosing a Grounded Theory approach seemed suitable. Grounded theory is not a linear but rather an iterative or circular research process that has multiple layers and one of its advantages is that it leaves the outcome of the study completely open within the process. Therefore, the method facilitated a process that I would describe as 'diving deep into the data, swimming, almost drowning, resurfacing and finally going on shore, fully knowing how the water tastes, smells and feels like'.

However, that process of ‘diving deep into the data’ was a difficult one as I have outlined in Chapter 3.3. Having originally started using a computer-assisted qualitative data analysis software and persisting with it for quite some time, I found the software more and more exhausting and unsupportive in collecting and connecting all my thoughts and the constant comparison process. I could not find a way to use the software meaningfully for this complex process of constructing Grounded Theory. However, the constant comparison process with one of my supervisors as well as the ongoing reflection about codes and categories, themes and constructs with the whole team and the consultation of additional sources, were still key for me.

In conclusion, the chosen methodology provided focus and flexibility at the same time and has proven to be congruent with the aims and objectives of this research project (see 5.2).

5.4.2 Preliminary Study

The idea to use the platform of an international mental health nursing conference for a discussion on the topic of uncertainty in illness among people living with mental illness came up early in the process of the initial search of the literature. However, conference presentations are usually limited to poster or brief verbal presentations, where the discussion with participants is short and limited. Using a workshop space of an hour to conduct a focus group interview was a rather new idea. Fortunately, the idea was well received and was accepted (see 3.4).

The choice to conduct a single focus group was related to the setting described above and to keep the effort of this preliminary study small. What speaks in favour of a focus group has already been discussed (see 3.4.4). Qualitative thematic analysis (Braun and Clarke 2006) was chosen for similar reasons as those that led to the implementation of a focus group: limiting the effort while still being able to show a meaningful result. The method proved to be suitable and provided a clear and easy to use framework for data analysis. However, considering the original aim of the preliminary study ‘to explore the concept of uncertainty in illness among mental health nurses and to provide an understanding of its relevance to people living with mental ill health’ (Wolfensberger et al. 2019), it could be argued that another methodological approach such as a Delphi technique (Keeney et al. 2001) could have provided more in-depth view and consensus on the topic.

> "However, as it was not the intention to achieve consensus about the meaning of the concept of uncertainty in mental ill health, an exploratory approach using a focus group seemed appropriate" (Wolfensberger et al. 2019, p.185).

The statement indicates that to fully understand methodological choices, one not only needs to consider the aims and objectives of a research project but also the researcher's intentions behind these.

5.5 Limitations

As in all research projects there are limitations, ranging from the methods chosen to the findings and more. The biggest limitations are those inherent to this PhD research project: limited time resources that could be invested in the project or the challenge of multilingualism and the translation of spoken colloquial language into a written form of another language (see Section 3.3.6). Additional challenges include how to limit the points of discussion and reflection because the topic is potentially boundless. It is easy to lose oneself or get carried away in philosophical thoughts and arguments. However, this is part of the personal reflection process and learning experiences (see 6.5.2). Therefore, the limitations here focus on the findings and methodology of the main study. Limitations concerning the preliminary study are outlined in the respective publication (Wolfensberger et al. 2019).

5.5.1 Limitations Concerning the New Theory

The strengths of the Creating Meaning Theory (CMT) are sufficiently outlined in the findings (see 4.3*ff*) as well as in the discussion (see 5.3). However, depending on the reader's perspective, some strengths could also be seen as weaknesses or limitations. One of these limitations is that within the CMT the different categories are not mutually exclusive and have several overlaps. This can be said about all three categories and any connections between them. This fluidity within the CMT potentially weakens the understanding and comprehensibility of the theory. Another potential limitation that depends on the reader's perspective is that all elements of the CMT can also be found in the existing literature about personal recovery and therefore, the knowledge gain of the CMT could be questioned. However, this criticism is sufficiently refuted and discussed elsewhere (see Sections 5.3.2 and 6.1).

A clear limitation is that the CMT has not been directly discussed with the participants of this study to verify its credibility. However, the findings have been used to inform my own clinical practice including the development of a group therapy. Constant reflection with the group therapy's co-leaders and the participants of the sessions serve as a form of sounding-board and as an implicit verification process of the CMT. Additionally, I used and still use the findings of this research project in various other discussions and conversations with health-care professionals, service users and other people interested in adaptation processes. Nevertheless, the verification of the CMT by the participants of the study is missing.

5.5.2 Limitations Concerning the Methodology of the Main Study

A critical reflection on the choice of the methodology of the main study can be found above (see 5.4.1). However, these are the limitations that need to be pointed out in regard to the use of the methodology and contextual factors such as the research context and sampling issues:

a) As described in the research process section (see 3.3.2, 3.3.3 and 3.3.5.5), data collection and sampling have not been in full accordance with the Grounded Theory methodology. Nevertheless, the rigorous data analysis process still proved broad consistency with the methodology and theoretical sampling.
b) Auditability to confirm the trustworthiness of this study (see 3.3.7) is only generally described but lacks an exact representation based on examples of how the analytical process was progressed. This is due to the relatively flexible, long-lasting, iterative nature of the data-analysis process, which was not consistently documented in each phase.
c) Sampling was limited to people living in Switzerland. All participants were in a fairly stable health condition and there were no differences in the main cultural affiliation and ethnicity among the participants. Additionally, no participant seemed to belong to another significant minority group such as for example sexual minorities, physically disabled people, the homeless

population or any another affiliation that may have led to multiple stigmatisation. The relative homogeneity of the sample may have limited the expressiveness of the narratives and potentially also the validity of the findings of this study. However, ensuring credibility and validity in qualitative research is a controversial topic and is discussed in the methodology chapter (see 3.3.7).

d) The research context within the Swiss health-care system is another relevant limitation of this study. Even though accessibility of different health-care services varies in Switzerland as well, all participants had access to a variety of mental health-care services and could use them whenever needed. Narratives of people living in other countries with different experiences or even no experiences with mental health care could have added to the findings of the study. There is no such comparability within this study.

6 CONCLUSIONS

Private Library, Sternenberg, Switzerland, 2019

“Man is reaching out for, and actually reaching,

finally attaining, the world – a world, that is,

which is replete with other beings to encounter,

and meanings to fulfil”

(Frankl 2014, p.17)

6.1 What This Research Adds to the Body of Knowledge

Much is known about personal recovery in mental health care and numerous studies support that knowledge around adaptation to illness and living with mental illness. One could say, the bookshelf is filling up with knowledge around this topic, as the picture at the front of this chapter suggests. However, the present study was not conducted to confirm or refute existing models or theories; rather to describe the process of living with mental illness from a patient perspective. Out of that investigation the Creating Meaning Theory (CMT) has emerged, an original theory that provides a new and unique understanding of the adaptation process to living with mental illness from a service user perspective. Creating meaning is a non-linear, rather infinite and ongoing process in the lives of those living with mental illness. Therefore, the CMT, with its new and unique content, adds to existing knowledge around personal recovery in mental health care and other adaptation to illness theories.

The CMT highlights some profound insights into several aspects of the individual process of adapting to living with mental illness. One of those aspects is understanding what is going on throughout the process of illness experience and what might have led to becoming ill; it is about constructing explanations to understand and make sense of what is going on. A second aspect is the process of defining or redefining self-identity that goes along with the adaptation process to illness and finally it is the aspect of finding a sense-of-life and taking control over one’s life and therefore, in its final conclusion, creating meaning in life. Creating meaning is what people living with mental illness ‘do’ and listening to what they have to say is what professionals need to do to understand that process and be able to support it.

It is the voices of the people living with mental illness that distinguish and differentiates the CMT from other theories and models. Voices that need to be heard and have found their expression in this conceptual model. In summary, the findings of this study contribute to a much-needed discussion in the field of mental health and psychiatric care about its dedication to person-centeredness and recovery-orientation.

6.2 Conclusions for People Living with Mental Illness

As the focus of this research is on the experiences of people living with mental illness, there are several conclusions, based on their stories, that can be outlined for that population. These conclusions are also relevant for mental health professionals as they may help them to better understand the situations of service users. A profound understanding of the experiences of people living with mental illness can be beneficial for professionals in developing more service-user friendly, person-centred and recovery-oriented approaches of care. However, as the results of this study show, the experiences of people living with mental illness are highly individual and vary widely. Therefore, generalisations are only possible at a higher level of abstraction.

The following are the key conclusions for service users:

- **The uniqueness of each situation:** This research suggests that there are no two exactly identical or similar life events, neither in one's own life nor in comparable life situations of other people. Every single situation is unique and experienced individually. Therefore, no one can fully anticipate or know what to expect from such unique situations. However, friends and relatives, peer supporters, other persons concerned and health-care professionals who appreciate that uniqueness may offer helpful support in sharing their own concerns, knowledge and experiences. Nevertheless, the specific experiences and their evaluation, as well as the implementation of possible changes, remain the responsibility of the individual service user.
- **The responsibility of the service user:** As long as the ability to judge is not fundamentally questioned, or has been medically disqualified, an adult service user is considered responsible for his or her actions and capable of making decisions. Therefore, that responsibility should not be taken away easily and needs to remain with the service user as long as possible. However, the ability to make informed decisions depends not only on legal possibilities and whether sufficient information is available, and alternatives have been identified, but also on the conscious willingness and ability of the service user to take responsibility for him- or herself.

- **Different understandings in health-care services:** The accounts of the participants of this research show that the uniqueness of each situation that people living with mental illness find themselves in and the responsibilities they have in dealing with their situation may be valued differently in different health-care services and among its personnel. Depending on the underlying value system or understanding of mental health and mental illness, the treatment approaches may differ widely. An individual and person-centred approach to treatment and professional support with the aim of personal recovery is not carried out equally everywhere. Therefore, service users may find themselves confronted with knowledge or attitudes that do not match their personal needs for help and support. Similar experiences occur in non-professional settings such as in their own environment among family and friends or colleagues.
- **Finding a common ground for treatment:** According to the participants of this study it is essential to find some common ground for treatment with health professionals leading the case. Even if a common understanding or appraisal of the situation cannot be achieved, it is a minimum requirement that they can agree on a treatment approach, where the service users' needs and value system is considered and validated. Without a common ground it is difficult to develop a professional relationship between the service user and the health-care professional.
- **Seeking support where it is available:** Sometimes help and the initial or immediate support needed rests in the hands of people in one's own environment such as family members, friends, colleagues or other people with mental illness experiences. It takes a person who listens, believes what the service user tells them and who does not judge the person in need. Participants found such relationships in various contexts and describe them as helpful and supportive because they involve openness, trust and a caring, non-stigmatising attitude. However, that does not mean that professional help should be neglected or dismissed, but that some important aspects of empowerment may start or happen outside of institutionalised health-care structures. Professional help is often unavoidable, but the majority of someone's personal recovery process takes place in their own personal environment.

In conclusion it can be said that the creating meaning process, or personal recovery process, as it would be stated elsewhere, that participants describe in this study, is an on-going process with no clear starting point or final goal apart from living a fulfilling life. The findings reveal that no matter how difficult, severe or painful some experiences may be, there are ways of dealing with them and moving on in one's life. Even though there are no generally valid answers to the most important questions of life that apply to all, it still became apparent that a person with mental illness can trust the process of creating meaning or personal recovery. Some people may call this confidence in the process hope.

6.3 Relevance for Nursing Practice

What are the implications of the findings of this PhD project for nursing practice? As a mental health nurse, I reflected on this and came to the following conclusion: The important shift for nursing practice is a change of perspective, i.e. nurses need to learn to see and value patients' needs from patients' perspectives rather than from their own. Mental health professionals, including nurses, tend to judge and interpret statements and perceptions automatically with their own professional knowledge which may lead to false conclusions or the setting of wrong priorities. In doing so, nurses often adopt an institutional or medically oriented stance on treatment without critically reflecting on what it would mean to fully incorporate a person-centred and personal recovery-oriented position that really supports patients' needs.

The stories of the participants of this study show that mental health care in Switzerland still very much fluctuates between a clinical and a disability model of care (see Table 2.1) both of which value external evidence and professional knowledge higher than patients' perspectives. This is in contrast to the growing body of knowledge of new treatment approaches such as person-centredness and recovery-orientation, which are often said to have already been introduced and implemented.

Trying to see through the patient's eyes needs communication and interaction, creating trust and being fully human rather than being the professional who is assessing, categorising and diagnosing. This does not mean that nursing assessments are not important. A professional assessment can be useful to specify or clarify patients' needs or help guide supporting treatment measures. However, as mentioned before, it is a matter of attitude and of adopting the patient's perspective. In Switzerland, it is not the nurse's task to make a medical diagnosis and therefore, nurses can focus on the activities of daily life and the corresponding functional abilities of the patient in these. In doing so, nurses can be the patient's advocate or psychological parent.

This understanding of the role of the nurse is not new though and various examples of participants of this study show that it still exists. Therefore, it just seems that nurses and nursing practice need to be reminded of it. The following aspects were generated from critical examinations of statements of the study participants. These aspects provide insights into what service users actually expect from nurses. However, not all of these aspects were explicitly mentioned for nurses only but actually for anyone who wants to support service users:

- **Listening & being present:** This first and most important implication sounds quite simple and yet, is apparently often lacking: Nurses and other health-care professionals need to listen to people living with mental illness and hear what they have to say, read between the lines and try to figure out what is important to them. This is indeed not an easy task, as it demands profound communication skills but even more so an open heart and mind, and an integrating and positive basic attitude towards people with mental illness. Additionally, to listen carefully, even when nothing is being said, needs presence. Being present is not only a matter of time but requires an honest and inner willingness to get involved with the other person. Unconventional and new approaches and ideas may be heard in listening to service users. Active listening and being present in a non-judgmental way are the first steps in building trust and in being recognised as a human being rather than a task-oriented, 'never has time anyway' professional, a statement all too often heard from service users.
- **Questioning:** Along with the first implication goes the second one, it is almost inevitable: Nurses need to critically challenge and question their own knowledge and ideas with what is heard from and conveyed by service users. This includes critical reflections on treatments that are well known, even if they are so called 'evidence-based'. This is nothing more than a professional way of critically examining existing knowledge and

placing it in the context of the current situation which always includes the service user's values and ideas. This process could be called reflective practice (Johns 2004; Rolfe 2005). In mental health nursing, questioning and reflective practice are key to a person-centred and personal recovery-focused approach.

- **Advocating:** Mental health nurses need to be advocates for psychiatric patients in terms of seeing them as the main experts in their illness and supporting them in what they want, seek and need in accordance with universal human rights. It seems that particularly in hospital environments service users often feel isolated or mistrusted due to their current mental health crisis and because their power of judgment is questioned or denied. The latter often seems to be an excuse or even the justification for coercive measures or other dehumanising approaches. It is not only in these moments that service users need someone who trusts and supports them. Nurses could be that someone, even if a situation demands a position that seems against their clinical expertise or knowledge. Being the patient's advocate in such potentially humiliating situations may bring back a sense of humanity.
- **Supporting personal recovery:** Participants ask to be supported in their personal recovery process. The first three implications that have been stated above (Listening, Questioning, Advocating) form a good basis for appropriate support in personal recovery. Additionally, nurses can provide the information that service users need to be empowered in decision-making processes. However, as stated at the beginning of this section, supporting personal recovery requires a shift from a clinical and paternalistic model of care towards a more person-centred, empowering approach that tries to convey and build hope and purpose for people living with mental illness. This demands a personal attitude that should be positive and optimistic about change and that is accepting and values diversity and different forms of living.
- **Speaking up:** This is the only aspect that was not directly mentioned by the participants of this study. However, hearing their stories and experiences, one cannot deny that their voices need to be heard not only within health-care environments but also in the context of broader society. Belonging to a marginalised group of people, service users can use the

support of professionals such as nurses in getting the attention deserved for their concerns and needs. The aspect is also highlighted in the recommendations (see Section 7.3.2)

6.4 Adding to Knowledge for Mental Health Care

As discussed in the previous chapter (see Section 5.3) and outlined at the beginning of the conclusions (see 6.1), the Creating Meaning Theory (CMT) adds to existing knowledge of person-centred and personal recovery-oriented mental health care. Additionally, many aspects that have been pointed out as conclusions for people living with mental illness (see 6.2) and that are relevant for nursing practice (see 6.3) apply in a figurative sense also to mental health care. The ones that are most relevant are listed and summarised here. The following three aspects stem from the conclusions for people living with mental illness and use their respective titles:

- **The uniqueness of each situation:** Any situation, any crisis is different for each person and each time. Even though some participants value the knowledge of their specific illness and medical diagnosis, their illness experiences, the occurrence of symptoms are always different and vary each time they occur. Therefore, only individualised care and treatment approaches seem to be appropriate and they need to be re-evaluated each time.
- **The responsibility of the service user:** It seems that service users' power of judgment is often questioned or denied and (mis-)used to enforce unwanted treatment or even coercive measures. However, it would be extremely important to always involve the service user in the responsibility for treatment and the corresponding decision-making process. According to several statements of participants this is all too often missing.
- **Finding a common ground for treatment:** Sometimes it does not seem possible to find a common understanding or appraisal of the situation between a service user and health-care professionals. However, even in these situations a common ground for treatment that considers and validates the service user's needs and value system could be sought.

The next two aspects stem from the issues pointed out as relevant for nursing practice:

- **Listening & being present:** This seemingly simple task is what most participants value very highly of mental health professionals but is often lacking. Behind it lies also the legitimate claim to a professional attitude. However, from a service user’s perspective and what participants of this study expect, this can only be a person-centred and recovery-oriented attitude that values the individual’s situation.
- **Supporting personal recovery:** As previously stated, supporting personal recovery requires a shift from a medically oriented understanding of recovery (see 2.8) and paternalistic model of care towards a primarily person-centred, empowering approach. Because personal recovery is different for every person, there is no other way than asking service users what they want to achieve, as participants of this study suggest.

The aspects outlined above are quite broad and generic. However, there is another issue that has not been mentioned so far and also adds to the knowledge for mental health care: Participants remember and talk about numerous experiences with mental health professionals and treatment experiences within the mental health-care system but neither professional and therapeutic relationships nor the use of medication or other specific treatment options are mentioned as most important in dealing with their illness. This personal assessment of people living with mental illness in relation to professional services and the use of medication and treatment seems quite inconsistent with the majority of the treatment options in mental health care that often focus on proper use of medication and psychotherapy.

However, participants do not deny the value of mental health services or the use of medication and other treatment options in context of their illness. Most of them are still using one or the other to varying degrees. It is not even the relevance of the services that is questioned, but the overall impact of mental health treatment and the therapeutic relationships with health-care professionals in their lives. This quite clearly shows how mental health professionals and service users view treatments and their effects differently. Mental health professionals including nurses often see their efforts in clinical practice and the use of specific treatments as of upmost importance and indispensable to their service users. And they probably are in these moments: preventing suicides and self-harm, helping service users through all kinds of crises and supporting them in the process of rehabilitation and reintegration into the ‘real world’ are all important tasks.

Participants value all of that but point out that the main factor for personal recovery is always the service user him- or herself and his or her own environment, which consists of so much more than professional services and support. Not a single participant said that mental health services saved their life but rather recall traumatic experiences, especially within closed wards in psychiatric facilities. Quite often in the context of acute psychiatric wards positive experiences are countered by several negative ones. Among those are also the lack of well-coordinated interdisciplinary and interprofessional treatment approaches between doctors, therapists, nurses and the service user. People living with mental illness are their own experts who may need some help to recognise and understand this and to use this expertise effectively, but it seems that they are often not even involved in decision-making processes.

Therefore, mental health services and their professionals are encouraged to focus more on a personal recovery-oriented approach. Even though they are only a small cog in a big and complicated wheelwork of a service user’s life, where they might be a crucial one at times, but never the only one that matters, it is important that mental health services continue to exist and fill the gaps where and when they are needed. However, it is helpful to understand health and illness more holistically than dualistically and move towards a social disability model (Sayce 2000) rather than remaining in a clinical model with a cause, treatment and effect framework.

Hopefully, promoting empowerment and working with a person-centred and individual recovery-oriented approach will increasingly become the guiding framework for mental health services. Personal recovery means so much more than recovering from an illness or injury and includes first and foremost a confrontation with the whole self and life, a deeply personal process of creating meaning.

6.5 Personal Learning Experiences

Doing a doctoral degree has affected all domains of my life. The section is divided in two subsections covering learning experiences in my personal and my professional life including the challenge to balance the different life domains as a researcher, a health-care professional and a human being.

6.5.1 Challenging Balance of Life Domains

Castello et al. (2017) argue that the challenge of maintaining a balance between work, personal life and doctoral studies is the most common motive of post graduate students intending to drop out of a doctoral programme and that it is significantly higher among part-time students than among full-time students. Organising and keeping a good balance of life domains has certainly been my biggest challenge throughout the process of achieving a doctoral degree. This has been especially difficult due to the fact, that I am studying part time and have a demanding job. Even though I never considered doing the doctoral degree full time because of my personal life situation, it certainly is an issue that I have underestimated. One of the challenges has always been prioritising the high demands of both the doctoral studies and the work situation. Looking back, it probably would have been easier not to retain or take on certain responsibilities at work in order to have more capacity for the thesis. However, it is unclear what implications such decisions and limitations would have had for my ongoing career.

Now, towards the end of the writing process of my doctoral thesis, it is clear that the original timeline was far from realistic and had to be adapted and extended several times. The whole process took much longer than expected. However, I never intended to give up and drop out and have learnt to set realistic intermediate goals and to achieve them with the different possibilities available to me. In all this, the support of my supervisors and my employer has been indispensable.

I am sure that I could only get through this long period of studying and working because I have always maintained a nurturing private life with my husband, our dog, family and friends, and most of my hobbies. Of course, there were some sacrifices, such as reducing time in the chorus, abandonment of other commitments, fewer visits to the movies or concerts and hardly any holidays with my husband. And still, the relationship with my partner, his endless love, compassion and patience were and are my most important support. At the same time I learnt how important it is to do things just for myself, even though time with my partner, friends and relatives has already been reduced and limited. Hiking and long walks, enjoying nature and taking photos, became an important compensation and replacement for the lack of time elsewhere. Basically, I had to learn to do things more consciously and attentively and way more selectively due to my limited resources. Overall, I am proud of having kept a fairly good balance of my life domains. I still make jokes about it, saying that I should have written my doctoral thesis on how to keep a good balance in life. Well, actually, the current topic is not that far away from it.

6.5.2 Professional Life

Being a research student and a professional at the same time has been challenging as I have pointed out earlier (see 6.5.1). Fortunately, my working environment and professional network and commitment widely match and complement my area of studies. However, this was not clear at the beginning of my PhD studies (see 1.2 and 1.3). The process at the beginning of my studies helped me though to strengthen my commitment for my current working area in mental health care. Over time, the PhD project further supported that commitment of my working situation in clinical practice of mental health. Therefore, I can say now that the two areas, my PhD studies and my professional engagement, have mutually enriched each other over the past couple of years. I often talked about my PhD project in my working environment and professional network and could use these discussions for my self-reflective process about the project, the methodology and life as a post-graduate research student.

However, due to part-time studies and not being a full-time member of a research team or community, I lacked a permanent critical and scientifically informed discussion and debate. Therefore, keeping a clear and constant focus on my studies and research project was difficult sometimes. This applied especially to the process of constructing a Grounded Theory (GT) which I found extremely challenging. However, submitting several papers for conference presentations and presenting regularly were important tasks to keep the process going. Also, I am glad I have had an opportunity to prepare an article for publication. Writing the article and getting it published was a helpful learning experience. It not only helped to improve my skills in academic writing but also in defending and promoting the relevance of my research. Overall, I have improved my research skills and endurance in projects and more than ever I am convinced that I like to continue working with and for people living with mental illness.

Doing a doctoral programme has also facilitated extending my professional network. This is due to active networking, regular conference attendances and participation in professional discourses and health policy debates at institutional, regional, national and international level. Additionally, being an active member of the Academic Society of Psychiatric Nurses in Switzerland and the England Chapter of Sigma – the International Honour Society of Nursing is helping to build professional and even personal relationships. Being a doctoral student has also helped me to become a reviewer of a qualitative journal and a member of the scientific committee of an international mental health nursing conference held annually. All these forms of cooperation enrich the scientific and professional discourse and help me to continue to learn and grow as a professional but also and mainly as a human being.

However, the main learning experience for me as a professional is how much the stories of the people we care for as professionals enrich our understanding of what they need. This supports the chosen direction of professional development in mental health care with a clear focus on person-centredness and personal recovery. From now on, I will ask even more if what we do is what is needed and wanted, and in doing so it will hopefully strengthen the discourse between professionals and service users.

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7 RECOMMENDATIONS

Lighthouse, Nolsoy, Faroe Islands, May 2019

7.1 Chapter Introduction

In this last chapter of the thesis the knowledge gained from the results of this study and its discussion and conclusions are summarised and ‘translated’ in a number of recommendations and concluding thoughts. Over the last couple of years, I have come across many people who are very concerned about the issue of dealing with mental illness; mental health professionals, service users, friends and relatives alike. Looking back at many of those encounters it seems that there is quite a high agreement about what all these people consider important in dealing with mental illness or what they would claim for themselves if they were in such a situation. However, some of the experiences shared within this research project as well as many other accounts I have come across over the years, still show a different reality. Therefore, the following list of recommendations may also contain aspects that are probably well known to some and accepted by some but lack sustainable realisation and implementation in particular areas of mental health care or society in general. And even though this research has been conducted in the German-speaking part of Switzerland, the recommendations are not limited to Switzerland.

7.2 Recommendations for People Living with Mental Illness

In relation to the insights and findings of this research project and to the respective conclusions for people living with mental illness (see Section 6.2), the recommendations for service users are as follows:

- **Speak up, your story and your experiences matter:** As each situation of a person living with mental illness is unique and different, people who are meant to care and those who plan and do treatment need to hear and understand it from the service users’ individual perspectives and experiences. It is essential to build trusting relationships or to establish an individually personalised and person-centred care and treatment plan. In addition to that, individual stories and experiences, if made available, visible or hearable, may change public awareness of mental health and mental illness and therefore, can help to reduce stigma.

- **Take on your responsibilities:** Whenever possible and when service users are willing and capable they have to demand their involvement in any decision-making process concerning their own personal recovery process. Personal recovery is their process and needs to be owned by them. Therefore, no question is too much asked to understand something, no clarification is superfluous that contributes to mutual or personal understanding and every argument that takes a person further or beyond is worthwhile.
- **Show and demand humanity and respect:** Understanding of and attitudes towards mental health and mental illness and approaches to treatment and recovery may vary between service users and health-care professionals or other parties such as relatives or the public. As the owner of their personal recovery process service users need to demand humanity and respect from others that do not share their perspectives and values. Differences in understanding and approach then need to be addressed and displayed and common foundations must be sought to enable the relationship to continue. This is particularly important in a treatment situation.
- **Seek and accept help:** Owning the process of personal recovery does not mean that everything has to be done and achieved without help. In contrast, help must be sought when needed and should be accepted in the process when available or offered. Help can be provided by various sources including health professionals, friends and relatives or other service users. However, help that is offered but does not suit the service user's needs and cannot be adjusted to it, can be declined.
- **Stay connected:** Creating meaning demands connections and connectedness as they are essential for all aspects of the process. However, staying connected does not only mean building or uphold relationships with family and friends and or a professional support network, but also non-personalised connections to interests and hobbies. It can be just as much the little things of everyday life such as enjoying a walk in the woods or the joy of flowers on the table, a sunrise or anything else that brings joy and gives meaning to life. Connectedness helps staying alive.

7.3 Recommendations for Nursing Practice

With regard to the results of this research project and its many conclusions and their relevance for nursing practice (see Section 6.3) the following are the two main recommendations that need to be considered for future mental health nursing practice.

7.3.1 Focus on Patients' Needs and Their Process of Creating Meaning

Seeing through the patient's eyes is key to this first recommendation. In order to be capable of doing so and to put this first recommendation into practice, a number of conditions are required:

- **Stance and attitude**: Understanding and supporting a process of creating meaning can best be achieved if one's own attitude is person-centred (see 2.3) and consistent with the basic concepts of personal recovery (see 2.8).
- **Education and training:** Moving away from a paternalistic understanding of mental health care and developing a congruent attitude towards contemporary approaches needs knowledge and understanding of these concepts. Therefore, specific training is suggested as a means of learning about person-centred care, personal recovery and the key concepts of the Creating Meaning Theory (CMT). Such training should be included in all basic and continuing nursing education programmes as well as in clinical training programmes. Peer involvement is highly recommended (see below).
- **Structure and processes:** Person-centred recovery-oriented care and supporting a process of creating meaning demands adaptations of clinical processes and procedures to fulfil the requirements of truly holistic treatment. Good clinical leadership and management is required to enable individual care and optimal use of resources.
- **Service user involvement:** Implementation of peer support work in all fields of clinical practice and training and close collaborations with service user networks help patients and professionals in their reflection and in the enhancements of clinical practice and training contents.

7.3.2 Educating the Public

Whereas the first recommendation is about becoming more person-centred and recovery-oriented in clinical practice, the second recommendation takes up the social responsibility of nurses in the wider social context: Mental health nurses must take public and social action against the discrimination and stigmatisation of people with mental illness. Nursing does not end at the end of the shift or stay within clinical practice. In order to successfully raise mental health awareness in society and work towards anti-stigmatisation, certain actions are recommended:

- **Start with yourself:** Discrimination and stigmatisation always start with oneself. In order to fight against it, mental health nurses need to face their own prejudices, reflect on them and learn from available knowledge.
- **Speak up:** Knowing and self-reflection are not enough. Being a good nurse in clinical practice and working in a patient-centred and recovery-oriented way with patients is not enough. Nurses need to speak up whenever confronted with issues around mental health and mental illness. A proactive stance should be sought that can be heard.
- **Collaborate**: Collaborations with service user networks, mental health charities and public health organisations are essential to reach a wider audience. Public engagement in local groups and clubs or even in politics may be beneficial for educating people that cannot be reached elsewhere.
- **Listen to service users:** Personal and professional knowledge is important. However, in relation to educating the public about mental health and mental illness always include service users' views and use their advice. As professionals we are not the experts but allies.

Some of these recommendations may be formulated in a somewhat commanding way and that was quite deliberately done. Changes in the health-care system do not just happen when it comes to the well-being of patients. I personally hold the opinion that nurses are (co-)responsible for achieving the best possible results for service users and for advancing necessary developments. Therefore, a polite request and 'it would be nice' just does not seem enough. The same can be said about the following recommendations for developments of mental health care.

7.4 Recommendations for Developments of Mental Health Care

Most of what has been pointed out as recommendations for nursing practice, specifically the focus on patients' needs that includes a person-centred and recovery-oriented approach, applies to mental health care as a service in general as well and is considered inevitable. However, the following are the recommendations for developments of mental health care that are not meant for an individual care situation but on a systemic level:

- **Service user involvement**: No changes in services and developments without service user involvement. The expertise of service users needs to be valued and considered in combination with internal and external evidence. Assessing and evaluating what is needed and where to go in developing mental health care and its facilities and services always has to include service users' perspectives. Therefore, service user involvement has to take place on all levels of developments. Collaborations with service user networks and organisations should be sought at all times. In addition to direct participation of service users or their organisations, other forms of cooperation such as sounding boards or monitoring committees are also possible.
- **Optimising interprofessional and interdisciplinary collaboration:** The complexity of individual care situations, but also the growing specialisation within professions and disciplines and the health-care system as a whole, increasingly demands interprofessional and interdisciplinary approaches. Therefore, attention should be paid to the following aspects:
    - A mutual understanding of each profession's or discipline's specific competences and specialist areas (who can contribute what and why)
    - The coordination of tasks and responsibilities between the actors (also who coordinates them)
    - The exchange of useful and comprehensible information between the different actors
    - The use of a technical language or terminology that is understood by all (and could potentially be used by all)

    - The use of a common language with service users (eventually a shared terminology made comprehensible or no technical language at all)

  It all culminates in better understanding each other across professions and disciplines and in optimised communication with each other. If this could also include a better understanding and communication with service users, mental health care would gain a lot of credibility and trust.

- **Constant learning:** Demands and challenges in mental health care are continuously changing. At the same time, new knowledge is constantly being generated, also because increasingly research studies are being carried out with the participation of service users. Therefore, it is essential that mental health professionals do not stop learning and remain in continuous education to keep their knowledge up to date. Learning from each other, from other professions and especially from service users must be part of that process. Constant learning also means investing in knowledge development such as research that evaluates current or new treatment approaches or service user experiences.
- **Harmonising funding and legislation:** This recommendation applies specifically to Switzerland where psychiatrists are among the least paid doctors and contemporary mental health services such as home treatment are not sufficiently financed. Additionally, even though mental health-care services already work highly interprofessional, legislation does not provide mutual competencies as doctors still have to prescribe everything and are ultimately solely responsible for the treatment. Therefore, leaders in mental health care should work towards this much needed goal in harmonising funding and legislation.

7.5 Recommendations for Future Research

There are a number of recommendations for future research based on the findings of this thesis and its discussions and conclusions:

- **Service user involvement**: First and foremost, all research activities concerning mental health care must be able to ensure adequate representation of service users. Service user involvement should start at the very beginning in the development of future research projects.
- To further develop the Creating Meaning Theory (CMT) and to be able to use or implement it in clinical practice, **research on quality indicators** must be conducted**:**
    - to be able **to measure the process of creating meaning** as outlined within the CMT
    - **to measure attitudes** that support the CMT
    - **to develop specific knowledge** on the topic of the CMT that supports the process of creating meaning (from a service user and/or professional perspective)
    - With measurement and evaluation tools available that can be used for the CMT, additional qualitative or quantitative research could be conducted among different populations and with different characteristics (diagnosis or background specific, comparisons of people from different countries, etc.).
- To implement the CMT and its core aspects as a form of treatment approach into clinical practice, **action research or an intervention study** is suggested
- On a rather superordinate level though, **research on equal and supporting communication** is suggested, as it has been shown that communication and the use of language, misunderstandings and feelings of not being understood or heard, are important issues that service users experience in professional health-care situations. How can communication be improved?
- Another aspect at the outset of this project is **the influence of the attitudes of professionals** (see also the recommendation above 'quality indicators to measure attitudes that support CMT'): How important are

attitudes of professionals in the process of creating meaning or personal recovery of service users? There is whole range of possible research approaches from measuring attitudes to qualitatively investigating their effects on service users.

In addition to these suggestions, research supporting the further development, implementation and evaluation of other personal recovery-oriented care approaches are welcomed and will hopefully help to increase not only the quality of care but also the personal well-being of people living with mental illness.

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8 Concluding Thoughts

Bournemouth Beach 2017

With this short and last chapter the product and result of a long process of a PhD research project finally comes to an end. A photo of a beautiful sunrise at Bournemouth Beach introduces the beginning of a new era. Much has been written and discussed and a new model of adaptation to mental illness has been developed, the Creating Meaning Theory (CMT). The section is about my concluding thoughts.

Concluding thoughts could contain anything and everything. However, I will not summarise the whole thesis here nor will I try to create a glorious climax. Most issues that were important in the overall process of doing a doctoral degree and this unique PhD research project have been addressed sufficiently in this thesis. Therefore, I want to pause and look forward from my own personal perspective.

Seven years of my life were dedicated to this project, which is a very long time. Life goes on, mine as well as those of the people around me and the participants of this study. I am very fortunate and grateful that I had a chance to do this and to have been supported so tremendously. I enjoyed every bit of that process but most of all getting to know the participants and their stories. Some of them I have met again in various situations. They were and still are my biggest inspiration.

However, it is time to move on now and to look forward to what the future might hold in store for me. There is one thing that I am certain of; issues around mental health will always be an important part in my life.

> “If we add up all those humans who are or have been depressed, addicted, anxious, angry, self-destructive, alienated, worried, compulsive, workaholic, insecure, painfully shy, divorced, avoidant of intimacy, and stressed, we are compelled to reach a startling conclusion, namely, that psychological suffering is a basic characteristic of human life” (Hayes et al. 2012, p.4).

The quote illustrates the omnipresence of mental suffering. Professionally, this has always been and still is one of my core motivations to support people in dealing with such difficulties and helping them to move on. Now that I know even more about these processes and better understand the different dimensions, it encourages me to keep doing this and include creating meaning as a central aspect.

Nevertheless, I have also realised that there are aspects to which I would like to pay even more attention in the future and which I would like to explore further.

Among those are personal recovery and person-centred psychiatry that have already been part of this thesis. The issues raised in this thesis need further exploration and practical realisation. Additionally, I do want to focus more on spiritual care and spirituality that I have only slightly touched upon within this thesis.

However, the time to start new projects has not yet come. Before new activities can take place I need time for contemplation. Therefore, I would like to finish this thesis with another quote from Anna Biley's artistic excerpt from her doctoral thesis (Biley 2017a) in remembrance of her beloved husband and my dear friend and mentor Francis C. Biley. The quote and the beautiful picture of Bournemouth Beach at the beginning of this chapter invite the reader to pause and contemplate. I will not comment or explain that quote any further as it speaks for itself, fully knowing that it may not speak to everyone who reads it and may not be understood. However, that seems to be an appropriate ending for this thesis which emphasises the importance of understanding the experiences of people living with mental illness. Something we can only achieve in listening with an open heart: I certainly tried and listened. And I will continue doing that. There is always time to care!

"Re patterning birth,
inner knowing, intimacy and comfort,
sacred feminine, strength and mystery in purpose.
All is connected in the labyrinth,
memories, mindful touch, transcended pain,
simple humanity, compassion, silent dignity,
caring presence.
Nursing transformed into living purpose.
Ancient remembering"
(Biley 2017a)

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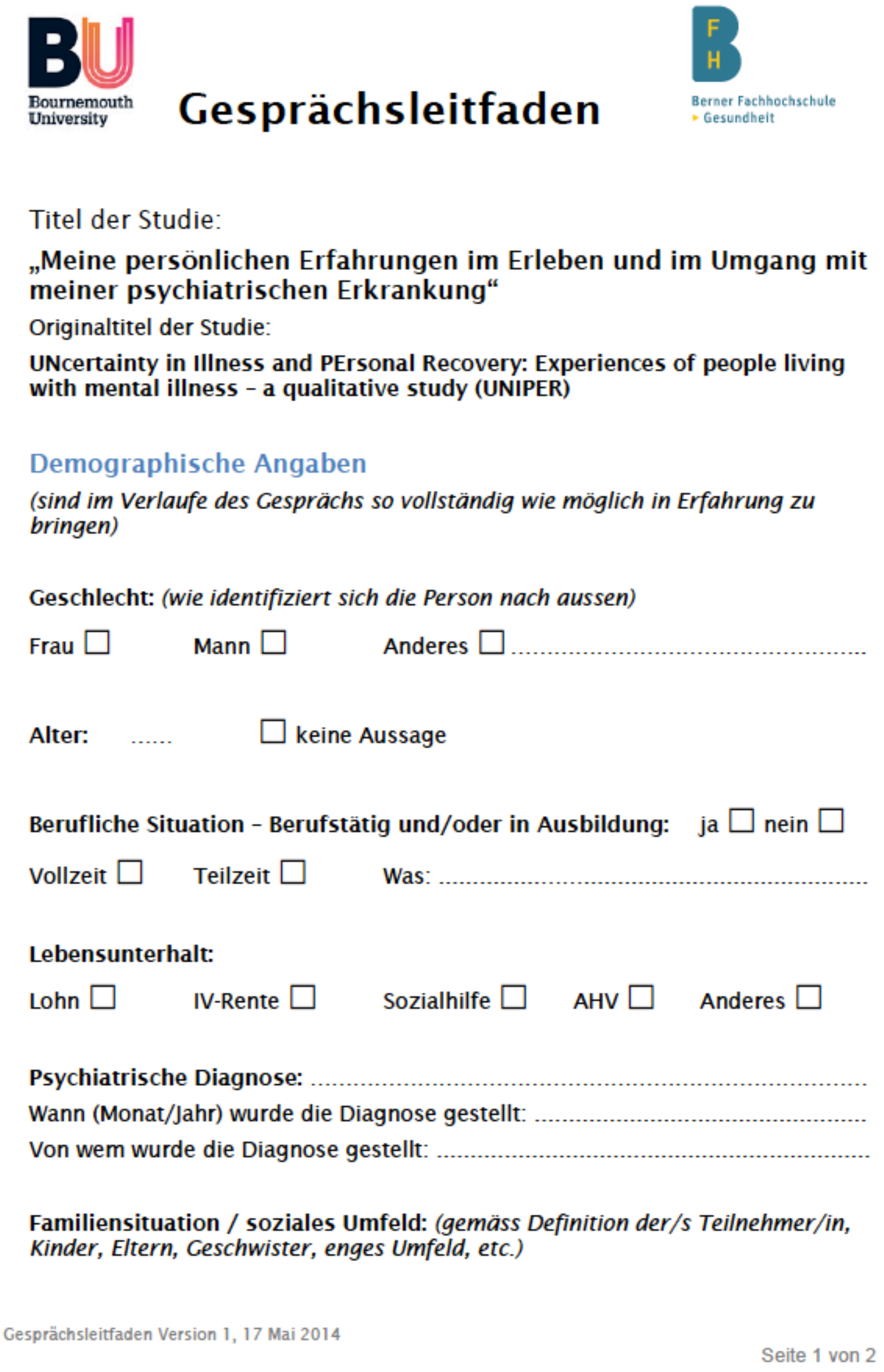
10 Appendices

10.1 Appendix 1: Interview Guide

(German and English version)



Gesprächsleitfaden

Titel der Studie:

„Meine persönlichen Erfahrungen im Erleben und im Umgang mit meiner psychiatrischen Erkrankung“

Originaltitel der Studie:

UNcertainty in Illness and PErsonal Recovery: Experiences of people living with mental illness – a qualitative study (UNIPER)

Demographische Angaben

(sind im Verlaufe des Gesprächs so vollständig wie möglich in Erfahrung zu bringen)

Geschlecht: *(wie identifiziert sich die Person nach aussen)*

Frau ☐ Mann ☐ Anderes ☐ ....

Alter: ...... ☐ keine Aussage

Berufliche Situation – Berufstätig und/oder in Ausbildung: ja ☐ nein ☐

Vollzeit ☐ Teilzeit ☐ Was: ....

Lebensunterhalt:

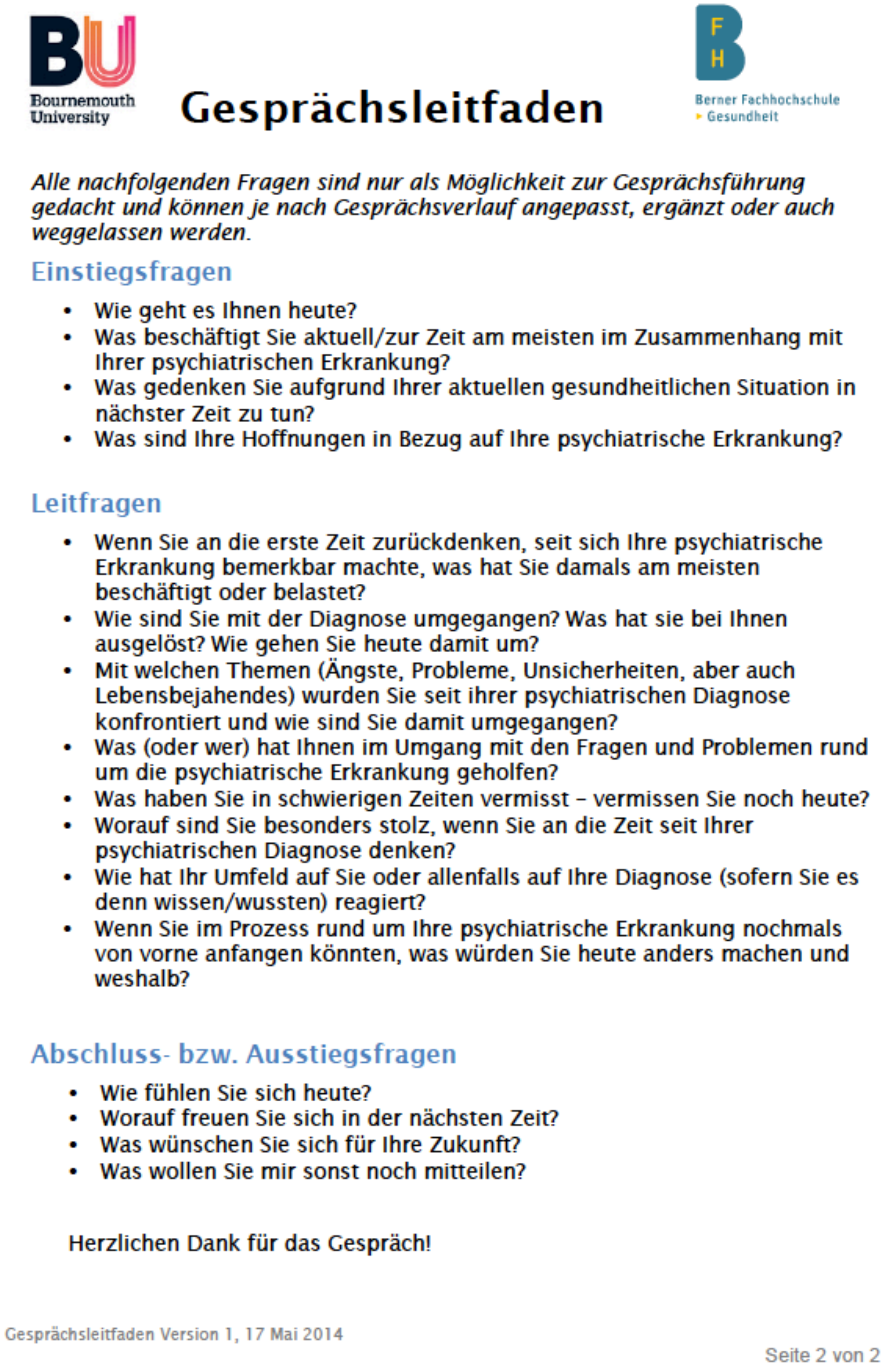
Lohn ☐ IV-Rente ☐ Sozialhilfe ☐ AHV ☐ Anderes ☐

Psychiatrische Diagnose: ....

Wann (Monat/Jahr) wurde die Diagnose gestellt: ....

Von wem wurde die Diagnose gestellt: ....

Familiensituation / soziales Umfeld: *(gemäss Definition der/s Teilnehmer/in, Kinder, Eltern, Geschwister, enges Umfeld, etc.)*



Gesprächsleitfaden

Alle nachfolgenden Fragen sind nur als Möglichkeit zur Gesprächsführung gedacht und können je nach Gesprächsverlauf angepasst, ergänzt oder auch weggelassen werden.

Einstiegsfragen

- Wie geht es Ihnen heute?
- Was beschäftigt Sie aktuell/zur Zeit am meisten im Zusammenhang mit Ihrer psychiatrischen Erkrankung?
- Was gedenken Sie aufgrund Ihrer aktuellen gesundheitlichen Situation in nächster Zeit zu tun?
- Was sind Ihre Hoffnungen in Bezug auf Ihre psychiatrische Erkrankung?

Leitfragen

- Wenn Sie an die erste Zeit zurückdenken, seit sich Ihre psychiatrische Erkrankung bemerkbar machte, was hat Sie damals am meisten beschäftigt oder belastet?
- Wie sind Sie mit der Diagnose umgegangen? Was hat sie bei Ihnen ausgelöst? Wie gehen Sie heute damit um?
- Mit welchen Themen (Ängste, Probleme, Unsicherheiten, aber auch Lebensbejahendes) wurden Sie seit ihrer psychiatrischen Diagnose konfrontiert und wie sind Sie damit umgegangen?
- Was (oder wer) hat Ihnen im Umgang mit den Fragen und Problemen rund um die psychiatrische Erkrankung geholfen?
- Was haben Sie in schwierigen Zeiten vermisst – vermissen Sie noch heute?
- Worauf sind Sie besonders stolz, wenn Sie an die Zeit seit Ihrer psychiatrischen Diagnose denken?
- Wie hat Ihr Umfeld auf Sie oder allenfalls auf Ihre Diagnose (sofern Sie es denn wissen/wussten) reagiert?
- Wenn Sie im Prozess rund um Ihre psychiatrische Erkrankung nochmals von vorne anfangen könnten, was würden Sie heute anders machen und weshalb?

Abschluss- bzw. Ausstiegsfragen

- Wie fühlen Sie sich heute?
- Worauf freuen Sie sich in der nächsten Zeit?
- Was wünschen Sie sich für Ihre Zukunft?
- Was wollen Sie mir sonst noch mitteilen?

Herzlichen Dank für das Gespräch!

Gesprächsleitfaden Version 1, 17 Mai 2014

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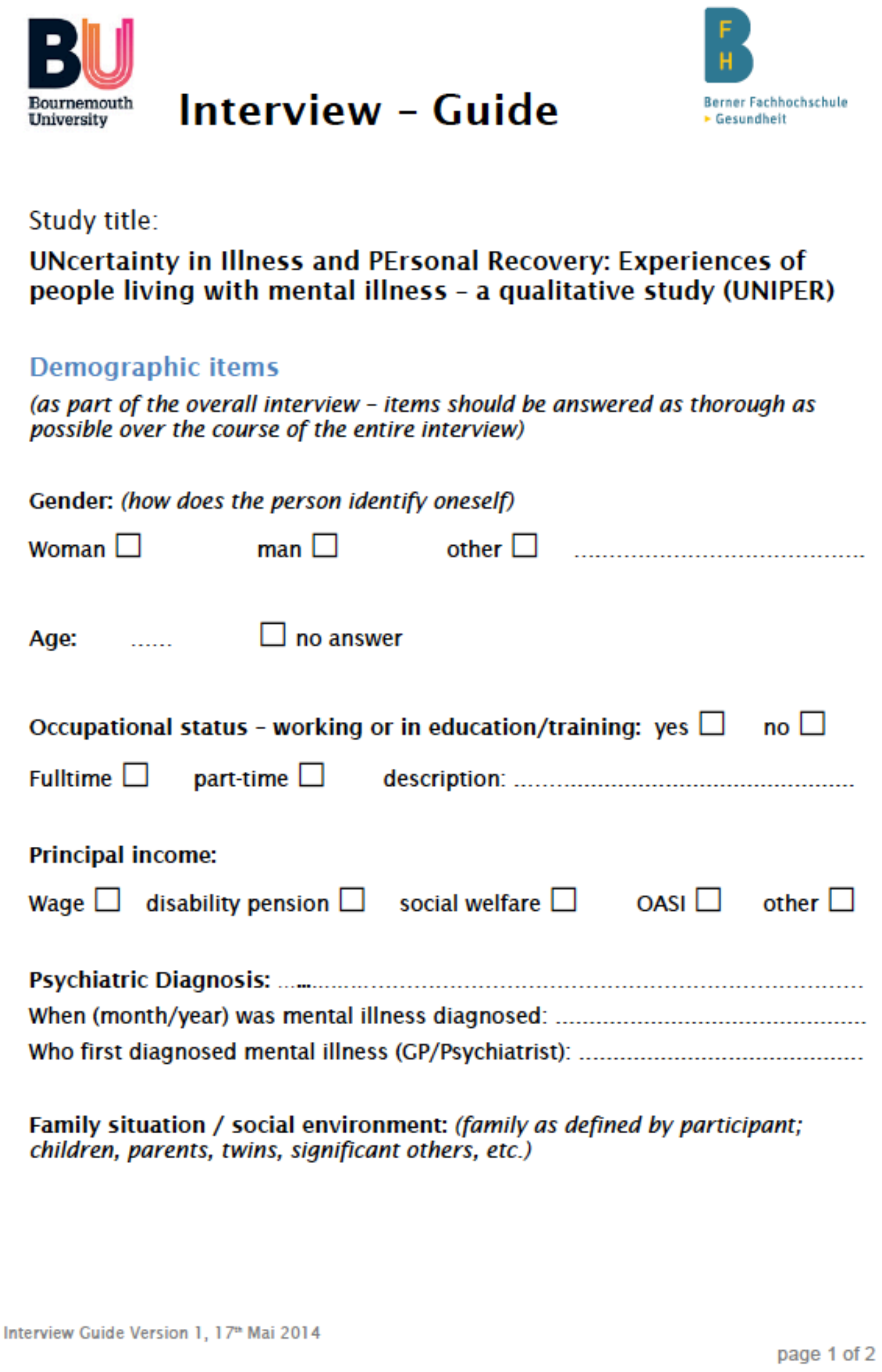

Bournemouth University

Interview – Guide

Berner Fachhochschule Gesundheit

Study title:

UNcertainty in Illness and PErsonal Recovery: Experiences of people living with mental illness – a qualitative study (UNIPER)

Demographic items

(as part of the overall interview – items should be answered as thorough as possible over the course of the entire interview)

Gender: *(how does the person identify oneself)*

Woman ☐ man ☐ other ☐ ....

Age: ...... ☐ no answer

Occupational status – working or in education/training: yes ☐ no ☐

Fulltime ☐ part-time ☐ description: ....

Principal income:

Wage ☐ disability pension ☐ social welfare ☐ OASI ☐ other ☐

Psychiatric Diagnosis: ....

When (month/year) was mental illness diagnosed: ....

Who first diagnosed mental illness (GP/Psychiatrist): ....

Family situation / social environment: *(family as defined by participant; children, parents, twins, significant others, etc.)*

Interview Guide Version 1, 17th Mai 2014

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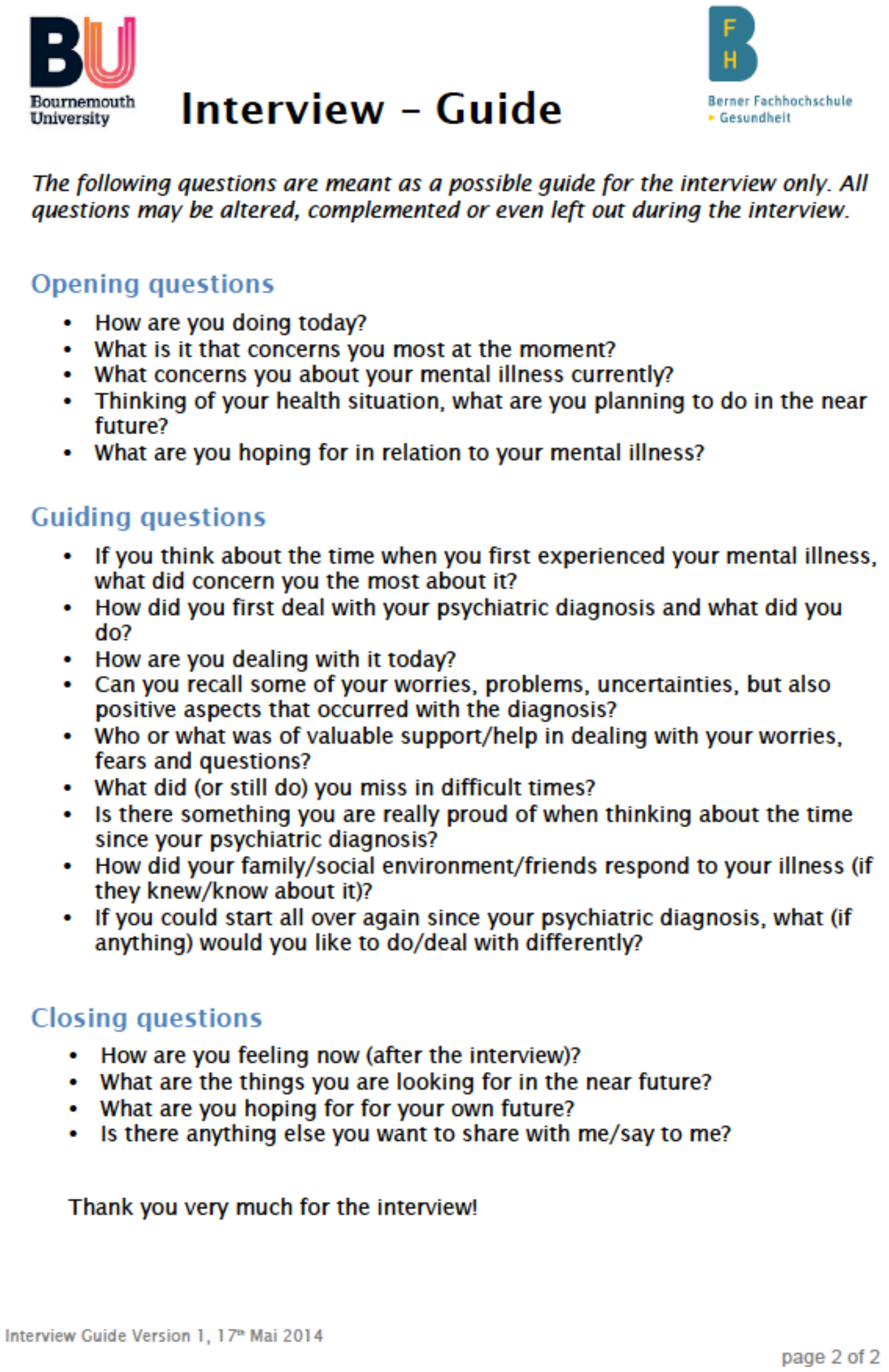

Interview – Guide

The following questions are meant as a possible guide for the interview only. All questions may be altered, complemented or even left out during the interview.

Opening questions

- How are you doing today?
- What is it that concerns you most at the moment?
- What concerns you about your mental illness currently?
- Thinking of your health situation, what are you planning to do in the near future?
- What are you hoping for in relation to your mental illness?

Guiding questions

- If you think about the time when you first experienced your mental illness, what did concern you the most about it?
- How did you first deal with your psychiatric diagnosis and what did you do?
- How are you dealing with it today?
- Can you recall some of your worries, problems, uncertainties, but also positive aspects that occurred with the diagnosis?
- Who or what was of valuable support/help in dealing with your worries, fears and questions?
- What did (or still do) you miss in difficult times?
- Is there something you are really proud of when thinking about the time since your psychiatric diagnosis?
- How did your family/social environment/friends respond to your illness (if they knew/know about it)?
- If you could start all over again since your psychiatric diagnosis, what (if anything) would you like to do/deal with differently?

Closing questions

- How are you feeling now (after the interview)?
- What are the things you are looking for in the near future?
- What are you hoping for for your own future?
- Is there anything else you want to share with me/say to me?

Thank you very much for the interview!

Interview Guide Version 1, 17th Mai 2014

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10.2 Appendix 2: Study Leaflet

(Original in German & English translation)

Bournemouth University

Berner Fachhochschule
▸ Gesundheit

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Gerne möchten wir etwas lernen über

Ihre persönlichen Erfahrungen im Erleben und im Umgang mit Ihrer eigenen psychiatrischen Erkrankung!

Information für interessierte Menschen &
Einladung zur Teilnahme an einer Studie

UNcertainty in Illness and PErsonal Recovery: Experiences of people living with mental illness – a qualitative study (UNIPER)

Ein Forschungsprojekt im Rahmen eines Studiums
zur Erreichung des Titels Dr. Phil (PhD) in Pflegewissenschaft.

Version 2, 27. Juli 2014

Sehr gehrte Interessentin
Sehr geehrter Interessent

Sie haben oder hatten eine psychiatrische Erkrankung und können sich vorstellen, uns über Ihre persönlichen Erfahrungen im Erleben und im Umgang mit dieser Erkrankung zu berichten. Dann würden wir uns freuen, wenn Sie an unserer Studie teilnehmen.

Worum geht es in dieser Studie?

In dieser Studie wollen wir von Ihren persönlichen Erfahrungen im Erleben und im Umgang mit Ihrer psychiatrischen Erkrankung lernen. Wir interessieren uns für Ihre ganz eigenen Erfahrungen rund um Ihre Erkrankung, was Sie bewegt und beschäftigt, worunter Sie leiden oder wachsen, was Sie bestärkt und mit welchen Unsicherheiten Sie konfrontiert sind. In einem persönlichen Gespräch möchten wir mit Ihnen diesen Inhalten nachgehen.

Es ist bisher wenig bekannt, wie Menschen mit einer psychiatrischen Erkrankung Unsicherheiten erleben und mit ihnen umgehen, oder welchen Einfluss sie auf den persönlichen Genesungsprozess haben.

Ihre Antworten dienen dazu, ein besseres Verständnis für das Erleben der Erkrankung aus Sicht der Betroffenen zu erhalten und daraus möglicherweise verbesserte Unterstützungsangebote abzuleiten.

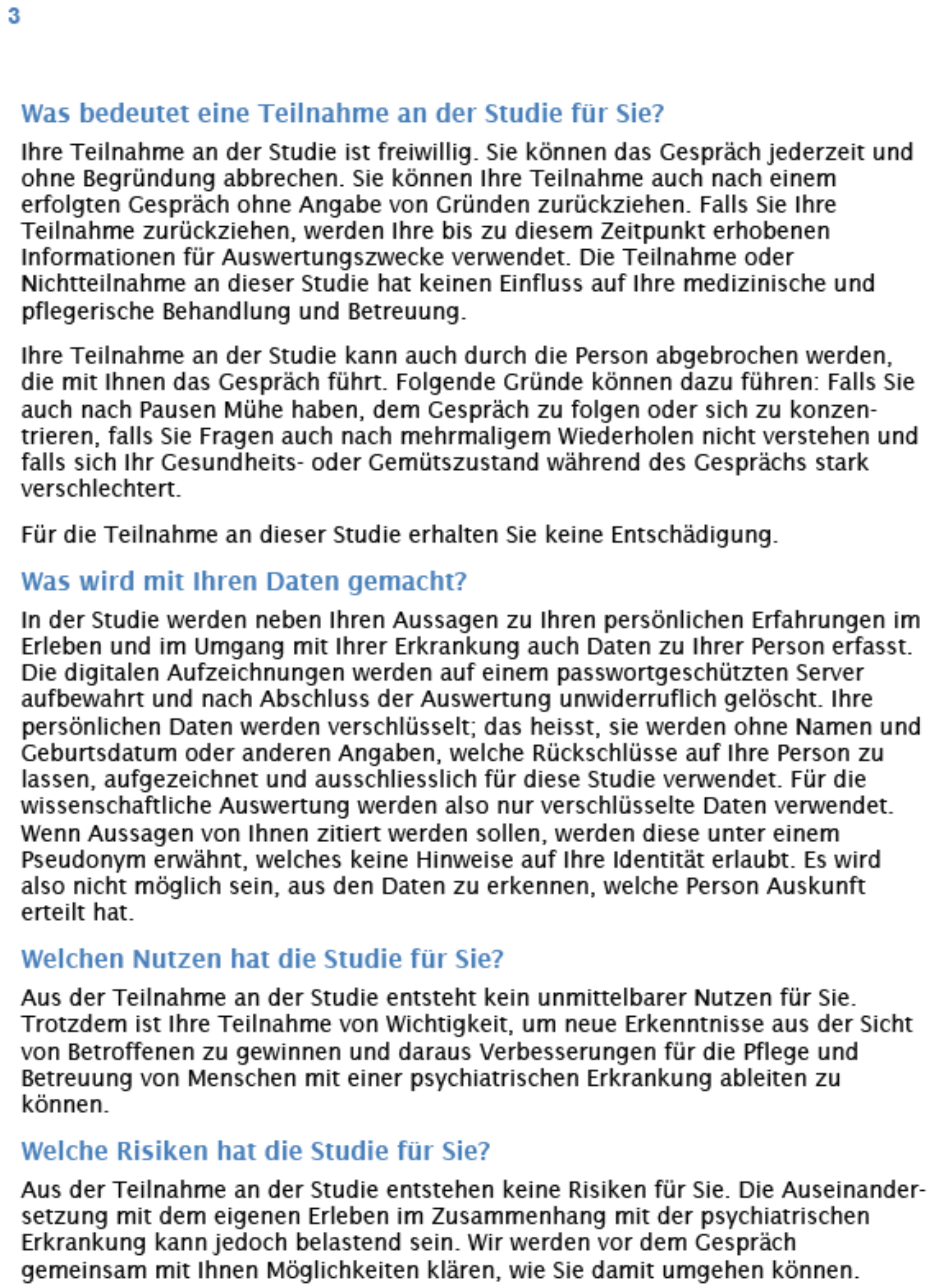
Wer führt die Studie durch?

Die Studie wird von der Berner Fachhochschule Gesundheit (BFH) in Zusammenarbeit mit der Universität Bournemouth in England von einer Pflegefachperson mit wissenschaftlicher Ausbildung durchgeführt. Die Studie wurde von der zuständigen Ethikkommission des Kantons Bern genehmigt. Sie wird in Übereinstimmung mit der schweizerischen Gesetzgebung und nach international anerkannten Richtlinien durchgeführt.

Wie läuft die Studie ab?

Wenn Sie sich für die Teilnahme an der Studie interessieren, nehmen Sie bitte mit der Kontaktperson, welche auf der letzten Seite dieses Flugblattes aufgeführt ist, Kontakt auf. Die Kontaktperson wird Sie genau über die Studie und den Ablauf mündlich informieren und erst nachdem Sie die mündliche und auch die ausführliche schriftliche Studieninformation verstanden haben, entscheiden Sie sich, ob Sie an der Studie teilnehmen wollen.

Falls Sie sich dafür entscheiden, wird die für die Studie zuständige Person mit Ihnen ein, allenfalls zwei persönliche Gespräche an einem von Ihnen für das Gespräch ausgewählten geeigneten Ort durchführen. Die Gespräche werden mit Ihnen frühzeitig abgemacht und finden zwischen September 2014 und August 2015 statt. Sie dauern jeweils maximal 1 ½ Stunden und Pausen während des Gesprächs sind jederzeit möglich. Die Gespräche werden offen und ohne festgelegten Fragenkatalog geführt. Für die Auswertung werden die Gespräche digital aufgezeichnet.



Was bedeutet eine Teilnahme an der Studie für Sie?

Ihre Teilnahme an der Studie ist freiwillig. Sie können das Gespräch jederzeit und ohne Begründung abbrechen. Sie können Ihre Teilnahme auch nach einem erfolgten Gespräch ohne Angabe von Gründen zurückziehen. Falls Sie Ihre Teilnahme zurückziehen, werden Ihre bis zu diesem Zeitpunkt erhobenen Informationen für Auswertungszwecke verwendet. Die Teilnahme oder Nichtteilnahme an dieser Studie hat keinen Einfluss auf Ihre medizinische und pflegerische Behandlung und Betreuung.

Ihre Teilnahme an der Studie kann auch durch die Person abgebrochen werden, die mit Ihnen das Gespräch führt. Folgende Gründe können dazu führen: Falls Sie auch nach Pausen Mühe haben, dem Gespräch zu folgen oder sich zu konzentrieren, falls Sie Fragen auch nach mehrmaligem Wiederholen nicht verstehen und falls sich Ihr Gesundheits- oder Gemütszustand während des Gesprächs stark verschlechtert.

Für die Teilnahme an dieser Studie erhalten Sie keine Entschädigung.

Was wird mit Ihren Daten gemacht?

In der Studie werden neben Ihren Aussagen zu Ihren persönlichen Erfahrungen im Erleben und im Umgang mit Ihrer Erkrankung auch Daten zu Ihrer Person erfasst. Die digitalen Aufzeichnungen werden auf einem passwortgeschützten Server aufbewahrt und nach Abschluss der Auswertung unwiderruflich gelöscht. Ihre persönlichen Daten werden verschlüsselt; das heisst, sie werden ohne Namen und Geburtsdatum oder anderen Angaben, welche Rückschlüsse auf Ihre Person zu lassen, aufgezeichnet und ausschliesslich für diese Studie verwendet. Für die wissenschaftliche Auswertung werden also nur verschlüsselte Daten verwendet. Wenn Aussagen von Ihnen zitiert werden sollen, werden diese unter einem Pseudonym erwähnt, welches keine Hinweise auf Ihre Identität erlaubt. Es wird also nicht möglich sein, aus den Daten zu erkennen, welche Person Auskunft erteilt hat.

Welchen Nutzen hat die Studie für Sie?

Aus der Teilnahme an der Studie entsteht kein unmittelbarer Nutzen für Sie. Trotzdem ist Ihre Teilnahme von Wichtigkeit, um neue Erkenntnisse aus der Sicht von Betroffenen zu gewinnen und daraus Verbesserungen für die Pflege und Betreuung von Menschen mit einer psychiatrischen Erkrankung ableiten zu können.

Welche Risiken hat die Studie für Sie?

Aus der Teilnahme an der Studie entstehen keine Risiken für Sie. Die Auseinandersetzung mit dem eigenen Erleben im Zusammenhang mit der psychiatrischen Erkrankung kann jedoch belastend sein. Wir werden vor dem Gespräch gemeinsam mit Ihnen Möglichkeiten klären, wie Sie damit umgehen können.

Ihre Erfahrungen sind uns wichtig!

Es würde uns sehr freuen, wenn Sie uns an Ihren Erfahrungen teilhaben lassen und Sie an der Studie teilnehmen würden.

Haben Sie Fragen oder sind Sie interessiert?

Wenn wir Ihr Interesse zur Teilnahme an der Studie wecken konnten, oder Sie Fragen haben, bitten wir Sie, sich mit uns in Verbindung zu setzen.

Bitte vergewissern Sie sich, dass Sie uns in jedem Fall Ihre Kontaktangaben, mindestens jedoch Ihren Namen und Ihre Telefonnummer, mitteilen, damit wir Sie zurückrufen können. Sie erreichen uns per Email, Post oder Telefon:

Ihre Kontaktperson

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Bournemouth University

Berner Fachhochschule
Gesundheit

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We would like to learn about...

Your personal experiences in living and dealing with your own mental illness!

Information for people who are interested in participating in a study

Original title of study:

UNcertainty in Illness and PErsonal Recovery: Experiences of people living with mental illness – a qualitative study (UNIPER)

This is a research project in partial fulfilment of the academic degree of Doctor of Philosophy (PhD) in nursing.

English translation of version 2 27th July 2014

To anyone interested

You are or have been living with a mental illness and you could imagine telling us about your personal experiences in living and dealing with this illness. If so, we would be very pleased if you were participating in our study.

What is this study all about?

This study focuses on the experiences of people living with mental illness. We would like to learn about your own personal experiences in living and dealing with a mental illness. What are your thoughts, feelings and concerns, what kind of uncertainties are you dealing with and how do you move on, where do you get your strength from and how you manage your personal recovery process. In a personal interview we would like to address these issues.

So far there is not much known about, or at least not scientifically investigated in, people's experiences in dealing with their mental illness and how it affects their personal recovery process.

Your narratives will help us to get a better understanding of the experiences of those affected by mental illness and therefore, potentially, develop better professional support.

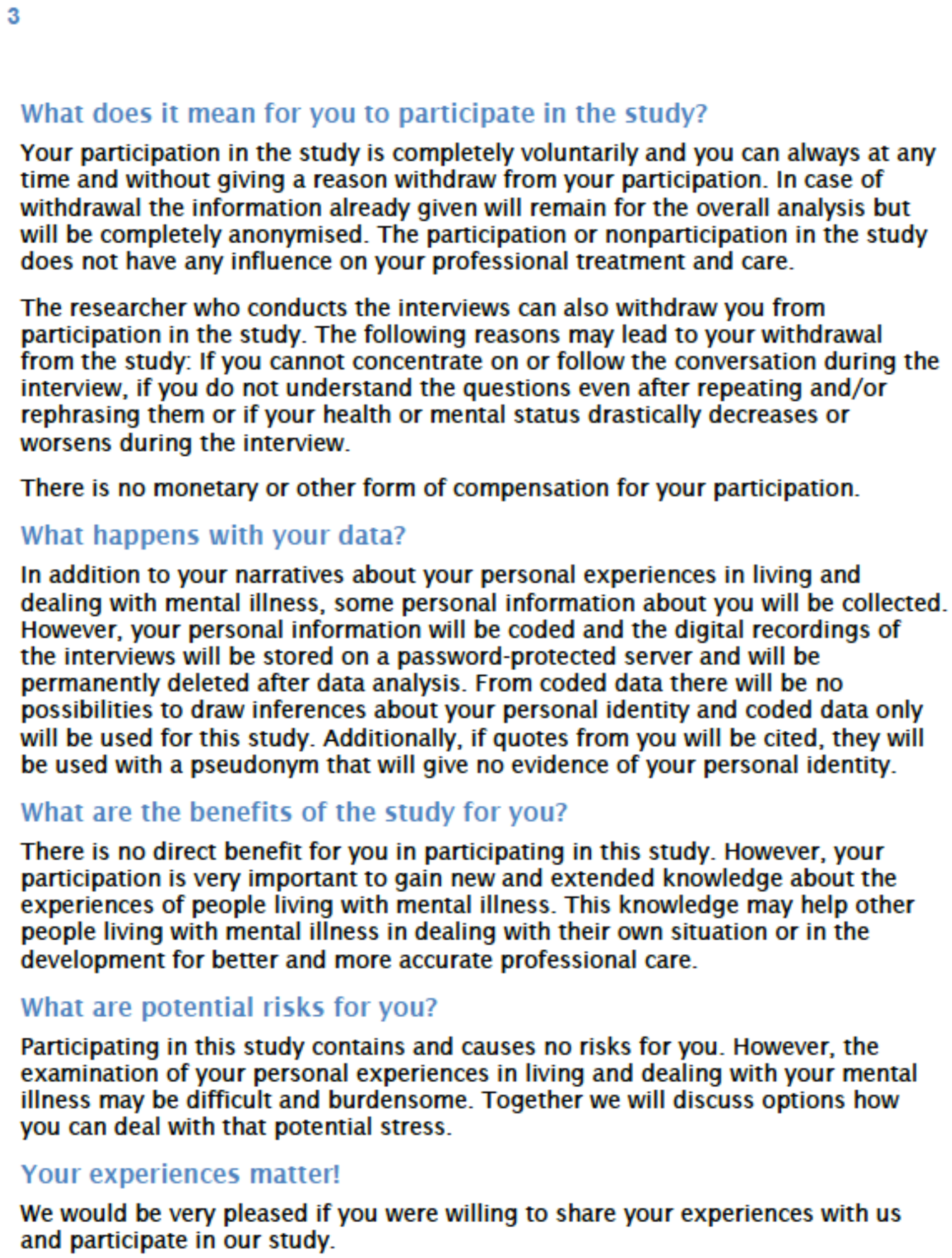
Who is conducting the study?

The study is conducted by a nurse researcher in collaboration between Bern University of Applied Sciences, Health Division, Department of Nursing in Switzerland and Bournemouth University, School of Health and Social Care in England. The study has passed the requirements of the ethics committee in Bern and fulfils Swiss and international regulations for research projects with humans.

What is the proposed scheme of the study?

If you are interested in participating in this study, we would like to encourage you to get in touch with the contact person mentioned on the last page of this leaflet. That person will give you all the necessary information about the study and its procedure. Only after you have understood the entire verbal and written information about the study you will decide to participate in the study or not.

In case you do decide to participate in the study and after giving your written consent, the contact person, who is also the nurse researcher, will plan and conduct one or possibly two personal interviews with you. The interviews will take place between September 2014 and August 2015 at a location of your choice. Each interview lasts for a maximum of 90 minutes and breaks are always possible. For analytical reasons the interviews will be digitally recorded. However, the interviews are much like an open conversation and do not follow a strict catalogue of questions.



What does it mean for you to participate in the study?

Your participation in the study is completely voluntarily and you can always at any time and without giving a reason withdraw from your participation. In case of withdrawal the information already given will remain for the overall analysis but will be completely anonymised. The participation or nonparticipation in the study does not have any influence on your professional treatment and care.

The researcher who conducts the interviews can also withdraw you from participation in the study. The following reasons may lead to your withdrawal from the study: If you cannot concentrate on or follow the conversation during the interview, if you do not understand the questions even after repeating and/or rephrasing them or if your health or mental status drastically decreases or worsens during the interview.

There is no monetary or other form of compensation for your participation.

What happens with your data?

In addition to your narratives about your personal experiences in living and dealing with mental illness, some personal information about you will be collected. However, your personal information will be coded and the digital recordings of the interviews will be stored on a password-protected server and will be permanently deleted after data analysis. From coded data there will be no possibilities to draw inferences about your personal identity and coded data only will be used for this study. Additionally, if quotes from you will be cited, they will be used with a pseudonym that will give no evidence of your personal identity.

What are the benefits of the study for you?

There is no direct benefit for you in participating in this study. However, your participation is very important to gain new and extended knowledge about the experiences of people living with mental illness. This knowledge may help other people living with mental illness in dealing with their own situation or in the development for better and more accurate professional care.

What are potential risks for you?

Participating in this study contains and causes no risks for you. However, the examination of your personal experiences in living and dealing with your mental illness may be difficult and burdensome. Together we will discuss options how you can deal with that potential stress.

Your experiences matter!

We would be very pleased if you were willing to share your experiences with us and participate in our study.

Do you have questions or are you interested in participating?

If we have raised your interest in participating in our study or if you have more questions that need to be answered, please do not hesitate and contact us.

Please make sure that in any case you provide us with your contact details, at least your name and phone number, so that we can get back to you. You can contact us by email, mail or phone:

Your contact person/responsible for study

Peter Wolfensberger
Clinical Nurse Specialist in Mental Health Nursing, MScN
Alte Tösstalstrasse 56
8487 Rämismühle
Phone (during the day): +41 52 224 33 16
Email: pwolfensberger@bournemouth.ac.uk

Person responsible at Bern University of Applied Sciences:

Health Division
Prof. Dr. Sabine Hahn
Head of Nursing Discipline
Division Head of Applied Research & Development in Nursing
Murtenstrasse 10
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Email: sabine.hahn@bfh.ch

Person responsible at Bournemouth University:

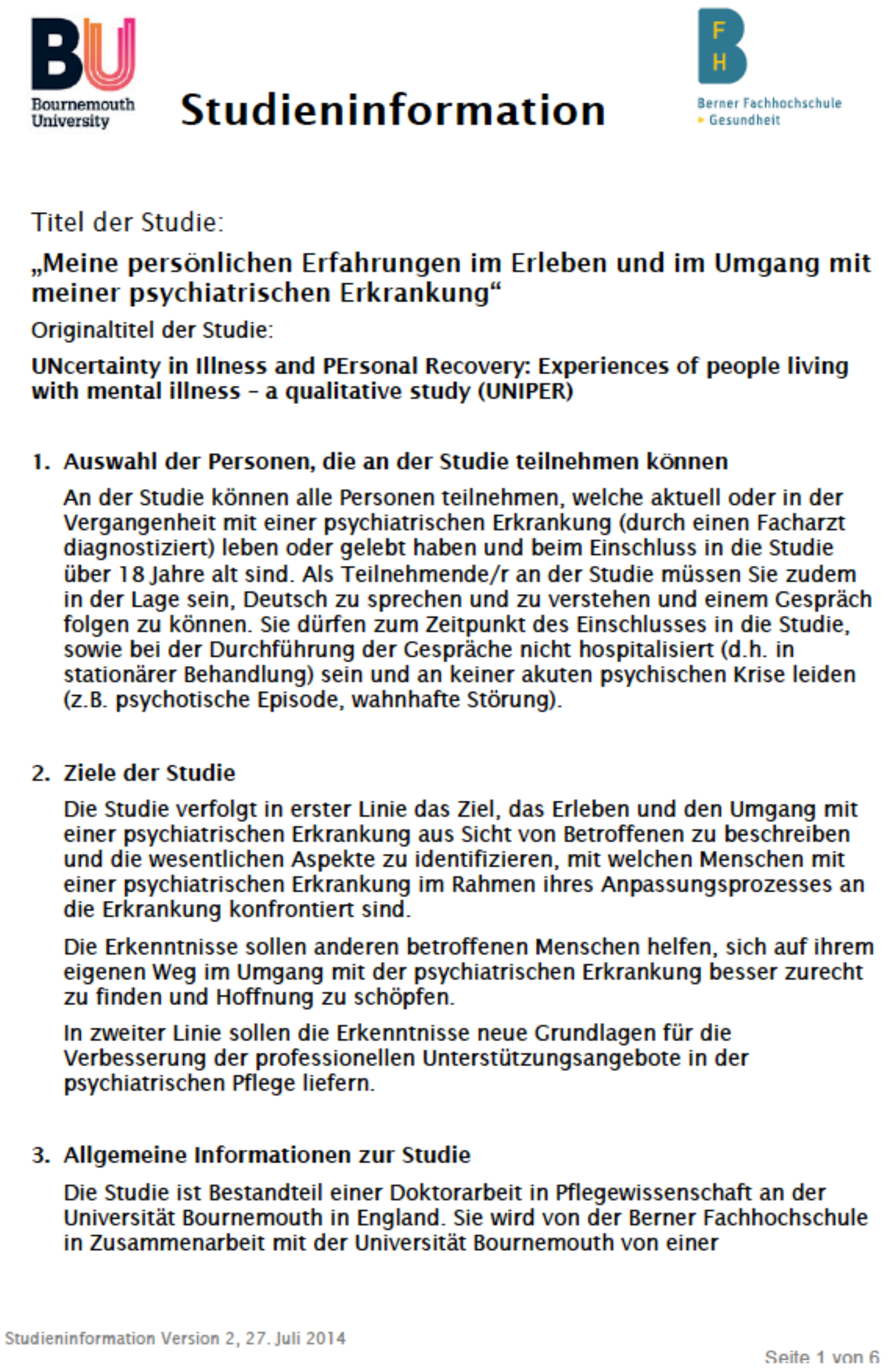
School of Health and Social Care
Dr. Sarah Thomas
Senior Research Fellow, Bournemouth University Clinical Research Unit (BUCRU)
R506b, Royal London House
Christchurch Road
Bournemouth, Dorset, BH1 3LT, UK
Email: saraht@bournemouth.ac.uk

Bournemouth University

Berner Fachhochschule
▸ Gesundheit

10.3 Appendix 3: Study Information

(German version only; for English see Research Protocol **Fehler! Verweisquelle konnte nicht gefunden werden.**)



Bournemouth University

Studieninformation

Berner Fachhochschule
▸ Gesundheit

Titel der Studie:

„Meine persönlichen Erfahrungen im Erleben und im Umgang mit meiner psychiatrischen Erkrankung"

Originaltitel der Studie:

UNcertainty in Illness and PErsonal Recovery: Experiences of people living with mental illness – a qualitative study (UNIPER)

1. Auswahl der Personen, die an der Studie teilnehmen können

An der Studie können alle Personen teilnehmen, welche aktuell oder in der Vergangenheit mit einer psychiatrischen Erkrankung (durch einen Facharzt diagnostiziert) leben oder gelebt haben und beim Einschluss in die Studie über 18 Jahre alt sind. Als Teilnehmende/r an der Studie müssen Sie zudem in der Lage sein, Deutsch zu sprechen und zu verstehen und einem Gespräch folgen zu können. Sie dürfen zum Zeitpunkt des Einschlusses in die Studie, sowie bei der Durchführung der Gespräche nicht hospitalisiert (d.h. in stationärer Behandlung) sein und an keiner akuten psychischen Krise leiden (z.B. psychotische Episode, wahnhafte Störung).

2. Ziele der Studie

Die Studie verfolgt in erster Linie das Ziel, das Erleben und den Umgang mit einer psychiatrischen Erkrankung aus Sicht von Betroffenen zu beschreiben und die wesentlichen Aspekte zu identifizieren, mit welchen Menschen mit einer psychiatrischen Erkrankung im Rahmen ihres Anpassungsprozesses an die Erkrankung konfrontiert sind.

Die Erkenntnisse sollen anderen betroffenen Menschen helfen, sich auf ihrem eigenen Weg im Umgang mit der psychiatrischen Erkrankung besser zurecht zu finden und Hoffnung zu schöpfen.

In zweiter Linie sollen die Erkenntnisse neue Grundlagen für die Verbesserung der professionellen Unterstützungsangebote in der psychiatrischen Pflege liefern.

3. Allgemeine Informationen zur Studie

Die Studie ist Bestandteil einer Doktorarbeit in Pflegewissenschaft an der Universität Bournemouth in England. Sie wird von der Berner Fachhochschule in Zusammenarbeit mit der Universität Bournemouth von einer

Studieninformation Version 2, 27. Juli 2014

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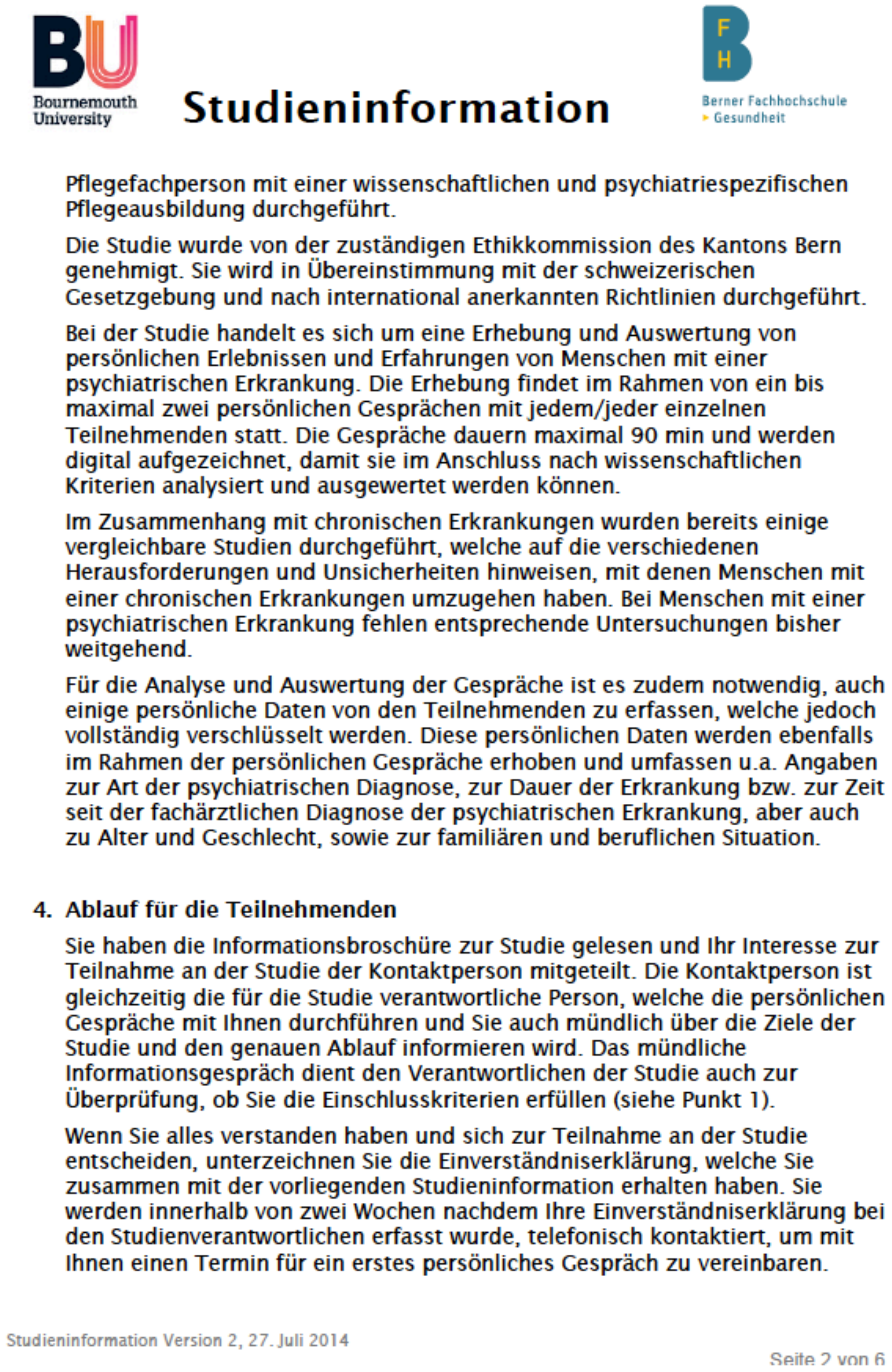


Pflegefachperson mit einer wissenschaftlichen und psychiatriespezifischen Pflegeausbildung durchgeführt.

Die Studie wurde von der zuständigen Ethikkommission des Kantons Bern genehmigt. Sie wird in Übereinstimmung mit der schweizerischen Gesetzgebung und nach international anerkannten Richtlinien durchgeführt.

Bei der Studie handelt es sich um eine Erhebung und Auswertung von persönlichen Erlebnissen und Erfahrungen von Menschen mit einer psychiatrischen Erkrankung. Die Erhebung findet im Rahmen von ein bis maximal zwei persönlichen Gesprächen mit jedem/jeder einzelnen Teilnehmenden statt. Die Gespräche dauern maximal 90 min und werden digital aufgezeichnet, damit sie im Anschluss nach wissenschaftlichen Kriterien analysiert und ausgewertet werden können.

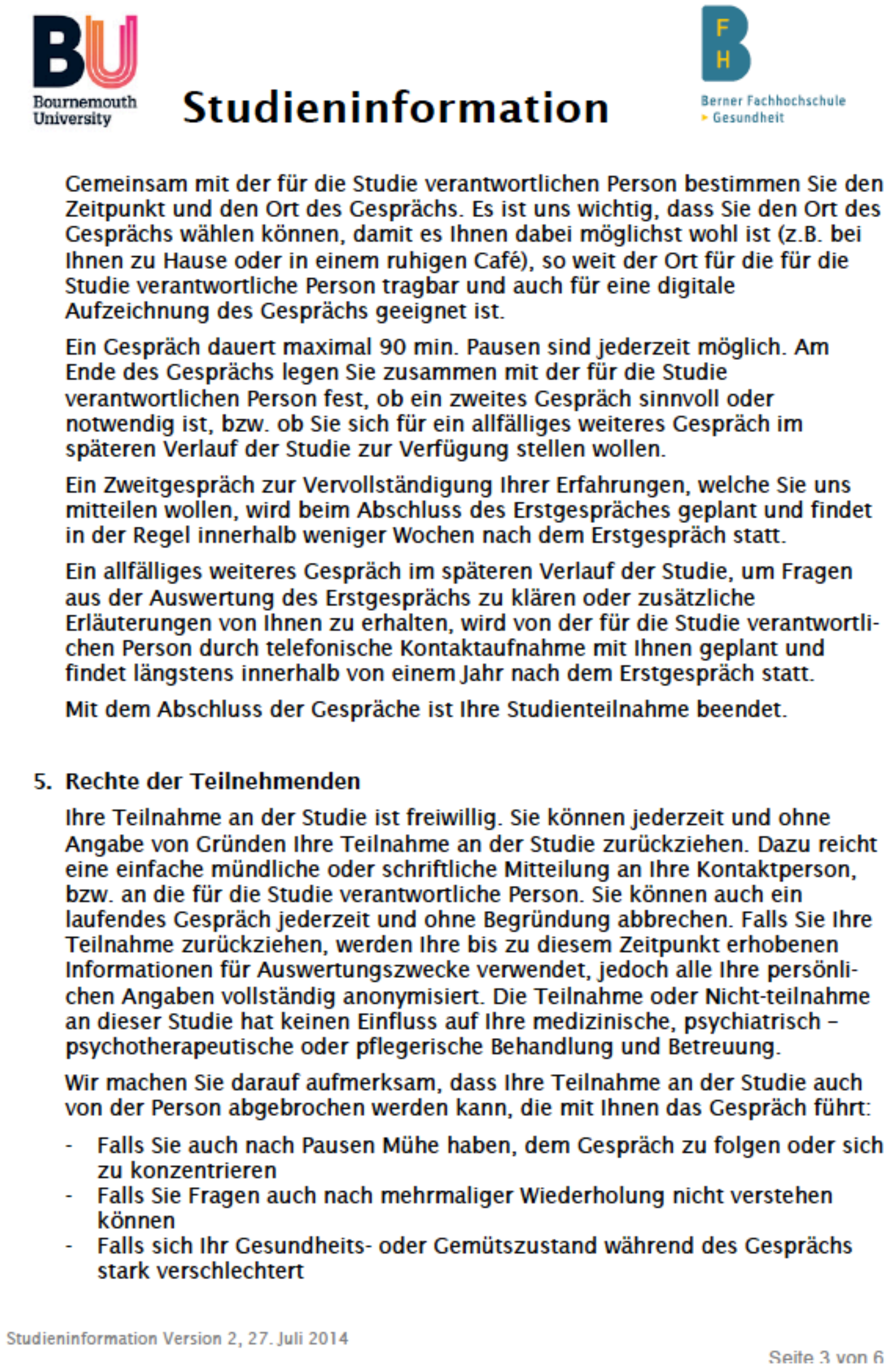
Im Zusammenhang mit chronischen Erkrankungen wurden bereits einige vergleichbare Studien durchgeführt, welche auf die verschiedenen Herausforderungen und Unsicherheiten hinweisen, mit denen Menschen mit einer chronischen Erkrankungen umzugehen haben. Bei Menschen mit einer psychiatrischen Erkrankung fehlen entsprechende Untersuchungen bisher weitgehend.

Für die Analyse und Auswertung der Gespräche ist es zudem notwendig, auch einige persönliche Daten von den Teilnehmenden zu erfassen, welche jedoch vollständig verschlüsselt werden. Diese persönlichen Daten werden ebenfalls im Rahmen der persönlichen Gespräche erhoben und umfassen u.a. Angaben zur Art der psychiatrischen Diagnose, zur Dauer der Erkrankung bzw. zur Zeit seit der fachärztlichen Diagnose der psychiatrischen Erkrankung, aber auch zu Alter und Geschlecht, sowie zur familiären und beruflichen Situation.

4. Ablauf für die Teilnehmenden

Sie haben die Informationsbroschüre zur Studie gelesen und Ihr Interesse zur Teilnahme an der Studie der Kontaktperson mitgeteilt. Die Kontaktperson ist gleichzeitig die für die Studie verantwortliche Person, welche die persönlichen Gespräche mit Ihnen durchführen und Sie auch mündlich über die Ziele der Studie und den genauen Ablauf informieren wird. Das mündliche Informationsgespräch dient den Verantwortlichen der Studie auch zur Überprüfung, ob Sie die Einschlusskriterien erfüllen (siehe Punkt 1).

Wenn Sie alles verstanden haben und sich zur Teilnahme an der Studie entscheiden, unterzeichnen Sie die Einverständniserklärung, welche Sie zusammen mit der vorliegenden Studieninformation erhalten haben. Sie werden innerhalb von zwei Wochen nachdem Ihre Einverständniserklärung bei den Studienverantwortlichen erfasst wurde, telefonisch kontaktiert, um mit Ihnen einen Termin für ein erstes persönliches Gespräch zu vereinbaren.



Studieninformation

Gemeinsam mit der für die Studie verantwortlichen Person bestimmen Sie den Zeitpunkt und den Ort des Gesprächs. Es ist uns wichtig, dass Sie den Ort des Gesprächs wählen können, damit es Ihnen dabei möglichst wohl ist (z.B. bei Ihnen zu Hause oder in einem ruhigen Café), so weit der Ort für die für die Studie verantwortliche Person tragbar und auch für eine digitale Aufzeichnung des Gesprächs geeignet ist.

Ein Gespräch dauert maximal 90 min. Pausen sind jederzeit möglich. Am Ende des Gesprächs legen Sie zusammen mit der für die Studie verantwortlichen Person fest, ob ein zweites Gespräch sinnvoll oder notwendig ist, bzw. ob Sie sich für ein allfälliges weiteres Gespräch im späteren Verlauf der Studie zur Verfügung stellen wollen.

Ein Zweitgespräch zur Vervollständigung Ihrer Erfahrungen, welche Sie uns mitteilen wollen, wird beim Abschluss des Erstgespräches geplant und findet in der Regel innerhalb weniger Wochen nach dem Erstgespräch statt.

Ein allfälliges weiteres Gespräch im späteren Verlauf der Studie, um Fragen aus der Auswertung des Erstgesprächs zu klären oder zusätzliche Erläuterungen von Ihnen zu erhalten, wird von der für die Studie verantwortlichen Person durch telefonische Kontaktaufnahme mit Ihnen geplant und findet längstens innerhalb von einem Jahr nach dem Erstgespräch statt.

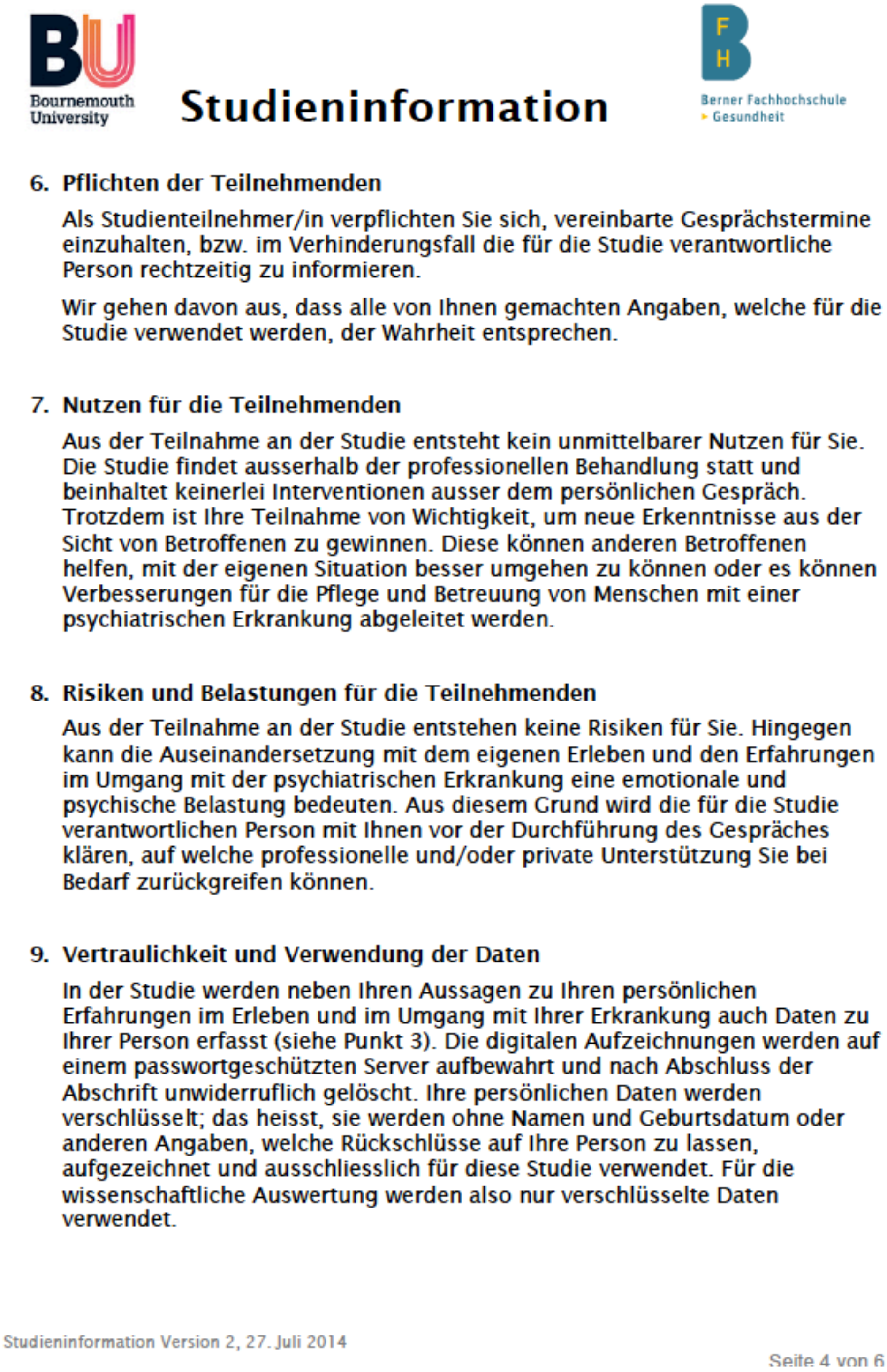
Mit dem Abschluss der Gespräche ist Ihre Studienteilnahme beendet.

5. Rechte der Teilnehmenden

Ihre Teilnahme an der Studie ist freiwillig. Sie können jederzeit und ohne Angabe von Gründen Ihre Teilnahme an der Studie zurückziehen. Dazu reicht eine einfache mündliche oder schriftliche Mitteilung an Ihre Kontaktperson, bzw. an die für die Studie verantwortliche Person. Sie können auch ein laufendes Gespräch jederzeit und ohne Begründung abbrechen. Falls Sie Ihre Teilnahme zurückziehen, werden Ihre bis zu diesem Zeitpunkt erhobenen Informationen für Auswertungszwecke verwendet, jedoch alle Ihre persönlichen Angaben vollständig anonymisiert. Die Teilnahme oder Nicht-teilnahme an dieser Studie hat keinen Einfluss auf Ihre medizinische, psychiatrisch – psychotherapeutische oder pflegerische Behandlung und Betreuung.

Wir machen Sie darauf aufmerksam, dass Ihre Teilnahme an der Studie auch von der Person abgebrochen werden kann, die mit Ihnen das Gespräch führt:

- Falls Sie auch nach Pausen Mühe haben, dem Gespräch zu folgen oder sich zu konzentrieren
- Falls Sie Fragen auch nach mehrmaliger Wiederholung nicht verstehen können
- Falls sich Ihr Gesundheits- oder Gemütszustand während des Gesprächs stark verschlechtert



6. Pflichten der Teilnehmenden

Als Studienteilnehmer/in verpflichten Sie sich, vereinbarte Gesprächstermine einzuhalten, bzw. im Verhinderungsfall die für die Studie verantwortliche Person rechtzeitig zu informieren.

Wir gehen davon aus, dass alle von Ihnen gemachten Angaben, welche für die Studie verwendet werden, der Wahrheit entsprechen.

7. Nutzen für die Teilnehmenden

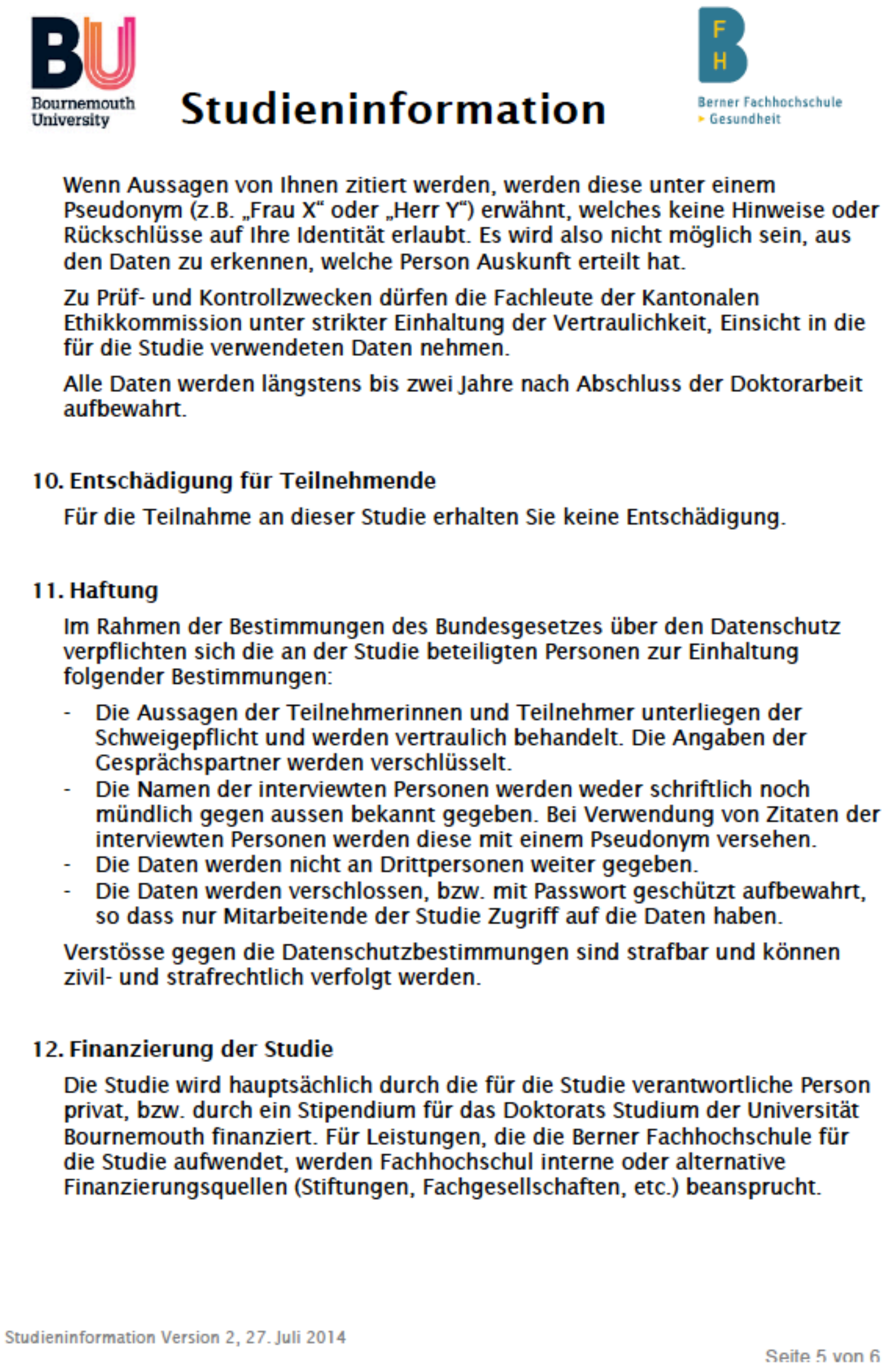
Aus der Teilnahme an der Studie entsteht kein unmittelbarer Nutzen für Sie. Die Studie findet ausserhalb der professionellen Behandlung statt und beinhaltet keinerlei Interventionen ausser dem persönlichen Gespräch. Trotzdem ist Ihre Teilnahme von Wichtigkeit, um neue Erkenntnisse aus der Sicht von Betroffenen zu gewinnen. Diese können anderen Betroffenen helfen, mit der eigenen Situation besser umgehen zu können oder es können Verbesserungen für die Pflege und Betreuung von Menschen mit einer psychiatrischen Erkrankung abgeleitet werden.

8. Risiken und Belastungen für die Teilnehmenden

Aus der Teilnahme an der Studie entstehen keine Risiken für Sie. Hingegen kann die Auseinandersetzung mit dem eigenen Erleben und den Erfahrungen im Umgang mit der psychiatrischen Erkrankung eine emotionale und psychische Belastung bedeuten. Aus diesem Grund wird die für die Studie verantwortlichen Person mit Ihnen vor der Durchführung des Gespräches klären, auf welche professionelle und/oder private Unterstützung Sie bei Bedarf zurückgreifen können.

9. Vertraulichkeit und Verwendung der Daten

In der Studie werden neben Ihren Aussagen zu Ihren persönlichen Erfahrungen im Erleben und im Umgang mit Ihrer Erkrankung auch Daten zu Ihrer Person erfasst (siehe Punkt 3). Die digitalen Aufzeichnungen werden auf einem passwortgeschützten Server aufbewahrt und nach Abschluss der Abschrift unwiderruflich gelöscht. Ihre persönlichen Daten werden verschlüsselt; das heisst, sie werden ohne Namen und Geburtsdatum oder anderen Angaben, welche Rückschlüsse auf Ihre Person zu lassen, aufgezeichnet und ausschliesslich für diese Studie verwendet. Für die wissenschaftliche Auswertung werden also nur verschlüsselte Daten verwendet.



Wenn Aussagen von Ihnen zitiert werden, werden diese unter einem Pseudonym (z.B. „Frau X“ oder „Herr Y“) erwähnt, welches keine Hinweise oder Rückschlüsse auf Ihre Identität erlaubt. Es wird also nicht möglich sein, aus den Daten zu erkennen, welche Person Auskunft erteilt hat.

Zu Prüf- und Kontrollzwecken dürfen die Fachleute der Kantonalen Ethikkommission unter strikter Einhaltung der Vertraulichkeit, Einsicht in die für die Studie verwendeten Daten nehmen.

Alle Daten werden längstens bis zwei Jahre nach Abschluss der Doktorarbeit aufbewahrt.

10. Entschädigung für Teilnehmende

Für die Teilnahme an dieser Studie erhalten Sie keine Entschädigung.

11. Haftung

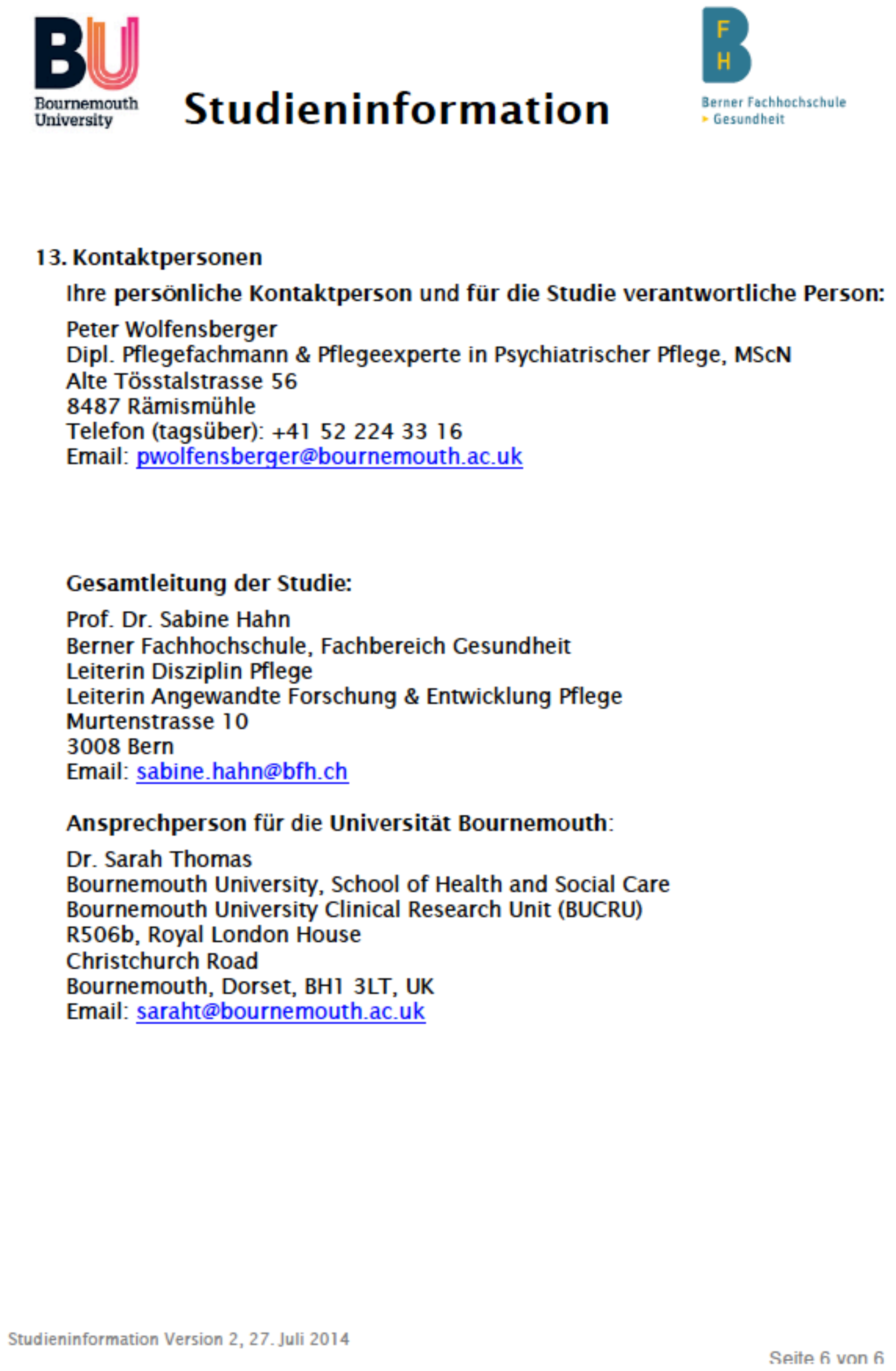
Im Rahmen der Bestimmungen des Bundesgesetzes über den Datenschutz verpflichten sich die an der Studie beteiligten Personen zur Einhaltung folgender Bestimmungen:

- Die Aussagen der Teilnehmerinnen und Teilnehmer unterliegen der Schweigepflicht und werden vertraulich behandelt. Die Angaben der Gesprächspartner werden verschlüsselt.
- Die Namen der interviewten Personen werden weder schriftlich noch mündlich gegen aussen bekannt gegeben. Bei Verwendung von Zitaten der interviewten Personen werden diese mit einem Pseudonym versehen.
- Die Daten werden nicht an Drittpersonen weiter gegeben.
- Die Daten werden verschlossen, bzw. mit Passwort geschützt aufbewahrt, so dass nur Mitarbeitende der Studie Zugriff auf die Daten haben.

Verstösse gegen die Datenschutzbestimmungen sind strafbar und können zivil- und strafrechtlich verfolgt werden.

12. Finanzierung der Studie

Die Studie wird hauptsächlich durch die für die Studie verantwortliche Person privat, bzw. durch ein Stipendium für das Doktorats Studium der Universität Bournemouth finanziert. Für Leistungen, die die Berner Fachhochschule für die Studie aufwendet, werden Fachhochschul interne oder alternative Finanzierungsquellen (Stiftungen, Fachgesellschaften, etc.) beansprucht.



Studieninformation

13. Kontaktpersonen

Ihre persönliche Kontaktperson und für die Studie verantwortliche Person:

Peter Wolfensberger
Dipl. Pflegefachmann & Pflegeexperte in Psychiatrischer Pflege, MScN
Alte Tösstalstrasse 56
8487 Rämismühle
Telefon (tagsüber): +41 52 224 33 16
Email: pwolfensberger@bournemouth.ac.uk

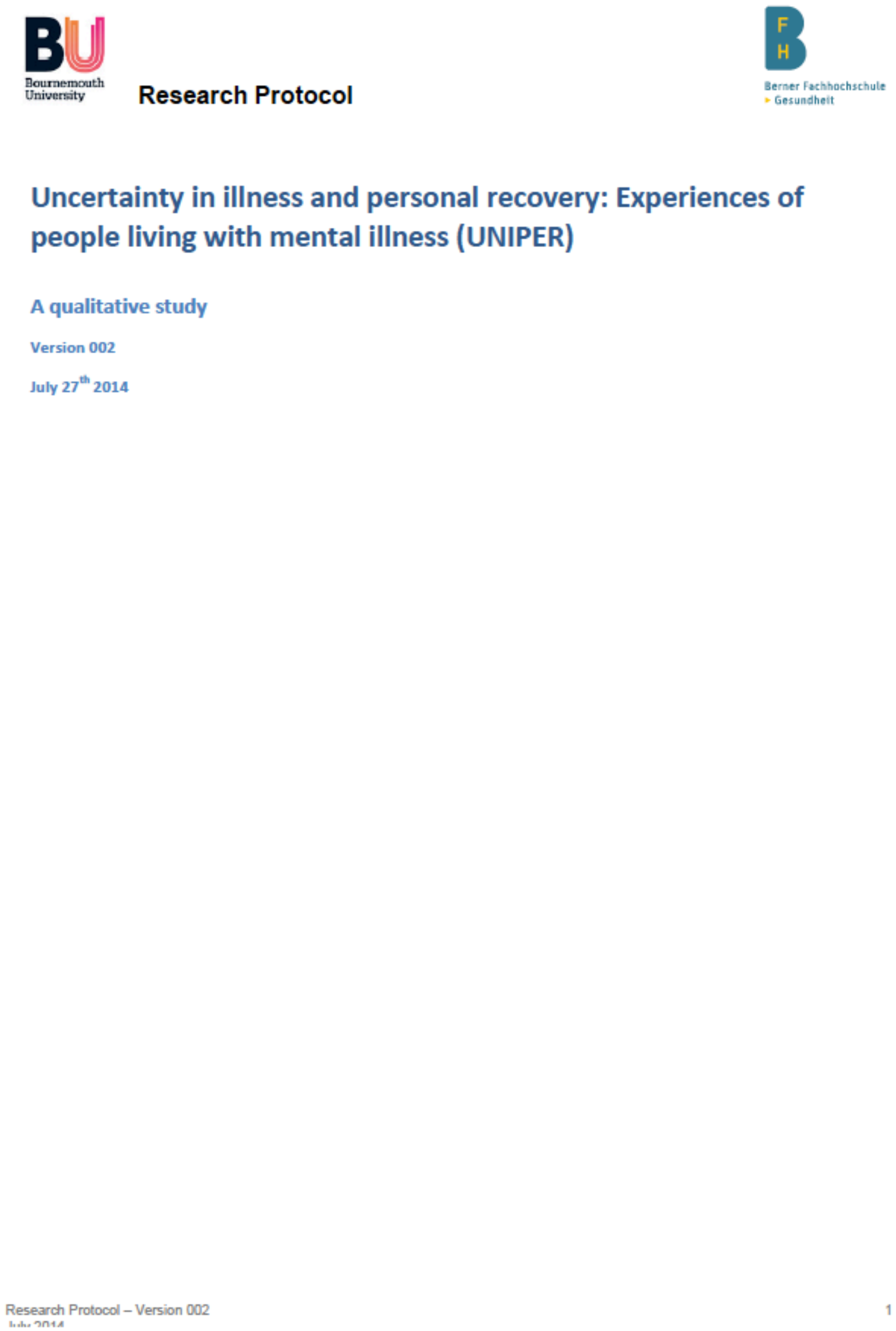
Gesamtleitung der Studie:

Prof. Dr. Sabine Hahn
Berner Fachhochschule, Fachbereich Gesundheit
Leiterin Disziplin Pflege
Leiterin Angewandte Forschung & Entwicklung Pflege
Murtenstrasse 10
3008 Bern
Email: sabine.hahn@bfh.ch

Ansprechperson für die Universität Bournemouth:

Dr. Sarah Thomas
Bournemouth University, School of Health and Social Care
Bournemouth University Clinical Research Unit (BUCRU)
R506b, Royal London House
Christchurch Road
Bournemouth, Dorset, BH1 3LT, UK
Email: saraht@bournemouth.ac.uk

10.4 Appendix 4: Research Protocol



Bournemouth University

Berner Fachhochschule
Gesundheit

Research Protocol

Uncertainty in illness and personal recovery: Experiences of people living with mental illness (UNIPER)

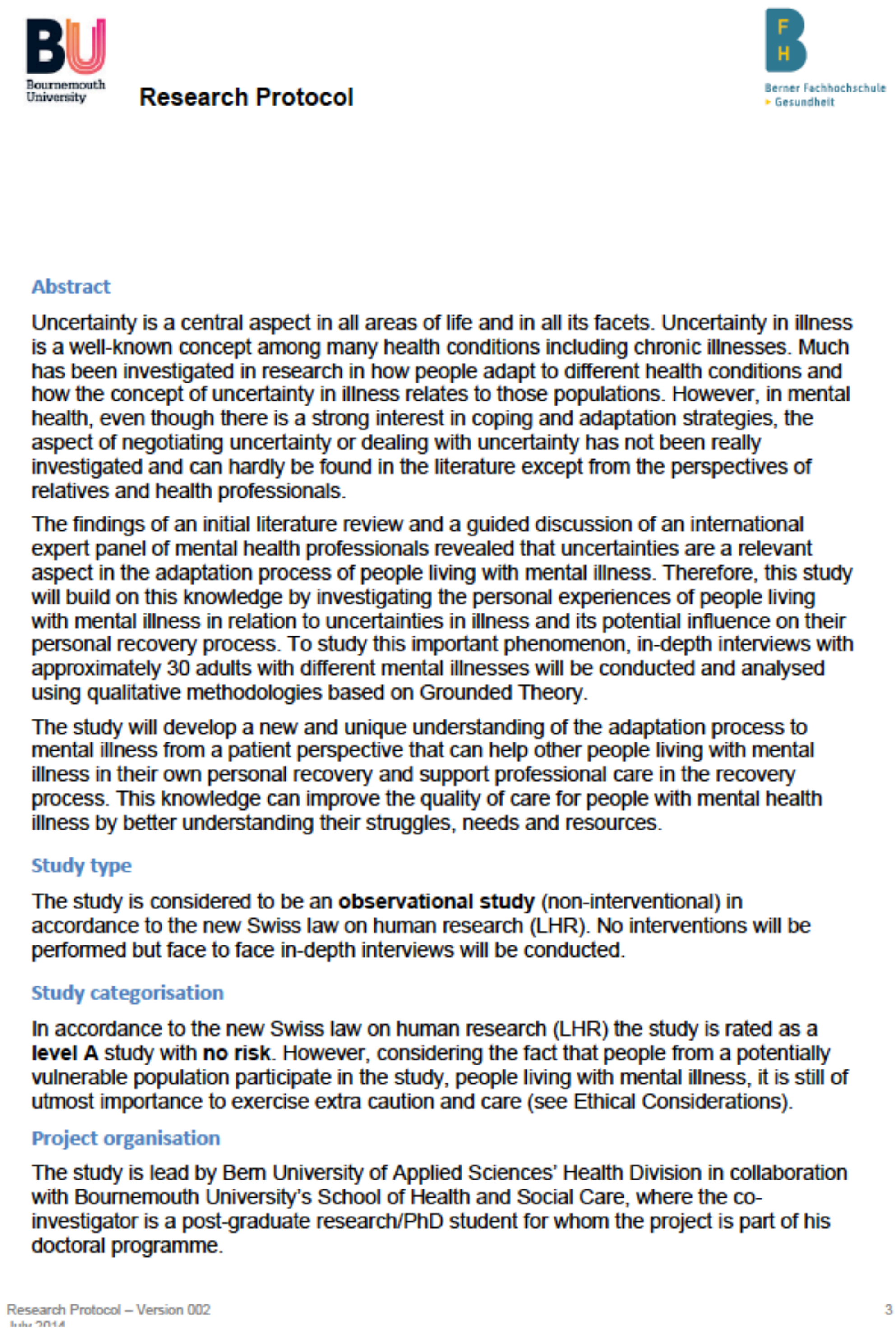
A qualitative study

Version 002

July 27th 2014

Research Protocol – Version 002
July 2014 1

Content



Abstract

Uncertainty is a central aspect in all areas of life and in all its facets. Uncertainty in illness is a well-known concept among many health conditions including chronic illnesses. Much has been investigated in research in how people adapt to different health conditions and how the concept of uncertainty in illness relates to those populations. However, in mental health, even though there is a strong interest in coping and adaptation strategies, the aspect of negotiating uncertainty or dealing with uncertainty has not been really investigated and can hardly be found in the literature except from the perspectives of relatives and health professionals.

The findings of an initial literature review and a guided discussion of an international expert panel of mental health professionals revealed that uncertainties are a relevant aspect in the adaptation process of people living with mental illness. Therefore, this study will build on this knowledge by investigating the personal experiences of people living with mental illness in relation to uncertainties in illness and its potential influence on their personal recovery process. To study this important phenomenon, in-depth interviews with approximately 30 adults with different mental illnesses will be conducted and analysed using qualitative methodologies based on Grounded Theory.

The study will develop a new and unique understanding of the adaptation process to mental illness from a patient perspective that can help other people living with mental illness in their own personal recovery and support professional care in the recovery process. This knowledge can improve the quality of care for people with mental health illness by better understanding their struggles, needs and resources.

Study type

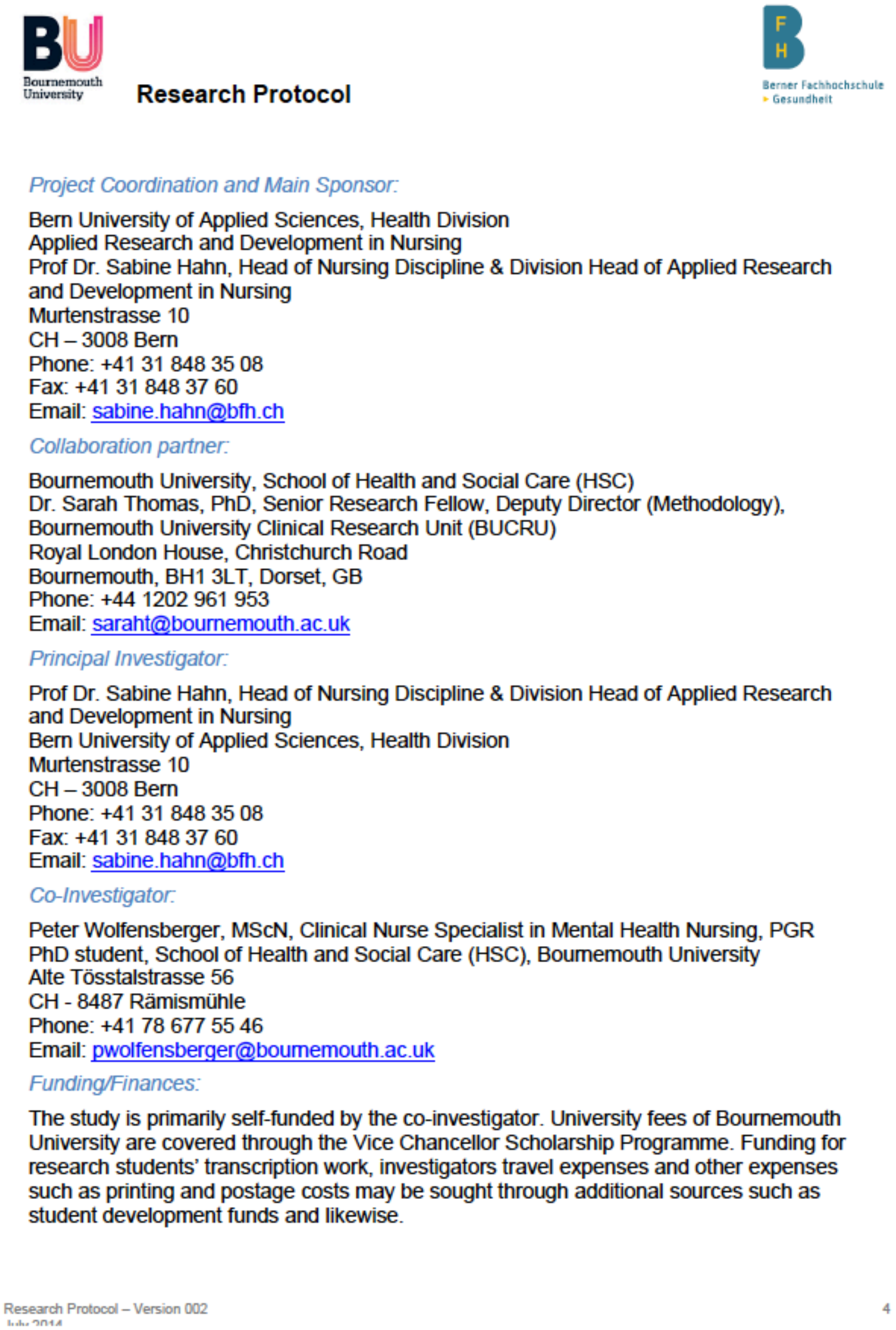
The study is considered to be an **observational study** (non-interventional) in accordance to the new Swiss law on human research (LHR). No interventions will be performed but face to face in-depth interviews will be conducted.

Study categorisation

In accordance to the new Swiss law on human research (LHR) the study is rated as a **level A** study with **no risk**. However, considering the fact that people from a potentially vulnerable population participate in the study, people living with mental illness, it is still of utmost importance to exercise extra caution and care (see Ethical Considerations).

Project organisation

The study is lead by Bern University of Applied Sciences' Health Division in collaboration with Bournemouth University's School of Health and Social Care, where the co-investigator is a post-graduate research/PhD student for whom the project is part of his doctoral programme.



Research Protocol

Project Coordination and Main Sponsor:

Bern University of Applied Sciences, Health Division
Applied Research and Development in Nursing
Prof Dr. Sabine Hahn, Head of Nursing Discipline & Division Head of Applied Research and Development in Nursing
Murtenstrasse 10
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Fax: +41 31 848 37 60
Email: sabine.hahn@bfh.ch

Collaboration partner:

Bournemouth University, School of Health and Social Care (HSC)
Dr. Sarah Thomas, PhD, Senior Research Fellow, Deputy Director (Methodology), Bournemouth University Clinical Research Unit (BUCRU)
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Phone: +44 1202 961 953
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Principal Investigator:

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Fax: +41 31 848 37 60
Email: sabine.hahn@bfh.ch

Co-Investigator:

Peter Wolfensberger, MScN, Clinical Nurse Specialist in Mental Health Nursing, PGR PhD student, School of Health and Social Care (HSC), Bournemouth University
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CH - 8487 Rämismühle
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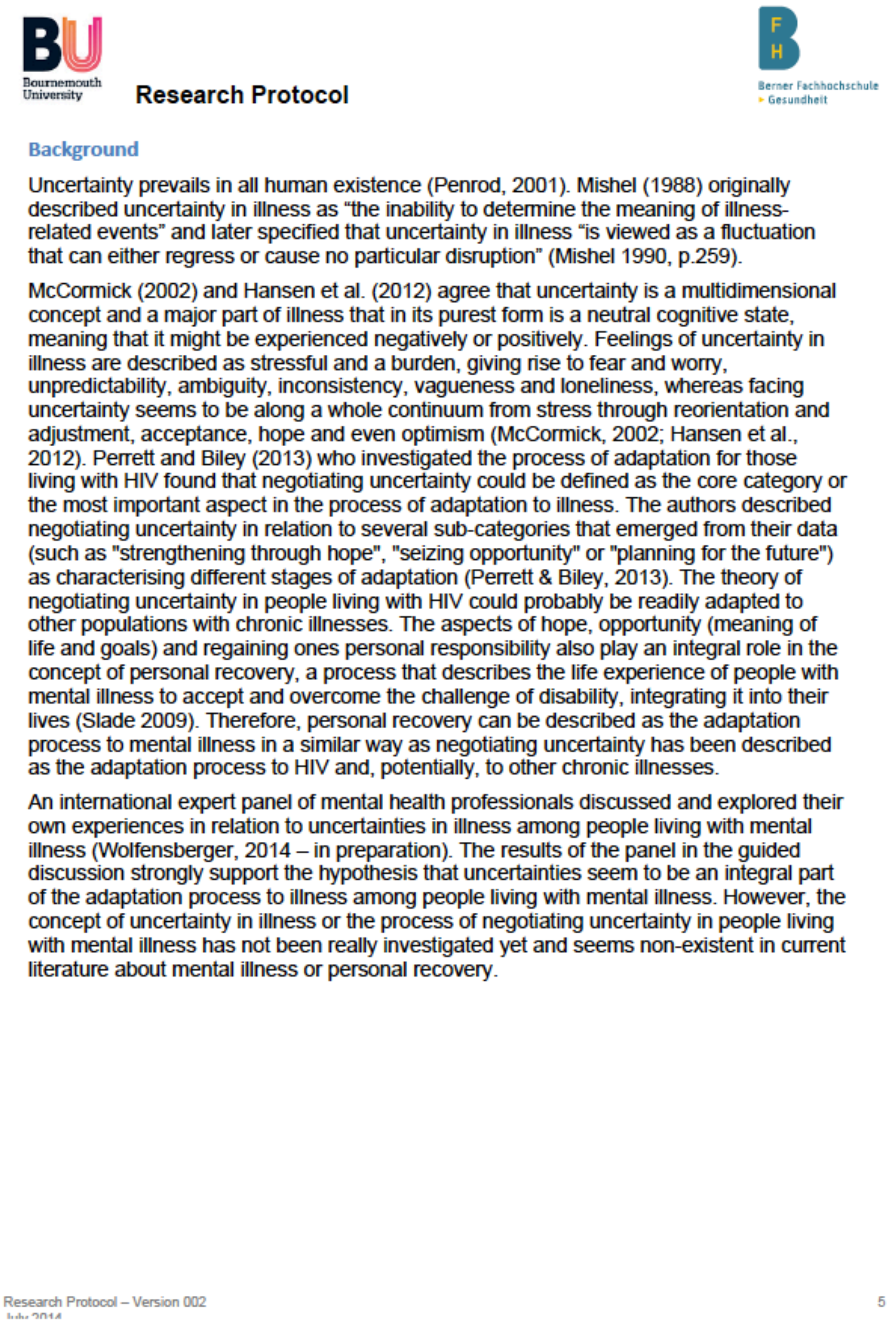
Email: pwolfensberger@bournemouth.ac.uk

Funding/Finances:

The study is primarily self-funded by the co-investigator. University fees of Bournemouth University are covered through the Vice Chancellor Scholarship Programme. Funding for research students' transcription work, investigators travel expenses and other expenses such as printing and postage costs may be sought through additional sources such as student development funds and likewise.

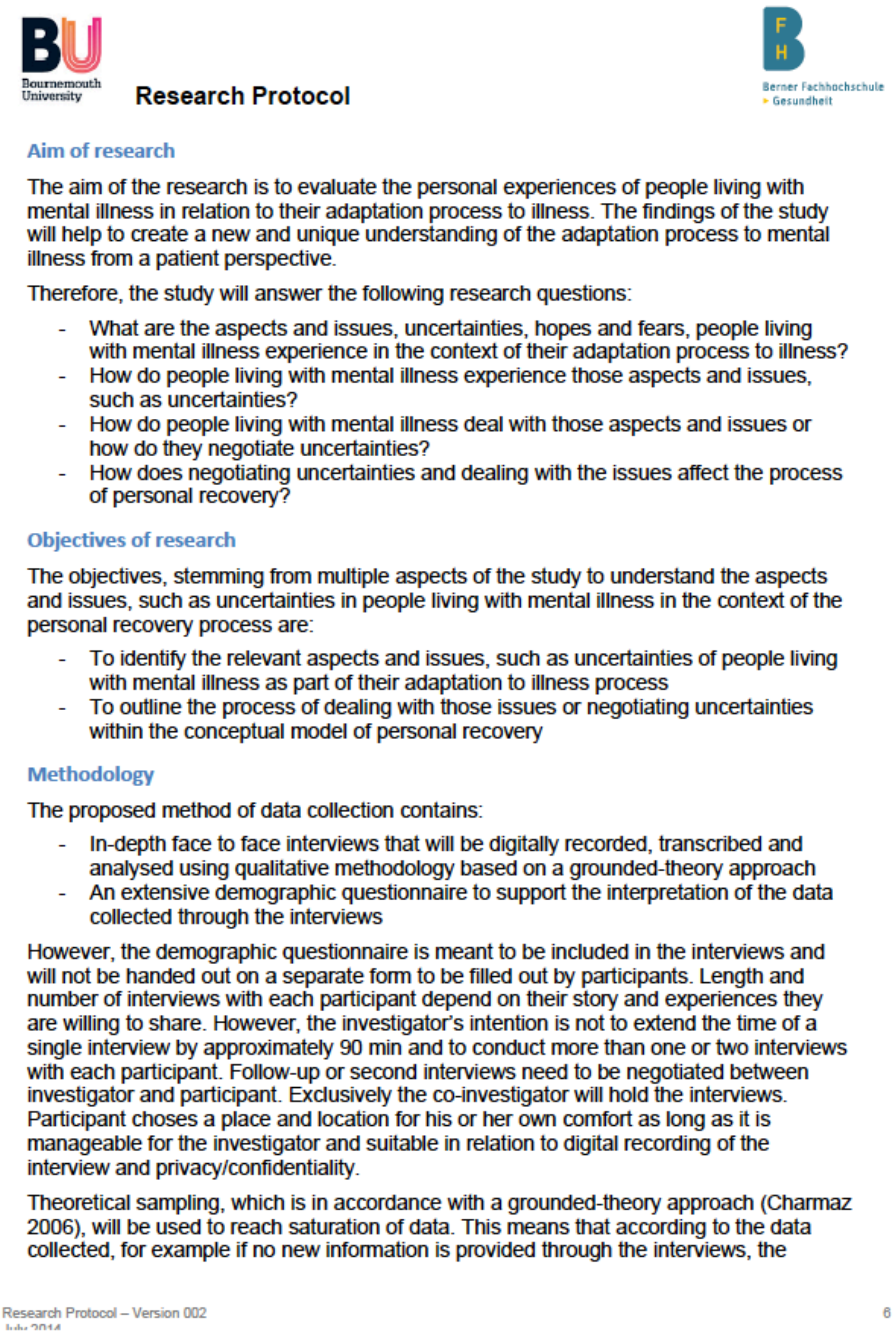


Background

Uncertainty prevails in all human existence (Penrod, 2001). Mishel (1988) originally described uncertainty in illness as "the inability to determine the meaning of illness-related events" and later specified that uncertainty in illness "is viewed as a fluctuation that can either regress or cause no particular disruption" (Mishel 1990, p.259).

McCormick (2002) and Hansen et al. (2012) agree that uncertainty is a multidimensional concept and a major part of illness that in its purest form is a neutral cognitive state, meaning that it might be experienced negatively or positively. Feelings of uncertainty in illness are described as stressful and a burden, giving rise to fear and worry, unpredictability, ambiguity, inconsistency, vagueness and loneliness, whereas facing uncertainty seems to be along a whole continuum from stress through reorientation and adjustment, acceptance, hope and even optimism (McCormick, 2002; Hansen et al., 2012). Perrett and Biley (2013) who investigated the process of adaptation for those living with HIV found that negotiating uncertainty could be defined as the core category or the most important aspect in the process of adaptation to illness. The authors described negotiating uncertainty in relation to several sub-categories that emerged from their data (such as "strengthening through hope", "seizing opportunity" or "planning for the future") as characterising different stages of adaptation (Perrett & Biley, 2013). The theory of negotiating uncertainty in people living with HIV could probably be readily adapted to other populations with chronic illnesses. The aspects of hope, opportunity (meaning of life and goals) and regaining ones personal responsibility also play an integral role in the concept of personal recovery, a process that describes the life experience of people with mental illness to accept and overcome the challenge of disability, integrating it into their lives (Slade 2009). Therefore, personal recovery can be described as the adaptation process to mental illness in a similar way as negotiating uncertainty has been described as the adaptation process to HIV and, potentially, to other chronic illnesses.

An international expert panel of mental health professionals discussed and explored their own experiences in relation to uncertainties in illness among people living with mental illness (Wolfensberger, 2014 – in preparation). The results of the panel in the guided discussion strongly support the hypothesis that uncertainties seem to be an integral part of the adaptation process to illness among people living with mental illness. However, the concept of uncertainty in illness or the process of negotiating uncertainty in people living with mental illness has not been really investigated yet and seems non-existent in current literature about mental illness or personal recovery.



Bournemouth University

Berner Fachhochschule Gesundheit

Research Protocol

Aim of research

The aim of the research is to evaluate the personal experiences of people living with mental illness in relation to their adaptation process to illness. The findings of the study will help to create a new and unique understanding of the adaptation process to mental illness from a patient perspective.

Therefore, the study will answer the following research questions:

- What are the aspects and issues, uncertainties, hopes and fears, people living with mental illness experience in the context of their adaptation process to illness?
- How do people living with mental illness experience those aspects and issues, such as uncertainties?
- How do people living with mental illness deal with those aspects and issues or how do they negotiate uncertainties?
- How does negotiating uncertainties and dealing with the issues affect the process of personal recovery?

Objectives of research

The objectives, stemming from multiple aspects of the study to understand the aspects and issues, such as uncertainties in people living with mental illness in the context of the personal recovery process are:

- To identify the relevant aspects and issues, such as uncertainties of people living with mental illness as part of their adaptation to illness process
- To outline the process of dealing with those issues or negotiating uncertainties within the conceptual model of personal recovery

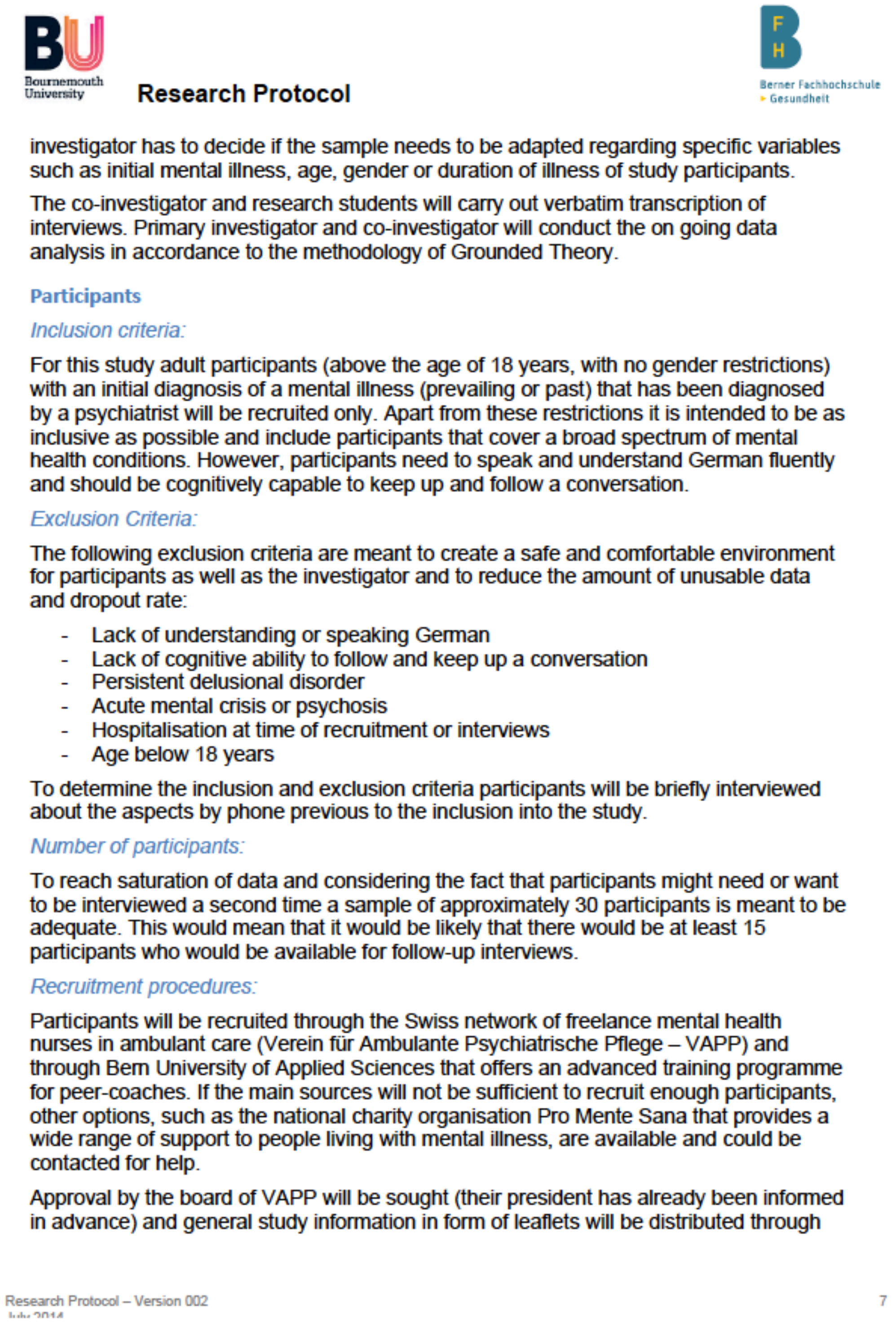
Methodology

The proposed method of data collection contains:

- In-depth face to face interviews that will be digitally recorded, transcribed and analysed using qualitative methodology based on a grounded-theory approach
- An extensive demographic questionnaire to support the interpretation of the data collected through the interviews

However, the demographic questionnaire is meant to be included in the interviews and will not be handed out on a separate form to be filled out by participants. Length and number of interviews with each participant depend on their story and experiences they are willing to share. However, the investigator's intention is not to extend the time of a single interview by approximately 90 min and to conduct more than one or two interviews with each participant. Follow-up or second interviews need to be negotiated between investigator and participant. Exclusively the co-investigator will hold the interviews. Participant choses a place and location for his or her own comfort as long as it is manageable for the investigator and suitable in relation to digital recording of the interview and privacy/confidentiality.

Theoretical sampling, which is in accordance with a grounded-theory approach (Charmaz 2006), will be used to reach saturation of data. This means that according to the data collected, for example if no new information is provided through the interviews, the



investigator has to decide if the sample needs to be adapted regarding specific variables such as initial mental illness, age, gender or duration of illness of study participants.

The co-investigator and research students will carry out verbatim transcription of interviews. Primary investigator and co-investigator will conduct the on going data analysis in accordance to the methodology of Grounded Theory.

Participants

Inclusion criteria:

For this study adult participants (above the age of 18 years, with no gender restrictions) with an initial diagnosis of a mental illness (prevailing or past) that has been diagnosed by a psychiatrist will be recruited only. Apart from these restrictions it is intended to be as inclusive as possible and include participants that cover a broad spectrum of mental health conditions. However, participants need to speak and understand German fluently and should be cognitively capable to keep up and follow a conversation.

Exclusion Criteria:

The following exclusion criteria are meant to create a safe and comfortable environment for participants as well as the investigator and to reduce the amount of unusable data and dropout rate:

- Lack of understanding or speaking German
- Lack of cognitive ability to follow and keep up a conversation
- Persistent delusional disorder
- Acute mental crisis or psychosis
- Hospitalisation at time of recruitment or interviews
- Age below 18 years

To determine the inclusion and exclusion criteria participants will be briefly interviewed about the aspects by phone previous to the inclusion into the study.

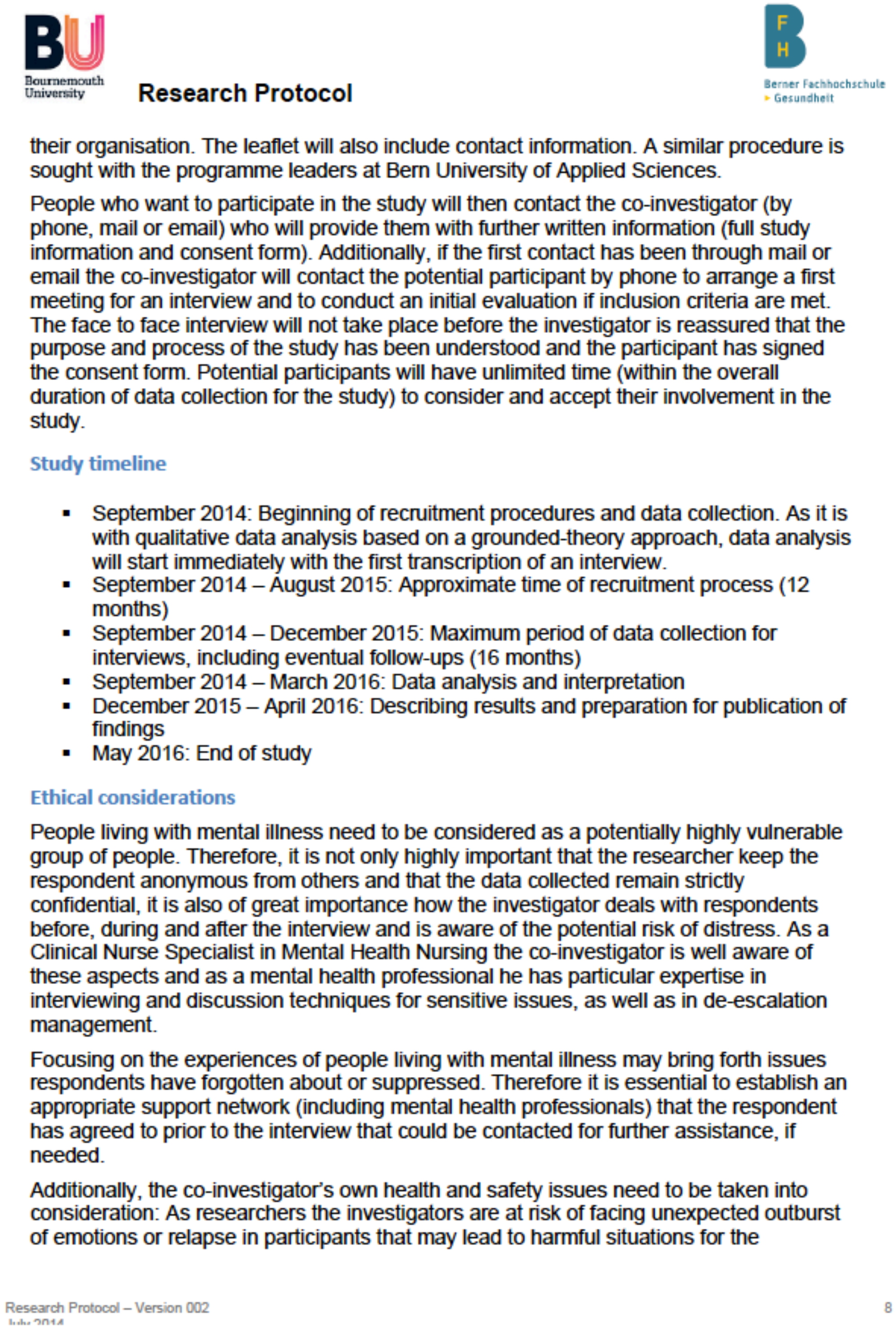
Number of participants:

To reach saturation of data and considering the fact that participants might need or want to be interviewed a second time a sample of approximately 30 participants is meant to be adequate. This would mean that it would be likely that there would be at least 15 participants who would be available for follow-up interviews.

Recruitment procedures:

Participants will be recruited through the Swiss network of freelance mental health nurses in ambulant care (Verein für Ambulante Psychiatrische Pflege – VAPP) and through Bern University of Applied Sciences that offers an advanced training programme for peer-coaches. If the main sources will not be sufficient to recruit enough participants, other options, such as the national charity organisation Pro Mente Sana that provides a wide range of support to people living with mental illness, are available and could be contacted for help.

Approval by the board of VAPP will be sought (their president has already been informed in advance) and general study information in form of leaflets will be distributed through



their organisation. The leaflet will also include contact information. A similar procedure is sought with the programme leaders at Bern University of Applied Sciences.

People who want to participate in the study will then contact the co-investigator (by phone, mail or email) who will provide them with further written information (full study information and consent form). Additionally, if the first contact has been through mail or email the co-investigator will contact the potential participant by phone to arrange a first meeting for an interview and to conduct an initial evaluation if inclusion criteria are met. The face to face interview will not take place before the investigator is reassured that the purpose and process of the study has been understood and the participant has signed the consent form. Potential participants will have unlimited time (within the overall duration of data collection for the study) to consider and accept their involvement in the study.

Study timeline

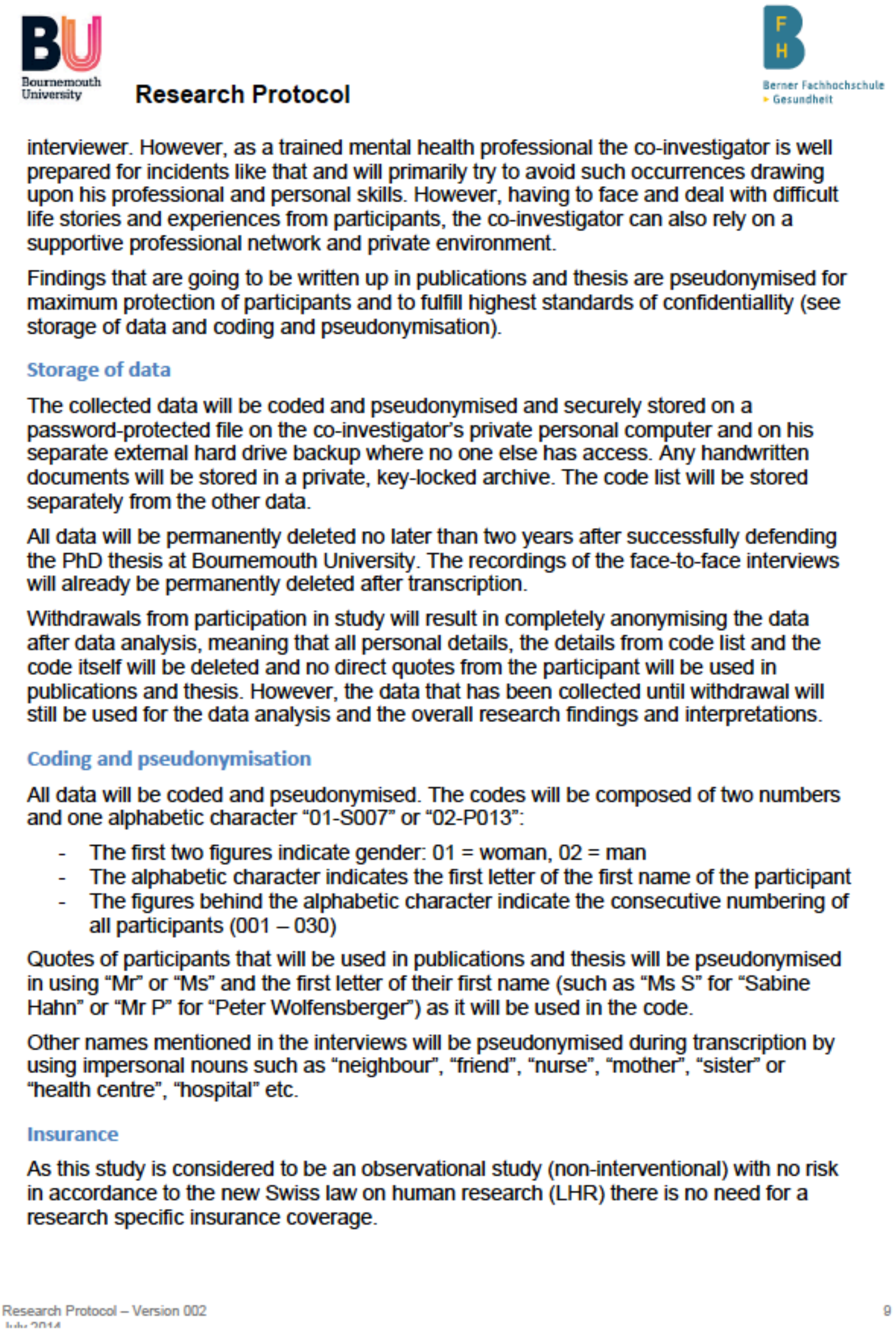
- September 2014: Beginning of recruitment procedures and data collection. As it is with qualitative data analysis based on a grounded-theory approach, data analysis will start immediately with the first transcription of an interview.
- September 2014 – August 2015: Approximate time of recruitment process (12 months)
- September 2014 – December 2015: Maximum period of data collection for interviews, including eventual follow-ups (16 months)
- September 2014 – March 2016: Data analysis and interpretation
- December 2015 – April 2016: Describing results and preparation for publication of findings
- May 2016: End of study

Ethical considerations

People living with mental illness need to be considered as a potentially highly vulnerable group of people. Therefore, it is not only highly important that the researcher keep the respondent anonymous from others and that the data collected remain strictly confidential, it is also of great importance how the investigator deals with respondents before, during and after the interview and is aware of the potential risk of distress. As a Clinical Nurse Specialist in Mental Health Nursing the co-investigator is well aware of these aspects and as a mental health professional he has particular expertise in interviewing and discussion techniques for sensitive issues, as well as in de-escalation management.

Focusing on the experiences of people living with mental illness may bring forth issues respondents have forgotten about or suppressed. Therefore it is essential to establish an appropriate support network (including mental health professionals) that the respondent has agreed to prior to the interview that could be contacted for further assistance, if needed.

Additionally, the co-investigator's own health and safety issues need to be taken into consideration: As researchers the investigators are at risk of facing unexpected outburst of emotions or relapse in participants that may lead to harmful situations for the



interviewer. However, as a trained mental health professional the co-investigator is well prepared for incidents like that and will primarily try to avoid such occurrences drawing upon his professional and personal skills. However, having to face and deal with difficult life stories and experiences from participants, the co-investigator can also rely on a supportive professional network and private environment.

Findings that are going to be written up in publications and thesis are pseudonymised for maximum protection of participants and to fulfill highest standards of confidentiallity (see storage of data and coding and pseudonymisation).

Storage of data

The collected data will be coded and pseudonymised and securely stored on a password-protected file on the co-investigator's private personal computer and on his separate external hard drive backup where no one else has access. Any handwritten documents will be stored in a private, key-locked archive. The code list will be stored separately from the other data.

All data will be permanently deleted no later than two years after successfully defending the PhD thesis at Bournemouth University. The recordings of the face-to-face interviews will already be permanently deleted after transcription.

Withdrawals from participation in study will result in completely anonymising the data after data analysis, meaning that all personal details, the details from code list and the code itself will be deleted and no direct quotes from the participant will be used in publications and thesis. However, the data that has been collected until withdrawal will still be used for the data analysis and the overall research findings and interpretations.

Coding and pseudonymisation

All data will be coded and pseudonymised. The codes will be composed of two numbers and one alphabetic character "01-S007" or "02-P013":

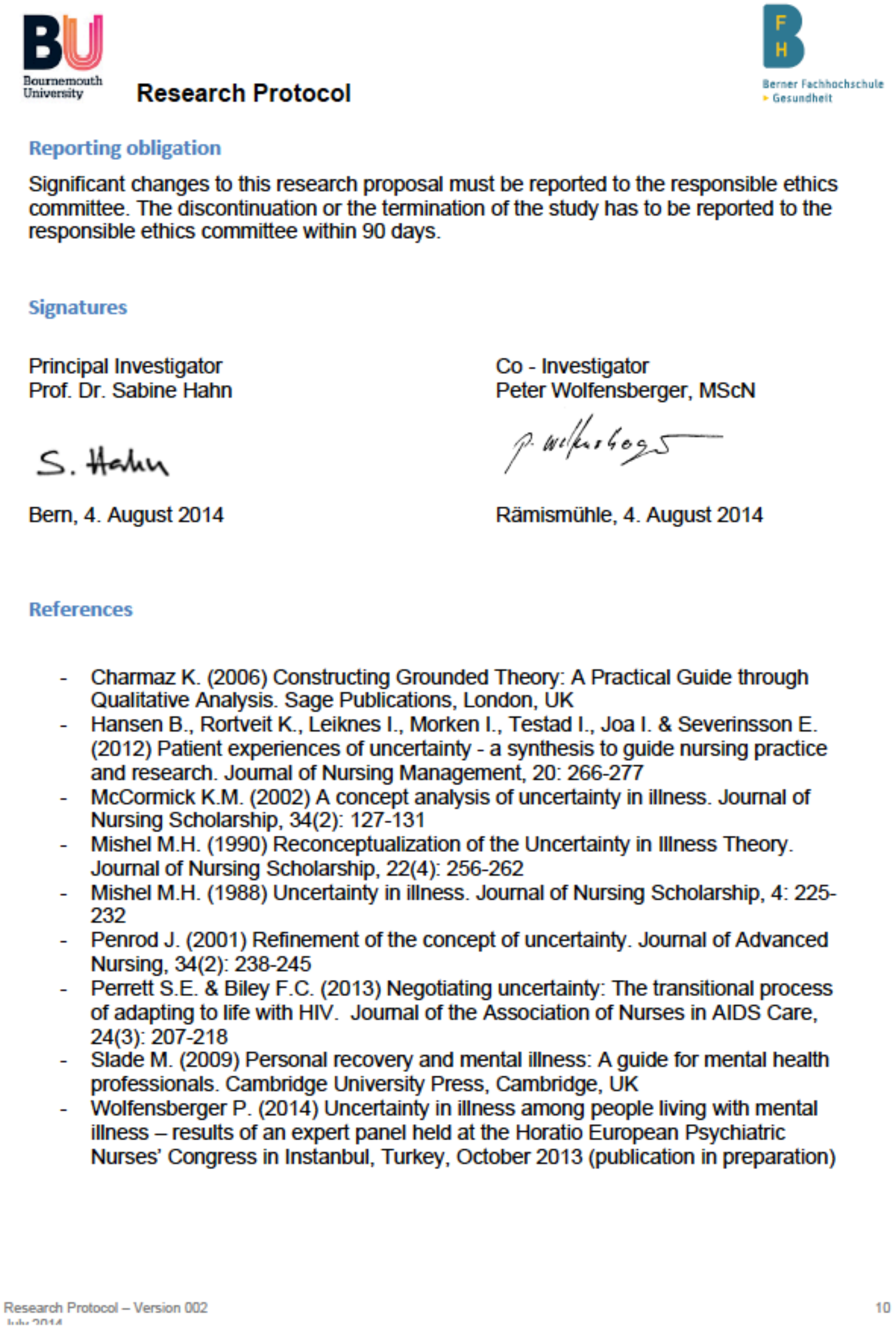
- The first two figures indicate gender: 01 = woman, 02 = man
- The alphabetic character indicates the first letter of the first name of the participant
- The figures behind the alphabetic character indicate the consecutive numbering of all participants (001 – 030)

Quotes of participants that will be used in publications and thesis will be pseudonymised in using "Mr" or "Ms" and the first letter of their first name (such as "Ms S" for "Sabine Hahn" or "Mr P" for "Peter Wolfensberger") as it will be used in the code.

Other names mentioned in the interviews will be pseudonymised during transcription by using impersonal nouns such as "neighbour", "friend", "nurse", "mother", "sister" or "health centre", "hospital" etc.

Insurance

As this study is considered to be an observational study (non-interventional) with no risk in accordance to the new Swiss law on human research (LHR) there is no need for a research specific insurance coverage.



Research Protocol

Reporting obligation

Significant changes to this research proposal must be reported to the responsible ethics committee. The discontinuation or the termination of the study has to be reported to the responsible ethics committee within 90 days.

Signatures

Principal Investigator Prof. Dr. Sabine Hahn	Co - Investigator Peter Wolfensberger, MScN
S. Hahn	P. Wolfensberger
Bern, 4. August 2014	Rämismühle, 4. August 2014

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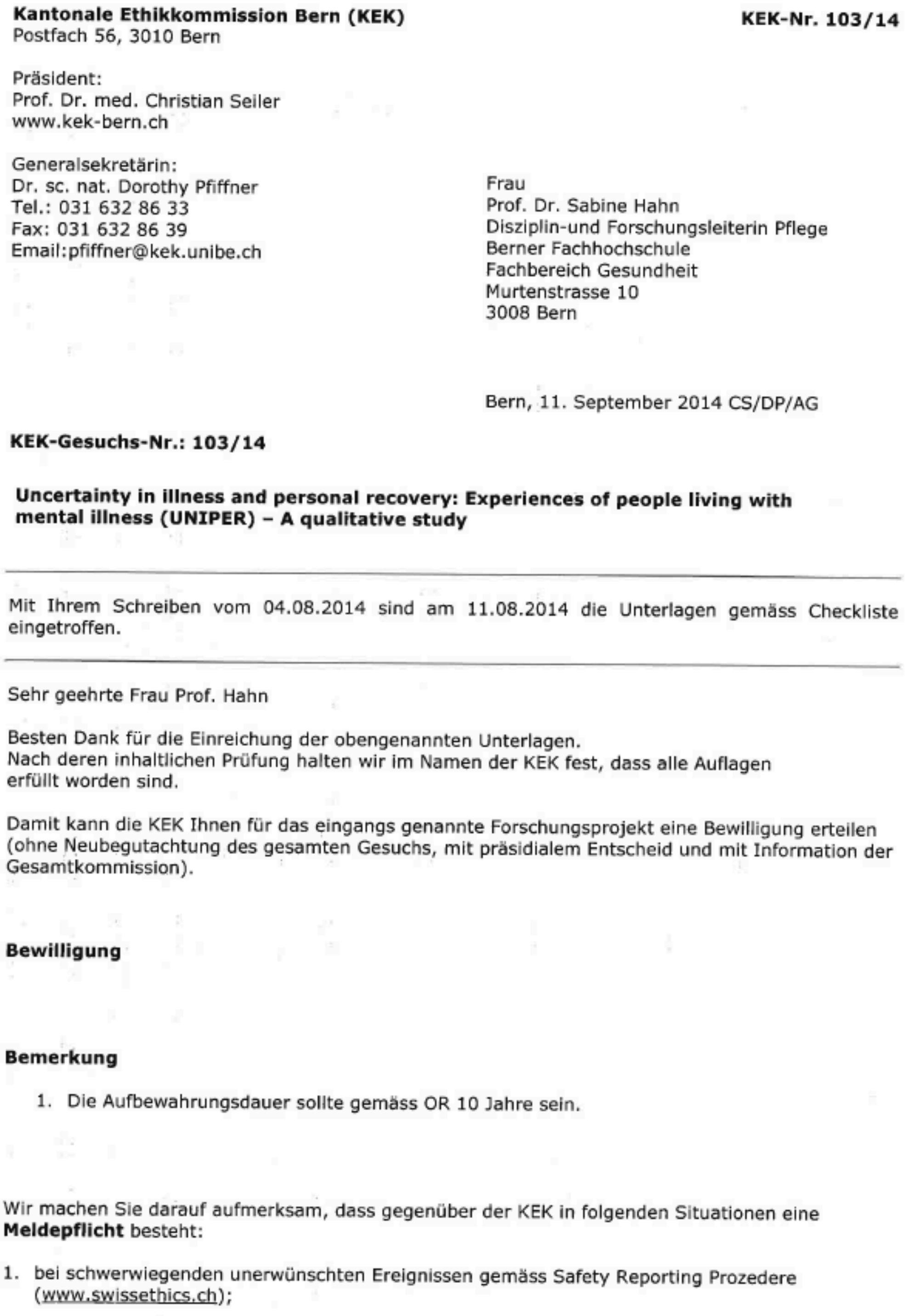
10.5 Appendix 5: Approval of the Ethics Committee



Kantonale Ethikkommission Bern (KEK)
Postfach 56, 3010 Bern

Präsident:
Prof. Dr. med. Christian Seiler
www.kek-bern.ch

Generalsekretärin:
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Tel.: 031 632 86 33
Fax: 031 632 86 39
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KEK-Nr. 103/14

Frau
Prof. Dr. Sabine Hahn
Disziplin-und Forschungsleiterin Pflege
Berner Fachhochschule
Fachbereich Gesundheit
Murtenstrasse 10
3008 Bern

Bern, 11. September 2014 CS/DP/AG

KEK-Gesuchs-Nr.: 103/14

Uncertainty in illness and personal recovery: Experiences of people living with mental illness (UNIPER) – A qualitative study

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Mit Ihrem Schreiben vom 04.08.2014 sind am 11.08.2014 die Unterlagen gemäss Checkliste eingetroffen.

Sehr geehrte Frau Prof. Hahn

Besten Dank für die Einreichung der obengenannten Unterlagen.
Nach deren inhaltlichen Prüfung halten wir im Namen der KEK fest, dass alle Auflagen erfüllt worden sind.

Damit kann die KEK Ihnen für das eingangs genannte Forschungsprojekt eine Bewilligung erteilen (ohne Neubegutachtung des gesamten Gesuchs, mit präsidialem Entscheid und mit Information der Gesamtkommission).

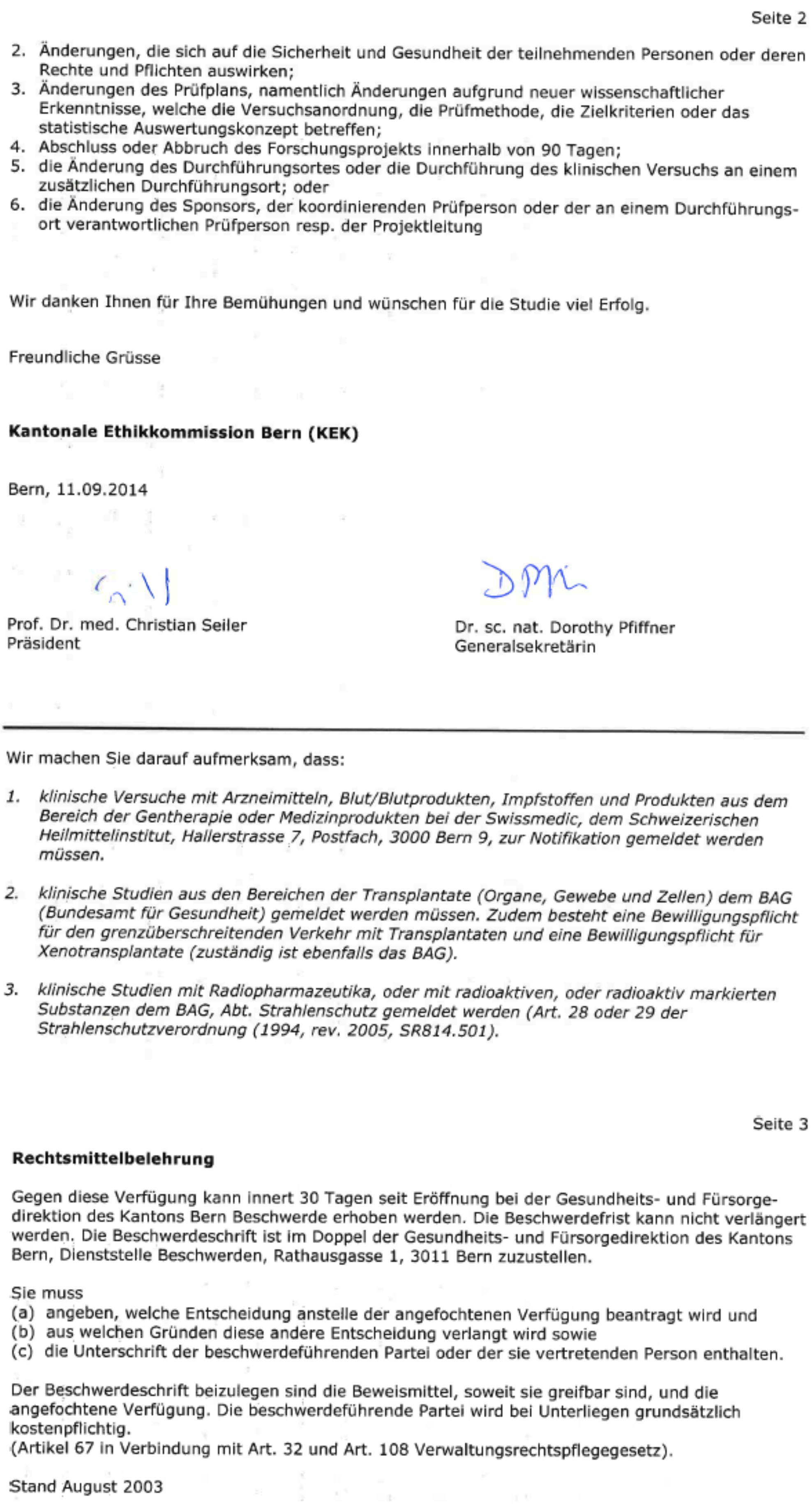
Bewilligung

Bemerkung

1. Die Aufbewahrungsdauer sollte gemäss OR 10 Jahre sein.

Wir machen Sie darauf aufmerksam, dass gegenüber der KEK in folgenden Situationen eine **Meldepflicht** besteht:

1. bei schwerwiegenden unerwünschten Ereignissen gemäss Safety Reporting Prozedere (www.swissethics.ch);



2. Änderungen, die sich auf die Sicherheit und Gesundheit der teilnehmenden Personen oder deren Rechte und Pflichten auswirken;
3. Änderungen des Prüfplans, namentlich Änderungen aufgrund neuer wissenschaftlicher Erkenntnisse, welche die Versuchsanordnung, die Prüfmethode, die Zielkriterien oder das statistische Auswertungskonzept betreffen;
4. Abschluss oder Abbruch des Forschungsprojekts innerhalb von 90 Tagen;
5. die Änderung des Durchführungsortes oder die Durchführung des klinischen Versuchs an einem zusätzlichen Durchführungsort; oder
6. die Änderung des Sponsors, der koordinierenden Prüfperson oder der an einem Durchführungsort verantwortlichen Prüfperson resp. der Projektleitung

Wir danken Ihnen für Ihre Bemühungen und wünschen für die Studie viel Erfolg.

Freundliche Grüsse

Kantonale Ethikkommission Bern (KEK)

Bern, 11.09.2014

Prof. Dr. med. Christian Seiler
Präsident

Dr. sc. nat. Dorothy Pfiffner
Generalsekretärin

Wir machen Sie darauf aufmerksam, dass:

1. *klinische Versuche mit Arzneimitteln, Blut/Blutprodukten, Impfstoffen und Produkten aus dem Bereich der Gentherapie oder Medizinprodukten bei der Swissmedic, dem Schweizerischen Heilmittelinstitut, Hallerstrasse 7, Postfach, 3000 Bern 9, zur Notifikation gemeldet werden müssen.*

2. *klinische Studien aus den Bereichen der Transplantate (Organe, Gewebe und Zellen) dem BAG (Bundesamt für Gesundheit) gemeldet werden müssen. Zudem besteht eine Bewilligungspflicht für den grenzüberschreitenden Verkehr mit Transplantaten und eine Bewilligungspflicht für Xenotransplantate (zuständig ist ebenfalls das BAG).*

3. *klinische Studien mit Radiopharmazeutika, oder mit radioaktiven, oder radioaktiv markierten Substanzen dem BAG, Abt. Strahlenschutz gemeldet werden (Art. 28 oder 29 der Strahlenschutzverordnung (1994, rev. 2005, SR814.501).*

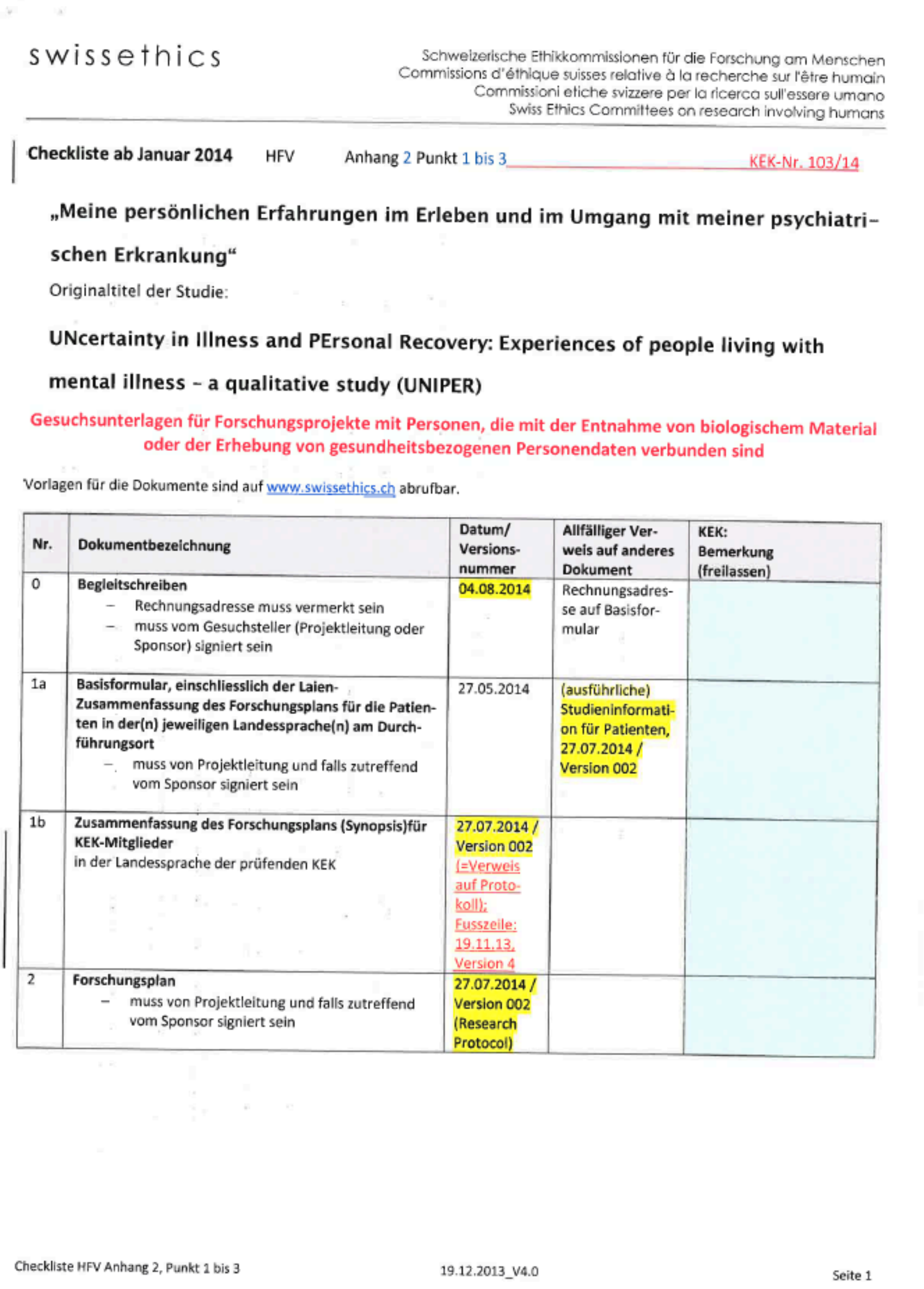
Rechtsmittelbelehrung

Gegen diese Verfügung kann innert 30 Tagen seit Eröffnung bei der Gesundheits- und Fürsorgedirektion des Kantons Bern Beschwerde erhoben werden. Die Beschwerdefrist kann nicht verlängert werden. Die Beschwerdeschrift ist im Doppel der Gesundheits- und Fürsorgedirektion des Kantons Bern, Dienststelle Beschwerden, Rathausgasse 1, 3011 Bern zuzustellen.

Sie muss
(a) angeben, welche Entscheidung anstelle der angefochtenen Verfügung beantragt wird und
(b) aus welchen Gründen diese andere Entscheidung verlangt wird sowie
(c) die Unterschrift der beschwerdeführenden Partei oder der sie vertretenden Person enthalten.

Der Beschwerdeschrift beizulegen sind die Beweismittel, soweit sie greifbar sind, und die angefochtene Verfügung. Die beschwerdeführende Partei wird bei Unterliegen grundsätzlich kostenpflichtig.
(Artikel 67 in Verbindung mit Art. 32 und Art. 108 Verwaltungsrechtspflegegesetz).

Stand August 2003



swissethics

Schweizerische Ethikkommissionen für die Forschung am Menschen
Commissions d'éthique suisses relative à la recherche sur l'être humain
Commissioni etiche svizzere per la ricerca sull'essere umano
Swiss Ethics Committees on research involving humans

Checkliste ab Januar 2014 HFV Anhang 2 Punkt 1 bis 3 KEK-Nr. 103/14

„Meine persönlichen Erfahrungen im Erleben und im Umgang mit meiner psychiatrischen Erkrankung"

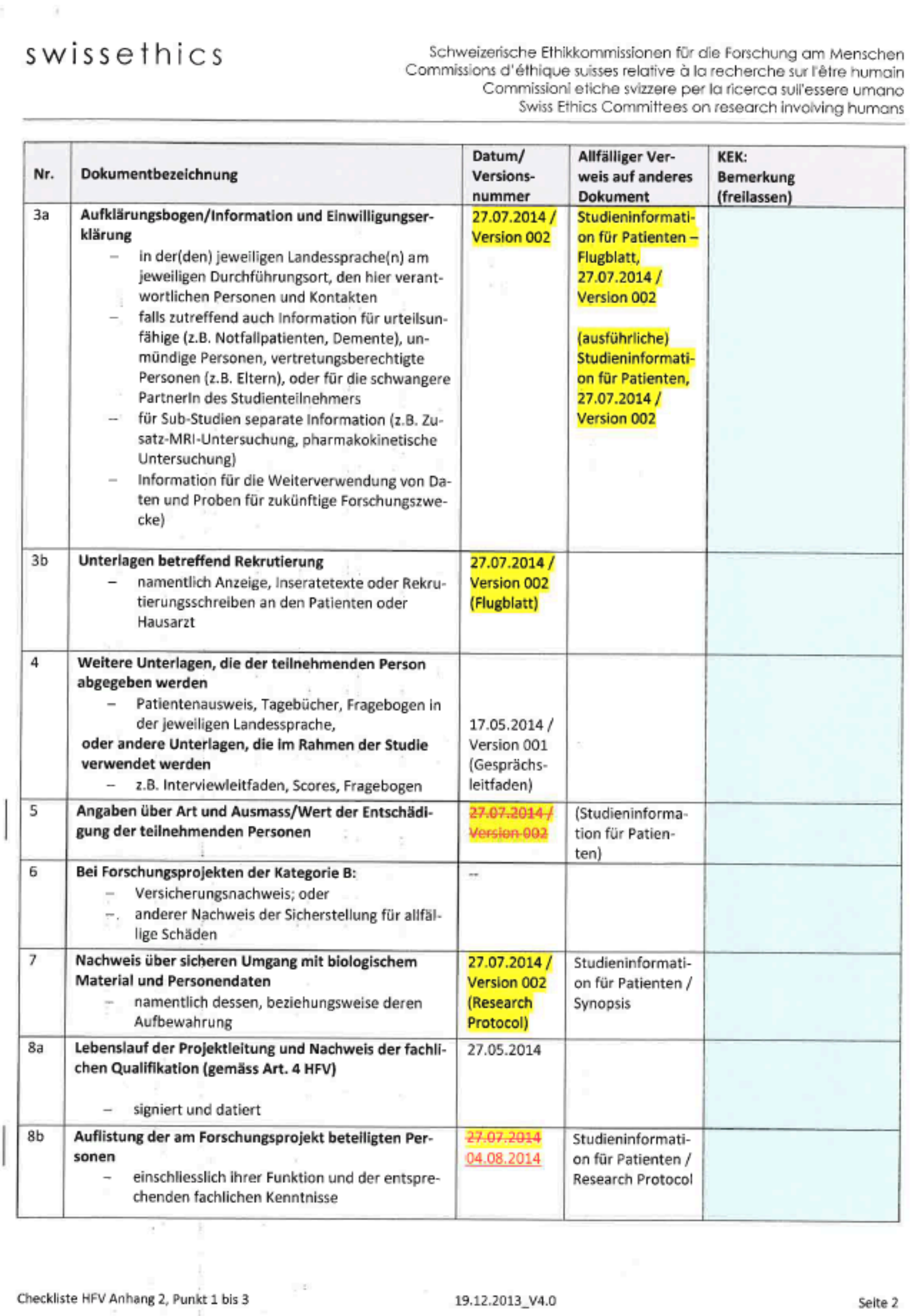
Originaltitel der Studie:

UNcertainty in Illness and PErsonal Recovery: Experiences of people living with mental illness – a qualitative study (UNIPER)

Gesuchsunterlagen für Forschungsprojekte mit Personen, die mit der Entnahme von biologischem Material oder der Erhebung von gesundheitsbezogenen Personendaten verbunden sind

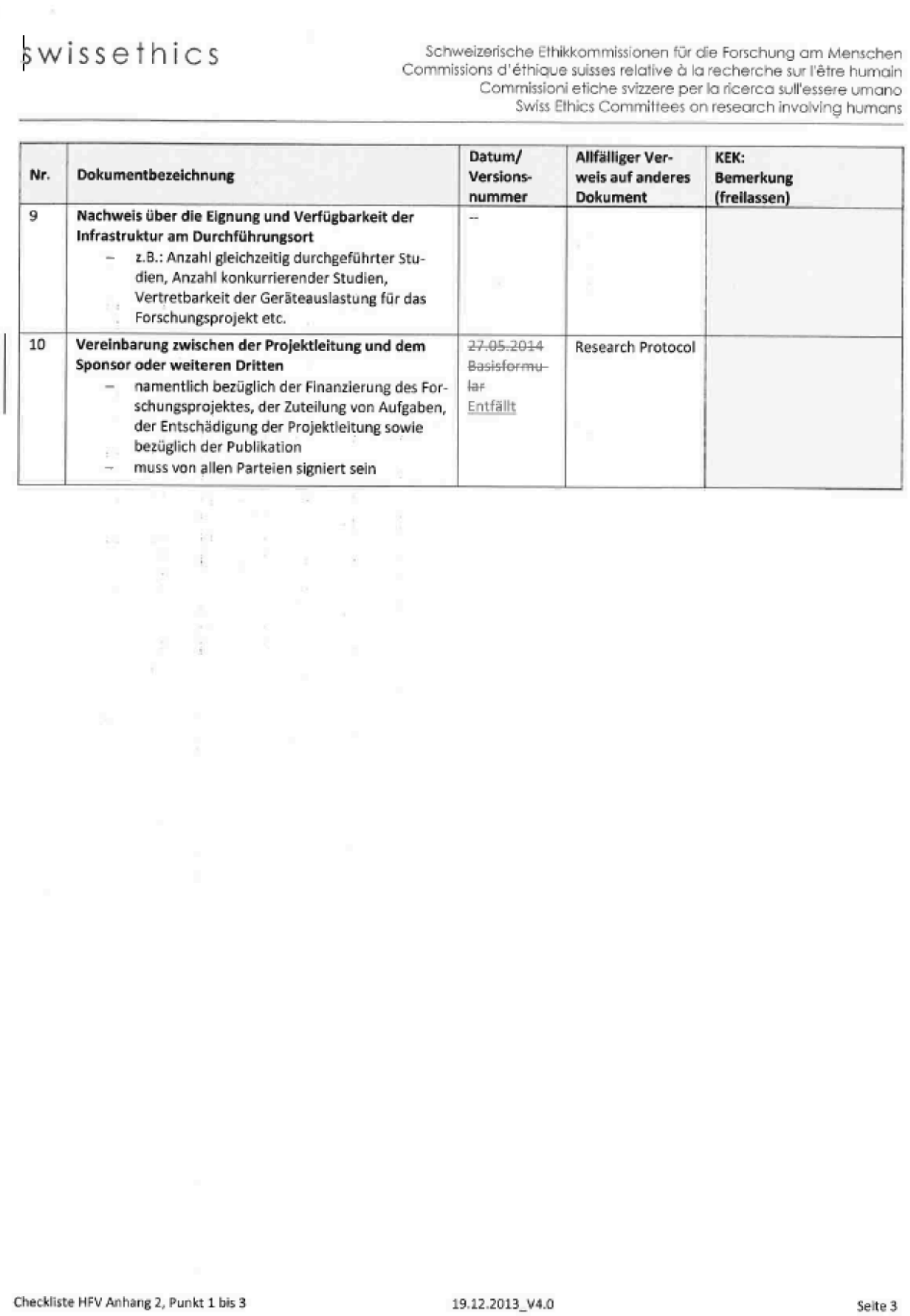
Vorlagen für die Dokumente sind auf www.swissethics.ch abrufbar.

Nr.	Dokumentbezeichnung	Datum/ Versionsnummer	Allfälliger Verweis auf anderes Dokument	KEK: Bemerkung (freilassen)
0	**Begleitschreiben** – Rechnungsadresse muss vermerkt sein – muss vom Gesuchsteller (Projektleitung oder Sponsor) signiert sein	04.08.2014	Rechnungsadresse auf Basisformular	
1a	**Basisformular, einschliesslich der Laien-Zusammenfassung des Forschungsplans für die Patienten in der(n) jeweiligen Landessprache(n) am Durchführungsort** – muss von Projektleitung und falls zutreffend vom Sponsor signiert sein	27.05.2014	(ausführliche) Studieninformation für Patienten, 27.07.2014 / Version 002	
1b	**Zusammenfassung des Forschungsplans (Synopsis)für KEK-Mitglieder** in der Landessprache der prüfenden KEK	27.07.2014 / Version 002 (=Verweis auf Protokoll); Fusszeile: 19.11.13, Version 4		
2	**Forschungsplan** – muss von Projektleitung und falls zutreffend vom Sponsor signiert sein	27.07.2014 / Version 002 (Research Protocol)		

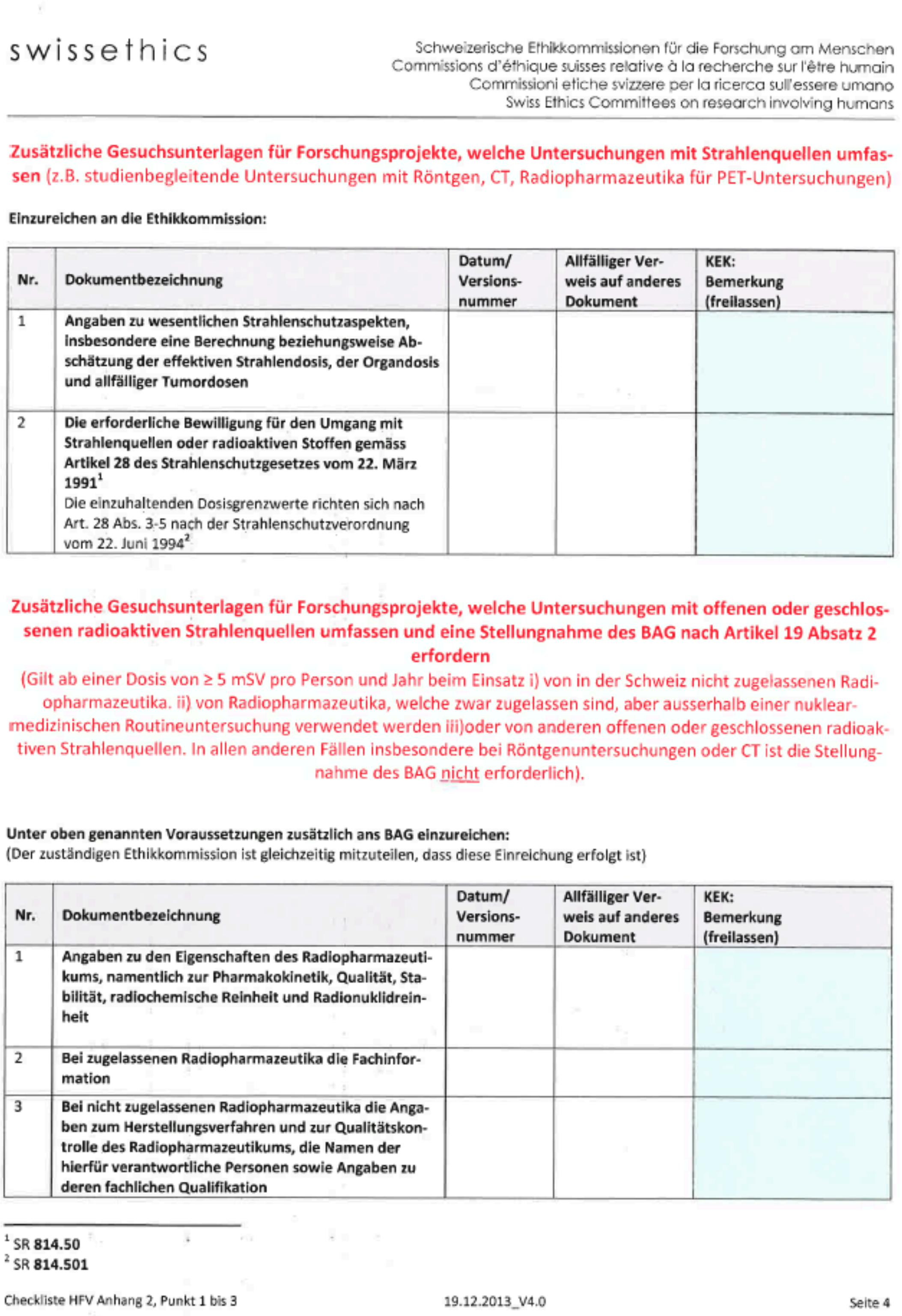


Nr.	Dokumentbezeichnung	Datum/ Versionsnummer	Allfälliger Verweis auf anderes Dokument	KEK: Bemerkung (freilassen)
3a	**Aufklärungsbogen/Information und Einwilligungserklärung** – in der(den) jeweiligen Landessprache(n) am jeweiligen Durchführungsort, den hier verantwortlichen Personen und Kontakten – falls zutreffend auch Information für urteilsunfähige (z.B. Notfallpatienten, Demente), unmündige Personen, vertretungsberechtigte Personen (z.B. Eltern), oder für die schwangere PartnerIn des Studienteilnehmers – für Sub-Studien separate Information (z.B. Zusatz-MRI-Untersuchung, pharmakokinetische Untersuchung) – Information für die Weiterverwendung von Daten und Proben für zukünftige Forschungszwecke)	27.07.2014 / Version 002	Studieninformation für Patienten – Flugblatt, 27.07.2014 / Version 002 (ausführliche) Studieninformation für Patienten, 27.07.2014 / Version 002	
3b	**Unterlagen betreffend Rekrutierung** – namentlich Anzeige, Inseratetexte oder Rekrutierungsschreiben an den Patienten oder Hausarzt	27.07.2014 / Version 002 (Flugblatt)		
4	**Weitere Unterlagen, die der teilnehmenden Person abgegeben werden** – Patientenausweis, Tagebücher, Fragebogen in der jeweiligen Landessprache, **oder andere Unterlagen, die im Rahmen der Studie verwendet werden** – z.B. Interviewleitfaden, Scores, Fragebogen	17.05.2014 / Version 001 (Gesprächsleitfaden)		
5	**Angaben über Art und Ausmass/Wert der Entschädigung der teilnehmenden Personen**	~~27.07.2014 / Version 002~~	(Studieninformation für Patienten)	
6	**Bei Forschungsprojekten der Kategorie B:** – Versicherungsnachweis; oder – anderer Nachweis der Sicherstellung für allfällige Schäden	--		
7	**Nachweis über sicheren Umgang mit biologischem Material und Personendaten** – namentlich dessen, beziehungsweise deren Aufbewahrung	27.07.2014 / Version 002 (Research Protocol)	Studieninformation für Patienten / Synopsis	
8a	**Lebenslauf der Projektleitung und Nachweis der fachlichen Qualifikation (gemäss Art. 4 HFV)** – signiert und datiert	27.05.2014		
8b	**Auflistung der am Forschungsprojekt beteiligten Personen** – einschliesslich ihrer Funktion und der entsprechenden fachlichen Kenntnisse	~~27.07.2014~~ 04.08.2014	Studieninformation für Patienten / Research Protocol	

Checkliste HFV Anhang 2, Punkt 1 bis 3 19.12.2013_V4.0 Seite 2



Nr.	Dokumentbezeichnung	Datum/ Versionsnummer	Allfälliger Verweis auf anderes Dokument	KEK: Bemerkung (freilassen)
9	**Nachweis über die Eignung und Verfügbarkeit der Infrastruktur am Durchführungsort** – z.B.: Anzahl gleichzeitig durchgeführter Studien, Anzahl konkurrierender Studien, Vertretbarkeit der Geräteauslastung für das Forschungsprojekt etc.	--		
10	**Vereinbarung zwischen der Projektleitung und dem Sponsor oder weiteren Dritten** – namentlich bezüglich der Finanzierung des Forschungsprojektes, der Zuteilung von Aufgaben, der Entschädigung der Projektleitung sowie bezüglich der Publikation – muss von allen Parteien signiert sein	~~27.05.2014 Basisformular~~ Entfällt	Research Protocol	



swissethics

Schweizerische Ethikkommissionen für die Forschung am Menschen
Commissions d'éthique suisses relative à la recherche sur l'être humain
Commissioni etiche svizzere per la ricerca sull'essere umano
Swiss Ethics Committees on research involving humans

Zusätzliche Gesuchsunterlagen für Forschungsprojekte, welche Untersuchungen mit Strahlenquellen umfassen (z.B. studienbegleitende Untersuchungen mit Röntgen, CT, Radiopharmazeutika für PET-Untersuchungen)

Einzureichen an die Ethikkommission:

Nr.	Dokumentbezeichnung	Datum/ Versions-nummer	Allfälliger Verweis auf anderes Dokument	KEK: Bemerkung (freilassen)
1	**Angaben zu wesentlichen Strahlenschutzaspekten, insbesondere eine Berechnung beziehungsweise Abschätzung der effektiven Strahlendosis, der Organdosis und allfälliger Tumordosen**			
2	**Die erforderliche Bewilligung für den Umgang mit Strahlenquellen oder radioaktiven Stoffen gemäss Artikel 28 des Strahlenschutzgesetzes vom 22. März 1991**[1] Die einzuhaltenden Dosisgrenzwerte richten sich nach Art. 28 Abs. 3-5 nach der Strahlenschutzverordnung vom 22. Juni 1994[2]			

Zusätzliche Gesuchsunterlagen für Forschungsprojekte, welche Untersuchungen mit offenen oder geschlossenen radioaktiven Strahlenquellen umfassen und eine Stellungnahme des BAG nach Artikel 19 Absatz 2 erfordern

(Gilt ab einer Dosis von ≥ 5 mSV pro Person und Jahr beim Einsatz i) von in der Schweiz nicht zugelassenen Radiopharmazeutika. ii) von Radiopharmazeutika, welche zwar zugelassen sind, aber ausserhalb einer nuklearmedizinischen Routineuntersuchung verwendet werden iii)oder von anderen offenen oder geschlossenen radioaktiven Strahlenquellen. In allen anderen Fällen insbesondere bei Röntgenuntersuchungen oder CT ist die Stellungnahme des BAG nicht erforderlich).

Unter oben genannten Voraussetzungen zusätzlich ans BAG einzureichen:
(Der zuständigen Ethikkommission ist gleichzeitig mitzuteilen, dass diese Einreichung erfolgt ist)

Nr.	Dokumentbezeichnung	Datum/ Versions-nummer	Allfälliger Verweis auf anderes Dokument	KEK: Bemerkung (freilassen)
1	**Angaben zu den Eigenschaften des Radiopharmazeutikums, namentlich zur Pharmakokinetik, Qualität, Stabilität, radiochemische Reinheit und Radionuklidreinheit**			
2	**Bei zugelassenen Radiopharmazeutika die Fachinformation**			
3	**Bei nicht zugelassenen Radiopharmazeutika die Angaben zum Herstellungsverfahren und zur Qualitätskontrolle des Radiopharmazeutikums, die Namen der hierfür verantwortliche Personen sowie Angaben zu deren fachlichen Qualifikation**			

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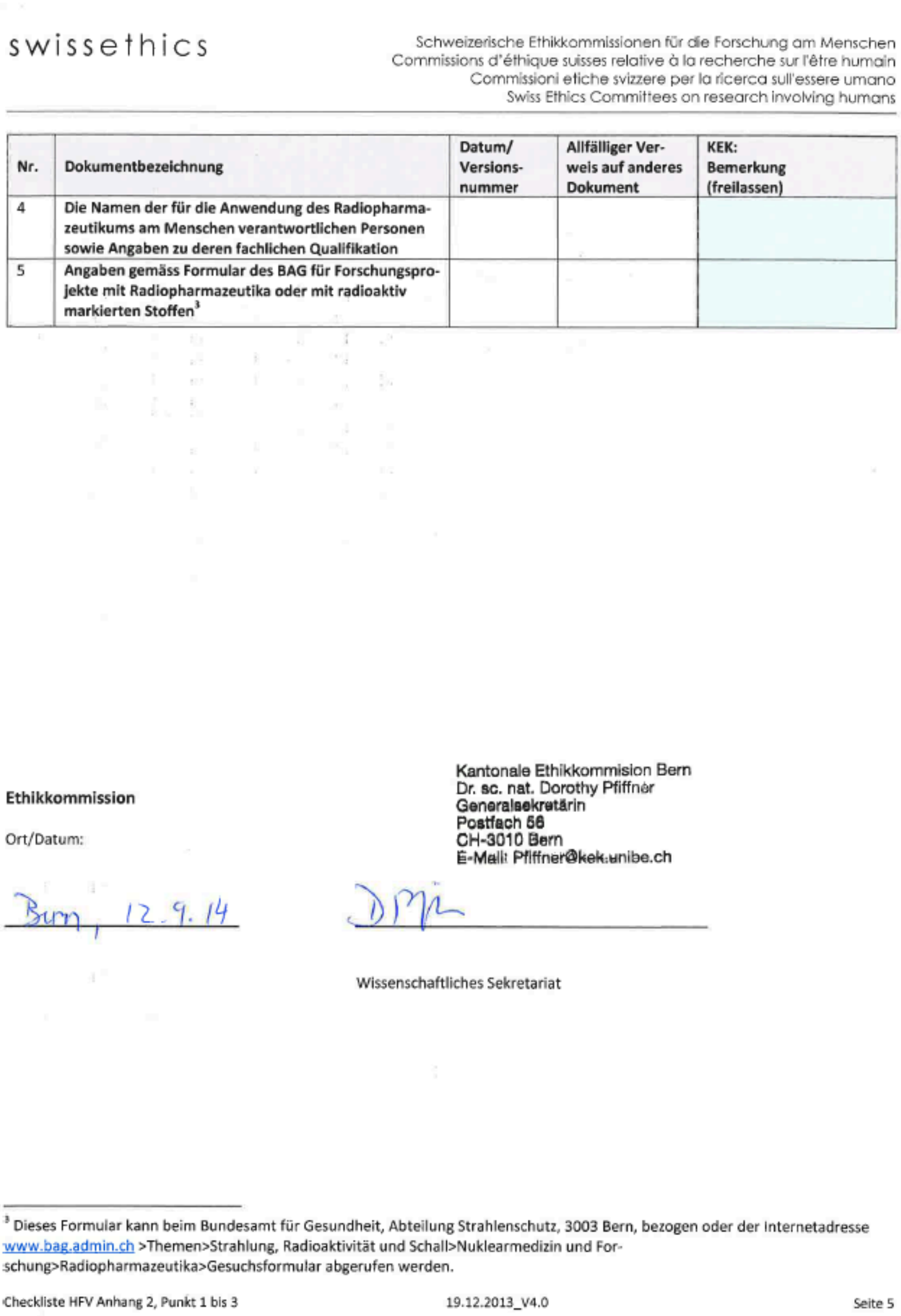
[1] SR **814.50**
[2] SR **814.501**



Nr.	Dokumentbezeichnung	Datum/ Versions-nummer	Allfälliger Ver-weis auf anderes Dokument	KEK: Bemerkung (freilassen)
4	**Die Namen der für die Anwendung des Radiopharmazeutikums am Menschen verantwortlichen Personen sowie Angaben zu deren fachlichen Qualifikation**			
5	**Angaben gemäss Formular des BAG für Forschungsprojekte mit Radiopharmazeutika oder mit radioaktiv markierten Stoffen[3]**			

Ethikkommission

Ort/Datum:

Bern, 12.9.14

Kantonale Ethikkommision Bern
Dr. sc. nat. Dorothy Pfiffner
Generalsekretärin
Postfach 56
CH-3010 Bern
E-Mail: Pfiffner@kek.unibe.ch

Wissenschaftliches Sekretariat

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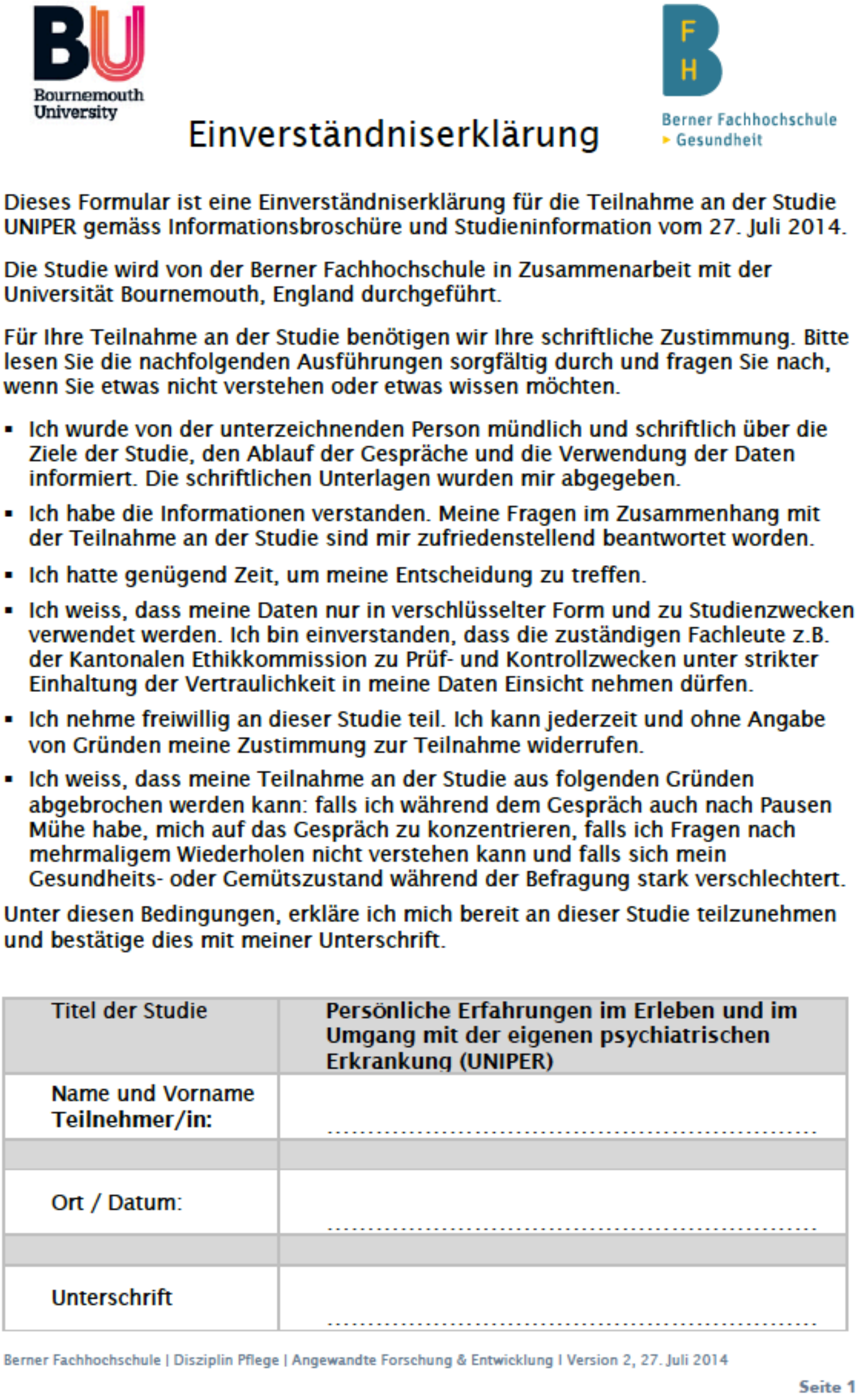
[3] Dieses Formular kann beim Bundesamt für Gesundheit, Abteilung Strahlenschutz, 3003 Bern, bezogen oder der Internetadresse www.bag.admin.ch >Themen>Strahlung, Radioaktivität und Schall>Nuklearmedizin und Forschung>Radiopharmazeutika>Gesuchsformular abgerufen werden.

10.6 Appendix 6: Consent Form

(German only)



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Einverständniserklärung

Dieses Formular ist eine Einverständniserklärung für die Teilnahme an der Studie UNIPER gemäss Informationsbroschüre und Studieninformation vom 27. Juli 2014.

Die Studie wird von der Berner Fachhochschule in Zusammenarbeit mit der Universität Bournemouth, England durchgeführt.

Für Ihre Teilnahme an der Studie benötigen wir Ihre schriftliche Zustimmung. Bitte lesen Sie die nachfolgenden Ausführungen sorgfältig durch und fragen Sie nach, wenn Sie etwas nicht verstehen oder etwas wissen möchten.

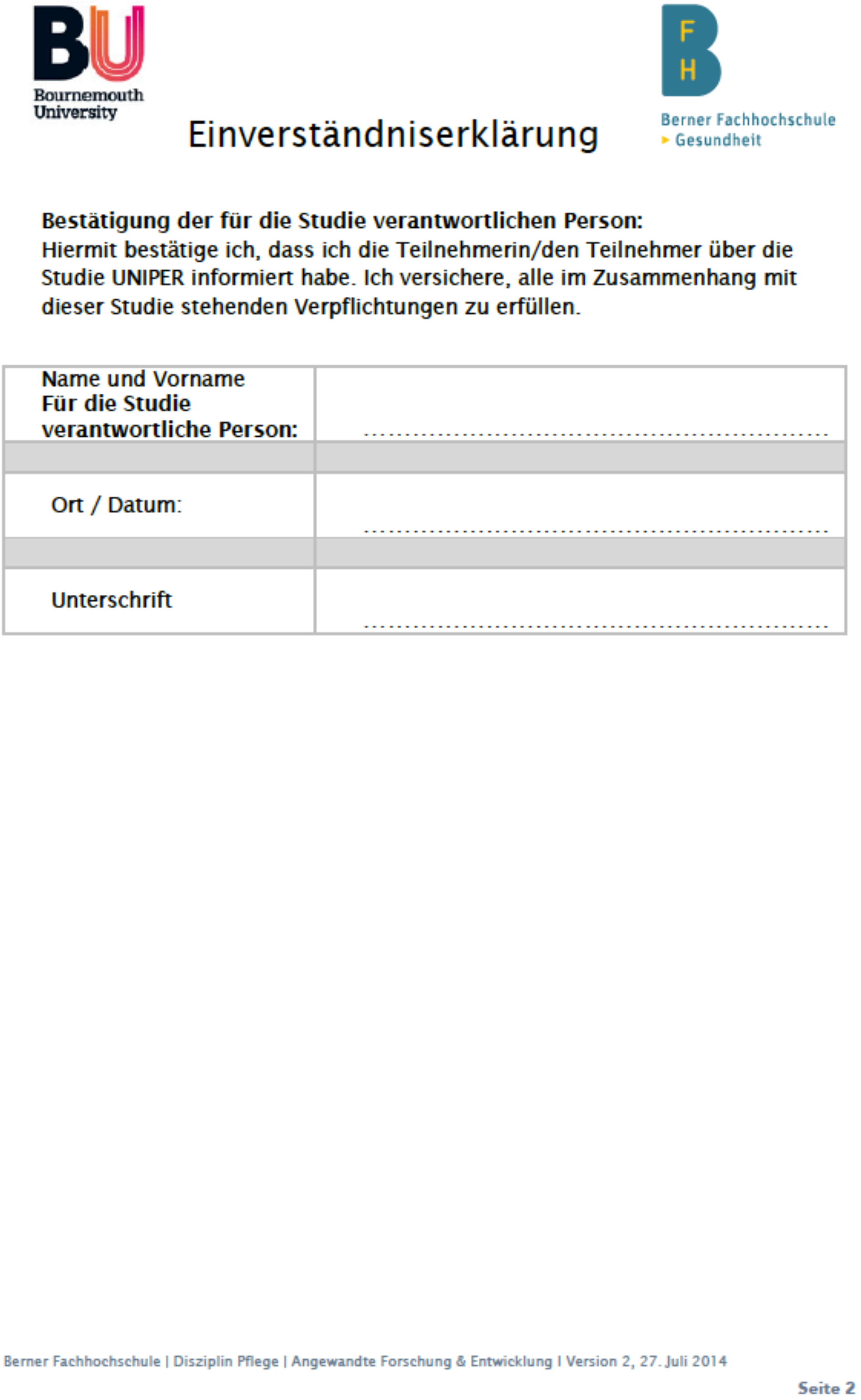
- Ich wurde von der unterzeichnenden Person mündlich und schriftlich über die Ziele der Studie, den Ablauf der Gespräche und die Verwendung der Daten informiert. Die schriftlichen Unterlagen wurden mir abgegeben.
- Ich habe die Informationen verstanden. Meine Fragen im Zusammenhang mit der Teilnahme an der Studie sind mir zufriedenstellend beantwortet worden.
- Ich hatte genügend Zeit, um meine Entscheidung zu treffen.
- Ich weiss, dass meine Daten nur in verschlüsselter Form und zu Studienzwecken verwendet werden. Ich bin einverstanden, dass die zuständigen Fachleute z.B. der Kantonalen Ethikkommission zu Prüf- und Kontrollzwecken unter strikter Einhaltung der Vertraulichkeit in meine Daten Einsicht nehmen dürfen.
- Ich nehme freiwillig an dieser Studie teil. Ich kann jederzeit und ohne Angabe von Gründen meine Zustimmung zur Teilnahme widerrufen.
- Ich weiss, dass meine Teilnahme an der Studie aus folgenden Gründen abgebrochen werden kann: falls ich während dem Gespräch auch nach Pausen Mühe habe, mich auf das Gespräch zu konzentrieren, falls ich Fragen nach mehrmaligem Wiederholen nicht verstehen kann und falls sich mein Gesundheits- oder Gemütszustand während der Befragung stark verschlechtert.

Unter diesen Bedingungen, erkläre ich mich bereit an dieser Studie teilzunehmen und bestätige dies mit meiner Unterschrift.

Titel der Studie	**Persönliche Erfahrungen im Erleben und im Umgang mit der eigenen psychiatrischen Erkrankung (UNIPER)**
Name und Vorname Teilnehmer/in:	....
Ort / Datum:	....
Unterschrift	....

Berner Fachhochschule | Disziplin Pflege | Angewandte Forschung & Entwicklung I Version 2, 27. Juli 2014

Seite 1



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Einverständniserklärung

Bestätigung der für die Studie verantwortlichen Person:
Hiermit bestätige ich, dass ich die Teilnehmerin/den Teilnehmer über die Studie UNIPER informiert habe. Ich versichere, alle im Zusammenhang mit dieser Studie stehenden Verpflichtungen zu erfüllen.

Name und Vorname Für die Studie verantwortliche Person:	....
Ort / Datum:	....
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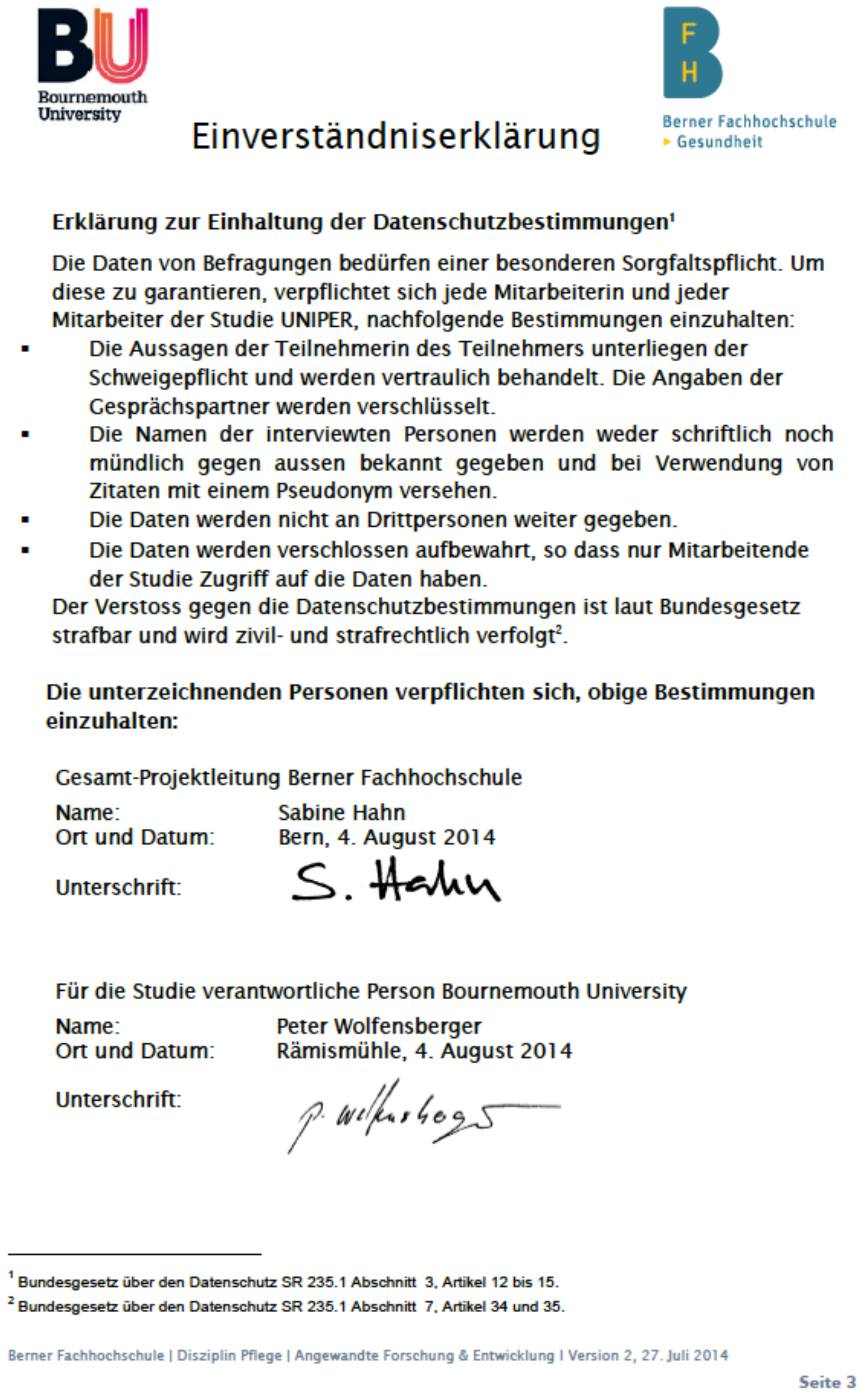

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Erklärung zur Einhaltung der Datenschutzbestimmungen[1]

Die Daten von Befragungen bedürfen einer besonderen Sorgfaltspflicht. Um diese zu garantieren, verpflichtet sich jede Mitarbeiterin und jeder Mitarbeiter der Studie UNIPER, nachfolgende Bestimmungen einzuhalten:

- Die Aussagen der Teilnehmerin des Teilnehmers unterliegen der Schweigepflicht und werden vertraulich behandelt. Die Angaben der Gesprächspartner werden verschlüsselt.
- Die Namen der interviewten Personen werden weder schriftlich noch mündlich gegen aussen bekannt gegeben und bei Verwendung von Zitaten mit einem Pseudonym versehen.
- Die Daten werden nicht an Drittpersonen weiter gegeben.
- Die Daten werden verschlossen aufbewahrt, so dass nur Mitarbeitende der Studie Zugriff auf die Daten haben.

Der Verstoss gegen die Datenschutzbestimmungen ist laut Bundesgesetz strafbar und wird zivil- und strafrechtlich verfolgt[2].

Die unterzeichnenden Personen verpflichten sich, obige Bestimmungen einzuhalten:

Gesamt-Projektleitung Berner Fachhochschule

Name: Sabine Hahn
Ort und Datum: Bern, 4. August 2014
Unterschrift: S. Hahn

Für die Studie verantwortliche Person Bournemouth University

Name: Peter Wolfensberger
Ort und Datum: Rämismühle, 4. August 2014
Unterschrift:

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[1] Bundesgesetz über den Datenschutz SR 235.1 Abschnitt 3, Artikel 12 bis 15.

[2] Bundesgesetz über den Datenschutz SR 235.1 Abschnitt 7, Artikel 34 und 35.

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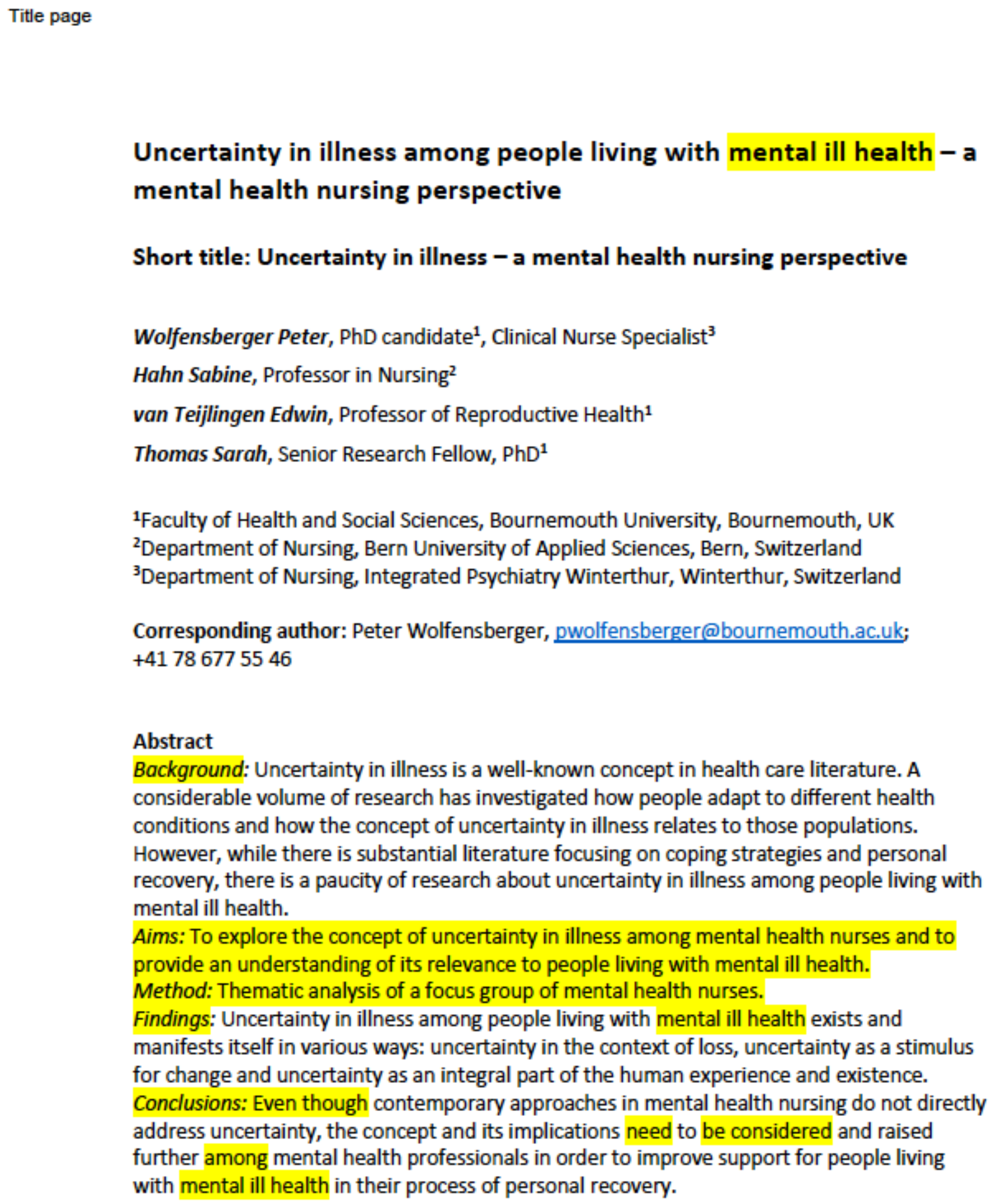
Seite 3

10.7 Appendix 7: Journal Article Accepted for Publication



Title page

Uncertainty in illness among people living with mental ill health – a mental health nursing perspective

Short title: Uncertainty in illness – a mental health nursing perspective

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Abstract

Background: Uncertainty in illness is a well-known concept in health care literature. A considerable volume of research has investigated how people adapt to different health conditions and how the concept of uncertainty in illness relates to those populations. However, while there is substantial literature focusing on coping strategies and personal recovery, there is a paucity of research about uncertainty in illness among people living with mental ill health.
Aims: To explore the concept of uncertainty in illness among mental health nurses and to provide an understanding of its relevance to people living with mental ill health.
Method: Thematic analysis of a focus group of mental health nurses.
Findings: Uncertainty in illness among people living with mental ill health exists and manifests itself in various ways: uncertainty in the context of loss, uncertainty as a stimulus for change and uncertainty as an integral part of the human experience and existence.
Conclusions: Even though contemporary approaches in mental health nursing do not directly address uncertainty, the concept and its implications need to be considered and raised further among mental health professionals in order to improve support for people living with mental ill health in their process of personal recovery.

Uncertainty in illness among people living with mental ill health – a mental health nursing perspective

Abstract

Background: Uncertainty in illness is a well-known concept in health care literature. A considerable volume of research has investigated how people adapt to different health conditions and how the concept of uncertainty in illness relates to those populations. However, while there is substantial literature focusing on coping strategies and personal recovery, there is a paucity of research about uncertainty in illness among people living with mental ill health.

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Findings: Uncertainty in illness among people living with mental ill health exists and manifests itself in various ways: uncertainty in the context of loss, uncertainty as a stimulus for change and uncertainty as an integral part of the human experience and existence.

Conclusions: Even though contemporary approaches in mental health nursing do not directly address uncertainty, the concept and its implications need to be considered and raised further among mental health professionals in order to improve support for people living with mental ill health in their process of personal recovery.

Keypoints/Reflective statements

- Uncertainty is a multidimensional concept and a major part of any illness, but this concept is not well known among mental health nurses
- Uncertainty is seen in the context of loss and as stimulus for change, and losses in a person's life are among the key challenges mental health nurses should be prepared to address
- Awareness about uncertainty in illness in mental health care needs to be increased among health care workers, service users and the wider society
- Recognising uncertainty and helping service users to deal with it and move beyond it, could be a valuable intervention that mental health nurses can offer

What is known about uncertainty in illness?

Uncertainty prevails in all human existence (Penrod 2001) and can be defined as a *"state or character of being uncertain in mind; a state of doubt; want of assurance or confidence; hesitation, irresolution" (OED 2019).* In relation to illness and specifically in nursing, Mishel (1990) defines uncertainty in illness as *"a fluctuation that begins in only one part of the human system [...] (it) can either regress or cause no particular disruption or spread to the whole system. [...] Uncertainty competes with the person's previous mode of functioning"(p.259).* However, the concept of uncertainty is used differently in the theoretical literature of several disciplines. This paper focuses on the nursing context. McCormick (2002) and Hansen et al. (2012) agree that uncertainty is a multidimensional concept and a major part of any illness that in its purest form is a "neutral cognitive state" (McCormick 2002, p.128). Feelings of uncertainty in illness are described as stressful and a burden, giving rise to fear and worry, unpredictability, ambiguity, inconsistency, vagueness and loneliness, whereas facing uncertainty seems to span the continuum from stress through reorientation and adjustment, acceptance, hope and even optimism (McCormick 2002; Hansen et al. 2012). In one of the few studies that focus on uncertainty in people living with mental ill health, the author argues that people with schizophrenia experience uncertainty; not necessarily about the illness directly, but about how the situation will affect their family, job or social networks (Baier 1995). Tan et al. (2014), investigating the experiences of people with early psychosis, consider uncertainty one of the main factors influencing the adaptation process to illness. Among their participants uncertainty caused hopelessness and a sense of feeling disconnected with their environment. However, apart from these two studies (Baier 1995; Tan et al. 2014) no other studies were found that referred to uncertainty from a service user perspective in mental health conditions. Additionally, the term "uncertainty" does not seem to feature in the current literature about personal recovery in mental health.

Recovery and Uncertainty

The concept of recovery has been applied to physical disability and illness long before it was adapted to people who have severe and persistent mental ill health (Anthony 1993). However, the term 'recovery'has several meanings in mental health: 'Clinical recovery' emerged from professional-led research and refers to an observable, clinical outcome that is rated by expert clinicians and usually means full remission of symptoms, whereas 'personal recovery' refers to a user-based understanding of recovery, which is individually defined and experienced (Slade 2009). The definition that still guides the current literature on personal recovery and mental ill health is: "*Personal recovery is a deeply personal, unique process of* *changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"* (Anthony 1993, p.20). Therefore, personal recovery is not what health care professionals do, but what people with disabilities do for themselves, how they cope and adapt to their illness. Mental health nursing aims to help people access and review their private experiences in order to begin the healing of distress and to continue further human development and personal recovery (Barker and Buchanan-Barker 2005; Slade 2009). To what extent dealing with uncertainty in illness might be part of that personal recovery process remains unknown. Considering the vast literature around the topic of uncertainty in illness among other health conditions and how it influences health and wellbeing, it is important to find out more about uncertainty in illness in relation to mental ill health. To support people with mental ill health in their personal recovery it is important to understand all the different aspects which might influence that process. These may include uncertainty and how to deal with related potentially stressful feelings.

Aim of the study

Within the deductive assumption that uncertainty in illness exists among people living with mental ill health as much as it has been described among other health conditions, the aim of this study was to explore mental health nurses' perceptions of uncertainty in illness in people living with mental ill health.

Method

A qualitative study comprising a focus group with mental health nurses was conducted. A focus group serves to explore participants' expertise, their knowledge, understanding and experiences about a predefined and limited topic (Kitzinger 1995; Robinson 1999). Additionally, the focus group method seems ideal to examine not only what the participants think but also how and why they think that way (Kitzinger 1995). Van Teijlingen and Pitchforth (2006) argue that the dynamic interactions within a focus group, the constant negotiation of meanings are key to the data received and distinguish focus groups from other group methods.

Ethics

All procedures were performed in compliance with institutional guidelines of the first author's university and in accordance with the International Ethical Guidelines for Health-related Research Involving Humans (CIOMS 2016). Additionally, permission to conduct the focus group was granted by the scientific committee of the international psychiatric nursing conference where the study took place. With the exception of the first author (lead facilitator) no member of the scientific committee of the conference nor any of the participants in the study had any previous affiliation with the project.

Sample and setting

Mental health nurses were chosen as participants. They are usually the ones who are seeing and interacting with service users 24 hours a day. In hospital settings, and even when they are working in outpatient or home treatment services, they are often in the position of supporting the service user through a crisis.

The focus group took place in the form of a workshop at an international psychiatric nursing conference and lasted 1 ½ hours. The setting enabled the inclusion of a broad and varied group of mental health nurses. Participants had to be willing to participate in the study and speak and understand English. As the focus group was held at a nursing congress and was open to registered attendees of the conference only, no further inclusion and exclusion criteria were used. Participants did not have to sign up for the workshop in advance and therefore, the number of participants remained unknown until it started.

Focus group

Participants received an information sheet and consent form as well as a demographic questionnaire with six topic specific questions at the beginning of the workshop. Participants were also informed verbally about the author, his intentions and the planned content of the focus group discussion. There was time for questions about the project including its methodology and participation was fully voluntarily.

The group discussion was led by the first author, who is a clinical nurse specialist in mental health nursing. He was supported by a senior nurse researcher in mental health nursing who also participated in the focus group discussion. A group discussion guide was used to remain focused on the topic.

Analysis

The group discussion was digitally recorded, transcribed and analysed using qualitative thematic analysis (Braun and Clarke 2006). The method describes several phases of the analysis that all have been performed in this study: In transcribing the data, mainly through paraphrasing, the first author familiarised himself anew with the data and noted down initial ideas (phase 1). Generating initial codes (phase 2) from what appeared to be most relevant to the analyst, and searching for themes (phase 3) in analysing the initial codes, led to a variety of potential themes or outcomes. Those were reviewed (phase 4) with the initial ideas and codes and then defined and named as main themes (phase 5). The final stage of the analytical process, producing a study report (phase 6), involved relating findings back to the original aim of the study and the literature. The main themes were validated by one of the participants of the focus group. Vaismoradi et al. (2013) argue that thematic analysis provides researchers with a clear and user-friendly method for analysing qualitative data due to transparent structures and defined analytical stages.

Results

Eleven conference attendees provided informed consent and participated in the focus group discussion. One participant chose not to share personal information as asked in the demographic questionnaire, but was still willing to take part in the discussion and have their contributions recorded and included in the analysis. The ten other participants represented six different European countries, eight were female and two males.

Eight participants were nurses/mental health nurses, one was a psychologist working in mental health development and one was a health instructor working in mental health service user support. All participants had university level education. The nurses had spent a median of 21 years (with a range of 6 – 32 years) in health care and nursing and were currently working in nursing management (n=2), nursing education (n=3), nursing practice (n=2) and nursing research (n=1).

All participants had either worked with, were still working with, or knew people with severe mental ill health such as major depression, schizophrenia or bipolar disorder. Nearly all had a friend or relative who had been diagnosed with a mental health condition and three participants considered themselves to have personally experienced mental ill health. Concerning the theoretical knowledge of the defined topic area, most participants (n=9) were familiar with the concept of personal recovery (Slade 2009) but no one was familiar with the concept of uncertainty in illness as described by Mishel (1988, 1990) or McCormick (2002).

Three main themes emerged from the thematic analysis; uncertainty in the context of loss, uncertainty as a stimulus for change, uncertainty as an integral part of the human experience and existence.

Uncertainty in the context of loss

People living with mental ill health often face a tremendous amount of loss; participants recalled reports and experiences of people who talked about complete loss of self and self-identity or, as someone described: "a mind shattered in a thousand pieces" (Participant (P) 7). Stigma related to mental ill health can lead to social isolation and exclusion and there is an increased risk of loss of employment, hobbies and friends. However, loss of social status is only one of many facets that people living with mental ill health may experience. Questions as profound as "who am I?" or "what is happening to me?" easily create a tension of uncertainty and may cause hopelessness, fear and pain. Loss of identity strikes a person at the core of his/her existence: "This extremely talented and creative guy couldn't tolerate the uncertainty of the diagnosis and couldn't make sense of who and what he was anymore and killed himself"(P4). One of the participants who had a history of mental ill health herself recalled her loss of control and identity: "I couldn't bear the uncertainty, I had to regain control over my life and reclaim who I am"(P9).

Uncertainty as stimulus for change

Sometimes action might arise out of uncertainty (as suggested in the quotes above). This is supported by numerous contributions of participants who recollected experiences of service users they cared for or of family members and friends with mental ill health: "I felt that enormous drive for autonomy (in him)"(P8) or "she was determined to find something satisfying, useful growth and relevance in life"(P5). Negotiating uncertainties as a process was referred to as a learning experience, decision-making, soul-searching or simply as making sense of what was happening. Uncertainty could be overcome by hope and taking action.

Uncertainty as an integral part of the human experience and existence

The discussion around the topic of uncertainty repeatedly returned to the understanding that it is nothing more and nothing less than a normal human experience and most likely prevails in all human existence: "it's part of who we are, with uncertain times in the world, the climate, politics etc"(P11). Participants mentioned various types of uncertainties that their service users or relatives with mental ill health experience and that were considered normal and understandable: "in that situation I would have felt the same, it's such an overwhelming experience with so many unknowns"(P10). However, it became clear that there is no single understanding of the concept of uncertainty.

These findings from the focus group with health professionals can be succinctly summarised by the following observation made by one of the participants: "Uncertainties (among people living with mental ill health) are the same as for anybody else except maybe more extreme…"(P9).

Discussion

The results of this study suggest that uncertainty is indeed an aspect of experiencing mental ill health. However, it seems that uncertainty manifests itself in more ostensible issues such as experiences of loss. Among those experiences, loss of identity might be the most difficult one. Strauss (1975) proposed that when living within an uncertain illness trajectory, *"a person's view of his trajectory and the shifting social relations that may occur as it progresses can profoundly affect his sense of personal identity" (p.52).* Such impact might be greater still if there is stigma attached to the illness or symptoms. This is in accordance with some of the reports in this study of people who have experienced loss of self or identity along with a shift in personal relationships. These experiences are often interwoven with experiencing stigmatisation. Stigma experiences related to mental ill health are common (Rüsch et al. 2005) and often painful and have an impact on self-awareness and identity that need to be addressed (Amering and Schmolke 2012). Therefore, identity seems to be one of the most important aspects to look at in dealing with mental ill health as Slade (2009) suggests in his four tasks of recovery where developing a positive identity marks the first task. According to Buck et al. (2013) the *"discomfort elicited by the loss of, or threads to, a previous sense of identity"(p.136)* and the realisation of concrete losses in a person's life are among the key challenges mental health professionals should be prepared to address in assisting recovering persons with serious mental ill health. Loss of control or loss of identity may easily compromise one's ability to feel or stay safe. Barker (2005) argues that a person has a fundamental need for security, both existential and physical and that within the context of mental ill health this sense of safety and security might need to be regained. This could be achieved by supporting an individual to draw upon their existing personal and interpersonal resources. Slade (2009) suggests that by promoting well-being and supporting goal-planning mental health professionals can help developing a positive identity in people living with mental ill health. Dealing with identity issues and losses are important aspects in the adaptation process to mental ill health, a process that may go hand in hand with feelings of relief but also fear and uncertainty (Buck et al. 2013).

In mental health, recovery is seen as an individual journey and the progression from the limitations of illness into *"a satisfying and fulfilling life, despite psychiatric symptoms"* (Schmolke et al. 2016, p.100). In that process uncertainty can be a stimulus for change as it ranges from feeling hopeless and lonely to facing it through hope and willingness to reprioritise aspects of life (Hansen et al. 2012). Therefore, uncertainty could be seen as a driving force for a new beginning or a new outlook in life and may lead to hopefulness. Hope is often seen as one of the key factors facilitating recovery in mental health and without hope, recovery is considered not possible (Slade 2009; Amering and Schmolke 2012). Within the individual recovery journeys of people with mental ill health the right support at the right time is essential. This can only be achieved by recovery-oriented, person-centered mental health practice that includes service user involvement and self-determination based on the concepts of empowerment and shared decision-making (Schmolke et al. 2016). However, within that, the focus on uncertainty in illness is still missing. Recognising and naming uncertainties could be a good starting point in a professional relationship between a service user and a mental health nurse. Identifying uncertainty is important to provide accurate and realistic information and share knowledge that may help to reduce anxiety and stress in service users (Hansen et al. 2012). Therefore, recognising uncertainty and helping service users to deal with it and move beyond it, could be a valuable intervention that mental health nurses can offer.

In summary, the lack of literature on uncertainty in illness among people living with mental ill health might be due to the profound and wide-ranging impact of mental ill health. The categories or themes that account for experiencing uncertainty are diverse, broad and multi-layered as the data from this study suggest. This is in accordance with Hansen et al. (2012) who found that uncertainty as part of illness *"is explained by several individual issues such as physical health, treatment, family, hope, self-understanding and/or control"(p.274)*, all issues that were referred to in this study as well.

Limitations

There are limitations to this study. The number of participants was small due to the single focus group discussion and therefore, the amount of data collected was limited and no data saturation was sought which might restrict its validity. Methodologically it could be questioned if another form of inquiry would have been more expedient, such as the Delphi technique (Keeney et al. 2001) that could have helped to gain a clearer consensus among a panel of experts. However, as it was not the intention to achieve consensus about the meaning of the concept of uncertainty in mental ill health, an exploratory approach using a focus group seemed appropriate.

Implications for Practice and Future Research

Findings from this study highlight the complexity of uncertainty in people living with mental ill health from a mental health nursing perspective. They suggest that recognising uncertainty and supporting service users in coping with it could be a valuable intervention that mental health nurses can provide. However, mental health professionals need to be more aware of the concept of uncertainty in illness.

This study will form the basis for further research into the topic of uncertainty in mental ill health. Especially relevant is research on service users' experiences, as from a nursing perspective it is important to take service users' experiences into account and link them to nursing interventions to achieve best practice (Hansen et al. 2012). Research such as this is intended to raise awareness of and encourage discussion about the issue of uncertainty in mental ill health particularly among mental health nurses who care for people living with mental ill health. Understanding the social, emotional and spiritual impact of mental ill health on daily life and its influencing factors such as uncertainty will help nurses to better provide holistic nursing care. Neville (2003) concludes that *"assessment and intervention to manage uncertainty, when possible, are vitally important aspects to providing comprehensive nursing care to the individual and family faced with illness"(p.213).* Interventions to manage uncertainty depend on the issue or theme that is linked to uncertainty in the individual situation. It is part of the first authors' current research project to identify those issues and themes for people living with mental ill health and how they influence their individual adaptation process to illness.

Conclusions

The findings of this study support the original deductive assumption that uncertainty exists among people living with mental ill health and that it is an integral part of their experiences in the context of mental ill health. This is well supported by statements and expert knowledge from the study participants, including those who had experienced mental ill health themselves.

However, there is a need for further research focusing on experiences of people living with mental ill health to highlight the issues they consider important and relevant in their adaptation process to illness and in personal recovery. It is this anticipated knowledge that will bring the concept of uncertainty in mental health care to the fore and highlight its relevance and importance.

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11 List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
APA	American Psychiatric Association
BU	Bournemouth University
CAQDAS	Computer-Assisted Qualitative Data Analysis Software
CHIME	Personal Recovery Framework: ‘Connectedness’, ‘Hope’, ‘Identity’, ‘Meaning’ and ‘Empowerment’
CMT	Creating Meaning Theory
CNS	Clinical Nurse Specialist
DSM	Diagnostic and Statistical Manual of Mental Disorders
EDK	Schweizerische Konferenz der kantonalen Erziehungsdirektoren / Swiss Conference of the Directors of the Education Departments
GBD	Global Burden of Disease Study
GT	Grounded Theory
HIV	Human Immunodeficiency Virus
ICD	International Statistical Classification of Diseases and Related Health Problems
LGBTIQ+	Lesbian, Gay, Bisexual, Trans, Intersex, Queer or Questioning
MScN	Master of Science in Nursing
MUIS	Mishel’s Uncertainty in Illness Scale
NAMI	National Alliance on Mental Illness (USA)
OECD	Organisation for Economic Co-operation and Development
OED	Oxford English Dictionary
PBNUT	Perrett & Biley Negotiating Uncertainty Theory
PhD	Doctor of Philosophy
PubMed	Search Engine of the United States National Library of Medicine
QDA	Qualitative Data Analysis
SUHB	Science of Unitary Human Beings
UAI	Unitary Appreciative Inquiry
VAPP	Verein für Ambulante Psychiatrische Pflege / Association of Psychiatric Community Nurses
WHO	World Health Organization
WMA	World Medical Association