UNMAKING MADNESS.

EXPLORING COLLECTIVE FIRST-PERSON EPISTEMOLOGY

A Thesis Submitted for the Degree Doctor of Philosophy

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ABSTRACT

This PhD research investigates the potential emergence of a new paradigm in understanding and approaching madness that is grounded in the first-person, collective knowledge of people who have personal experience of madness and who oppose its biomedical explanation. Unlike established participatory approaches in mental health and psychiatric research that involve experiential perspectives as subjective, add-on components, this inquiry takes first-person knowledge as a departure point and centers it throughout the research process. The notion of experiential knowledge in this thesis also extends to the researcher's background. The emphasis is on the process of merging diverse first-person perspectives into a collective body of knowledge of madness that can offer a counter-discourse to the dominant, biomedical one.

The investigation was undertaken in two main phases. In the first phase, I analysed a selection of written sources (conceptual, analytical and research work) authored by people who have first-person experience of madness and its treatment, and whose work challenges the biomedical paradigm. In the second phase, the analysis of written sources was used to generate questions for interviews with a subsample of the authors and activists from phase one. Fourteen people from six countries participated in this phase. Documenting the process of knowledge generation in these interviews is the central part of this inquiry.

This thesis contributes to, and can be situated within Mad Studies, an emerging field of inquiry and activist scholarship. The overall approach is informed by the key values and principles of emancipatory disability research and, more specifically, by the key values and principles of survivor-controlled research in mental health. The research process is of equal importance to the findings. This thesis offers a methodological and ethical example of the value of solidarity, dialogue and working with difference whilst searching for connections and generating knowledge of complex human experiences.

CONTENTS

DECLARATION

The following publications related to this thesis emerged in the course of my eight years' part-time work on it. The research they are based on is owed to this PhD and I hereby state that I have retained parts of their content in the text of this thesis, the majority of which can be found in Chapters 2 and 3:

Russo, J. (2012) Give me the stories and I will take care of the rest? The case of "Agnes's Jacket: A Psychologist Search for the Meaning of Madness" by Gail A. Hornstein. *Asylum. The Magazine for Democratic Psychiatry*, 19 (4): 28-30.

Russo, J. (2016) In Dialogue with conventional narrative research in psychiatry and mental health. *Project MUSE. Philosophy, Psychiatry & Psychology*, 23 (3/4): 215-228, doi: 10.1353/ppp.2016.0021

Russo, J. (2016) Establishing first-person knowledge of madness: Must this undertaking elide our differences? Project MUSE. Philosophy, Psychiatry & Psychology, 23 (3/4): 237 – 240, doi: 10.1353/ppp.2016.0024

Russo, J. (2016) Towards our own framework or reclaiming madness, part two. In: Russo, J.; Sweeney, A. (Eds.): *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*. Monmouth: PCCS Books, pp. 59-68.

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ACKNOWLEDGEMENTS

The journey behind this PhD research was a long one. My personal, political and research work around madness did not start with this PhD, and is unlikely to end with it. It would therefore be impossible to name all the people who have inspired and supported my work and thinking over the years. Without naming them, I want to acknowledge the people from the international movement of survivors of psychiatry that I joined in 1991 who indirectly – but nonetheless crucially – contributed to the making of this thesis.

In the academic component of what I consider to be my life journey, I received invaluable support from my supervisory team which was made up of three extraordinary people. They stayed with me throughout the entire eight years, even though that period exceeded their own employment at Brunel University. Each of them took the role of principal supervisor at some point, and I mention them here in the chronology of that role: Peter Beresford, Elizabeth McKay and Debbie Kramer-Roy. Peter was the reason I chose to study for a PhD at Brunel University. He had a decisive influence on my research work long before I started the PhD. The topic of my thesis directly builds upon his work around a social model of madness and distress. Peter also introduced Beth and Debbie into my life, for which I am grateful. They each brought a different angle and provided continuous constructive advice. Jointly, my three supervisors provided a very stimulating and encouraging academic environment that enabled me to adopt a research approach that was rooted in my life experiences and guided by my personal values. They also showed great understanding of the circumstances of my self-employed life and made the whole process as accommodating as possible. I was ‘handed over’ gently and thoughtfully to my last minute supervisor, Yohai Hakak, who was very helpful in his late, rather formal role. All in all, my supervisory experience was a privilege that I hope to document and reflect upon in future work, as approaches to academic supervision are relevant to the emerging field of Mad Studies that this PhD is a part of.

I am also immensely thankful to three fellow survivors and English native speakers for their committed copy editing of my writing, and for a more than friendly price. Those are (in chronological order): Alex Callow (deceased in 2017), Debra Shulkes and Angela Sweeney.

The acknowledgment of the participants’ contributions, and my appreciation of the way they shaped this study, is detailed in Chapter 5.

My partner, Zofia Rubinsztajn, provided precious emotional, intellectual and practical support on a day-to-day basis, and enabled me to dedicate time to this research. I will also never forget

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CHAPTER 1 INTRODUCTION

This chapter provides background information about this research project, explains the motivation behind it and situates the inquiry in the context of some recent scholarly developments. After providing preliminary information about the use of language, I outline the aim of this inquiry, its overall approach, its design and the key research questions.

1.1 Preliminary notes on language

1.1.1 What is meant by ‘madness’?

The way that we use language, and our never-ending search for the ‘right’ words, constitutes an important part of the territory that this research explores. Some of the concepts central to this thesis – such as mental health service users, survivors of psychiatry, emancipatory and survivor-controlled research – will be introduced in subsequent sections. Madness is the topic under investigation, which means that it is explored, rather than defined from the beginning. Nonetheless, I think that some explanation is needed because ‘madness’ is a term that can have very different meanings to different people; its meaning also shifts at different times and in different contexts, or in the words of survivor researcher Erick Fabris (2011):

> “The word madness unlocks my story like a key or locks it up like a safe.” (p. 27)

To define the scope of this thesis, I am using the term ‘madness’ to refer to experiences and situations that transcend people’s day-to-day lives and their usual ways of communicating with the outside world, as well as the world’s communication with them. I use it for a range of experiences that seem to be completely beyond understanding or logic; situations where communication becomes extremely hard or impossible; feelings of entering another dimension where places and things acquire completely different meanings, and so on. ‘Distress’ is a term which I considered and consciously chose to omit in order to narrow the focus onto those experiences which produce an unreadable ‘otherness’ and seem to justify ‘intervention’. I am also deliberately avoiding the word ‘psychosis’ throughout this work, because it exemplifies a number of ways in which the experience of madness has been appropriated by the discipline of psychiatry. Along with many other survivor authors and activists, I share an intention to re-appropriate this experience, as described by Shayda Kafai (2013, n. p.):

> “Mental illness is language that is entrenched within the medical model. Madness on the other hand, while it was used as a derogatory term, has been reclaimed. Similar to the term queer, madness, in its reclamation and re-appropriation by individuals from within the community possesses agenic power. The use of madness within this article speaks to this history.”

However, as the research unfolded, the use of the term madness became further problematised and challenged, as will become clear in Chapter 5. In summary, I use madness as a term for all those frightening experiences that nobody desires for themselves or for their loved ones, situations that overwhelm us and profoundly unsettle what we know, or what we think we know, about ourselves and others. My work is an attempt to open up a different way of understanding those experiences, and possibly to map out some different ways of approaching them.

In keeping with the topic of first-person epistemology, I tried to write in as inclusive and accessible a way as possible. This means that rather than ‘academising’ first-person knowledge, I sought to open up and extend the notion of ‘academic’ and academic writing in order to embrace and accommodate experiential ways of knowing.

1.1.2 About the terms ‘mental health service users’ and ‘survivors of psychiatry’

To know me is to not know my name.

(Old First Nations saying)[1]

This thesis is grounded in the hope that one day, there will be no need for any particular terms to describe people who experience madness. It aims to contribute to the understanding of the experiences of madness, rather than to offer any description of those who go through it as a separate group in society. People who experience madness continue to be subjected to various medical and non-medical labelling. However, for many years now, we have also organised ourselves politically and chosen our own self-definitions as well as the names of our

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[1] This saying is quoted by a participant in the documentary ’Self Labelling and Identity’ available at http://www.youtube.com/watch?v=pxbw7dDMX60&feature=relmfu [last accessed on November 11, 2018]. This documentary is a part of the online course 'Mad People's History' at the School of Disability Studies at Ryerson University in Toronto, Canada. I have not been able to find any further source of this proverb.

organisations.[2] My use of the terms 'mental health service users'[3] and 'survivors of psychiatry'[4] in this thesis has its background in my long-term engagement with the European movement of people who self-define using these terms. The issue of self-definition is a complex one, calling up fundamental questions that are explored in this study. In this preliminary note, I provide some background to the particular terms that I will use in this inquiry, whilst also noting my awareness of their many limitations.

As I embarked on exploring the possibilities of our collective understanding of madness, I retained the terms and concepts that were of personal importance to me and that brought me to this research in the first place. As the terms 'user' and 'survivor' have a particular history situated in the socio-political context of the Global North, I am in no way suggesting these terms as 'right' or universal. In the course of my work on this thesis and beyond, I have increasingly encountered the concept of psychosocial disability, largely adopted in African[5] and Asian[6] movements. This is a relatively new concept in the European movement, and one which is embraced by some of its members (Russo and Shulkes 2015).

A number of documents show that the terms 'service user' and 'survivor of psychiatry' refer to the two main political streams within the movement of people who have received mental health and psychiatric services in the Global North (Chamberlin 1990, O'Hagan 1993, Plumb 1993, European Network of (ex)Users and Survivors of Psychiatry 1994a, Wallcraft, Read, and Sweeney 2003, Morrison 2006, European Network of (ex)Users and Survivors of Psychiatry 2012). What the two terms have in common is their reference to mental health and psychiatric systems, rather than to personal experiences of madness and distress. One strategic document of the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP) offers the following general distinction between the two groups comprising the Network:

> "The added value of the European Network lies in the fact that it brings together the two major political streams of our movement, expressed in the notions 'users' and 'survivors'. The first group ('users') focuses more on reforming and improving psychiatric services while the second ('survivors') fundamentally questions the psychiatric system as a whole, including the very premise of 'mental illness'. The current name of the Network, adopted in 1994, expresses recognition of our different standpoints towards mental health and psychiatric systems as well as respect for our

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[2] See more at http://studymore.org.uk/mpu.htm [last accessed on November 11, 2018].

[3] The term 'consumer' is commonly used in the USA, Canada, Australia and New Zealand and has a similar meaning to the European 'mental health service user'.

[4] The term 'mental health system survivor' is specific to the UK context.

[5] The Pan African Network of People with Psychosocial Disabilities was founded in 2005. See more at https://www.facebook.com/PANPPD/ [last accessed on November 11, 2018]

[6] Transforming communities for Inclusion of persons with psychosocial disabilities (TCI Asia) was founded in 2012. See more at http://www.tci-asia.org/aboutus.html [last accessed on November 11, 2018]

> diverse experiences, self-definitions and political aspirations.” (European Network of (ex)Users and Survivors of Psychiatry 2012, 3)

Arguably, the lived experience of participating in the user/survivor movement is itself a challenge to the assumption of a static ‘user’ or ‘survivor’ identity. Morrison (2006, 13) documents this in her research about the US consumer/survivor movement:

> “Clearly, a simplistic dichotomized analysis of anti-psychiatry survivors and co-opted drug-popping consumers is inadequate to convey the complex political and personal realities of these activists and their movement. The 'survivor' and 'consumer' identities are not separate entities; they can occur simultaneously or serially in the same person.”

All these concepts, even when self-adopted, have multiple shortcomings as none can capture the complex lived reality of a person and our many simultaneous and intersecting identities. However, it should not be underestimated that these collective acts of self-labelling serve a purpose: they enable people to come together, to define their interests and to work for change. As Bakhtin (1981, 293) says, it is not possible to separate terms from the social context in which they emerge: “Each word tastes of the context in which it has lived its socially charged life; all words and forms are populated by intentions.”

For me personally, the European user/survivor movement has been a place to interact, learn and grow. Over the years, I have found reinforcement and support for some of my personal positions and have had to revise others, sometimes substantially. In this thesis, I have settled on the phrase ‘first person knowledge’ in the belief that this expression might give both participants and myself more space and freedom within which to explore madness. In particular, I hope that the use of this term will enable us to move beyond self-concepts that are based largely on experiences of the psychiatric system.

The members of the US consumer/survivor movement who took part in Morrison’s study (2006) expressed their resistance to the use of any categories and labels to define them, whether those came from psychiatry or other discourses. The following statement exemplifies the way in which individual experience always takes place outside normative categories:

> “Mental health consumers, psychiatric survivors, ex-patients, it's not in terms of my experience. And if we all reframed the experience, we may find other words." (p.13)

This project finds its aim in this task of ‘re-framing’ the experience of madness and finding ‘other words’. Yet in exploring our individual and collective knowledge, I continue to use ‘user/survivor’ as working terms, remaining aware that these words refer to our experiences of diagnosis and treatment, rather than to the experience of madness itself. In this text, both the term ‘service user’ (or ‘user’) and ‘survivor’ always relate to the context of mental health services and psychiatry. I also use ‘people with psychiatric experience’ to include both users and survivors, as well as people who have been subjected to psychiatrisation but have not participated in the movements from which these terms emerged.

In this work I do not seek to replace these terms: that is, to advance any new definition for individuals or groups of people who have experiences of madness. Rather, I want to focus on these experiences themselves, which, I believe, can be shared and understood. I consider re-finding our own words for the experience of madness to be part of a larger process of individual and collective re-appropriation of that experience. At the same time, the words of survivor author Erick Fabris (2011, 31) remind me of what a complex task this is:

> “How do mad-conceived people defend themselves against sanism, the dividing of thought into mad and sound? Is there an autonomous position that is not reducible to either of these two categories? If we deny any mental exceptionality, what language would we use to speak of our experiences?”

I believe that there is a decisive difference between seeking to define a group of people - on the one hand and attempting to understand their experiences together with them – on the other. People who have experienced madness already use language to speak and think about our experiences, and it is important to explore whether there are points where our individual understandings can connect. This process might open up a space beyond the mad/sound dichotomy described by Fabris. Giving up the goal of defining and re-defining ‘mad-people’ might help us to understand madness within the spectrum of other human experiences.

1.1.3 About the terms ‘survivor researcher’ and ‘survivor research’

‘Survivor researcher’ refers to researchers who are open about their personal experiences of madness and psychiatric treatment along with the fact that these experiences inform their work. Angela Sweeney (2011, n.p.) sees the explicit adoption of this identity as a “political statement meaning that people want to challenge dominant ideas that are about mental distress and about us” – an explanation that I personally subscribe to. However, it must be stressed that there is no *single* survivor researcher perspective; this small but growing research community is composed of members with different backgrounds and aspirations. In this text I refer to myself as a ‘survivor researcher’, reflecting my own positions; the term is not meant as a universal term that would silence anybody else.

‘Survivor-controlled research’ in mental health (‘survivor research’), which should be distinguished from service user *involvement* in research, describes research projects designed and conducted by people with lived experience of madness and distress. This approach is identified far more with specific values and principles than with any particular methodology, which I will explain further in Chapter 3. For the purpose of this very brief explanation, I wish to emphasize the preference of survivor research for 'closeness' to the topic under investigation (as opposed to traditional aspirations to 'neutrality' and 'distance') and researchers' commitment to working together with participants in the analysis and interpretation phases of research (Turner and Beresford 2005, Faulkner 2004, Sweeney et al. 2009, Russo 2012b). I refer to survivor-controlled research in the context of its development in the UK; I also use this term as an equivalent to 'user-controlled research'.

1.2 First-person knowledge and responding to madness

Building on the work of other survivor researchers, such as David Webb from Australia, I am deliberately not using the term 'subjective' as an attribute for knowledge that comes from experience because this would automatically imply that other, expert knowledge is 'objective'. Both these attributes are heavily loaded in the context of research. I believe that referring to these different stances as first- and third-person perspectives can help establish first-person or experiential knowledge as integral to official knowledge. Webb (2010, 109) describes the limitations of 'third-person' knowledge, which continues to prevail in social science:

> "The essential experiential data of consciousness are subjective, invisible and unmeasurable first-person data which cannot be reduced to third-person data without losing their most important properties, which are the subjective *value and meaning* of an experience to those who live it. The reductive, third-person methods of traditional science will simply not help us to understand, describe and explain the first-person, lived experience of consciousness." (emphasis in original).

I also argue that third-person methods will not help us to achieve ethical, appropriate and authentic responses to human crises, including madness. The third-person approach, which can also be described as monological, is based on 'speaking about' rather than 'speaking to and with'. This approach, which by definition excludes dialogue, may continue to prove effective in developing various interventions and treatments. However, it is not suited to the complex task of *responding* to a person in crisis, which is something quite different from intervention and treatment. Responding requires second-person address – 'speaking to and with' rather than 'speaking about' – which is often marginal to the discipline of psychiatry and in services based on the medical model of mental illness. The reason I believe in the potential of first-person knowledge, and the need to establish its authority in the field of mental health, is that I cannot see any other way to develop systems of support based on authentic and mutual relationships. This is something that many survivor authors consistently call for, such as Filson (2011b, 75) when she writes about conceptualising radically different responses to self-harm:

> "What is our responsibility to each other in this pain? What journey do I undertake to find myself in you, and you to find yourself in me? If we are to live in this world, we must work this out."

I perceive the ability for dialogue – in other words, the ability for second person-address – as a fundamental precondition and feature of all true systems of support. Such support systems are unlikely to occur unless first-person knowledge has established itself as a central, rather than auxiliary epistemic source in a social, rather than medical, field. The search for and conceptualisation of non-medical and non-damaging responses to madness exceeds the scope of this thesis. However, through exploring the possibilities of a different epistemology, grounded in first-person knowledges of madness, this inquiry seeks to offer some preliminary work in that direction.

1.3 Psychiatrisation and the dominant epistemology

Since the establishment of psychiatry as an institution and a discipline, there have been protests from, and knowledge claims by, the subjects of its treatment. The first documented collective protest dates back to the beginning of the 17th century (The Opal Project, 2007, Hornstein, 2008).[7] However, in the centuries that have followed, and in distinction to expert knowledge, the perspectives and voices of people deemed mad or mentally ill have not been perceived as valid epistemic sources. As Veronica Dewan writes (2011, 6):

> "We can write our own words, but as service users/survivors we are written about. Our lives are recorded, reinterpreted, they stagnate in official documents."

Both the truths of our individual lives, as well our accumulated knowledge as a societal group treated for madness, continue to be subject to marginalisation and disqualification. Before moving on to the possibilities of a first-person, counter-epistemology of madness, it is important to mention the legal framework that supports the status quo, exemplified in various Mental Health Acts around the globe. Australian scholar Fleur Beauport (2018) analyses the

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[7] *The Petition of the Poor Distracted People in the House of Bedlam.* London: 1620

inhibiting effects of this legislation on the freedoms of opinion and expression by people deemed mad; freedoms that are an essential precondition of knowledge making:

> "[T]he medico-legal discourse of mental health laws, by consecrating this symbolic violence, operates to manipulate and nullify individual ways of knowing and being, and to radically diminish opportunities for the epistemologies of users and survivors to exert influence on societal systems and structures. Constructions of people with psychosocial disability as lacking capacity and 'insight' are central to these processes of dehumanisation." (p.16)

Canadian scholar Maria Liegghio (2013) analyses psychiatrisation as a form of epistemic violence, which she defines as

> "[t]he very denial of a person's legitimacy as a knower – their knowledge and their ways of knowing – that renders that person out of existence, unable to be heard and to have their interest count." (p.124)

Referring specifically to people with psychiatric diagnoses she writes:

> "[B]eing constructed as 'incompetent' and 'dangerous' becomes a powerful mechanism leading to their disqualification as legitimate knowers." (p.125)

This argumentation is of relevance to this thesis: rather than focusing on madness as grounds for epistemic violence, the process of psychiatrisation is instead recognised as central to the denial of the knowledge authority and knowledge claims of both individuals and entire social groups. Through centring the knowledge of people who have undergone psychiatric treatment throughout this inquiry, I seek to make epistemic violence visible and respond to it. The exclusive focus of this project on the knowledge of people with psychiatric experience is not meant to give authority to the institution of psychiatry, nor adopt any of its categorisations. It is also not intended to essentialise or ontologise madness, nor to suggest that there can ever be a separate group of 'mad' people. Rather, through making personal experience of psychiatrisation one of the two main inclusion criteria for participation in this study (in both its phases), I aim to emphasise the continued erasure and devaluation of our (collective) first-person knowledge and actively work against it.

In light of the developments of the last two decades in Western countries such as the UK - characterised by increased calls for the inclusion of 'lived experience' perspectives in mental health and psychiatric research (Department of Health, 2001) – it is legitimate to ask how timely and justified this PhD inquiry is. The potential for the experiential knowledge of mental health service users to inform and improve both policy making and the delivery of psychiatric services is generally gaining increased attention in the Global North. Consider, for instance, the introduction of the peer workforce in psychiatric services. In the US this occurs under the job title ‘peer specialist’ (Felton et al. 1995, Brown and Stastny 2016), in Australia and UK as ‘lived experience practitioners’ (Byrne, Happell, and Reid-Searl 2016, Oxleas NHS 2017) and in Germany as recovery attendants (Genesungsbegleiter) (Jahnke 2012). The recent calls for co-production in social and mental health services (Clark 2015, Roper, Grey, and Cadogan 2018) also promote working side-by-side with people with psychiatric experience. So one could ask, why undertake this thesis at a time when our perspectives and even our ‘expertise’ are being recognised to a greater extent than ever before? The answer to this question leads to the second distinctive characteristic and inclusion criteria of this inquiry: namely the centering of non-medical knowledge and perspectives that oppose the dominant biomedical discourse of mental illness.

People with psychiatric experience do not constitute a homogeneous group – neither in regard to our experiences, nor in regard to our stances towards those experiences and the processes of meaning making. Initiatives to include experiential knowledge in research, and particularly in the development of policy and mental health services, clearly favour those service users who accept the biomedical explanatory frameworks. Counter-perspectives, articulated in large parts of the political movement of people with psychiatric experience and also expressed in the term ‘survivors of psychiatry’[8], remain excluded from mainstream participatory and co-production initiatives (Wilson and Beresford 2002, Russo and Wallcraft 2011, National Survivor User Network 2018). This, crucially, limits the overall reach of such initiatives: rather than enabling a fundamental transformation in knowledge production about madness, these developments extend and ultimately expand the biomedical paradigm through adding subjectivity and sociocultural aspects (Russo 2016a). Participatory initiatives in psychiatry and mental health entail not only immense power disparities (Beresford 2002b, National Development Team for Inclusion 2016, Carr 2018) but also take biomedical presumptions for granted (Russo 2018). This is something that prevents clinician-led collaborative projects from working towards a much needed paradigm shift (Beresford 2002a, Lewis 2014, Penney and Prescott 2016). Elaborating on the reasons why such a paradigm shift is needed would exceed the scope of this thesis; both the lack of a scientific basis for the biomedical model, and the harmfulness of

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[8] See European Network of (ex-) Users and Survivors of Psychiatry at http://enusp.org/ and World Network of (ex-) Users and Survivors of Psychiatry http://www.wnusp.net/

resulting psychiatric treatment, have been well documented and continue to be scrutinized from various angles (Whitaker, 2010, American Psychological Association Division 32, 2011, Burstow, 2015), including from the psychiatric profession itself (Breggin 1993, Mosher 1998, Breggin 2009, Moncrieff 2009, 2013). Nevertheless, the biomedical explanatory model continues to dominate and determine knowledge production, including involvement initiatives (Lewis 2014). Frequently, subscription to this model is not made explicit but occurs as a matter of course, limiting the range of research projects that are likely to receive recognition and resources (Russo and Stastny 2009, Sweeney 2016a).

These circumstances make projects that rest on different premises even more important. However, as Angela Sweeney (2016b, 46) accurately observes:

> "[s]uch approaches are rare beyond master's and doctoral work. This is in part because most survivor researchers currently lack the seniority to generate research bids or questions from radical survivor perspectives, and so our research is often conducted in response to or alongside a mainstream question; most often, 'What about this service could be improved from the perspective of its users?'"

So, at least in certain parts of the world, it can no longer be said that first-person knowledge never finds a place in official knowledge production on madness. But it remains true that such inclusion extends only to a particular kind of first-person knowledge: one that conforms to the dominant paradigm. At the same time, many well-articulated and well-documented first-person critical perspectives continue to be structurally excluded from the 'scientific' knowledge base of madness. The philosophical concept of epistemic injustice, recently developed by Miranda Fricker (2010), offers a more nuanced tool to capture this selectivity and understand the different layers of epistemic exclusion. For Fricker, epistemic injustice consists "most fundamentally in a wrong done to someone specifically in their capacity as a knower" (p.1). The value of this concept is in its broad applicability to different oppressed social groups, as well as in the analysis of the mechanisms that erase the truths and knowledges of these groups from official knowledge. Fricker also powerfully describes the implications of such erasures for societies at large.

In the next chapter, I will describe the ways in which experiential knowledge tends to be used in mental health research. Here, I will briefly focus on an aspect of knowledge denial that is particularly hard to challenge because it persists even when the knowledge of marginalised social groups is apparently taken into account. Fricker's distinction between two main forms of epistemic injustice can also help to better locate the scope of this thesis and its contribution:

> "Testimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word; hermeneutical injustice occurs at a prior stage, when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences." (p.1)

Examples of testimonial injustice range from situations in everyday life, such as who is likely to be approached on the street and asked for directions and who is not, to far graver situations such as court hearings where some testimonies have more credibility and weight than others based on the speaker's appearance and identity. To exemplify hermeneutical injustice, Fricker often describes sexual harassment.[9] Many women routinely had this experience before the notion of sexual harassment existed. However, it was only after the concept came about that these experiences could be given voice and validated. In other words, hermeneutical injustice occurs when some social groups have no officially recognised concepts that would enable them to communicate their experiences, and simultaneously, society as a whole has no epistemic resources to understand those experiences.

The concepts of testimonial and hermeneutical injustice prove extremely helpful in understanding the general status of the knowledge of psychiatrised people and its place in the official knowledge base, not only about madness but more broadly about the societies we live in. A slow progression towards testimonial justice can be observed as the perspectives of 'mental health service users' gain visibility and acknowledgment in involvement and co-production initiatives. Yet at the same time, there seems to be minimal progress in achieving the hermeneutical justice that would enable a shift in understanding madness and distress within the structures and systems from which they emerge. And there is even less progress towards providing the services that are able to address and transform those structures and systems, allowing more space for and acceptance of these human experiences. So when thinking in terms of the contribution of first-person knowledge to mental health research, and assessing the impact of involvement and co-production initiatives, it is important to consider the extent to which these attempts – which remain largely within the individualising biomedical paradigm – are capable of moving us beyond testimonial and towards hermeneutical justice.

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[9] Source: the two-days conference 'Understanding Epistemic Injustice' at the University of Bristol that I attended in 2014. More information is available at http://www.bristol.ac.uk/philosophy/research/epistemic-injustice-/

One immensely important milestone on the road to achieving hermeneutical justice for people with physical and sensory impairments was the creation of the social model of disability by disabled researchers and activists. We, the people who have been or are being medically treated for madness, occasionally borrow from this model[10] but we have yet to generate an equivalent model rooted in our collective knowledge that feels true to and fits our experiences, and most importantly, that can help us advance our rights and improve our lives. This PhD research is intended to be a step in that direction.

In the first years of my work on this thesis, the need for this kind of inquiry was not considered a priority. Although this is now beginning to change, there were times when I was searching for academic argumentation to support this project but finding that there was very little written. The publication of the thematic issue of *Disability Studies Quarterly* in 2013 on 'Disability and Madness' was exceptional in this sense, and greatly validated and encouraged my work. In particular, the opening article entitled "The Absence of Psychiatric C/S/X[11] Perspectives In Academic Discourse: Consequences and Implications" (Jones and Brown 2013) justified this inquiry and gave it a new context. Even though these authors do not deny the neurological basis of what they term 'psychiatric disability' - a stance that I personally don't share - they analyse the implications of the processes of 'professionalisation' and 'clinicalization' and observe how "a strongly pathologising approach to and conceptualization of 'mental illness' proceeds largely uncontested within academia" (Jones and Brown 2013, n.p.). Furthermore, they explain the ways in which academic environments inhibit the work of scholars with personal experience of psychiatrisation and observe significant differences with Disability Studies in regard to the value of first-person knowledge:

> "In Disability Studies, conversely, the importance of first-person perspectives, as well as the integration of disability with other aspects of identity, including academic identity, is well-accepted. Indeed, disability studies has been characterized as a place from where 'crips strike back' (Davis 1999)." (n.p.)

Jones and Brown (2013) also pointed to the downsides of being explicit about one's own political and social justice agenda while pursuing an academic career:

> "[i]n fields in which explicit activist scholarship is rare, researchers' commitment to the advocacy community runs the risk of being viewed as proof of such academics' 'compromised' science." (n.p.)

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[10] For a comprehensive discussion of these issues see the collection *Madness, Distress and the Politics of Disablement* edited by Helen Spandler, Jill Anderson and Bob Sapey in 2015.

[11] C/S/X is the abbreviation for 'consumer/survivor/ex-patient' that is commonly used in the US.

Only five years after the publication of the *Disability Studies Quarterly* special issue, and with the emergence of Mad Studies as a distinctive field of activist scholarship, the situation began to change significantly; these kinds of projects are now less rare than when I started this PhD. These developments not only complement, but also disrupt and challenge, the dominant epistemology regarding ‘mental illness’ or ‘psychiatric disorder’.

1.4 Situating this thesis: working at the intersection of survivor research and Mad Studies

In distinction to empirical research projects that are commonly underpinned by a particular theoretical approach or school, what inspired and motivated this thesis was precisely the lack thereof. The idea for this PhD arose from my extensive work as a survivor-researcher[12] and my commitment to promoting first-person knowledge in research (Russo 2004, Coldham and Russo 2009, Russo 2012b). I was motivated by the understanding that attempts to advance survivor-controlled research are not only hindered by a continual lack of resources and scientific recognition, but also by the lack of an underpinning theoretical framework. Peter Beresford‘s analysis of the implications of this, his strong argumentation for the need for such a framework, and his own research on this topic (Beresford 2005b, 2009, Beresford, Nettle, and Perring 2010) strongly resonated with me, and finally made me decide to undertake PhD research that directly builds upon and extends his work. Beresford’s most recent joint piece of research on the social model of madness and distress (Beresford et al. 2016) was published in the course of my PhD inquiry and informed this thesis.

Another vital source of motivation for this project were the lessons learned from my long-term engagement with the international user/survivor movement. The need to advance our own knowledge and strengthen our autonomous political action are issues that the movement frequently revisits:

> “[…] we must begin by developing our own agenda and our analysis into something much more coherent.” (Campbell 2001, n.p.)
>
> “We need to start again and re-write all the textbooks ourselves and we can do it but we need to work very hard.” (European Network of (ex)Users and Survivors of Psychiatry 2009, 9)

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[12] For an explanation of survivor research see Chapter 3.

With the increasing recognition of the experiential knowledge of mental health services users, and the expansion of what is known as service user involvement in mental health research (Wallcraft, Schrank, and Amering 2009, Staddon 2013), the need to preserve and strengthen the distinctiveness of survivor-controlled research became ever more pressing. In an article that I wrote directly before developing my PhD proposal (Russo 2012b), I suggested that these new circumstances pose fresh demands on those pursuing a survivor research approach in order to prevent its cooptation or the erasure of its important values and principles. I referred to Beresford's clear call (2005b, 6) to not let the achievements of survivor-controlled research rest on moral claims alone:

> "[…] unless we can make a strong case for the differences it embodies, ultimately it may be marginalised. We need to look more carefully at where it comes from and what it may be able to offer. It is unlikely to be enough to make the moral case for it, important though this is, yet so far this has been the main argument offered."

With the emergence of Mad Studies in Canada – beginning with courses in Mad people's history at Ryerson University in Toronto in 2004 and its subsequent rapid expansion – the situation started changing. In the words of Kathryn Church (2013, 186), Director of the School of Disability Studies at Ryerson University, the distinctive characteristic of this type of academic teaching is that "[w]orking against the dominant psychiatric paradigm, the course places the perspectives of the 'mad, insane or mentally ill' at the centre of knowledge formation". The seminal collection of essays introducing Mad Studies (LeFrançois, Menzies, and Reaume 2013) entitled "Mad Matters: A Critical Reader in Canadian Mad Studies" was published two years after I started this PhD. From the moment I engaged with that publication (Russo 2013) this thesis found its second 'natural' home: the framework situating this inquiry expanded from survivor research as its sole and most important reference point to include Mad Studies, a much broader and more comprehensive field. This is not only due to the multidisciplinarity of Mad Studies, in contrast to which psychiatry and mental health can never fully accommodate survivor research. Through merging first-person knowledge, political activism, research and theory formation, Mad Studies enables knowledge making from precisely that place where these – usually separate areas – meet. Menzies et al. (2013, 13) depict Mad Studies as

> "a project of inquiry, knowledge production, and political action devoted to the critique and *transcendence* of psy-centred ways of thinking, behaving, relating, and being". (emphasis added)

The abbreviation ‘psy’ is meant to cover not only psychiatry, but also other related disciplines such as psychology, psychiatric nursing and clinical mental health social work that together form a so called ‘psy-complex’ (Scott and Marschall 2009).

Like the developments of Women, Black, Queer and Disability Studies, Mad Studies transforms and re-defines the praxis of academic work. Ingram (2016, 13) conceptualises Mad Studies as an “in/discipline” and describes it as “both a discipline and an indiscipline“.

Mad Studies opens up new possibilities for survivor research and offers a new home to this research approach (Sweeney 2016b). This dynamic home is grounded in the knowledge of preceding generations of activists and scholars labeled mad, as well as their allies. As a unique form of activist scholarship, Mad Studies anchors and underpins this thesis.

The main principles of survivor-controlled research, and the way in which they are adopted in this inquiry, will be explained in more detail in Chapter 3. I will be returning to Mad Studies in the last two chapters of the thesis, as it was also a topic in the interviews conducted in the interactive phase of this research. For this introduction, I would like to situate this project at an intersection between survivor research and Mad Studies; a new framework for survivor research that emerged at the time of my work on this thesis. In her comprehensive analysis of the history and relationship between the two, Sweeney (2016b, 45) argues that

> “Mad Studies and survivor research should foster a strong relationship so that each can be reinforced by the strengths of the other.”

I share this author’s conviction that Mad Studies can take survivor research beyond “service user involvement arguments” (p.48) and

> “[o]ffer a unifying theoretical framework that has as its central goal the critique of biomedical psychiatry and the development of critical and radical counter-discourses.” (p.47).

Yet, this particular inquiry focuses much more on the latter: in adopting the principles of emancipatory disability and survivor-controlled research it deliberately sought to avoid engaging in criticism of the biomedical model and instead aimed to explore the possibilities of a counter-discourse. Additionally, whilst working on this PhD I have also contributed to the development of Mad Studies (Russo and Beresford 2015, Beresford and Russo 2016b, LeFrançois, Beresford, and Russo 2016, Russo and Sweeney 2016, Beresford, Russo, and Boxall forthcoming). In retrospect, I see this thesis as growing together with the field of Mad Studies, and hope that this project will offer what Sweeney (2016b, 36) highlights as a potential contribution of survivor research to Mad Studies: “preliminary thinking around the ethics and means of knowledge generation”.

1.5 Aims and the distinctive contribution of this research

This study belongs to the range of efforts and initiatives taking place worldwide which challenge the ‘mental illness’ paradigm. So far, such efforts have come from diverse theorists and practitioners who strongly disagree with the biomedical approach and its resulting psychiatric practice. These initiatives include the anti-psychiatry movement (Laing 1960, 1961, 1982, Cooper 1978, 1967, Szasz 1974), critical psychiatry (Bracken and Thomas 2005), dissident psychiatrists (Stastny and Lehmann 2007), proponents of the capabilities approach in mental health (Hopper 2007, 2012), criticism of psychopharmacology (Breggin 1993, 1995, 2009, Moncrieff 2009, 2013, 2016) and alternative practices such as Soteria (Mosher and Hendrix 2004), Windhorse (Podvoll 2003) and Open Dialogue (Seikkula et al. 2006). The most recent example is an initiative led by two UK psychologists involving people with first-hand experience which focused on developing an alternative framework to psychiatric diagnoses (Johnstone and Boyle 2018). In all these cases, the authors have succeeded in presenting significantly different theories of madness, including those which powerfully question the premise of ‘mental illness’ or ‘mental disorder’. Nevertheless, all these alternative models and approaches have one characteristic in common: *they were neither developed nor authored by people who have personal experience of madness and its treatment.* As Beresford and Wallcraft (1997, 72) observe:

> "As far as the dominant debate is concerned, survivors and the survivors' movement still seem to be primarily seen as a source of experiential data, rather than creators of our own analysis and theory."

Standpoints and approaches rooted in *collective* first-person knowledge are traditionally absent from debates and work around madness, including those that open up counter-discourses to the dominant one. Such a continuous and deep-rooted absence cannot be compensated for by the virtue of occasionally considering single first-person perspectives, re-interpreting our experiences, or speaking on behalf of the ‘mad’. In her critical analysis of the ways in which the principles of co-production are being implemented and practiced in the UK, Carr (2018, 80) qualifies such efforts as insufficient and argues for the need to create “a *separate* platform and power base from which service users can work” (emphasis added). This thesis is intended as one such separate platform.

Inspired by the development of the social model of disability by disabled scholars themselves, this study seeks to explore the potential and reach of collective experiential knowledge of madness. Calling for methods based on respect, trust and reciprocity the disability scholar Mike Oliver (2009, 110) writes: “After nearly 200 years of social research we still do not have the faintest idea of how to produce collective accounts of collective experience”.

This general failure of social science, and the conviction that research from first-person (plural) perspectives are possible, are the key departure points for this PhD. Imparting insider perspectives, this study began as a small-scale, systematic search for a framework that could adequately encompass the complexity of experiences of madness. From the outset, the aim was to move us towards such a framework, rather than to seek in any way to establish *the* ultimate model which will subsume and do justice to all our diverse experiences. The most important aspect of this thesis is the research practice itself, which I approach as an intense and ongoing learning process about how to conduct research differently or, again in the words of Mike Oliver (2009, 115), how to find “a language that enables us to talk about research not premised upon the researcher/researched distinction”. The main contribution of this study is its character as an example of a systematic attempt to collate and connect first-person knowledges of madness, undertaken from *within.*

In summary, this PhD research has two main aims. The first is to explore the accumulated knowledge of authors with psychiatric experience who oppose the biomedical model and who propose alternative understandings. In the first phase of the research, I investigated whether a set of shared values and principles can be identified in this vast and unique body of work that could move us a step closer to our own model or theory. The second and equally important aim, pursued in the next phase of the research, was to explore the possibility of enacting a collective process capable of advancing our knowledge. In direct opposition to the dominant modes of mental health research (such as observation, measurement and interpretation), this thesis aimed to explore the value of interaction, shared identity and dialogue in generating knowledge and understanding complex human experiences. Demonstrating these principles at work, as well as documenting and discussing their potential and the challenges involved, forms an integral part of this study’s findings.

1.6 Study design: the initial plan and the reality

The task of connecting first-person knowledges of madness into something more coherent and able to stand on its own and eventually offer an official counter-understanding to the dominant one, struck me as both enormous and essential. The responses I received to the consultation, through email forums of users/survivors, about what written sources to include in this inquiry (initiated in 2011)[13] as well as to presentation about this research (at the 7th ENUSP Congress in Denmark in 2014)[14] confirmed the relevance of this topic for the movement. The positive reception and great interest did not only feel affirming; it reinforced my sense of responsibility towards this community and also reminded me of the weight of expectations. From the very beginning, as I decided on the topic for this study, I was aware that its task exceeds the scope of my small-scale and entirely self-funded research. But despite substantial constraints, and for all the reasons I explained earlier, I was determined to at least start working in this direction. Subsequently, the more I engaged in this research the more I kept realising that whatever I am able to do, it can never be sufficient to pull together the vastness of first-person knowledge of madness. In the first research phase, this meant that I continually discovered more sources to include, and was frustrated by technical constraints, such as having no resources for translation. In the second phase, I was confronted with the time-consuming task of transcribing interviews, a task that determined the number of interviews that I was able to conduct. One of the biggest challenges that accompanied my work on this thesis was the imbalance between the significance and size of the topic on one side, and the limits of what one person can achieve within a PhD framework on the other. The fact that it took me time to accept those limits had implications for the work plan.

My initial plan included a third research phase to review and ‘wrap up’ the findings with the phase two interview participants in two focus groups. This approach to concluding a research process is one of the central features of survivor-controlled research (see Chapter 3 on methodology). However, convening the focus groups did not prove feasible within the time and financial constraints of this project, and I decided to postpone this step until after the PhD. The participants have been informed about this change and the reasons for it.

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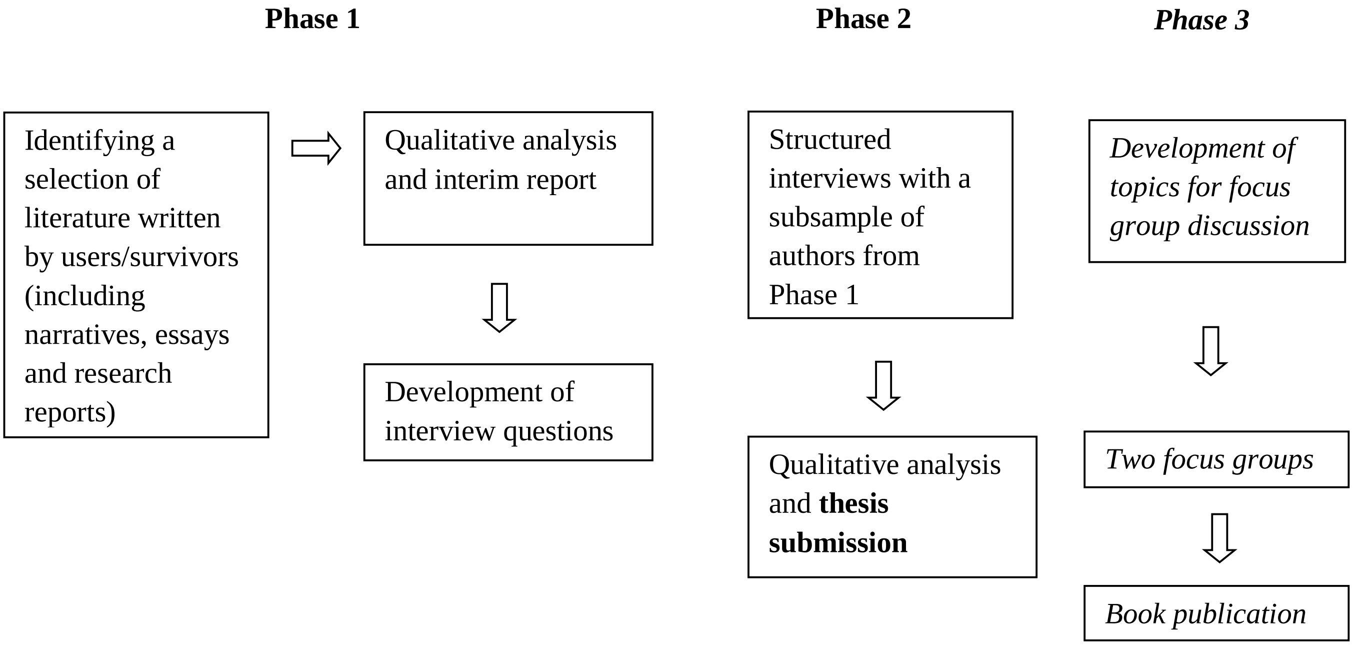
[13] This included the mailing lists of the European Network of (ex)Users and Survivors of Psychiatry (ENUSP) with ca 60 addressees, the Survivor Researcher Network in the UK (SRN) with ca. 50 addressees and 15 US users/survivors whom I met in the USA at the conference “Rethinking Psychiatric Crisis: Alternative Responses to First Breaks” held in New York on 23rd of November, 2009.

[14] http://enusp.org/eventsdates/

The following chart shows the main phases of the research process, including the third phase (in italics) as integral to the study design. In the context of the overall research process, this thesis represents an important milestone, but it is certainly not the final step. Given the magnitude of the topic and its open ended nature, this process will hopefully be continued in different ways and contexts.

Chart 1: Study design



1.7 Research questions

Before I list the research questions that guided this inquiry, I would like to reiterate what this research is not about: the topic of the investigation is *not* about how people who have been on the receiving end of psychiatric treatment understand and conceptualise their experiences, including of madness. This inquiry is restricted to people with first-hand experience of madness and its treatment who refuse biomedical explanations and who do not frame their experiences in psychiatric diagnostic categories. My use of the abbreviated expression, ‘we, people labelled mad’ relates solely to that group of authors, scholars and activists. A more detailed explanation of the inclusion/exclusion criteria and how they were applied in this study is provided in Chapter 3.

This inquiry began with the working title "Towards a first-person defined model of madness". The initial research questions were:

1. How do we, people labelled mad, describe our experiences of madness?
2. What terminology/language do we use?
3. How do we explain these experiences?
4. What meanings do we attach to madness?
5. How does madness relate to broader circumstances of our lives?
6. How do we approach/deal with madness?
7. Are any concepts of madness emerging? Have any names been suggested for them?

Whilst these questions remained relevant throughout the entire inquiry, they predominantly guided my work with written sources in the first phase. The new and more complex questions that emerged through that phase can be found at the end of each thematic section of the findings (Chapter 4) and also in the interview topic guide (Appendix D). The additional research questions that were central to the second phase can be summarised under the following four themes:

1. Is there a shared set of values and/or principles in our work on madness?
2. Should we attempt to come up with our own understanding of madness based on first-person knowledges? What are the advantages and disadvantages of such an attempt?
3. How should we best address structural differences amongst us, accommodate diversity, and not reproduce the ruling systems of oppression in our work, in particular racism and white dominance?
4. How can we work towards strengthening our own distinctive body of knowledge on madness? What are the most important features of such a process?

In this second phase, the focus of the research gradually changed: madness and experiences of madness were the starting points, the positions to think from, rather than a research topic. If, for a moment, we take being labelled as 'mad' as a social place that intersects with other social places, then it becomes easier to understand how *theorising from* that particular place is different to *theorising about* that place. The whole process of the second, interactive research phase was more about decentering madness and centering structures and systems that affect us and in which madness takes place. In order to express the outcomes of the interview analysis and capture the new arrival point of the research, I changed the working title of the thesis to, ‘Unmaking madness. Exploring a collective first-person epistemology’.

1.8 The structure of the thesis

The structure of this text charts the most important stages of this inquiry and the reflective journey behind it. Following on from this introduction, this is how that journey is documented in this thesis:

- I began this project investigating the ways in which first-person accounts are used in mental health and psychiatric research. My critical dialogue with conventional narrative research in this field, as well as the implications for this inquiry, are documented in Chapter Two.
- Chapter Three explains the approach I adopted and its background, and outlines the main methodological principles.
- As described earlier, in the first phase of the research I analysed publicly available written sources authored by people who are open about their psychiatric experience. The findings of that analysis, as well as the selection criteria and information about the type and number of sources, are presented in Chapter Four. This chapter, shared with participants prior to the interviews, is also referred to as the ‘interim report’.
- The findings from the second research phase mark the heart of this thesis and are presented in Chapter Five. This chapter also provides information about the 14 participants, the recruitment process, how the interviews were conducted and the approach to analysis.
- In the last chapter (Six), I discuss the findings. This closing chapter captures the main arrival points of this inquiry, reflects on its limitations and makes suggestions for future work.

CHAPTER 2 IN DIALOGUE WITH CONVENTIONAL NARRATIVE RESEARCH IN PSYCHIATRY AND MENTAL HEALTH

First person accounts of madness have become an object of increasing interest for non-survivor scholars with backgrounds in anthropology, psychology and psychiatry. At the outset of this study, I was familiar with some of this literature. This literature review aimed to gain a deeper knowledge of this expanding body of academic work and situate my project in relation to it. This chapter discusses some fundamental issues that arose in the process of my closer engagement with this work. It also describes how I re-examined my intentions and repositioned my research approach as a result of that process.

I use the phrase ‘conventional narrative research in psychiatry and mental health’ for studies based on the standard division of research roles into the participants, who contribute their personal stories in spoken or written form, and the researchers, who are responsible for all other parts of the process including its outcome. My comments here necessarily stop short of Literary Studies and the vast domain of life writing since I aim to address one growing practice: the processing of the personal accounts of people with psychiatric diagnoses in psychiatric and mental health research.

The first draft of this chapter was written in 2012. This final version includes the content of papers published since then. (Russo 2012a, 2016b, c).

2.1 The literature search and selected papers

My initial literature search took place in 2012 via the PsycINFO and Ovid MEDLINE databases. I combined each of the search terms ‘narratives’ and ‘stories’ with the terms ‘mental’, ‘psych$’ or ‘survivors’ as key words. These searches yielded a total of 467 articles. The majority of the retrieved articles referred to sexual abuse and domestic violence; physical conditions such as cancer, stroke, brain injury etc.; trauma (war, Holocaust, torture); and experiences of disasters such as earthquake or fire. Thirty-three of the retrieved papers were relevant to the topic of this study, most published from 2000 onwards. Further searches of the bibliographies of these papers revealed additional papers, as well as one valuable anthology on the ethics of narrative inquiry (Josselson 1996a). I focussed on the articles most closely connected with my planned work, i.e. the papers that do not simply draw on qualitative work with the narratives of 'psychiatric patients', but which explore the potential of those narratives to disrupt dominant theories in psychiatry and mental health. The papers that I engaged with in more depth were based both on the analysis of publicly available accounts of (ex-) psychiatric patients (Adame and Hornstein, 2006, Estroff, 2004, Hornstein, 2002, Jacobson, 2001, Jones, 2005, Ridgway, 2001, Torn, 2011, Young, 2009), and the analysis of individual interviews (Adame and Knudson, 2007, Crossley, 2004, Thornhill et al., 2004, Judge et al., 2008). I was also able to trace some studies about user/survivor groups and our movement (Crossley 2004, Morrison 2005, Hornstein 2009). However, I was not able to identify any systematic explorations of the theoretical and research work of survivors, and this has remained the case throughout my work on this thesis. In the closing section of this chapter, I will describe how this gap in the literature impacted on my selection of written sources in the first research phase.[15]

As a result of my critical reading of the academic work with first person accounts of madness and psychiatry, my interest extended to publications dealing with the ethics of narrative inquiry, the researcher's role, and the question of interpretative authority (Riessman 1993, Etter-Lewis 1996, Chase 1996, Josselson 1996b, Apter 1996, Rosenwald 1996, Smythe and Murray 2000, Josselson 2006, Josselson 2011).

I then elected to stop further searching as the aim of the literature review was not to provide a comprehensive account of academic work on survivor narratives but rather to explore the possibilities of a different epistemology grounded in collective first-person knowledge of madness. However, the selection of included articles is sufficient to depict main trends, and this has helped me to gain more clarity and to distinguish the values which I want to subscribe to from those that I do not. Whilst this process slowed down my research progress considerably, by re-opening some very fundamental questions – such as, what is it that would entitle me to undertake work with personal life stories? – I value this experience and the insights gained along the way.

My special interest was in studies based on the published accounts of (ex) psychiatric patients. The following table provides an overview of the papers central to these reflections.

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[15] For study design and research phases see Chart 1 on p. 29.

Table 1: Academic work with published first-person accounts in psychiatry and mental health: selected papers

Author(s)	Narratives used	Approach to the analysis
Adame, A.L. & Hornstein, G. A. 2006, USA	Ten personal accounts published as books between 1908 and 1995	A set of questions was constructed for each narrative to generate ‘profiles’; six different “types of subjective experience of emotional distress” were identified.
Estroff, S. E. 2004, USA	“Poetry and other forms of narration and performance by c/s/x[3]”; personal correspondence	No particular research project was undertaken. Estroff analysed several published works by people with psychiatric diagnoses along with the correspondence of one of them. The focus was on including first-person accounts in scholarship on schizophrenia.
Jacobson, N. 2001, USA	Thirty narratives of recovery (two unpublished manuscripts, three conference papers and 25 articles in journals and educational materials)	A dimensional analysis identified four central dimensions in narratives as well six explanatory models of recovery.
Jones, R. 2005, UK	Two personal accounts of bipolar disorder found on the Internet.	The analysis explored the “identity commitments that arise from the confluence of three aspects of the personal account.” These aspects were the text’s plan and realization; domain transversality; and the moral space into which the text leads us.
Ridgway, P. 2001, USA	Four women’s accounts of recovery published in scientific journals	The researcher used a constant comparative method alongside thematic analyses which identified the “core narrative.”
Torn, A. 2011, UK	Narrative of Mary Barnes from her book co-written with Joseph Berke	Bakhtin’s concepts of chronotope and unfinalizability were used as analytical tools.
Young, E. 2009, USA	Four memoirs (book publications) of authors diagnosed with mental illness	The researcher identified consistent elements in the narrative plots (symptoms, diagnosis, treatment and acceptance). Both the “writers’ shared understanding of the social construction of mental illness” as well as their differences were noted.

When it came to the value of these studies and their contributions to broadening and advancing the knowledge of madness, my judgments varied greatly. Rather than discussing their particular findings, however, I want to reflect here on some emerging ethical and epistemological issues in working with the first-person accounts of people who have been subject to psychiatrisation.

Whether those accounts are already publicly available (in anthologies, journals or online) or they take the form of interview transcripts produced in a research context, the approach to their analysis and interpretation raises similar questions. For all the considerable differences between writing (and publishing) a personal account and being interviewed as a research participant, the two situations have a key point in common: people with psychiatric experience are treated as data sources. By assigning the tasks of understanding and making meaning of madness to 'experts' and not to those directly concerned, the great majority of narrative analyses perpetuate the role and power divisions central to psychiatric treatment. In the remainder of this chapter, I will review the literature selection detailed above with a particular focus on: issues of consent in narrative inquiry and the question of narrative ownership; the way that the analysis is conducted and the question of ultimate interpretative authority; and the prospects of giving voice to the 'Other'.

2.2 First-person accounts: Our lives or researchers' data?

Despite the vast differences in the analyses they undertake, what most of these papers have in common is the uninhibited way that their researchers turn publicly accessible survivor work into *data* for analysis. This matter-of-course approach is quite obvious from the way that some of these authors refer to the publications which they interpret. Estroff explicitly defines "forms of narration and performance" by consumers/survivors/ex-patients (including their poetry) as "primary data" (2004, 285); Adame and Hornstein use the phrase "our data" (2006, 149) to refer to the book publications which they analyse. Is there anything wrong with this? Are survivor personal accounts any different from journal articles, official statistics or anything else that is fodder for research? All the researchers take a positive stand toward survivor narratives and assert that this was the main motivation behind their work. It appears that such statements are made in place of any further discussion on ethics. In a field dominated by traditional, biomedical research, the very interest in patients' perspectives told in their own words appears in itself to guarantee a better, more ethical approach. All the authors value individual patient narratives and aim to introduce them as additional and legitimate sources in the disciplines of psychiatry and psychology:

> "As psychologists, we have a great deal to learn from such works." (Adame and Hornstein, 2006, 152)

> "One goal of this chapter is to place these overlooked narratives in a scholarly landscape in a deliberately remedial move." (Estroff, 2004, 284)

Can such well-intended gestures raise any ethical concerns at all? Is it possible for the analysis of survivor narratives to even cause damage? How can the authority of lived experience be established if accompanied by "exploitation or 'colonization' of the participant's story by the researcher?" (Smythe and Murray, 2000, 325). There is generally a lack of attention paid to these questions:

> "Although narrative researchers have begun to explore the ways in which our exchange with participants in the interactional phase of our research may affect those who share their lives with us, we have paid less attention to how what we write down may affect those about whom we write." (Josselson, 1996b, 61)

Only one researcher raises the issue of authorial consent: Jones (2005), who worked with personal narratives published on the Internet by people with the diagnosis bipolar disorder, sought informed consent from the authors for her in-depth analysis. When she was unable to contact one of them she abandoned the planned analysis of their story. This researcher clearly distinguishes the 'private' and the 'public' life of the text:

> "In the private life of the text, the story and its telling are a function of the identity processes of the teller. In its public life, the participation of the story in cultural discourses becomes 'decoupled' from the person as such." (p.298)

Such 'decoupling' is of course problematic as Smythe and Murray (2000, 318) accurately observed in their comprehensive paper *"Owning the Story: Ethical Considerations in Narrative Research"*:

> "[…] research in the narrative study of lives yields information that cannot be dissociated so readily from one's fundamental human values and meaningful life experiences."

These authors recognise the question of narrative ownership as the central ethical issue in empirical narrative research, and define it as "the issue of who has control over the presentation and interpretation of research participants' narratives" (p.312). The concerns at stake here are clearly bigger and more complex than the conventional notion of consent to participation in research and demonstrate the limitations of the ethical principles generally used to govern qualitative research. The key to those limitations lies in the fundamental differences between *data* collected in narrative inquiry and in what Smythe and Murray call 'nomothetic' and 'variable-centered' research:

> "[…] although research participants are to be treated with personal dignity while serving as data sources, the data they provide in the process often are not something in which they have much personal investment. Whether these data take the form of reaction times, perceptual judgments, memory performances, or ratings of artificial stimuli, they tend not to touch on issues of fundamental human concern involving one's personal identity or the meaning of one's own life experiences." (p.317)

The question of 'narrative ownership' emerges as a result of this fundamental difference. Whilst Smythe's and Murray's discussion primarily focuses on the qualitative analysis of interviews, I hold that this applies equally to work carried out on published accounts, too. The question of narrative ownership may seem completely irrelevant in this type of research since stories are self-evidently 'owned' by their authors just as analyses 'belong' to researchers. However, when we consider the inequality of power to name and define that is intrinsic to the psychiatric treatment context, it is clear that subjecting survivors' published accounts to another analytic gaze re-opens the issues of ownership. Inevitably we are faced with questions about to whom the story – and the very experience – ultimately belongs (see Costa et al. 2012). Some researchers fail to understand how pressing this issue can be:

> "While the story in question was not written about this particular person, it was, for him, exquisitely *about him*. For me, the journal article was a publication; for him, it was *his* identity, *his* life, a liability of and for people like him. Schizophrenia is a word to me. I don't get it." (Estroff, 2004, 290, emphasis in original)

The fact is that survivor authors have already undergone classification and interpretation of their experiences in the course of receiving psychiatric diagnoses and prognoses. This reality makes any further processing of our published accounts a highly complex and delicate matter. Acting as allies to the international user/survivor movement, some academics conduct their studies within our communities (Estroff 1981, Hornstein 2009) and call for inclusion of 'survivor voices' into the disciplines of psychiatry and psychology. However, they do so by turning these 'voices' into primary data for *their* analysis:

> "The inclusion of c/s/x[16] experiences as legitimate subjects and subjectivities worthy of study, serious examination, and inclusion in the science of schizophrenia would challenge brain-based paradigms, but is not of necessity incompatible." (Estroff, 2004, 299)

Leaving aside the issue of the 'compatibility' of survivor knowledge with the biomedical model, what remains overlooked here are the questions of whether psychiatrised authors should be 'seriously examined' further as *subjects* and whether we at all want our *subjectivities* to be

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[16] "C/s/x" is the abbreviation for 'consumer/survivor/ex-patient' that the author uses.

integrated into the (apparently objective) 'science of schizophrenia.' That the translation, interpretation and appropriation of our experiences are inherent in such undertakings remains unspoken.

As psychiatric survivors, many of us write our way out of patienthood and beyond our psychiatric case histories:

> "The stories we tell ourselves, about ourselves, and about the world and our place in it, have a huge influence on how we feel and what we're capable of. When people who have been labelled mentally ill can talk to each other about these stories, without fear of being judged, the feedback we get, and give, can be enormously liberating." (Shimrat 1998, n.p.)
>
> "We develop stories in which we recognize ourselves. We search for the right words to do justice to our experiences and in doing so we regain our own identity." (Boevink 2007, 109)

The published narratives of survivor authors often have a vital role in their personal and collective journeys of emancipation from psychiatric judgment. As such, the question looms whether anyone has the right to assess those authors again and to impose any kind of classification on their stories. This question equally applies to me, a researcher who shares the identity of psychiatric survivor. Like any other perspective brought to research, my experiential standpoint certainly plays a role, but it neither gives me more rights nor provides any guarantee that I will do things better. Ultimately, I hold the purpose and nature of the analysis undertaken to be far more relevant than the identity of the researcher.

2.3 The question of interpretative authority: Who should have the last word?

Table 1 above shows the various approaches taken to the task of analysis in the studies under review. Several of these studies may be seen as having a positive impact: they open up first-person perspectives on important issues around recovery and lead to valuable conclusions and recommendations (see for example Ridgway 2001 and Jacobson 2001). Even so, in research based on published accounts there is typically no direct contact between researchers and participants. This also means that there is limited or no opportunity to verify the analysis and reduce the room for the researcher's own interpretation – the central concerns of survivor-controlled research in mental health (Beresford 2003; Faulkner 2004; Russo 2012). Such opportunities are also limited in conventional narrative research based on interviews: the analysis phase is typically not interactional and is performed on texts (interview transcripts) only. Despite the important differences between them, what connects studies based on published first-person accounts and narrative interviews is, thus, the absence of the authors/participants from the further processing of their own accounts.

In a comprehensive literature review that focuses on making meaning of madness, Casey and Long (2003) emphasise the fact that the 'sense making' applied to the accounts of people with psychiatric diagnoses is performed by researchers and discuss the risks involved:

> "In narrative analysis, there is a risk that researchers may be responsible for suppressing the very meanings they are purporting to uncover through the analysis and may, in fact, be replicating 'expert professional' vs. 'passive patient' relationships of unequal power." (p. 95)

Further on, these authors explicitly reflect on the role of the researcher as 'classifier' of the experience and refer to the larger biomedical context in which the narrative inquiry takes place (p.96). Such a role division can be seen at work in Adame and Hornstein's (2006) analysis. Although they aim to provide "an alternative to medical conceptions of mental illness" (p.137), these researchers propose their own taxonomy of three "clearly defined types of subjective experiences of emotional distress" (p.137). One of those categories describes psychiatric oppression as "the *feeling* of being in some way abused, mistreated, coerced or denied human rights by mental health professionals […]" (p.141, emphasis added). Combined with the researchers' effort to identify a "turning point that distinguishes the predistressed from the postdistressed narrator" (p.141), this gives the whole procedure a rather clinical character; it also patently contradicts their statement that "this narrative genre gives authority to the voices of the 'mentally ill' and puts their accounts of personal suffering on an equal plane with the medical/psychiatric master narrative" (p.151). Instead, through the acts of overwriting, grouping and re-naming experiences, this approach diminishes the authority and power of the first-person voice that the authors gained through their own publications. The analysis imposes a new and controlling narrative. In my view, and as I will explain in the next chapter, the emancipatory potential of the analysis lies somewhere altogether different: it lies in the researcher's relationship to the narrator, to the *person* behind the story, the *owner* of the experience. I want to give greater consideration to the complex question of interpretative authority and highlight further researchers' perspectives, as I see this as key to understanding the task of analysis.

Campbell (2009), who pioneered consumer-directed research[17] in the USA, describes “mental health service user ’voice’, as an approach to defining an authentic research methodology” (p.113) and critically observes:

> “The effect of professionals validating the ‘raw’ material of service user experience, and placing it in ‘perspective’ reinforces the biomedical research ideology that sees people as sources of data rather than shapers and interpreters of their own experience.” (p.126)

Casey and Long (2003, 95) remind us of the “pitfalls inherent in regarding peoples’ accounts and stories as ‘text’ for researcher interpretation”. The same danger is recognized by Arthur Frank (2000, 355) in his extensive work on illness narratives:

> “However valuable analysis can be, analysts risk misunderstanding if they move too quickly outside the storytelling relation as they transform the story into a ‘text’ for analysis. […] The risk of reducing the story to a narrative is that of losing the purpose for which people engage in storytelling, which again is relationship building.”

In the psy-complex disciplines (see explanation on p. 24), discussions about the ethics of analysis have focused mostly on empirical narrative research. Josselson (2011, 39) depicts the appropriation of others’ experiences as a central and routine element of interview-based narrative studies: “As interpreters, we appropriate the interview text and subject it to our interpretative gaze. But this is seldom a process we explain to our participants.” Elaborating on the difference between the participant’s life and the interview transcript, this author makes clear that solely the latter is of interest for the analysis (p.37). The researcher is the one who creates and authors a new narrative based on their own interpretation; meanwhile “participants are less likely to find a match with their own experience” (p.39). Josselson claims that this disparity with the participant’s own understanding may even lead to a *better* analysis:

> “Co-construction of a text doesn’t imply that we have similar aims as our participants or that we are somehow working together to produce the research results. If we have done our work well, we are likely, in some ways, to offer a dissonant counterpoint to their self-understanding.” (p.39)

This stance is the very opposite of the approach in dialogical narrative analysis, which does not seek “privileged insight into particular stories, and much less into the mind of storytellers” (Frank 2011, 46). Certainly, Josselson is aware of other kinds of studies where there is little interpretation at all. She calls these works “descriptive studies of marginalized[18] groups, where

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[17] The UK equivalent would be ‘user-led research’.

[18] All the quotations in the text use the original spelling.

the aim is social awareness or action" (2011, 37), and I suppose this is where we can locate survivor-controlled research, with its explicit aim of minimising the researcher's interpretation and its commitment to fostering change (Nicholls 2001; Beresford 2003; Faulkner 2004; Lindow 2010). Labeling such studies 'descriptive' implies that there are other studies which go beyond description and offer a deeper understanding. Furthermore, Josselson brings to the point the unspoken purpose of many narrative studies: "Think of Freud's interpretation of the Dora case. He may have gotten Dora all wrong, but he did show us how to think psychoanalytically" (p.39). Inevitably, this plain assertion opens up the question of the responsibility and implications of a research which purports to position itself beyond the question of whether it is *getting it* right or wrong. Are studies whose focus is "conveying as faithfully as possible the person's account" (Casey and Long 2003, 95) of less depth and less value? We cannot know what would have happened if Dora had had the authority and the last word on her 'case', but we do know of the impact of Freud's theory of infantile sexuality on the treatment of women (and men) who have experienced sexual abuse in childhood and adolescence (Masson 1984).

Being fully aware of the complex nature of first-person accounts and the multitude of possibilities for their interpretation – I still hold that at least an effort to *get it right* remains the key requirement for research and theory building. Otherwise - what kind of knowledge do we produce if the question of responsibility for *getting it wrong* or *not getting it* is not even to be raised?

Though, there are different perspectives on the issue of ultimate authority:

> "If we continuously map our own perspectives onto those of the interviewee's, then we will learn nothing." (Etter-Lewis 1996, 116)
>
> "Some interpretations seek to finalize stories, cutting off dialogue by claiming to speak the last word." (Frank 2010, 87)

It may seem naive to believe there is such a thing as a last word, even if only for the moment, or to insist on the question of who has that last word. However, when we consider the perspectives of those who have undergone psychiatric treatment, the centrality of these issues becomes more obvious:

> "Diagnosed into being objects, imprisoned with or without walls, cut off from meaningful dialogue, the psychiatric consumer/survivor/ex-patient (c/s/x) must adapt to an other-constructed, authority-blessed reality." (Bassman 2001, 15)

For people labeled mad, gaining back authority over our own lives and having the right to the last word remain core issues at both the individual and collective level:

> “We are refusing to allow others to speak for us and are reclaiming ownership of our experience.” (Bassman 2001, 23)

I maintain that any analysis of our narratives must take account of these circumstances and should aspire for the last word to rest with the narrators.

Reflecting on the ethics of narrative research, Smythe and Murray (2000, 321) accurately observe:

> “[O]nce the researcher’s account is taken as the authoritative interpretation of an individual’s experience, the individual’s own understanding of their experience inevitably is compromised.”

This opens up the question of whether it is possible for a research account to establish and even increase the authority of the narrator’s own understanding of their experience – without compromising it. I choose the phrase ‘research account’ here rather than ‘researcher’s account’ since the researcher is just one of the agents in the research process, and the research account can be co-created or agreed upon with the participants. These possibilities are limited in research with published accounts where there is no interactional phase. In these cases, however, the analysis process poses a similar challenge: how to generate a research account that includes the author/participant’s own understanding of their experience and brings it into dialogue with other authors/participants and the researcher? Such an undertaking requires alternative approaches and methods since it fundamentally questions the conventional division of roles and assignment of authority in psychiatric and mental health practice and research. Nevertheless, I am convinced that work of this kind does not have to stop at a ‘descriptive’ level. On the contrary, such joint undertakings have great potential to deepen and expand the understanding of complex human experiences – like madness - in a way that cannot be achieved by a single researcher who claims sole interpretative authority.

2.4 What does it mean to give a voice to the ‘Other’?

It is becoming increasingly recognised that psychiatric patients have historically been silenced in the course of their medical treatment and that such traditions should be challenged. This development can be observed in legislation and policy (Minkowitz 2014, 2015, Beresford and Carr 2018) but also in studies of survivor narratives:

> “Psychiatrists have not simply ignored patients' voices; they have gone to considerable lengths to silence them. Patient narratives are filled with reports of their authors' being

> locked in isolation rooms, deprived of writing materials, having correspondence censored, or being threatened with violence for making their views public." (Hornstein 2002, n.p.)

Following on from my initial literature search, and in the course of my work on this thesis, I have observed a growing research interest in the stories of people with psychiatric diagnoses (Chassot and Mendes 2015, Natland and Celik 2015, Johnstone and Watson 2017, Johnstone and Boyle 2018). This development is in line with the following claim made almost 20 years ago:

> "To understand and facilitate processes of resilience and recovery, we must end the silence imposed on people with psychiatric disabilities, attend much more carefully to their personal and collective voices, and value and honor their stories." (Ridgway 2001, 341)

This is a legitimate and sensible claim. However, it begs further questions, including who is to end that silence? And by what kind of process? Despite their shared commitment to 'end the silence', some contemporary studies of survivor narratives seem to impose a different, more contemporary kind of silencing (Russo and Beresford 2015). As said earlier, this phenomenon primarily occurs as a result of the exclusion of users'/survivors' own analysis from the academic discourse on madness. Hornstein accurately observes that reducing patients to 'case illustrations' builds a barrier and prevents them from entering related disciplines on equal ground:

> "More subtle forms of silencing are equally widespread. Patients cannot publish in any mainstream journal in psychiatry, clinical psychology, nursing or social work. (They are allowed only as case illustrations.) Patient support and activist organizations are denied the funding and research facilities that would allow them to evaluate the methods they develop." (Hornstein 2009, 159)

What this and some other authors seem not to notice is that by their insistence on 'patient' identity, by gathering our experiences, interpreting them and taking on the role of bridge builders between survivors and academia, they inevitably contribute to the very same process of silencing which they are aiming to combat. It seems that a commitment to *giving a voice* to psychiatric patients makes any further reflection about the purpose and the ethics of one's own work superfluous.

In times when people with psychiatric experience author much more than personal accounts, the exclusive focus on our individual narratives becomes a way to suppress our research and our academic work, which in consequence slows down the process of users/survivors developing our own theories. On a mission to collect and explain our individual and collective stories rather than giving ‘psychiatric patients’ a voice as they claim, some academics are conquering another territory of narrative research. Long-term US activist Ted Chabasinski (2012, n.p.) observes how “many academics […] tend to be rather elitist and consider themselves to be rightfully the leaders of someone else’s cause.”

Seeing parallels to Etter-Lewis’s (1996, 117) description of African American women as “a group historically exploited by researchers and do-gooders alike” I ask myself - what does it actually mean to give a voice to the Other? Can this be accomplished at all unless that Other is allowed to find their own voice to speak for themself? How can the Other begin to speak if constantly described and explained? Resourcing the Other to author their own perspectives is rarely the practice in psychology and psychiatry:

> “We write, as scholars, *for* our peers *about* our participants. […] We have to hold this doubleness at all levels.” (Josselson 2011, 46, emphasis in original)
>
> “How to communicate the legitimacy of their views and experiences and retain credibility?” (Estroff 2004, 297)

To open up a scholarly dialogue through inviting and allowing the owners of the experiences to join in without intermediation does not seem like a viable option, even when working on our behalf proves difficult for some of these academics:

> “Authenticity of experiences is theirs alone, yet the inability of others to offer them authentic empathy and recognition is a source of substantial suffering, humiliation and outrage. If we do not by choice, and cannot by insufficiency understand, know, and recognize, then what are we to do?” (Estroff 2004, 299)

Perhaps a dialogue on equal ground could lead a way out of such dilemmas. It could possibly even demonstrate that *all* humans not only have authentic experiences but also the capacity to understand, communicate, explain and conceptualise them. Such a realisation could certainly lessen the gap between ‘us, scholars’ and ‘them, subjects of our interest’. But a dialogue requires two voices and cannot take place when there is only one party speaking, both for themselves and for the Other. Regardless of how well intentioned such *speaking for* or *on behalf of* may be, it remains a monologue and blocks the agency of the Other.

Despite the strong evidence they display, individual survivor narratives have not as yet been able to mount a challenge to the biomedical model on an equal level. Some narrative researchers’ intermediation attempts (Estroff 2004, Hornstein 2002, 2009) can be perceived as creating another form of subtle and persistent barrier to the establishment of the first-person voice in psychiatry and psychology. If the first-person voice is not to be compelled to remain singular, the question is – how a *'we',* which in this case implies service user/survivor voice in relevant disciplines – can be established by anybody other than users/survivors themselves. Appropriating this task and performing it *for us* cannot enact such a '*we'*.

Because all oppressed groups have a great need for allies – not only in terms of individual biographies but also as political movements - it is particularly hard to challenge practices that subscribe to the same or similar goals but are not emancipatory in their nature. I will draw one parallel in order to make this clearer. Hornstein (2002, para. 4) writes: "Patient memoirs are a kind of protest literature, like slave narratives or witness testimonies."

This comparison encourages me to borrow one of the six stories discussed by Arthur Frank (Frank 2010, 11-12) in his book on socio-narratology. The story was originally told by Frederick Douglass, an escaped Afro-American slave who became a leading emancipator, orator and author. Douglass describes his experiences of abolitionist meetings in the 19th century:

> "During the first three or four months, my speeches were almost exclusively made up of narrations of my own personal experience as a slave. 'Let us have the facts,' said the people. So also said my Friend George Foster, who always wished to pin me down to my simple narrative. 'Give us the facts,' said Collins, 'and we will take care of the philosophy.'" (Douglass 1994, 367)

This small excerpt, taken from a very different context and very distant time feels so close and expresses so pointedly the mixture of feelings that some survivors have towards undertakings such as *'Agnes's Jacket: A Psychologist's Search for the Meaning of Madness'* (Hornstein 2009). "Give me the stories and I will take care of the rest" - remains the undertone, the distinctive flavour of this detailed diary of Hornstein's journey through survivor groups.

There are certainly multiple ways in which survivors actually experience the process of bringing our 'voice' into academia and we hold varying opinions on how much the overall 'feel' of this process matters. In her reflections on what she terms 'methodology of voice', Jean Campbell (2009, 126) raises similar questions:

> "I wonder how traditional researchers can give perspective to someone else's experience without violating that person's view of his/her experience? Do such methodological problems apply to my own work as a mental health service user?"

I agree with Campbell's answer that, "it is necessary *for all of us* to pause and engage in critical dialogue and self-reflection" (p.132, emphasis added). However, I would also add that we need to consistently scrutinise our own work, reviewing how truthful we are to what we claim and how different our own research actually is from the practices that we are criticising. By 'we', I mean any researcher who claims to work in a different way based on either their identity or their critical stance regarding the dominant biomedical understanding of madness, or indeed both. Morrison's (2005) inquiry into the US survivor movement is a rare example of a study conducted by a researcher who had been "diagnosed and treated by psychiatry" (p.34); yet, it exemplifies the famous words of Audre Lorde (1984, 112) that "the master's tools will never dismantle the master's house" through its' confirmation that the researcher's identity alone holds no guarantee that the participants' experiences will not be overwritten and their voices substituted. Morrison (2005) chose a conventional research approach in treating her interview partners as 'subjects'. In the first step she analysed four published accounts which she named 'heroic survivor narratives' (pp.102-103) and identified a 'five-phase framework' in those narratives. Subsequently she conducted twelve interviews with "ordinary local activists" (p.105). In the analysis of the content of those interviews the same five-point framework was applied. Despite Morrison's comprehensive presentation of participants' resistance to psychiatrisation, the value judgment implicit in her sharp distinction between "ordinary activists" and movement leaders on which the whole inquiry was based is disturbing. Moreover, even though the analytical framework that she developed is very different from clinical frameworks, a pre-set interpretive framework was still imposed on participants' experiences.

In their detailed reflections on how emancipatory their own research projects are, Stone and Priestley (1996, 16-17) distinguish between 'collectivizing experience' and 'collective analysis'. I will return to this important difference when presenting my own work on this project and its many challenges in the next Chapter. For now, I want to use their analysis to situate Morrison's work and my criticism of her approach:

> „In this approach, the researcher attempts to collectivize findings by drawing together diverse personal experiences in the analysis. However, the collectivization of experience is still ordered within *the researcher's* chosen frame of reference (albeit a framework is informed by the agenda of the disabled people's movement)." (p.16, emphasis in original)

The following words of bell hooks (1990, 343) are a powerful and universal reminder of processes that can become oppressive and ultimately work to "annihilate and erase":

> "No need to hear your voice when I can talk about you better than you can talk about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I write myself anew. I am still author, authority. I am still the colonizer, the speaking subject and you are now at the center of my talk."

By its very definition, academic research involves re-writing voices for the sake of scientific publications, and anybody who enters that arena – regardless of their background and motivation – will face similar demands and expectations. In the words of Stone and Pristley (1996, 13), "[t]he researcher both acts and is acted upon within these power relationships". Exploring and enabling a collective, first-person epistemology of madness therefore goes beyond a question of methods. Above all, it means working to principles and values that are very different to those that rule in the academic world, coupled with a commitment and preparedness to honestly and continuously question those values and principles.

2.5 Implications for this study

There is a wide agreement among the authors included here that stories are an essential part of human lives. However, the various analyses of survivor narratives and some of the discussions on the ethics of this type of research demonstrate that there is multitude of ways to approach our stories. Being aware that I am in no way a neutral recipient of this scholarly work I considered my criticism very carefully. My search for a fair way to approach survivor accounts is certainly informed by my own experiences of being interpreted instead of being heard and responded to in the course of psychiatric treatment, as well as those of my many peers. As with the great majority of narrative analyses, one of the central features of psychiatric treatment is that the tasks of understanding and meaning making of madness are assigned to 'experts' and not to those directly concerned. Rather than suppressing this experiential knowledge as something which stands in the way of my ability to judge 'objectively' I have taken it seriously and let it guide this review. As mentioned earlier, this process has substantially slowed down my planned research but has provided invaluable insights. My attempt to just familiarise myself with the main trends in academic work with user/survivor narratives has unexpectedly opened up some very fundamental questions and concerns about the way I intend to proceed. In the next chapter, I will present the methodological underpinnings of this study. Here I want to summarise the implications of my critical engagement with the use of the personal accounts of people with psychiatric diagnoses in mental health and psychiatric research for this thesis.

Whilst inquiries based on both narrative interviews and published accounts give rise to very similar ethical questions, unique to the latter is that there is no direct contact between researchers and participants. This also means limited or no opportunity to verify the analysis and reduce interpretation, which is one of the central features of survivor-controlled research (Faulkner, 2004, Lindow, 2010, Russo, 2012). Coupled with the absence of even standard research procedures such as that of obtaining informed consent or introducing a possibility of post-study consent withdrawal, it seems that the interpretative freedom of researchers, already inherent in mainstream mental health studies, even increases when working with published individual narratives. Such circumstances in my opinion impose the need for more ethical scrutiny rather than permitting the payment of less or even no attention whatsoever to ethical issues, both courses followed by the authors of some of the work included in this small review. The decision to make a personal account publicly available[19] thereby identifying oneself as a person with psychiatric experience – in my view implies an agreement for the account to start its independent life; independent in the sense that the author will not be able to control the way their story is received by varying readerships. However, when such an individual narrative by becomes analysed within a research project and its excerpts used in a research report, I hold that the issue of informed consent arises automatically. This does not imply that published personal narratives of madness should not be at everyone's disposal as powerful resources to "think with" (Frank 2010, 47) or that these texts' reception and consumption – basically their life – should be limited or controlled in any way. My reflections here focus narrowly on the use of personal narratives in psychiatric and mental health research and on the further processing of our stories as part of the official production of knowledge about madness within a field that may be seen as a competitive academic enterprise.

The various existing regulations for research with human participants are obviously proving insufficient. Developing general ethical guidelines on how best to deal with this issue remains a task for the future. Following on from the practices that I criticised in this literature review, I considered piloting a consent procedure in this study; however, neither my research with written sources nor the interviews included any biographical accounts or simple narrations of individual experiences. The interviews in the second phase will not aim to collect personal stories, but instead will be a joint process of reflection and further analysis; this aim was clear from the outset as an integral part of the study design (see the participant information sheet and interview topic guide in Appendices B and D). However, it should also be noted that the

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[19] As a book publication, book section, anthology contribution, journal article, web publication etc.

decision not to work with first-person narratives of madness in phase one gradually developed after I commenced this research, and was directly inspired by the literature review.

As stated earlier, I focused specifically on those projects that not only researched first-person perspectives, but – similar to my intended inquiry – explored the potential of those perspectives to disrupt biomedical understandings of madness. My review also included narrative studies conducted by researchers who themselves have psychiatric experience (Ridgway 2001, Morrison 2005). The decision to reverse the order of my planned work with written sources resulted from this intense process: that is, witnessing the disparity between growing academic interest in our personal stories on the one side, and the persistent neglect of our scholarly contributions on the other. I decided to begin with survivors' conceptual and research work, rather than with a selection of first-person narratives as originally intended. In taking a different departure point, focusing on the research and conceptual work of survivors, I intended to open up an alternative to the third-person approach to collecting and examining our individual accounts, and instead to create a space - even if only within this very limited project - for *jointly* thinking through the experience of madness based in first-person knowledges. This approach ultimately led me to leave aside narrations of personal experiences, and to focus on published sources that also provided general opinions and made broader statements.

This approach is not intended to create a sharp division between the 'experiential' and 'conceptual' because the uniqueness and potential of first-person accounts lies precisely in the cohesion of both. Many authors of what are considered to be personal narratives are already suggesting broader explanations and concepts. The purpose of my work with published individual narratives (including my own) is to explore the possibilities of connecting and advancing first-person knowledge of madness. I do not seek to explain and interpret individual experiences but instead to center authors' own perspectives and concepts. The specific way in which I worked with written sources is explained in Chapter Four.

My engagement with conventional narrative research has both confirmed and encouraged my conviction that ethics plays a key role in any approach to studying people's lives. In the context of narrative inquiry, ethics centrally relates to the purpose and the nature of the analysis of first-person accounts. In relation to the topic of this study, this means carefully approaching and prioritising the process of the research, rather than simply its findings; or in the words of Stone and Priestley (1996, 7), "anti-oppressive practices must begin with the research production process itself".

CHAPTER 3 WORKING OUT AN APPROACH TO FIRST-PERSON ACCOUNTS

In the previous chapter, I criticised some of the practices of conventional narrative research; this chapter, in contrast, will frame the approach that I aim to adopt in more positive terms. I will describe the steps of the analysis in more detail when reporting my work with the written sources in Chapter 4, and the interview findings in Chapter 5. Here - before actually commencing the research - I want to share the key values and principles which inform this study's approach as well as acknowledging their origins. By outlining the methodological underpinnings of this inquiry, I hope to map out the way I intend to treat personal and other information shared by people with psychiatric experience throughout my work on this thesis. The extent to which I succeeded in working to these requirements can only be judged retrospectively.

My first reflections on the methodology of this study were written during the early stages of this project. Following on from the literature review, the initial draft of this chapter largely related to the first research phase I was about to commence: that is, building upon existing research work that I personally value alongside trying to develop my own approach to published accounts. One publication that emerged from this and from the previous chapter (Russo 2016c) has received two commentaries by survivor researchers (Kelly 2016, Carr 2016). In general, those commentaries confirmed my standpoint, but also highlighted further complexities. Being reminded of those issues and engaging with them proved helpful in my further work on this project, particularly in the second research phase (the interviews). I have therefore retained parts of my reply to these commentaries (Russo 2016b) in this chapter.

3.1 Changing the game: towards an emancipatory research paradigm

The disability theorist Mike Oliver (1992) emphasizes the social relations of research production and distinguishes positivist, interpretative and emancipatory stages in the history of research. Applying this framework, he doubts the potential of qualitative research to shift the positivist paradigm:

> "[W]hile the interpretative paradigm has changed the rules, in reality it has not changed the game. Interpretive research still has a relatively small group of powerful experts doing work on a relatively large group of powerless research subjects." (p.106)

In this vein, he holds that "interpretative research is just as alienating as the positivist research" (p.106). Oliver also makes a powerful call for a shift to a research methodology which is built on trust and respect as well as participation and reciprocity (p.107). This author's understanding of research, its process, and its values continues to shape and influence what I aspire to in research. Rather than any concrete advice or guidance, those are the key questions, raised by Oliver, that I continually return to. Those questions point to the inadequacies and failures of existing social research approaches, and are too big to be resolved with any set of techniques or skills; they clearly call for much more exploration and for many more projects. I cannot claim that Oliver's vision of research is being 'implemented' or 'practiced' within this project, but I will try to explain how his vision of emancipatory research resonates with this inquiry, and what emancipatory paradigm can mean for knowledge production about madness.

Personal experiences like madness are the target of psychiatric and therapeutic interventions. What connects all established theories behind those interventions is the fact that they have not been developed and authored by people who have undergone these experiences. It is true that individual users/survivors do create concepts and explanations of madness, but so far we have not collectively initiated any school of thought or made any systematic attempt to pull our knowledge together and explore whether it can stand as a model/theory on its own. As previously described, when depicting emancipatory methodologies in disability research, Mike Oliver (2009, 110) highlights the general failure of social research "to produce collective accounts of collective experience". Any work which aims to move us in that direction must therefore give careful consideration to its own methodology. This is especially vital if it is to avoid reproducing the old division between those who solely *experience* and those who claim to *know* (and own) the experiences of Others. Ignoring the fundamental questions of who develops the knowledge and what process lies behind this can result in the further appropriation of individual and collective experiences. Even when they are not clinical, such research efforts can still suppress first-person knowledge. Beckmann and Davies (2013, 57) warn of this turn:

> "Without due sensitivity to questions of ownership, we risk simply adding a new chapter to the categorization and disempowerment that characterize the life history of a person with mental health difficulties."

Works by psychiatric survivors often build upon the personal experiences of their authors and take the reflections and knowledge gained from those experiences as a departure point. This means that personal accounts are not only to be found in so called first-person narratives; they are also embedded in the essays, research reports, and concepts authored by mental health service users/survivors. Furthermore, the official documents of groups in our movement such as conference reports often contain the personal accounts of their participants (see for example the documents of the European Network of (ex) Users and Survivors of Psychiatry 1994a, 1994b, 1997). If these sources are to be treated responsibly and with respect, it is important to establish values and principles regarding how best to approach this particular body of work.

The task of working with survivor accounts faces two main demands: on the one hand, the essence of each unique first-person experience has to be preserved so that the owner of that experience can find themselves in the outcomes. And, on the other, the individual experience should be enabled to communicate with the experiences of other contributors so that it joins in a first-person plural - ‘we’ that can create distinct knowledge about madness in social science. As discussed earlier, shared identity between the researcher and those whose life experiences are the topic of the investigation can be helpful in this process, but it cannot itself offer a solution. Rather than just ‘collectivizing experience’ (Stone and Priestley 1996) the emancipatory approach

> “[w]ould seek to collectivize the entire process of data collection and analysis, either through bringing respondents together in one room, or through feeding back the views of other respondents in a dynamic and democratic way […]” (p.16).

This inquiry aims to explore the ways in which we, people labeled mad and largely excluded from the production of knowledge about madness can own the analysis collectively, without overwriting individual experiences. This is certainly a complex and immensely challenging task. Aside from all the individual differences among us, there are structural inequalities and injustices at work that affect the aspiration to such a ‘we’. Advocating for intersectional scholarship, Hill Collins (2012, 453) reminds us that knowledge “cannot be separated from the power relations in which it participates and which shape it”.

How, then, do we arrive at a methodology to respond to these key demands? This is for sure a task for the future and one too big for any single researcher or any single study. If we are ever to achieve what Oliver (1992) calls an ‘emancipatory research paradigm’ and start producing ‘collective accounts of collective experience’ (Oliver 2009, 110), we need to learn how to share the tasks of interpretation and analysis in our work. Unfortunately, there is little existing scholarship that can equip us with guidelines on how to do this. The task ahead of us might actually be about unlearning what we know and are used to. Such a process is certainly complex and multi-layered. Among its tasks are re-defining the division of authority between the ‘researcher’ and the ‘researched’ in knowledge production and creating methods that can achieve this; learning how to stop reproducing and reinforcing a ‘white, Western Mad subject’ (Gorman, 2013, 271); disrupting academic spaces that focus on individual careers and competition, and developing a multitude of new ‘thinking environments’ in and outside of academia. This work is undoubtedly highly challenging, not least because of the many pressures and constraints imposed on survivor-led projects. However, despite all the risks and hardships, if we, people labelled mad are ever to work together on developing our own theories, there is no way round confronting precisely these kinds of challenges. The point here is not just to author another model or theory but to do so in a way that is fundamentally different from the traditional ways of building models and theories of madness. This is where I think the truly transformative potential of our collective first-person epistemology lies.

In line with Vivien Lindow’s (2010, 143) reflections on ethical issues in survivor research, I believe that some methodological approaches are best known by trying them out:

> “[I] certainly cannot claim always to have reached all these standards all the time: we learn as we go along.”

When it comes to conducting emancipatory research, Oliver (1997, 25) reminds us that there are no ready-made recipes or formulae for the successful conduct of emancipatory research:

> “[…] the question of doing emancipatory research is a false one, rather the issue is the role of research in the process of emancipation. Inevitably this means that research can only be judged emancipatory after the event; one cannot 'do' emancipatory research (nor write methodology cookbooks on how to do it), one can only engage as a researcher with those seeking to emancipate themselves.”

In order to give ourselves space for such engagement, it might be plausible *not* to have all the methodological answers in advance which dictate the way forward, but instead to be guided by the research process itself.[20] In the next two sections, I share part of the methodological heritage that I bring in into this inquiry. The approaches that have had the most decisive influence on my research work come from survivor-controlled research (largely from the UK) and socio-narratology developed by the Canadian sociologist Arthur Frank in his many years of work with narratives of physical illnesses, including his own.

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[20] For the research design of this study, please see Chart One on p.29

3.2 Learning from survivor research

In their groundbreaking article, the *Survivors History Group takes a critical look at historians* (2011), a group of UK survivor authors explains why objectivity has a higher value in their work than in that of academic, non-survivor historians:

> "Because the story is our story, the credibility and detail of it matters to us in a different way than it does to the academic historian. This can mean we are more, not less, concerned about objectivity." (p. 17)

Leaving aside the notion of 'objectivity' – which has been critically debated in both feminist and survivor research - there is a point of connection between the statement above and survivor research: for this same reason – 'because the story is our story' –approaches to the analysis of survivor accounts matter to us, survivor researchers, in a different way. In line with the different concerns of survivor historians and non-survivor historians, survivor-controlled research projects scrutinise the overall methodology and, in particular, the ethics of the analysis of personal information, in far greater depth than conventional mental health research does. The sensitivity to and respect for the ownership of personal stories is an issue of major concern for survivor researchers:

> "Having collected the data or information from participants, there is a question about how we, as researchers, treat or deal with that data in an ethical way. The respect that we held for participants needs to be followed through by respecting the information they shared with us." (Faulkner, 2004, 26)

My work is greatly informed by values and principles of survivor research in mental health (Nicholls, Faulkner, and Blazdell 1999, Nicholls 2001, Faulkner 2004, Turner and Beresford 2005, Sweeney et al. 2009, Lindow 2010). By the expression 'survivor research', I refer primarily to survivor-controlled and led studies[21]. Besides being inspired by concrete research projects (Faulkner 1997, Faulkner and Layzell 2000, Fleischmann and Wigmore 2000, Rose 2001, Wallcraft 2001, Jackson 2002b, Nicholls et al. 2003, Wallcraft, Read, and Sweeney 2003, Turner 2003, Read 2005, Halsall 2006, Webb 2010, Beresford, Nettle, and Perring 2010, Kalathil et al. 2011, Fabris 2011, Tenney 2014, Beresford et al. 2016), my own research work builds, in particular, upon the reflections of survivors on their approach to research (Beresford and Wallcraft 1997, Nicholls, Faulkner, and Blazdell 1999, Beresford 2002b, Faulkner and Morris 2002, Rose 2003a, b, Wallcraft 2003, Faulkner 2003, Beresford 2003a, b, Faulkner 2004, Rose 2008, Wallcraft 2008, Sweeney et al. 2009, Wallcraft, Schrank, and Amering 2009,

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[21] This expression also covers 'user-controlled' and 'user-led' studies.

Lindow 2010, Staddon 2013, Sweeney 2016a, b). In this respect, it is worth highlighting that survivor research does not offer up any separate set of methods and techniques; rather, it emerges as a radically new understanding of the research process itself as well as of the larger social and historical context in which knowledge of madness and distress and their treatment is produced. In this respect, there is a strong parallel with the emancipatory research paradigm. In their description of its main principles, Stone and Priestley (1996, 10) advise that:

> "[i]t would be misguided to equate emancipatory disability research with any one approach to data collection since both qualitative and quantitative methods can be used in an oppressive or an emancipatory context. While it is important to give primacy to the personal experience of disablement, the central issue is how this experience can be used at an early stage in the formulation and *choice* of appropriate research methods." (emphasis in original)

There is a significant overlap in the distinct sets of underlying principles and/or key values which some survivor researchers identify in this research approach. In her work on the ethics of survivor research, Faulkner (2004) comes up with the following underlying principles: clarity and transparency, empowerment, identity, commitment to change, respect, equal opportunities, theoretical approach and accountability. The key values in user-controlled research identified by Turner and Beresford (2005) include: empowerment, emancipation, participation, equality and anti-discrimination. Despite the fact that they were conducted[22] and structured slightly differently, these two studies address all stages of the research process, and each one describes in detail what makes user/survivor-controlled research different to conventional mental health research. Looking back at her work on ethics, Faulkner states:

> "One of the issues that emerged at an early stage was a clear distinction to be made between 'ethical practice' and 'ethics approval'." (Faulkner and Tallis 2009, 54)

The ethical practice of survivor research goes beyond complying with various ethics committees' rules; it challenges the presumptions of mental health and psychiatric research, particularly the traditional role division in knowledge production. To elucidate this point, I want to focus for a moment on the analysis stage of the research process.

The central feature of the analysis stage of survivor-controlled projects is the involvement of the participants, most usually through the convening of focus groups after the researchers have done the first thematic analysis. Focus groups are not used as a data collection method but instead serve as forums where findings are presented, discussed, prioritized and jointly

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[22] Both projects build upon interviews and group discussions with service users and service user researchers. Turner and Beresford's report includes a literature review as well.

interpreted. Depending on the project design, this joint work with participants can take additional forms (see Russo 2012). The value placed on participants' involvement at the stages of analysis and interpretation remains a distinctive characteristic of this research approach, and it is also what clearly separates survivor-controlled research from participatory approaches. These features also clearly distinguish this research direction from the trend known as 'service user involvement' in mental health research (Sweeney and Morgan 2009, Rose, Carr, and Beresford 2018). In this respect, it is telling that in survivor-controlled empirical research, the researcher's identity is just one key part of the process (Faulkner 2004, Nicholls 2001, Nicholls, Faulkner, and Blazdell 1999, Russo 2012b, Turner and Beresford 2005); equally important is the way participants' perspectives are included in the analysis and interpretation of the findings. In their comprehensive investigation of user-controlled research, Turner and Beresford (2005) report that whether researchers actually share a service user identity with participants is, in fact, less important than the role of service users and their experiential knowledge in shaping the whole research process. Other authors in the survivor researcher community have also called for the development of quality control standards which speak to more than the researcher's standpoint:

> "Whether it is research from a user perspective or not, research must stand by the quality of work, not by the quality of meaning of the standpoint alone."(Straughan 2009, 107)

Since most survivor research work is empirical, the descriptions of the analysis process refer to the ways participants are invited and enabled to join that process (Faulkner 2004, Lorenz, Russo, and Scheibe 2007, Russo and Fink 2003, Russo, Scheibe, and Hamilton 2009). Drawing on the principles and values of survivor-controlled empirical research, we can explore how they might apply to the analysis of our published work. I take this approach not because I seek to adopt any rigid set of steps and procedures, but because I wish to maintain the principles, of co-research and co-production of knowledge, even when working with published accounts.

In the remainder of this section, I outline the steps that I will take in that direction. They relate to the inclusion of my own published accounts, the choice of written sources that I will work with (and will not), and my understanding of my own role as a researcher and of the task of the analysis.

A consequence of equalising the research roles and adopting a principle of reciprocity is that everyone involved (including the researchers) can contribute their own experiences. Some survivor-researchers explicitly choose to work in this manner (see Kalathil et. al. 2011, Tang, 2017). Vanessa Jackson (2002, 24) emphasizes one's own story as the starting point for researchers:

> "The most important lesson I learned during my research was to start with the oral history collection to help ground the researcher in the importance and validity of the individual voice. I will add that the first oral history that should be collected should be your own story."

The section on inclusion criteria for written work by authors with psychiatric experience in the next chapter will explain the way that material was chosen in more detail. At this stage, I will only state that my own published accounts of madness, and of how I perceive this experience, will be included along with those of other survivor authors. In regards to the requirement that the task of the analysis is shared, I wish to emphasise that I will only work with those accounts which go beyond the description of events and feelings and contain the author's broader views, opinions and concepts. This means that prior to my work with any written account, the author's own analysis, interpretation and framing of their (and presumably not only their) experience will already have taken place. The fact that I will not analyse anyone else's personal experience and will continue my work from the places where survivors' own thinking about madness has already arrived, considerably reduces the room for interpretation. In psychiatric and mental health qualitative research, the analysis of written material (whether published personal accounts or interview transcripts) is usually an act done *to* that material, and each account is treated as a separate entity. In contrast, I intend to position the analysis in the spaces that open up *between* the experiences and reflections of the authors, and my own. Furthermore, I aim to focus on the ways our experiences and thoughts interact with each other.

I understand my main tasks as being to bring our perspectives into conversation and to explore points of connection. In this dynamic process, my own experiences will inevitably be cast in the light of other survivor authors' perspectives, and it is likely that I will see these experiences differently and perhaps also re-interpret them. In this respect, I believe that placing the focus of the analysis on the dialogue and interplay among our diverse perspectives, rather than on discrete individual accounts, disrupts the static role division between the researcher and the researched. In its place, a space opens up for the co-creation and enlargement of knowledge. Again, I see similarities here with the aims and working style of the Survivor History Group (2011). While my own focus is not the history of the survivor movement, but exploring the possibilities of developing a joint understanding of madness based on our experiences and our knowledges, I feel very close to, and encouraged by my colleagues' approach:

> "We use our own stories (memories) and archives to create a collective history of the movement we identify with. Weaving together the stories different survivors tell of our own lives, we use our archives to check and enrich them. Many people have contributed their stories, providing a strong base for checking narratives against one another. Our aim is a history that relates individual biographies to the movements of history in a way that is both subjectively meaningful and subject to the ever ongoing test of falsification by the data." (p. 17)

Concerning the division of roles in the research process, I perceive this as being more a matter of technical tasks than of substantive content: as a researcher, I will have to find ways to select and structure the material, to bring it into conversation, to document the overall process and to suggest some emerging topics for us (survivor authors, including me) to jointly consider. I am fully aware that none of this work can be done in a value-free way, and it will be greatly informed by my own standpoints. However, the understanding of the analysis task which should apply throughout this work remains quite different from dominant 'scientific' claims of the researcher's ultimate interpretative authority. I see here many parallels with Frank's (2005; 2010) understanding of dialogical research, which I will refer to in the next section in more detail. At this point, I would only single out one of his remarks, with the aim of positioning my own researcher's voice as one of the many voices engaged in what I understand as quite a dynamic study:

> "One story *calls forth* another, both from the storyteller him or herself, and from the listener/recipient of the story. The point of any present story is its potential for revision and redistribution in future stories. This principle of *perpetual generation* means that narrative analysis can never claim any last word about what a story means or represents. Instead, narrative analysis, like the story itself, can only look toward an open future. Narrative research—both as initial storytelling (whether in formal interviewing or in the course of observations) and as eventual report—participates in shaping this future. The analytic voice presents itself as another voice that participants will incorporate and contest." (Frank, 2005, 967, emphasis in original)

At this first stage of the research, the main outcome of the analysis of survivors' published works will be a set of issues and questions about understandings of madness which I will bring into further dialogue in the next, interactional stage of the study. All the emerging topics are then explored in more depth in the individual interviews. The outcome of this process will certainly not mark an endpoint, and I would again draw on the words of the Survivor History Group (2011, 18) about the completion of the process:

> "Our history is always, of necessity, incomplete because it is an ongoing process."

Seeking to 'weave' our perspectives and our truths together, this study similarly heads to no ultimate destination such as an explanatory model that would be able to fit all our diverse experiences once and forever more. In contrast with the narrow diagnostic categories foreseen by the biomedical model of 'mental illness', this research aims to figure out ways to enlarge first-person knowledge about madness. As such, it could instigate a process of our collective creation of such knowledge or in words of survivors Filson and Mead (2016, 111-112):

> "When we become part of each other's narratives, we not only offer possibility for alternate and mutually enriching interpretations, our new shared story becomes a way to negotiate future challenges and crises while building community."

3.3 Learning from socio-narratology

At the outset of a project, researchers are usually expected to declare which school they belong to, especially in relation to their analysis. This apparently simple requirement can turn into a rather difficult task for survivor researchers because of the absence of a coherent theoretical framework with which our research can align entirely. Outside of survivor research, my approach to the task of analysis is greatly inspired and encouraged by the work of Canadian sociologist Arthur Frank. I cannot say that my discovery of Frank's work transformed my approach to the task of analysis because it overlaps in important ways with the values of survivor-controlled research (Nicholls, Faulkner, and Blazdell 1999, Faulkner 2004, Turner and Beresford 2005, Sweeney et al. 2009, Lindow 2010, Beresford and Croft 2012, Russo 2012b) and emancipatory research (Oliver 1992, 1997, Beresford and Wallcraft 1997), which had already shaped my work decisively. But Frank's presentation of dialogical analysis (2010) spoke to my own understanding of what research should be about.

At the very outset of this project, the titles of his articles such as "*The Standpoint of Storyteller"* (Frank 2000) and *"What is Dialogical Research, and Why Should we Do It?"* (Frank 2005) attracted my attention; they felt inviting and supportive of my own work. Having now confirmed that I can fully subscribe to the approach which Frank defines as socio-narratology in his book *"Letting Stories Breathe"* (2010), I consider it important to briefly discuss the main principles of this approach. And, in turn, I want to sketch out the links between these principles, survivor research and this thesis.

Although Frank does not choose madness or mental health issues as his area of interest, he assigns great value to narratives of illness and the power of first-person stories in general. Largely concentrating on physical illness, his work excludes 'medical voices' - an attitude that clearly resonates with the focus of this thesis:

> “Medical voices relegate ill people to patienthood and render their stories into fragments of a larger medical story; that is their work but not my topic.”(Frank 2000, 360)

Frank recognises the immense potential of human stories, including their ability to heal and connect people, to open up new possibilities and to shift paradigms. Several of his broad formulations about the potential of stories apply equally, in my opinion, to psychiatric survivor accounts; they reiterate the power and strength that our stories offer:

> “In our stories, we humans can bring back to life parts of ourselves that have been broken. That is a significant act of healing.” (Frank 2009, 194)
>
> “Stories connect so effectively because their interpretative openness allows individuals to fashion their own variations, which more of less shift the shape of the paradigm.” (Frank, 2010, 62)

So what is the best way to approach our stories and learn from them? Frank emphasises the key role of relationships in storytelling. Furthermore, he underscores the analyst’s responsibility to enter the storytelling relationship. In line with the way I have sketched out my intended work with survivor accounts, Frank stresses that the analysis is not something done to the story as some kind of discrete entity. Rather his focus is squarely on the relationship between the storyteller and the participating listener:

> “I believe that any good story analyst has both an ethical and an intellectual responsibility to enter relations of storytelling; I have trouble conceiving listening outside of a relationship. When story analysis accepts its place in relations of storytelling, then it can model listening so as to expand the community called into being by the story.” (Frank 2000, 355)

The implications he draws from this approach align closely with survivor research’s insistence on the ethics of the research process:

> “From my standpoint, one cannot analyze this relationship without *entering* it, which means putting ethics before methodology.” (Frank 2000, 359)

Another strong point of connection is the critical nature of the researcher’s standpoint:

> “[…] standpoints are not optional; the only difference is whether or not they are acknowledged. No one can opt out of having a standpoint.” (Frank 2000, 356)

Frank’s understanding of the researcher’s standpoint corresponds with the concept of identity in survivor research:

> “I understand a standpoint as a political and ethical act of self-reflection: To take a standpoint means to privilege certain aspects of what your biography shares with others. These biographical selections constitute whom you want to be, including what work

> your biography best suits you to do. Taking a standpoint requires self-consciousness about how the fate and choices in your life have positioned you in the world and with whom you have been positioned.” (Frank 2000, 356)

Survivor researcher Angela Sweeney (2016a, 51) emphasises the researcher’s deliberate choice of survivor identity and its political meaning:

> “Adopting the explicit label of survivor researcher is often a political statement meaning that we want to challenge dominant ideas about mental distress and about us. […] Thus, survivor research can be an unashamedly political activity.”

Of particular value is Frank’s (2000, 356) reminder of the evolving nature of standpoints as well as of our ‘responsibility’ to stay open to change:

> “[…] standpoints are never static: One aspect of my responsibility for my standpoint is that it continues to change as experiences and communities change.”

These vivid reflections on the power of human stories and the centrality of the relationship and standpoint in storytelling do have concrete implications for work with written sources. As already mentioned, Frank introduces principles of dialogical narrative analysis. This approach emerges in opposition to ‘monological research’, a mode of work, which largely describes mainstream psychiatric and mental health research, including some recent work with patient narratives (see previous chapter):

> “Monological research imagines the words of research participants as raw material for its analyses. […] In monological research, the space belongs to the researcher, and research subjects - whatever they are called: respondents or participants - occupy that space on condition that they act according to rules of method that are the province of the researcher as a member of a scholarly community. Within this research space, participants are allowed to say *what the researcher requires* to make her or his point; a quotation serves to illustrate a theme that the researcher has located in the data.” (Frank 2005, 970, emphasis in original)

The historical absence of dialogue from psychiatric and mental health research has immense consequences for the general approach to madness, and in particular, to its treatment. Modern psychiatric treatment continues to rest on a ‘scientific’ monologue:

> “Mental health service users have traditionally been excluded from the knowledge that is used to treat us, and many of us have suffered from the misunderstanding of our needs by people who have been taught to see us as by definition incapable of rational thought.” (Wallcraft 2009, 133)
>
> “The dominant epistemology has worked to prohibit mental health service users from being producers or knowers of their own knowledges. Psychiatric knowledge has been based on the ‘knowledge claims’ of others about the experience of mad people and mental health service users. They have played the key role in interpreting service users’

> experience, while the latter's own interpretations have, as has been argued, been excluded or devalued." (Beresford and Boxall 2012, 71)

In my opinion, any attempt to shift social responses to madness and create viable alternatives to its medical treatment must rely on a dialogical methodology. In this regard, it should be stressed that the growing fashion for mere 'involvement' of service users in mental health research is not sufficient; it does not give any guarantee of a qualitative improvement in research methods, or of the overall process becoming dialogical (Beresford 2002b, Stickley 2006, Russo 2012b, Sweeney 2011). So, what does a dialogical approach concretely mean? Aside from giving up ambitions of interpretative dominance, and requiring 'second-person address'[23] (Frank, 2010, p.100), this approach invokes one principle which is particularly relevant to any work with survivor accounts. Substantially building on Bahktin's work on Dostoevsky (1984), Frank singles out the principle of the 'unfinalizability' of another person as one of the fundamental working principles in dialogical analysis:

> "*Dialogue* begins with recognition of the other's unfinalizability. Within a dialogical relation, one person can never say of another, 'This is who such a person *is*.' One can say, at most, 'This how I see this person now, but I cannot know what she or he will *become*.' Dialogue depends on perpetual openness to the other's capacity to *become someone other* than whoever she or he already is. Moreover, in a dialogical relation, any person takes responsibility for the other's becoming, as well as recognizing that the other's voice has entered one's own." (Frank 2005, 967, emphasis in original)

This claim comes very close to many survivors' standpoints on the psychiatric diagnostic approach to their experiences and its implications (Burstow and Weitz 1988, Pembroke 1994, Shimrat 1997, Bassman 2001, Bassman 2007). Frank (2005) hones the argument even further, stating that "[i]n existential terms, the claim of unfinalizability is a claim of freedom" (p.967). Long before I found out about this notion of 'unfinalizability', I encountered a quite different wording by survivor Terry Simpson (2002), which, I think connects profoundly with this claim. It is from a poem which Simpson wrote for his son:

> "I wish for you a world of simplicity and
>   compassion.
> Tenderness, that's always new,
> and that there is no limit to what you
>   are." (p.94)

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[23] 'Second-person address' is a principle of Frank's 'dialogical analysis'. This principle refers to "not speaking *about* but *with"* (Frank, 2010, p.100).

The right to have no limits to who we are is directly at odds with some of the contemporary analytical surgery being done to the narratives of 'psychiatric patients' (see for example Adame and Hornstein, 2006). The purpose of such approaches is questioned by survivor Louise Pembroke, and also by Frank's socio-narratology:

> "I have come to the conclusion that *people* are not studied by psychiatry and psychology, merely categorised and described. That their rigid frameworks serve only to fragment people, turning a break-up into a breakdown. In categorising the distress, the distress itself is not acknowledged. The individuals' right to *own* the experience has been stolen." (Pembroke 1994, 43, emphasis in original)
>
> "Narratology in its early structuralist versions cuts stories up into small pieces in order to formulate principles of how those pieces are assembled. Stories become patients on narratological dissecting table. Socio-narratology then let the stories breathe by studying how they can do what they can do." (Frank 2010, 16-17)

The way Frank describes socio-narratology corresponds powerfully with my understanding of the scope of the analysis of survivor accounts in this study. Socio-narratology studies "how stories give people the resources to figure out who they are, and how stories both connect and disconnect people" (Frank 2010, 71).

At the start of this research project, when I was trying to define the purpose of the analysis of published survivor works, I distinguished clearly between two possible options: *interpreting* survivor knowledge on the one hand, and *connecting and advancing* our knowledges on the other. My choice of the latter was confirmed and supported by my discovery of Frank's work. I want to close this section by expanding on my preference to *engage with* survivor accounts rather than *interpret* them, by way of some more ideas from Frank's dialogical approach. Frank (2010) criticises interpretation when it is deployed as a 'decoding scheme'; he argues that "these concepts make people's inability to know their own truth a principle of the human condition" (p.93). In contrast, he sets out the role of interpretation in dialogical research as follows:

> "The themes situate the stories; they do not substitute for the stories." (Frank 2005, 969)
>
> "A good interpretation is a response that seems to fit the story, complementing it." (Frank 2010, 87)
>
> "Interpretation seeks not to stand over the story, speaking about it. Interpretation seeks to be an ongoing dialogue with the story." (Frank 2010, 104)

This mode of interpretation, which survivor research sees as reducing the distance between an experience and its interpretation (Beresford 2003a), also defines the outcomes of the research process. The process-oriented design of this study aims to encourage the continuation of the process rather than mark its ending. This corresponds with what Frank (2005, 966-967) perceives as Bakhtin's dialogical ideal:

> "In Bakhtin's dialogical ideal the research report must always understand itself not as a final statement of who the research participants are, but as one move in a continuing dialogue through which those participants will continue to form themselves, as they continue to become who they may yet be."

However, Frank (2005, 968) is also aware that this kind of open-endedness may be perceived as a weakness by a scholarly audience:

> "The significant question is whether research that presents itself as part of an ongoing process is evaluated as *inconclusive*, in a pejorative sense, or as *open ended*, which in dialogical theory is both empirically correct and ethically appropriate."

As I performed the analysis twice within this inquiry (at the end of each of the two research phases), I found it important to detail my understanding of that task which builds on all three traditions described in this chapter. I will be returning to some of these principles when describing the concrete steps of the analyses in the next two chapters.

3.4 Intersectional analysis and the study of confluence

As previously stated, I will share part of my response to the commentaries (Russo 2016b) I received from two survivor authors (Kelly 2016, Carr 2016) on my paper which was based on this and the previous chapter (Russo 2016c). By the time of publication, I had already completed the analysis of the written sources, which meant that this exchange with my colleagues impacted more on the second research phase (the interviews).

Central to both commentaries was a discussion of the opposition between intersectional analysis and a unifying survivor narrative. Though they pursued this question to different ends, both authors reminded us all of the dangers of imposing a unifying narrative and urged that we recognize "heterogeneities of experience" (Kelly 2016):

> "Can we be confident that in creating a 'community', we do not exclude, essentialise and homogenise, as Hill Collins warns (2000)?" (Carr 2016, 235)
>
> "How do we develop situated knowledge as an analytic in our methods, construct knowledge that is transferable from one person – or context – to another without erasing difference that may be central to the experiences of marginalization, liberation and healing of so many?" (Kelly 2016, 231)

I share these concerns but maintain that the best way to address them is via actual working processes rather than through an extended search for scholars who will equip us with the right answers. While I doubt that these answers are achievable, I believe that our ever evolving practice is always open to improvement. This is especially so if we approach research as social production (Oliver 1992, 2009) and take responsibility for our roles in that process:

> “[r]esearch is not an attempt to change the world through the process of investigation but an attempt to change the world by producing ourselves and others in differing ways from those we have produced before.” (Oliver 2009, 116)

In that sense, the questions raised by Carr and Kelly can be used as guiding principles in research (and practice) rather than being seen as reasons to delay or abandon it. While these authors do not argue for the latter course, both their commentaries highlight how the issue of difference stands in the way of establishing first-person knowledge about madness. I agree with Kelly that research conducted by ‘insiders’ has the potential to produce “homogenous narratives that claim to capture a unified survivor experience” (p.231). We can see this approach at work in the investigation of the survivor movement by Morrison (2005). However, if we take seriously the fact that survivor-controlled research is not justified solely by the identity of the researcher but far more through its overall approach and understanding of research roles, then we cannot avoid the question of how each of us deals with the complexities involved. What does it actually mean to acknowledge differences and not overwrite them? Do the “heterogeneities of experience” imply that there can be no such thing as collective experience and that collective accounts (Oliver 2009, 110) can never become part of social science? Should we relinquish such a project since it can by definition only take place at the cost of differences and will by its very nature always involve unification, erasure and dominance?

Joseph (2015) summarizes the problems with work that over-attends to intersectional analysis and argues powerfully for the study of confluence where “an appreciation of complexity directs the methodology, examining for continuities rather than differences” (p.30). What I appreciate most is this author’s emphasis on our own roles and contributions:

> “Confluence does away with any foreseeable idea of sovereignty and is more concerned with how we are all imbricated, implicated, and complicit within the hegemonies, hierarchies, and struggles of our human condition. There exists no stabilized and transfixed analytical position where one can view forms of difference or identity intersecting (race, gender, sexual orientation, class, ability) or systems of domination operating in a matrix or interlocking (racism, patriarchy, heteronormativity, etc.) as if one were not complicit within its formation and then its (re)production.” (p.24)

I do not see what more we can do as researchers besides continuing to address, question and improve our own work. Survivor-controlled research is not an established school or discipline and we who bring in our diverse experiences and knowledge of madness are *all* responsible for its further development. Once we start to take part in organised knowledge production within academia, we cannot really position ourselves outside that role to observe where this research direction is heading. Acutely aware as I am of the limitations of identity politics and the fact that our identities will always remain too narrow to capture the complex social world we inhabit, I want to echo Webb's (2015, 166) point that "real change will only be possible if it's led by those directly affected for the urgent need for change". In the case of first-person knowledge of madness, I see the owners of those experiences as the ones to take the lead. The fact that many of us have been denied a space for our own interpretations during our encounters with different systems of support and control is not itself a guarantee that we will not end up imposing our personal truths on each other. But we can choose to keep paying careful attention to our methods and our ethics and so try to make a unique contribution to the paradigm shift in approaching madness.

3.5 In summary

This chapter documents where my thinking about the task of analysis has got to prior to embarking on my work with published survivor accounts. It also maps out some of the key thinkers and researchers whose texts and practices have influenced and encouraged me. I have not set out here to promote any new techniques, but rather to think through the epistemology of this study and debate some key values. Even though I have tried to maintain clarity, in the course of writing up these reflections, I have watched as more questions emerge and old ones re-open in a new way. I have reached a temporary stopping place in this process – and though I was clear about how I would like to work, I was far from certain about exactly how I would do this. At the same time, I found myself increasingly welcoming of the new complexities and uncertainties that have opened up. My aim was not to resolve them, but to work with them. This intention found confirmation in the following words of Stone and Priestley (1996, 11):

> "[a]s researchers who have decided to explore disablement, we believe that it is vital to face up to these challenges and that, where we anticipate contradictions and difficulties, we might use them as a point of entry into a more critical analysis of the emancipatory paradigm. This is an ongoing and reflexive process […]."

CHAPTER 4 CREATING OUR OWN STORY: SURVIVOR WRITTEN WORK

This chapter reports the findings from the first research phase in which I analysed a selection of publications by authors with experience of psychiatric treatment. Prior to presenting the findings, I explain the criteria for the selection of these publications, provide information about the type of sources included and describe the steps of the inquiry. This chapter is a shortened version of the interim report which concluded the first phase of the research and served as an introduction to the second part: the interviews with some of the authors whose publications I worked with.[24]

The main purpose of my work with written sources was to provide a preliminary base from which to continue exploring first-person knowledge of madness and generate questions for joint research with the participants in the second phase. At the end of each section of the findings, I provide my thoughts and suggest topics to consider in more depth. These sub-sections are entitled ‘Reflections and emerging issues’.

4.1 Inclusion criteria for publications

In order to identify relevant literature, I searched a variety of sources. As will become clear in the section on the types of resources included, only a small proportion of writings could be found in peer reviewed journals (25% of the publications included). Furthermore, the most important inclusion criteria – the author’s self-identification – could not be searched for via key words. My familiarity with a great deal of survivor authored works through years of reading that literature proved very helpful in locating relevant works. Additionally, through my long-term engagement with the international user/survivor movement, I was able to receive advice about where to find further sources.[25]

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[24] My interview partners also included people whose work was not explored in this phase, as will be explained in the next chapter.

[25] In April 2011, I presented my PhD idea to the email list of the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP), to the Survivor Researcher Network from the UK and to survivors whom I met in the USA at the retreat and conference “Rethinking Psychiatric Crisis: Alternative Responses to First Breaks” held in New York in November, 2009. The responses I received were greatly encouraging and directed me to additional sources.

There are two main, and several subsidiary, criteria that guided the selection process for literature. The main considerations were:

1. the author identifies as having experienced psychiatric treatment (as a service user/survivor of psychiatry or mad-identified)
2. the author seeks alternatives to biomedical explanations of madness

Neither of these criteria are self-evident (the second especially), and I am aware that they inevitably rest on my value judgement as a researcher. The subsidiary criteria arose as a result of the time, capacity and financial constraints of this study.

In the following sections, I explain each of these criteria in more detail.

4.1.1 Personal experience of psychiatric treatment

How people who have experienced madness actually self-identify is a topic to be discussed throughout this project. For publication selection, this means that I have only included written works by those authors whom I either know as survivor authors and/or who make explicit connections to their own experiences of psychiatry in their work. My strict adoption of this criterion felt odd at times and confronted me with the fact that whether or not somebody has experienced madness and its treatment is no measure of how relevant that person’s work is. However, the awareness that people labelled mad have been (and continue to be) excluded as an entire group from organised knowledge production about their own lives and beyond, made me keep this criterion as an ‘entry requirement’ for writings in this particular inquiry. The author’s identification as a service user/survivor, person with a psychosocial disability or some similar term is particularly important in the case of conceptual and research work and less so for personal narratives. The identity of service user/survivor primarily refers to experiences of psychiatry and receiving mental health services; the experience of madness is, however, broader than this and in no way reserved only for people who have come into contact with psychiatry (Hall 2013). In this sense, the distinctive characteristic of a personal narrative of madness is that it is written in the first person and based on one’s own experience. So, the first criterion – that the author identifies as a service user/survivor – is not decisive when it comes to personal narratives. Even so, since publication of one’s own story often happens in connection with activism within user/survivor groups and organisations, the majority of personal narratives included in this study are authored by people who are, in one way or another, part of the user/survivor movement.

In contrast with the case of personal narratives, the author's explicit self-identification as a service user/survivor is crucial when it comes to the research and conceptual work included in this study. Authors who decide to be open about their experiences as (former) psychiatric patients, in addition to their academic and educational backgrounds, usually consciously take this approach as a political statement, which suggests "that we want to challenge dominant ideas that are about mental distress and about us" (Sweeney 2016a, 51). The written sources explored consists solely of contributions by authors whose theoretical and practical work is openly informed by their experiential knowledge of madness and its treatment to address the main aim of the study.

4.1.2 Seeking alternatives to the biomedical model

Across the globe, people who have experienced madness understand and conceptualise their experiences in a variety of ways. For a multitude of reasons, many adopt biomedical explanations, to various extents. Their reasons may be of a deeply existential and pressing nature and should be understood and respected in that context. The question of why some people choose the medical framework to explain their experiences is certainly a legitimate one to explore, however such an exploration goes beyond the scope and the capacity of this project. Furthermore, the research process in this study does not seek to initiate or achieve any global agreement among all of us or to provide a comprehensive picture of the range of our views. Peter Campbell (2001), a long-term activist in the UK movement, argues for the legitimacy and the importance of views that might not be at all 'representative':

> "We need to be realistic that some service users will be issuing different messages and fighting different battles to ours. We should confront the suffocating blanket of representativeness and legitimacy and assert that our cause is worth considering even if 51% or more of our peers do not agree with us." (n. p.)

This inquiry's focus on first-person perspectives on madness is meant not just in opposition to third-person perspectives generally but also as a counterpoint to the *dominant* third-person perspective, which is the biomedical model. So, exploring first-person epistemology here implies working towards a *different* understanding of madness to the dominant one, or working towards a paradigm shift. The literature included in this study is therefore limited to *non-medical* explanations of madness authored by people who have gone through those experiences themselves.

This inevitably raises questions such as ‘What are the decisive features of approaches that are not medical?’ and ‘How are they to be distinguished from other approaches?’ Since this study will specifically explore first-person approaches to madness that open up a different understanding from the biomedical one, I will not define these features from the outset. The inclusion criterion ‘seeking alternatives to biomedical model’ relates to the overall message of these works. This may mean that their authors explicitly state that experiencing madness is not a matter of any brain or nervous system dysfunction or they imply in other ways that such an approach to these experiences is wrong. And alternatively, it may simply mean that these authors are searching for non-medical explanations and meanings of madness without making any ultimate statement about the nature of that experience.

I embarked on the process of selecting contributions for inclusion *after* reading through as many works as possible. My selection was made based on my sense of the text as a whole and not according to any simple ‘identifier’ such as a title or use of language. Relying on a single inclusion/exclusion criterion like whether the author uses psychiatric diagnoses in their writing runs the risk of misrepresenting the meaning of the whole. Survivor researcher Jan Wallcraft highlights this issue in her study of first breakdowns. The fact that most of her interview partners did use the language of psychiatry and psychology to describe the onset of their crisis is in her opinion “not a reliable indication that an interviewee has accepted a professional account of their crises” (Wallcraft 2001, 136). Rather, it signals ambivalence and people’s struggle to find the right words to express what they were going through.

4.1.3 Additional inclusion/exclusion criteria

Restrictions relating to time, personal capacity and finances inevitably determined further criteria for the literature selection process. I only worked with publicly available works, which meant printed and electronic material that could be found in the public domain (books, journals, web, etc.). As this study was not meant to be of a historical nature, I focused on texts from the 1980s onwards, the period corresponding with the emergence of the contemporary user/survivor movement (Sweeney 2009, 29). In particular, I tried to include as many of the most recent publications as possible so as to capture current ideas and debates arising from growing research and theoretical contributions authored by mad-identified scholars and activists. Finally, this study was restricted to material available in the English language due to financial constraint. A small number of works are already translated into English; the large majority of texts are from English-speaking countries. This restriction and the unequal access of users/survivors to publishing opportunities (due to differences in education, class, ethnicity, age, etc.), mean that this review is certainly of a partial nature.

I believe it is important to document and reflect on the entire research process so that research can eventually continue beyond this study. Rather than aiming to pronounce any last word, this investigation seeks to inspire wider and more systematic explorations of survivor knowledge. These will hopefully expand the geographical spread of the sources, include those in non-written formats (i.e. visual and other expressions) and generate new research questions.

4.2 Selected publications and initial research questions

The grouping of user/survivor published works below has been undertaken only for working purposes within this study. In order to facilitate the analysis, I organised the texts into six main groups. The following groups include a range of works from short texts to whole books:

1. **Personal narratives** refer to works in which the personal experiences of the author and their reflections on those experiences form the main part of the text.
2. **Essays** refers to analytical works on various topics. To different extents, these texts may include accounts of personal experiences or refer to them. Essays can be further grouped according to their particular topics such as human rights, forced treatment, medication, research, user involvement, etc.
3. The group **research reports** is self-explanatory. The majority of the selected reports are authored solely by user/survivor researchers. Sometimes the research report and essay groups overlap – for example, where a published book emerges from the author's PhD research. The content of these books is usually more comprehensive than the content of the works grouped under research reports.[26] A smaller number of the reports included emerge from collaborative research projects where user/survivor researchers made a substantial and distinctive contribution.
4. **Conceptual work** refers to concepts of support developed by users/survivors as well as their own theories of madness.
5. **Documents from the user/survivor movement** include conference reports, press releases, position papers and other publications of service user/survivor organisations.

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[26] See for example Webb, D. 2010. *Thinking About Suicide: Contemplating and comprehending the urge to die,* Ross-on-Wye, PCCS Books or Fabris, E. 2011. *Tranquil Prisons: Chemical Incarceration under Community Treatment Orders* Toronto, University of Toronto Press.

6. **Other sources** include poems and writings that cannot be brought into any of the above groups.

The variety of these sources and the fact that they were not tailored to answer this study’s questions certainly posed challenges for the analysis. Even so, I see advantages in trying to adjust the research and analysis process to the sources’ different topics and structures rather than the other way round. This kind of exploratory work has required me to consider each account as a whole and in its own context.

The table 2 provides some insight into the number of sources examined as well as their dates and countries of publication:

Table 2: Research phase one: types of publications included

Type of publication	**Number**		**Publication dates**[27]	**Publication countries**
Books	45	• Edited books: 32 (13 anthologies with essays and 19 collections of first-person narratives) • Authored books: 13	1978-1990: 3 1991-2000: 10 2001-2010: 22 2011-2016: 10	Canada: 6 Germany: 2 India: 2 Ireland: 1 New Zealand: 1 UK: 24 USA: 9
Handbooks and guides	9		1978-1990: 0 1991-2000: 2 2001-2010: 6 2011-2016: 1	Germany: 1 UK: 4 USA: 4
Book chapters[28]	14		1978-1990: 0 1991-2000: 4 2001-2010: 5 2011-2016: 5	Canada: 1 India: 2 UK: 11
Reports	46	• Reports of the events of the user/survivor movement: 8	1978-1990: 0 1991-2000: 3 2001-2010: 2 2011-2016: 3	Belgium[29]: 1 Denmark: 3 South Africa: 2 UK: 1 N/A: 1
		• Research reports: 38	1978-1990: 0 1991-2000: 4	Canada: 3 New Zealand: 1

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[27] These are the first publication dates.

[28] Distinct from the 'Books' category, this category refers to those books that were not examined as a whole.

[29] These are the countries where the events took place; N/A applies to one ENUSP strategy document.

			2001-2010: 22 2011-2016: 12	UK: 29 USA: 5
Articles	69	- In peer-reviewed journals: 48	1978-1990: 0 1991-2000: 5 2001-2010: 24 2011-2016: 19	Canada: 6[30] Germany: 5 India: 2 New Zealand: 1 UK: 22 USA: 12
		- In other journals and the internet: 21	1978-1990: 0 1991-2000: 2 2001-2010: 8 2011-2016: 11	Canada: 2 Germany: 1 New Zealand: 1 UK: 10 USA: 7
Conference papers	11		1978-1990: 0 1991-2000: 2 2001-2010: 8 2011-2016: 1	Australia: 2 New Zealand: 1 Norway: 1 Spain: 1 UK: 4 USA: 2
Other	2	One website with a collection of personal stories and one PhD	1978-1990: 0 1991-2000: 0 2001-2010: 2 2011-2016: 0	UK: 1 USA: 1
TOTAL	**196**		1978-1990: 3 1991-2000: 32 2001-2010: 99 2011-2016: 62	Australia: 2 Belgium: 1 Canada: 18 Denmark: 3 Germany: 9 India: 6

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[30] According to the first author's country of residence.

				Ireland: 1 New Zealand: 5 Norway: 1 South Africa: 2 Spain: 1 UK: 106 USA: 40 N/A: 1

Regardless of the type of source, I asked the same questions and recorded the answers to the extent they could be found in the selected material. To some degree, this systematic approach felt like conducting an interview equipped with the questions below:

1. How do we, people labelled mad, describe our experiences of madness?
2. What terminology/language do we use?
3. How do we explain these experiences?
4. What meanings do we attach to madness?
5. How does the experience of madness relate to broader life circumstances?
6. How do we approach/deal with madness?
7. Are any concepts of madness emerging? Have any names been suggested for them?

By collecting text excerpts that might be read as answers to these questions, I compiled the first set of documents for subsequent analysis. As might be expected, not all of the examined sources provided answers to the above questions. Also – and as previously explained – I did not collect quotes from accounts that only describe their authors' personal experiences and make no broader claims or statements. This means that I included excerpts from fewer sources in the documents that I prepared for the analysis than the number I initially examined. Ultimately, I incorporated 150 works by a total of 108 authors along with 7 reports produced by a total of four organisations. Not all of these texts, however, are quoted in this report. Table 3 provides information about the types of sources in which I identified answers to my research questions:

Table 3: Research phase one: types of publications analysed in more depth

Type of publication	**number**
Book chapters	93
Articles from journals or online sources	18
Books	13
Reports	13
Peer-reviewed articles	9
Guides	5
Conference papers	5
PhD thesis	1
Total	**157**

The authors were 70 women and 38 men. I have no information about whether any of them were trans people. The vast majority of the authors were white. To my knowledge, there were 23 people of colour (17 women and 6 men) among the 108 authors, but again, the information about people's self-identification was not always available. Table 4 shows the authors' countries of residence.

Table 4: Research phase one: Authors' countries of residence

Country	**Number of authors**
UK	60
USA	24
Canada	11
Germany	5
India	2
Australia	2
New Zealand	1
Denmark	1
Sweden	1
Italy	1
Total	**108**

Of the four organisations that authored a combined seven reports, two were based in Canada and two were international. The dominance of white authors from the Global North is evident from the above tables. Among other things, this is a result of the considerable constraints on this study and is an issue that will be considered at future stages of the research as well as in the discussion of the findings.

4.3 The analysis process

Identifying the answers to the research questions and compiling them in documents for further analysis was an extensive and exciting process. It led to my re-discovery of many great texts and, within them, of profound thinking that resonated with my own experiences. At the same time, in trying to bring some structure to this considerable material and make it easier to navigate, I experienced repeated difficulties including my own resistance to what in a way felt like a process of regulating and 'classifying'. These sources are rich and their content is intense; all at once they address different issues and could certainly be 'matched' with more than one of my questions. The following words of the survivor editors of the anthology *Speaking Our Minds* speak well to my own experience and make me realise that there will always be unwanted 'side effects' to this kind of process:

> "If the feelings, behaviour and thoughts of people who receive psychiatric treatment defy psychiatrists' best efforts to categorise them into definable illnesses, we had a similar problem with their writing. In attempting to put structure to this book we found that our desire for neatly described episodes of distress, courses of treatment and periods of recovery were constantly thwarted by the writers' insistence on bringing their whole lives into their accounts." (Read and Reynolds 1996, xv)

Similarly, I could not neatly separate the excerpts or decide with certainty whether they were, for example, better understood as 'descriptions' or as 'explanations' of madness. But being conscious that there could be no hope of proceeding and identifying emerging themes if I had to keep returning to about 200 sources, I was determined to continue with this task.

Here, then, are the shortened headings under which I have grouped the quotes now prepared for further analysis. Their order aligns with that of the questions above:

1. Description
2. Language
3. Explanation
4. Meaning
5. Circumstances
6. Approach
7. Concepts
8. Other[31]

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[31] This document contains text excerpts that are relevant to the overall topic of this research but do not directly address any of my initial questions.

In the next step, I analysed the above documents, consisting of excerpts from different written sources. I identified common topics and issues using qualitative analysis software (NVivo, Version 10). During this process, I re-grouped the collected quotes into 31 thematic categories and ten sub-categories (see the coding frame in Appendix A). The report of the findings is based on 41 of these new documents.

Each section of the findings concludes with my personal thoughts concerning the main issues, as well as questions that have arisen from the findings. I wanted to explore these issues together with the participants during the next stages of research. While bringing the authors into conversation with each other, I have also tried to maintain my own dialogue with the findings, encouraged by the already mentioned Frank's (2010, 104) understanding of interpretation that “seeks not to stand over the story, speaking about it” but “seeks to be an ongoing dialogue with the story”.

This inquiry could certainly be approached in many different ways, and the report that follows does not attempt to suggest how these accounts should be read or analysed. I am fully aware that I have inserted myself into this analysis and, as such, do not aspire for my work to be value free. However, I have purposefully abstained from drawing any conclusions. The central task of this report has been to ‘weave’ the authors’ perspectives and truths together, and to organise them around key answers to my initial research questions.

The findings from my inquiry into published works by survivor authors are organised around seven main themes.

Chart 2 summarises my journey through the material and the process of arriving at these findings.

Chart 2: Research phase one: Steps of the analysis of written sources

Systematic examination of 196 sources (see Table 2) guided by the following research questions:

1. How do we, people labelled mad, describe our experiences of madness?
2. What terminology/language do we use?
3. How do we explain these experiences?
4. What meanings do we attach to madness?
5. How does the experience of madness relate to broader life circumstances?
6. How do we approach/deal with madness?
7. Are any concepts of madness emerging? Have any names been suggested for them?

⇩

Identifying answers from 157 sources (see Table 3) and arranging the original excerpts into the following documents for further analysis:

1. Description
2. Language
3. Explanation
4. Meaning
5. Circumstances
6. Approach
7. Concepts
8. Other

⇩

Thematic qualitative analysis using NVivo (version 10). See the list of 31 nodes, 10 child nodes and the number of references in Appendix A.

⇩

Structuring the findings into the following report sections:

1. Searching a language for madness
2. What is madness?
3. The social nature of madness
4. Making room for madness
5. Generating meaning and learning from madness
6. The transformative potential of madness
7. Concepts of madness

4.4 Findings

In conventional qualitative research reports, the quotes of individual participants are often framed by the researcher’s detailed explanations and analysis. I have purposefully tried not to repeat this practice so as to let the authors speak for themselves. My main role has been to introduce some thematic order and connect the authors’ statements in order to guide the reader through the material. The quotes are not used as illustrations or in support of my own ideas. Rather, I have attempted to organise the flow of quotes and create a bridge between them with my own voice. This may be contrary to the requirements of academic work, as described by Carr (2009, 183):

> “As ‘patients’, we inhabit the system which prevents us from sharing our experiences on our own terms, and as academics we are forced into competitive situations not conducive to sharing experience and knowledge.”

By retaining a large number of quotes within this report, I hope to demonstrate how our perspectives connect and the ways that the same or similar thinking can be traced across different writings and different contexts. Furthermore, I have organised the quotes with the aim of emphasising these shared ideas across a variety of sources. This report is written in the tradition of several other survivor research reports in which extensive quotes from participants form the central part (Faulkner 1997, Faulkner and Layzell 2000, Fleischmann and Wigmore 2000, Jackson 2002b, Beresford, Nettle, and Perring 2010, Kalathil et al. 2011, Beresford et al. 2016). These quotes are usually presented in succession with the researcher’s explanations coming before or after these blocks of the participants’ own words. My use of ‘we’ when reporting findings recognises that my own writings are included in the inquiry. Additionally, it positions my own voice as a researcher among the other voices referenced in this report.

This presentation of the findings does not attempt to summarise or replace these rich sources, which I highly recommend reading. The main scope of this report is to instigate and inspire a joint research process into these topics during the next research phase.

4.4.1 Searching a language for madness

Many authors describe both the central role of language in making sense of experiences and their own struggles to find the right words. The dominance of the biomedical model, and the fact that both the expert and the lay discourses around madness have traditionally been created by people without any personal experience of it, limits and pre-defines the space for our authentic self-expression. The following excerpts call attention to the lack of and need for our own language about madness:

> "Madness has been described again and again by people who have never experienced it. Mad people's definition of it has seldom made it into the dictionary or into conversation, media stories, literature or mental health discourse. Our definition of madness can even elude us. We lack a validating language to make a meaning from it. Our madness stands outside in the dark, knocking on the door to meaning, struggling to get in. My own stories of my madness struggled to take shape while other people's stories of it took instant inspiration from the dictionary, diagnostic manuals and a wider culture that completely shuns it." (O'Hagan 2014, 46)
>
> "The psychiatric narrative is the dominant ideology in our society; its words are not easy to challenge, especially by those it is authorized to label and define. To question this authority by providing another standpoint is a charged and political act: to demand recognition of subordinate voices, the views of the people in the movement, of those who are silenced as objects of treatment, as people who are mad." (Morrison 2005, xii)
>
> "The much talked about 'stigma' surrounding the mentally ill is, at some fundamental level, a problem about not having an ordinary, existential *language* for talking about mental distress experiences." (Davar 2000, 62, emphasis in original)
>
> "[H]ad someone asked me at that time, 'What happened to you?', I most likely could not have said. Not for want of this knowledge, but for want of a language that could articulate what I needed to say." (Filson 2016, 22)

One of the main difficulties in finding a "reasonable language to talk about madness" (McNamara and DuBrul 2004, 81) is our continued relationship to the mental health system that has defined us. Our attempts to redefine our experiences and ourselves still have the biomedical model and the psychiatric system as the central points of reference:

> "There isn't even a word for patients that doesn't put us in relationship to the system that dominates us." (O'Hagan 2014, 160)

> “In terms of the discourse of mental illness, we grow up internalising our powerlessness to define our own bodies and minds without the concepts of madness and sanity. [...] Even if we are critical, it is almost impossible to conceive that madness might be largely a creation of language and theory, developed to suit particular historical needs. It might no longer be a useful concept in its current form, but it is almost beyond our power to ‘unthink’ it, hedged around as it is with many writings, and a panoply of institutions.” (Wallcraft 2009, 136)

Even when we do manage to detach our identities from the mental health system, the fundamental problem remains: how do we create a discourse of madness that does not ‘other’ this experience or draw another line between madness and sanity? Some authors point to the on-going risk of falling into that trap:

> “How do mad-conceived people defend themselves against sanism, the dividing of thought into mad and sound? Is there an autonomous position that is not reducible to either of these two categories? If we deny any mental exceptionality, what language would we use to speak of our experiences? How can we argue for the importance of emotional and mental differences, and for the need to respect distress and lived experience, without naming them and therefore appealing to reason that marks them out of the void?” (Fabris 2011, 31)
>
> “Paradoxically in naming the discrimination and calling attention to the needs there is a risk of a discriminatory, violent, and objectifying response, an essentializing of our identity that diminishes our full humanity. This is the challenge faced by every equality seeking movement and it is not the end of the story but, rather, is an ongoing call for humanity to grapple with injustice.” (Minkowitz 2014, 131)

These questions will be addressed throughout this report. I have already raised them here because language is so integral to our understandings and concepts of madness.

Despite the authors’ struggles to find the right words, the accounts demonstrate the power wielded by the language of direct experience against the dominant discourses, and the emancipatory potential embedded in the very act of using our own words to communicate extreme emotional and mental states:

> “There’s magic in words, and instead of allowing people who haven’t had these experiences to form the language around it, discussing it with other people who’ve dealt with these emotions has allowed us to claim ownership of the ways of living our lives and moving with them. Just changing ‘Depression’ to ‘Deep Pressing End’ allows me entry into my own understanding of what I’m experiencing, which allows me to take part in my own healing.” (Shive 2008, 182)
>
> “The language of direct, first-hand experience - intimately personal and subjective, sometimes irrational and paradoxical, often poetic and spiritual, and possibly frightening to some - must be included in our discourse to empower others to speak up and to dismantle the ignorance and stigma around suicide.” (Webb 2002a, 1)
>
> “[U]ntil we are able to use our own words to tell our own stories, the context we find ourselves in – in this case, the psychiatric system – says our stories for us, and usually gets it wrong. In the context of the medical model, the story we learn to say is that we are *ill*. We begin to see ourselves as *ill*. We tell stories of illness, and the psychiatric system and, by extension, society accepts illness as the story of our distress. Being able to tell your own story – not the illness story – sets a new social context – one in which mad people are seen in a new light.” (Filson 2016, 22, emphasis in original)

Writing one’s own madness can change the power relations that surround that experience and can ultimately redefine its ownership. All the accounts included in this investigation are proof that this happens. Together, they create a strong body of evidence demonstrating that it is possible to communicate and understand extraordinary experiences using ordinary language. Some authors additionally highlight that speaking or writing in one’s own, first-person, voice is not only possible but actually crucial to understanding all our experiences, including madness and distress:

> “The world isn’t just *described* by language and by our ideas about it. It’s actually *ordered* by those things. Language determines how we catalogue our experiences […]” (Shimrat 1997, 168 quoting Persimmon Blackbridge, emphasis in original)

> “Writing the phenomenology of one’s distress is writing one’s own history. The phenomenology textualises and casts, in objective sequence, the unfolding of intimate and often tragic experiences, allowing one to see oneself from a distance as a ‘subject experiencing madness’ and to deal with it.” (Davar 2000, 74)

However, a smaller number of authors remind us that the experience of madness is not always easy to articulate, or at least not in the language of the majority. Exploring the possibilities of the “language of madness and not about it” Hutchinson (2014) emphasises a ‘poverty of listening’ distinct from the ‘poverty of speech’ that is traditionally ascribed to madness. The following excerpts point out to situations where verbal expression is minimal or does not take place at all:

> “[I]t often becomes very clear to me that we don’t all move at the same speed or experience the same versions of reality. Even though we are all supposedly living under the same conventions of linear time, there are other things happening that are much harder to describe, much harder to grasp and hold on to with the language we are given to make sense of our lives.” (Scatter 2004, 7)
>
> “[Y]ou can’t explain in ‘normal’ language what it means to see the world utterly differently... not just in terms of ‘belief’ or ‘worldview’ but as a body with completely altered organs and senses, and as a heart with completely open gates and windows.” (Fabris 2016, 104)
>
> “Pain is always difficult to talk about and whilst abuse can still feel like a taboo it can be easier to communicate feelings through self-harm instead of words. […] If you are dealing with strong emotions and the trauma of abuse then it is understandable that you might resort to a multi-functional coping mechanisms like self-harm.” (Walker 2004, 21)

> “So what is it [*self-harm*]? It’s a silent scream. It’s about trying to create sense of order out of chaos. It’s a visual manifestation of extreme distress. Those of us who self-injure carry our emotional scars on our bodies.” (Ross 1994, 14)

> “[H]ow can social ideologies and cultural meanings be challenged and deconstructed if I embody a refusal to speak?” (Kafai 2013, n. p.)

Though aware that madness and distress are not always communicable, that some experiences occur beyond words and, by their very nature, contradict the way that language is organised, the large majority of authors perceive the possibility of telling one’s own story (including in fiction) as decisive in the process of coming to terms with one’s own life:

> “Writing gives language to madness. The act of writing is a public confession, an open protest. […] The re-inscribing of madness in the textual space of literature would perhaps be, I want to suggest, an attempt at self-cure, for writing is also in a sense an admission, a facing of facts, and a self-evaluation.” (Kalathil 2001, 302)
>
> “The healing of any personal crisis of the self always begins with telling your story.” (Webb 2010, 57)
>
> “There was and always had been a story that I must tell, a life I carried that needed sorting out. I needed to weave the chaos of events into something that could bear all of my regret, become greater than my grief, and hold me up, transforming ‘What happened Beth?’ to ‘this is what happened, what meaning I made out of it, what selfhood means to me now, and what I will do with it all.’” (Filson 2011a, 15)
>
> “Most of the stories of those who look on, seeing only snatches of madness, portray it as all bad. My story is fuller than the stories of those who looked on. As well as being the most intricate story, it is the only unbroken one, the only story that had a witness present from start to finish and every moment in between. This witness was me.” (O'Hagan 2014, 46-47)
>
> “I know that speaking and writing my subjective truth is absolutely essential for my mental health. When I realised that, I finally experienced the wonder of making informed and responsible decisions.” (Armes 2009, 150)
>
> “By reclaiming madness, as well as the language surrounding it, I can use language and the sharing of narrative as a form of protest. […] By claiming madness, by stating that

> I am a mad border body, I am acknowledging the ways history is rewritten through language. I am taking apart what I have been taught of madness in order to create my own story." (Kafai 2013, n. p.)

Being able to share individual stories and truths is also a pre-condition for creating and reclaiming collective histories. This becomes visible in survivor research reports and in collections of personal accounts and oral histories:

> "Creating a place to tell our truths is an act of self-love, liberation and reclamation of our full history. As African-American survivors we need to render ourselves visible to the psychiatric community, the historical community, the consumer/survivors/ex-patients community, the wider African-American community and, most importantly, to ourselves." (Jackson 2002a, 26) (p.26)
>
> "There is an old African proverb which states that 'until the lion is able to tell its own story, the hunter will always glorify the hunt'. In this book the story is truly told from the perspective of lions." (Jones 2008, 1)

As we move away from the individual level, finding a common language for whole communities or movements becomes more complex. It seems that the larger the group, the harder it becomes to find a language with which everybody is comfortable. This difficulty can be traced through some documents of the user/survivor movement, and relates in particular to the debates around organisational names and self-definitions (see, for example, the report of *The Second European Conference of Users and Ex-Users in Mental Health*, 1994, and also *Our Own Understanding of Ourselves. Report on the Kolding Seminar*, 1994). Although the search for the acceptable umbrella terms has never been an easy and straightforward part of political organising of people with psychiatric experience, assuming the right collectively to self-identify has certainly opened up an immense liberatory potential:

> "Users/survivors of psychiatry have used various terms such as 'madness', 'mental distress', 'disability', and 'disturbance' to refer to what we experience and live with (while psychiatry offered only one term, 'disorder'). Each of these terms created new possibilities of constructing oneself and one's identity as well as new critical questions.

> Within the user/survivor movement, each term has had its own use as well as nuance to allow for choices.” (Davar 2015, 197)
>
> “Reclaiming the authority to speak for ourselves, including the very act of acquiring an identity other than ‘mentally ill’, has huge emotional and political significance. […] When we reflect on the difficult and delicate task that was undertaken by (former) psychiatric patients across Europe in finding a name under which we could all work together, we find great value in that process itself. The adoption of *user and survivor* identities has helped us to articulate and develop our own political agenda over the last two decades. However imperfect these terms may be, they also represent powerful and emancipatory acts of collective self-identification.“ (Russo and Shulkes 2015, 33)
>
> “Lack of agreement about terminology can be expected to create barriers in the way of advancing shared thinking and action. But it is also interesting to note that this does not seem to have prevented the development of a lively service user/survivor movement in mental health which has enough space for a diversity of views of people’s issues to be embraced and sometimes argued over.” (Beresford, Nettle, and Perring 2010, 23)

Not being able to reach a full agreement on terminology across different cultures and socio-political systems, including our different positions within those systems, comes as no surprise. The issues of language and umbrella terms seem to have different effects on local and regional political organising on the one hand, and on research and theory-building on the other. Fundamental disagreements on terminology seem to be more of a hindrance for the latter. Our thinking takes place on territory already marked, and there are

> “[n]egative associations of most of the terminology in use. This creates significant barriers and problems in the way of advancing thinking and action towards different understandings of mental health issues.” (Beresford, Nettle, and Perring 2010, 7)

The UK survivor research report quoted above is based on an inquiry into the attitudes of service users towards social understandings of madness and distress (Beresford, Nettle, and Perring 2010). The findings show that “the strongest personal reactions were to the words ‘mad’ and ‘madness’” (p.21) and that

> “[b]roader understandings of madness in society were still associated with a medical model which pathologised people, so for a number of participants, the term did not offer

> the basis of an alternative understanding, but rather another negative way of expressing medicalised individual thinking." (p.22)

A journal article by Forsythe (2012, 19) offers a further explanation of why this might be:

> "If you are judged by a psychiatric professional to be not 'in your right mind' you can effectively be imprisoned for it. So it's not surprising that people wouldn't want to own up to a bit of madness. It would be like owning up to being a criminal."

The attribute 'mad' and the freedom to deliberately identify as such intersect with other systems of oppression to which we are disproportionately exposed. Rachel Gorman (2013) highlights the term 'Mad' in its social and political contexts, and stresses the impossibility of people of colour adopting a Mad identity[32], which would only endanger them further and worsen the structural discrimination and legal repercussions they already face.
A subsequent UK research report by (Beresford et al. 2016) has confirmed the reluctance of a number of mental health-service users to identify as mad:

> "While there is increasing interest in the term 'madness', with the emergence, for example, of 'mad studies', there does not yet seem to be widespread support for such language among service users themselves." (p. 6)

However, some participants in that study do reclaim 'madness', similarly to the large majority of authors included in this inquiry as described by Mary O'Hagan (2014, 7):

> "Even of some of the words started off as neutral they have become polluted by pervasive stigma. In response to this, some of us have reclaimed the word 'madness' – we have removed it from the trash can of insults and polished it to reveal the unique pattern of human experiences."

With the emergence of Mad Studies as a distinctive field of activism and inquiry, more emphasis has necessarily been placed on the word 'mad'. Indeed, it is possible to perceive the whole project of Mad Studies as directed towards reclaiming this term and taking it out of its

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[32] This author uses capitalisation for Mad.

narrow biomedical interpretational framework. The fact that the stigma surrounding the lay use of this term can create obstacles and have an exclusionary effect on people speaks for the need to scrutinise our own practices in order not to end up simply replacing the old categories with new ones. Many authors (as well as some research participants in the studies included in this inquiry) are aware of such a danger and explicitly claim everybody's right to self-identify:

> "We should be able to describe ourselves and our experiences however we like. Services and our circumstances can take away choices, and this is one thing we can chose for ourselves. Please let's not take that away or attempt to regulate it." (Pembroke 2009, 9)
>
> "If it is clear how people do not wish to be described, it is not so certain how people really see themselves. Unsurprisingly, in view of lives spent in the shadow of psychiatric and other expert definitions, members of service user/survivor movement have been reluctant to impose new terms, however positive on each other." (Campbell 1999, 196)
>
> "Findings highlighted the complexity of service users' views, their reluctance to impose monolithic interpretations on their feelings and experience and desire to take account of both personal and social issues." (Beresford et al. 2016, 7)
>
> "There can't be any right or wrong when it comes to self-definition. Instead, an open-ended exploration of what different terms and concepts mean to different people might be the only way to take our thought and action forward." (Russo and Shulkes 2015, 34)

4.4.1.1 Reflections and emerging issues

The findings confirm both how hard it is to separate our language from particular concepts and understandings of madness and how integral the search for the right words is to the search for a new paradigm. Furthermore, the authors claim the right to speak in one's own voice, and demonstrate the power of that voice to redefine one's self and to reclaim experiences. As the subsequent arguments will show, madness is usually understood as an experience that is not reserved for one group of people alone, but rather as something that belongs to everybody. If we take such a stance, then any attempt to find a name for us as a separate kind of people on the grounds of having experienced madness becomes surplus and retrograde. In other words, madness should not be approached as an ontological category.

Furthermore, there is a difference between finding the right language and finding the right terminology. However difficult it may be, and the former does seem easier than the latter, we may want to focus our efforts on deepening understanding rather than suggesting any better or 'right' terms. The following words of Faulkner and Fabris offer some more arguments as to why this may be a better way forward:

> "Language can broaden and describe so much better than it can abbreviate and classify. It seems to me that we need more words rather than less to describe experiences." (Faulkner 2002, 7-8)
>
> "[s]tories provide us ways of exchanging ideas, *and transcending them*. A 'self' can be described in so many ways. So the identity of Mad or patient status, different as they are, cannot encompass all that we are becoming." (Fabris 2011, 80, emphasis added)

I would like to close here with Tam's (2013, 287) suggestion that 'madness is something we can have, without identifying as such', and invite us further to explore our use of language in connection with the other issues emerging from this inquiry.

4.4.2 What is madness?

As described in Chapter Three, the purpose of my research has not been to collect and interpret people's personal experiences. Reading through many sources has confirmed the large spectrum of individual experiences, as well as Pembroke's (1994, 36) statement that "[i]t is unhelpful and damaging to group together people's distress."

There are, of course, powerful moments of recognising ourselves, our feelings and our experiences in each other's accounts. The following descriptions, some of which use similar metaphors, might speak to many people who have experienced madness:

> "There is a moment when the universe seems to expand – we find ourselves with boundless energy and sharpened vision, noticing more and more of connections

> between everything in the world around us, and feeling compelled to talk about them constantly.” (McNamara and DuBrul 2004, 26)
>
> “At some point our own theories and fantasies become the worlds we inhabit, and we position ourselves in the center as messianic figures, mystics, or simply the only person who really knows… Everything we encounter fits into our own personal mythologies, which become written in the symbolic language that used to belong to our dreams but now bleeds over into our waking lives.” (McNamara and DuBrul 2004, 27)
>
> “The kaleidoscope starts spinning faster. My mind loses focus. There are no sequences, no causes or consequences, no depth of being – just a speeding parade of fragmented thoughts, sensations, intentions and movements. The anchors that moor my thoughts to the past and the future have snapped. I am getting lost in the ever-present.” (O'Hagan 2014, 63)
>
> “When you allow yourself to descend into the depths of an altered state, the need for safety moves from foreground to background. When you pass death’s threshold as described in near death experiences, safety’s demands are radically modified. I believe that we actively make a decision to let go when we enter a different realm of consciousness.” (Bassman 2007, 241)
>
> “Madness was about being completely lost and feeling no borders, about being totally exposed and being alone with everything at the same time.” (Russo 2001, 37)
>
> “I was a lost explorer in the extreme zones of existence, wandering around the uncharted edges of human experience with no one to guide me.” (O'Hagan 2014, 113)
>
> “[W]hen these ‘actively suicidal’ feelings are aroused, the addiction metaphor is not a bad one. There is a craving, a deep, urgent craving. And the holding your breath analogy is not bad either. It is like you’re gasping for air, unable to breathe. But it is not air that you are grasping for, it is life.” (Webb 2010, 31)

Many authors make it explicit that these experiences are neither diseases nor disorders, and altogether not of a medical nature at all:

> “We, who have been locked up, labelled and treated against our will without a hearing or trial, are not and never were ‘mentally ill’, ‘manic-depressive’ or ‘schizophrenic’. We were just angry, sad, confused, up-tight or non-conformist.” (Weitz 1998, 301)
>
> “Yes, some people go mad and become disconnected from or uninterested in their usual realities. Yes, some people become so unhappy they can’t cope with life. And it’s a safe bet that when these things happen, brain chemistry is affected, just as it is when you are frightened, angry or in love. But saying such changes are caused by the chemical imbalances is like saying that fear is caused by adrenaline.” (Shimrat 1997, 8)
>
> “We, who were able to come out on the other side of our ordeals and positively transform our experiences, know that the biochemical disease model of mental illness attacks our humanity and crushes our spirit.” (Bassman 2012, 273)

The accounts make it clear that the large majority of authors have been treated for ‘mental illness’. In order to come to terms with their own and other people’s madness, they needed to ‘demedicalise’ it. The notion of ownership and regaining ownership of one’s own experience is frequently referred to in this context:

> “I needed to make the experience my own again after hiding it away in the hospital ward.” (Fabris 2011, 33)
>
> “Giving up being a schizophrenic is not an easy thing to do, for it means taking back responsibility for yourself, it means that you can no longer blame your illness for your actions. It means there is no disease to hide behind, it means no more running back to hospital every time things get a bit rough, but more important than all these things it means that you stop being a victim of your experience and start being the owner of your experience. For the voice hearing experience belongs to the voice hearer, not to the psychiatrist, not to the psychologist, not to the nurse, not to the social worker, not even to the carer or family but to the voice hearer alone. It is only if the voice hearer accepts ownership that growth is possible.” (Coleman 1999, 160-161)

> “I embrace my distress, continue to experience it, learn from it and often find it life enriching as well as painful. I'm empowered because I've taken the right to self-determination for myself. No one can ever take that away from me again. No one can take my madness away from me either. It belongs to me and only I can work through it with support that I define as appropriate.” (Pembroke 1992, 26)
>
> “Demedicalizing human experiences is part of what I try to help people do. I attempt to create opportunities for people to negotiate their own realities, on their own terms, with all of the opportunities one can have to risk, to fail, to succeed.” (Tenney 2016, n. p.)

In the authors’ experiences, madness and distress are states vulnerable to interpretations and actions of different kinds that often neglect or deny the person’s own agency. Fabris (2011, 27) illustrates this vulnerability very accurately with the following words:

> “The word madness unlocks my story like a key or locks it up like a safe. It readies the story for interpretations that would dismiss my pretence, agency and will. Without ‘madness’ the story could read like most other coming-of-age tales.”

In all probability, the most significant issue that the authors agree upon is that madness is a profoundly individual experience, unique to each person. There is a clear demand to pay due attention to this fact, and to respect that however similar our experiences might be, the ultimate authority in understanding madness lies with the person in question, and not with anyone else:

> “My feeling is that my experience has certainly given me insight into the concept of other worlds, but that is not for one moment to say that I can understand anyone else’s other world. I would not presume that any two psychoses are the same. What is so frightening about psychosis is the fact that no one else can ever understand it fully. I have certainly been on both sides of the fence, but I will never know the ultimate truth.” (Holloway 1999, 52)
>
> “We may gain understanding from each other but no one should assume that we are all the same; that we react the same, experience the same and that the same things work for us. Being a mental health service user, in both positive and difficult senses, really is

> about the difference and the fact that we are all of us as human beings different." (Beresford 2010, 10-12)
>
> "Resources would be better spent on the meaningful enabling of individuals to assert their own definitions. Madness is a personal experience, unique to each individual. Its treatment must be too."
>
> "Any realistic model of mental health has to begin by accepting that there is no standard model for a mind and that none of us are single units designed for convenience and efficiency." (The Icarus Project 2013, 3)

4.4.2.1 Reflections and emerging issues

The fact that many authors explicitly stress the uniqueness of each person and their madness suggests that the deliberate refusal to 'group people's distress' might be a principle that we wish to adopt when moving towards our own framework. The inclusion of such a principle might also be a fundamental prerequisite and an important safeguard for any further exploration of madness. Pembroke (1994, 36) reminds us of the failures of any attempts to define people's experiences from the outside, and the consequences of making such attempts:

> "The medical and nursing disciplines are taught to see certain sets of images. Every person is compared to the learnt set. Different images and interpretations are not seen. This process leads to treating people as a falsely homogenous group."

In distinction to this kind of approach, which may be seen as one of the central features of the dominant paradigm, Ingram (2016, 15) argues for quite the opposite:

> "As we are always dealing with multiplicities, trying to pin down madness as one thing is I think to miss the point: it is a million things."

Hall (2007, 15) points out that "[b]ecause medical science doesn't have definitive answers about what madness and extreme states are, it is up to each person to understand their experience in the way that makes sense to them". If we agree with the second part of this statement, the question remains: do we want to work towards creating a science that has definite answers or whether an altogether different kind of science might be more desirable and suitable for the phenomena under investigation? Or as Filson (2016, 219) puts it:

> “What would be different if we came to our relationship with each other out of a sense of curiosity rather than certainty? If we saw each other as people with many stories -- rather than people with many symptoms? How does an emphasis on learning from each other revolutionise the way we think about being with each other in distress?”

4.4.3 The social nature of madness

The accounts included in this inquiry clearly stress the decisive role of one’s immediate environment in relation to madness but also acknowledge the importance of the larger societal structures in which we live. The authors emphasise social circumstances, relations and interactions as obvious causes of madness and distress:

> “[M]any psychiatric survivors’ accounts talk about the external circumstances that have led them to be emotionally distressed and/or temporarily behaviourally out of control.” (Lee 2013, 107)
>
> “Negative societal experiences can lead to an erosion of the sense of identity and self.” (Kalathil et al. 2011, 42)
>
> “I think of depression as multiply interacting states of mind, body and spirit trying to survive difficult existential circumstances.” (Davar 2007, 84)
>
> “People do not ‘go crazy’ for no reason. Often they are afraid to recognize that their ‘happy marriage’ is making them miserable, that their ‘good job’ is drudgery, that their ‘loving family’ is a mass of unspoken, simmering tensions. These are pressures that can, indeed, drive one crazy.” (Chamberlin 1988, 70)
>
> “Sharing our stories finally gave us the courage to believe that we are not mad: we are angry; that what we are saying is not all the result of deluded thinking; distressing things

> really have happened to us, and our distress and anger is often a reasonable and comprehensible response to real-life situations which have robbed us of our power and taught us helplessness." (Wallcraft 1996, 191)
>
> "[T]here is no doubt that there are real links between what happens to people in their wider world and madness and distress. The latter can only be truly understood in terms of us and our relation with our worlds." (Beresford 2010, 122-123)

The world(s) we live in are often characterised as oppressive and damaging. Numerous individual accounts and research reports address experiences of racism, sexism, poverty and trauma as direct causes of madness. The long list of quotes that follows also illustrates the fact that these topics have been addressed in one way or another in most if not all of the sources examined:

> "[W]e do not reduce these 'mad' or 'ill' experiences to problems of the individual. We also see our experiences not as faulty or disordered, but as lived experiences that are connected to oppression, social disparity, and conflict." (Fabris and Aubrecht 2014, 188)
>
> "It seems to me we are living from the legacy of slavery where we now are traumatised, trying to get back our culture, religion, name, language and living in a state of confusion. I have a deep feeling of a people without their history and no knowledge of themselves, not knowing where we have been or where we are going. Oppression is not a good feeling. We have to re-programme our minds from mental slavery." (Muhxinga et al. 2008, 16)
>
> "The larger issue of cultural violence in the form of the suppression and violation of our civil rights is also ignored in psychiatric literature, but is an ever-present reality in our daily lives. How do we address these issues, while avoiding yet another psychiatric label? If an entire group experiences symptoms of post-traumatic stress disorder, when does it shift from being an individualized psychiatric disorder to a public health crisis that must be addressed at its root?" (Jackson 2002a, 23)

“The patriarchy created the conditions that put me in the hospital in the first place. If there was no rape, if there was no abuse, if there was no horrendous violence that women experience every day, then we wouldn’t have these intense emotional reactions, would we? ... So what you have is a very clear link between women’s oppression in the home or on the street and her subsequent incarceration in psychiatric institutions.” (Nabbali 2009, 6, participant’s quote)

“Difficulties around nutrition are not merely questions of shape and weight. Like differences in perception these are metaphors for other things which have a wider meaning. It is also a very complex form of self-harm. It is my belief that eating distress is part of a struggle against socio-political gender oppression.” (Pembroke 1992, 26)

“The issue of oppression was a constant theme throughout the interviews, including class oppression and its impact on the manifestation and treatment of mental illness. Sexism was an issue for males and females because it contributed to the normalization of the sexual victimization of female survivors and served as a barrier to males openly expressing their pain and distress.“ (Jackson 2002a, 23)

“[I] have yet to find a single person who did not enter the system after some precipitating trauma.” (Shimrat 2013, 146)

“Oppressive practices and traumatic experiences, such as sexual and physical abuse, domestic violence, bereavement and loss, and stress from the obligations of fulfilling family roles were significant in how women in this study made sense of mental distress.“ (Kalathil et al. 2011, 9)

“Poverty, violence and loneliness are inherent in society that puts profits above people, and these are things that drive people crazy.” (Shimrat 1997, 164)

“We also know that pressures from poor working conditions, poverty and social and family breakdown can all contribute to personal distress and breakdown.” (Beresford 2010, 111)

The authors make it clear that it is impossible to separate experiences of madness from our immediate environments and from the societies in which we live; madness actually originates from society itself. In other words, madness does not come from inside us; it comes from our lives:

> "[I] finally realized that my unhappiness came not from something being wrong with me, but from many things being wrong with the social system. My society had taught me to accept and want and believe things that did not necessarily make any sense." (Shimrat 1997, 39)
>
> "Madness has no real meaning outside the context of our social relationships and how we understand things like productivity, communication, independence and status." (O'Hagan 1993, 17)

However, the authors also stress that madness is a highly personal matter. Though this may always be in a particular social context, people who experience madness are dynamically involved in that context, and their experiences of madness cannot be explained entirely by a broader social order or reduced to politics:

> "The women's movement seemed to be saying to those who were experiencing psychological disability and periods of profound personal vulnerability 'We are political agents first and we should unpack our inner experiences in order to explicate that agency.' The social justice and empowerment discourses did not allow legitimate personalized conversations about intense experiences of psychophysical well-being, vulnerability and disability." (Davar 2008, 268)
>
> "Survivor discussions about their lives and experience tend to accent the *holistic* nature of their situation. This includes and interconnects the physical, mental (emotional and perceptual), spiritual, social and political. In this sense they go much further than traditional 'psycho-social' approaches to 'mental health' issues, which have sought to focus attention on both the personal/psychological and the social/structural. Here the emphasis of survivors is on the complex (non-medicalised) interrelations of ourselves, our lives, our minds, our bodies and our environments." (Beresford 2005a, 113, emphasis in original)

While they argue strongly that madness is not located *within* a person, the authors likewise do not try to locate it in any particular place *outside* of the individual. Rather, they perceive madness as the outcome of a multitude of relations, as described in the quote above. Therefore, the argument that madness is of a social nature does not imply a unidirectional relationship. In fact, the relationship is mutually fulfilling: society makes madness, which in turn performs a designated function within society. This dynamic, however, is mediated by the powerful institution of psychiatry. Psychiatry and the biomedical model interfere in the relationship between madness and society by protecting the latter from the former. A participant in one of the research studies included in this inquiry expressed this interference as 'creating a comfort blanket' for society:

> "Those of us with mental health issues represent some of the most frightening aspects of being human. We literally embody things people fear at a profound level – unreason, challenge to social contract, highlighting issues people can't tolerate such as the futility of living, familial abuse, vulnerability to violence and mortality. What better way to wipe away these fears than by locating them in a 'broken' person rather than acknowledging them as consistent, frightening features of society – and so the medical model acts as a kind of comfort blanket obscuring these bigger issues from view." (Beresford et al. 2016, 19, participant's quote)
>
> "People who end up as mental patients are people in trouble – with their family, their job, or the community at large. A diagnosis of mental illness lets everybody else off the hook – the mental illness of one participant is responsible for whatever difficulties or conflicts have been occurring. Business can go on as usual." (Chamberlin 1988, 121)
>
> "Thus, states of mind that are seen to interfere with a person's productivity, communication, independence and status are devalued and become the burden of the 'deviant' minority of mad people." (O'Hagan 1993, 17)
>
> "The crazy one is just a product of the fears of a competitive society where only the material exists." (Minkowitz and Dhanda 2006, 11, contribution by Elena from Peru)

> “When people violate the norms of societal behaviour, we’re taken aback. And one of the ways that we deal with it is by pathologizing that behaviour. Instead of saying, ‘Here’s someone who has done something that I didn’t expect,’ we say, ‘Here’s someone who must be sick, because he’s done something I didn’t expect.’ (Shimrat 1997, 74)

From the authors’ perspectives, the individual’s social environment is not only where madness comes from, but also where we ought to look for the responses to madness. This is because we are all inseparably embedded in the world around us, as is vividly described by The Icarus Project (2013, 3) from the USA:

> “No matter how alienated you are by the world around you, no matter how out of step or depressed and disconnected you might feel: you are not alone. Your life is supported by the lives of countless other beings, from the microbes in your eyelashes to the men who paved your street.”

Mead (2005, 18) also stresses our connectedness to the world and inter-connectedness with each other when she reflects on ‘mental health’:

> “For me, mental health is simply one’s ability to feel connected in the family (whatever that is for you) and in the world while continuously learning and growing. It is a creative process rather than a coping process. It is also not an individual phenomenon. It’s more like playing with a great jazz band where you’re giving, getting and creating together.”

The key to madness seems to lie in our relationships, in the way we live our lives, and not just within the boundaries of our individual minds. In a multitude of ways, the accounts contain a unequivocal message that the actions around madness should not target the person experiencing it, but primarily their environment and relations:

> “Psychosis is not just an individual problem. My own ‘madness’ was about dis-connecting from a world I struggled to identify with. Therefore in my work with people I am keen to consider how can we make the world around them one that is worth connecting to and negotiating with.” (May 2004, 257)

> “To recover, I didn’t only have to change what was inside my mind but also what my mind was inside of. I had to change my circle of friends, both male and female, my place of work, the kind of work I did, the town I lived in, and how I lived and expressed myself. If anything, the changes were as much of things *outside* myself as of things inside myself. After all, people don’t want to be changed, they want to be loved.“ (Chadwick 2010, 18, emphasis in original)
>
> “First we must be committed to changing the environments that people are being asked to grow in.” (Deegan 1996a, 9)
>
> „Most participants felt that mental health problems were a complex issue, affecting people in different ways. They mainly felt that their understanding of mental health issues fitted within a social approach and they found this helpful. A common view was that mental health was affected by and a response to broader social and environmental factors. These could have a short- or long-term effect. They located the individual’s experience within their broader social context, rather than thinking it could be understood in isolation. They felt that there was no one way of understanding mental health issues because of the range of different problems and issues that could affect people in different ways.” (Beresford, Nettle, and Perring 2010, 16)

Finally, as expressed in the findings of the research report quoted above, the social nature of madness certainly does not imply that there is or should be one single and unified social response to it.

4.4.3.1 Reflections and emerging issues

The following words from Beresford (2010, 128) provide a good summary of this part of the findings:

> “We should never lose sight of the connections that there may be between people’s madness and distress and the nature of the world and society they live in. We must always include the latter in the equation and work for big change as well as for change within ourselves.”

The biomedical approach to madness clearly stands in the way of seeing these connections and inhibits the changes that madness calls for, as O'Hagan (2001, 31) accurately observed:

> "[w]hen disability and mental illness are viewed as inherent facts about individuals, it places these concepts beyond questioning. It also limits the discourse or self-examination by society, on how it may contribute to the causes of mental illness and disability, and how it might perpetuate them through harmful treatments, coercion, and discrimination."

If we use the metaphor that the biomedical model serves as a 'comfort blanket' that covers and prevents us from seeing and addressing the bigger picture, then the opposite approach to madness means taking away that blanket and uncovering the issues at stake. Such an 'uncovering' should take place at both the individual and societal levels; it makes the demand that "we address the broadest structural concerns *and* the most intimate aspects of our individual selves" (Beresford 2010, 130, emphasis added).

The task ahead of us now is to explore what the interplay between madness and society could be like if there were no biomedical approach to govern it. It seems that the biomedical model not only covers the real issues and depoliticises madness, but also suppresses its transformative potential and prevents change at all levels. Refocusing radically on the social relationships around madness would have far-reaching implications for both our individual lives and society as a whole.

4.4.4 Making room for madness

Many of the authors argue strongly for valuing and accepting madness. The accounts "rest on the revolutionary idea that madness is a full human experience" (O'Hagan 2009, i). This is expressed in many different ways and refers equally to our own and other people's madness.

The following excerpts speak about accepting madness as part of one's life and as integral to one's sense of selfhood. Even though the experience itself is not described as pleasant, the authors find meaning in it, and prefer to understand and embrace their madness rather than to have it 'fixed' or removed:

> "I feel now that this is part of my life's work: letting go when That Feeling comes, and learning from it." (Mason 1996, 8)

“Even if I could not stop my madness I could change the way I viewed it and live *with* it instead of *against* it. I could even change the experience of being mad, or I could lessen the threat that madness made to my inner life. I needed to find a place for my madness instead of allowing psychiatrists to make their futile attempts to get rid of it.” (O'Hagan 2014, 117, emphasis in original)

“I think that my psychiatric experience has hurt me in ways that I’ll never get over. I’ll always feel damaged by the way society has responded to my label. But if somebody came along and ‘fixed’ me I wouldn’t be myself anymore. And that would be a problem for me, because all that stuff is part of who I am.” (Shimrat 1997, 81, quoting David Reville)

“I think that despite psychiatry, the very experience of madness conserved me. I found preciousness in getting lost, noticed that my personal chaos contained logics and finally found courage to say: I was right and all my extreme reactions were right. I started reclaiming madness that was taken away from me, I started listening to it, figuring out its principles and wanting to make them part of my life. I stopped desperately exchanging them for some alienated normality, I stopped neutralizing myself with sleeping pills.” (Russo 2001, 38)

“Ultimately, even a paranoid delusion is a miraculous thing, testimony to the infinite wonder that is the human mind. Learning to integrate such bizarre phenomena into my life and still find meaning has enriched my life, for all its hardships.” (Champ 1999, 126)

“Suicidality is a legitimate human experience. That is, it is something that some people feel at some times in their life. This is simply undeniable to me. To declare it bad, mad or wrong is to deny a valid human experience. It is valid because it happens and it is real. Sure, some people never have this experience and good luck to them; I could say that I envy these people. But actually I wouldn’t say that because I am in fact grateful for my suicidality. It has been such an important part of my life’s journey that I could not imagine myself being where I am today without it.” (Webb 2010, 30)

> “It is notable that many people with a mental illness diagnosis do not want their unusual capacities removed from them, either because they have positive aspects or because they are so essential to who they are.” (Campbell 2010, 24)

As in their own individual lives, the authors also value and accept other people’s madness. While recognising the inherent challenges that this kind of acceptance brings, many of the authors are committed to making room for madness and take this stance as a matter of principle:

> “I want to make the world safe for people to go crazy in, if going crazy is what they need to do. If everyone weren't so terrified of madness, if we looked at it as a breakthrough, rather than a breakdown, if we put in place smart, compassionate ways of helping people get through it and out the other side, madness itself could be liberating. And if we could teach the so-called normal people to relax a little and give some room, and some credit, to the crazy, free being inside them, maybe they could have a lot more fun, and stop giving the rest of us such a hard time.” (Shimrat 1998, n. p.)
>
> “The issue is not how do we ‘cure’ these ‘illnesses’ of mental, emotional and spiritual distress, but how do we embrace them into our unique lives and how do we support each other in allowing us the full experience of whatever life brings us.” (Webb 2002b, 173)
>
> “[…] it is our job to wait patiently, to sit with, to watch with wonder, and to witness with reverence the unfolding of another person's life.” (Deegan 1996a, 8)
>
> “When people experience extreme emotional distress, regardless of cause, attempts to negotiate and relate are challenging. Understanding that this situation is a language with meaning and emotion, no matter what’s happening, grounds the supporters in understanding that the first priority is to help the person feel welcome, safe and heard.” (Mead 2007, 215)
>
> “[U]nderstanding and accepting somebody is not just the first step in constructing a helpful response; it’s the very core of that response.” (Shaw 2016, 82)

Many authors see madness as an experience that can happen to anybody, and thus decidedly oppose divisions that place ‘mad’ on the one side, and ‘sane’ or ‘normal’ on the other:

> “We realise that confusion and distress are understandable parts of being human and that using a dualistic concept of health and illness may actually add to our problems.” (May et al. 2013, 246)
>
> “There were only two options for self-identification: either ‘properly mad’ or ‘not mad’. I didn’t belong in either category and that felt frustrating. It was no good unilaterally declaring that one was, or had been, ‘a shade of mad’. This wasn’t a recognized category.“ (Forsythe 2012, 18)
>
> “Identifying a border existence in the context of madness allows for movement away from the ableist assumption that one is either sane or mad, that one can never simultaneously exist between both spaces.” (Kafai 2013, n. p.)
>
> “[O]ne of the first tasks of a service user/survivor point must be to challenge the ‘reason/unreason’ dichotomy.” (Armes 2009, 145)
>
> “Madness is a subset of sanity. It is not only sensible, or rationalizable in any circumstance, it is necessary to order and consciousness. Its gap informs the way we configure memories into chapters. What is madness but a break from self-monitoring?” (Fabris 2011, 33-34)
>
> “[I] cannot see the origins of my madness and my sanity as two parallel stories; they are one story in two dimensions. Madness and sanity are not two different garments, they are the warp and the weft of the same fabric.” (O'Hagan 2014, 16)
>
> “We need to be explicit: the world does not consist of ‘normals’ and the ‘mentally ill’; it consists of *people*, all of whom may experience mental or emotional distress at some time(s) in their lives.” (Wilson and Beresford 2002, 144, emphasis in original)

Madness is seen as belonging to a continuum of human experiences, as part of everything else we go through in our lives. This profoundly challenges the biomedical understanding of madness that targets particular populations and defines those who experience it as a categorically separate group:

> "They [*psychiatric system*] tend to present psychiatric service users as 'other' – a separate and distinct group – rather than acknowledging madness and distress as part of broader continuum of perceptions, understandings and experience which are inherent part of the human condition and may be socially related." (Wilson and Beresford 1999, 147)
>
> "[W]hat we have in common with everyone is far greater than those differences that c/x/s[33] share with each other. We all have varying levels of ability to construct inner and outer worlds and establish where the two meet." (Bassman 2007, 242-243)
>
> "Cigarettes. Mindless telly. Alcohol. We all know what it's like to cause harm to ourselves. Self-injury is not some strange, marginal, pathological behaviour. In many ways it is at the heart of how we live; it's what we expect of each other. […] I am suggesting that it's useful to move away from the notion of an 'us' and 'them', to recognise that we all self-harm, and to use this as the most useful starting place for understanding self-injury and how we might most helpfully respond to it." (Shaw 2016, 78-79)
>
> "We all have our own personal sense of self. We have all had times when our sense of self has felt challenged, wounded or in crisis in some way or other. This may not necessarily have been a suicidal crisis but the experience and knowledge of a self in crisis is something that we all share and are familiar with. This automatically breaks down the 'them-and-us' thinking that lies behind much of the stigma around suicide so that there is no longer a them-and-us, only us." (Webb 2016, 92)

Rather than probing madness and seeking explanations for it, some authors actually question 'normality', and they are suspicious of some people's inability ever to go mad. This is, for instance, clearly expressed in the following statement, published on the back cover of one of

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[33] Abbreviation for consumers/ex-patients/survivors.

the issues of the Canadian magazine "*Our Voice. Viewpoints of the psychiatrized since 1987"* (2016):

> "Be wary of someone who tells you that they never had a 'mental health problem', or that they had one years ago and now it's completely gone. 'Mental health problems' are part of daily life. If your living address as a human being is planet earth located somewhere in this universe – you will go through various emotions from the good, the bad, the very bad and the in-between until your last breath. Remember that some people who deny this fact from their very existence can be more harmful than the ones whom they label as having a 'mental disorder'.

As described in the section 'The social nature of madness', the authors also discuss madness in the broader socio-political contexts of people's lives. The consequences of medicalising madness, as opposed to acknowledging it as a legitimate human experience, are also discussed in relation to those contexts:

> "We need to stop medicalising inequality. We need to refute the idea that mental illness is some kind of personal defect, something in us that needs to be fixed. We need to say: There is nothing wrong with us. What is glaringly wrong is outside of us, deeply embedded in the vagaries and cruelties of modern industrial capitalism, a wounded beast more dangerous than ever in its desperate death throes. We need to say: Is it any wonder we are mad, when our incomes, our prospects, our very souls are being attacked from all sides?" (Brown 2013, 14)

Replacing the search for ever more sophisticated 'normalising' interventions with the principle of accepting madness and making efforts to enlarge the space allowed for it, could have far-reaching transformative implications for the communities and societies in which we live:

> "We don't want to be mainstreamed. We say let the mainstream become a wide stream that has room for all of us and leaves no one stranded on the fringes. The goal of the recovery process is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human. The goal is not normalization. The goal is to become the unique, awesome, never to be repeated human being that we are called to be." (Deegan 1996b, 92)

> "Taking the approach of accepting an individual's own reality and belief system makes for a less simplistic more varied existence. Who wants to live in a society where only evidence-based beliefs are acceptable and all difference is pathologised?" (Knight 2009, 9)

4.4.4.1 Reflections and emerging issues

The tradition of labelling and segregating people perceived as mad is a long one, and cannot be abolished with legislation and policy alone. Lay beliefs around madness are largely informed by the biomedical categorisations that pathologise and 'other' this experience. The findings suggest that the unmaking of the division between 'mad' and 'sane' is one of the core aspects of disrupting that tradition. However, working against that dichotomy is not only a theoretical issue, but must necessarily involve reshaping our everyday relationships and unlearning both the fear of madness and much of the received wisdom:

> "We don't get taught about how to support a friend who is sad or lonely or frightened. We don't get thought about how understandable sadness and confusion are in hard times. Because of that we fear what is not talked about, we call it weird and when we come across emotional pain or fear we seek to control it or shun it away. The more we shun it the worse the pain and fear become. We have an apartheid approach to our emotional discontent." (May et al. 2013, 233)

Working towards a different approach requires learning to accept madness and expand room allowed for it both within ourselves and our relationships and within the broader systems in which we live. The following words of Knight (2009, 43) raise a point that I personally find helpful and greatly relevant if undertaking such a project:

> "It is important to note that accepting people's unusual beliefs does not mean that the helper has to agree with or share the person's beliefs. Accepting a person's unusual beliefs is similar to accepting another's religion as being valid without having to personally share it."

We may want to further discuss the limits of this acceptance and whether these are any different from the other limits that we inevitably pose and negotiate with each other.

4.4.5 Generating meaning and learning from madness

The authors do not romanticise or idealise madness. Their accounts describe the experience as a profound personal and existential crisis. And yet, despite all the accompanying hardships, they perceive these crises as important learning opportunities and chances to grow. Experiences of madness are not meaningless. They make sense in the context of a person’s life and are therefore not just a burden that one needs to get rid of. Reporting the findings from her research into people’s first breakdown, Wallcraft (2001, 99) writes:

> “The most significant finding for this study is that many people have survived extreme distress and are able to find meaning in their experiences.”

Many other accounts offer further evidence that madness is a meaningful experience from which we can learn:

> “The psychotic ‘films’ are grounded, they relate to me and my life. They are a mirror and a message for me, like my dreams at night. I must take my psychosis seriously just like others do with a heart attack. I must pay attention to the signal that my psychosis emits.” (Bellion 2002, 289)
>
> “I learnt to make meaning, not in spite of my madness but because of it. It was not the kind of meaning that answers ambitious intellectual questions such as ‘Why?’. Like haunting music or poetry, the meaning I found was saturated with soul. It was an intuitive expression of being without the labour of logic.“ (O'Hagan 2014, 113)
>
> “Mental health problems need to be respected; they are powerful messengers that give us big clues about what social and relationship tragedies people need to heal from.” (May et al. 2013, 234)
>
> “If I don’t push away my psychotic experiences with psychiatric drugs then I am left with important material to help me rethink and reorder my life.” (Bellion 2007, 82)

> “A depression is something to get rid of and the goal of psychiatry is to ‘cure’ people of depression. That my depression might be telling me something about my own life was a possibility no one considered, including me.” (Chamberlin 1988, 23)
>
> “*People want to gain understanding of and from their crises.* We want to learn from our crises things that are relevant to the rest of our lives. We want to integrate these experiences into the weave of all our other experience and not to carry them around with us as some separate and unsightly garment.” (Campbell 1996b, 181, emphasis in original)

Some authors claim that even extreme states of mind entail logic and truth. Among other things, they see states of madness as particular ways of knowing:

> “But the *content* of people’s madness can have value and meaning, if only symbolic meaning. There is often a grain of truth in even the wildest ideas.” (Shimrat 1997, 168, emphasis in original)
>
> “We do not lose our minds, even ‘mad’ we are neither insane or sick. Reason gives way to fantasy – both are mental activities, both productive. The mind goes on working, speaking a different language, making its own perceptions, designs, symmetrical or asymmetrical; it works. We have only to lose our fear of its workings.” (Millett 1990, 315)
>
> “Madness is an embodied way to know. It is intelligent, searching and valuable. It is not regression, but conscious reaching out, as is technical work, healing love, or creative feeling. Purpose is not impossible in ‘madness’ but is also not easily described in a non-normative relation to the world.” (Fabris 2011, 32)

If, however, madness is to be understood and learned from, then it first needs to be taken out of its segregated social place and recognised as a valid human experience:

> “Behaviour has meaning in the context of people’s lives; psychiatric labelling separates out certain behaviour and calls them part of a disease process. It is impossible to

> understand what is going on in the life of a person in crisis if his or her behaviour is discredited in this way.” (Chamberlin 1988, 118)
>
> “The pain of madness is probably on a par with major grief, torture, surviving a battlefield, or being falsely accused of a serious crime. There’s a big difference though; these other experiences have legitimacy. Society enables a pathway though them towards growth, recovery or justice. Though they are not well understood by the majority, surviving them is often regarded as admirable or heroic. Madness however, is met with pity, fear and reproach. It does not have status as a full human experience, and this has provided justification for cruelty, segregation and coercion.” (O'Hagan 2008, 16)
>
> “When the actions we take to cope, or adapt, or survive are deprived of meaning, we look – well, *crazy*. [...] What I learned about madness is this: whoever has the power determines what it means. I knew that what I was experiencing made sense given what had taken place in my life. Even then I understood my reactions as sane responses to an insane world.” (Filson 2016, 21, emphasis in original)

Through ascribing meaning to madness, and always considering it within the broader context of a person’s life, the authors firmly contend that madness is an experience that can be understood and shared:

> “It is possible to communicate with perceptual differences. They are real and have meaning origin and history. There is a lot to learn from them, and we should be interacting with them as opposed to trying to obliterate them with tranquillisers. Sometimes, these differences can be metaphors or an external form for intolerable feelings to talk back to us. The common shared concept of reality can be overwhelming, and other realities develop which can be both life-threatening and life-enriching. These realities are not meaningless and can be understood.” (Pembroke 1994, 31)
>
> “Spirituality and faith were important to some participants’ identity. The meaning given for mental distress was sometimes a part of a personal spiritual crisis or religious experience. Faith and/or personal spiritual grounding were important in their recovery.“ (Kalathil et al. 2011, 9)

> “The answers we form to the most basic of all questions, ‘Why?’, is the first step out of senselessness. The answers – no matter what they are – help us make sense out of our suffering. The answers give us reason; the answers organise our experience.” (Filson 2016, 23)

Many of the authors report being denied both the space to understand their own madness and any chance to learn how to cope with it. This is different from learning strategies for reaching ‘normality’. Several accounts reiterate that allowing madness rather than suppressing it might be the best way to respond. Because we are not usually allowed to have the experience at all, we are likewise denied any opportunity to learn how to deal with it on our own terms:

> “We’re taught from a young age how to be in the world and how to experience it. We’re not taught how to experience the world while going crazy. It’s defined as a bad, ugly, negative situation. When I was crazy I kept thinking, isn’t there someone who knows about how to do this? People keep telling you how to act in order to be normal again. It seems like all the language and ideas are aimed at trying to shut you down.” (Shimrat 1997, 165, quoting Persimmon Blackbridge)
>
> “Our minds have a way of helping us grow. Things that look crazy to other people can be growth experiences if they are not interfered with, which they are of course with drugs. We don’t know how to get to the other side because we are never allowed to go there.” (O’Hagan 1993, 10, quoting Suzy from the USA)

Learning how to live with/through/after madness, or knowing how to ‘be mad’, seems key to avoiding being subjected to unwanted interventions and treatments, as the following words of Knight (2009, 42) explain:

> “Lots of people have beliefs that others may consider to be strange, unusual or not based in fact, and there are many people in society who are living successful independent lives who have beliefs that meet the criteria for delusions. The difference between people with unusual beliefs who do not become psychiatric patients, and those who do, has little to do with the beliefs themselves but rather is about whether or not that person can *cope* with their unusual beliefs.” (emphasis in original)

Some authors describe how it was actually the experience of madness that taught them how to live and become who they are:

> "Because this territory in my internal universe is continually shifting, I've learned to look for patterns and rhythms in the chaos that I can use as guides when I can't locate steady ground. So I make maps from my memories. I make maps out of words and stories." (Scatter 2004, 8)
>
> "Because each of us is different, it is as if we are navigating through a labyrinth, getting lost and finding our way again, making our own map as we go." (Hall 2007, 8)
>
> "There is inside of me a self, a spirit, which is gradually becoming more aware of me and others. That self is becoming my guide. It encompasses all that I am. My self includes, but is greater than my chemicals, my background and my traumas: it is the me I am seeking to become in my relationships, in that moment of creative uncertainty when I make contact with another. From that moment of harmony, when, together we defy the odds and say 'yes', our lives will go on differently, regardless of how we live the following moment. We are all inventing our lives at each moment." (Fisher 1999, 132-133)
>
> "[M]y capacity for recovery did not just precede my madness, it lay within it. My recovery began to show itself where my madness began to show itself – in the black box." (O'Hagan 2014, 126)

The journey through madness is usually risky and difficult. Generally, the authors do not recommend this experience though they clearly value it. While diverse and always highly individual, the accounts attest, over and over, to the possibility of 'reaching the other side':

> "It is possible to be lost in the depths, but one can also know there is something both within and outside, shrouding and protecting in its gentle darkness." (Conroy 1999, 66)

> "I have followed my pain and my fear toward what I thought would be death, and instead I had found a source of life, my own sense of self, which had always been hidden from me. Out of struggle and pain, I had been reborn." (Chamberlin 1988, 67)
>
> "But for me, giving up was not a problem, it was a solution. It was a solution because it protected me from wanting anything. If I didn't want anything, then it couldn't be taken away. If I didn't try, then I wouldn't have to undergo another failure. If I didn't care, then nothing could hurt me again. […] I believe that becoming hard of heart and not caring anymore is a strategy that desperate people who are at the brink of losing hope, adopt in order to remain alive." (Deegan 1996b, 93)
>
> "I would not wish anyone to go to the place that I went to, but I can confidently assert to those who have found themselves in their own hall of mirrors that there is a way out." (Albone 2004, 85)
>
> "Some people, even experiencing the worst depths of madness, say that by going through their experiences rather than suppressing them, they emerge stronger and healthier in the end. Sometimes 'going crazy' can be the doorway to personal transformation, and some people are thankful for even the most painful suffering they have been through." (Hall 2007, 20)
>
> "Without my experiences, I wonder if I would ever have stumbled upon the reserve of inner strength that enabled me to reach out and achieve the richness of my life today." (Davison 2004, 15)

O'Hagan's memoir *Madness Made Me* (2014) is an insightful testimony to the value and the necessity of madness. It offers a strong counter narrative to the dominant discourse aimed at pathologising and erasing madness from our lives. The author powerfully describes all the things that madness has taught her; everything that she has become thanks to her madness and not in spite of it. The following excerpts from O'Hagan's memoir profoundly connect to what many other authors, including myself, say, and speak to many of our experiences:

> "My madness did not just take away, it gave to me as well. It was like a prolonged and brutal rite of initiation that came close to destroying me before I discovered what it gave

> me. Though on the surface madness took away some of my competence, like thinking straight or talking, it gave me a route to a deeper competence, like a richer understanding of life and the ability to face existential terror. It also gave me strength – the strength to withstand the terrible grief I felt, to keep looking for answers, to put my life back together, to know that if I could survive years of madness I could survive almost anything.” (p.121)
>
> “My madness took me places I had never been. It showed me the universe without its clothes. It stripped my mind of all its chattels. It rubbed my nose in the divine. It turned the lights off all over the undulating continent of my brain. Many people pass through this territory at some time in their lives. Most manage to skirt their way around the edge of it and look on with dread and distance. But those who are forced right into its belly come out with richer pictures of a being that had been lost and found again.” (p.113)
>
> “Madness gave me the experience of being ‘othered’. It removed me from a life soaked in privilege and allowed me to see that privilege from the outside-in for the first time.” (p.122)
>
> “Madness taught me that there are many things I cannot control and that good health, wellbeing and life itself are not part of predictable design but accidents waiting to be nurtured.” (p.122)

Finally, madness also shows ‘normality’ in a new light. Some authors explain their refusal to become ‘normal’:

> “Sometimes I worry about being un-mad. […] I don’t want the rough edges knocking off my life. I don’t want to be perfectly in control. I welcome my shadow side, and I embrace the ups and downs in my life. The lower I go, the higher I can rise.” (Green 2004, 47)
>
> “The vision of me turning into a chronically normal, functioning person frightens me deeper than any diagnosis or prognosis of my ‘mental illness’ ever did. I don`t want to become a subject that works, earns, has holidays, rents flat, procreates, counts on stability of its little world and is always able to delay pleasure. I trust my

> ‘schizophrenic’ talent to take a break from normal people’s paradise, have an honest look at my existence sometimes and dare to question my day-to-day functioning. The constant desire for intensity complicates my life a lot but it is a part of who I am and I don`t want to soften it.” (Russo 2001, 38)
>
> “Normality can be a burden. We spend so much energy on not being ourselves, on keeping everything inside, on looking cool. We’re supposed to devote our lives to meeting the expectations the world has placed on us: being heterosexual, getting married, having children, being thin, dressing nicely, being ‘productive’, accumulating money and prestige. We’re supposed to make do with substitutes for real contact: a handshake, a polite smile, a ‘how are you’ that doesn’t really want an answer. But I believe that mad movement can take us far beyond that. It has thought me to dream big, to trust big and to take big chances. To dare real closeness and joy and play.” (Shimrat 1997, 169)

4.4.5.1 Reflections and emerging issues

The accounts clearly demonstrate that madness has a meaning and can be understood. Again, the authors emphasise that such an understanding can be reached only in connection with the rest of the person’s life. Furthermore, madness is also an experience from which we learn, both in terms of our own lives, and beyond them. This learning and growth, however, can only take place if experiencing madness is permitted, and not feared or combated. The findings ultimately point us to a question that has been formulated by Mary O’Hagan (2014, 116): “Is madness such a bad thing? […] How different would our experience of madness be if it was valued and given status?”

4.4.6 The transformative potential of madness

Experiencing madness in a variety of forms and appearances is usually tough, and not only because it is socially sanctioned. However, despite having had tough experiences, a number of authors highlight the important potential for change that madness entails. Madness is not only a visible manifestation of things going wrong but also a powerful call to make substantial changes and a chance to put those changes into effect. Many authors share this stance and make it clear in their work:

> "My madness arose as a means of forcing me into a new life. The torments I suffered at the time were, on the one hand, signals that the state of life at the time was not good and, on the other hand, they were the driving force which pushed me to search for a way out of my unbearable and pointless life situation and to find an authentic life. Without this inner drive I would not have moved." (Jesperson 2002, 76)
>
> "Depression does involve internal *pain*, but the pain that one is called to overcome. In the experience of depression, a self that is waiting to be reborn, is buried." (Davar 2007, 85, emphasis in original)
>
> "Madness and the loss of the confident ego can also be the attainment of a new way of life; suddenly, the total sensibility turns around." (Solomun 2007, 66)
>
> "For experience like breakdown, or other forms of sever loss, pitch us into the deeper and darker places within ourselves, changing the route of our life's journey and taking us down paths we would not have chosen to travel. If we are to move on, we would almost certainly have to change our perceptions of ourselves and our life from the very centre; a turning not just of direction but of the whole of ourselves." (Fergusson 2004, 41)
>
> "A crisis is the height of an extreme experience but it is also a turning point, time-limited and followed by something new. A crisis questions what has been previously lived, and challenges certain habits. By interfering with our previous attitude to life, crises give us a chance to break out of cognitive prisons." (Krücke 2007, 102-103)

Nevertheless, experiencing madness can also mark a negative turning point in one's life. This is often due to the conventional treatments and interventions that people receive. The authors emphasise that the approach taken to madness is decisive for the question of where that experience will ultimately lead, and whether its potential for positive change will actually be realised. Indeed, several of them contrast 'breakdown' to 'breakthrough' in order to stress the central significance of our understanding of and approach to madness:

> "There are important points in life that make changes necessary. Or a change in your attitude to life becomes necessary. Sometimes a new orientation is called for, a new beginning with largely unknown starting conditions cannot be averted. The fact that things have gotten to a critical point is often preferably swept under the carpet." (Bellion 2002, 289)
>
> "By approaching my situation in terms of illness, the system has consistently underestimated my capacity to change and has ignored the potential it may contain to assist that change." (Campbell 1996a, 61-62)
>
> "A crisis is a moment of great tension and meeting the unknown. It's a turning point when things can't go on the way they have, and the situation isn't going to hold. Could crisis be an opportunity for breakthrough, not just breakdown? Can we learn about ourselves and each other as a community through crisis?" (McNamara and DuBrul 2004, 38)
>
> "I decided then that I could not allow my madness to be demeaned, criminalized and medicated from me. It was clear to me that moments of crisis, trauma or "breakdown" could also be opportunities for "breakthrough". (Shive 2008, 178)

However crucial our immediate surroundings and their responses, the importance of the approach taken to madness equally includes our own response, and the stance we personally take. When writing about the transformative potential of madness, many authors mention taking responsibility for themselves and for their lives. The right to make our own choices and to take risks is seen as vital for personal growth and achieving change:

> "[P]eople with psychiatric disabilities who have regained their lives, often say that using their strengths and abilities to take responsibility for themselves was the most important factor in their recovery." (O'Hagan 2001, 34)
>
> "[I]f you talk to people who have recovered – whether we're talking about recovery from trauma, recovery from an extreme mental or emotional state, or recovery from learned helplessness and institutionalization – that people who have recovered are people who have made choices on their own. Choice in an integral part of the healing

> process. It’s not just something that we can tack on to treatment when we feel it’s convenient. If choice isn’t available, then healing cannot occur.” (Penney 1994, 32)
>
> “That process of making mistakes, failing, working out what went wrong and trying again was essential if I was to have even a remote chance of success.” (Bhakta 2016, 149)
>
> “Each person using psychiatric services is on an individual journey; a journey which has often been crudely interrupted by the intervention of psychiatric treatments designed to impede thought and action. Allowing someone to restart their own journey is risky, but if we don't allow people to take risks they cannot learn and grow. Empowerment is risky, but it is our right as human beings.” (Wallcraft 1996, 196)
>
> “Even people who are truly in trouble and making bad choices share everyone’s right to learn from their own mistakes, and what others might consider ‘self-destructive behavior’ may be the best way someone knows how to cope, given other things they are struggling with. Forced treatment may be more damaging than their ‘self-destructive’ behavior.” (Hall 2007, 36)

When they refer to the personal changes that can arise from madness, it is notable that the authors do not understand such processes as fixed or as having a designated (happy) ending. Many accounts describe our ever-evolving ways of coping with and understanding madness. The metaphors of ‘journey’ and ‘story’ are often used in this context:

> “Most always, healing is not a destination or an objective. Healing is a daily thought process, a series of infinite questions and choices, a skill that is not taught, much less revered, in our culture.” (Muscio 2008, 90)
>
> “Our self-descriptions often evolve over time, reflecting changing experience and analysis.” (Pembroke 2009, 6)
>
> “I have no doubt that my personal story and my explanations of my own mental health will continue to be rewritten and retold until my story comes to an end.” (Faulkner 2010, 41)

> “It is more helpful to see each individual’s mental health as a unique and evolving story, which is importantly influenced by social and relational experiences.” (May 2004, 246)
>
> “Remember that life is a constantly changing range of feelings and experiences: it is okay to have negative feelings sometimes: such feelings may be part of the richness and depth of who you are.” (Hall 2007, 28)
>
> “We all have the opportunity and power to radically reinvent the person we think we are, or are told we have to be. I am on a journey of discovering who that is all the time.” (Shive 2008, 183)

Aside from the transformative potential for the individual, the authors also make clear that changing the ways in which we deal with our own and with other people’s madness could have equally transformative effects on the communities where we live. In this context, questions about our own agency and about taking responsibility for enabling such changes are all posed in the first-person plural:

> “Can we learn about ourselves and each other as a community through crisis? Can we see crisis as an opportunity to judge a situation and ourselves carefully, not just react with panic and confusion or turn things over to the authorities?” (McNamara and DuBrul 2004, 38)
>
> “[S]ometimes we have stayed stuck in our analysis of our powerlessness and in the powerless roles we have grown so accustomed to. As people struggling to emerge from oppression we do not always recognise what power we do have to change ourselves or the people and systems around us. We also hold a key to the door.“ (O'Hagan 2001, 34)
>
> “It is difficult to listen to the history of African-American survivors without feeling intense rage and profound sadness. We can be torn apart or immobilized by these feelings or we can use them as a force to unite and mobilize us in our search for the truth, a past and present truth of our experiences as African-American psychiatric survivors.” (Jackson 2002a, 27)

Many accounts stress the value of our own contribution – as people who have been treated for madness – to changing to the dominant understandings of ‘help’ and ‘support’. When they outline a different perception of role divisions in relation to madness, several authors fundamentally question the need for professional expertise. As opposed to the static role division central to the notion of ‘professional help’, there is a clear emphasis on mutuality, caring, and learning from each other:

> “Only by reaching out to one another, by replacing professional ‘expertise’ with human concern and psychiatric labeling with the recognition of our shared humanity, will we create the opportunity for all of us to change and develop.” (Chamberlin 1988, 241)
>
> “The alternatives for those of us who have rejected the values of the mainstream society, which uses the profession of psychiatry to deal with us, is to care for each other; to help each other from being lost in the underworld, the underclass of the mental patient.” (Pembroke 1992, 15, contribution by Philip Hutchinson)
>
> “Mutuality is the reciprocal process of creating new meaning out of dialogue. The value of mutuality lies in the assumption and practice of each person both giving and receiving in the relationship, rather than the traditional assumption of one person being there to 'help' the other (creating a power imbalance and assuming one person has more 'expertise').” (Mead 2008, 2)
>
> “If I learned one important thing during this long, multistage process called the Recovery Dialogues, it is this: Communication is only possible between equals.” (Penney 2000, 52)
>
> “When the focus is on the relationship, rather than on the individual, there is an opportunity to be affected by each other and to know ourselves as integral in the lives of others, and for both people to undergo a process of change as a consequence of the relationship.” (Mead and Filson 2016, 112)

Similarly to the ways in which personal growth and self-discovery are understood as lifelong and continuously evolving journeys, madness is seen as holding immense and unlimited transformative potential in relation to larger communities and society as a whole. Again, however, the way we approach madness as communities and societies is decisive in setting free that potential and making use of it:

> "As people practice new ways of 'being' together through even the most difficult times, possibilities for breaking old patterns and creating new opportunities are endless. Crisis then just becomes another word for re-defining our experience and ourselves and instead of needing to be locked up we can begin to break free." (Mead 2008, 4)
>
> "Since our way of making change is from the bottom up and begins with working for change within ourselves, we will always be able to make progress. There is no limit to where that may take us." (Beresford 2010, 132)

4.4.6.1 Reflections and emerging issues

The authors understand madness as an integral part of the personal journeys and evolution that we all go through over the course of our lives. In this way, their approaches strongly oppose not only the idea of madness as pathology but also the static nature of psychiatric diagnoses. That madness can lead to positive life changes and that the way that we approach it – both individually and as a society – plays a decisive role in bringing about these changes, are certainly points of agreement. However, various attempts to capture how these processes work exactly, to integrate this knowledge into existing concepts of 'help' and treatment and even to invent new ones, have largely failed to change the dominant discourse about madness. There is increasing recognition and analysis of the reality that first-person knowledge is being appropriated and co-opted in ways that do not alter but preserve the status quo in psychiatric research and practice (Russo and Beresford 2015, Beresford and Russo 2016a, McWade 2016, Penney and Prescott 2016). The following words from Fabris (2016, 103) may be particularly relevant for future thinking about how to avoid these scenarios:

> "I believe there is no way to prevent the investors and their machines from using the next best hope as part of their marketing strategy. Which is why I say we must keep trying to avoid a falling back to 'least restrictive' options. We need to keep moving forward, towards doing something mutual, not by formula, but not by accident either."

Later in this same text, Fabris suggests that “our ideas about how to move to less coercive ways, even ‘systems’ of interaction, cannot be packaged; they are perpetual beginnings.” (p. 105)

In the light of all this, I would like us to consider some key questions: What principles and values in our approach to madness could allow us to preserve – and make full use of – its potential? What can we do at the same time in order to prevent our stances from being understood and applied as the latest methods and techniques? How do we “pull our dreams out of each other in as many languages as we can find to describe them” (Shive 2008, 186)?

4.4.7 Concepts of madness

Several authors included here explain the framework that they apply in their work or even give a name to their own approach or model of madness. This section presents the approaches of individual authors as well as the findings of two UK survivor-led inquiries into our own understandings of madness and distress (Beresford, Nettle, and Perring 2010, Beresford et al. 2016)

Erick Fabris introduces **Mad consciousness** as an analytic framework in his Master’s thesis on community treatment orders (2011) and later on again in his other writings (2013). He uses the capitalised term ‘Mad’ as a historical category “to mean the group of us considered crazy or deemed ill by sanists [...] and [*who*] are politically conscious of this. Thus ‘Mad’ is historical rather than a descriptive or essential category, proposed for political action and discussion.” (Fabris 2013, 139). According to Fabris (2011, 187), this concept “cannot be envisioned as separate from institutionalization because madness and treatment are entwined in madness discourse.” Nevertheless, Mad is not used here in its common sense, which implies divisions into the ‘mad’ and the ‘sound’. The purpose of ‘Mad Consciousness’ and ‘Mad relations’ is to “try to provide an autonomous societal space, at least from which to conceptualize psycho-medical force as othering” (p. 34).

In an argument which strongly opposes the medical model and points to its non-existent evidence base, **Kate Millet** (2007, 32) uses the term **reality model**:

> “In other words, life is very difficult: death is hard to endure, bereavement, the death of love, love's labour lost, hard economic times, lost employment, lost opportunities, the embittering frequency of every form of disappointment in life. This is a reality model,

> built upon reality. The medical model, on the other hand, is not based upon any reality, nor is it medical, though it uses the prestige of physical medicine and the reality of physical disease to mystify us and to command a general social consent, lay or legal."

Maths Jesperson (2016) uses the jungle as a metaphor for madness. His **Jungle model** sheds particular light on the role of the supporter or companion:

> "The jungle is a dangerous place, with no paths to follow and no maps to guide you; a place where you are surrounded by wild animals and many traps. Once you have entered it, it's hard to find the way out, and there is always a risk you will be lost in it for ever. There is no way back so you must try to find your way out the other side. It's good to have a companion on this journey. I don't mean an expert who knows the way out, but four eyes see more than two, and it's good to have someone to discuss your thoughts and ideas with while walking. This companion shouldn't try to pull you out of the jungle, which is impossible. Instead he should enter the jungle himself and make his way to the place where you are, even if this is a reality unknown to him. The main task for the companion is to accept your experience, to dialogue with it – and to start the journey out of the jungle from there." (pp. 136-137)

Based on her personal experiences and informed by queer and critical race theories, **Shayda Kafai** (2013) argues for the 'third positionality' that she names **Mad Border Body**. She explains that

> "[t]his body functions as an alternative to the historical and cultural belief that madness is one half of a static binary structure. In honoring a space that allows for movement, the experience of the mad border body serves as a counter-narrative for madness and sanity." (n. p.)

Kafai points to the potential long-term implications of adopting this concept:

> "If the dominant culture begins to acknowledge the mad border body, that individuals can exist simultaneously in states of sanity and madness, then it must also question the belief that sanity is stable. The power in this questioning does not simply rest in the unhinging of binaries and re-visioning of language. I see the potential for activism in this revision, for the occurrence of tactile changes in how dominant culture and

> Madness Studies views the mad. In this way, the mad border body creates a space for dialogue, a framework for the political reframing of madness." (n. p.)

Jan Wallcraft (2001, 2007, 2009) distinguishes between the biomedical and psychosocial models and what she terms the **self-advocacy model**:

> "The third, emerging model, I call the self-advocacy model, developed by service users/survivors and their allies, challenges the power of professionals and their right to define and treat so-called mental illness. It emphasizes the value of personal experience in knowledge creation and the importance of regaining power and control over one's own life." (Wallcraft 2007, 343)

This model focuses on "establishing full legal and citizenship rights for people with mental illness diagnoses" (Wallcraft 2001, 101). Moreover, though it overlaps to a certain extent with the psychosocial model, the self-advocacy model is fundamentally different:

> "Both psychosocial and self-advocacy discourses argue that crises arise mainly from life experiences. However, the self-advocacy discourse asserts the right to self-definition and argues that any understanding of crisis should be grounded in personal experience, challenging models based on professional expertise and power." (Wallcraft 2001, 281)

The role of the supporter in the self-advocacy model is similar to the companion's role in Jesperson's 'Jungle model':

> "The role of professional help according to self-advocacy discourse, should be to work alongside the person in crisis as an enabler, ally and supporter, rather than to define, control and treat a 'sick' person. This is not a rejection of professionalism, but a challenge to the legal and social power and status of professional expertise, to the detriment of expertise based on personal experience of crisis." (Wallcraft 2001, 100-101)

The discourse of self-advocacy is often also implied in the context of user/survivor activism and organising, as described by Campbell (1999, 199):

> “[T]he movement also shares important positive beliefs. Pre-eminent among these is the belief in self-advocacy – the possibility and desirability of people speaking out and acting for themselves.”

With the adoption of the United Nations (2006) Convention on the Rights of Persons with Disabilities (UN CRPD), parts of the international user/survivor movement have started using the concept of **psychosocial disability**. This concept and the topic of disability in general have been controversial within the European movement (Russo and Shulkes 2015). In some parts of the world (e.g. Asia and Africa), the psychosocial disability concept seems to be embraced more widely than it is in the Global North[34] (Robb 2012, Robb and Shulkes 2013). A discussion of the advantages of this approach, particularly in relation to feminist understandings of women’s mental distress, can be found in the work of **Bhargavi Davar**, who is from India. Davar (2008) strongly supports the conceptualising of mental ill health in terms of psychosocial disability:

> “The disability discourse affirms the expertise of experience. The women’s movement did not address the issue of women’s fragility, the real experience of disability, the possibility of insight into the disability, and the desire for healing, recovery, joy and growth.” (p.269)
>
> “While mental illness could be a myth, the suffering and disability were not. We wanted to talk about feeling sick and the right to ask for support and to be cared for.” (p. 273)

Pointing to the potential of the CRPD, Davar (2008, 284) emphasises the non-stigmatising nature of disability discourse:

> “For users/survivors of psychiatry, reference to psychosocial disability names that aspect of nameless suffering that they have carried in their lives without the stigma. Disability normalises the experience with respect to humanity as a whole and does not set up a regime of exclusion.”

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[34] See Pan African Network of People with Psychosocial Disabilities at https://www.facebook.com/PANPPD/# and Asian Alliance of people with psychosocial disabilities at http://www.tci-asia.org/aboutus.html

As we will see, many people with psychiatric diagnoses disagree with this stance. Davar herself warns of the potentially retrograde implications of simply replacing ‘mental illness’ with another category:

> “While bringing the disability discourse into mental health thinking is promising and prominent in public policy today, merely replacing the notion of mental illness with psychosocial disability would be nominal, and could once again result in mirroring errors from the past.” (Davar 2008, 284-285)

The social model of disability is increasingly being discussed within the international user/survivor movement. Two UK survivor-controlled research reports (Beresford, Nettle, and Perring 2010, Beresford et al. 2016) into service users’ views about social approaches to madness and distress, reveal that people with psychiatric diagnoses are ambivalent about adopting a disability framework for their experiences. Both these inquiries worked with individual interviews and focus groups; the second project also included an online survey. The 2010 research extended to 51 persons; in 2016, a total of 82 people took part. The inquiries produced similar results; the following excerpts give some insight into participants’ perspectives on the social model of disability. An enduring controversy surrounds the notion of ‘impairment’ inherent in this model, which

> “[w]as an important barrier for a number of people in the way of seeing the social model of disability as helpful or transferable to them as mental health service users. So while many felt they were ‘disabled’ as mental health service users, they did not necessarily see this as underpinned by some actual specific impairment.” (Beresford, Nettle, and Perring 2010, 26)
>
> “However, in the original form of the social model of disability, impairment tended to be seen as something objective, a measurable absence of or lack of functioning in some bodily part or mechanism. What some comments from participants suggest is that if the model is to be transferrable to mental health issues, then impairment may also need to be seen, at least in some cases, as socially constructed, like disability.” (Beresford, Nettle, and Perring 2010, 28)

The second inquiry into this topic confirmed that “[a]ny attempt to impose the social model of disability crudely on mental health issues and mental health service users is unlikely to gain widespread support from service users at present.” (Beresford et al. 2016, 6). As well as highlighting the contested nature of impairment both inquiries revealed some other problematic implications of simply applying a social model of disability to madness and distress:

> “For example, it could result in a tendency to see all distress as the same and reinforce the negative labelling of mental health service users and reinforce an unhelpful perception of them as a separate and permanent group.” (Beresford, Nettle, and Perring 2010, 25)
>
> “Some participants in our project (indeed like some disability commentators) also feel uncomfortable with drawing over-simplistic distinctions between the personal and the social; the psychological and the social and highlight the need to recognise the interactions of the two and the value of a holistic approach.” (Beresford et al. 2016, 59)

In our analysis of the use of the concept of disability within the European user/survivor movement (Russo and Shulkes 2015) we came to the conclusion that we cannot simply subscribe to the social model of disability. We stressed the need to develop our own understanding of madness and distress:

> “Even though the disablement experienced by users/survivors might have a similar or even the same effect as other kinds of disabilities, one fundamental difference remains: ‘mental illness’ cannot just be pronounced equivalent to physical or sensory impairment. Aware that the latter is also being challenged as a construct, we maintain that people with psychiatric experience cannot simply adopt the social model of disability one-on-one without further examining the nature of the ‘impairment’ in our case. This powerful, emancipatory model resulted from the efforts of disabled people themselves. However close these experiences are to our own, simple appropriation of this achievement cannot replace the equivalent systematic work and effort needed from users/survivors ourselves. It remains our task to work towards a similarly comprehensive framework for understanding madness and distress which does justice to *our* experiences and *our* lives in the same way that the social model of disability captures the realities of many disabled people.” (p.36, emphasis in original)

Some other works included in this inquiry suggest that the relationship between the social model of disability and a potential social model of madness is not static and that these two models could influence and enrich each other:

> "[I] don't think we need a separate model of our own, any more than we need a social model of blindness, or deafness or physical disability. […] I do, however support the call for a social model of madness, though for me this would be based on, not instead of, the social model of disability." (Webb 2015, 154)
>
> "Paul Abberley and other disabled theorists since, have highlighted the *social origins* of impairment and impairment as a *social construction* (Abberley, 1987; Barnes, 1999). Impairment understood in these terms fits the experience and understanding of many psychiatric system survivors much more closely and no longer represents such a difference or barrier between survivors, disabled people and disability." (Beresford 2000, 170)
>
> "The concept of disability is continually evolving such that being mad, being autistic, being a Down syndrome person [sic], being a Deaf person using sign language and experiencing life within Deaf culture, being a person with any kind of body configuration and body experience, may one day no longer be classified as disability. The concept itself may one day be obsolete. But it has utility as a way of describing a cluster of situations relating to discrimination, the hegemony of 'normality' as a value judgement against the full range of human diversity [...]." (Minkowitz 2014, 130)

The most comprehensive reflection on the **social model of madness and distress** can be found in the work of **Peter Beresford** (2002a, 2004a, b, 2005a, 2009, 2010, 2013, 2015). Notably, both Beresford's understanding of this model and the ways that he outlines it have evolved over the years as he moves away from issues of mental health and psychiatry towards broader and more complex social questions. So, for example, in an early text written together with Gloria Gifford and Chris Harrison (1996), it is envisioned that the social model of madness and distress will highlight the following topics:

- "the social causes of our madness and distress;

- the medicalisation of our experience and distress;
- the restrictive and discriminatory response to it from both psychiatry and broader society;
- the need for a social response to the distress and disablement which survivors experience, addressing the social origins and relations of their distress, instead of being restricted to people’s individual difficulties;
- the need for survivor-led alternatives to prevent distress and offer appropriate support for survivors.” (p. 211)

Fourteen years on, Beresford outlines the principles and values of the social model as follows:

- “prioritising self-advocacy
- being rights-based
- building on the philosophy of independent living
- self-management and self-support
- commitment to anti-oppressive practice
- supporting race equality and cultural diversity
- minimising compulsion
- breaking the bad/mad link
- prioritising participation
- equalising power relations” (Beresford 2010, 64)

In writings about the social model, Beresford emphasises the complex interrelationship of individual experience and social responses (2009, 50), the importance of first-person authority and the need for attention to issues of difference. These factors, he notes, are integral to this model:

> “[I]t is crucial that this is a discussion in which mental health service users have a lead role. This involvement needs to be as broadly based as possible to reflect difference, according to gender, age, sexuality, ethnicity and class, as well as experience of the psychiatric system.“ (Beresford 2002a, 584)

Beresford’s article “Developing self-defined social approaches to madness and distress” (2005a) draws an important distinction between this social model and social approaches that do not challenge the notion of mental illness. Referring to these approaches, he says:

> “While they may emphasise explanatory factors outside the individual as well as within him or her, they do not necessarily challenge underpinning conceptual frameworks which may be involved. They may simply relocate the explanation for them. Thus the cause(s) of the individual’s ‘mental illness’ or ‘disorder’ may now be seen to lie (at least in part) in the wider world, but as ‘mentally ill’, the individual is still deemed to be problematic and defective. The individual model of ‘mental illness’ remains unchallenged.” (pp.111-112)
>
> “There is no question that there has been an awareness of social issues in some mental health disciplines and professions for some time. But this has tended to focus on social issues as *factors* in the creation of mental health problems. It has tended still to take mental illness or disorder as a given – to accept the idea – rather than attempting to reconceptualise mental health within a social framework.” (Beresford 2010, 57, emphasis in original)

While the service user/survivor movement has not developed a philosophy of its own, Beresford documents how its activities have been underpinned by a set of key values and principles. In his opinion, those values and principles ‘reconceive the social’:

> “Survivors’ discussions about their lives and experience tend to accent the *holistic* nature of their situation. This includes and interconnects the physical, mental (emotional and perceptual), spiritual, social and political. In this sense they go much further than traditional ‘psycho-social’ approaches to ‘mental health’ issues, which have sought to focus attention on both the personal/psychological and the social/structural. Here the emphasis of survivors is on the complex (non-medicalised) interrelations of ourselves, our lives, our minds, our bodies and our environments.” (Beresford 2005a, 113, emphasis in original)

The constraints imposed on the actual options of users/survivors have inhibited the development of these discussions in the direction of a more comprehensive framework:

> “Service user/survivor discourses address both material and spiritual issues; the personal as well as the political. Service user/survivor organisations have frequently been characterised by their twin emphasis on mutual aid/personal support and campaigning and action for broader (social and political) change. While, as has been said, their activities have frequently had to focus on the (mental health) service system – because this is where they have been able to access resources – their concern has been much broader.” (Beresford 2004b, 42)

Several authors or participants in research included in the present inquiry emphasise that users/survivors require our own model of madness and distress or else a more coherent framework that would enable us to advance our thinking and action:

> “I think we need to have the equivalent of a fundamental philosophy to shape where we go, like the disabled people’s movement has, and we need to reject the mental illness model of distress and madness, and we haven’t done that as a movement yet.” (Wallcraft, Read, and Sweeney 2003, 50, participant's comment)
>
> “I am actually in favour of survivors taking action against biomedical psychiatry but not unless that action is well-considered and directed. There are dangers in gathering around a flag that someone else has planted, just because it flies quite proudly and has colours similar to ours. But if we have doubts, the answer is not to stand colour-less but to raise our own flag with our own true colours and fight on alongside The current initiative on biomedical psychiatry deserves a survivor-response and in the course of it, perhaps a second flag.” (Campbell 2001, n. p.)

Nevertheless, when it comes to this question about our own model or theory, the need to maintain first-person authority and agency remains a strong point of agreement among these authors and research participants:

> “Some comments highlighted people’s reluctance to impose another single monolithic interpretation of their experience on service users/survivors. So while valuing social models over medical models, they didn’t want to impose crude new exclusions.” (Beresford et al. 2016, 43)

> “One respondent suggests that the issue is not so much one of replacing one model with another as of shifting power towards service users/survivors […]” (Wallcraft, Read, and Sweeney 2003, 50)

4.4.7.1 Reflections and emerging issues

There is significant overlap among the concepts and frameworks presented in this section. While they use different names and prioritise different aspects of madness and distress, these understandings do not oppose but rather complement and echo one another. There seems to be scope to merge them and so form a set of joint core values and principles which might be the object of further discussion. At the same time, I believe that the concepts presented in this section speak to other findings of this inquiry and affirm that “having our strong body of knowledge, framed outside a medical model, can be better than seeking an overarching monolithic theory which can overshadow us.” (Beresford 2015, 258). For this reason, instead of trying to merge these models, I would like to pool together all the main findings, including these models, in the last chapter of the thesis.

4.5 In summary

The findings from this research phase and the issues that emerged from the analysis of survivor written accounts marked the departing point for the interviews in the next research phase. The summary of the main findings and the key issues for further exploration can be found in one place in Appendix B.

As stated earlier, the extended version of this chapter was shared with all participants prior to the interviews. It served as the basis for the second research phase that I describe in the next chapter.

CHAPTER 5 UNMAKING MADNESS. REPORT OF THE INTERVIEWS

After engaging intensely with the written sources in this study (see the previous chapter), I moved on to interviewing some of their authors. Before I describe the stages and outcomes of that process, I need to note that aside from being incredibly profound and enriching experiences, these fourteen interviews marked a turning point in this inquiry and in my overall approach to the topic. During the previous phases, my work had been very much focused on the ways the authors approach and explain madness. And though I did not analyse any individual accounts or search for an explanation all the authors would consent to, in retrospect I can see that I was actually putting these perspectives on madness under the microscope. The interactive phase of this study allowed me to experience what it means to ‘flip the micro-scope’, a move which Lucy Costa (2014) highlights as a distinctive contribution of Mad Studies (LeFrançois, Menzies, and Reaume 2013, Beresford and Russo 2016b, LeFrançois, Beresford, and Russo 2016, Ingram 2016, Russo and Sweeney 2016). The interviews meant re-directing the microscope that is usually aimed at us and our experiences and instead magnifying what *we* found important, or more precisely, what each of the participants chose to focus on. Rather than straightforwardly progressing towards a shared view of madness, each interview, then, uncovered other issues at stake and brought these into the conversation. The whole process turned into a deconstruction of the very concept of madness that exposed its important intersections and real life features. This chapter describes that process and the knowledge gathered in this phase.

5.1 The interview partners

Initially I had planned to invite a sub-sample of the people whose work was included in the previous phase but it soon became obvious that this approach would only reinforce the existing dominance of white authors. For this reason, I diverged from the initial plan and also invited people whose work was not among the sources I had been reading either because I discovered it later on or because they had not published anything but were contributing importantly to activism and knowledge production in other ways. Of the twenty-one people whom I invited to join this study (see the participant information sheet and the consent form in the Appendices C and D), fourteen were able to take part.

As I noted in the introductory chapter, my goal was not to achieve any kind of representativeness. Instead I invited people on the basis of their academic and political work and its relevance to the topic being investigated. For this reason, describing the participants via standard demographic categories does not accord with the overall approach of this project. Furthermore, the right to self-define and avoid subjection to an external gaze or classification system is at the core of what this research is about. Such classification systems are not limited to psychiatric diagnostic categories. The notion of 'race' was also called into question throughout the interviews; many participants rejected this category as a matter of principle. I will come back to these important issues when presenting the findings.

The list below contains short (auto)biographies of my interview partners ordered alphabetically by their first name. Wherever possible, I have endeavoured to preserve their voices by reproducing their self-description. Three participants chose to stay anonymous. The others opted to use their real name.

Abena identifies with 'her','she' and other woman-centred markers. She is an independent scholar, whose work has focused on matters in health care, specifically the sociology of deviance, medicalisation and social control. Her anti-capitalistic/authoritarian/universalising/psychiatry perspective grew out of her anger at the electroshock treatment her grandmother endured following the deaths of her first born and her husband within two years of each other. This would come to a head later on when Abena had to negotiate the Canadian medico-legal system and the (violent) complicity required as a condition of access to this system.

Colin King writes**: "**Diagnosed with schizophrenia after a escalator of structural and cultural racism within the English education system. Progressed to acquiring over nine degrees in the transition to a senior mental health practitioner to endure three further admissions into the new slavery within mental health care. An activist, writer and instigator of a new coproduction of changing and the empowerment race equality and whiteness within the institutions of psychiatry to address a new 'drapetomania' experienced by the over-representation of black men."

David Webb completed what is thought to be the world's first PhD on suicide by someone who has attempted suicide. His research evolved into the book *Thinking about Suicide* (2010). David argues that suicide is best understood as a crisis of the self, and he rejects the prevailing view that it is a consequence of some pseudo-scientific 'mental illness'. He regards human rights as the core issue in mental health. Before embarking on his PhD (and the 'four years of madness' that motivated that research), David worked in the computer industry as a software developer and university lecturer. He has been a board member of the World Network of Users and Survivors of Psychiatry and worked as a research/policy officer with the Australia Federation of Disability Organisations. David has lived in New York, Delhi and London. After many years as a (psychosocial) disability advocate/activist, he was forced into early retirement by chronic illness and now lives quietly in Castlemaine, an old gold-rush town near Melbourne, Australia.

Dominic Makuvachuma is the co-chair of National Survivor User Network, England. He has been contributing to the voice of direct, lived experience of using mental health services for over 20 years through a range of platforms. He is a Zimbabwean father of three, and the first African survivor to contribute as a panellist to an Independent Homicide inquiry as well as an internal inquiry into a Serious and Untoward Incident leading to the Death in Custody of an African Caribbean Patient. Dominic was the Development Manager of the national black and minority ethnic mental health service user/survivor network in England, Catch-A-Fiya, from 2006-2008. At the time of the interview Dominic worked as an Engagement Manager for Mind.

Irit Shimrat writes: "I was born in 1958 in Israel. My parents, Polish Jews by birth, moved first to America and then to Canada when I was small. I graduated from high school in Toronto, completed one year of university, and then went nuts and got locked up in late 1978. I was an incarcerated mental patient for most of the following two years, first on locked wards in general hospitals and then in a minimum-security psychiatric facility. After escaping from the latter, I gradually recovered from psychiatry. Starting out in office work, I went on to complete a community college course in editing and, in 1986, become the editor of *Phoenix Rising: The Voice of the Psychiatrized*, a national magazine.[35] In the early 1990s I co-founded and coordinated the Ontario Psychiatric Survivors' Alliance and presented two anti-psychiatry shows on Canadian national radio. In 1993 I moved to Canada's west coast and in 1997 published *Call Me Crazy: Stories from the Mad Movement*. Then I went nuts and got locked up a bunch more times, most recently in 2007. Again at large, I have continued to edit, and to expose abuses perpetrated in the name of 'mental health'."

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[35] See http://www.psychiatricsurvivorarchives.com/phoenix.html

Jan Wallcraft has been a leading member of the UK survivor/service user movement for many years. She is a freelance researcher and has worked in service user involvement for a range of non-governmental organisations in England. Jan has a PhD from London South Bank University based on her research with the narrative accounts of people's first psychiatric hospitalisation, which from her own experience she regards as as a turning point, not always in the right direction. Jan was a fellow of Birmingham and Hertfordshire Universities and a research associate with Wolverhampton University. As an author and editor, she has contributed to a number of publications including *On Our Own Terms. Users and survivors of mental health services working together for support and change* (2003) and *Handbook of Service User Involvement in Mental Health Research* (2009). Due to health issues, Jan retired in 2014.

Kathy is in her 60s and is white British. She first came into contact with psychiatry when she was in her twenties and was admitted to a psychiatric hospital three times. The third time, something happened which made her realise that the hospital staff didn't have her best interests at heart and she vowed never to be admitted to a psychiatric hospital again. She found it incredibly difficult to live on her own without support but, somehow or other, managed to keep herself out of hospital and eventually went on to study and gain full-time employment. Kathy developed her own ideas about her madness and distress, but didn't tell anyone until she joined the survivor group Survivors Speak Out many years later. It was only through meeting other people with experiences similar to hers that Kathy began to realise that her life need not be as restricted as it was and that she could do all sorts of things that the psychiatrists had said would not be possible. Since then, she has been taking full advantage of life's opportunities!

Lauren Tenney is a psychiatric survivor and activist first involuntarily committed in 1988 at age 15. On her website[36] she writes: "I have an anti-psychiatry, pro-human rights framework. I have been working to abolish psychiatry for more than two decades. I have overcome many obstacles in life, including escaping psychiatry. I have done things people said were impossible to do. I continue to try to do more. I am not unique." Lauren has a PhD in environmental psychology from City University of New York and master's degrees in the philosophy of psychology and public administration. She is an adjunct assistant professor at the College of

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[36] http://www.laurentenney.us/

Staten Island, City University of New York and an adjunct professor at Montclair State University.

Mary O'Hagan was a key initiator of the mental health service user movement in New Zealand in the late 1980s and served as the first chairperson of the World Network of Users and Survivors of Psychiatry between 1991 and 1995. She was a full-time mental health commissioner in New Zealand between 2000 and 2007. She has been an advisor to the United Nations and the World Health Organization and has written and spoken extensively in many countries. Her award-winning memoir *Madness Made Me* was published in 2014. Mary is now the director of PeerZone[37], a peer-led social enterprise which develops and delivers resources and supports by and for people with experience of mental distress. Mary was made a member of the New Zealand Order of Merit in 2015 for her services to mental health.

Prateeksha Sharma, born in 1972, is a musician from India, who has known 'psychosis' for the better part of her life. It started with a diagnosis which lasted for 18 compliant years of patienthood. A chance encounter with alternative, social constructionist perspectives altered her worldview radically. Today, based on those long winding alleys, she is also a researcher in three areas- one of which takes her towards a doctoral degree. Her doctoral research is also about understanding psychosis and recovery in an Indian milieu. The other two areas of work and research are applied musicology, and counselling. She works on a new model of counselling which begins from her experiential perspectives, in which she assumes the position of a peer-therapist.[38] Braving a series of failed entrepreneurial ventures, Prateeksha is now putting together a sole entrepreneurship venture, called *Hansadhwani- mind.mood.music,* a knowledge enterprise which works towards empowering diverse groups of people. She lives with dogs, fish and cockatiels inside her home and regularly sinks her fingers into gardening, teaching classical music, and working on new musical compositions, to keep herself playful, light and internally anchored.

Ron Bassman writes: "I am a 73-year-old white Jewish male of East European ancestry - first generation in the United States. I have a PhD in counseling psychology. My journey through 'schizophrenia' and recovery has given me an understanding of madness, recovery and

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[37] https://www.peerzone.info/

[38] www.prateekshasharma.com

transformation that challenges mainstream assumptions and theories about mental illness. After more than forty years of studying madness or what I prefer to call extreme and diverse mental states, my beliefs and understanding have continued to evolve. When I was 22 years old, I was involuntarily committed to a psychiatric institution for six months where I was diagnosed with paranoid schizophrenia and subjected to massive doses of medication along with a combined series of forty insulin induced comas and electroshock. Discharged after six months with extensive memory loss, my climb to recover began with a job as a case worker for the Welfare Board in Newark, New Jersey. I was disavowed of my belief that my hospitalization was an anomaly when three years later I was hospitalized again for another seven months and diagnosed with schizophrenia, chronic type. After I recovered from my second hospitalization - 7 months locked up - I returned to graduate school, earned my PhD in psychology and became a licensed psychologist. I believe that by writing and speaking my truth to power, I can challenge the misconceptions of both mental health professionals and the general public with the hope to bring about much needed changes."

Shayda Kafai is a lecturer in the Ethnic and Women's Studies Department at California State Polytechnic University, Pomona. She earned her PhD in Cultural Studies from Claremont Graduate University. Her dissertation titled *Re-inscribing Disability: The Performance Activism of Sins Invalid* explores the performance art and disability justice work of *Sins Invalid,* a San Francisco Bay Area- based performance project. Asked to describe herself, Shayda replies: "I identify as a queer, crip woman of color. I am Iranian-American and I am 33 years old. I write actively about the different ways the body rebels against the discipline and regulation of institutions of power and am committed to exploring the numerous ways we can reclaim our bodies from intersecting systems of oppression." Shayda lives in Los Angeles with her wife, Amy.

T is a 35-year-old white British woman.

Vanessa Jackson is an activist, Soul Doula and clinical social worker based in Atlanta, Georgia. On the website of Healing Circles, Inc.[39], her counselling and coaching private practice she writes: "As a Soul Doula, I invite people to go deep, to tap into their most soulful

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[39] http://www.healingcircles.org/

desires and to create a life that reflects their more passionate and powerful selves." Together with Elaine Pinderhughes and Patricia A. Romney, Vanessa edited *Understanding Power: An Imperative for Human Services* (2017). She is the author of the monographs *In Our Own Voice: African-American Stories of Oppression, Survival and Recovery in Mental Health Systems* (2002b) and *Separate and Unequal: The Legacy of Racially Segregated Psychiatric Hospitals* (2003). Vanessa has published chapters in anthologies in the United States and has presented at several international narrative therapy and community work conferences. Her discussion of African American psychiatric history was featured in the Friday Afternoons at the Dulwich series. Vanessa holds a Master of Social Work from Washington University-George Warren Brown.

Overall, the study's participants were ten women and four men living in the following countries: USA (4), UK (4), Canada (2), Australia (2), India (1) and New Zealand (1). No one identified as non-binary or transgender. Six participants were people of colour and eight were white. The participants ranged in age from in their thirties to in their seventies but most (nine of the fourteen) were older than fifty at the time of the interview. The vast majority held a higher education degree; eight people had a PhD and two were pursuing one. Although I didn't contribute an interview, I participated in this study in the role of researcher. So here is my brief bio as well:

Jasna Russo comes from the former Yugoslavia where she experienced forced psychiatric detention and treatment. Her immigration to Germany in 1992 helped her escape further psychiatrisation. In the same year, she joined the international user/survivor movement. She remained an active member of the European Network of (ex-)Users and Survivors of Psychiatry in different roles until 2016. Jasna is based in Berlin and works as an independent researcher. She has a master's degree in clinical psychology and has worked on both survivor-controlled and collaborative research projects, including several large-scale international studies. Before becoming a researcher in 2002, Jasna worked for ten years as a social worker. She worked with young refugees and also as a counsellor in a shelter for women and child victims of domestic violence and on a women's rape crisis hotline. Her articles have been published in anthologies and journals in Germany and the UK. Together with Angela Sweeney, she edited *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies* (2016).

5.2 The interviews

The interviews took place between October 2016 and April 2017. With the exception of one phone interview, all were conducted via Skype. Most of the conversations lasted about 1 hour and 15 minutes. The longest one lasted 2 hours and the shortest 25 minutes (for more details about the short duration of this interview, see pages 178-180).

As I search for a way to describe these interviews, "conversation" or "structured conversation" are the terms that come closest to what actually took place. The interviews were inevitably far more conversational than is conventionally the case since the departure point was the work I'd done in the previous phase and my invitation to join this inquiry and continue exploring the topic together. Additionally, since I am also an inhabitant of the "territory" explored in this thesis, participants often wanted to know my opinion about the issues I was asking them about. As I engaged in these conversations, I was in a way co-creating the data. I tried my best to stay within the interview format, but this sometimes proved hard since the entire process was very much about exchanging ideas and thinking together. Some questions were so big that it was clear that they were unlikely to generate any simple answers or solutions. However, those same questions led to valuable thoughts and ideas about how we might continue addressing these issues and what to consider in future work. In this way, progress was made even with the questions that seemed unsolvable. This realisation dawned on me as I listened carefully to what had been said while transcribing the interviews. Each interview either encouraged me to keep thinking in the direction I had been pursuing already and brought new clarity or else it posed a lasting challenge and raised new questions. On most occasions, I had experienced both and so each interview has immense personal meaning for me. These fourteen conversations were the most rewarding and enriching experiences I have had in all my years of personal, activist, research and theoretical work around madness.

The interviews were transcribed in the order they were conducted in, and I completed ten of these transcripts myself. With a small bursary from Brunel University, I was able to arrange for the transcription of the remaining four interviews, but I re-listened to those audio files and checked the transcripts myself before sending them to the participants. As these transcription funds were the sole financial support I received in the course of my part-time PhD[40], I needed to stay in employment throughout my studies. This circumstance combined with my slowness as a non-native speaker caused considerable delays in completing the transcripts. I am thankful for the participants' understanding, encouragement and support throughout this process. After

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[40] The transcription bursary was for GBP 250 in total.

receiving their transcripts, eight participants made edits and six approved the document as it was.

5.3 The analysis

Despite consuming a great deal of time, my transcription work proved worthwhile as it enabled me to engage on a deeper level with what my interview partners had said. Some authors consider transcription to be the first step in the analysis because it helps the researcher immerse themselves in the data (Braun and Clarke 2006). In my case, I often felt submerged in the 'data' and conscious of it shaping my thinking. Occasionally it overwhelmed me so I had to note down my thoughts even as I transcribed. Transcribing my own voice also proved helpful. Often during the interviews, I summarised the participant's words to check my understanding of what they had said. Sometimes I also shared my thoughts on the subject.

Besides the fourteen transcripts, the body of data included three additional documents compiled from participants' emails[41] amounting to more than 92,000 words. In order to better navigate this substantial material, I worked with qualitative analysis software (NVivo, version 10).

While some researchers claim thematic analysis is more of a tool than a specific method (Boyatzis 1998, Ryan and Bernard 2000), others recognise this widely used approach as "a method in its own right" and praise its "theoretical freedom" (Braun and Clarke 2006, 78). Thematic analysis is common in survivor-controlled research because it reduces the room for the researcher's own interpretation and demands adherence to the participants' intended meanings. (Faulkner 2004, Turner and Beresford 2005, Russo 2012b). Braun and Clarke's (2006, 97) summary of the advantages of thematic analysis (quoted in full below) demonstrates why this approach is so well suited to the topic and purpose of this inquiry:

- "Results are generally accessible to educated general public.
- Useful method for working within participatory research paradigm, with participants as collaborators.
- Can usefully summarize key features of a large body of data, and/or offer a 'thick description' of the data set.
- Can highlight similarities and differences across the data set.
- Can generate unanticipated insights."

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[41] Three participants emailed me relevant material. These emails were either (1) their comments after receiving the report from the previous phase or (2) their amendments to what they had said during their interview. I obtained their permission to add these emails to the analysis.

In my first round of coding, I aimed to arrange the material into themes and sub-themes. The second coding was about checking everything again and seeing whether any of the sub-themes could be merged. The fourteen main themes (nodes[42]) largely followed the topics of the interviews (see the interview topic guide in Appendix E) while the eighty-one sub-categories (child-nodes) mapped my own journey through the data and the themes identified. The coding frame that I developed (see Appendix F) shows the inductive nature of that process. In this approach, to quote the words of sociologist Arthur Frank (2005, 969), "[t]he themes situate the stories; they do not substitute for the stories." In the next step, I explored connections among the different themes and re-organised the material accordingly to report the findings.

As with my research with written accounts, the principles that best describe my work can be found in the socio-narratology approach developed by Frank. Most relevant are his principles of dialogical interpretive practice (Frank 2010) by which the "analysis becomes another voice in the polyphony". As I understand it, dialogical practice does not offer an easily applied set of working techniques. Rather, this approach cannot be detached from an underlying set of values concerning the ethics of the analysis. Typically, in mental health and psychiatric research, the ethical issues relate to the recruitment of participants, their informed consent and their right to withdraw; the researcher's approach to the analysis is hardly ever addressed as an ethical concern. This conventional approach ultimately enables the dominance of the researcher's voice (see my discussion in Chapter Two). For Frank (1995) on the other hand, from the very beginning of his work with narratives, this dominance is problematic. He clearly perceives it as an ethical issue:

> "Those who have been objects of other's reports are now telling their own stories. As they do so, they define the ethics of our times: an ethic of voice, affording each a right to speak her own truth, in her own words." (p.xiii)

Along with the principle of non-finalisability (see my discussion in Chapter Three), dialogical practice calls for the use of second-person address (not speaking *about* but *with*) and the renouncing of the privilege of interpretive authority (Frank 2010, 100). As such, it encouraged me to keep questioning and modifying my role and to make this process transparent. At the same time, I couldn't avoid being aware of the conventional demands for 'neutrality' and 'distance' in academic work (Harding 1991, Beresford 2003a, Faulkner 2015). In his foreword to the book *Whiteness Made Simple*, Colin King (2007, ix) describes "how academics have

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[42] The NVivo software operates with the terms 'nodes' and 'child-nodes' to describe themes and sub-themes.

been persuaded to believe that you lose your objective status if you reveal how your analysis has been affected by the evidence you see, feel and hear.” Among other things, the analysis in this report reflects a conscious decision to resist this conviction.

As a matter of principle, when reporting research findings, I always attempt to separate my voice as a researcher from the participants’ voices so that readers may form their own impressions without my interference. In the past, my usual practice had been to first describe participants’ views using as much of their own wording as possible and then add my own thoughts at the end of each section. When it came to writing up the present report, however, the difference I experienced was that I was no longer able to keep my voice separate from the voices of participants since this would mean distancing myself and writing myself out of the research process. At the same time, I felt no desire to merge our voices into one. What I actually wanted was to *respond* in my own first-person voice and *continue the conversation* while reporting because the participants’ thoughts continued to shed new light on my own experiences and open up new perspectives. But this was not only about the things I was coming to understand or the insights I was gaining. The analysis made me want to bring myself into the reporting process and record the memories, feelings and thoughts that were being evoked. This is different from undertaking positioned research or recognising that our work is always informed by our standpoints (Harding 1991, Frank 2000, Beresford 2003a). My standpoints had been decisive at the outset of this project when I had chosen the topic and designed this study. But after I entered the research process, those standpoints were anything but static. Sometimes I could barely keep hold of them anymore because my thinking was by turns being validated, challenged and transformed.

Generally, I approached the task of analysis in the same way I had in my work with written accounts (see Chapter Three). In exploring those written sources, I had tried not to focus on discrete accounts but instead positioned the analysis in the spaces that opened up between individual accounts and explored the ways different experiences and thoughts connected and interacted with each other. In other words, I had focused the analysis on the dialogue and interplay among our perspectives. This approach intensified in the interactive phase of this study when the dialogue that I had set up in the previous phase turned into an actual dialogue. I didn’t know where this approach would lead as I had never worked in this manner before but could clearly see the difference. I will return to these issues and address Oliver’s notion of emancipatory research paradigm (1992) in the closing chapter of the thesis.

Finally, this approach to the analysis has implications for the structure and style of my report of the findings. This chapter is an attempt to find a format to document the interviews that would allow the important conversations they initiated to extend beyond the boundaries of this particular study and hopefully continue in many different contexts.

5.4 Findings

5.4.1 Feedback on the interim report and emerging issues

Everyone who agreed to take part in an interview received the report about my work with written sources in the previous phase.[43] As the full report was 74 pages long, I also wrote up a 13-page summary. Seven people read both documents before their interview, five read the summary and two didn't have time to read either document. The interviews usually started with the participant sharing their thoughts and impressions of the report(s). Sometimes we entered into this conversation even before the interview had begun as the following excerpts from an email exchange between Abena and me show. I am providing some insight into this exchange because it raises issues that I believe are relevant to all research with written accounts.

Referring to the information I'd given about the authors in the previous phase, Abena wrote:

> "[I] did wonder about the way that you engaged with 'race' and gender. I appreciate the nod that you made to having no information on whether authors were trans. But in that same token, how did you ascertain gender otherwise? By their given name? Did you ask? Or perhaps, in some instances, there was a gender pronoun in their writing that would have alluded to their self-identification? I'm finding my own research frustrating, as I purposefully made no effort to recruit participation based on gender. However, I'm now faced with translating participants onto a page, with no idea how they would want me to engage with them in writing. […] In a similar vein, I can't help but wonder about the whiteness that you remark among your authors. It is not that I doubt the 'dominance of white authors,' but it is not clear from your reflection that you are not conflating 'race' with geographic locations (re: having paired it with a table of countries). I very much recognize that these answers are perhaps found in your findings, which I never did get to. I also know that, if one is to adopt intersectionalities to its fullest, we could

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[43] This document is also called the 'interim report'.

> spend an entire dissertation with caveats and reflections of who each participant is (and/or is not). To which I then wonder, what is important to share? But more so, why I am sharing this? Is this important? If yes, how is it important? If not, what am I risking by sharing? […] Thoughts/brainstorming back always welcomed, but I really just wanted to employ my read-through as peer feedback” (email, 3 Oct 2016)

I wrote back:[44]

> *“[Y]our email already kind of starts the conversation that I am looking for. I will just briefly reply to some of the issues you raise. Re. gender - yes, I was considering people's names (not always easy), the pronoun they used (if they used one) or some other descriptions. Identifying as transgender was not a topic included in any of the texts I analysed, but as already said there might have been trans authors among the people included who simply did not write about that. When trying to figure out how many people of colour were among the authors, I relied on my own knowledge of some of them and also considered the information provided in their texts, which is certainly problematic as it presumes that those who don't mention their ‘racial’ identity are white. Most of the Black authors come from the UK or USA. Do you think I should have allocated numbers to the countries? All this counting activity has the dubious side effect of me also assigning people to certain groups. On the other hand, I needed to figure out this number for myself and face it rather than leave it just at 'the vast majority are white'.”* (email, 4 October 2016)

The question of how to deal with the expectation to provide demographic information about research participants was re-opened during my interview with Abena. I will come back to this important question in section “Prospects of joint work within the context of inequality and injustice” (pp.173-190) but for now I want to focus on the other insights participants shared about the interim report.

The general feedback I received was very encouraging. Besides commending the number of sources I’d examined and the rich literature list offered for further exploration, participants were very pleased that this kind of project was taking place at all:

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[44] Throughout this chapter, my emails and my voice in the interviews are depicted in italics.

> “I was really happy to see that you are kind of highlighting the narratives of folks who have gone through the process and I think that just adds very important layer to the conversation that is missing right now.” (Shayda Kafai)
>
> “I was just as encouraged by your consideration of how you want your research to unfold; and why you've taken the steps that you’ve taken.” (Abena)
>
> “There is a quite coherent, a very respectful appreciation of other people that I find endearing actually. […] And I like this sensibility with which you’re approaching and trying to make meaning, and trying to say that okay, this is a network in the direction of advancing knowledge, and I’m not the only one whose responsibility it is, I’m one of the people, you know, I am trying to bring the people in. That’s a wonderful thing, I think, it’s a great effort.” (Prateeksha Sharma)
>
> “I think the issues that you raise are important, I am delighted that you are using the language of first-person rather than consumer, user, all that sort of business. It’s the first-person perspectives so that pleases me very much. I think it’s challenging but you've recognised that already because you are not going to - and you say this - you have no expectation to come to some final, precise, universal definition. It’s more about creating a space where these first-person experiences and perspectives can be brought into the larger conversation.” (David Webb)

Several participants noted the clarity of the entire project and approved my decision to leave out the perspectives of people who favour the conventional medical approach to madness and distress. However, they also queried some other omissions from the interim report including the topic of spirituality. The interviews with Lauren Tenney and David Webb gave me the chance to reflect on this omission with people whose work gives spirituality a significant role. This excerpt from the conversation with David Webb starts with my own explanation:

> *“I can only say that I felt totally incompetent to touch on this topic and that’s why I left it out. Not that I found many things on spirituality. I found it in your work, and in some other sources spirituality was just mentioned, but in your work it has been the most elaborated on [...] While I was typing things, creating documents and analysing, I had the category ‘spirituality’ but I felt so incompetent and small in front of it and scared*

> *to do something wrong. So I thought - either I touch on it properly or not at all and then I decided to leave it out but it doesn't have to stay that way. I expected that people would raise this. I was really careful and fearful."*
>
> "I think that's really wise for you to think that way and to decide that because I know it from my work - spirituality is not something that can be addressed in just a paragraph or two. There are so many preconceptions, there are so many disclaimers that you need to make, there are so many problems with the definitions of the words that before you can even begin the conversation you actually need to cover a lot of ground. I think it might be useful to acknowledge it as an important part of the first-person experience to some, perhaps many people and if you don't want to ramble with it, to acknowledge it and declare it to be outside of the scope of your work. That's a perfectly legitimate thing to do."

Other feedback raised issues I had wanted to discuss with the participants anyway and had covered in my topic guide. I will return to these issues in the relevant sections of the findings. At this point, however, I want to highlight some of those themes in the words of individual participants. One comment was about the importance of looking at the bigger picture and the intersections of madness:

> "I think culturally madness varies so significantly and economically it varies and so I would want to see a little bit more around these things cause I think it really matters." (Lauren Tenney)

Another participant, Kathy, suggested there was an over-emphasis on madness in the project and queried the use of one particular expression in the interim report:

> "On page 3 you talk about that this study explores the possibility of a model of madness developed by the direct owners of experiences of madness, so when I read that I thought - I don't like that, I don't like direct owners, but when I read more and you said it a bit differently later on, I wasn't objecting so much. […] My impression was - oh, okay, so, this is quite focused on people's experiences of madness, when actually for me, I don't think that's that important. What I think is important is responses to those experiences."

I had come across the notion of ‘ownership’ in the work of other survivor authors (Pembroke 1994) and also used the expression ‘ownership of madness’ elsewhere in my work. It was therefore important for me to realise this phrase could imply something I hadn’t intended. Later on, during my conversation with Kathy, I noticed how my chosen wording also preserved a dialogue with psychiatry I had wanted to disrupt. This excerpt from our conversation captures one of the many moments in this phase of the research when I became conscious of potential traps this work might fall into:

> *“English is not my first language and I was struggling not to use ‘users/survivors’, not to use ‘people with lived experience’ so with ‘owners’ I tried to express – people who had these experiences. It’s not the best expression. Once I gave a speech – ‘Who does madness belong to?’ – trying to say psychiatry appropriates it but it’s not theirs. What irritated you there?”*
>
> “I didn't like it because I don't want it located in me.”
>
> *“OK!!”*
>
> “I think that it's about things going on in the world, or the environment in which I find myself, and the way that people respond to me, the way I respond to myself. But I'm responding to myself because of the kind of social pressures of people around me. So, I don't think I want to be the direct owner.”

I will close this section with two more remarks by participants that were not explored further in the interviews. Since, however, they both reflect themes I believe are relevant for future research, I want at least to document them so they are not lost. The first one is about intimacy, a topic rarely connected with madness, while the second questions the very notion of ‘social science’:

> “While I was reading one of the things that came up strongly is – there is mention of relationships a lot you know and the healing of relationships. But there is very little about the intimacy that I think is really important - intimacy and the sexual drive of people. Whether it’s buried or... you know, it’s such a driving force within people and people who have the experiences that we’ve had often are curtailed in many of things

> they do. […] It’s clear from what we know and what you summarised that there are different experiences and you can’t put a formula or a principle that guides everyone but I think that a very significant aspect is loneliness whether you define it as intimacy or sexuality or whatever there is that blocks human connection.” (Ron Bassman)
>
> “The ‘science’ bit was the only sticking point for me. I dislike and am alarmed by the categorization of anything social – people’s thoughts, or interactions between people – as science. So I find the notion of social science troublesome. If such a thing has to exist, then, sure, we should be contributing to it. We should be contributing to everything. But I wish that people didn’t think in terms of social science.” (Irit Shimrat)

5.4.2 The prospect of connecting our experiences: Value, complexities and dangers

One of the purposes of the interviews was to hear participants’ general thoughts about taking this project forward. I was particularly eager to hear their opinions on certain questions that had arisen during my work with the written accounts (see the interview topic guide in Appendix 3). I began by asking my interview partners whether they saw the overall sense in connecting our diverse experiences and knowledges into something more coherent or they thought there were any disadvantages in such an undertaking. On the whole the participants thought these efforts made sense and didn’t see any major drawbacks. At the same time, their responses revealed some of the main tensions associated with working in this direction. They also confirmed how careful and sensitive any work towards a first-person-defined model of madness must be.

The most frequent concern was about the need to safeguard the personal meanings of experiences and protect against the overwriting or categorising of subjectivity:

> “I want to believe that you can connect different experiences and quotes, and how people express their experiences through those quotes if there is an acceptance of what the quote means for the individual. And it's not actually interpreted by some sort of dominant theme, or philosophy, or theory, but more how someone is trying to express their quotes or experiences. I think that's one of the major reservations I have about talking about my experiences and trying to connect it to other people's experiences.” (Colin King)

> "Connecting can mean categorising, which can detract from the attention that should be paid to differences and individuality. So I think maybe to collect and describe (rather than connect) incidents is beneficial. Madness is important and needs to be talked about and written about. Its varieties are important to describe, and I think we need to amass those descriptions without necessarily connecting them by way of a common explanation. But I'm not sure I agree with myself! In another way I think that connecting the experiences is very important, because it's the way to show that what's crazy is the world, and our reacting to it by going crazy actually makes sense." (Irit Shimrat)

Another view held - it was not categories that were problematic so much as the social capital and values attached to those categories:

> "My position on that is that as humans our brains are kind of wired towards classifications. So we like to split the world into little groupings. My objection to the whole diagnostics regime – well I've got few of them, but one is that it is the grouping that leads to othering and social exclusion. There are other groupings that enhance people's status. Let's say in academia there are groupings – as A-students something like that – so that is a grouping that enhances your social status. So I don't think that it is the process of grouping itself, I think it's where the grouping puts you on a hierarchy of human status." (Mary O'Hagan)

Generally, all the participants suggested focusing more on social responses and the social position of the human experiences treated as madness and less on the experiences themselves. However, in response to my question about the work of connecting our experiences and the knowledge gained from them into something more coherent, the majority grappled with two thoughts: on the one hand, they saw the need for such a project and on the other, they had a clear sense of how it should *not* be done:

> "I think that, whether or not we are searching for common threads, when the commonalities become evident it's suitable to take note of that. And of course we shouldn't categorise. We have such a problem with being categorised already. But I

> think there should be ways, and there probably are ways, of talking about common threads without clumping people together." (Irit Shimrat)

The following words from Lauren Tenney accurately summarise the main challenge – and central task – for any work aiming to advance our understanding of madness based on first-person knowledge:

> "I think that is the problem – as soon as somebody else tries to come and put a framework around somebody's experience there is resistance. So that is the exact thing – we need to find something that is loose enough, that can hold everything and keep a form."

Referring to her own PhD research (Tenney 2014), Lauren shared how she had dealt with the tensions between the personal meanings of experiences and the larger structures in which those experiences were embedded:

> "The model that came out of *(de)Voiced* I still really value. […] I merged Goffman's modification process to turn a person into a patient so 'person – pre-patient – patient' with Cross's black liberation psychology that goes oppression – encounter – and then the sequence towards liberation which has four different stages to it. And I merged them together resting on the encounter and based on what the encounter is working towards: either modification or oppression or toward liberation depending on how that interaction works. But to find what the oppression or the liberation was would be impossible. Because for some people the same oppression can be a liberation. So it is that level of individualisation that is required but there was like this – something that doesn't talk to the experience but talks to the structure of how something happens, meaning the functional aspect of it as opposed to the how, as opposed to the why. Because then it allows each individual to determine the why."

The very fact that another survivor researcher had struggled with this question – how to safeguard an individual's right and ultimate authority to make meaning while addressing the structures in which things happen – felt highly validating to me. And while the current research project is unlikely to solve this problem, I was comforted that we could at least articulate this central demand for any project seeking to create a body of knowledge rooted in diverse first-person experiences.

The remainder of this section outlines participants’ understandings of what the main purpose of establishing our distinctive body of knowledge should be. The conversation here moved on to seeking (and finding) common ground from which to proceed while recognising and respecting the diversity in our experiences and in our work. Several participants confirmed they did see common threads in our diverse experiences and – even more importantly – in the work we were doing in our respective fields of interest. In their own way, they each made a case for focusing on these commonalities and exploring connections rather than pursuing any unifying ‘catalogue’:

> “[B]y and large I think we are all sort of pushing in a similar direction, we all stand on some common ground but with differences and variations and generally a respectful acknowledgement of those differences. They are just differences; they are not conflicts. I think there is now thankfully a body of work and a body of people that constitutes a movement. Some of them are doing political work, some of them are doing grass-roots work, some of them are doing academic work – that I think even with these very different activities, with different focuses we share much in common.” (David Webb)
>
> “I'm not interested in taking over the asylum, I'm interested in having what I went through become part of some of the positive transformations that can happen in mental health services or in life quite frankly. To see how could they get it so wrong in my case, how could they allow on their watch for things like this, for such injustices to carry on. And then I'm a part of writing that narrative, I've just never had a chance to. So there's something about the combination of writers like you, loud speakers like me, practical doers […] This diversity, diverse approaches with diverse people, putting together the opportunity for people to have a bank, a reserve of saying - you know, I've seen one like this, have a look at how they did it there. I'm not interested in having an all-in-one catalogue [...] I'm not interested in that particular pick; I just want a sense of a feeling of connectedness of the madness of people.” (Dominic Makuvachuma)
>
> “The variety is fascinating. I think it’s important, though, to talk about and look into what mad experiences have in common, as well as looking at what is individual. The

> different and the similar directions in which madness can go. There is a richness in the content of madness that is important, philosophically and morally and intellectually, to the richness of being human." (Irit Shimrat)
>
> "If there is some way to boil it down to a common denominator - what is it that people are talking about that would be great. But I think it is also important to be able to show that people who don't know each other are talking about the same things and that's historically accurate. All the 19th century writings that I looked at – that was one of the things [*I saw*] not only of how they fit with each other but how they fit with what we're still talking about. But to find something that satisfies everybody is the complicated thing." (Lauren Tenney)

One pressing reason for establishing common ground for our future work is the need to change dominant social responses to madness. Participants saw the value in connecting our knowledge and building a 'counter-narrative' that could catalyse or even lead much needed change in the prevailing responses to what is labelled madness. This idea was stressed in several interviews:

> "[T]he co-production of knowledge also creates a powerful narrative that institutions can't ignore and that is the energy fueling change, or is fueling ideas of change, or is fueling the 'mainstream' to think about change. If you don't have these narratives that are essentially being screamed at the 'institutions', then you don't have the understanding from the 'mainstream' that ideas of change need to come." (Abena)
>
> "People are going to have different positions but I think this is true of any field [...] So I think it's not so much a disadvantage, I think it's going to be like how to support that process of us coming together, clashing, clarifying and saying - well there's actually a lot different paths. And our politics, and our training and our lived experience is gonna shape that. [...] I think that some of the biggest innovations are gonna come from people who say – look, this stuff is killing us, what they are doing; it is certainly not healing us and we could do better by ourselves. I think that there's some really innovative [*stuff*] coming out - pairing the politics with healing practices - that is central to people healing. And consumers/survivor/ ex-patient activists know that stuff. We just know it and so I don't really see any disadvantage. I just think this is long overdue." (Vanessa Jackson)

As well as highlighting the potential for our knowledge to drive change, several conversations also focused on the question of how to generate and deepen our knowledge so it may truly be transformative. Abena described the need to make knowledge *together* and distilled the difference between efforts to group people's experiences and the work of connecting and jointly enhancing the knowledge base:

> "Nobody has the same experience. We are seven billion people on this planet and nobody has the same experience. […] And how people understand their own experiences differ. And how those experiences change them is different. […] But on a basic fundamental level of having a home and having family and having support and getting access to work and food and water; on this level, something has to be done and if that comes through the form of a social model of madness that can be advanced in a way that can be taken up at meta-levels, that is where I think the value is – in connecting, in co-producing knowledge. So it's not that knowledge is going to be co-produced if it's going to be one that is – 'oh, let's group all the people who have A experience together and people who have B to work in focus group on that and people who have C in focus group on that'. This will never happen because there are no As and Bs and Cs which is the problem of not recognising the diversity and humanity to begin with. So I don't think that there is any value in reproducing the same systems. But the co-production of knowledge has an immediate benefit of creating a bond […] We find in someone else's similar struggles to connect with, that you can work together on, or support each other with."

An important point about sustaining our collective knowledge was raised by Dominic Makuvachuma:

> "Bringing it together is one thing, keeping it connected is another."

I will return to this legitimate concern in the closing section of this report when I pull together the findings. One critical question when creating a distinctive body of first-person knowledge is how to ensure that knowledge is not only diverse and accessible but remains open, easy to engage with and always capable of being refined and enhanced. These words from T. warn of the dangers of first-person knowledge establishing itself as another type of formal expertise:

> “It could be seen as being like a profession, professionalisation of people, or deciding whether people have got the right type of views, or the right type of knowledge, and then some people would, like with a profession, you got to pass an exam or do whatever, cause they're doing that profession.”

The risk of reifying madness was also mentioned in this context but as this issue was raised in different ways throughout the interviews, I have chosen to consider it separately in section “Decentering madness, centering our own perspectives”. For now, I would close this initial discussion of the overall value – and possible pitfalls – of connecting our experiential knowledge by drawing on a metaphor from Abena. She invoked the idea of a ‘trunk’ and shared her thoughts about how this might work in practice:

> “There is value in creating a social model of madness in a sense that it becomes a trunk, it becomes a way, a bridge of understanding, especially to connect the ‘mainstream’. […] I think that trunk or funnel of knowledge is key to changing ideas so I believe in the power of knowledge and I think that that funnel becomes more changeable so that people whom I ultimately engage with, who are part of my family, let’s say for instance, who aren’t exposed to critical theory - changeable, comprehensible social models make it really easy for them to jump on board as well. And this is the value of the social model of disability, too.”

5.4.3 The role of language

The following section of the findings confirms how integral language is to our understandings of experiences and, thus, how vital it is to the topic of this research. This discussion also makes clear that the relationship is reciprocal: not only does the general approach we take to madness shape the discourse about it, but words and the way we use them can transform how we understand and respond to experiences. Several participants spoke of the central role of language in the creation of knowledge, particularly when it comes to generating alternatives to the dominant model. Abena put it:

> “Language is so important to the way that we take up knowledge. Forever. It is not a colonial enterprise. Oral stories have been told for millennia and this is how ideas have

> been able to develop, evolve, flourish or die. So language is – I would argue – quintessential to the plight of justice. […] And I am not using language to equal writing, I want to be clear, because writing, of course, is a new enterprise whereas oral stories as I said have existed forever. […] The language that is used communicates ideas and opens possibilities for new ideas because, of course, when you are debating you are creating knowledge, when you are writing you are creating new knowledge, when you are telling a story you are creating new knowledge or ultimately with a possibility of new knowledge because the person who is listening or reading or debating with you is going to take away something and that person's going to share eventually."

This important reminder of the need to expand the definition of language beyond written sources was repeated in other interviews, and I will come back to it in the section "Prospects of joint work within the context of inequality and injustice" (pp.173-190).

My interview topic guide included two questions that specifically addressed language about madness, but in many interviews, participants brought this topic up themselves. Sometimes this happened at the very beginning in response to my work with written accounts:

> "It was just very exciting and amazing to see that the use of language was being threaded throughout and also that language was being used as protest. We need to reconsider the words we are using, how we are using them and the impact these words have. […] One common theme that I saw through the different pieces was this idea that – yes, madness is existing but language needs to be ascribed to it in order for us to have these more complex conversations." (Shayda Kafai)

Ultimately, the interviews revealed various difficulties and failures involving language but also the great emancipatory power of words. I want to start by considering the difficulties and contradictions before turning to some of the suggested ways forward.

5.4.3.1 Language as a way of (not) othering

The fundamental incompatibility of experiences of madness with existing language structures was highlighted in some of the written sources included in the previous phase. In the same vein, some of my interview partners stressed the inadequacy and limitations of language as a way to communicate certain experiences and take them out of the realm of the unspeakable:

> “[W]hat gets grouped as madness – those are some kind of very basic life experiences which bring us back to the time before we had words in our lives, basic child experiences when we didn’t have words and when we are feeling like that – we can think that we are mad but we are not mad, we are just raw, unformed. Our experiences are unformed and therefore they are hard to describe and when people try to describe and group them, they tend to stigmatise them because they don’t want to admit that they had these awful feelings. […] It is hard to think about these things and put them into words because that is doing what we are trying not to do.” (Jan Wallcraft)
>
> “The second we try to put the language around we are screwed up, that’s the problem. There is no language to explain this. The language is the problem.” (Lauren Tenney)
>
> “It’s tricky because there is a part of me that wants to say – look, this is just part of the tapestry of human experience. It might be towards the edge of that tapestry but it’s still part of this whole spectrum of human experience. […] But not everyone has these experiences. But then – you know – not everyone loses a child, not everyone has had a great physical illness so there are many experiences in that tapestry that not everyone has. One of the difficulties people have is – they look at these experiences and they think – oh that’s really weird, I don’t understand it because I’ve never heard voices or I never believed things that other people completely disagree with or I’ve never felt in such despair that I just wanted to end it all. So how do we bring those experiences into the diversity of human experience?” (Mary O’Hagan)

In order to communicate experiences, including those “at the edge of the tapestry of human experiences”, we use the language available to us. But the fact that there are so many preconceptions about madness inhibits our communication of those experiences and shuts down rather than enhances our understanding of what is actually happening. Though they appear different, professional and lay discourses of madness are both filled with these inhibiting preconceptions:

> “In a way there’s two classes of language that I think are a problem. One class of language or one type of language is the professional language which uses mainly medical explanatory models and I think encourages social distance. Then you’ve got

> the more colourful vernacular language that – ‘axe-murder’ or ‘psycho’ or ‘barking [*mad*]’ sort of language - which is really about othering people and excluding them and reducing their status as human beings. So I think those two types of language, those two sorts or groups of language are equally problematic and I think that the professions don’t like the vernacular language but I don’t think that they realise that their language is more insidious and more subtle in ways but it actually has a very similar impact.” (Mary O’Hagan)
>
> “The language is so peppered with ‘crazy’ and ‘insane’, just in general talk. And so there's a whole sort of meta-analysis of what all that has done to us. And how it separates people who are helpers from people who have a lived experience. So I think it’s crucial because it is one of those places where a Mad Studies perspective gives us a place to explore what that means. Because the history of mental health globally is, the power to define is in very small hands that have a vested interest of people not getting well. And to otherise people so that they are allowed to do things to them.” (Vanessa Jackson)
>
> “Well, language can already close down a lot of options because we feel the need to use language to explain mental health issues and once we start to do that we close down some avenues already, we start using the words. It is hard to talk about mental health issues without using pre-defined concepts, that is the problem – pre-defined language.
>
> *Do you think there is a way to get around that?*
>
> I don’t know. Phenomenological explanations seem to work best, if we keep looking at what people’s experiences are without trying to frame them in medical concepts – just what happens. […] It is quite hard to do that but we have to try somehow.” (Jan Wallcraft)

Even in situations where we are explicitly asked to say how things are for us, there are often unspoken expectations that reduce the room for our own accounts. Colin King described how the rules and presumptions of the academic research can stop us from speaking our truth. This can compromise or even drive out first-person voices:

> “[Y]ou're trying to fit yourself into a narrative that is more about what the academic wants you to say or portray or to identify rather than what you want to say. For instance, when I talk about my experiences as a black man in the mental health settings, I talk about issues of whiteness, I would use different types of narratives that may be offensive, or seen as overtly critical of the people I'm talking about. So I'm trying to find a language that conveys what I’m trying to say without being offending and I then think I end up being compromising, or trying to assimilate or integrate into those sort of narratives that people use. So I’m not really talking about myself, I’m talking about myself almost through the third person, which itself feels like a bit of delusion […] because I’m trying to guess what the reality of that person is, that makes them sure that I don’t offend them.”

This awareness that our experiences might not fit in some invisible conventional template of what is imaginable and acceptable also affects our everyday lives. As Kathy explained, knowing how risky it is to “meddle with the social order” may lead to a decision that it is best not to communicate certain experiences at all:

> “Because, you know, people really believe in this medical stuff and the chemical imbalances, so many people […]. In a way, it’s so embedded in our culture, in our everyday lives, it’s actually really difficult to challenge it. And that’s partly why I took a decision a long time ago. It’s not a political decision, and it’s not a public-spirited decision, but I took a decision in terms of my own survival that I can reach my own kind of understanding of what happened to me. And while I might talk to some other people, including other people who survived psychiatry, I don’t know that I want to do that, I don’t know that I need to do that, but also a bit of me is a bit worried about doing that. Because what if I unsettle my settledness now? You know, I have worked out where I am with it all. If you start meddling with that, you know, I’ve got to feel really strong in this. So the way I feel really strong in it is to keep it to myself mostly.”

The participants were very familiar with the ways the dominant discourse of madness harms people’s lives. They observed how this discourse reduces people’s social status and contributes to their exclusion:

> "Well, the language implies an explanatory concept so it implies an explanation, but I think the language can also cast people as Other or be used to reduce their status." (Mary O'Hagan)
>
> "I think the way we talk about madness in various cultural ways is also very damaging because again it's just like either you are mad or you are not. Or it is place from which you do not return." (Shayda Kafai)
>
> "[T]hat's the basic issue that words both don't adequately describe or explain what the situation is and even words that at one moment seem to be sufficient – through a different lens or even somebody else repeating it back to you becomes a problem because they have tone and they have meaning. And then my question is why we have to define us whereas this goes back to how the others perceive us. If they other us to this degree then why haven't we been successful in othering them because there's still a small group of people?" (Lauren Tenney)

Though language was a disputed territory full of preconceptions about madness that restrict communication, the participants also stressed the potential of words to do the opposite – to liberate and affect personal identity in positive ways:

> "[T]hat sense of being able to be real with somebody is, I think, where the discourse needs to go. Because somebody is responding to a different reality or perspective than you are doesn't mean that you have to say – OK they are outside of framework of human communication so we need to treat them a certain way. To me it's treating everybody as having something to say." (Ron Bassman)
>
> "[L]anguage is the vehicle of our thoughts and our constructions about our Self […] I just figured that psychiatry has assigned a certain 'expert' language to me, and suppose I don't want that language, it's not working for me. So what language do I want to use for myself? That is where the shift happened, because of language. I was not an ill bipolar person any more. […] So, language was the basic thing which changed everything for me […] – language as the basis of the construction of power and the construction of knowledge and the construction of relationships." (Prateeksha Sharma)

Another important issue raised in this context was the power of language to ‘normalise’ experiences and so dismantle the ‘us’ and ‘them’ division inherent in both expert and lay discourses of madness. Jan Wallcraft suggested that this might be the key to disrupting and transforming the dominant discourse:

> “I think maybe to assert that it’s very common for people to have these difficult experiences, that they are more as normal in a way, in terms of numbers of people experiencing them. Anybody can have experiences of distress, experiences that they can’t explain and can’t deal with – it doesn’t have to be anything that abnormal. Kind of taking it out of the frame of abnormal and saying this is very common actually but because we don’t have a good language or good way of describing it, we end up with the stigmatising language being used. It’s simply because these experiences are not so unusual. Everybody is a child at some point, everybody is helpless, everybody has experiences which are frightening and alienating – so it’s that kind of format to me, something like that.”

The participants clearly preferred using ordinary language rather than some specialised or new discourse to communicate experiences not shared by everybody. David Webb reiterated the central role that first-person language can play in this process:

> “[W]hen we explore this fully and openly and honestly, then the ‘them’ and ‘us’ quality of this discourse which dominates – when you examine it closely, including the first-person perspective – then that ‘them’ and ‘us’ just disappears, it tumbles, it falls away and we recognise that there is no ‘them’ and ‘us’, there is only ‘us’. I’d say the problem exists because of the very skewed nature of our current discourse that is dominated by so-called objective, so-called scientific perspectives to the exclusion of the first-person perspective. That is where the ‘them’ and ‘us’ comes in and if the first-person perspective is engaged more fully, which is a large part of what your work is about, then that border, that boundary, that difference will crumble away.”

5.4.3.2 The diversity of first-person languages and rejecting the notion of ‘madness’

Asked about the most important issue concerning the language used about madness, several participants stressed the right of each individual to use words of their own choice:

> “I think [what is] important about language is that it is decided by us, and not always referred to as like ‘users and survivors’, or ‘service users’, when that’s all somebody else’s language […]. I definitely think madness as part of the individual experience, in fact, go with the person’s ways of explaining that rather than imposing something else on them, like to systematise it. You know, whether it’s a psychiatrist or psychologist or social worker just pushing their language on the person. I think it’s important to find the person’s own language.” (T.)

At the same time, our attempts at connecting and jointly organising, advocacy and theorising revealed the potential incompatibility of our preferred personal terms. Irit Shimrat observed how some people’s terms of choice might be the same ones that put others off:

> “As you know, my book is titled *Call Me Crazy*, and I would certainly always rather be called crazy or mad or nuts or any of those things than be called schizophrenic or sick or bipolar. I have friends who strongly object to the words I like to use, words like ‘mad’ or ‘crazy’. It’s a very difficult subject. So it would be good to have a way of talking about it that allowed for a variety of opinion.”

The participants noted that the same term might have different connotations depending on one’s cultural context and other circumstances. And even the same person might not always give the same meaning to a particular term. This fluidity meant we had to give ourselves the freedom to refine and transform our language; it should not be prescribed:

> “I think the first thing is an appreciation that language won’t mean the same thing to all people and also what you feel and say at one moment maybe does not reflect what you’re trying to express about other experiences in your life.” (Colin King)
>
> “I think it’s about being generous with our language and [...] about people’s right to define and holding spaces for us to transform our language. [...] I think we’re going to continue to refine our language and I think the ways that we can be generous with each other as we are changing language but also have spaces to talk about what this language means.” (Vanessa Jackson)

Abena raised the issue of multilingualism and the fact the words don’t always directly translate or imply the same concepts across languages:

> “[W]e should be sensitive to language and the way that people use it and not be immediately offended or cringeful when the language of another is not ‘our’ language or our desire for language.”

Referring to her own research work in a country where she didn’t speak the language, Abena said we should be careful about creating an ‘inside group and outside group’ and stay attentive to the ways people use language. How we listened was, thus, as important as our choice of words:

> “[T]here was so much originality created and at first when I was listening to it – it was always framed in these stories of mental illness. But then when I get to the end of the story – the story was one of the resilience and strength and desire to change the system and not the self, an understanding of social complexity and not just individual problem. But, of course, I can only get to that point of understanding if I listen to the whole story.”

Dominic Makuvachuma explained how Western medical concepts invalidate understandings rooted in other cultures. He noted that this erasure of all other approaches persisted within the Western survivor movement. About the conceptualisation of ‘depression’ in his country of origin (Zimbabwe), he said:

> “It is called ‘kufungisisa’. It means ‘deep thinker’ and there’s a positive value that is ascribed to that deep thinking. And yet when I’m in England, and if I experience depression the perception is that of the negative value that is ascribed to that condition, isn’t it? It actually becomes a condition. […] Yet I understand it to be a positive value. I don’t know about you, but for me a deep thinker is somebody that I value.”

Some participants explicitly rejected both the attribute ‘mad’ and the entire idea of ‘madness’ as White concepts developed in the global North. They explained why efforts to reclaim this term and give it positive meaning didn’t ring true with them or their culture:

> “I'm quite disturbed by the whole notion of ‘madness’, even as a narrative, the words. I don’t particularly like the way it’s being embraced by certain people to kind of reinterpret what mental health or mental illness or the experience of mental health can be like. For my community it’s a very dangerous term to actually begin to engage with. And maybe that’s due to the limitations of my cultural processes and thoughts but I can't really kind of think about it as an analytical, conceptual tool – which I think you could do, maybe one day I’ll get there, to look at madness as a conceptual tool that looks at sanity and what normative and non-normative behaviour is. […] I think in my community people find that really difficult to invert those terms and see the power they can have to transform how people think about where we are in this world.” (Colin King)
>
> “[W]hen I’m called mad, there’s an element of madness that’s attached to this toxic negativity that’s at the centre of who I am. They don’t say he’s Black, so he’s dangerous, but you can tell that more people are seen or said to be at large and potentially dangerous when they are Black. […] What is important is to not ignore the subtle implications for certain groups. There is a real danger. From my understanding of ‘mad’ in the United Kingdom, we’re not ready to come to light. I won’t wear that hat, I would run a mile from being called ‘mad’. […] It’s all tainted with badness and negativity. Why would I have anything to do with it? It’s a life sentence!” (Dominic Makuvachuma)
>
> “Part of my resistance to the words ‘mad studies’ or ‘mad pride’ originates from the difference I sense in how ‘madness’ is seen and represented in the North – as a protest and a reclamation. Culturally it makes me uncomfortable. Where I am, the words ‘mad’, ‘mad studies’, ‘mad matters’, ‘mad pride’ – it doesn’t work. So, whoever I feel is doing that here is actually just trying to parrot something which is produced in a different context in a different manner. But by saying ‘mad’ in India, you don’t really carve out a position for yourself, you actually end up stigmatising yourself further. So you actually stand out in society saying you’re mad. I mean, I’m not going to accept that, I’m not going to buy the mad label ever.” (Prateeksha Sharma)

Before conducting the interviews, I had been familiar with criticisms of ‘madness’ as an ontological category and, for instance, Gorman’s (2013) comprehensive explanation of why adopting a mad identity is unacceptable for people of color, who face additional forms of structural oppression. And though I myself oppose the adoption of ‘mad’ identity and use the term solely to describe a range of experiences I think anybody can have, these clear statements by participants made me rethink everything. Reclaiming and de-psychiatrising madness have been ongoing personal and political projects for me and ones that are central to my work (Russo 2001, 2016d). I've never felt pride around madness and don't use 'mad' as an attribute to describe anybody. Still when faced with a choice between medical and layperson's language, I have always chosen the latter. I cannot suddenly erase this deliberate decision or pretend it was never taken. At the same time, I don't want to impose it on anybody, particularly if this means failing to recognise the structural reasons why the 'madness' framework costs some groups more than others. I can only start to recognise and understand the circumstances that enabled me to adopt this concept, which is something I haven't considered before. It is important to repeat here that the interviews and my work on this report have not just been a means of gaining new knowledge and insights; all this has resonated with me on a deeply personal level. This work made me remember that I actually started using the term 'madness' in languages that were not my own. This distance from the mother tongue in which both my madness and its medical treatment occurred gave me the space to start thinking and talking about these matters at all. I don't actually know how the process of finding a language for these experiences would have unfolded or what terms I would have used if I hadn't left the place where it all happened. In the interview with Prateeksha Sharma, I felt comfortable enough to share my thoughts, and our conversation helped me move on – at least temporarily – from what at one time felt like a point of irreconcilable difference:

> "*For me personally – and I am now only talking about myself – using diagnosis is far more stigmatising than the word 'mad'. My politics is not to use words like 'psychosis' and 'schizophrenia', as if they were not there. I know that they are there but by not using them, I am making a statement. I know that 'mad' is also stigmatising but using 'mad' gives me more hope because there are only laypeople involved in that stigmatisation, whereas with experts, I feel I don't stand a chance. But what I learned is – while we use different terms there is a level beyond those terms. For example, when I read your stuff, I see 'bipolar' in the title but as I keep reading, I feel that we connect and another level opens up for me. Then I say – OK, I shouldn't have paid attention to this word in the title because what you write speaks to what I feel and think. Personally I don't think that there will ever be perfect terms, and the same terms will also mean something different to different people, so I think we shouldn't insist on the same terms being used by everybody and we should allow ourselves to go beyond that and see what we mean.*

> Jasna, I'm just fine with that because I understand that this is some kind of journey we are going on where we are looking for language which is expressive. And as long as we agree to disagree, also we agree that okay, if it works for you, it doesn't work for me, and still we are talking of working on the same or on parallel tracks, or converging tracks somewhere. So, I'm okay with that, it's perfectly fine."

Rereading my comments, I realise that my personal sense that it is easier when "there are only laypeople involved in that stigmatisation" might be very different if other oppressive forces and structures such as racism came into play. The fact is that it is not only our lives but also our work which takes place within these structures, and this includes any efforts at joint knowledge-making. This broader context of oppression and inequality also surrounds this particular study, and I will come back to the implications of this in the next section. For now, however, I want to consider the role of words in reproducing or disrupting that context and the ways we formulate and reformulate language. Several participants spoke of revisiting – and rethinking – the term 'mad':

> "I probably use the words 'mad' and 'madness' less these days. Much of the time I really like it as a word and I think it's a powerful word in some ways but I think over the years I just stopped using it so much because I just feel a little bit of uneasiness about whether I am othering myself when I use that word. I am not saying anything definitive here, just a little bit of discomfort about it. Because as long as one of the basic principles of Mad Studies is that every person alive on the planet today is mad – I mean to be mad is to be human, to be human is to be mad – but not if we are going to set up madness as something special." (David Webb)

Again and again throughout the interviews, the participants redirected the focus of the inquiry away from madness and towards the real circumstances of people's lives, including social attitudes and responses to madness. This refocusing ultimately questioned the very notion of madness:

> "I think that madness, or whatever you want to call it, matters, but I don't think it's the most important thing. Because if we didn't have all the kind of societal responses, I think we would just get over things much more quickly and get on with our lives. Or

> maybe it wouldn’t even happen because the responses might be causing it to happen. Yeah, I just think that emphasis for me isn’t quite right.” (Kathy)
>
> “And then when you really sort of separate out how many of these things are at its base not madness but economics or systemic oppression or inequity – if all other things were fine, would this even be an issue?” (Lauren Tenney)

5.4.3.3 Moving beyond the ‘correct’ terms

Questions about language can never be settled or resolved since they are integral to our ever-evolving ways of knowing (and being). Nevertheless, I want to close this discussion for now by presenting a few more thoughts and ideas that our conversations about language generated. These ideas highlight some more potential principles to consider when jointly developing a distinctive first-person knowledge base about madness.

T. emphasised the need to move away from a search for single terms and instead turn to longer narrative explanations, preferably in language available to everybody:

> “I'm thinking of things that are away from short words, or, you know, short terms. […] and giving a bit more context to it rather than to just say one word like ‘madness’ […] or something like a bit more of a description of it rather than just picking like one word or two words, which is supposed to describe the whole thing […], describe that massive experience that’s so complex. If it was more about using ordinary language, it would give more sort of background.”

Referring to a list of plain English terms vs. psychiatric jargon produced at an annual international conference on human rights and psychiatric oppression in Toronto back in 1982, Lauren Tenney questioned the very idea definitions were necessary:

> “I like that you are moving away from an actual definition or putting the brackets around it because that is in another way securing the story.”

Drawing on her years of experience as an activist, Lauren also observed how the search for single terms that were acceptable to everybody wasted energy that could better be invested elsewhere:

> “Even when I am in a full agreement in a room full of people and we are all at the same wavelength, we are still fighting about some stupid word and it’s like why have we just spent the last three hours fighting about this word when we have so many important things to do?”

Perhaps we should accept that first-person language is by its very nature not something to be agreed on. This would also mean accepting that this language’s apparently problematic resistance to rules and regulations and efforts to reach a consensus may be central features for us to protect and nurture. It would mean that we should do this rather than engage in prescriptive procedures. This is of particular relevance to any collective efforts to enhance first-person knowledge about experiences like madness:

> “I think perhaps the most important thing is that we are honest. And that we speak with integrity. And that doesn’t necessarily mean that we always speak with accuracy or precision. But we articulate from our experiences. And in my own work […] I state that I need to be able to use my first-person voice because so much of what we are talking about is ambiguous, contradictory, paradoxical, emotional, erratic and you know – poetic. This is the language that we need to use if we are going to talk about first-person experiences because that’s what they are. And to try to exclude that from the discourse is, I think, doing a great injury to our inquiry so if you ask me the most important thing, it’s that honesty and that integrity. And that’s never finished, that’s always there – every time we try to find words for something, such as now. I mean I try to find words for this – it’s to speak honestly of your experiences.” (David Webb)

Lastly our conversations about language touched on the place of my own first-person voice as a researcher within this project. In line with the point Abena had made about her research abroad, David Webb stressed that listening was integral to our efforts to find the right words:

> “And perhaps hand in hand with that – and bringing in the second person perhaps – is to listen honestly and by that I mean to listen people talk with an open mind but also with an open heart. So there is a great need for looking in the academic sense […] at this point they start talking about intersubjectivity, which is the first-person plural, the ‘we’. That includes things like empathy and compassion. […] The part of the first-

> person enterprise is that in this case you as the researcher, you are your own first person and you have your own first-person experiences of what we are talking about here, and again I would say that the most important thing is honesty and integrity, both as the speaker and as the listener."

Abena reflected on the increasing calls to "situat[e] the researcher within the work and allow […] the reader to understand the researcher just as much as the researched". Whilst seeing these calls as legitimate, Abena was also conscious of all the recording systems that surround us. She shared her ambivalence about what this process might entail:

> "So in theory, that makes sense but in this world that we live in, it is so digitised and anything can be taken out of context forever and be limiting in ways that will blight this body indefinitely (through the internet I'm thinking in particular). […] I haven't really thought it through, but if a huge part of my issue is the issue of surveillance and the way in which we are policing bodies and psychiatrising bodies and then overdosing bodies, if this is my aim to challenge these ideas, why would I open myself up to that kind of policing and possible psychiatrisation and prescription? I think of this all the time and I am very conscious of that, part of that, is why I am not sure whether I want to be named in this work or not."

For me personally as the researcher in this study, the critical question is less about general surveillance and more about implicit and effective academic surveillance. The latter translates into a question: To what extent may I inscribe my feelings and thoughts in this research without compromising its value and credibility and above all its contribution to the official knowledge? Writing up this report has meant constantly navigating the space between the conventional expectations of social science and the encouragement the interviews gave me to use my first-person voice and keep situating myself within this research.

5.4.4 Prospects of joint work within the context of inequality and injustice

When talking about the intersections of inequality and injustice with madness, the large majority of participants focused on 'race' and the consequences of racialisation. The interviews with people from the USA took place in November 2016, immediately after the presidential elections. This shed a different light on, and intensified concerns about, ‘race’ as a fundamental and immediate determinant of our lives. Other such determinants raised in this context included class and gender:

> “Gender has been central to my own social difficulties and then to my own madness, because women are seen as being somehow less than men. I think a lot of women’s madness comes from having been belittled and hurt and violated because we are female. As for class, people who are rich and respected are likely to be seen as eccentric when exhibiting the same kind of behaviour for which less privileged people are called ‘sick’. Injustice can make you crazy, and people of a gender or a ‘race’ or a sexual orientation or a class that’s seen as inferior are by definition subjected to a great deal of injustice.” (Irit Shimrat)
>
> “I think some others [*c/x/s organisations*] that are more mainstream get more funding and replicate the same kind of stuff of not addressing race and class which is huge and I think the class issue has got even bigger as we professionalised peer support, and the fact that you are having a lived experience often means that you're impoverished anyway […] When you're working class and poor you're always used to people telling you who you are and who your people are and who your community are. So when someone puts a label on you, you're actually more susceptible than somebody that has had class privilege, who gets to be eccentric.” (Vanessa Jackson)

This section focuses on the inequalities and injustices that are rooted in institutional and structural racism in its many forms, and their implications for projects such as this one that seek to strengthen our *collective* first-person knowledge of madness. The low number of people of colour among the authors whose work was included in the previous research phase was described in the interim report. I hoped that the interviews would generate more thoughts and ideas about what has become my main issue of concern - how to work together within the broader context of inequality without reproducing it. My interview question - how can we ensure that our work encompasses as many different realities as possible and that its outcomes are widely owned – did not result in precise and implementable answers, but did initiate important discussions and generate valuable thoughts on how to take (and how not to take) our joint work forward. Most importantly, this question has opened up a space to share our experiences, feelings and desires about how together we can address and confront structures that do not affect us equally:

> “It's a really difficult question. And I think that by asking the question you're beginning to ensure that it's feasible, permissible for people to begin to talk about it. I’d still think there's an uncomfortable silence about talking about things that may threaten our own sort of sense of reality or fear of getting it wrong.” (Colin King)

The interviews broke that silence without necessarily resolving it, or transforming it into neatly formulated statements about how to move forward collectively; this became a central challenge in the analysis and writing. I greatly missed the opportunity to continue the conversation with participants in the form of group discussions (focus groups), which unfortunately proved unfeasible. I am not suggesting that continuing the conversations in and of themselves would lead us to a set of firm answers or solutions. But having the opportunity to come together and jointly discuss the interview findings would at least mean that I do not stay alone with all the thoughts and emotions that people shared, including my own, that emerge and evolve as I write this.

This section of the findings is about the fractures that open up when we attempt to work together across differences in a profoundly divided world. Above all, I refer here to differences enacted by the concept of ‘race’, because although class, gender and cultural differences were mentioned, they did not operate in the same way as ‘race’ in this particular group of participants, myself included. I see my task as not shying away from the rupture that opened up around ‘race’; as documenting it; and as enduring the reality that there are things that this project will not mend. At the same time, I maintain that this project should, as a minimum, not reproduce or contribute to the already existing divisions among us and our experiences. The interviews generated some ideas about how we might potentially move forward. First, though, I will describe participants’ reflections on the issue of ‘race’ in the user/survivor movement, as well as in the survivor research that results from that movement.

5.4.4.1 White dominance in the user/survivor movement

Several participants drew on their experiences in activism when responding to the question of how we work with differences. They pointed to the fact that people join user/survivor organisations from different places and bring diverse ‘baggage’ with them – the expression

Dominic Makuvachuma used. The question, then, is how much space and willingness our organisations have to deal with people's baggage, such as everyday and institutional racism:

> "[T]he question for me is: Do we have enough structures in the survivor movement to be able to work together with people with such a diverse range of baggage? And my answer – I think – is probably not yet." (Dominic Makuvachuma)
>
> "There was something that came up on one of the calls recently that really made me take seriously just how I approach things. Somebody said all we ever hear is about antipsychiatry, the restraint and seclusion and drugging and all this. And this woman says – it's not that African Americans are not court ordered and that all these things aren't important but if you experienced racism you would see why that was the priority to be dealt with. And until that's dealt with nothing else matters because everything is funneled through that experience. It really shined a light on my privilege in a way that I just had to take a step back and obviously agree that if this was what was at the start of every interaction than it would be the thing that I would need to have relieved. And we'd been working, I'd always been involved with people of colour and in multicultural environments – it's not like that's new but really looking at how our movement does not go out of our way to make sure that people of colour are included in leadership positions – it is something that I no longer could make excuses for and felt the need to start more actively trying to do something about it." (Lauren Tenney)

The situation in both the UK and the US is characterised by the overrepresentation of people of colour in psychiatric settings, and at the same time their absence from leading positions in the movement. Whilst this imbalance is far from resolved, it is at least a topic in the US movement:

> "I think this is the crucial moment where we are in States. There is a tremendous amount of racism in the movement in terms of people of colour not being in leadership roles, people of colour being tokenised when they are. […] If you look at court ordered psychiatry African Americans are three times more likely to be court ordered, five times more likely to stay court ordered and yet you barely anywhere in this country can find people of colour in leadership roles in this movement. It should be minimally half but if you are really reflecting the numbers white people would be underrepresented

> because white people are underrepresented in services and especially in services that are forced or are court ordered.” (Lauren Tenney)
>
> “One of the things from the US perspective, and I don’t know if it’s better in other places, is that the movement in the US, while there are some great people, it reflects society so it’s very racist. So for example even though African-American people are just proportionate to our numbers locked up we are underrepresented in leadership positions and that is by design. […] And I think it’s actually getting worse with the professionalisation of consumer, peer educators, peer counseling is who gets tapped to be part of that, who goes to the training, who’s got the connections to become a director or something, who gets tapped to give the training […]. So I think there’s some race and class biases inherent in, that are reflected in general society that show up in the movement and I don't feel quite frankly that it's being addressed in a meaningful fashion.” (Vanessa Jackson)

Lauren Tenney sees the need to radically change this situation as the central task that lies ahead of us:

> “I think that the 21st century challenge is creating equality inside our movement. And more than equality I think the privileging experiences of people who have been most oppressed by the system.” (Lauren Tenney)

Several participants also raised the issue of the allocation of responsibility for change:

> “We need to make sure that the onus should not be on the person who feels excluded, the onus should be on the survivor movement, on the assumption that we have enough or better resources to be able to engage meaningfully with those groups that inadvertently have been excluded. I think that the survivor movement has the responsibility to engage with people who have got, shall we say colourful parts or colourful journeys to contribute, to bring diversity to the narrative of madness.” (Dominic Makuvachuma)

> “It’s not the responsibility of people oppressed to call out the power […] White people need to hold each other responsible for this. And need to change it.” (Lauren Tenney)

The above statements about the movement, and the experiences of exclusion from that movement, are directly relevant to survivor research – an endeavor that this project is a part of. This is because survivor research emerges from that movement and continues its heritage. That heritage is not only expressed in emancipatory values and principles as central to knowledge making, but also encompasses the tradition of white dominance. The feeling that one’s reality is not seen and validated prevents people from racialised groups from engaging in activism and research, meaning that they walk away and stay ‘on the fringes’ – the expression used by participants from the US and UK:

> “I don’t think it's gotten any better although you know here we have strong leaders and I feel […] MindFreedom is an example of something, as a group I think that does struggle with that. I don't know because I'm not active, I’m on the fringes and I'm on the fringes mostly because of this race issue. Like I'm not going to try to do that again.” (Vanessa Jackson)
>
> “[I]f I don't fit in, I'm not going to force myself to fit in, there's an element of assimilation here. I have got a sense of self-value and I need to be clear about it. I have a sense of my value and that is judged on my sense that I have from what my community feel that I contribute to them. It will never be judged by the white survivor research community. So, if the white survivor research community makes me feel like I don't belong, good luck to them! I will continue to be on the fringes and excluded. And I wonder how many people feel like me.” (Dominic Makuvachuma)

While talking about experiences of exclusion from research initiatives in the UK, Dominic Makuvachma used the term “research fraternity”. In the following excerpt he describes how the accumulation of such experiences creates mistrust in survivor research which then becomes seen as yet another exploitative enterprise:

> “[W]hile I was walking through psychiatric systems – how come there's so many black people in this system that is supposed to be looking after mad people, people who had been traumatised? And yet the word, their word – on their own terms and in their own

> language – is very limited, few and far between the majority voices has been the voice of my white counterparts and that always resonates as extremely unfair to me. So, the work that I do for example incorporates people who feel, as a default position - well their word is probably worthless, is disregarded, or at best misquoted and used to further oppress them. So they don't engage with the many narratives that are floating about because they don't identify themselves with it and they feel that they are used as tools for further oppression. So, any written literature, any engagement with people like you who do studies, and try to advance studies, is traditionally by many of the people from my community seen as, you know - vultures trying to kind of siphon energy off me again. And that's the sad reality.”

The interviews confirmed the negative effects of the broader context of inequality and injustice in which we live out our attempts to work together. I was able to share my own dilemmas and difficulties around the issue of collectively developing a first-person knowledge of madness that *does not* reproduce existing structures. This raised some specific considerations about the potential role and responsibility of survivor research.

5.4.4.2 The responsibility of research

As previously stated, several large topics opened up in the interviews but cannot be resolved within this study, at least not in the sense that a final point of clarity or agreement is achievable. It also became clear that far more time and space is needed to get to know one other, and to discuss and exchange our stances and backgrounds before embarking on a research project.
Although the interview with Colin King was the shortest, it also went furthest in terms of the question of how we should (not) approach research if we are to work together for change. The fact that we lost the skype connection and then never re-connected makes it even more important to document Colin’s brief contribution. Referring to the alarming numbers of people of colour in institutions, he described the kinds of conversations that need to take place *prior* to any research project, and how strictly adhering to research protocols can inhibit such conversations:

> “And if we don't have the opportunity to talk about that as a collective, or mutually, together about why that's happening and the failure of researchers to look at their own – I won't say 'cultural bias', I would say that they are sort of reluctant to open themselves

> up to those types of truths that maybe my research is part of the process: it may collude with it, it may not challenge it, it may be that I'm really scared of beginning to address these issues. And maybe it's too painful for me to go there. I think there’s an acknowledgement that very few white researchers want to go there. But also I think it’s allowing those people that feel that they are – I wouldn't say oppressed but I think marginalised from the debate – to talk about what is a 'lived experience'; and not in the sort of traditional sort of research, but what is a lived experience from when you wake up and when you go through the world and you experience these things, and then you could have tried to do that in the research context. What does research do to stop us from really doing and looking at those issues? For me as a Black man – and I don't think I am a Black man but I’ve been labelled by structures as a 'Black man' – is being able to sit down with a person who perceives and understands their whiteness and the prospect of an open discussion about what does it actually do to us when we have those discussions. I think the problem is when you feel marginalised, and you feel that you've been attacked, and you retreat back into the very sort of emotional narratives that are defensive, and block us from actually talking about the issues. And the issues around race equality in mental health work I think is a really important collective thing that we should be addressing together. And I think we should then maybe say – well, let’s forget about the research, let's just talk about what we feel is really going on and then say – how does that fit into my research? –while doing it instead of – I'm doing my research, this is the question that I need to add, this is the information I think I'm looking for.”

In retrospect I can see how I failed to do precisely what Colin suggested here. I could have diverted from the interview topic guide at this point, and perhaps said more about myself and the particular ‘baggage’ I carry from the circumstances of my life, my country of origin, its recent history and the ways in which this places me in this world. But, nervous of saying the wrong thing, I continued with the interview topic guide. The fact that I said nothing about my particular nuance of whiteness exemplified Colin’s remark that whiteness “has never been made accountable for its own emotional experience”. In addition, Colin said:

> “I think it's an interactive relationship Blackness and Whiteness, if they actually exist. So, I don't really want to talk to people who subscribe to a notion called Blackness, not if they don't want to tell me who they are in their Whiteness. I think that's really emotionally unfair. And what are the models that stop us from looking at those crucial

> truths about relationships and the power, the cultural capital within relationships? […] I mean, I'm open to talking, I'm talking to you, about two people who really want to look at what's going on and doing it together, and not people who want to ask me: ‘So, what's going on for you as a Black person?’ That’s my problem because I think that’s a complete denial about what research should really actually do. I think that research should open up to those truths that fly amongst us, that hurt us, that emotionally disturb us, that distract us from what we're looking at, which is our responsibility together in terms of what we want to change.”

I wish that we had been able to “explore our responsibility together” and I hope that there will be an opportunity to do so in the future, not only for Colin and me but also within other projects of this kind. The need for research to engage with issues of inequality as issues that concern *us all,* and not as issues of particular groups, is one of the central messages of this research. I will return to this in the closing part of the thesis in relation to Oliver’s (1992) understanding of research as social production.

Another important issue relating to our attempts to engage in transformative research opened up in my interview with Abena, who was also pursuing a PhD at the time. We talked about the contradictions and hardships of doing this kind of research within the conventional frameworks of social science that build on classification systems, including ‘race’. Whilst seeking to challenge and question those systems we are simultaneously expected to work within their categories:

> “I think about this all the time when people ask me – oh, what are you? I can’t tell you how many times I get that question and the answer you want to answer is ‘human’, because of course you want to be part of the narrative that challenges the differentiating of racialised bodies. On the other hand, to ignore race is obviously to ignore the racialising that has taken place of the body, that has created ultimately the DSM which is based on ‘white’ norms, colonial norms, hetero-patriarchal norms – so my personal, organic answer is - fuck race. This is my answer but this is not the answer that addresses the inequality that exists when you have a racialised body who is now also being psychiatrised. And more importantly - and I am not trying to trivialise it - what I hate the most about the system is that psychiatry is being exported to populations of people who don’t have ‘white’ norms. [...] It’s like the problem of criminality and psychiatry – the two are inherently together and yet I am trying to find ways in which to separate

> them so that I don't reproduce the very problem of racialising a body when I'm ultimately talking about anti-normalisation – now I am racialising a body in order to communicate my research. How do you communicate the theories of inequality that are existing without reproducing the ideologies that are creating the serious inequalities that are existing? I am sure you weren't expecting to get perfect answers through the process."

In working towards achieving a PhD as an institutionalised entry-card into official knowledge production, having the space to question and challenge taken-for granted approaches to, for instance, participants' demographics is ever more restricted:

> "The problem is that we are institutionalised and we are working within the disciplinary knowledge that will get us our PhD. This is a problem that we are working within that framework. But there should be room and a place for exploration, there should be room to also challenge what are now considered the 'currencies' of our discipline. To me – I don't want to write anybody. Period. And I don't know how to accomplish the goal of getting the PhD which is this exploration of research because the reader will want to know who I am, who you are, who this person is – they will want to know where the knowledge is coming from as opposed to just taking a knowledge for what it is."

Even though this is another issue that could not be resolved within this project, the very fact that we were able to have an exchange about this, and the realisation that we face similar dilemmas, was immensely important. It also clearly pointed to the need for further scholarship and action around these issues in the future.

5.4.4.3 Some suggestions on how to move forward

Finally, whilst acknowledging the complexity and lack of resolution on these issues I wish to document participants' thoughts regarding potential ways of moving forward. Although their suggestions relate to this particular research, they are also relevant for any future work that aspires to be truly collective whilst operating within, and taking account of, the broader frameworks of injustice and inequality within which all research takes place.

As this inquiry started with the exploration of written work by people with psychiatric experiences, and because of the limitations of this endeavour, it was important for me to acknowledge the significant bias that was already built into this project. This was partly due to the material constraints resulting from the fact that this is a small scale, self-funded study, but also due to the broader structures of inequality and injustice within which this research is situated. Participants generally showed understanding about the limitations of the study, and also appreciated some of the corrective steps that I took in this phase of the research (see chapter ‘The interview partners’) in order to counter the dominance of white authors:

> “Your approach resonates very well with my own tradition - crediting people like me who don't necessarily publish material. I've got a lot to say, perhaps maybe things that might help with the vision of advancing what's out there, written by us and for us, and so on, but I think, most importantly, I think for me, the culture of damaging approaches to knowledge for people with an oral tradition who often get excluded in such studies and writing of such material because we don't find a way of amalgamating the written and the oral.” (Dominic Makuvachuma)

A clear outcome of the conversations around this is the need for future work on first-person knowledge of madness to move away from written sources alone. This was voiced by several participants who explained that prioritising published works marginalises important epistemic sources, perpetuating exclusion:

> “You see all these people out there who have really important things to say, really important perspectives, but haven't had the opportunities to write or get published.” (T.)
>
> “You know middle aged, middle class white people tend to write quite a lot in order to communicate. I think once you get outside that population group I would seek more oral communication. It’s not to say that other people don’t write but I think in order to be really inclusive... I mean we have this issue in our country New Zealand. We have the indigenous Maori people who are very oral in their communication. Their whole cultural approach is not so much about writing stuff so I think in order to get those kinds of voices relying solely on written works would not bring in the voices of people from cultures or even from socio-economic groups where they rely more on oral communication rather than written. To me the key would be getting oral accounts from people.” (Mary O’Hagan)

> "I talk a lot with people, I don't write material about that experience with people and because it is spoken about in groups, sometimes closed groups, but sometimes groups that can be tapped into, like the way you're doing, somehow, somewhere down the line, that knowledge, that wisdom, that experience is not fairly represented in literature. And I think that's a really difficult position for me as a Black man in England, knowing that there's a disproportionate number of my people that end up at the harsher end of psychiatry, they end up getting the cosh, a bad cosh, that's either through medication or physical, forcible treatment, which is of a more harsh nature than for my white counterparts. I think that the word of people of colour must be incorporated in many of these studies, more than it is. And I think the excuse of saying – 'we only – with the new technology that obviously has immense emerging opportunities – we only can take the written journals from BMJ' – I'm exaggerating to make a point here. I think those days are gone, you need to find ways to tap into some leaders that are emerging from my community, that are there, that we know are there, I meet them all the time." (Dominic Makuvachuma)
>
> "There are a lot of people who are doing great stuff but are not publishing. That's another power differential inside of this." (Lauren Tenney)

Vanessa Jackson highlighted the question of where the work of people of colour tends to be published, alongside the types of knowledge sources that are likely to be seen as legitimate:

> "[P]eople can put some very complex issues on Facebook. So what do we consider legitimate sources of knowledge exchange? If you only go for what is published in a journal or something it is going to be white. And if you expand written so that you're looking at published sources but you look at blogs, you look at other kind of things I think you're going to find more people of colour and some of their written work. But their written work will not be published in books and journals and that kind of thing. So that's already going to lead you know - I know you know – to that class bias as well as to that race and ethnicity bias."

Several participants described the importance of identifying gaps in the available literature and making clear recommendations for future work. Referring to her oral history research project with African American psychiatric survivors (Jackson 2002b), which was the first project of its kind, Vanessa Jackson stressed the potential of small studies to foster change and enhance people's prospects of getting their work published:

> "And so if we're really going to change this either we've got to create journals of our own where there are opportunities for people to publish. And I would say, you know, I do writing and I did some other kind of writing on some of the African-American history stuff, but it was being invited into an African-American history project where I began to publish more of my thinking about mental health and then that sort of cascaded into some other things. So some of it is looking at pathways to publication. But also in the meantime, for your purposes, is looking for where's the hidden information. Because what I found with the psychiatric history is, you know, nobody cared about African American history like psychiatric history and yet there was a lot of information out there and since my little teeny tiny monograph there's three or four people who've done their dissertations on this topic. And so now, because of a little thing, there has been within a decade or two more interest, people building on it. So I think what you call your little project I think is actually really beginning to gather together Mad Studies. And because you're seeing this bias - it exists, I mean it just exists - and so what you can do is to make recommendations about work to be done. But this is what we've got."

The interview with Vanessa greatly encouraged me, helping me to move on from focusing on what this project is not able to achieve:

> "So I think what you're doing is super important because the obvious conclusion is - there's huge under-representation in publications by people of colour and if we don't interrupt that now and create a pipeline for people to publish including what you did with the book that you edited – is opening up space to get that knowledge out. And what we know about publication – if you get published over here somebody reads it, they invite you to publish over here and that's how people get published."

Before I turn to some more suggestions about what must be considered when working in the context of structural inequalities, I wish to document one more important point about oral accounts. Abena reminded me that it is not only vital to include such accounts as legitimate epistemic sources, but also to be sensitive in how we approach them. She argued for a recognition of metaphors as ways of making and communicating knowledge, but also as ways of understanding that Indigenous people's stories are not necessarily organised in, what the Western world knows as, personal narratives:

> "Oral storytelling has been the way forever but those oral stories that have been the way forever were most often, at the time at least, in a lot of traditional peoples, done through metaphors. They weren't through making yourself vulnerable and exposed to the greater world to then be ripped apart in pieces and then have these psychiatrists or the researcher or whoever pick apart the story they are going to use to their benefit. This is the problem with our storytelling practice nowadays – that these vulnerable stories are being taken up and exploited, whereas this guy who tells me this metaphor about the forest – how the roots are kissing while the branches are fighting – this communicates a lot of ideas without actually doing so. He taught me the metaphor in the forest – while the roots are kissing, the branches are fighting on the top – and then you begin to know things through that. They are fighting for the sun, they are fighting for the light – whatever they are fighting for – you are putting that in those stories for the metaphor. There's other metaphors like that, too. Like the metaphor for peace and for reconciliation; for the eagle doesn't have to become the crow. This is to say that the eagle doesn't have to become the crow – for both the eagle and the crow can live in peace and thrive, they don't have to become the same. These are metaphors without exposing anybody to the risk of surveillance. There should be room for that somewhere."

Another point made in several interviews was about the need to make every possible effort to address exclusion and act upon it. Participants did not refer to research alone, but more broadly to the user/survivor movement and any work we undertake together:

> "For the movement, we need to be able to reach out to people from different cultures and places and languages and let people all over the world know that we want to know their perspectives, and that our collective story is incomplete unless it includes theirs. I don't know how it's done, but I think that it's something we should keep in mind. It's especially important because a disproportionate number of people of colour and people whose first language is not English are incarcerated in psychiatric institutions." (Irit Shimrat)

> “The important thing is to be very careful to not either deliberately or inadvertently try and speak on behalf of those that you cannot possibly hope to represent. I also think that those of us that do have the opportunity to speak, and you and I, and I think most of your interviewees probably need to consider this privilege. We do have the opportunity to speak a bit, not as much as we’d like at conferences and journals and everything. In a way we are banging on the door trying to say – let us in, let us in but we already have much more advantage than many other people that are not even at the site banging on the door, they are not even in the building. So I think we need to acknowledge that and support their claim to be included and to highlight exclusion whenever we see it. […] And if we are going to be true and honest about engaging in first person perspectives then obviously every effort must be made to bring these people into the discourse.” (David Webb)
>
> “It is a big question. What do we do? We keep making efforts to include people from a wide range of cultures.” (Jan Wallcraft)

Talking about things that happened to him as a Black man in the UK, Dominic Makuvachuma described the importance of separate safe spaces:

> “I needed to process some shit in a space that was safe and with only Black people, quite frankly. So, I needed to put that into context. You see, when we say - should we include Black people in that? - that's fine but that should not be a subtext that says - there should be no spaces for Black people on their own either. […] We need to make sure that people have a choice based on their journey to understanding who they are and their contribution to life. […] If they want the space to meet on their own I think they should be, well, entitled to it and be given it. That does not take away the survivor movement's responsibility to collate and find ways to engage with that narrative.”

Several participants suggested that we should focus on commonalities. Kathy found it important to move the focus away from ourselves and place it on the mental health and psychiatric systems:

> “The collectivity has to be about the kind of socially imposed stuff rather than individual stuff, I think. […] There is a collectivity in the way that the health system, the mental

> health system, psychiatry medicalise and put chemicals in you, and all those things. You know, there's that, that happens to a whole range of different people. Black people are more likely to be medicalised and given a combination of different drugs, we know about that, but we do have a commonality and that is that our distress is fuelled in this way, and that is problematic."

When thinking about how to connect across and beyond our many differences, David Webb took the example of the disability movement and how that movement eventually found political goals to unite around:

> "I've had great inspiration and thought I was very fortunate to have had a few years where I was working very closely with the disability community. I think that the disability community are quite amazing and it's extraordinary what they've achieved. In particular their slogan – nothing about us, without us – that is inherently a first-person slogan. And the people I was fortunate to work with were very conscious of the need to not leave anybody behind, and started to realise that there is almost this sort of hierarchy in the disability world like, you know, at the top of the hierarchy are mostly blind people, they are the rock stars of disability and then at the bottom of the hierarchy probably are people with intellectual disabilities, and stuff like that, who really struggle to find a voice. Perhaps they don't speak, so extraordinary efforts need to be made to hear them and to create opportunities for their first-person experiences to be expressed and included. I found that that movement was really powerful […] But talking about the UN Convention which was one of the biggest achievements for the disability movement - imagine if each disability group had to fight on their own so that we have the UN Convention for the rights of the blind, the UN convention for the rights of the deaf, the UN Convention for the rights of the physically disabled, the UN convention for the rights of the intellectually disabled – it would be ridiculous. But they found unity and solidarity and commonality and the commonality was actually a political struggle. So I think that one of the tricky things that we have in our work is that certainly on the one hand we want to be good scholars, good academics and do good academic work but our work is inherently political. I think we need to try and approach that with eyes wide open and not pretend it isn't when it is and vice versa."

I would like to close this section with one final suggestion from Shayda Kafai. In her answer to my question about how to ensure that the work we do is widely owned, Shayda said:

> "I don't know about the widely owned part. But I know that there are communities that are seeing the same gaps that you are and that are directly addressing them."

Talking about current developments in the US disability rights movement "that was predominantly focused on physical disabilities and was really [*initiated*] by white middle class folks", Shayda described increased efforts to include disabled people from different communities such as immigrants, queer people and people of colour that can be seen like "almost the second wave of disability justice and disability rights work". I couldn't resist the opportunity to share my concerns regarding Mad Studies:

> *So with Mad Studies, that is just emerging and I feel that my work belongs there – I ask myself how we avoid having to wait until the next generation because this happened also with feminism and other movements. Firstly, there were privileged or more privileged people who started something and then it took another wave so that other issues could come in and become visible and acknowledged. This is nothing new, we have this history in different movements and I am obsessed with this question – can Mad Studies learn from that and work differently from the beginning, can we disrupt that pattern and not always produce more minorities within minorities? I know this is a big question and am sorry about that. I keep thinking of this because I don't want to be part of something when I know how it goes and how it can go, I don't want to contribute to that. At the same time, I am in front of these huge inequalities and injustices that I haven't produced myself but I work in that context, I am part of it if you like, so how do I work against that?*
>
> It's such a good question because you are right – we've seen that in all the different disciplines that we had, even queer studies – we have to wait for waves, and you want to know how we don't wait for the waves, how we avoid that.
>
> *Yes, how we start on different ground or take a different point of departure?*

> I think part of it would rely on the folks that do the publishing. [...] I'm thinking of conferences or online journals and things like that, that even they have to start thinking if their calls are intentionally intersectional. Because I have seen calls for different disciplines that don't specify a necessariness of having like race and sexuality and class and all of these things brought into the conversation. [...] I think that's an important part, it has to start from that place where it's written into what we want and what we are going to accept. And also why not just have somebody – maybe yourself or just a group of folks write a piece that says just that. How radical and amazing would it be to have in one of these anthologies or in one of these scholarly publications a piece that kind of poses the question and says – let us not repeat the same mistakes that other disciplines travelled, let us start with the intention of or craft the principles of Mad Studies perhaps. I know small organisation do this when they list the principles that are integral to their discipline or to their social justice movement. Why not craft something like that that is collectively written? Ten principles that are always going to be considered when we publish something in this discipline that we are calling Mad Studies.
>
> *That's a good point.*
>
> Your question made me think of it because I never thought about this question. But I think it's really important. Why not craft something like that, that's looking for intersectionality or for the elements that are critical to us so that we don't repeat those same cycles from the very beginning. That's such an important question.

There has previously been an initiative to draft principles for Mad Studies (Mad Studies Network 2014). However, the conversations that I have described in this chapter demonstrate that this work should be planned and taken forward collectively. For me, I had hoped to use the focus groups as an opportunity to do just that. Now that the focus groups will have to wait for another project, I hope that Shayda's idea will find another way to be realised, and will personally continue working in that direction.

5.4.5 Decentering madness, centering our own perspectives

I wish to start this section with words from Lauren Tenney that I think best express why it was important to move the focus of this inquiry away from experiences of madness:

> “Every time we focus on us we are continuing to build the system.”

This section details the interview findings that ultimately led to the above conclusion. It reports participants’ thoughts about how (not) to approach and understand madness, about the need to build a counter-discourse to the dominant one, and the possible principles of such a discourse. This section also documents how my thinking and my initial understanding of the goal of this inquiry (expressed in the working title ‘Towards a first-person defined model of madness’) gradually changed as the interviews unfolded.

5.4.5.1 The need for a counter-discourse of madness and the place of first-person contributions

Sharing the lessons learned from their own work, several participants appreciated the fact that I have not included authors who subscribe to biomedical explanations of madness. They found this to be a legitimate and helpful decision. In this context, David Webb raise the importance of explicitly acknowledging the exclusion of ‘consumers’, which in Australia is “the short term for a person who accepts the biomedical model”, because “pretending that they don’t exist is not an honourable thing to do”. Additionally, he raised the issue of how much we define ourselves and our experiences in relation to psychiatry:

> “I sometimes think, if I fired my magic bullet and psychiatry just completely disappeared from the planet how would we talk about ourselves if we didn’t have that thing to define ourselves against? And I think what we’ve got to say is valuable and important not just to critique psychiatry and get rid of it but I sometimes feel really uneasy in the way that there is always this huge psychiatric jargon that still dominates so much that even those of us that are challenging it still fall into talking about it, talking about our concerns by way of reference to what psychiatry says. And I think in some ways it’s a measure of how dominant that way of thinking is.”

Lauren Tenney reflected on people’s existential and economic reasons for accepting psychiatric diagnoses:

> “When the system offers somebody something that they need, and that something is based in economics, they are much more likely to accept and want the label because what they’re getting is meeting a need that they have. The subjugation to the label seems more in a deliberate way a fashion [*among some young consumers*] so I think that that’s part of the complication – really getting people to talk about what are these things that can be resolved economically. And if something can be resolved economically then it is not madness. If you can get people to start to fully acknowledge that, then maybe we could create systems that help people who are struggling with poverty and not have their thoughts challenged in the process, so we are then really getting at that economic issue, and the issue of racism in diagnoses.”

On the whole, participants strongly argued that a counter-discourse to the dominant biomedical model is very much needed. The main reason for this is the damage caused by biomedical psychiatry:

> “[T]raditional mental health hasn’t worked, it has pathologised people, has brutalised people. People had to go back out and find what really works for them. And so for me, being able to pull that together into like Mad Studies, that has both a theoretical perspective but also has healing applications [...] I think that it's really crucial to sort of bring those voices together and you know some stuff we are going to agree on and other stuff we don’t but that is just how any field is. But I think it is really crucial to have the information out there. And to honour it as a discipline and the body of expert knowledge - that could be really helpful.” (Vanessa Jackson)
>
> “I agree with you that we have to have something that counters the narratives that are screwing us, and it needs to be consolidated, even though we are so various and, in my experience, we are not the most organised people. Often, we can’t even get along with each other. To me, the answer is connecting the social and political determinants of madness and the fact that madness *always* comes from trauma. It’s a reaction to what happens to us, rather than the manifestation of a brain defect.” (Irit Shimrat)
>
> “I'm actually thinking that there is a need to take the knowledge wider. I say take the knowledge wider because wherever we are, we are very marginalised, even within our

> own spaces. And largely it's psychiatry which is heard or audible everywhere." (Prateeksha Sharma)

In particular, I was interested in my interview partners' thoughts and feelings about the prospect of connecting our work into something more coherent, creating a our counter-discourse. This discussion started at the beginning of the interviews in relation to the scope of this research and my exploration of the written accounts (see the chapter "The prospect of connecting our experiences: values, complexities and dangers", pp. 152-158). As the conversations evolved, we continually returned to and deepened the idea of a first-person defined model (as I described it), because I asked more questions on this topic (see the interview topic guide in Appendix D). In the following excerpts, three participants explain why they see developing our collective first-person knowledge base as a timely and necessary project:

> "I think it's radically necessary. I think it's incredibly necessary. I mean feminism has started for a while now emphasising standpoint theory. So the idea of looking at disability, race and gender from the perspective of the individual who experiences the oppression - I think it is just as important and just as necessary that folks who – to use the language that you have now – users or survivors develop their model […]. If the model is from folks who are from the outside looking in – there are gaps, there are parts of the conversation that are left missing. So it's incredibly important and realistic because there are so many of us so we would have a very dynamic and inclusive model." (Shayda Kafai)
>
> "I've been thinking about it quite a bit since, and I think that would be helpful. […] Then people can say: Oh, they are social workers or psychologists, or psychiatrists, that's a recognised body of knowledge, or seen as valid, whereas all this lived experience of madness is a bit denitegrated though, denied to be seen as a valid type of knowledge, and seen as 'our own thing'. […] If we could, somehow all come together and be referred to in a way that people, you know, respect our own valid type of knowledge and knew what we're talking about." (T.)
>
> "I think the prospect is promising and also needed, because that is how knowledge advances. And when people who traditionally have been subjects of knowledge creation are now becoming the driving force behind that knowledge creation, it is an

> emancipatory leap for society, you know. […] So there is a need to reclaim your position in society instead of saying: I want to be/am a subject of study. And therefore there is not only a need, there is time for it. The internet has opened up a space where we can actually touch each other's lives, and not only in an academic way, but having this kind of dialogue also. It's not just that people who have the means or who have big networks to travel globally are the ones who are being heard, but people who are sitting like me in a corner, being a practically invisible person." (Prateeksha Sharma)

In this context David Webb stressed that a first-person perspective by itself holds no guarantee of good quality, reliable knowledge. In the same vein he argued that third-person knowledge does not by definition represent a bad or unreliable type of knowledge. I find these remarks greatly important to keep in mind as we move towards establishing and strengthening a first-person knowledge base:

> "I will say that I've had tension and indeed conflict with some people who have first-person experience of madness and that's mostly occurred with people who have pretty much wholeheartedly accepted the biomedical model as the explanation of their experience. And it's not that I totally reject the biomedical model. I just find it inadequate and incomplete. I actually find a large part of it erroneous and misleading. […] You know why I hate subjective and even objective and much prefer the first and third person? With that first and third person language it's a sort of both end, instead of either-or. They are both legitimate and I have two criticisms - probably more when I think about it but it's two criticisms that I'll make first of all. The two concerns I have – the advocates of the biomedical model often completely reject non-medical ways of knowing. Maybe sometimes they will be sympathetic towards psychological science but it is still a very traditional notion of science and they use that to reject and exclude first-person perspectives. So I completely contest that and do not accept being excluded on those grounds. The second thing – I do think third-person knowledge, third-person ways of knowing, the traditional understanding of the scientific method – I've got a great respect for it and with first person, third person I am not exclusive both end, not either-or - but when we include third-person knowledge along with our first-person perspectives – when we look at that third-person knowledge, we need to distinguish between good quality third-person knowledge and lousy third-person knowledge, good science and bad science. And what we find in psychiatry in particular is bad science.

> So it is not that I reject third-person ways of investigating things – it is a perfectly legitimate mode of inquiry, but it still needs to be done with integrity and that's not the case with most of what psychiatry has done. Psychiatry is not an honest scientific discipline. I think it's really important to make that distinction between the aspects of validity of good quality third-person knowledge but I reject the validity of poor quality third-person knowledge."

All in all, participants agreed that first-person knowledge is largely missing and has so far not been part of the official knowledge base of madness.

5.4.5.2 Pitfalls to avoid

When thinking about creating a counter-discourse, and/or a counter-model to the biomedical one, some participants emphasised what we should not do. Above all, they pointed to the inevitable failure of any attempt to establish *the* ultimate explanation or meaning of what gets labelled as madness:

> "I think that it would be a terrible mistake to posit a single explanation. I am not even sure if the word 'explanation' gives us the right way of looking at it. Perhaps 'description' would be a better term. But I do think that it is vital to look at why people go crazy; so maybe that's the same as 'explaining' madness." (Irit Shimrat)
>
> "[I]t can be in the common language, the spiritual emergency, but I think following that trial exclusively and making it a major issue is like following other trials – the limitation of trying to examine and trying to make one explanation the exclusive meaning of madness. People have issues based on a multiplicity of factors – it could be from your birth, you can look at it as intergenerational, you can look at it as karma, you can look at it as abuse at certain times when they are growing up – you know all the different factors but the issue becomes - how does a person come to grips with all that they are and be allowed to find some way of growing by either integrating or compartmentalising or forgetting or repressing as their way to grow, some way to grow beyond the experience.“ (Ron Bassman)

> “[M]aybe it is not about madness, it is about responses to madness. And the line isn't between the mad and the not-mad, the line is between those who have had their experiences categorised as 'madness' and been subjected to psychiatry and all those things, and those who haven't.” (Kathy)

In several interviews it became clear that any efforts to explain madness may actually lead to a reification of the concept. This would further reinforce madness as the grounds for excluding and separating certain people, and would in Kathy’s words “put the line in the wrong place”. Kathy distinguished between the experience itself and social responses to madness, arguing that we should focus on the latter. Hers was one of the arguments that persuaded me to leave aside this project’s strong focus on madness:

> “What the rest of the world wants to do is to divide people into the mad and the not-mad. And if anything that we were to do would reinforce that division [...] in a way that would reify this madness or mental illness, I think that would be problematic. I think that the way in which the distinction needs to be made is about responses. So you don't locate the problem in the individual but you locate the problem in people's responses to that individual, including that individual's responses to themselves [...]. So, the division is between people who have had the experience not of madness but who have had the experience of being psychiatrised, or who have had the experience of being shunned by people.” (Kathy)

In different ways, participants pointed to the need to abandon the damaging binary logics around madness and bring the experience back into the spectrum of human experiences, rather than further manufacture it into something distant and special:

> “The experiences of people that are deemed ‘mad’ are the experiences that people experience everywhere around the world at all times; the only difference is that there’s these boundaries around money, and gender, and social positioning that place some bodies in more vulnerable positions than others. It’s a very human experience to go through experiences of distress, to go through experiences of anxiety, especially living in this violent world.” (Abena)

> “[T]he potential is there in all of us to have a mystical experience or to get a grave illness or whatever but at the same time not all of us will experience that. So this is where the medical model says there are some genes or physical attributes that had created this class of people who go mad and that explanation almost put us on a different tapestry and that is comforting for people because they say – but that’s just those people, we don’t have that potential in us so we are happy on our tapestry. […] There is much more possibility for seeing people as not too different from you when you are looking at social explanations for madness rather than biological ones.” (Mary O’Hagan)

Prateeksha Sharma described why she refuses to even conceptualise certain experiences as ‘mad’. Her explanation reveals that this is not only about a refusal of the term ‘mad’, but about creating an entire approach that, as a matter of principle, does not single out any human experience:

> “I don't want to call it mad because … Say, if you have an ability to hear between 20 and 20.000 Hertz, that's your audible range but suppose somebody has an audible range which is far more than this. It has been just the same problem in the domain of consciousness: somebody is exposed to a different level of consciousness than the average person is exposed to and this is *that* experience. I think once you have an expanded experience, integrating that experience and coming back again into your audible frequency where you can hear everything like a normal person, even though you have that ability now, but you'd rather not be tuned into that ability – so I would like to see it like that rather than saying that it's a mad experience. I think it's an expansion of possibilities of the mind. I see it like that.”

Participants suggested that all these issues should be carefully considered whilst we are creating our collective knowledge base; here, I summarise how they resonate with me and how I think they should guide this work:

- We should not search for any singular or ultimate explanation of madness because there can never be such a thing.
- The responses to madness (including our own responses) and the question of how to ‘grow out of experience’ are far more important than a focus on the experience of madness itself.

- Keeping the emphasis on madness (including the efforts to explain it) can reify madness, meaning that it becomes the grounds for exclusion.
- Our efforts should be towards ‘normalising’ madness and keeping it within the spectrum of human experiences.

5.4.5.3 The emphasis on the social

The interconnectedness and inseparability of what people experience as madness (or what becomes defined as their madness), and its occurrence within the broader societal contexts of our lives was stressed in different ways in all of the interviews”. Participants emphasised the need to see a person in context and to pay due attention to the current and past circumstances of someone’s life:

> “I think you can’t look intelligently at what gets called mental illness without examining the social and political context; the relations, both individual and collective, between people. I know that situations caused by poverty and oppression and other ills that befall humankind frequently result in madness.” (Irit Shimrat)
>
> “My madness is a response to the madness of the world around me and because I can't make sense of it, I can't make sense of the cruelty of people around me, I can't make sense of whatever is going on - so, I think it's easier to break down. Somewhere, some system within my body says that this is incongruous, this does not make sense. And if this is sense, then I'm nonsense.” (Prateeksha Sharma)

I explicitly asked participants about the transformative potential of madness both on an individual level and for the societies we live in. This question, like several others in my interview guide, assumed the acceptance not only of the term and concept of madness, but also of the possibility of its positive features. In the previous section, I reported that some participants saw madness as a predominantly white concept, unaffordable to people exposed to structural oppressions such as racism. Still, the potential to bring about positive and necessary changes through breakdown was acknowledged by several participants, along with the hardship and pain involved:

> “Madness comes with a lot of pain and a lot of suffering, but I think it can also pave people in different directions and transform or change people's lives for the positive, and learn stuff through madness that one might have not gotten otherwise. But I think, you know, if we are sort of saying that, we just ought to say it I think, publicly, in a way that doesn't make it sound like everything is great about madness. […] So, I think that message just doesn't really go out that easily: it can be transformative and lead to positive changes, but while at the same time acknowledging that madness can be actually horrific and not sort of play down people's pain or suffering.” (T.)
>
> “I see it as spiritual and I think it is important to distinguish because I think that those experiences of your world collapsing for whatever your world, your experiences opening up and expanding the vision can be an opportunity for people to change. Why is this important? […] From my own experience, with sort of my world cracking open is - it was scary and I could have died so I don't ever minimise that part. When people are most in distress you can die, you can kill yourself, you can end up in shit that can kill you so I'm not romanticising that part of the distress. But it also can be transformative in a sense of making you dive down, dissent, pull up, throw away everything you thought you ever believed in and with support create a new frame for who you want to be and what you want to do and shape in freer things than you just assumed are true […]. So I really see the possibility of not just people feeling broken.” (Vanessa Jackson)

The decisive question that came up in this context was about how much room – if any - society has to accommodate people’s breakdowns, and to support us to move on, grow stronger and reach a better place in our lives:

> “The potential is always there but with any experience which is out of the ordinary the potential can be limited if the response that people get curtails their freedom of thought and action. That is what I was looking for in my study but I am not sure how far I got with looking at the potential for transformation for the person in crisis, and then finding that intervention in the crisis tends to limit that potential […] and force it down the usual channels. So yes, the potential is enormous for learning and growing but society doesn’t want that so it stops it. The mental health system is there to stop people learning

> new things, to re-impose norms and not get to explore that potential very often.” (Jan Wallcraft)
>
> “First, I think that madness has a great deal of meaning in that it can symbolise experiences that you have either had or witnessed. I think madness is never meaningless, and that its meanings can become tools for change. That is one of the reasons that the psychiatric suppression of madness is so terrible: that the content of madness is not only meaningful, but important.” (Irit Shimrat)

In several conversations, we explored what people’s individual madness says about the world we live in, and what role and meaning the experience of madness could have in inspiring social change, if it were approached with interest and respect:

> “If we could collectively learn from people’s experiences of madness we could learn what could be transformative in our society to enable more creativity and learning and permission rather than reinforcing old norms. We have that right now – the politics of our different countries – societies don’t like to have their norms challenged. Madness challenges all those norms, always has done - one of the things that madness is about is challenging restrictions and norms. If we looked at it collectively, at the problems that people are expressing who end up in the system, we could learn a lot about what we could do to make a better society. But there is no chance that happens at present if they are told to take their medicine and shut up.” (Jan Wallcraft)
>
> “Much of what happens in people’s minds when they go mad could form part of the basis of social change – not to mention that art and creative expression of every kind can be enhanced by madness, when madness is not feared or suppressed. [...] In short, the more we collect, listen and pay attention to people’s stories of what went on in their minds when they were crazy, the more we can bring together solid ideas about making life better and making the world less crazy.” (Irit Shimrat)
>
> “In our bizarre world especially in the U.S. these days – like what the hell is success? This is where the consumer/survivor/ex-patient movement has incredible potential to help people redefine normal, redefine success, look at how some societal expectations make people sick, get them disconnected, get them stressed out and so I think it has

> incredible potential. But we have to create spaces individually and collectively for exploration of that.” (Vanessa Jackson)

Shayda Kafai described the implications of individualising madness and breakdown, and reversed the usual assumptions about where ‘change making’ should take place:

> „[I]f we say it’s the individual’s problem, then we never step back to see how it is an issue of language, how it is an institutionalised issue that we don’t explore in our educational system, in our family systems. So you can then think of it in a context of how it can shift society, then maybe we could take the focus off the individual and say where are the different societal ways where these oppressions are getting replicated and placed on the individual. It’s like putting the change making on a person when it has to be on society at large.”

It became clear in the interviews that radically different social responses to madness are needed in order to understand and enable the changes that these experiences are calling for.

5.4.5.4 Responding to madness

In trying to move us towards envisioning possible responses to madness that are substantially different to current responses, I asked participants to imagine the interplay between madness and society if there were no institution of psychiatry to govern it. Some participants pictured such an option as a great step forward:

> “Oh, I think that's a good question. […] I think it would be a more honest society if we weren't having to dress things up and hide them away. How could, what could it be like? I think it would be good, it would be intense, I think people would feel more alive, I think it would be exhausting as well.” (Kathy)
>
> “If difference were seen as good and interesting and important, the world would be a better place. Legitimising madness could help in getting rid of a lot of prejudice. And there’s an aspect to some kinds of madness which is childlike; being open to wonder and being excited by strangeness, rather than frightened by it. The hegemony of psychiatry and psychology – all of this so-called science – pushes people down; pushes

> difference down. This is part of what makes capitalism go. The profit motive is huge in the so-called health sciences and the so-called caring professions.” (Irit Shimrat)
>
> “[I]f all this pharmaceutical industry would fall apart you know, all the Big Pharma is gone as well, there wouldn't be that sort of push to get people on medication, and it might be more, really, what is the cause of this […], whatever that is, to sort of deal with those real causes. It's problems in society - thinking about violence, or inequality, or, you know, people not having enough money, that kind of thing - which maybe encourage people or a community or a society to deal with those societal issues, which might prevent some of the suffering in the first place.” (T.)

The main consequences of the imaginary abolition of psychiatry were for the ways in which we relate to each other, or, as T. put it, “the awareness that that isn't an option any more [*would imply that*] people would have to take more responsibility for supporting each other”. Building on her knowledge of the potential of communities of people of colour, as well on her experiences as a counselor and therapist, Vanessa Jackson stressed the importance of taking a radically different approach to the question of ‘what’s hurting’:

> “Well I think it’s what it was before we’ve built all these institutions. And this is what I think is missing from that people of colour analysis. Now again I'm not minimizing that there is suffering going on in my community and in other communities of people of colour. But there also is a wide acceptance of people's behavior that might be flagged, swept up and locked up. And for people, finding and honoring people's gifts in spite of them having a different way of relating to the world. And if people had resources. So the interplay for me is about being free of these expectations and labelling, and if people had supports like cash money and adequate housing a huge part of folks would just be OK because some of them are just stressed about these things. They might be allowed to be freer folk and offer their contributions in a way that makes sense and they could be really powerful. So I see lots of potential and I think that when people were in distressed states that were life threatening, that were confusing and hurtful for them and other people, we'd find more compassionate and more useful - quite frankly - ways of helping someone move through those experiences and maybe figure out what's hurting. Preventing is like - I don't want to assume that something is going on in your head first, tell me what’s going on around you first. What are you reacting to? – is always my kind

> of first inquiry. Like – what’s going on? And I think that one of the biggest flaws in modern psychiatry is that ‘never mind’. They knew that that wasn't the problem, they knew that this larger societal stuff were a much bigger problem than bad biology.”

Before I go on to report further ideas for potential, non-damaging societal responses to madness, I want to stress that several participants made it very clear that the current socio-economic and political climate in which we live does not allow for anything like this:

> “We live in a Western society. […] There is this kind of xenophobia, there’s a fear of difference, there’s - let’s shut out everyone else who’s different sort of thing. So how would madness without the biomedical model play out in that kind of world? […] Not well. If we had a republican right-wing, xenophobic America, if we got rid of the biomedical model in that world – madness would be criminalised. I am not in favor of the insanity defense and I think the whole criminal justice system is flawed and I think it’s terrible - but it would be criminalised in a way you know, you lock them up, you throw away the key. So what about that other expression of our community which is much more about tolerance, much more accepting and embracing of diversity – yes, I think in that context doing away with the medical model there would be some hope that another approach that was going to restore people, that was going to kind of at least understand people’s experiences as a full human experience and insist that people have equality in the world - yes I think we could be quite hopeful that we would have the kinds of responses that those of us who talked about the recovery approach, before it was colonised, where we have our own self-determination, where we were treated as equals, where we had a really broad range of responses that dealt with whole systems, all parts of our lives and the real seeds of social justice – then I think yes, we could have a set of responses that would be a lot better than the medical model responses. […] We don’t have a singularly good accepting society and we have quite a divided society and I think America demonstrates that better than any other country.” (Mary O’Hagan)
>
> “I don't think society wants that. And society is not ready for that.” (Prateeksha Sharma)
>
> “I think the limits come from within the people who are interacting. To be sensitive to what that person is expressing, what they need and what their reality is - it is difficult to expect so much of people. People go about their business and we don’t exactly – well

> I could speak for the United States – we don’t live in a nurturing culture. We live in a time where self-interest - to use that nasty word Trump has exploited – is everything now. And there are good people around who are helpful and do things, but I think there’s a great deal of threat and fear that I think we don’t recognise or we deny, you know.” (Ron Bassman)

Deep fear of otherness, the manufacturing of collective panic and prevalent, negative representations of madness were seen as decisive forces that maintain the status quo:

> “The big problem with psychiatry is that it takes difference and makes it into a problem. Diversity of every kind, including mental diversity, is at the root of – I really don’t want to say ‘progress’, because that is a concept that has become so ugly – but the enlightenment and enrichment of the world. I am looking at what is going on in America right now; the promotion of hatred and prejudice and fear of otherness. It’s quite terrifying how many people are attracted to that.” (Irit Shimrat)
>
> “The only thought that just popped into my head was something about fear, like the fear of people like me when I got caught up in the psychiatric system, fear about myself, like, what would I do, what would happen next; but also other people's fear of me, you know, that stuff is very real and you can't ignore it - the collective fear of the rest of society, the collective fear of the not-mad about the mad, that's a big deal, isn't it?” (Kathy)
>
> “[S]ociety has very normative, cruel standards, where they just want to isolate people, and more than that - I think the word 'fear' is something which is very important here, because the whole of psychiatry, and the whole structure of power, is based on fear. So, you instill fear of a certain kind of people in the hearts of other people, and therefore you garner a collective consensus, you sort of build a consensus that this thing is dangerous, you know - this thing or person there is dangerous. This person’s anger is dangerous and therefore this anger needs to be subdued, or should be sedated […] And you say - this here can be harmful, this can happen, that can happen. I have never, in anybody's story that I have heard or read, I've never found any irrationality. And I think that whatever psychiatry makes of that, they just want to make something out of

> anything […] Because it's so easy to label people, based on anything.” (Prateeksha Sharma)
>
> “I think a limit to the acceptance of madness is that the images that are called up when you hear the word are so rigidly set in our imagination […]. I think we’ll have to do significant work to revise it.” (Shayda Kafai)

A further interview topic was the limits to the acceptance of madness and whether such limits are, or should be, any different from all the other limits that we inevitably impose in negotiating with each other as we go about or daily lives. The clear majority opinion was that there are limits to what is acceptable in terms of people’s actions and behaviour – as always – but that the rules should be the same for everybody. Several participants highlighted the reality that people deemed mad are treated as an exceptional group whose behavior is subject to additional laws and regulations. This was seen as greatly dishonest, and also as central to discrimination:

> “As you know my primary topic is suicide which many people will use as an example of where we might make exceptions, and I say bullshit to that. There are so many things that we do that are dangerous like riding motorcycles to parachute jumping, unsafe sex are some of my favorite examples. As humans we do lots of seriously crazy dangerous things. That is part of the human experience and we don’t hear the discussion of limitations or exceptions. That really is just a rationalisation of some dominant power […] to deny me my rights. And I think we’ve seen this a hundred times in the past, whether it is to do with race or sexuality or whatever - these are bullshit arguments, they are demonising the Other. We see it in Australia with the immigration policy again there is that ‘them’ and ‘us’ thing coming into play. And this whole notion of – you know there are exceptional times when we do need to limit the freedoms of a person if they are so crazy that they might do something dangerous. […] In this area I think madness encounters its greatest obstacle. It is in this area where we see the most prejudice in society, that is society’s prejudice against a particular group. This is the most vicious and extreme prejudice that is applied to mad people that is not applied to anyone else. Even in the genocidal policies of Australia against the Aboriginal people perhaps they are comparable on the basis of what we now know is just pure vicious racism. Terrible, terrible things were done to Aboriginal people and I don’t see that as any different to the current status quo where extreme madness is used as a justification

to abuse those people. And the way it’s wrapped up as compassion and doing the right thing for poor vulnerable people is obnoxious. So no, I don’t accept those limitations, they are crap. You peel them up just a little bit and they are just power politics.” (David Webb)

“Just like anybody else mad people should be subject to the law of the land, not mental health law.” (Kathy)

“Well I think there’s always limits on acceptance of behavior. […] We don’t go beating other people up, or killing them, abusing them - you know there are certain things that are not acceptable. Now one of the problems that I think we are getting to is – it doesn’t matter what the causes of the behavior are, we should all always be accountable for our behavior. Then at a secondary level, society should be saying - well are there mitigating reasons for the behavior? - and there often are. There are all sorts of reasons. We have a very dichotomized view about free will in our legal system – you know from people going into the criminal justice system - there are crazy people who are not responsible for their behavior and then there are non-crazy people who are fully responsible for their behavior usually, although sometimes they bring mitigating circumstances. And I think that’s really a bizarre type of construction. I think that any crime has some mitigating circumstances – we should consider those whatever the reasons, whatever the circumstances – whether that is because you’ve been provoked, you are in self-defense mode or you are a battered woman or you had experienced psychosis. I think we separated madness out from all these other mitigating circumstances. And I think that’s discriminatory. I think the issue of human responsibility is a highly complex one and needs a much more nuanced kind of treatment than the dichotomy we have now between people who are legally insane and the rest who are fully responsible. […] I think we should accept that there are certain behaviours that we don’t accept as a society and we shouldn’t accept them for mad people either. You know, I was in a drop-in place once and there was a guy who came in every afternoon. He was very angry and had reasons to be angry because his life was fucked up by the system. He was very angry and he was frightening the women so much they stopped coming to the drop-in and the professionals who ran the drop in wouldn’t confront him because they said he’s unwell! And I just thought that’s a form of discrimination, and actually it’s not enabling him to

> confront the consequences of his behavior. And he scared a whole lot of women. So I don’t agree with that approach.” (Mary O’Hagan)

Additionally, Vanessa Jackson pointed to the economic interests involved in singling out and then acting against certain groups of people:

> “[W]hy do we treat it so differently - people's other ways of being that might worry us or scare us? […] I think that's why it's important to understand […] the history of psychiatry which then informed mental health - is that that was economically useful to people. And so to carve up this group of people and act upon them first of all is a societal projection - you know because these people are deemed to be so far from normalcy, we got to sort of sequester them somewhere. To put all other people on notice not to get too weird or bad things can happen to them - also was a cash cow historically, and still is. So for me I don’t think it has to be treated differently but then we need to analyse why this particular category of people have been treated so differently and I think it's for some of those reasons.”

Some of the conversations went into more detail about how we should be treating - or being with - each other when going through difficult states. Jan Wallcraft importantly highlighted the contradictions involved in attempting to identify universally applicable solutions:

> “It is possible to think about that, it’s not possible to formulate it because when you try to formulate it you end up putting rules around it, structuring. But it has to be safe for the people who are going through the crisis. I’ve seen the stuff written about sort of walking with people through their crisis or running with them if they need to run and that sort of thing. People who are in crisis having somebody with them who can support them all the time, individually but in a way which doesn’t disrupt their exploration of what is going on in their life.”

When considering responses to madness, participants did not suggest any particular concepts; their emphasis instead was on overall attitudes, such as the ability to accept, communicate and create safety:

“I think part of it is – and it’s not absolute – but when you negotiate you have to communicate. And if you don’t have the ability to communicate back and forth with understanding, it’s difficult. […] Whenever I’ve spoken or done things, some people are interested in how you’ve got out of this, what’s helpful and not, but the greatest curiosity I’ve found is – what it’s like to be crazy? What is it like to go mad? What did you feel like? They want to know the specific kinds of things. I’ve never been fond of talking about that but I realised […] that there’s such an interest in it that I need to. […] One of the examples I used is, if it was raining and I was soaked I would say I’m not wet and it’s not raining. And I was convinced, that’s my reality. So how do you communicate with me when I’m standing in the rain and saying that it’s not raining and that I am not wet and the person next to me is soaked and saying – yes, you are. So I think with that extreme I don’t know how you would negotiate except for the concept of being with the person. You know – he’s not wet, I’m not wet, OK so move on. And if I don’t want to come out of the rain, just let me be if I am enjoying what I am doing. So there is the kind of acceptance, tolerance and being able to be with the person without feeling that you need to make them move into your reality.” (Ron Bassman)

“I think it’s similar to the other relationships we have with each other and the sense that when you negotiate a relationship with another individual, you come from a different place and you have to listen. And the acceptance of madness hopefully will craft space for that listening.” (Shayda Kafai)

“I don't think that there could be any limit to madness, there shouldn't be. Because if you want to be inclusive, then you really have to embrace it all, the whole diversity. […] There is something rational, there is something the person is trying to express through their suffering, and it is looking like mad to you, but it makes sense if only you could have the language to understand that, that compassion and that peace in the heart that knows that it's nothing, that there's nothing, no madness.” (Prateeksha Sharma)

“You need a place where you can go kind of bizarre, but use that energy that is being expressed in a way that is not dangerous but helpful. We’ve got to start on that, we have to do it step by step, working with people in crisis, working with people who’ve been through crisis. I kind of got enough material in my PhD, I wanted to see what people would really want and if they could imagine what would have made them feel safe and

> supported when they are in crises and how that could be made available to other people. It’s kind of like a learning process, starting with people who have been through a crisis, looking back at that and collecting what they felt like and what would have helped them at that time. People do feel very unstable in a crisis very often and they want some kind of safety and security but it would be nice if they could have it in a way that wouldn’t limit their growth. But I think that only the people who’ve been through that could tell what it would be like. I think I needed to cry and be angry and have people around me that would just keep me safe but not stop me from feeling and experiencing.” (Jan Wallcraft)

All the ideas presented here point to several important avenues for the further exploration and advancement of our knowledge. They also make clear the uniqueness of first-person knowledge in developing different responses to madness, both in terms of policy and legislation but also in re-defining and re-claiming the notion of support. I wish to close this chapter with one more suggestion by Irit Shimrat. Among other things Irit’s suggestion challenges the Western concept of ‘care’ as an income generating profession:

> “My friend and I, before she died, were planning to write a book called ‘Paid to Care’, about the problem of people earning their living by ‘caring’ for ‘the less fortunate’. If we were able to blow psychiatry out of the water, maybe we could live in a world where people care about each other because they know that it’s good to do so; that it works for everybody. Maybe we could have real communities. Instead of a single hospital in a region, where people are forced to go when they are having difficulties, we could have a house on every block of every neighbourhood, in every village, town and city. A safe place where people could come and be cared for and be treated like human beings. There would be no financial incentive. People would be doing this because they wanted to. And I think that there is a huge, untapped reserve of potential for this, in old people who don’t know what to do with their lives. Who come from a time that, despite all kinds of hardships, was in some way gentler than our time. Whose life experience has taught them the values of kindness and gentleness. I have a dream of people, who are just thrown away in Western society because they are old, instead being instrumental in helping others, including younger people, who are in trouble. […] I think that, from both ends of the age spectrum, you could have really positive forces that have nothing to do with making money; making it a better world by being interested in different ways

> of thinking and being. Being interested in craziness, not just out of compassion but because you see its importance."

5.4.6 From 'a first-person defined model of madness' to advancing our collective body of knowledge

My interview topic guide focused very much on the idea of a first-person defined model of madness, the term I used in the working title of my thesis. As previously stated, the interviews changed my perspective, moving me away from the idea of a model and towards thinking about strengthening and advancing a first-person knowledge base of madness. Ultimately this led to rewording the title from 'a model of madness' to 'a first-person epistemology'. I will elaborate on this in the concluding part of the thesis. In this chapter, I report participants' thoughts about a potential (social) model of madness, about the applicability of the social model of disability to madness, and the way participants perceive Mad Studies as a field that best situates this inquiry.

5.4.6.1 Resisting explanations and definitions of madness

One of the recurring issues throughout the interviews was the caution needed, and the pitfalls to avoid, in establishing and advancing first-person knowledge. Participants expressed this in many different ways. In the very first interview that I conducted, Abena shared her ambivalence about the goal of this inquiry. Warning that the knowledge that we create can be "taken up and potentially exploited and abused", Abena said:

> "I don't know if I see myself within this synthesis that you created around what could be presented as a definition for madness, or working definition for madness, to then activate for social activism and ultimately a social model of madness. Beyond the extreme anti-essentialism, beyond these like extreme proposals that I am presenting to you right now - this is where I feel my work dissents."

Abena problematised prescriptiveness as something embedded in all of our work. In the following exchange, I explain the intentions behind this research and she warns of the possible implications of any such effort:

> "*You are encouraging me to use the term social model even though my working title is 'first-person defined model'. I didn't want to say social. I thought – let's see what happens when we, who are defined as a problem, when we start defining the problem, let's see where that takes us. When I said 'first-person defined' I also meant first person plural – however small that plural is within this study. I wanted to explore where that will take us and I think it actually takes us to a social model. To me it is important – how to connect our multitude of experiences without overwriting them, without packaging them into some explanations that are then supposed to fit everybody. I want to believe that there could be a model or a theory that holds that freedom for everybody to have their own experiences and not to have them totally subscribed to any universal explanation. That is what I would like to do in a way – to connect and to move certain issues forward but without saying – this is now the new philosophy that we invented, we, people who've been there and this is going to be valid for everybody. I wouldn't like to have that kind of process.*
>
> I think freedom is… like true freedom, not liberal freedom but true freedom – I think that is the fight. So I encourage you to look for a more freedom-based vision because I think that's the fight. That, to me, is the fight. This notion of prescription and surveillance, surveillance that has now created the world to make it a prescription. Surveillance is the overview and prescription is the end result. And theoretical models are also prescriptive; of course they are, so is knowledge. […] This is to me the problem also of textualisation, of prescribing ourselves in our own work; it's the whole mechanism of surveillance. And also policing ourselves as well."

I appreciate Abena's emphasis on a "freedom-based vision" and also understand her point about the danger of "prescribing ourselves in our own work". But because this project is not likely to result in any kind of model, I feel that the issues she raises – especially those around the many possibilities of the co-optation and abuse of our knowledge - don't have to be resolved immediately. And knowing that such issues might never be resolved, part of me thinks that we should continue with our work regardless. This is certainly one of the dilemmas that I would have liked to have discussed in the (postponed) focus groups.

However, some participants could also see positive developments, and highlighted that our knowledge does impact on the mainstream, even if slowly and insufficiently. Referring to the US consumer/survivor movement, which in her view repeatedly asserted, "we are not schizophrenic, we've got some trauma and some of our trauma is your label" Vanessa Jackson observed:

> "I think some of the ways that it's shown up in values and policies is really about what consumers/survivors were saying. And so it did have, I think, a policy impact. We're going to see some bad sides of that but I just think that we've always seen how things won clarity in the analysis and in the political analysis about madness that we can get changes even in our system. Not as big they need to be - let me be clear not anywhere where they need to be."

Lauren Tenney was unambiguous in her answer to my question regarding whether madness can or should be explained:

> "No. Just no. Because it's so much on other people's perceptions. It can be explained by other people's judgmental perceptions. And that is not the explanation of it – it is other people's assessments of one's experience. They then put this frame on and it is like negative eugenics and positive eugenics."

Considering how quickly alternative explanations can be inverted and ultimately used to extend and strengthen biomedical approaches, Lauren felt we should not use our energy to bring our work together to generate another such explanation. Referring to what is currently happening with the trauma model she said:

> "They managed to take these situations where people have been injured [*by trauma*] – now there is a new model for biological mental illness. So there is this fear that anything that you try to explain as fundamental to what the issue is - as opposed to being a biological thing which is the root of what this trauma has been about – the power structure eats and turns it for their own needs."

Her main argument was that the debate is not actually about the validity of any particular knowledge but much more about power and the different systems that maintain and support the status quo:

> “Obviously the medical model as the explanation needs to be challenged, refuted and exposed. Absolutely. And it always amazes me that they operate from what otherwise could probably be set up as a delusion on their own terms. So if I have no legitimacy or no evidence for my experience as real and you have no legitimacy and no evidence for your assessment of my experience being real - so why is it that your assessment is being taken as opposed to my stated experience? Right? And that’s the power, and the industry, and the money, and we are an easy target for them. It’s required, there is class in order to have the industry of power. The social, political, economic, cultural context of it all cannot be removed. […] Taking the existential thread that the only way that you can prove something is by disproving it – the attack has to be on the system. Every time we focus on us we are continuing to build the system. So many people have tried brilliantly […] they’ve just been doing it for all this time – so if the dissident psychiatrists and psychologists are marginalised in their attempt to counter the master narrative of the biomedical model then it’s only logical that we [*are as well*] as the people subjected to it.”

A further argument against any attempt to explain madness, raised by Lauren is that the resulting explanations would inevitably give people “something to hold on to” and would also support our own processes of “mentalising” ourselves. She made the following suggestion about what we should instead aspire to in our joint work:

> “I think that it would be good to create something that has a challenge to the biomedical model, that has loose enough boundaries, and with lack of specific definition, that people would be able to stand with it and that challenge would then be heard by people who have yet to be psychiatrised.”

Abena and Lauren Tenney were the participants who explicitly challenged the very purpose of moving towards our own model of madness. Their arguments are centrally important to this inquiry, and to its future shape. There is also a significant overlap with the concerns raised by other participants. In my opinion, everything that was formulated in negative terms - in terms of what we should *not* do – offers important guidance on how to further establish and advance our collective knowledge. One of the main outcomes of the above debate is that the deliberate absence of a specific definition can, and should, be integral to, and one of the distinctive features of, a first-person knowledge base of madness.

5.4.6.2 Values and principles

In some interviews, I asked participants if there were core values and principles that they would suggest for a potential model of madness that centers our collective first-person knowledge. Several people stressed the need for variety, arguing that no universal framework or concept should be enforced as a matter of principle. This related to the individual as well as to the realities of entire social groups, including the dominance of perspectives from the industrialised world:

> "So, as long as we can recognise that […] there are differences in the resources where you're coming from and where I'm coming from, and yet, despite that, in this discourse there is going to be no such hegemony as has been there in psychiatry, so the global North is not leading over the global South, the way it has been with psychiatry." (Prateeksha Sharma)
>
> "I think we need to keep aware of not imposing a fixed view that comes from a few people. For me it would really have to be one in which people are really open and not tied to a concept that was important for us in particular. I know my experience, what happened to me and I can generalise to some people but to a lot of people it doesn't work. I think that we have something valuable to offer but we'd have to really clearly have a developed position that understands how diverse it is – each person's experience - and there are themes and similarities but they are tied together so differently. The best progress would be made if we can really take a strong stance and come to a position that doesn't make people into objects and drives this simplistic, mechanistic formulistic picture of who we are. And I think that could be a powerful thing to have a strong, arguable, articulate position about how far off these formulae are, and allow us to be open to contemplation rather than simplistic answers to the miraculous mystery of life." (Ron Bassman)

> "It would be nice if we could use a model that contained as much variety as possible." (Irit Shimrat)

In the following excerpts, the participants described more aspects that they find important. Rather than simply providing a list of the core values they suggested, I am also documenting the argumentation. I have italicised the phrases that I think best highlight participant's suggestions, and have retained the context:

> "I think values are hugely important. I hate prescriptions, prescribed rules, I do really hate rules but I love guidelines. […] We need to be very clear and very fierce. On the one hand I would say – we *need to be uncompromising*. And that doesn't mean that we are exclusive but we just don't buy the shit. And that requires incredible diligence and consciences because there is so much shit that is just taken for granted. So these are the qualities or the values — *honesty, integrity, humility, diligence, vigilance, clarity and solidarity*." (David Webb)
>
> "If we can somehow figure out how to *make space for people who in societies are most oppressed and marginalized* then everybody else will find space. If we are looking out for the person in most need, everybody else will be satisfied. If you can balance that… I know it's a high challenge. People have been trying and trying to do it but I like the idea of creating something so loose and leaving that *room for individual interpretation* and individual experience to be legitimate *and to allow two individuals to have diametrically opposed experiences* and both be able to fall under this thing." (Lauren Tenney)
>
> "A really important part of this model would be not solely focusing on madness as our primary identity but perhaps as something that just is a narrative that connects us - I wouldn't say that it unifies us because everyone's narrative is different. A core value for me would be *the inclusion of other identities* and specifically seeing how they shift, engage with or create dialogue with madness as an identity. And […] not just race, ethnicity, class, socio-economic status but immigration status, family dynamics - and just really ask that we honour the different ways our identities speak with our madness." (Shayda Kafai)

> “I think the core value is *equality*. The reason I say it is – I think in our Western cultures it is such a core value that no one can argue against it. If you say this group of people have been treated as unequal and they’ve been discriminated against – people just don’t argue against that because that’s such a fundamental value. So I think if we talk about a social model of madness – at the core of the UN CRPD is equality and non-discrimination. That would be one thing and of course a very aligned principle is the *principle of self-determination*, of having control over our own lives and that means a non-coercive system.” (Mary O’Hagan)

One thing that became obvious was that participants were not inclined to just ‘theorise’: thinking in terms of our own model proved inseparable from the question of whether and how such a model would impact on the lives of people labelled mad. This was articulated as a matter of principle in the following two statements:

> “I think it could count as a value or a principle about our model of madness not just being a model for the sake of a model but having some use - if the model then helps direct the kind of support people might find helpful - you know, not just being a sort of abstract, academic thing. About how to sort of captivate it, the value of the experience of the people who go through it, and how to really value that.” (T.)
>
> “The same thing as I said before really - that it mustn't be too focused on experiences and it must be focused on responses to perceived difference.” (Kathy)

Several answers about the core values of a potential first-person model of madness focused on social responses to madness. Participants formulated some of the principles that an approach grounded in our collective knowledge should include:

> “Another principle in a social model of madness would be something around how society resources, or how society constructs a range of responses for people. The social model of madness suggests that actually we have a multifaceted life and the experience of madness can interfere with many facets of our lives. If you understand that madness is a social thing that comes from your life and your environment rather than your biology, then you must construct the whole *range of responses* that you need *to assist people who go through this experience*. Because what we have at the moment is an

incredibly one-sided system. When you talk to people about what they find useful in their recovery, and when you see where the resources go, there is an inverse relationship. Most of the resources go into stuff that people tend to find least useful. There are a whole range of things that people need in order to experience madness and the return from it in a personally safe way. I think that's really fundamental." (Mary O'Hagan)

"For me one of the core values would be looking at the person in context. So what's going on around you – that's got to be the first step. […] I just think that the first core value is really *understanding the person's context - social, political and economic context*. I think one is *privileging the person's experiences and also looking for what are the gifts*. That sounds weird on some level - but what are the gifts in this experience, and helping people because oftentimes we will abuse people [*in the system*] and never once ask – what's that meant to you? […] So I think one is like sort of finding ways to always privilege the person's experience of what's happening for them and being able to say what have been the benefits for them of these experiences. […] And so for me we don't want to miss the opportunities. I guess following your question - is really privileging the wisdom of people with lived experience because there's so many techniques for healing, opportunities for healing, looking at it as a spiritual experience and re-working relationships with what we call symptoms. And also I think really oftentimes people just try to make meaning. So I think having a philosophical approach to it and also having people who are *clear about the basic – what is a safe enough environment* like food, clothing shelter. For me it sucks to have all those experiences and you're sitting homeless under a bridge and no one pays attention to your ass. That is another thing that I would think about." (Vanessa Jackson)

"*Empathy and patience* would be core values." (Irit Shimrat)

"I think that there would be core values but I'm not sure what they would be apart from *keeping people safe in a crisis but not oppressing them*. That's what it comes down to I think. Giving people what they need to survive and learn from their crisis without hurting them. That's a sort of commonality, that could be a thing that we could possibly all agree on. The extents of what the limits of safety would be and what that would mean would be very variable, but we could sort of agree on principle that we need to

> be looked after when we are in crisis but we don't want to be hurt and damaged. And we don't want the oppression that we've already experienced to be repeated. I think we can agree on those values." (Jan Wallcraft)
>
> "The basic foundational principle for me is that everything is possible for people. The probability is a different issue but to keep open the possibility for a person to progress on their life journey. Maybe it means taking a different path, understanding something differently or maybe just having the opportunity and the freedom to play out all these connections, including mental connections that are not working. I think that's an extensive and intensive task for most people but I think for some people they can do it more quickly, it's just different. Important for me is to live with the uncertainty but *to feel possibility without the certainty*. That's the grounding that I feel. I believe that within most people there is a kind of path that works for them, where they can fulfill more of their potential while exploring alternative routes. We all might search and strive to be and if I am stymied by where I am, some other person might find that place where I am stymied to be where they will find what they are seeking." (Ron Bassman)

Although I abandoned the idea of directing this inquiry towards a first-person defined model, participants' suggestions for its core values and principles are nonetheless invaluable for future work. Here I don't simply mean research and theory building, but also activism and political work. Becoming aware of the richness and depth of the ideas that the interviews brought about, I regret not asking everybody about the core values; not all the conversations evolved in this direction. At the end of this section I wish to document one more opinion that was mentioned just once:

> "I'd like to see having fun as one of the core values in whatever we do. Making space and, as far as we can, creating opportunities for enjoyment and for creative activity and for comfortable social interaction – and for wildness." (Irit Shimrat)

5.4.5.3 Some thoughts on methodology

The interviews didn't generate many ideas about how to concretely work on strengthening and expanding a first-person knowledge base of madness; this is one of the issues that I wanted us to explore in the focus groups. However, some important ideas were raised. In the following excerpt, Abena argues for the value of conversation as a method of knowledge making. She also raises concerns about the utilisation of people's personal stories. Although I decided not to analyse any personal stories (see Chapter Four), I believe it is important to document another argument in favour of not doing so, which I think could be adopted as a general methodological principle:

> "When I'm fifty I want to be able to tell my own story as opposed to have someone tell my story based on my writings from when I'm thirty. I want to be able to tell my own story forever. And they should be able to tell and use their stories forever how they want to. It doesn't mean that knowledge can't be created from their stories. Where I get my best ideas is from debating with people; that's why I want to hear what you think. I am so curious to read your paper and what you have been able to synthesise. This focus group is so intimidating to me but also so exciting because that is where the best ideas always come from. It is from more than one, we gain. The possibilities of co-producing knowledge is not what I am trying to squash; I am just trying to squash the way in which we utilise other people's stories. I think other people's stories are important, it is how we co-produce knowledge […] You are ultimately going to synthesise these first-person ideas into what might be some major theme. This is the co-production of knowledge. But do I want my prescriptive story in there? No, I want to be able to tell my own story at 50 - if I want it differently and if I decide I don't want that story to be told anymore, I just won't tell it anymore."

Abena's words correspond to Frank's principle of non-finalisability (2010) and his general concept of dialogical analysis (2005, 2010); a concept that greatly inspires and encourages my work.

David Webb highlighted the fact that first-person research methods have been very much neglected in the history of research, and emphasised the need to invest much more work in developing our methods if they are to stand alongside conventional scientific ones:

> "For the last 200 years or more we have collectively, globally invested a huge amount of energy and money and everything else into developing and refining and enhancing third-person methods of inquiry, to the point that they are as sophisticated and robust as we have today, you know the scientific method and everything. But first-person

> methods are sort of really back where science was 200 years ago. So when I think in those terms I think we need to be a bit humble as there is a huge amount of work to be done. We need to stand on the shoulders of those that are gone before and there are some, quite a few, but really we are pioneers. This is new territory. And there are debates within academia about this as there are in society at large. I think there is a great enthusiasm in the community for a better appreciation of first-person knowledge, but that we are really floundering because we don't have the tools to engage with it. So the work that you are doing is hugely important. But 100 years from now people will look back at your PhD - saying ha, ha look what they used to think."

Referring to her work on adapting Amartya Sen's capabilities approach[45] to mental health (Wallcraft and Hopper 2015), Jan Wallcraft shared her skepticism around people's readiness to commit to complex tasks:

> "The more complicated things are the less people you will have that will really apply themselves to these things and really think about them. They are like - oh no, it's too complicated, we don't want to explore it – that's part of the problem. Even teaching about it – I found it so hard so actually I didn't do it as successfully as I wanted. I tried to make it crystal clear so that anybody could get it but I think I failed with that, it's almost inaccessible. It is conceptual and then people go – well, if it's not practical then why you are bothering? It's supposed to be easy to apply, like the social model of disability is mostly straightforward while the social model of mental health is not."

The few suggestions made regarding methods to develop a first-person knowledge base of madness were about the need to work *jointly* and involve as many people as possible:

> "I think that collecting of stories is the first step, and the step that has to be repeated throughout the process." (Irit Shimrat)

Kathy raised the importance of being inclusive, of accommodating people's madness throughout the process, and also of ensuring that the work remains relevant and beneficial to one's own life:

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[45] See more at https://www.iep.utm.edu/sen-cap/#SH8a (accessed on 26 August 2018)

> “Just being willing and prepared to communicate in different ways, or to listen to people who might want to express themselves in different ways, and to accept that some people might find the processes of developing stuff more difficult than other people and might need support to do that and providing them with that support. Another thing, this is an interesting thing, because I think that when people get involved in doing something collectively, it is about wanting to do something collectively, but also – for me – it was about, like, wanting to make it better for me, wanting to make things better for me. So there needs to be space in any collective thing for people to bring their own distress, to have an opportunity to work collectively with people on their individual distress and help make it better. It mustn't be a space where that distress, or madness, or whatever you want to call it, isn't acceptable.”

The further development of appropriate methodologies for working towards a first-person knowledge base of madness remains a central task for the future. Not telling anybody’s story for them; working together and in an inclusive manner with different means of communication; making sure that our work remains accessible and open for others to join; and also that it makes our own lives better – these are some of the principles that we may want to adopt along the way.

5.4.6.4 The social model of disability and madness

Most of the participants were familiar with the social model of disability. It was interesting that even people who said that they didn’t read much about it and wanted to check their understanding with me were able to accurately summarise what the model is about. This speaks for the accessibility of the social model of disability and its reach, or as Prateeksha Sharma describes, “you just internalise the knowledge and forget the label where it's coming from”.

Generally, the participants greatly valued the social model of disability but saw some difficulties in applying it to madness. In the following excerpts, participants describe different aspects of the social model of disability that would need to be extended and adjusted:

> “I think that the social model of disability would have a lot to offer to madness. But then, I do wonder as well, if that would be enough, or whether it would need something a little bit extra as well. I suppose linking it into all this sort of extra stuff that what

we've seen before, the transformational potential of madness. I don't know whether that would be adequately captured in the social model of disability or whether something specific has to be added on to include that as well." (T.)

"It needs to be changed and adapted because the ways in which people experience being disabled in mental health are very different to the ways that people experience physical disability although some people would say that physical disability also is incredibly variable so it isn't such a big difference. And people with physical disabilities also have mental oppression, and emotional oppression and emotional experiences, but the social model of physical disabilities is not easily adapted to mental health." (Jan Wallcraft)

"The social model came out of sheer necessity because we had this biomedical model that was pathologising disability, suggesting that you don't have humanness unless you are fixed or cured, so the social model was an intervention to that image, and I think the social model was extremely important in saying – it's not an individual's issue, you are disabled by your environment and the inaccessibilities of your environment - so in that sense I think it's so so so important. But the pitfall of the social model for me, or the part that I think we need to continue thinking about is - even if our world for every person was 100% accessible, or 110% accessible, we are left to negotiate the realities and the lived experiences of our minds and bodies and I don't know how much space the social model makes for that." (Shayda Kafai)

"The social model of disability says that society creates disability through creating barriers to participation. I think it makes perfect sense on a conceptual level. On a practical level it is a bit harder to apply, because if you are in a wheelchair the barrier are the stairs so you just build a ramp or lift or something. This is a very simplistic example and there is more to it than just that, there is a whole lot of mistreatment as well. But if you have a psychosocial disability at the practical level it is how to find the application of the social model of disability in a meaningful way – it's more about attitudinal barriers or social structures than physical structures. So I think that's where it's a bit difficult. But it absolutely fits at the conceptual level. And I've been very influenced by it." (Mary O'Hagan)

The following two excerpts – each in their own way - remind us of the designated social positioning of people labeled mad as well as prejudice and stereotypes associated with madness that complicate applying the social model of disability to our situation:

> “[W]here does the element of harm to another come into a social model? I am not sure. The answer is that we have to separate criminalisation and psychiatry – that is obvious but we also know that criminalisation takes place based on social norms, the same social norms that psychiatry is implementing. The two institutions are so tightly bound and it is so hard to separate them but there is this element of social fear and issues around security that frustrate a social model of madness as opposed to the social model of disability that has been able to invent itself without the same kind of barriers.” (Abena)
>
> “So applying the social model to madness – I think it could be explanatory and it could help with certain kinds of things except I think we are a long way from that, with madness being able to do that. There are so many factors involved in terms of political will and money and how much we want to bother with these people – let’s just get them out of the way so we don’t see them or whatever. But I think if we had the resources and the unlimited commitment we could do a lot of great things with that. […] I think it’s a good model for certain kinds of things, it’s not an overarching model like anything is an overarching model” (Ron Bassman)

Some participants found it rather easy to apply the social model of disability to madness and stressed the need to liaise with other oppressed groups in this context:

> “Well, I think it's quite easy. I think you just get rid of impairment and say - there is no impairment, there's only perceived impairment. And you use perceived impairment and disability in the same way as you would with the social model more conventionally.” (Kathy)
>
> “I think it’s extremely applicable. And I think it is a great idea for disability activists and mad activists to interact and do things in common, just as I think we should be collaborating with queer and other initiatives. I think people who are subject to different kinds of oppression can benefit by interacting with each other. And if we say that

> physical disability is a social construction and needs to be re-thought, obviously that is also true for madness, so that's a nice coming-together." (Irit Shimrat)

In my short interview with Colin King I asked him about the view of some white scholars – which I personally disagree with - that the social model of disability is not suitable for the experiences of people of colour (Mollow 2006). Colin was not familiar with that view, but this is what he said:

> "I think it's dangerous when you're asking anybody to subscribe to any one model and then you're measuring whether your Black or White by how you subscribe to models. For me that's quite dangerous. I think I'd subscribe to anything that comes closest to the reality, the truth of what it is to be constructed through being Black and mentally ill. […] I think the interpretation of a model emerges free of values and so you could say - oh, this model may be better for Black people, maybe we need a conspiracy model, or we need a psycho-dynamic model, or we may need a markers model - but for me it's more about the values behind the people, the operational model of impetus and impacts, and I think that sometimes it's a bit reductionist to just then say: 'This model is better for Black people' and 'This is better for certain people' because I think it's quite dangerous."

I find Colin's stance on this issue greatly important. I wish to close this brief debate with the words of David Webb who describes the aspects of the social model of disability that could inspire and guide our future work:

> "As a preamble I'll say – we can really tear ourselves apart by nitpicking about this bit or this bit of the social model of disability and I just don't want to have those conversations. For me in looking to the social model of disability to help us in our work – I am looking at what are the key points of inspiration to be found in it? Well, first of all – nothing about us, without us. It is a great, great slogan and we can dissect that and see that it's a first-person statement and we can see it's also a political statement, a very powerful statement. Second, that point I made before about the incredible unifying force that the social model of disability represents. I wasn't around when all of that stuff first got off the ground. I'‘ve met people and worked with people who were and I was struck by the extraordinary achievement of bringing together the deaf, the blind, the physically

> disabled you know - incredible achievement. And so my reading in our community – and now I am resorting to the labels that we hate - but bringing together the schizophrenic, the depressed, the autistic, the bipolar – all these different labels, all these various categories of madness and I don't have different labels for all of them – but such huge diversity there, comparable to the diversity that exists in the wider disability world that has been brought together. And why was it brought together and why was it brought together so successfully? Because there was an urgent need for all of those people. And what was their urgent need? It was inclusion or the end of exclusion. The number one battle which unified all these people was social exclusion and the recognition that experience of disability has got nothing to do with my so called impairments and everything to do with living in a society that excludes me because of who I am. Really powerful ideas. […] In my particular area of interest, in suicide I could take as a starting point the social model of disability and develop a social model of suicide prevention. And in doing that I would adjust and add all sorts of variations to it relevant to the specific question of suicide prevention but the underlying model both as an inspiration and as a blue print, again – guidelines, not rules - is tremendously useful. And it speaks about inclusion, it speaks about ending that 'them' and 'us' nonsense. It is also a very anti-medical model which is wonderful."

5.4.6.5 Mad Studies and academising our knowledge

In comparison to the social model of disability, participants were less familiar with the emerging field of Mad Studies. Some people had heard the expression 'Mad Studies' but didn't know more beyond that:

> "I don't know that much about what is being done in Mad Studies. I've heard of concepts from a lot of sides but I haven't followed it in enough detail to know what it is or what's being done." (Jan Wallcraft)
>
> "I don't know what Mad Studies is. People are talking about Mad Studies in capital letters like it's a thing and I don't know what that thing is. In contrast, if you talk to me about a social model of madness I have an understanding of what that is. But I don't have an understanding of what Mad Studies is." (David Webb)

Several other participants were knowledgeable of recent publications and developments in Mad Studies and/or had contributed to those themselves. They saw this inquiry as part of Mad Studies:

> “I do see your project in relation to that field. I thought it’s a very necessary, perhaps organic outgrowth from disability studies. The first wave of disability studies was very much focusing on visible disabilities, physical disabilities. The second wave started making space for invisible disabilities, illnesses, the conversation between disability and impairment. But even in the conversation of invisible disabilities madness wasn’t as explored as other things, so we did need the space where we can perhaps apply some of the conversations of disability studies specifically to madness because I think it has its own issues and parameters that have to be discussed within disability studies but very much in separation from it.” (Shayda Kafai)

Vanessa Jackson sees the emergence of Mad Studies in continuity with the many developments that have preceded and enabled it. Highlighting the importance of the historical perspective, she warns us to be careful about not erasing past contributions and voices while attempting to ‘mainstream’ our knowledge:

> “I think the problem that we have to watch is - what's new? And the caution of it is that if it didn't make it mainstream, or it didn’t get to university, it doesn’t make it not there. And it sort of goes back to your earlier point about who gets to be the purveyor of knowledge that's considered valid. […] Back in the 70s you had very important conversations happening about power, about what was healing, about the insanity and seeing the powers of racism, classism, sexism, homophobia and so I think when we look at Mad Studies we need to be super, super careful. And I think it’s like you said earlier - you're intending not to invisibilise people who were doing it, but were doing it at a time when it was not valued. So it's been there but now there's a department or as a discipline or as a degree and so I think providing that structure and that legitimacy is crucial and we have to be super careful because that’s one of the ways that things get stripped or sold out on some level […] That's why I think the historical perspective is important as we go back and say – wait, people have been talking about that for a while. So we're like the next phase, we are the fifth phase or something of Mad Studies with

> the possibility of putting it in universities. And then you are going to be careful about what happens when you do that.”

The most frequently raised issue in relation to Mad Studies was the danger of alienation of this field from its (grass)roots and the vigilance needed in the academic context:

> “Mixed feelings. I think a lot of what I’ve seen of Mad Studies – including some of the contents of the book in which I have a chapter[46] and other books that I’ve edited – floats up into the ivory tower of academic jargon and becomes something that is incomprehensible to ordinary people. It has nothing to do with their lives. Intellectualising and theorising is necessary as a basis for action to some extent, in some cases. But it can be somehow counterproductive, in terms of class issues. Still, I’m glad to be included in your project and others. Because academia does have good uses.” (Irit Shimrat)
>
> “[I] wouldn’t want psychiatric survivor perspectives diluted. […] Ten years ago I would have been delighted to be learning that the field of Mad Studies was emerging at Universities and in the public discourse. But when you talk about wanting to set up a University department or whatever in the field of Mad Studies that rings sort of alarm bells in my head. For instance, imagine setting up a department of women studies where all the staff were men.” (David Webb)
>
> “One thing that worries me about these so called service user academics – they put them in departments of psychiatry so they are not really working to an independent research agenda, they are just helping out with what the psychiatrists are doing. […] My understanding is that Mad Studies is a more independent approach to academia. It is not on the coat-tail of mental health professional academics. I don’t know whether that’s true or not.” (Mary O’Hagan)

The views expressed here resonate with, and importantly contribute to, recent debates around Mad Studies (Costa 2014, Beresford and Russo 2016b).

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[46] LeFrançois, B. A., Menzies, R. J. and Reaume, G. (eds.) (2013) *Mad Matters: A Critical Reader in Canadian Mad Studies,* Toronto: Canadian Scholar's Press Inc.

5.4.7 Feedback, expectations and prospects

This section is about the feedback I received from participants about their involvement in this inquiry, as well as their expectations of it, shared at the end of the interviews. Whilst their words greatly encouraged me, the reason I want to document their statements is because I think that they demonstrate how rare this kind of project is, and how important it is to take it forward, beyond the constraints of my PhD.

Generally, participants found the interview stimulating and rewarding in terms of inspiring their own thinking about the topics:

> “I appreciate these dense questions that we have to work through.” (Shayda Kafai)
>
> “I’ve never been forced to think through this myself.” (Abena)

It also became clear that there is a need for more exchange and collaborative thinking, outside of the research interview format. Participants preferred two-way communication and wished for it to continue:

> “I can’t think of anything, except a wish that we could do this regularly, rather than just once. I would like to talk more, and get to know you.” (Irit Shimrat)
>
> “It is so much more natural to have a conversation rather than the one-way thing.” (T.)
>
> “I am so curious to know how you are thinking through all this.” (Abena)

I asked my interview partners about their expectations of this project and what they would like to see emerge from it. Some people hoped that this study will contribute to changes in the ways we approach madness:

> “I don't have any major expectations. I just hope I've contributed to thinking, in particular through adding a bit of colour. And I hope sincerely that you achieve the sense of connectedness to all this thinking that's going on around you. The human mind is amazing. And I think that's a privilege. We need to have that sense of being privileged

> to be called 'mad', in particular the full advantage in running with it. Just reclaim that sense of madness, I think that's important through all the work that's happening in the next five years or so. […] And I just hope that working with you, and having this conversation with you, enables us to create those spaces where people are thinking - so what? […] Let's just do something good about this! Something good can come out of some really, really horrible, negative experiences that ended up with us being called 'mad'." (Dominic Makuvachuma)
>
> "What I would hope, and why I really feel the value of this study, is I hope this generates a new thread for people to study, to look at how we can develop ways of being supportive of individuals and not demeaning and stigmatising people." (Ron Bassman)

The most frequent and clear answer to my question about the expectations of this study was that the findings should not stay in the academic domain but should instead be widely and accessibly communicated:

> "I think whenever someone does a PhD the big risk is that it will just be read by half a dozen people and it won't ever get out to a wider readership. You mentioned in your materials that you are going to write a book as a result, which I think is a good idea. […] Well I'd really love to see it as a book that is not written in too academic a way, that is a more conversational book about this research. I'd love to see the research being made available to a wider audience." (Mary O'Hagan)
>
> "I was reading your proposal and I was reading the quotes of these folks and I just kept thinking […] that this needs to be a published book that somebody can access and I saw that as being necessary first and foremost. […] Instead of having folks speak about this, folks who haven't experienced these things, we should have folks speaking their own stories as a way to reinstall all the power relations that surround the experience of madness." (Shayda Kafai)
>
> "I think it's an important thing that you are doing. And I think that the results of it should not remain in the realm of academia only, but should be publicised as far as possible, and in as many different ways as possible." (Irit Shimrat)

The use of the internet and social media were mentioned in this context, both in order to enable people doing similar work to connect, but also to make space for counter-knowledge and, most importantly, to extend its reach:

> “I think the internet is quite an interesting thing, like having a Skype conversation with you, and I think that there needs to be more connections between people thinking about this sort of thing. The internet might be a good way of doing that. […] If that had been available and I could have found that, then I would have never spent all those years believing what they said to me, I just wouldn't have believed them, you know, it would have been gone very quickly. […] There need to be spaces, and not just for people who are academics thinking about this stuff, but just for anybody who's finding themselves on the receiving end of the medical model and psychiatry.” (Kathy)

Ron Bassman raised the issue of “people being written out of the textbooks”. Referring to his teaching experience, he described how the university curricula remains ignorant of the developments of the last 20 years, and said:

> “That is what I hope we are going to make sure doesn’t happen.”

T. shared her hope that a ‘survivor created model of madness’ could at least begin to be developed, and become recognised as one among the available options:

> “If even like a draft of that, or proposal for that, could come out of this, then I think it might be helpful. […] You know, how we explain madness to other people and get it seen as a valid type of knowledge? The academic world could even maybe have the medical model, psychological model, and then a slightly creative model. While I'm sure lots of people wouldn't agree with it, it would still be seen as one of the options, one of the models, like the proper thing.”

Whilst most of the participants didn’t talk in terms of a model, they stressed the need to increase our joint efforts towards advancing and deepening our own thinking. Our lack of resources, influence and opportunities became particularly important in this context:

> "I hope that you can get somewhere towards at least theoretically resolving the questions that come with the mental health model, showing up what they do, what the medical model does which is so bad for people. That's all we can keep trying to do, we can keep showing that it doesn't work for people. It is holding people back from developing their own lives and their own personalities, their own realities, and adding sometimes to the knowledge – this is what we could be doing." (Jan Wallcraft)
>
> "I think it's a very promising beginning, actually. I wish a lot could come out of it. […] Now, the challenges - will you or will the participants of this study be able to take this knowledge wider. That is the potential I see. I wonder how that can happen, because there is a need for that to happen, you know, there is a need to reclaim a lot." (Prateeksha Sharma)
>
> "I think we don't have enough of a community that works together to bring forward different kinds of ideas and really support each other. I think we have it in certain places but there should be a lot more is my feeling. […] I think it would be great to have time to spend in some way or another with this group of people and to really explore ideas and hopefully we can generate for each of us a new way of thinking about things, if we could be open with each other." (Ron Bassman)

Lauren Tenney and Vanessa Jackson were clear regarding what they want to come out of this inquiry, explaining why they find it important. Both their statements were about addressing racism and marginalisation in the user/survivor movement and seeking to build up our collective knowledge on a far stronger foundation:

> "I think that is a really wonderful and huge undertaking that you are approaching here, and I think that you are going to learn a tremendous amount from people as you go through these conversations, and that it's going to make it more complicated to the point that it will become frustrating. So just keep pushing through until you come to where the real divergent opinions are. Because it maybe in the places where there is the most conflict that the answers come up. I know you are not going to like this but what people

> are saying, what's coming out of *Surviving Race*[47], is that until the movement starts to address intergenerational trauma, economics, racism and spirituality, people of colour will not be interested in what we are doing. […] I think looking into intergenerational trauma, economics and racism as the root of the issues, we will also start to discover a lot of general white supremacy in psychiatry and how a lot of us get caught up inside of it. (Lauren Tenney)
>
> "One of the things that I would want to see come out of it is about how race, class, gender, sexuality - all these sort of marginalising – how folks on the margin, even within the movement, have to be more centered. And that you already have understood why this happens and that there has to be some affirmative action, strong commitment to centre those voices. And I think in doing this research, you have highlighted already a huge problem which could be a dissertation in itself. But it also can be a call to action for the movement to deal with its' racism. It's not like folks need to go in there and deal with racism – I'm not going to go in there and deal with what racism does. And so it means one, you are missing people, they could be in the movement and strengthen it - but I think it also reminds people about like, as you build this, let's not build it on a weak foundation. So that would be the single most important thing that I would love to see." (Vanessa Jackson)

Even though this inquiry - due to its many constraints - was not able to "push through" and reach the "places of conflict", the above words resonate with other important insights that the interviews brought about (see the section "Prospects of joint work within the context of inequality and injustice", pp. 173-190). I hope that documenting these insights will enable future projects to take a slightly more advanced departure point and move us further forwards. The calls to explicitly address inequalities in this report also exemplify how closely interweaved the activism of people with psychiatric experiences is with our theoretical work. Here, I particularly refer to the potential for our joint analysis and research to improve and strengthen our political action. However, the project of institutionalising our knowledge, especially in the form of an academic discipline, can also have the opposite effect and weaken our political organising, as Vanessa Jackson warned:

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[47] This refers to the Facebook group "Surviving Race: The Intersection of Injustice, Disability, and Human Rights" that describes itself as follows: "This group was created to explore the intersections between race and disability in the human rights movement."

> “[I]f you look at women's studies, you look at sexuality and gender studies – what can we learn from these when you sort of institutionalise these things that we don't want to repeat, because, you know, it will come back to undermine the political work. How do you talk about a movement in a discipline such as Mad Studies? And how does the movement intersect with Mad Studies, and especially within an institution? […] What can we learn from people who already have a foot in that world, and looking at models like anti-sexual assault, domestic violence, HIV - movements that then became social services that then also became specialty areas? […] We’ve got to look at these things as we evolve because we know where the capacity is to lose control of our movement. […] The movement can support and hold the social service - or the kind of institutional thing like Mad Studies program - accountable but you’ve got to be super-careful. […] It's so easy to get co-opted - I don't care how smart you are.” (Vanessa Jackson)

The danger of cooptation was a topic that recurred throughout the interviews. This issue was also raised in relation to the potential use of the outcomes of this research:

> “Basically our rights seem to be at risk, they [*our rights*] are not making much progress. That makes things difficult. We should perhaps try to have new ideas and new thoughts, and we need to look back at what has been taken from us and try to stop that from happening. That’s really hard.” (Jan Wallcraft)
>
> “I believe that this research that’s generated from us is just so valuable in its potential, and I would hope that people who are career professionals can see the value of supporting people and getting these kinds of things out that can change a lot of stuff, instead of speaking and using them as examples for whatever. It’s just another instance of people taking advantage of other people and their self-interest. I’ve found that there are professionals that I’ve worked with who don’t do that but they are a very small minority of people who have supported my work without necessarily getting something out of it, and sometimes taking some risk. I value that. I think what you are at now is real important – the process of collaboration and respecting each of the individuals is important and the notion of not coming out with a predetermined outcome - test the hypothesis that you want proved or whatever - is extremely important.” (Ron Bassman)

The end of the interview also meant the opportunity for me to share how I feel about this project and the things that frustrate me. The following excerpt is from the interview with Lauren Tenney:

> "I love your writing and your ability to pull these pieces of meaning from people, from such a wide array of thinkers that you have done. It's tremendous. You should be really excited for yourself and I am happy to be able to talk to you about it.
> *Thanks Lauren. I am just worried, I mean I'm aware that this should be a much bigger undertaking and not for one person's PhD. I am doing this with zero resources, I wasn't even able to obtain a scholarship, I am earning a living on the side, it's a struggle and at the same time I know – whatever I produce at the end it is going to be so little compared to all that could have been done. So it is frustrating to be touching on the topic that I consider big and very important and at the same time be really limited in terms of what I can do with my own resources. But I thought – if I am doing a PhD I'll start from what I see as the most important, and I think the most important is that we start bringing our knowledges together. [...] I really wish there could be something more coherent coming from people who are the subjects of this discipline, something that comes from us. I find that so important but I am afraid that my work will just scratch the surface."*

The ever-present awareness of the limits of this project, and how that makes me feel, is something that I shared with several participants. Their responses - informed by their own experience - encouraged me to think less about how comprehensive and inclusive this particular project is and more in terms of its potential to inspire and elicit future work:

> "[B]ased on my own PhD experience I suspect that perhaps the least important thing that will come out of this work will be your final thesis. I probably shouldn't say that. I think the most important thing that will come out through this work - and I think it's hugely important and valuable - is the conversations that you initiate and the networking that will follow on from that. […] You know you throw a stone in the water and the ripples ripple out and I always want to get a really, really big stone. And I am sure your work, which will be represented by the final published thesis, I am sure it will be a pebble in the tank. It probably won't be a huge rock but I am sure it will be more than just a tiny pebble. And the ripples that will come out from that will be valuable." (David

Webb)

“This is an amazing project and I don’t want you to minimize it. Because like I did a little project that was self-funded as well for a big chunk of it and it was amazing how that thing continues to live.

You mean “In Our Own Voice”[48]*?*

I mean I had very little funding and I totally ended up doing a whole lot of that research project because I ran out of all my savings trying to do that because the money they gave wasn’t enough […] I was broke from having funded a whole lot of it. But the way that it transformed my work, my clinical work, and then how it gave me an opportunity to define power, and how it has been a springboard more importantly for other people with more time and resources, different kinds of skills and interests to take it to new places. And so you are building on the work of other people obviously, but you are also holding for the movement these questions and they're so powerful, so this is not a little project. It’s not a well-funded project, right, and you are knocking on bigger places, but I think it’s so crucial and you're asking incredible questions and I think you're offering a challenge to both the movement and to institutions, and it could be the thing that helps slow down cooptation and keeps people really watching it more carefully. But I think it's really important at this phase in the development of Mad Studies to have this kind of inquiry. What you are doing is super important. I know you are there by yourself looking at this stuff. […] It’s like so big and you know there's so many more ways and so many more layers and you’ve got to keep your focus narrow because you've got to finish a dissertation. Keep your focus narrow because you are self-funding it and you’ve got to figure out how to feed yourself. And I just think that sometimes, you know, we don’t have spaces to acknowledge that, like our financial situations and pending poverty and financial stress affects our research. […] I just really want to appreciate you. That's what I am trying to do is appreciate you for taking on this big crucial topic and holding it, and doing your piece, and you're going to be offering to other people to follow up with this stuff, and then it's gonna make a huge difference. For real. I am not just saying that.” (Vanessa Jackson)

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[48] Jackson, V. (2002) In Our Own Voice: African American Stories of Oppression, Survival and Recovery in the Mental Health System. (http://www.healingcircles.org/uploads/2/1/4/8/2148953/inovweb.pdf, (accessed 3 June 2018)

The sense of being seen, understood and validated in my existential and other struggles around this work was invaluable on a personal level. But beyond that, I find it important to understand how such struggles - typical in the lives of many survivor researchers - centrally affect our work. At the same time, raising these issues means breaching the conventional rules of academic reporting. I will reflect on this issue in more depth in the closing chapter of the thesis.

The last quote about participants' expectations of this project relates to the focus groups. It is particularly difficult to document because it proved unfeasible to close the inquiry in this way. The project simply grew bigger than my PhD research. Rather than seeing that as a failure, I hope for Abena's words to serve as a reminder that these fourteen interviews are just a temporary end, and that our joint work needs to be taken to the next level:

> "I don't want to put pressure on you but would like to answer the question honestly.
> *I am under so much pressure anyway so don't worry, please go ahead.*
> […] I can't wait to learn from this version of discussion that takes place [*in the focus group*] and then to learn from how you have synthesised the discussion. There will be so much knowledge that you have collected, and you will be forced in some capacity to frame it. I understand that you will never do it all justice, because that is just not possible or you'll have to research forever. But you will be forced to think about all these different discussions within the context of the focus group and each other, and I can't wait to learn from that."

5.5 Summary of the interview findings

The end of the interviews, and of my reporting of the findings, feels more like the beginning of this inquiry rather than its conclusion. It is therefore challenging to be closing the research process in what is meant to be the penultimate chapter of this thesis, whilst simultaneously contemplating how best to take it forward. Thus, I decided to approach the task of summarising the findings not as a conclusion-drawing exercise, but as an attempt to describe the place that this inquiry has reached. In the last chapter of the thesis I will discuss the findings from both research phases (the written accounts and the interviews).

I believe that the interviews provide a sense of the contours of a distinctive first-person knowledge base of madness, as well as suggesting departure points for future inquiries. The following summary of the main findings is therefore not intended as any final word. Moreover, it should not be understood as a consensus because it has not yet been possible to discuss the findings with the participants. What I hope to provide is an accurate description of a stopover on the journey towards shaping a collective first-person knowledge base of madness; a stopover that the particular group of people who took part in this research reached, together with me, in the role of researcher.

With regards to the main scope of the interviews, which was to explore the prospects of jointly strengthening a first-person knowledge base of madness, my analysis did not identify any fundamentally opposing opinions. Whilst articulated in different intensities and focusing on different aspects, the issues and concerns raised by participants pulled in similar directions. This was reinforced by the fact that my analysis – the same as this whole inquiry – focused on the stances, values, principles and visions that we share. I wanted to capture the meeting points in our thinking in order to find a place that we can move on from. At the same time, I did not intend my search to occur at the expense of our many differences. I tried to open up and maintain spaces where our differences could be spoken, rather than attempting to resolve them. Throughout the analysis and reporting, my efforts focused on bringing together different stances and knowledges and placing them in relation to one other in order to create a temporary whole capable of naming and holding those differences. This approach is encouraged by Ameil Joseph's proposal for the study of confluence where "an appreciation of complexity directs the methodology, examining for continuities rather than differences" (Joseph 2015, 30). This summary is my attempt to provide an overview of those continuities. The participants themselves are, however, better positioned to judge whether those continuities are documented in a way that people can find their own perspectives adequately reflected, contextualised and perhaps amplified, rather than erased, overwritten or exploited. I consider this central to any survivor-controlled or emancipatory research project.

In this overview, I will not quote individual people but will instead try to synergise our voices. This means that whilst I am summarising the findings in my own words, I will also incorporate some of the original expressions used by participants. One of the many famous quotes by Buckminster Fuller highlights why synergy can perhaps offer the best format for presenting the summary of the findings in this type of inquiry:

> “The word synergy comes from the Greek sin-ergo, meaning, to work together. It describes a mutually supportive atmosphere of trust, where each individual element works towards its own goals, and where the goals may be quite varied; nevertheless, because all elements of a synergetic system support one another, they also support the whole.”[49]

Whilst trying to synthesise the main messages in what participants said I have identified ten key points. They are of equal importance; the numeration has no hierarchical meaning and instead reflects the order in which the issues unfold:

1.

All participants emphasised the need for fundamental changes to the dominant approaches to madness, and for creating a strong counter-discourse to the biomedical one. Whilst the interview topic guide did not include any questions about current systems of mental health care, people shared their anger about those systems, alongside their general dismissal of the knowledge claims that underpin psychiatry as a discipline. The need for fundamental change was seen much more within broader societal structures rather than in any specific aspect of mental health care provision. Consequently, the much needed shift in the way that madness is approached and that people psychiatrically diagnosed are treated, is unlikely to occur without recognising and addressing the real, material circumstances of our lives such as poverty, racism, violence and colonial heritage – the issues most frequently raised by participants.

2.

First-person knowledges of madness were seen as a rich and valuable but largely unexploited epistemic source that could generate different responses to human distress and contribute to broader social changes. Despite some acknowledgment that this knowledge source does impact on mainstream (mental health) policies, this impact was considered to be selective, insufficient and extremely slow. In particular, participants cited the inequitable opportunities to influence change that different groups of people labeled ‘mad’ face, as well as the danger of cooptation and the dilution of concepts and values once they enter the mainstream. Some participants cited recovery, peer support and trauma-informed approaches as examples of this.

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[49] https://www.azquotes.com/quote/1141441

3.

The idea of connecting first-person knowledges of madness into something more coherent was generally welcomed; indeed, some participants saw such a project as long overdue. Yet at the same time, the project of creating a first-person model of madness was also met with considerable caution. Arguments surrounding participant's reservations provided a set of issues to carefully consider in future work, and also resulted in changing the title of the thesis. Even though the goal of this inquiry was not to generate an ultimate model of first-person knowledge of madness, my work in the previous research phase focused on identifying the values and principles that could underpin such a model. The interviews re-directed this inquiry away from a potential model and towards how we might synergise and strengthen a collective body of knowledge of madness whilst retaining the diversity of first-person perspectives. I will elaborate more on this difference in the final part of this thesis, but I also wish to capture this central outcome here: that the interviews placed a clear priority on exploring *how* to work together and enable our distinctive body of knowledge to take shape, rather than defining the content of that body of knowledge. The remaining points in this summary relate to questions of how we might work towards such a knowledge base of madness, and what to avoid along the way.

4.

What counts as psychiatric knowledge was not only seen as invalid, but also as a colonial enterprise that spreads and imposes itself from the global North over the majority of the world's cultures and traditions. A counter body of knowledge based in first-person perspectives needs to establish itself on different ground from the outset. Participants emphasised the need to recognise and provide equal space to *all* first-person ways of knowing. The project of establishing such a comprehensive body of knowledge needs to thoroughly re-consider what counts as a valid epistemic source and include oral histories and non-written sources, as well as writings that have not been officially published such as those increasingly found in social media spaces (blogs, discussions in Facebook groups and/or within organisational email lists and so on).

5.

In relation to the different social positions that people with psychiatric experience occupy, (perceived) madness was seen as just one aspect of psychiatrisation. The social category and construction of 'race' were discussed as a key determinant of both experiences of madness, and the responses that those experiences attract. Other, less discussed, determinants included class and gender. The decisive question in this context was how we can work together within broader structural inequalities that profoundly divide us and impact on our attempts to find ‘collectivity’. For participants from countries that have political movements of people who identify as mental health service users, survivors and/or people with psychosocial disabilities, these questions were far from resolved. These participants were clear that if a project of creating a first-person knowledge base of madness is grounded in traditional exclusions, it can only ever be weak and partial. Participants also referred to political movements and their emerging scholarships, such as feminism and women’s studies, that needed a second wave in order to be revised and intersectionalised, and felt that these provided important and unique learning for our efforts: put simply, if we are to prevent history from repeating itself, we need to learn to work together without reproducing dominance and exclusions in our work. Participants shared their experiences, thoughts and feelings in this regard, with suggestions for ways forward including: not speaking in anybody else’s name; ensuring separate, safe spaces where particular communities can come together and share and reflect on their experiences if they need to; at the same time, keeping all other spaces open so that everybody can bring in their particular experiences of discrimination and oppression; approaching those experiences not as an issue belonging to particular individuals or groups, but instead exploring how our unequal exposure to injustices affects our joint work and making structural inequalities issues that belong to us *all*; creating opportunities to get to know each other’s backgrounds and exchange how we position ourselves in relation to those backgrounds before embarking on any joint project; collectively drafting a set of principles for Mad Studies; and seeking common political goals, rather than shared identities, to unite around.

5.

Strengthening a first-person knowledge base of madness should not be an end in itself, but instead should be centrally committed to improving our own and everybody else’s lives. Such a knowledge source should above all serve to enhance our capacity to communicate with the multitude of experiences that are considered to be madness and shift the ways we respond to one other, rather than offering another universal explanation of the experience itself. Efforts towards explaining or defining madness were seen as counterproductive; several participants were strongly opposed to even framing certain experiences as madness. This means that theoretical work based on first-person perspectives should avoid singling out this experience from the entire tapestry of human experiences, as that could reify madness and offer grounds for othering and exclusion. Instead, first-person frameworks should help to dismantle ‘us’ and ‘them’ divisions altogether, rather than shifting the line to a different place.

6.

As people whose experiences, truths and/or ways of being were subject to an external gaze and damaging classification systems, participants rejected any idea of grouping or categorising human experience. Each person should retain the ultimate authority to make meaning out of their own experience. Connecting our diverse knowledges should not mean imposing any universal explanatory framework on another person’s life or creating another type of expert knowledge. The ethical, legal and social rules regulating how we relate to one other and live together in the world should be the same for everyone. Although this was not discussed in all of the interviews, several participants were strongly opposed to any special laws for people categorised as mad, and considered such regulations to be discriminatory.

7.

Language was considered with regards to its potential contribution to othering. This included both psychiatric and lay discourses around madness. In the same vein, the transformative and liberatory potential of language was also recognised. It became clear that there is no such thing as neutral language as the words we use will always resonate differently according to their cultural, political and historical contexts. Some participants believed that we should not aspire to regulate and prescribe language, and instead should appreciate and foster a variety of expressions.

Working across difference also means taking care not to impose specific terms, and the meanings assigned to those terms, on one another. Within this inquiry, this particularly referred to the notion ‘mad’ as a predominantly White emancipatory concept. Participants also stressed the need to move away from defining/naming ourselves in relation to the systems that have defined/named us, and to collectively abandon the search for universally ‘correct’ terms. Ordinary, everyday language was seen as better suited to talking about experiences that might be seen as out of the ordinary, rather than any form of specialised language. Having the freedom to talk in the first-person was considered just as important as having the ability to genuinely listen and hear.

8.

Most of the participants were familiar with the main ideas underpinning the social model of disability. When reflecting on the potential application of this model to madness, participants raised several issues that would make a direct transfer difficult. Nonetheless, the social model of disability was considered an inspiration, and a unique 'role model' to guide our own work. Most importantly, it was developed by disabled people themselves and rooted in their own perspectives and knowledges, and demonstrates a commitment to working across a range of different lived realities of disabilities without leaving anyone behind.

9.

In comparison to the social model of disability, participants were somewhat less familiar with Mad Studies. They mainly understood Mad Studies as an emerging academic discipline and raised several reservations about the prospect of 'academising' our knowledge; these were connected to experiences of our knowledge being co-opted in various attempts to humanise and reform mental health systems without generating any real change. This inquiry was seen as contributing to the advancement of Mad Studies and as having the potential to ensure that first-person knowledge with the (historical) grassroots organising of people with psychiatric experience remains at the centre of its formation.

10.

Participants stressed the importance of continuing this exploration and enabling many more people to contribute. The main expectation of this project was that it does not remain hidden within the academic domain but is made widely accessible. A first-person knowledge base of madness should not only be easy to understand and share, but also easy to contribute to. It should feel welcoming and inviting to people from many different walks of life and with different means of communication. A first-person knowledge of madness is not envisioned as another brand of expertise with a circle of 'insiders'. Instead - to use the metaphor of a tree – it should be a trunk which grows branches in many different directions. This project was perceived as a small but important seed for such a tree.

CHAPTER 6 TOWARDS AN EPISTEMIC TURN IN KNOWLEDGE MAKING ON MADNESS

The research behind this thesis comprised several junctures that importantly shaped and re-shaped my thinking about madness and the epistemologies of madness. The working process continually shed new light on the pre-conceptions that I brought into this study, and if I were to choose the single most important lesson that I have learned along the way, it is that the topic of madness by its very nature does not allow the inquiry to reach a *final* destination point, or point of arrival. In particular, once we start thinking *through* rather than *about* madness – a redirection that occurred in the course this inquiry – the arrival points can only ever be temporary. In this sense, the findings are better understood as potential places for new departures, rather than being conceptualised as destinations. In this chapter, I reflect on the findings of this inquiry, bringing them into conversation with some current developments in psychiatric and mental health research, as well as with scholarly work outside of these fields. In this way, I hope to map possible departure points for future works.

As I do not consider myself to be more competent in fulfilling this task than anybody else who contributed their knowledge to this study, the discussion here holds no general claims and is intended to be my individual contribution to the next stage of the research process. That process started within this thesis but subsequently outgrew it, meaning that the final stage of the research had to be postponed (see Chart 1: Study design). The closing section of the previous chapter, which summarises the key findings from the interviews, lays the groundwork for future group discussion(s) with the participants.

All participants from the previous phase have received the report of the interviews (Chapter Five). I also explained the postponing of the focus groups and declared my commitment to search for funds to enable us to meet in person and round up the process together. Considering the time constraints, the volume of the report that I sent and the fact that no participants received any reimbursement for their time, I asked people to let me know if they had any objections to the presentation of the findings. By the time of writing this, I have heard back from nine people. Their feedback was greatly affirming. I have not heard back from five participants; for one person I know that this is due to a physical condition.

In this chapter, I share what I consider to be the key learning points, along with the concerns that opened up, and make additional comments regarding future research.

6.1 Concluding the research: in whose voice and for whom?

Before I embark on the challenging task of presenting the key messages of this study I need to again re-position my voice as a researcher. As explained in Chapter 3, an important principle in survivor research is an effort to complete the research process *together* with the participants. Often this is not simply about verifying the research findings, but involves jointly drawing conclusions and making recommendations. The discussion in this chapter is not meant to replace such practice, as I cannot possibly speak in the name of the whole group of people who took part in the second phase of the research. Here is where our voices temporarily part. However, my voice is not that same voice that I had at the beginning of this research: it continually changed with the inquiry and was profoundly impacted by the authors whose writings I firstly researched, and subsequently by my interview partners. That impact intensified and continued through the analysis stages. Hence, the reflections in this chapter are written from the place where the participants' voices have reached mine, giving me a different voice. Laura's (2013) outline of "an 'intimate' approach to qualitative inquiry" and her exploration of "place of 'love' in social research" (p.289) resonate with the way I experienced this study and legitimate my own experience of the research process as a position to write these concluding remarks from:

> "[t]aking love seriously in social research means that the process and product of scholarship has real consequences for the lives of three-dimensional human beings, the researcher him or herself included, not for imagined 'others' somewhere out there." (p.291)

Just as the key learnings from this inquiry did not emerge in isolation but were facilitated by the knowledge of many survivor authors and activists, they are also not just being addressed to a general audience. This means that I was not only researching from within a particular community but also *for* it. The primary motivation and intention of my work is to serve that community. Similarly, and in a straightforward way, the same researcher (Laura, 2013) opens up a core question about who our research work is for. Her words powerfully resonate with the goals of emancipatory disability research and survivor research, which are not conducted out of scientific curiosity nor from a place of distance and neutrality. Instead, these research approaches are explicitly committed to improving the lives of those whom they are about:

> "Qualitative researchers who invoke love in their work choose to witness, engage, and labor for the people who we admire and respect, and we treat them with the regard and reverence that we would extend to our own kin. Not 'the subjects', but '*my* people' inspire and direct such acts toward the negotiation of relationships – personal, social,

> political, historical – out of love and in solidarity. This kind of work demands an opening up and demystifying of the research process, nudges a broadened view of what qualifies as authentic and valuable knowledge, and begs questions of integrity and responsibility – like what do we do with all of our ‘good information’?” (p. 291, emphasis in original)

When choosing my PhD study, I decided to work towards crafting a missing piece that I considered urgently needed for me and ‘my people’. Here, I mean survivor researchers and activists lacking a suitable theoretical framework to underpin and advance our work. Regardless of the extent to which this research progressed in that direction, the work on this thesis has definitely brought me closer to and strengthened the bonds with ‘my people’ from different countries and different paths of life. The thoughts I share in this chapter are – like any other piece of academic work – meant for anybody who can make use of them. Yet while writing them, first and foremost I speak to ‘my people’; that is the internationally growing community of researchers and activists who bring personal experiences of psychiatrisation into their work building a counter knowledge base to ruling ideologies about madness and about our lives. The ‘we’ that I occasionally use in this chapter refers to that community.

6.2 Looking back: the starting and the arrival point of this inquiry

Apart from my inner resistance to concluding this research process in the absence of the participants’ input, a further challenge is rooted in the very concept of this study. From the start this inquiry, I did not seek to provide any definite answers but rather to open and explore a space for joint, first-person thinking of the topic of madness. The research began with a set of questions and even though I was able to trace the answers to those initial questions in my exploration of written sources, the process of collating our answers was primarily intended to identify the issues at stake, generate further questions and guide the interviews. Exploring the issues that arose from my analysis of written sources, the interviews in the second phase did not linearly progress towards developing a joint, first-person explanatory framework of madness as had been anticipated in the study design. Instead, they voiced more complexities, including questioning the very concept of madness. Rather than resolving these complexities or arriving at any concrete, implementable answers, this phase was much more about co-creating a discourse of madness. That discourse allowed us to think through madness on our own terms, as researchers, authors and activists who have been there and more or less back – whatever that place meant for each of us. It was in the course of the interviews that the intended direction of this research changed: from the idea of moving us a step closer to a first-person defined model of madness, the inquiry turned into exploring the very possibility of a collective first-person epistemology of madness ever being possible. Though this could potentially be seen as a step backwards, I hold that this turn opened up core questions for any model or theory of human lives, namely, *from whose perspective does the knowledge that holds universal claims emerge, and in what kind of processes?* Engaging with these fundamental questions, the people involved in this particular research did not necessarily arrive at any consensual solution but we thoroughly considered the key ethical and epistemological questions concerning all theories of madness, including questioning our own efforts towards theory building. In this sense the findings of this inquiry shed yet another critical light on the dominant biomedical theory, which has already been and continues to be scrutinised for lacking both scientific and ethical foundations. Through carefully unpacking the ways in which hermeneutical injustice persists in an era of peer-work, open dialogue and co-production in mental health, we indirectly addressed alternative models as well. Even though the validity of any such model was not the topic of this inquiry, the findings are relevant to those third-person approaches that come closer to the "mystery" of madness, bringing it into connection with the real circumstances of our lives (see Chapter One, p.25). This includes, for example, a recent initiative from within the British Psychological Society to develop an alternative to the psychiatric diagnostic system (Johnstone and Boyle 2018) which is unique for its involvement of 'survivor campaigners'[50], but also research efforts from within our own communities (Morrison, 2005). These knowledge-making projects have typically not paid sufficient attention, if any, to their own working processes and their epistemic claims. Whilst trying to develop a just way of bringing together our first-person knowledges of madness and psychiatrisation into a more coherent framework, we made that traditional omission visible. In the second research phase, I would say that the majority of the efforts in the interviews went into examining our own knowledge-making processes and thinking through what those processes need, and how we should work together, if we are to strengthen the distinctive first-person knowledge base of madness. Being a conversation partner to all the participants, and subsequently analysing the transcripts, I observed how each interview prioritised certain aspects of that process, and also found substantial agreements regarding those priorities. Those agreements above all focussed on the urgent need to recognise marginalising and exclusionary practices within our own work and

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[50] The full document is available at https://www.bps.org.uk/sites/bps.org.uk/files/Policy%20-%20Files/PTM%20Framework%20%28January%202018%29_0.pdf (accessed 9 December 2018)

communities, and stop them, always considering the broader oppressive structures that we are unequally exposed to. Psychiatry was understood as just one such structure, surrounded by and inseparable from all the others.

In many different ways, the participants here, together with the included authors, have voiced resistance to another explanatory framework and pointed to the overwriting and ultimate erasure of first-person knowledge inherent to all such undertakings. It is in this explicit refusal to engage in any 'grouping' or 'definition' of our experiences and in our determination to avoid the pitfalls of such ways forward, that I see our joint call for an epistemic turn in the official knowledge production on madness. In order to support this view, and to highlight the centrality of this call, I will for a moment leave the specific field of this thesis and borrow from the work of Portuguese sociologist and legal scholar Boaventura Santos. In his call for 'global cognitive justice', Santos (2014) argues that an 'epistemological break' is the only possible way to recognise injustice and overcome the oppression of "the institutionalized, harmful lies running our contemporary world" (p.viii). Criticising the Frankfurt School for its Western-centrism, this author distinguishes between "knowing about, explaining and guiding" and "*knowing with, understanding, facilitating, sharing and walking alongside*" (p. ix, emphasis added). The latter is a suitable expression for what emerged through this study just before its (temporary) ending. I can of course say this only for myself as a researcher and it will be on the participants to judge whether and to what extent we progressed in that direction. Having said that, I am also aware that moving in the direction suggested by Santos is not just a matter of a decision or a declaration: *knowing with* and *knowing together* require a great deal more work and a very different mind-set from the one that the conventional notion of social science and our academic upbringing call for. For this reason, this small-scale study is not in a position to produce certainty, nor deliver firm outcomes that could signify such an epistemic turn or 'epistemological break' in knowledge making on madness. Still, I appreciate the points we reached together and see them as important junctures on the long way to epistemic justice. I value the humility and caution that we shared, as well as our clarity and profound agreement about how *not* to proceed.

In this sense, even though we did not reach a first-person model or theory, this inquiry brings to light the chronic blind spot in knowledge making on madness: rather than saying, 'here is another, better explanation based in our experiences', it focuses on the unsettling questions about the process of knowledge formation and makes these questions central to both practice and theory building. The requirements articulated by participants go beyond bringing a particular standpoint or experience into our work and touch on the ethics and politics in all our doings.

How the knowledge production in psychology and psychiatry unhelpfully separates ethics and epistemology, and the implications of such separation, are analysed by Guishard et al. (2018). Identifying considerable gaps in the Ethics Code of the American Psychological Association (1953), the code that also covers qualitative research, these authors call for 'epistemological ethics'. Their call speaks to the project of joint knowledge making explored in this inquiry:

> "Knowing and knowledge production inherently come with an epistemological responsibility that is simultaneously, an ethical responsibility—how we ought to engage with the world and with *others* as a researcher and person. And these two aspects of being are never separable either." (para 36)

One of the paper's co-author's, Peiwei Li, describes two types of knowledge in qualitative research and holds that both are relevant to "navigating ethical conduct" (para 34). These are "*know-what* type of knowledge that aims for clarity and complexity" and "*know-how* type of knowledge, a communicative/relational competency to act and engage with others and the specific context with courage, and act in ways that upholds the principle of social justice" (para 34).

Applying this distinction, scholarship about madness can be characterised as focusing far more on *know-what* than *know-how* types of knowledge. The findings presented in this thesis suggest that perhaps the time has come to change this order of priorities and recognise that the way we treat each other in both our micro and macro worlds, including research, is key to knowing madness. I doubt that we will ever arrive at *transformative* or emancipatory knowledge if we do not prioritise the question of *how* we seek to know. Again - and in line with Oliver's (1992) understanding of the history of research that has yet to reach an emancipatory stage – that *how* comprises the questions, 'from whose standpoint and in what kind of process we claim to know?' I do not mean to imply that there can be one right standpoint and one right process but rather that the positions and processes that underpin our knowledge claims are integral to produced knowledge and need to be acknowledged rather than taken for granted.

In all established and less-established theories of madness, despite considerable differences in the *know-what* type of knowledge they propose, the standpoints and processes of knowledge making remain rather similar. In using the term standpoints, I do not refer to the authors' opinions and beliefs but to the fact that knowledge-making on madness traditionally occurs from third-person perspectives and is usually a project about the Other. This typically proves resistant to change even when partnering with that Other (see Johnstone and Boyle, 2018). This thesis and the research behind it offer a tiny glimpse into what *know-what* type of knowledge could look like when being generated from first-person perspectives and in a process that aims to be collective. It also documents many difficulties and challenges in an attempt to complete an epistemic turn.

6.3 Looking ahead: additional remarks

As this research is a work in progress, with the thesis as one stopover on the long journey ahead of us, in this section I provide some thoughts for future research and other knowledge-making initiatives. As stated earlier, my thoughts are primarily directed to the international community of survivor researchers in the hope that the exploration of our collective, first-person epistemology of madness will continue, and that our roles in future projects will rotate. By rotating I mean that, any participant in this study could take on a researcher's role in another inquiry, inviting other participants to join. This suggestion also extends to survivor scholars and activists who were not involved in this study.

To me, the greatest value of the findings of this inquiry is their potential to become departure points for further research. Rather than prioritising some of those findings myself, I prefer to leave that task to future projects. My role was primarily to comprehensively document the findings so that they can stand on their own and speak directly to anybody interested in taking this work forward.

At this stage of this inquiry, I want to add three more points to the findings. These relate to the notion of madness, the politics of working together in a profoundly divided world, and the rationale for strengthening a collective, first-person knowledge base on madness.

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This study was accompanied by struggles around language and involved continuous considering and re-considering of particular terms. Being aware of a range of different implications and possible readings, I choose to retain the terms 'mad' and 'madness'. However, I do not use 'mad' as an attribute to people or groups of people. Along with Fabris's (2011, 139) suggestion I use 'madness' as a historical "rather than a descriptive or essential category, proposed for political action and discussion". To me, this means recognising that while 'mad' or 'madness' might not exist at all, what cannot be denied is the existence of institutionalised routes of categorisation with their many real life implications. As long as such a powerful industry of othering operates, it makes sense to take the social positions it enacts as legitimate positions to work and think from, or in Fabris's words "to provide an autonomous societal space, at least from which to conceptualize psycho-medical force as othering" (p. 34). I also share Tina Minkowitz's (2014, 130) vision that the concept of disability "itself may one day be obsolete" and wish the same for 'madness'. At the same time, I am conscious of how far we are from that day, and the immense amount of work it will take for that to happen. Until then, if we are to unmake the category of madness as separate from the rest of human experience and make it obsolete, I see no-one better suited for such unmaking than the people who have been categorised as such (see the social model of disability). To me, maintaining the terms 'mad' and 'madness' does not mean holding on to any kind of individual or group identity. Mad is here as a place-marker; it signifies the social place of the Othered to talk back from, until that place dissolves.

*

Yet, the category 'mad' by itself does not enact the same societal positioning for all, but is always interwoven with other social markers. Attempting to collectivise a first-person knowledge base and its underpinning knowledge-making processes means more than just acknowledging the multiple and intersecting oppressions of our lives and making them part of our analysis; it requires finding a common ground from which to work together. As highlighted by Kumsa et al. (2014, 31):

> "We need anti-oppressive practices that honour all experiences without homogenizing them, honour differences without isolating them into separate cocoons, and reclaim that 'we' of our multiplicity without collapsing it into 'I' of our individuality or vice versa (Ahmed, 2000; 2009)."

These authors also reflect on the challenges of such an undertaking and ask, "[h]ow do we foster collaboration among oppressed groups and creatively engage the reality of competition that they are set up for?" (p.31), and "[w]ithout homogenizing our experiences, though, how do we sit down and work together?" (p.33) These remain central questions if we are to proceed in generating a first-person knowledge of madness that is not pre-determined to always stay partial and does not in itself perpetuate the dominances rooted in social categories of 'race' and ethnicity, class, gender and many others. Resolving these central questions is not just a matter of the awareness and analysis of difference with its historical, economic and other roots, but is much more about truly connecting and working together from a place where *all* our realities speak and where difference becomes integral to our research and other work. Working together and across difference is rather different from making ever narrower categories for ourselves and for each other. Jennifer Nash (2014) criticises the use of intersectionality when it is employed far from its social justice roots and reduced to a “theory of identity, injury, multiple marginalization, and subjectivity” (p.45). She compares this new use of the concept with smartphones that “can be endlessly updated, complicated, and ‘modernized,’ revised to resonate with the complexities of everyday life” (p.52). “The problem of intersectionality” Nash writes “is that its attention to particularity never challenges the structures of domination that incessantly reduce subjects to fictive categories” (p.57).

Re-directing the focus from ourselves onto oppressive structures and addressing them *together* is unlikely to be a straightforward undertaking, free of tensions and failures. However, I hardly see any other way than through engaging in joint work to understand where we fail, continue to learn and take responsibility not for who we are but for who we are becoming. We cannot afford to shy away from such work because there is no instant formula to mend the unequal and violent world that we inhabit. With this call to take every opportunity to work together and *against* the ingrained divisions among us, I do not imply that there should not be separate and exclusionary knowledge-making projects, undertaken from a particular angle and conducted within particular communities (see for example Jackson, 2002, Kalathil et al., 2011, Tang, 2017). On the contrary, such explorations are crucial to deepening and enhancing a comprehensive first-person body of knowledge of madness. Yet they cannot on their own make up for further efforts to work together across all kinds of borders, and to continue learning how to do so.

*

Whilst arguing for a turn in knowledge-making on madness towards a collective, first-person epistemology, I have no illusions that any knowledge base itself, no matter how sound or evidenced, is what ultimately informs, let alone transforms the ideologies that govern our lives. There is a considerable body of knowledge already in place that indisputably exposes all the wrongs of psychiatry and its biomedical model of ‘mental illness’, including perspectives from this very field. Unmaking madness is not just a supplement to that body of evidence, neither is it a project of theorising for its own sake. Unmaking madness is most of all about undoing dominant approaches and treatments of what is being marked and marketed as madness.

We live in the era of the United Nations (2006) Convention on the Rights of Persons with Disabilities (UN CRPD), ratified by numerous countries, that extends to guaranteeing human rights to people with psychiatric diagnoses. Those rights can generally be subsumed under *a right to a different treatment* from the traditional one, which continues to encompass the possibilities of forced interventions, deprivation of legal capacity and substituted decision making. Implementing these newly won rights is not only an extremely slow and painstaking process; it also requires *know-how* types of knowledge (Guishard et al. 2018) This is where, for example, the social model of disability as an outcome of researching and theorising from first-person perspectives of disability has a historic and ongoing critical role. Similarly, this is where I see the role and also the *responsibility* of our accumulated first-person knowledge on madness. To support this view, I will again quote Buckminster Fuller:

> "You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete." (quoted in Sieden, 2011, 358)

Having the achievement of full human rights at the top of their agendas, the organisations and movements of people who have been on the receiving end of psychiatric treatment are well versed at fighting the existing model. Building new models has not been our joint priority, and this thesis offers some insight into the reasons why. Yet this does not mean that the centuries of our dispersed and marginalised knowledge that we accumulated, shared and multiplied in our many personal and political struggles to make sense of our lives and find our place in the world – that all that knowledge grounded in our experiences does not amount to a whole new paradigm. The question of how to make the best and widest use of that knowledge is certainly more important than how to put it in a textbook. However, when we are in a position to contribute to change making processes concerning our lives, it is typically through terms that are set by far more powerful players. Exploring and strengthening our collective knowledge-base, as occurring within Mad Studies, might give us a better and stronger ground to work from.

In his analysis of how scientific revolutions occur, Thomas Kuhn (1996, 136) reminds us that "there are excellent reasons why revolutions have proved to be so nearly invisible" as well as that "most of them [...] have customarily been viewed not as revolutions but as additions to scientific knowledge". The possibility that we might be part of a paradigm change that is being kept invisible might give us another reason to value and foster the distinctiveness of our first-person knowledge and take responsibility for its advancement.

REFERENCES

2014. "Mad Studies Network – Shared Principles ", accessed 02.08.2018. https://madstudies2014.wordpress.com/2014/10/24/mad-studies-network-shared-principles/.

Adame, Alexandra L., and Gail A. Hornstein. 2006. "Representing Madness: How Are Subjective Experiences of Emotional Distress Presented in First-Person Accounts?" *The Humanistic Psychologist* 34:2:135-158.

Ahmed, Sara. 2000. *Strange encounters*. New York and London: Routledge.

Ahmed, Sara. 2009. "Embodying diversity: Problems and paradoxes for Black feminists." *Race Ethnicity and Education* 12 (1):41-52.

Albone, Jennifer. 2004. "An Exit From the Hall of Mirrors." In *Doorways In The Night. Stories From The Threshold of Recovery*, edited by Terry Simpson, 80-85. Leeds: Local Voices.

American Psychological Association. 1953. "Ethical standards of psychologists." accessed 09.12.2018. http://supp.apa.org/books/Essential-Ethics-for-Psychologists/1953ethicsCode.pdf.

American Psychological Association Division 32. 2011. "Open letter to the DSM-5 Task Force and the American Psychiatric Association.", accessed 25.10.2018. https://www.ipetitions.com/petition/dsm5.

Apter, Terri. 1996. "Expert Witness. Who Controls the Psychologist's Narrative." In *Ethics and Process in The Narrative Study of Lives*, edited by Ruthellen Josselson, 22-43. Thousand Oaks: SAGE.

Armes, David. 2009. "'Getting better - in theory': Creating, then using a Foucauldian mental health service user/survivor theoretical standpoint in my own journey of 'recovery'." In *This is Survivor Research*, edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose, 140-146. Ross-on-Wye: PCCS Books.

Bakhtin, Mickhail. 1984. *Problems of Dostoevsky's poetics*. Translated by Caryl Emerson. Minneapolis: University of Minnesota Press.

Bakhtin, Mikhail. 1981. *The Dialogic Imagination*. Austin and London: University of Texas Press.

Bassman, Ronald. 2001. "Whose reality is it anyway? Consumers/survivors/ex-patients can speak for themselves." *Journal of Humanistic Psychology* 41 (4):11-35.

Bassman, Ronald. 2012. "Never give up." *Psychosis: Psychological, Social and Integrative Approaches* 4 (3):269-274.

Bassman, Ronald 2007. *A Fight to Be. A Psychologist's Experience from Both Sides of the Locked Door*. Albany New York: Tantamount Press.

Beaupert, Fleur. 2018. "Freedom of Opinion and Expression: From the Perspective of Psychosocial Disability and Madness." *Laws* 7 (1).

Beckmann, Lanny, and Megan J. Davies. 2013. "Democracy Is a Very Radical Idea." In *Mad Matters: A Critical Reader in Canadian Mad Studies*, edited by Brenda A. LeFrançois, Geoffrey Reaume and Robert J. Menzies, 49-63. Toronto: Canadian Scholar's Press Inc.

Bellion, Regina. 2002. "After Withdrawal, the Difficulties Begin." In *Coming off Psychiatric Drugs*, edited by Peter Lehmann, 279-290. Berlin - Eugene - Shrewsbury: Peter Lehmann Publishing.

Bellion, Regina. 2007. "How We Discovered the Soteria Principle." In *Alternatives Beyond Psychiatry*, edited by Peter Stastny and Peter Lehmann, 75-83. Berlin: Peter Lehmann Publishing.

Beresford, Peter. 2000. "What Have Madness and Psychiatric System Survivors Got to Do with Disability and Disability Studies?" *Disability & Society* 15 (1):167-172.

Beresford, Peter. 2002a. "Thinking about 'mental health': Towards a social model." *Journal of Mental Health* 11 (6):581-584.

Beresford, Peter. 2002b. "User Involvement in Research and Evaluation: Liberation or Regulation." *Social Policy & Society* 1 (2):95-105.

Beresford, Peter. 2003a. *It's Our Lives: A short theory of knowledge, distance and experience*. London: Citizen Press in association with Shaping Our Lives.

Beresford, Peter. 2003b. "User Involvement in Research: Connecting lives, experience and theory." Towards increasing the effectivness of user-generated knowledge in practice and research University of Warwick

Beresford, Peter. 2004a. "Madness, Distress, Research and a Social Model." In *Implementing the Social Model of Disability: Theory and Research*, edited by Colin Barnes and Geof Mercer, 208-222. Leeds: The Disability Press.

Beresford, Peter. 2004b. "Social approaches to madness and distress: user perspectives and user knowledges." In *Social Perspectives in Mental Health: Developing Social Models to Understand and Work with Mental Distress*, edited by Jerry Tew, 32-51. London and Philadelphia: Jessica Kingsley Publishers.

Beresford, Peter. 2005a. "Developing self-defined social approaches to madness and distress." In *Mental Health at the Crossroads: The Promise of the Psychosocial Approach*, edited by Shulamit Ramon and Janet E. Williams, 109-123. Hants: Ashgate Publishing Company.

Beresford, Peter. 2005b. "Developing the theoretical basis for service user/survivor-led research and equal involvement in research." *Epidemiologia e Psichiatria Sociale* 14 (1):4-9.

Beresford, Peter. 2009. "Developing a social model of madness and distress to underpin survivor research." In *This is Survivor Research*, edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose, 44-52. Ross-on-Wye: PCCS Books.

Beresford, Peter. 2010. *A Straight-Talking Introduction to Being a Mental Health Service User*. Ross-on-Wye: PCCS Books.

Beresford, Peter. 2013. "Experiential Knowledge and Reconception of Madness." In *Madness Contested: Power and Practice*, edited by Steven Coles, Sarah Keenan and Bob Diamond, 181-196. Ross-on-Wye: PCCS Books.

Beresford, Peter. 2015. "Distress and disability. not you, not me, but us?" In *Madness, Distress and the Politics of Disablement*, edited by Helen Spandler, Jill Anderson and Bob Sapey, 245-259. Bristol: Policy Press.

Beresford, Peter, and Kathy Boxall. 2012. "Service Users, Social Work Education and Knowledge for Social Work Practice." *Social Work Education: The International Journal* 31 (2):155-167.

Beresford, Peter, and Sarah Carr, eds. 2018. *Social policy first hand. An international introduction to participatory social welfare*. Bristol: Policy Press.

Beresford, Peter, and Suzy Croft. 2012. User Controlled Research. Scoping review. Accessed 03.06.2018.

Beresford, Peter, Gloria Gifford, and Chris Harrison. 1996. "What Has Disability Got to do with Psychiatric Survivors?" In *Speaking Our Minds. An Anthology of Personal Experiences of Mental Distress and its Consequences*, edited by Jim Read and Jill Reynolds, 209-214. London MACMILLAN PRESS LTD.

Beresford, Peter, Mary Nettle, and Rebecca Perring. 2010. *Towards a social model of madness and distress? Exploring what service users say*. York: Joseph Rowntree Foundation.

Beresford, Peter, Rebecca Perring, Mary Nettle, and Jan Wallcraft. 2016. *From mental illness to a social model of madness and distress*. London: Shaping Our Lives.

Beresford, Peter, and Jasna Russo. 2016a. "Supporting the sustainability of Mad Studies and preventing its co-option." *Disability & Society* 31 (2):270-274.

Beresford, Peter, and Jasna Russo. 2016b. Supporting the sustainability of Mad Studies and preventing its co-option. *Disability & Society* 31 (2): 270-274.

Beresford, Peter, Jasna Russo, and Kathy Boxall, eds. forthcoming. *The Routledge Handbook of Mad Studies*. Oxfordshire: Routledge.

Beresford, Peter, and Jan Wallcraft. 1997. "Psychiatric System Survivors and Emancipatory Research: Issues, overlaps and differences." In *Doing Disability Research*, edited by Colin Barnes and Geof Mercer, 66-87. Leeds: The Disability Press.

Bhakta, Renuka. 2016. "Kindred Minds: a personal perspective." In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*, edited by Jasna Russo and Angela Sweeney, 142-151. Monmouth: PCCS Books.

Boevink, Wilma. 2007. "Survival, the Art of Living and Knowledge to Pass On: Recovery, Empowerment and Experiential Expertise of Persons with Severe Mental Health Problems " In *Alternatives Beyond Psychiatry*, edited by Peter Stastny and Peter Lehmann, 105 -117. Berlin - Eugene - Shrewsbury: Peter Lehmann Publishing.

Boyatzis, Richard E. 1998. *Transforming qualitative information: thematic analysis and code development* Thousand Oaks London New Delhi: Sage.

Bracken, Patrick, and Philip Thomas. 2005. *Postpsychiatry: Mental health in a postmodern world*. New York: Oxford University Press.

Braun, Virginia, and Victoria Clarke. 2006. "Using thematic analysis in psychology." *Qualitative Research in Psychology* 3:77-101.

Breggin, Peter. 1993. *Toxic Psychiatry. Drugs and Electroconvulsive Therapy: The Truth and the Better Alternatives*. 1st UK Paperback Edition edition ed. London: HarperCollins.

Breggin, Peter. 1995. *Talking Back to Prozac: What Doctors Aren't Telling You about Today's Most Controversial Drug*. St Martin's Paperbacks edition ed. USA: St Martin's.

Breggin, Peter. 2009. *Medication Madness: The Role of Psychiatric Drugs in Cases of Violence, Suicide, and Crime*. St Martin's Paperbacks edition ed. New York: St. Martin's Griffin.

Brown, Celia, and Peter Stastny. 2016. "Peer workers in the mental health system: a transformative or collusive experiment? ." In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*, edited by Jasna Russo and Angela Sweeney, 183-191. Monmouth: PCCS Books.

Brown, Michelle. 2013. "Fear and Loathing in the Con Dem Nation." *Asylum. The Magazine for Democratic Psychiatry* 20 (3):13-14.

Burstow, Bonnie. 2015. *Psychiatry and the Business of Madness. An Ethical and Epistemological Accounting*. New York: Palgrave Macmillan US.

Burstow, Bonnie, and Don Weitz, eds. 1988. *Shrink Resistant: The Struggle Against Psychiatry in Canada*. Vancouver: New Star Books.

Byrne, Louise, Brenda Happell, and Kerry Reid-Searl. 2016. "Lived experience practitioners and the medical model: world's colliding?" *Journal of Mental Health* 25 (3):217-223.

Campbell, Jean. 2009. "'We Are the Evidence,' an Examination of Service User Research Involvement as Voice." In *Handbook of Service User Involvement in Mental Health Research*, edited by Jan Wallcraft, Beate Schrank and Michaela Amering, 113-137. West Sussex: Wiley-Blackwell.

Campbell, Peter. 1996a. "Challenging Loss of Power." In *Speaking Our Minds. An Anthology of Personal Experiences of Menal Distress and its Consequences*, edited by Jim Read and Jill Reynolds, 56-62. London MACMILLAN PRESS LTD.

Campbell, Peter. 1996b. "What We Want from Crisis Services." In *Speaking Our Minds. An Anthology of Personal Experiences of Menal Distress and its Consequences*, edited by Jim Read and Jill Reynolds, 180-183. London MACMILLAN PRESS LTD.

Campbell, Peter. 1999. "The service user/survivor movement." In *This is Madness: A critical look at psychiatry and the future mental health services*, edited by Craig Newnes, Guy Holmes and Cailzie Dunn, 195-208. Ross-on-Wye: PCCS Books.

Campbell, Peter. 2001. System Survivors: Is there anything we can do? Accessed 25.07.2012.

Campbell, Peter. 2010. "Surviving the System." In *Voices of Experience: Narratives of mental health survivors*, edited by Thurstine Basset and Theo Stickley, 21-30. West Sussex: Wiley-Blackwell

Carr, Sarah. 2009. "The sick and the well?" In *This is Survivor Research*, edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose, 182-183. Ross-on-Wye: PCCS Books.

Carr, Sarah. 2016. "Narrative research and service user/survivor stories: a new frontier for research ethics?" *Philosophy, Psychiatry & Psychology* 23 (3-4):233-236.

Carr, Sarah. 2018. "Who owns co-production?" In *Social policy first hand. An international introduction to participatory social welfare.* , edited by Peter Beresford and Sarah Carr, 74-83. Bristol: Policy Press.

Casey, Briege, and Aishlinn Long. 2003. "Meanings of madness: a literature review." *Journal of Psychiatric and Mental Health Nursing* 10:89-99.

Chabasinski, Ted. 2012. "The History and Future of Our Psychiatric Survivor Movement." accessed 15.11.2018. https://www.madinamerica.com/2012/08/the-history-and-future-of-our-psychiatric-survivor-movement/.

Chadwick, Peter. 2010. "The Antidote to Madness: Crystallising out of the Real Self." In *Voices of Experience: Narratives of mental health survivors*, edited by Thurstine Basset and Theo Stickley, 13-19. West Sussex: Wiley-Blackwell

Chamberlin, Judi. 1988. *On our own: Patient-controlled alternatives to the mental health system.* London: MIND. Original edition, 1978 by Haworth Press.

Chamberlin, Judi. 1990. "The Ex-Patients' Movement: Where We've Been and Where We're Going." *Journal of Mind and Behaviour* 11 (3):323-336.

Champ, Simon. 1999. "The Most Precious Thread." In *From the Ashes of Experience: Reflections on Madness, Survival and Growth*, edited by Phil Barker, Peter Campbell and Ben Davidson, 113-126. London: Whurr Publishers.

Chase, Susane E. 1996. "Personal Vulnerability and Interpretative Authority in Narrative Research." In *Ethics and Process in The Narrative Study of Lives*, edited by Ruthellen Josselson, 45-59. Thousand Oaks: SAGE.

Chassot, Carolina S, and Felismina Mendes. 2015. "The experience of mental distress and recovery among people involved with the service user/survivor movement." *Health* 19 (4):372–388.

Church, Kathryn. 2013. "Making Madness Matter in Academic Practice." In *Mad Matters: A Critical Reader in Canadian Mad Studies*, edited by Brenda A. LeFrançois, Robert J. Menzies and Geoffrey Reaume, 181-190. Toronto: Canadian Scholars' Press.

Clark, Michael 2015. "Co-production in mental health care." *Mental Health Review Journal*, 20 (4):213-219.

Coldham, Tina, and Jasna Russo. 2009. "Telling Our Truths, Bringing about Change: Being a Survivor Researcher." In *This is Survivor Research*, edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose, 163-184. Ross-on-Wye: PCSS Books.

Coleman, Ron. 1999. "Hearing voices and the politics of oppression." In *This is Madness: A critical look at psychiatry and the future mental health services*, edited by Craig Newnes, Guy Holmes and Cailzie Dunn, 149-163. Ross-on-Wye: PCCS Books.

Collins, Patricia Hill. 2000. *Black feminist thought* 2nd ed. New York: Routledge.

Collins, Patricia Hill. 2012. "Social inequality, power, and politics: Intersectionality and American pragmatism in dialogue." *The Journal of Speculative Philosophy* 26 (2):442-457.

Conroy, Cathy. 1999. "Fire and Ice." In *From the Ashes of Experience: Reflections on Madness, Survival and Growth*, edited by Phil Barker, Peter Campbell and Ben Davidson, 54-67. London: Whurr Publishers.

Cooper, David. 1967. *Psychiatry and Anti-Psychiatry*: Paladin.

Cooper, David. 1978. *The Language of Madness*: Penguin.

Costa, Lucy. 2014. "Mad Studies - What it is and why you should care." accessed 05.05.2017. https://madstudies2014.wordpress.com/2014/10/15/mad-studies-what-itis-and-why-you-should-care-2/.

Costa, Lucy, Jijian Voronka, Danielle Landry, Jenna Reid, Becky McFarlane, David Reville, and Kathryn Church. 2012. "Recovering our Stories: A Small Act of Resistance." *Studies in Social Justice* 6 (1):85-101.

Crossley, Nick. 2004. "Not being mentally ill. Social movements, system survivors and the oppositional habitus." *Anthropology & Medicine* 11:2:161-180.

Davar, Bhargavi V. 2000. "Writing Phenomenology of Mental Illness: Extending the Universe of Ordinary Discourse." In *Existence, Experience and Ethics: Essays for S.A. Shaida*, edited by Raghuramaraju, 51-82. New Delhi DK Printworld.

Davar, Bhargavi V. 2007. "Depression and the Use of Natural Healing Methods." In *Alternatives Beyond Psychiatry*, edited by Peter Stastny and Peter Lehmann, 83-90. Berlin: Peter Lehmann Publishing.

Davar, Bhargavi V. 2008. "From Mental Illness to Disability: Choices for Women Users/Survivors of Psychiatry in Self and Identity Constructions " *Indian Journal of Gender Studies* 15 (2):261-290. doi: DOI: 10.1177/097152150801500204.

Davar, Bhargavi V. 2015. "Identity Constructions for 'Mentally Disturbed' Women: Identities versus Institutions." In *Gendering Mental Health. Knowledges, Identities, and Institutions*, edited by Bhargavi V. Davar and T. K. Sundari Ravindran, 193-219. New Delhi: Oxford University Press.

Davis, Lennard J. 1999. "Crips strike back: The rise of disability studies." *American Literary History* 11 (3):500-512.

Davison, Jean. 2004. "Give Me Back My Words." In *Doorways In The Night. Stories From The Threshold of Recovery*, edited by Terry Simpson, 8-15. Leeds: Local Voices.

Deegan, Patricia E. 1996a. "Recovery and the Conspiracy of Hope." "There's a Person In Here": The Sixth Annual Mental Health Services Conference of Australia and New Zealand, Brisbane, Australia, 16 September 1996.

Deegan, Patricia E. 1996b. "Recovery as a Journey of the Heart." *Psychiatric Rehabilitation Journal* 19 (3):91-97.

Department of Health. 2001. Research governance framework for health and social care.

Dewan, Veronica. 2011. "Foreword." In *Recovery and resilience: African, African-Caribbean and South Asian women's narratives of recovering from mental distress*, edited by Jayasree Kalathil, Beth Collier, Renuka Bhakta, Odete Daniel, Doreen Joseph and Premila Trivedi, 6. London: Survivor Reasearch and Mental Health Foundation.

Douglass, Frederick. 1994. *Autobiographies*. New York: Library of America.

Estroff, Sue E. 1981. *Making it crazy: An ethnography of psychiatric clients in an American community*. Berkeley: University of California Press.

Estroff, Sue E. 2004. "Subject/Subjectivities in Dispute: The Politics and Poetics of First Person Narratives of Schizophrenia." In *Schizophrenia, Culture, and Subjectivity: The Edge of Experience* edited by Janis Hunter Jenkins and Robert John Barrett, 282-302. Cambridge: Cambridge Univ. Press.

Etter-Lewis, Gwendolyn. 1996. "Telling From Behind Her Hand. African American Women and the Process of Documenting Concealed Lives." In *Ethics and Process in The Narrative Study of Lives*, edited by Ruthellen Josselson, 114-128. Thousand Oaks: SAGE.

European Network of (ex)Users and Survivors of Psychiatry. 1994a. "Our Own Understanding of Ourselves. Report on the Kolding Seminar." Kolding, Denmark, 16th - 18th December

European Network of (ex)Users and Survivors of Psychiatry. 1994b. "The Second European Conference of Users and Ex-Users in Mental Health." Elsinore, Denmark, 26th - 29th May

European Network of (ex)Users and Survivors of Psychiatry. 2009. Nothing about us without us. How to make this a reality? Report of the Empowerment Seminar, 13th - 14th March 2009 in Brussels. Brussels: European Network of (ex-) Users and Survivors of Psychiatry.

European Network of (ex)Users and Survivors of Psychiatry. 2012. "STRATEGIC PLAN 2012 - 2015." accessed 26.11.2012. http://enusp.org/wp-content/uploads/2016/01/enusp_strategic_plan_2012-2015.pdf.

Fabris, Erick. 2011. *Tranquil Prisons: Chemical Incarceration under Community Treatment Orders* Toronto: University of Toronto Press.

Fabris, Erick. 2013. "Mad Success: What Could Go Wrong When Psychiatry Employs Us as "Peers"?" In *Mad Matters: A Critical Reader in Canadian Mad Studies*, edited by Brenda A. LeFrançois, Geoffrey Reaume and Robert J. Menzies, 130-139. Toronto: Canadian Scholar's Press Inc.

Fabris, Erick. 2016. "Community treatment orders: once a rosy deinstitutional notion? ." In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*, edited by Jasna Russo and Angela Sweeney, 97-105. Monmouth: PCCS Books.

Fabris, Erick, and Katie Aubrecht. 2014. "Chemical Constraint: Experiences of Psychiatric Coercion, Restraint, and Detention as Carceratory Techniques." In *Disability Incarcerated: Imprisonment and Disability in North America*, edited by Allison Carey, Chris Chapman and Liat Ben-Moshe, 185-200. Palgrave Macmillan.

Faulkner, Alison. 1997. *Knowing Our Own Minds*. London: Mental Health Foundation.

Faulkner, Alison. 2002. "Introduction." In *Something Inside so Strong. Strategies for surviving mental distress*, edited by Jim Read, 7-8. London: The Mental Health Foundation.

Faulkner, Alison. 2003. "The emperor's new clothes." *Mental Health Today* 3 (8):23-25.

Faulkner, Alison. 2004. *The ethics of survivor research. Guidelines for the ethical conduct of research carried out by mental health service users and survivors*. Bristol: The Policy Press.

Faulkner, Alison. 2010. "Measuring the Marigolds." In *Voices of Experience: Narratives of mental health survivors*, edited by Thurstine Basset and Theo Stickley, 33-45. West Sussex: Wiley-Blackwell

Faulkner, Alison. 2015. "Randomised controlled trials: The straitjacket of mental health research?". McPin Foundation, accessed 05.06.2018. http://mcpin.org/wp-content/uploads/talking-point-paper-1.pdf.

Faulkner, Alison, and Sarah Layzell. 2000. *Strategies for Living: a report of user-led research into people's strategies for living with mental distress*. London: Mental Health Foundation.

Faulkner, Alison, and Brigid Morris. 2002. *Expert paper: User Involvement in Forensic Mental Health Research and Development*. Liverpool: National R & D Programme on Forensic Mental Health.

Faulkner, Alison, and Debbie Tallis. 2009. "Survivor research: Ethics approval and ethical practice." In *This is Survivor Research*, edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose, 53-62. Ross-on-Wye: PCCS Book.

Felton, Chip J., Peter Stastny, David L. Shern, Andrea Blanch, Sheila A. Donahue, Edward Knight, and Celia Brown. 1995. " Consumers as peer specialists on intensive case management teams: impact on client outcomes." *Psychiatric Services* 46 (10):1037-1044.

Fergusson, Linda. 2004. "Through Anxiety and Agoraphobia - My Journey." In *Doorways In The Night. Stories From The Threshold of Recovery*, edited by Terry Simpson, 28-43. Leeds: Local Voices.

Filson, Beth. 2011a. "Is Anyone Really Listening?" *National National Council Magazine: Breaking the Silence. Trauma-informed Behavioral Healthcare* (2):15.

Filson, Beth. 2011b. "The "the" of Self-Injury." In *Searching for a Rose Garden. Fostering Real Alternatives to Psychiatry - Project Documentation*, 75. Berlin: Verein zum Schutz vor psychiatrischer Gewalt e.V.

Filson, Beth. 2016. "The haunting can end: trauma-informed approaches in healing from abuse and adversity " In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*, edited by Jasna Russo and Angela Sweeney, 20-24. Monmouth: PCCS Books.

Fisher, Dan. 1999. "Hope, Humanity and Voice in Recovery from Mental Illness." In *From the Ashes of Experience: Reflections on Madness, Survival and Growth*, edited by Phil Barker, Peter Campbell and Ben Davidson, 127-133. London: Whurr Publishers.

Fleischmann, Pete, and Jon Wigmore. 2000. *Nowhere else to go*. London: Bramah House.

Forsythe, Nicky. 2012. "The Shades of Madness." *Asylum. The Magazine for Democratic Psychiatry* 19 (1):18-20.

Frank, Arthur W. 1995. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago and London: The University of Chicago Press.

Frank, Arthur W. 2000. "The Standpoint of Storyteller." *Qualitative Health Research* 10 (3):354-365.

Frank, Arthur W. 2005. "What Is Dialogical Research, and Why Should We Do It?" *Qualitative Health Research* 15(7):964-974.

Frank, Arthur W. 2009. "Tricksters and Truth Tellers: Narrating Illness in an Age of Authenticity and Appropriation." *Literature and Medicine* 28(2):185-199.

Frank, Arthur W. 2010. *Letting Stories Breathe. A Socio-Narratology*. Chicago and London: The University of Chicago Press.

Frank, Arthur W. 2011. "Practicing dialogical narrative analysis." In *Varieties of narrative analysis*, edited by James A. Holstein and Jaber F. Gubrium, 33-52. London: Sage.

Fricker, Miranda. 2010. *Epistemic Injustice. Power and the Ethics of Knowing*. New York: Oxford University Press.

Gorman, Rachel. 2013. "Mad Nation? Thinking through Race, Class, and Mad Identity Politics." In *Mad Matters: A Critical Reader in Canadian Mad Studies*, edited by Brenda A. LeFrançois, Geoffrey Reaume and Robert J. Menzies, 269-280. Toronto: Canadian Scholar's Press Inc.

Green, Phil. 2004. "Making Friends with Blackbirds." In *Doorways In The Night. Stories From The Threshold of Recovery*, edited by Terry Simpson, 44-47. Leeds: Local Voices.

Guishard, Monique A., Alexis Halkovic, Anne Galletta, and Peiwei Li. 2018. "Toward Epistemological Ethics: Centering Communities and Social Justice in Qualitative Research." *Qualitative Sozialforschung / Forum: Qualitative Social Research* 19 (3).

Hall, Will. 2007. *Harm Reduction Guide to Coming Off Psychiatric Drugs*. New York - Northampton: The Icarus Project and Freedom Center.

Hall, Will. 2013. "On the anti-identity identity politics of madness." accessed 09.12.2018. https://malingeringnormal.wordpress.com/2013/12/09/will-hall-on-the-anti-identity-identity-politics-of-madness/.

Halsall, Keith. 2006. *Forensic Users Research Project*. Liverpool: National Programme on Forensic Mental Health Research and Development.

Harding, Sandra. 1991. *Whose Science? Whose Knowledge? Thinking from Women's Lives*. Ithaca: Cornell University Press.

Holloway, Jan. 1999. "The Other World." In *From the Ashes of Experience: Reflections on Madness, Survival and Growth*, edited by Phil Barker, Peter Campbell and Ben Davidson, 37-53. London: Whurr Publishers.

hooks, bell. 1990. "Marginality as a site of resistance." In *Out there: Marginalisation and contemporary cultures*, edited by Russel Fergusson, Martha Gever, Trinh Min-ha and C ornel West, 341-343. Cambridge:: MIT Press.

Hopper, Kim. 2007. "Rethinking social recovery in schizophrenia: What a capabilities approach might offer." *Social Science & Medicine* 65 (5):868-879.

Hopper, Kim. 2012. "Reframing Early Psychiatric Crises: A Capabilities-Informed Approach." *Journal of Human Development, Disability, and Social Change* 20 (2):23-39.

Hornstein, Gail A. 2002. "Narratives of Madness, as Told From Within." *Chronicle of Higher Education* 48:20.

Hornstein, Gail A. 2008. "Bibliography of First-Person Narratives of Madness In English (4th edition)." accessed 02.10.2018. http://www.gailhornstein.com/files/Bibliography_of_First_Person_Narratives_of_Madness_5th_edition.pdf.

Hornstein, Gail A. 2009. *Agnes's Jacket: A Psychologist's Search for the Meaning of Madness*. New York: Rodale.

Hutchinson, Ali. 2014. "The Language of "Madness" and the "Madness" of Language: The Politics of Discourse." Alternative Psychiatric Narratives Birkbeck, University of London, 16-17 May 2014.

Ingram, Richard. 2016. "Doing Mad Studies: Making (non)sense together." *Intersectionalities. A Global Journal of Social Work Analysis, Research, Polity, and Practice* 5 (2):11-17.

Jackson, Vanessa. 2002a. "In Our Own Voice: African American Stories of Oppression, Survival and Recovery in the Mental Health System." *International Journal of Narrative Therapy & Community Work* 2:11-31.

Jackson, Vanessa. 2002b. "In Our Own Voice: African American Stories of Oppression, Survival and Recovery in the Mental Health System." accessed 03.06.2018. http://www.healingcircles.org/uploads/2/1/4/8/2148953/inovweb.pdf.

Jackson, Vanessa. 2003. "Separate and unequal: The legacy of racially segregated psychiatric hospitals - a cultural competence training tool." accessed 25.06.2018. https://www.patdeegan.com/sites/default/files/files/separate_and_unequal.pdf.

Jacobson, Nora. 2001. "Experiencing Recovery: A Dimensional Analysis of Recovery Narratives." *Psychiatric Rehabilitation Journal* 24:3:248-256.

Jahnke, Bettina. 2012. *Vom Ich-Wissen zum Wir-Wissen: Mit EX-IN zum Genesungsbegleiter*. Neumünster: Die Brücke

Jesperson, Maths. 2002. "Between Lobotomy and Antidepressants." In *Coming off Psychiatric Drugs*, edited by Peter Lehmann, 75-76. Berlin - Eugene - Shrewsbury: Peter Lehmann Publishing.

Jesperson, Maths. 2016. "Skåne's personal ombudsman service – a survivor-controlled personal assistant project." In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies* edited by Jasna Russo and Angela Sweeney, 134-141. Monmouth: PCCS Books.

Johnstone, Lucy, and Mary Boyle. 2018. "The Power Threat Meaning Framework: An Alternative Nondiagnostic Conceptual System." *Journal of Humanistic Psychology* 58:1-18.

Johnstone, Lucy, and Jo Watson. 2017. "Just listen to their stories." *Therapy Today. The voice of the counselling and psychotherapy profession* 28 (3):30-33.

Jones, Nev, and Robyn Lewis Brown. 2013. "The Absence of Psychiatric C/S/X Perspectives In Academic Discourse: Consequences and Implications " *Disability Studies Quarterly* 33 (1).

Jones, Raya A. 2005. "Identity commitments in personal stories of mental illness on the internet." *Narrative Inquiry* 15:2:293-322.

Jones, Robert. 2008. "Foreword." In *Lifting Barriers: African and Caribbean People Tell Stories of Struggle, Strength, and Achieving Mental Health*, edited by Zhenreenah Muhxinga, Corrine Douglas, David Francis, Mark Laville, Sidney Millin, Juliana Pamfield, Peter Smith and Raymond Smith. London: Mellow, SAFH, THACMHO, East London NHS Trust.

Joseph, Amail. 2015. "Beyond intersectionalities of identity or interlocking analyses of difference: Confluence and the problematic of “anti”-oppression." *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice* 4 (1):15-39.

Josselson, Rutheleen. 2011. "“Bet you think this song is about you”: Whose Narrative Is It in Narrative Research?" *Narrative works: Issues, Investigations & Interventions* 1 (1):33-51.

Josselson, Ruthellen, ed. 1996a. *Ethics and process in the narrative study of lives*. 10 vols. Vol. 4, *Narrative study of lives*. Thousand Oaks: Sage.

Josselson, Ruthellen. 1996b. "On writing other people’s lives: Self-analytic reflections of a narrative researcher." In *Ethics and process in the narrative study of lives*, edited by Ruthellen Josselson, 60-71. Thousand Oaks: Sage.

Josselson, Ruthellen. 2006. "Narrative Research and the challenge of accumulating knowledge." *Narrative Inquiry* 16 (1):3-10.

Kafai, Shayda. 2013. "The Mad Border Body: A Political In-betweeness." *Disability Studies Quarterly* 33 (1).

Kalathil, Jayasree. 2001. "Inscribing Madness: Another Reading of "The Yellow Wallpaper" and "The Bell Jar"." In *Mental Health from a Gender Perspective*, edited by Bhargavi Davar, 296-307. New Delhi: Sage.

Kalathil, Jayasree, Beth Collier, Renuka Bhakta, Odete Daniel, Doreen Joseph, and Premila Trivedi. 2011. *Recovery and resilience: African, African-Caribbean and South Asian women’s narratives of recovering from mental distress*. London: Survivor Research and Mental Health Foundation.

Kelly, Timothy. 2016. "Heterogeneities of Experience, Positionality and Method in User/Survivor Research." *Philosophy, Psychiatry & Psychology* 23 (3-4):229-232.

King, Colin. 2007. "Foreword." In *Whiteness Made Simple: Stepping into the Grey Zone*, edited by William (Lez) Henry, ix-xiii. London: Nu-Beyond Ltd: Learning By Choice!

Knight, Tamasin. 2009. "Beyond Belief. Alternative Ways of Working with Delusions, Obsessions and Unusual Experiences." In. Berlin - Eugene - Shrewsbury: Peter Lehmann Publishing. http://www.peter-lehmann-publishing.com/books/knight.htm (accessed 07.03.2014).

Krücke, Miriam. 2007. "Advance Directives - A Step towards Self-help." In *Alternatives Beyond Psychiatry*, edited by Peter Stastny and Peter Lehmann, 97-104. Berlin: Peter Lehmann Publishing.

Kuhn, Thomas S. 1996. *The Structure of Scientific Revolutions, Third Edition*. Chicago and London: The University of Chicago Press.

Kumsa, Martha Kuwee, Magnus Mfoafo-M'Carthy, Funke Oba, and Sadia Gaasim. 2014. "The Contours of Anti-Black Racism: Engaging Anti-Oppression from Embodied Spaces." *The Journal of Critical Anti-Oppressive Social Inquiry* 1:21-38.

Laing, Ronald D. 1960. *The Divided Self: An Existential Study in Sanity and Madness*. Harmondsworth: Penguin.

Laing, Ronald D. 1961. *The Self and Others*. London: Tavistock Publications.

Laing, Ronald D. 1982. *The Voice of Experience: Experience, Science and Psychiatry*. Harmondsworth: Penguin.

Laura, Crystal T. 2013. "Intimate Inquiry: Love as “Data” in Qualitative Research." *Cultural Studies ↔ Critical Methodologies* 13 (4):289–292.

Lee, Ji-Eun. 2013. "Mad as Hell: The Objectifying Experience of Symbolic Violence." In *Mad Matters: A Critical Reader in Canadian Mad Studies*, edited by Brenda A. LeFrançois, Geoffrey Reaume and Robert J. Menzies, 105-121. Toronto: Canadian Scholar's Press Inc.

LeFrançois, Brenda A., Peter Beresford, and Jasna Russo. 2016. "Destination Mad Studies." *Intersectionalities. A Global Journal of Social Work Analysis, Research, Polity, and Practice* 5 (2):1-10.

LeFrançois, Brenda A., Robert J. Menzies, and Geoffrey Reaume, eds. 2013. *Mad Matters: A Critical Reader in Canadian Mad Studies*. Toronto: Canadian Scholar's Press Inc.

Lewis, Lydia. 2014. "User Involvement in Mental Health Services: A Case of Power Over Discourse." *Sociological Research Online, 19 (1) 6* 19 (1).

Liegghio, Maria. 2013. "A Denial of Being: Psychiatrization as Epistemic Violence." In *Mad Matters: A Critical Reader in Canadian Mad Studies*, edited by Brenda A. LeFrançois, Geoffrey Reaume and Robert J. Menzies, 122-129. Toronto: Canadian Scholar's Press Inc.

Lindow, Vivien. 2010. "Survivor Research." In *This is Madness Too: Critical perspectives on mental health issues*, edited by Craig Newnes, Guy Holmes and Cailzie Dunn, 135-146. Ross-on-Wye: PCCS Books.

Lorde, Audre. 1984. *Sister Outsider*. Berkely, CA: Crossing Press.

Lorenz, Annette K., Jasna Russo, and Florian Scheibe. 2007. Aus eigener Sicht. Erfahrungen von NutzerInnen mit der Hilfe. Berlin: Der PARITÄTISCHE Berlin, Referat für Psychiatrie.

Mason, Pam. 1996. "Agoraphobia: Letting Go." In *Speaking Our Minds. An Anthology of Personal Experiences of Menal Distress and its Consequences*, edited by Jim Read and Jill Reynolds, 3-8. London: MACMILLAN PRESS LTD.

Masson, Jeffrey. 1984. *The Assault on Truth: Freud's Suppression of the Seduction Theory*. New York: Farrar, Straus and Giroux.

May, Rufus. 2004. "Making Sense of Psychotic Experience and Working Towards Recovery." In *Psychological interventions in early psychosis: a treatment handbook*, edited by John F.M. Gleeson and Patrick D. McGorry, 245-260. West Sussex: John Wiley & Sons Ltd.

May, Rufus, Rebecca Smith, Sophie Ashton, Ivan Fontaine, Chris Rushworth, and Pete Bull. 2013. "Speaking Out Against the Apartheid Approach to Our Minds." In *Madness Contested: Power and Practice*, edited by Steven Coles, Sarah Keenan and Bob Diamond, 233-246. Ross-on-Wye: PCCS Books.

McNamara, Ashley, and Sascha Altman DuBrul, eds. 2004. *Navigating the Space between Brilliance and Madness. A Reader & Roadmap of Bipolar Worlds*. New York: Icarus Project.

McWade, Brigit. 2016. "Researching Mad Pride: The Stigma and Violence of Knowledge Production." accessed 09.12.2018. https://thestigmadoctrine.wordpress.com/2016/02/03/researching-mad-pride-the-stigma-and-violence-of-knowledge-production/.

Mead, Shery. 2005. *Intentional Peer Support: An Alternative Approach*. Plainfield, NH.

Mead, Shery. 2007. "Trauma-informed Peer Run Crisis Alternatives." In *Alternatives Beyond Psychiatry*, edited by Peter Stastny and Peter Lehmann, 210-217. Berlin: Peter Lehmann Publishing.

Mead, Shery. 2008. "Sustaining Intentional Peer Support in Crisis Alternatives." accessed 08.05.2016. https://docs.google.com/document/d/1Tpso6GrlmYjbcDMdINjMPyZuy2az28YhNt08ZJCVFGs/edit.

Mead, Shery, and Beth Filson. 2016. "Becoming part of each other's narratives: Intentional Peer Support." In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*, edited by Jasna Russo and Angela Sweeney, 109-118. Monmouth: PCCS Books.

Menzies, Robert, Brenda LeFrançois, and Geoffrey Reaume. 2013. "Introducing Mad Studies." In *Mad Matters: A Critical Reader in Canadian Mad Studies*, edited by Brenda LeFrançois, Robert Menzies and Geoffrey Reaume, 1-22. Toronto: Canadian Scholars' Press.

Millet, Kate. 2007. "The Illusion of Mental Illness." In *Alternatives Beyond Psychiatry*, edited by Peter Stastny and Peter Lehmann, 29-37. Berlin: Peter Lehmann Publishing.

Millett, Kate. 1990. *The Loony-Bin Trip*. New York: Simon and Shuster.

Minkowitz, Tina. 2014. "Convention on the Rights of Persons with Disabilities and Liberation from Psychiatric Opression." In *Psychiatry Disrupted: Theorizing Resistance and Crafting the (R)evolution*, edited by Bonnie Burstow, Brenda A. LeFrançois and Shaindl Diamond, 129-144. Montreal and Kingston: McGill-Queen's University Press.

Minkowitz, Tina. 2015. "Advancing the rights of users and survivors of psychiatry using the UN Convention on the Rights of Persons with Disabilities." In *Madness, Distress and the Politics of Disablement*, edited by Helen Spandler, Jill Anderson and Bob Sapey, 171-182. Bristol: Policy Press.

Minkowitz, Tina, and Amita Dhanda, eds. 2006. *First person stories on forced interventions and being deprived of legal capacity*. Pune: WNUSP and BAPU Trust.

Mollow, Anna. 2006. ""When Black women start going on Prozac": Race, gender and mental illness in Meri Nana-Ama Danquah's "Willow Weep for Me"." *Melus* 31 (3):67-99.

Moncrieff, Joanna. 2009. *A Straight Talking Introduction to Psychiatric Drugs*. Ross-on-Wye: PCCS Books.

Moncrieff, Joanna. 2013. *The Bitterest Pills: The Troubling Story of Antipsychotic Drugs*. Hampshire: Palgrave Macmillan UK.

Moncrieff, Joanna. 2016. "Myth of the Chemical Cure " In *Outside Mental Health: Voices and Visions of Madness*, edited by Will Hall, 155 -162. Northampton MA: Madness Radio.

Morrison, Linda. 2006. "A Matter of Definition: Acknowledging Consumer/Survivor Experiences through Narrative " *Radical Psychology* 5.

Morrison, Linda J. 2005. *Talking Back to Psychiatry: The Psychiatric Consumer/Survivor/Ex-Patient Movement* New York & London: Routledge.

Mosher, Loren. 1998. "Letter of Resignation from the American Psychiatric Association." accessed 09.12.2018. http://www.moshersoteria.com/articles/resignation-from-apa/.

Mosher, Loren R., and Voyce Hendrix. 2004. *Soteria: Through Madness to Deliverance*. New Jersey: Xlibris Corporation.

Muhxinga, Zhenreenah, Corrine Douglas, David Francis, Mark Laville, Sidney Millin, Juliana Pamfield, Peter Smith, and Raymond Smith. 2008. *Lifting Barriers: African and Caribbean People Tell Stories of Struggle, Strength, and Achieving Mental Health*. London: Mellow, SAFH, THACMHO, East London NHS Trust.

Muscio, Inga M. 2008. "Slash an' Burn." In *Live Through This. On Creativity and Self-Destruction*, edited by Sabrina Chapadjiev, 79-90. New York: Seven Stories Press.

Nabbali, Essya M. 2009. "A 'Mad' Critique of the Social Model of Disability." *The International Journal of Diversity in Organizations, Communities and Nations* 9 (4):1-12.

Nash, Jennifer C. 2014. "Institutionalizing the Margins." *Social Text* 32 (1):45-65.

National Development Team for Inclusion. 2016. Position Paper: Are mainstream mental health services ready to progress transformative co-production? Accessed 15.09.2016.

National Survivor User Network. 2018. "Open Letter to the Organisers, Partners and Delegates of the Global Ministerial Mental Health Summit, London 9th and 10th October, 2018." National Survivor User Network accessed 26.10.2018. https://www.nsun.org.uk/news/global-ministerial-mental-health-summit-open-letter.

Natland, Sidsel, and Hilde Dalen Celik. 2015. "Service Users' Self-Narratives on Their Journey from Shame to Pride: Tales of Transition." *Journal of Evidence-Informed Social Work* 12 (1):50-63.

Nicholls, Vicky. 2001. *Doing Research Ourselves*. London: Mental Health Foundation.

Nicholls, Vicky, Alison Faulkner, and Blazdell. 1999. *The DIY Guide to Survivor Research*. London: The Mental Health Foundation.

Nicholls, Vicky, Sarah Wright, Rachel Waters, and Stephanie Wells. 2003. *Surviving user led research: reflections on supporting user led research projects*. London: Mental Health Foundation.

O'Hagan, Mary. 2001. "A Call To Open The Door. A psychiatric disability perspective on 'rethinking care'." Global Conference on Rethinking Care, Oslo, Norway, 22-25 April 2001.

O'Hagan, Mary. 2008. "Recovery: The true meaning of recovery." *Mental Health Today* December 2008/January 2009:16-17.

O'Hagan, Mary. 2014. *Madness Made Me*. Wellington: Open Box.

O’Hagan, Mary. 1993. *Stopovers on My Way Home From Mars*. London: Survivors Speak Out.

O’Hagan, Mary. 2009. "Foreword." In *This is Survivor Research*, edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose, i. Ross-on-Wye: PCCS Book.

Oliver, Mike. 1992. "Changing the Social Relations of Research Production?" *Disability, Handicap & Society* 7 (2):101-114.

Oliver, Mike. 1997. "Emancipatory Research: Realistic goal or impossible dream?" In *Doing Disability Research*, edited by Colin Barnes and Geof Mercer, 15-31. Leeds: The Disability Press.

Oliver, Mike. 2009. *Understanding Disability: From theory to practice, Second Edition*. Basingstoke: Palgrave Macmillan.

Our Voice. 2016. In *Our Voice. Viewpoints of the psychiatrized since 1987*. New Brunswick, Canada.

Oxleas NHS. 2017. "Lived Experience Practitioners - supporting our mental health patients." accessed 04.10.2018. http://oxleas.nhs.uk/news/2017/1/lived-experience-practitioners/.

Pembroke, Louise. 2009. "Mind Your Language." *Open Mind* 156 (March/April):6-9.

Pembroke, Louise Roxana, ed. 1994. *Self-harm. Perspectives from Personal Experience*. London: Survivors Speak Out.

Pembroke, Louise Roxanne, ed. 1992. *Eating Distress. Perspectives from Personal Experience*. London: Survivors Speak Out.

Penney, Darby. 1994. "Choice, Common Sense, and Responsibility: The System's Obligations to Recipients." In *Choice and Responsibility: Legal and Ethical Dilemmas in Services for Persons with Mental Disabilities*, edited by C.J. Sundram, 29-32. New York State Commission on Quality Care.

Penney, Darby. 2000. "The Recovery Dialogues. A Personal Reflection and a Cautionary Note." In *Participatory Dialogues: A Guide to Organizing Interactive Discussions on Mental Health Issues among Consumers, Providers, and Family Members*, edited by Gayle Bluebird, 41-42. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

Penney, Darby, and Laura Prescott. 2016. "The co-optation of survivor knowledge: the danger of substituted values and voice." In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*, edited by Jasna Russo and Angela Sweeney, 35-45. Monmouth: PCCS Books.

Pinderhughes, Elaine, Vanessa Jackson, and Patricia Romney, eds. 2017. *Understanding Power: An Imperative for Human Services*. Washngton, DC: NASW Press.

Plumb, Anne. 1993. "The Challenge of Self advocacy." *Feminism and Psychology* 3 (2):169-187.

Podvoll, Edward M. 2003. *Recovering Sanity. A Compassionate Approach to Understanding and Treating Psychosis*. Boston: Shambhala Publications.

Read, Jim. 2005. *Coping with Coming Off* London: Mind.

Read, Jim, and Jill Reynolds. 1996. "Introduction." In *Speaking Our Minds. An Anthology of Personal Experiences of Menal Distress and its Consequences*, edited by Jim Read and Jill Reynolds, xv-xvii. London MACMILLAN PRESS LTD.

Ridgway, Priscilla. 2001. "ReStorying Psychiatric Disability: Learning from first person recovery narratives." *Psychiatric Rehabilitation Journal* 24 (4):335-343.

Riessman, C. K. 1993. *Narrative Analysis*. London: Sage.

Robb, Annie. 2012. Towards Strengthening the Rights of Persons with Psychosocial Disabilities in Africa. Cape Town: Pan African Network of People with Psychosocial Disabilities.

Robb, Annie, and Debra Shulkes. 2013. Strengthening Our Voices: A Report On a Strategic Capacity-Building Seminar in Cape Town, 2013. World Network of Users and Survivors of Psychiatry (WNUSP).

Roper, Cath, Flick Grey, and Emma Cadogan. 2018. "Co-production. Putting principles into practice in mental health contexts." University of Melbourne accessed 25.10. 2018. https://recoverylibrary.unimelb.edu.au/__data/assets/pdf_file/0010/2659969/Coproduction_putting-principles-into-practice.pdf.

Rose, Diana. 2001. *Users' Voices: The Perspective of Mental Health Service Users on Community and Hospital Care*. London: The Sainsbury Center for Mental Health.

Rose, Diana. 2003a. "Collaborative research between users and professionals: peaks and pitfalls." *Psychiatric Bulletin* 27:404-406.

Rose, Diana. 2003b. "Having a diagnosis is a qualification for the job." *British Medical Journal* 326:1331.

Rose, Diana. 2008. "Service user produced knowledge." *Journal of Mental Health* 17 (3):447-451.

Rose, Diana, Sarah Carr, and Peter Beresford. 2018. "'Widening cross-disciplinary research for mental health': what is missing from the Research Councils UK mental health agenda?" *Disability & Society* 33 (3):476-481.

Rosenwald, George C. 1996. "Making Whole. Methods and Ethics in Mainstream and Narrative Psychology." In *Ethics and Process in The Narrative Study of Lives*, edited by Ruthellen Josselson, 245-273. Thousand Oaks: SAGE.

Ross, Maggy. 1994. "Personal account." In *Self-harm. Perspectives from Personal Experience*, edited by Louise Roxana Pembroke, 13-15. London: Survivors Speak Out.

Russo, Jasna. 2001. "Reclaiming madness." In *Something Inside so Strong. Strategies for surviving mental distress*, edited by Jim Read, 36-39. London: The Mental Health Foundation.

Russo, Jasna. 2004. "Forschung mit uns statt über uns [*Research with us instead of on us*]." *Rundbrief des Bundesverbands Psychiatrieerfahrener e.V [Magazine of the German Federal Organisation of Mental Health Service Users]* 4/2004:5-9.

Russo, Jasna. 2012a. "Give me the stories and I will take care of the rest? Review of "Agnes's Jacket: A Psychologist Search for the Meaning of Madness" by Gail A Hornstein." *Asylum. The Magazine for Democratic Psychiatry* 19 (4):28-30.

Russo, Jasna. 2012b. "Survivor-controlled Research: A New Foundation for Thinking about Psychiatry and Mental Health." *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* 13 (1).

Russo, Jasna. 2013. "Mad Matters: A Critical Reader in Canadian Mad Studies - book review." *Service Users in Research Bulletin*, 12-14.

Russo, Jasna. 2016a. "Betroffene in der psychiatrischen Forschung – Infragestellung oder Erweiterung des biomedizinischen Diskurses? [Survivors in psychiatric research: Challenging or extending the biomedical dicourse?] " *Kerbe. Forum für Sozialpsychiatrie* 2/2016:32-34.

Russo, Jasna. 2016b. "Establishing first-person knowledge of madness: Must this undertaking elide our differences?" *Philosophy, Psychiatry & Psychology* 23 (3-4):237-240.

Russo, Jasna. 2016c. "In dialogue with conventional narrative research in psychiatry and mental health." *Philosophy, Psychiatry & Psychology* 23 (3-4):215-228.

Russo, Jasna. 2016d. "Towards our own framework, or reclaiming madness part two." In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*, edited by Jasna Russo and Angela Sweeney, 59-68. Monmouth: PCCS Books.

Russo, Jasna. 2018. "Through the eyes of the observed: re-directing research on psychiatric drugs ". McPin Foundation, accessed 25.10.2018. http://mcpin.org/wp-content/uploads/talking-point-paper-3-final.pdf.

Russo, Jasna, and Peter Beresford. 2015. "Between Exclusion and Colonisation: Seeking a Place for Mad People's Knowledge in Academia." *Disability & Society* 30 (1):153-157.

Russo, Jasna, and Thomas Fink. 2003. Stellung nehmen. Obdachlosigkeit und Psychiatrie aus der Sicht der Betroffenen. Der PÄRITÄTISCHE Berlin.

Russo, Jasna, Florian Scheibe, and Sandra Hamilton. 2009. Versuch einer Einmischung. Bericht der Praxisarbeit Der PARITÄTISCHE Berlin, Referat für Psychiatrie.

Russo, Jasna, and Debra Shulkes. 2015. "What we talk about when we talk about disability: Making sense of debates in the European user/survivor movement." In *Madness, Distress and the Politics of Disablement*, edited by Helen Spandler, Jill Anderson and Bob Sapey, 27-41. Bristol: Policy Press.

Russo, Jasna, and Peter Stastny. 2009. "Beyond Involvement. Looking for a Common Perspective on Roles in Research." In *Handbook of Service User Involvement in Mental Health Research*, edited by Jan Wallcraft, Beate Schrank and Michaela Amering, 61-72. West Sussex: Wiley-Blackwell.

Russo, Jasna, and Angela Sweeney, eds. 2016. *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*. Monmouth: PCCS Books.

Russo, Jasna, and Jan Wallcraft. 2011. "Resisting Variables. Service user/survivor perspectives on researching coercion." In *Coercive Treatment in Psychiatry: Clinical, Legal and Ethical Aspects*, edited by Thomas W. Kallert, Juan E. Mezzich and John Monahan, 213-234. West Sussex: John Wiley & Sons, Ltd.

Ryan, Gerry W., and Russell H. Bernard. 2000. "Data management and analysis methods." In *Handbook of qualitative research, second edition*, edited by Norman Denzin and Yvonna Lincoln, 769-802. Thousand Oaks: Sage Publications.

Santos, Boaventura de Sousa. 2014. *Epistemologies of the South. Justice against Epistemicide*. Boulder/London: Paradigm Publishers.

Scatter, Sascha. 2004. "Making Maps with the Artifacts of Our Fleeting Memories or On Being a Time Traveler." In *Navigating the Space between Brilliance and Madness. A Reader & Roadmap of Bipolar Worlds*, edited by Ashley McNamara and Sascha Altman DuBrul, 7-9. New York: Icarus Project.

Scott, John, and Gordon Marschall. 2009. *Oxford Dictionary of Sociology*. online version 2014 vols. Oxford: Oxford University Press.

Seikkula, Jaakko, Jukka Aaltonen, Birgittu Alakare, Kauko Haarakangas, Jyrki Keranen, and Klaus Lehtinen. 2006. "Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies." *Psychotherapy Research* 16(2):214-228.

Shaw, Clare. 2016. "Deciding to be alive: self-injury and survival." In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*, edited by Jasna Russo and Angela Sweeney, 77-85. Monmouth: PCCS Books.

Shimrat, Irit. 1998. "Freedom." Alternatives '98 Long Beach, California.

Shimrat, Irit. 2013. "The Tragic Farce of "Community Mental Health Care"." In *Mad Matters: A Critical Reader in Canadian Mad Studies*, edited by Brenda A. LeFrançois, Geoffrey Reaume and Robert J. Menzies, 144-157. Toronto: Canadian Scholar's Press Inc.

Shimrat, Irit 1997. *Call Me Crazy - Stories from the Mad Movement*. Vancouver: Press Gang Publishers.

Shive, Bonfire Madigan. 2008. "Cello Speak: Exploring New Languages for Madness." In *Live Through This. On Creativity and Self-Destruction*, edited by Sabrina Chapadjiev, 173-186. New York: Seven Stories Press.

Sieden, Steven, ed. 2011. *A Fuller View - Buckminster Fuller´s Vision of Hope and Abundance for all*. Studio City, CA: Divine Arts Media.

Simpson, Terry. 2002. "No limit to what you are." In *Something Inside so Strong. Strategies for surviving mental distress*, edited by Jim Read, 93-94. London: The Mental Health Foundation.

Smith, Andy. 2007. "What Helps Me if I Go Mad?" In *Alternatives Beyond Psychiatry*, edited by Peter Stastny and Peter Lehmann, 50-53. Berlin: Peter Lehmann Publishing.

Smythe, William E., and Maureen J. Murray. 2000. "Owning the Story: Ethical Considerations in Narrative Research." *Ethics & Behavior* 10:4:311-336.

Solomun, Zoran. 2007. "What Helps Me if I Go Mad?" In *Alternatives Beyond Psychiatry*, edited by Peter Stastny and Peter Lehmann, 65-67. Berlin: Peter Lehmann Publishing.

Spandler, Helen, Jill Anderson, and Bob Sapey, eds. 2015. *Madness, Distress and the Politics of Disablement*. Bristol: Policy Press.

Staddon, Patsy, ed. 2013. *Mental health service users in research: critical sociological perspectives*. Bristol: Policy Press.

Stastny, Peter, and Peter Lehmann, eds. 2007. *Alternatives Beyond Psychiatry*. Berlin: Peter Lehmann Publishing.

Stickley, Theodore. 2006. "Should service user involvement be consigned to history? A critical realist perspective." *Journal of Psychiatric and Mental Health Nursing* 13 (5):570-577.

Stone, Emma, and Mark Priestley. 1996. "Parasites, pawns and partners: disability research and the role of non-disabled researchers." *British Journal of Sociology* 47 (4):699-716.

Straughan, Heather Johnson. 2009. "Influencing change: User or researcher? Elitism in Research." In *This is Survivor Reserach*, edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose. Ross-on-Wye: PCCS Books.

Survivors History Group. 2011. "Survivors History Group takes a critical look at historians." In *Critical Perspectives on User Involvement*, edited by Marian Barnes and Phil Cotterell, 7-18. Bristol: The Policy Press.

Sweeney, Angela. 2009. "So what is survivor research?" In *This is Survivor Research*, edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose, 22-37. Ross-on-Wye: PCCS Books.

Sweeney, Angela. 2011. "Introducing Survivor Research." Searching for a Rose Garden. Fostering Real Alternatives to Psychiatry, Berlin, 2nd and 3rd September 2011.

Sweeney, Angela. 2016a. "The transformative potential of survivor research." In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*, edited by Jasna Russo and Angela Sweeney, 49-59. Monmouth: PCCS Books.

Sweeney, Angela. 2016b. "Why Mad Studies Needs Survivor Research and Survivor Research Needs Mad Studies." *Intersectionalities. A Global Journal of Social Work Analysis, Research, Polity, and Practice* 5 (2):36-61.

Sweeney, Angela, Peter Beresford, Alison Faulkner, Mary Nettle, and Diana Rose, eds. 2009. *This is Survivor Research*. Ross-on-Wye: PCCS Books.

Sweeney, Angela, and Louise Morgan. 2009. "The Levels and Stages of Service User/Survivor Involvement in Research." In *Handbook of Service User Involvement in Mental Health Research*, edited by Jan Wallcraft, Beate Schrank and Michaela Amering, 25-35. West Sussex: Wiley-Blackwell.

Szasz, Thomas Stephen. 1974. *The myth of mental illness: foundations of a theory of personal conduct*. New York: Harper & Row.

Tam, Louise. 2013. "Whither Indigenizing the Mad Movement? Theorizing the Social Relations of Race and Madness through Conviviality." In *Mad Matters: A Critical Reader in Canadian Mad Studies*, edited by Brenda A. LeFrançois, Geoffrey Reaume and Robert J. Menzies, 281-297. Toronto: Canadian Scholar's Press Inc.

Tang, Lynn. 2017. *Recovery, Mental Health and Inequality. Chinese Ethnic Minorities as Mental Health Service Users* London and New York: Routledge.

Tenney, Lauren. 2016. "On Mad Activism." accessed 08.05.2016. https://www.psychologytoday.com/blog/rethinking-mental-health/201603/lauren-tenney-mad-activism.

Tenney, Lauren J. 2014. "(de)VOICED: HUMAN RIGHTS NOW (An Environmental Community-Based Participatory Action Research Project). A dissertation submitted to the Graduate Faculty in Psychology in partial fulfillment of the requirements for the degree of Doctor of Philosophy." Graduate Faculty in Psychology, The City University of New York.

The Icarus Project. 2013. *Friends Make the Best Medicine: A Guide To Creating Community Mental Health Support Networks*. Second ed. New York: The Icarus Project. Original edition, 2006.

The Opal Project. 2007. "Ourstory of Commitment: A living history." accessed 2.10.2018. http://www.theopalproject.org/ourstory.html.

Turner, Michael. 2003. *Shaping our Lives - from outset to outcome. What people think of social care services they use*. York: Joseph Rowntree Foundation.

Turner, Michael, and Peter Beresford. 2005. "User Controlled Research: Its meanings and potential." Shaping Our Lives and the Centre for Citizen Participation, Brunel University., accessed 05.06.2018. http://www.invo.org.uk/wp-content/uploads/documents/UserConRpt081205.pdf

United Nations. 2006. Convention on the Rights of Persons with Disabilities. . New York: United Nations.

Walker, Tamsin. 2004. "Why cut up?" *Asylum. The Magazine for Democratic Psychiatry* 14 (3):21-22.

Wallcraft, Jan. 1996. "Becoming Fully Ourselves." In *Speaking Our Minds. An Anthology of Personal Experiences of Mental Distress and its Consequences*, edited by Jim Read and Jill Reynolds, 191-196. London MACMILLAN PRESS LTD.

Wallcraft, Jan. 2003. "The Role of Experts by Experience." Different Truths: User Control and Involvement in Mental Health Research and Evaluation, online conference 4th December 2003.

Wallcraft, Jan. 2007. "User-led Research to Develop an Evidence Base for Alternative Approaches." In *Alternatives Beyond Psychiatry*, edited by Peter Stastny and Peter Lehmann, 342-351. Berlin: Peter Lehmann Publishing.

Wallcraft, Jan. 2008. "View point." *Mental Health Today* 8 (1):41.

Wallcraft, Jan. 2009. "From activist to researcher and part-way back." In *This is Survivor Research*, edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose, 132-139. Ross-on-Wye: PCCS Books.

Wallcraft, Jan, and Kim Hopper. 2015. "The Capabilities Approach and the social model of mental health." In *Madness, Distress and the Politics of Disablement*, edited by Helen Spandler, Jill Anderson and Bob Sapey, 83-97. Bristol: Policy Press.

Wallcraft, Jan, Jim Read, and Angela Sweeney. 2003. *On Our Own Terms. Users and survivors of mental health services working together for support and change* London: The Sainsbury Centre for Mental Health.

Wallcraft, Jan, Beate Schrank, and Michaela Amering, eds. 2009. *Handbook of Service User Involvement in Mental Health Research*. West Sussex: Wiley-Blackwell.

Wallcraft, Janet. 2001. "Turning towards Recovery? A study of personal narratives of mental health crisis and breakdown."Ph.D. Thesis, South Bank University

Webb, David. 2002a. "The Many Languages of Suicide." Suicide Prevention Australia Conference Sydney, June 2002

Webb, David. 2002b. ""Please Don't Die"." In *Coming off Psychiatric Drugs*, edited by Peter Lehmann, 164 - 173. Berlin - Eugene - Shrewsbury: Peter Lehmann Publishing.

Webb, David. 2010. *Thinking About Suicide: Contemplating and comprehending the urge to die*. Ross-on-Wye: PCCS Books.

Webb, David. 2015. "The social model of disability and suicide prevention." In *Madness, Distress and the Politics of Disablement*, edited by Helen Spandler, Jill Anderson and Bob Sapey, 153-167. Bristol: Policy Press.

Webb, David. 2016. "Thinking (differently) about suicide." In *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies*, edited by Jasna Russo and Angela Sweeney, 86-96. Monmouth: PCCS Books.

Weitz, Don. 1998. "Notes of A "Schizophrenic" Shitdisturber." In *Shrink Resistant: The Struggle Against Psychiatry in Canada*, edited by Bonnie Burstow and Don Weitz, 285-302. Vancouver: New Star Books.

Whitaker, Robert. 2010. *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America* New York: Broadway Paperbacks.

Wilson, Anne, and Peter Beresford. 1999. "Surviving An Abusive System." In *Ethical Practice and the Abuse of Power in Social Responsibility: Leave No Stone Unturned*, edited by Helen Payne and Brian Littlechild, 145-174. London: Jessica Kingsley.

Wilson, Anne, and Peter Beresford. 2002. "Madness, Distress and Postmodernity: Putting the Record Straight." In *Disability/Postmodernity: Embodying Disability Theory*, edited by Mairian Corker and Tom Shakespeare, 143-158. London/New York: Continuum.

Young, Elizabeth. 2009. "Memoirs. Rewriting the social construction of mental illness." *Narrative Inquiry* 19:1:52-68.

APPENDICES

Appendix A: Analysis of written sources – coding frame

	NODES	CHILD NODES[51]	References[52]
1.	Refocus on environment	- Racism (4) - Trauma (4) - Poverty (2) - Sexism (3)	45
2.	Concepts of madness		34
3.	Accepting madness	- The normality of madness (4)	33
4.	Valuing madness and learning from it	- Becoming through madness (2)	25
5.	The potential for change in madness		22
6.	About our own model	- About social model of disability (13) - The need for our own model (4) - The reluctance to impose another model (3) - How our own model should be (2)	22
7.	The role of language		16
8.	The positive in madness		15
9.	The search for language		13
10.	The role of madness in society and vice versa		12
11.	Against a dichotomy of mad/sane		11
12.	The intensity of madness		11
13.	Madness as process or journey		9
14.	A focus on mutuality		6
15.	Ownership/re-appropriation of experience		6
16.	Uniqueness – the individuality of madness		6
17.	Against new categories		5
18.	Learning to cope with madness		5
19.	The right to choose and take risks		5
20.	Identity and self-definition		4
21.	The incommunicability of madness		4

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[51] The number of references for a particular child node is in brackets.
[52] The numbers in this column also include the references for child nodes.

22.	The negative echo of the term 'madness'		4
23.	Spirituality		4
24.	Against the biomedical model		3
25.	Communicating madness		3
26.	First-person authority		2
27.	The necessity of madness		2
28.	Politics is not all		2
29.	Anger		1
30.	The context of madness		1
31.	Sameness in madness		1

Appendix B: Analysis of written sources - summary of findings and issues for further exploration

This document summarises the main findings from the first research phase and repeats the emerging issues that were presented at the end of each section in Chapter 4 (*Creating our own story. Survivor written work*). It serves to organise and prioritise the key issues for further exploration in the interview phase of the study.

1. Language for madness

Many authors describe both the central role of language in making sense of experiences and their own struggles to find the right words. The dominance of the biomedical model in both expert and lay discourses about madness limits and pre-defines the space for our authentic self-expression. Furthermore, madness and distress are experiences that often occur in a place beyond words and can, by their very nature, contradict the way that language is organised. Our attempts to redefine our experiences and ourselves still take the biomedical model and the psychiatric system as their central points of reference. A fundamental question, thus, persists: *How do we create a discourse of madness that does not 'other' this experience or draw another line between madness and sanity?*

The findings confirm both how hard it is to separate our language from particular concepts and understandings of madness and how integral the search for the right words is to the search for a new paradigm. At the same time, there seems to be a difference between finding the right language and finding the right terminology. We may want to focus our efforts on deepening our understanding rather than suggesting any better or 'right' terms that would inevitably enforce our 'othering'. I would like to consider Tam's (2013, 287) suggestion that 'madness is something we can have, without identifying as such', and explore our use of language in connection with the other issues emerging from this inquiry.

2. What is madness?

Many authors make explicit that experiences of madness and distress are neither diseases nor disorders and, all in all, not of a medical nature at all. These states are, however, vulnerable to interpretations and actions of different kinds that often neglect or deny the individual's own agency. The authors agree that madness is a profoundly individual experience, unique to each person. There is a clear demand to pay due attention to this fact and to respect the stance that however similar our experiences might be, when it comes to understanding madness, the ultimate authority lies with the person in question, and not with anyone else. This suggests that the deliberate refusal to 'group people's distress' (Pembroke 1994) might be a principle that we wish to adopt when moving towards our own framework. The inclusion of such a principle might also be a fundamental prerequisite and an important safeguard for any further exploration of madness.

An issue for further discussion is *whether we want to work at all towards creating an approach that has definite answers*. I find the following questions formulated by Filson (2016, 219) very helpful for exploring these concerns further:

> "What would be different if we came to our relationship with each other out of a sense of curiosity rather than certainty? If we saw each other as people with many stories -- rather than people with many symptoms? How does an emphasis on learning from each other revolutionise the way we think about being with each other in distress?"

3. The social nature of madness

The accounts included in this inquiry emphasise the decisive role of one's immediate environment in relation to madness but also acknowledge the importance of the larger societal structures in which we live. The authors make it clear that it is impossible to separate experiences of madness from the societies in which we live; madness actually originates from society itself. In other words, madness does not come from inside us; it comes from our lives. In one way or another, almost all authors address experiences of racism, sexism, poverty and/or trauma as direct causes of madness. However, they also stress that madness is a highly personal matter. Though this may always be in a particular social context, people who experience madness are dynamically involved in that context and their experiences cannot be explained entirely by a broader social order or reduced to politics. While they argue strongly that madness is not located *within* a person, the authors likewise do not try to locate it in any particular place *outside* of the individual. Rather, they perceive madness as the outcome of a multitude of relations. Therefore, the argument that madness is of a social nature does not imply a unidirectional relationship. In fact, the relationship is mutually fulfilling: society makes madness, which, in turn, performs a designated function within society.

This dynamic, however, is mediated by the powerful institution of psychiatry. The biomedical approach to madness clearly stands in the way of seeing these connections and inhibits the changes that madness calls for. If we use the metaphor that the biomedical model serves a 'comfort blanket' (Beresford et al. 2016, 19) that covers and prevents us from seeing and addressing the bigger picture, then the opposite approach to madness would mean taking away that blanket and uncovering the issues at stake. Such an ‘uncovering’ should take place at both the individual and societal levels; it makes the demand that “we address the broadest structural concerns *and* the most intimate aspects of our individual selves” (Beresford 2010, 130, emphasis added).

One of the tasks ahead may be to imagine *what the interplay between madness and society could be like if there were no biomedical approach to govern it.* Refocusing radically on the social relationships around madness would have far-reaching implications for both our individual lives and society as a whole.

4. Making room for madness

Many of the authors argue strongly for valuing and accepting madness. Their accounts “rest on the revolutionary idea that madness is a full human experience” (O’Hagan 2009, i). This is expressed in many different ways and refers equally to our own and other people’s madness.

Madness is accepted here as part of one’s life and integral to one’s sense of selfhood. Although the authors do not describe the experience itself as pleasant, they find meaning in it and would rather understand and embrace their madness than have it ‘fixed’ or removed. This also applies to other people’s madness. While recognising the inherent challenges that this kind of acceptance brings, many of the authors are committed to making room for madness and take this stance as a matter of principle.

In this context, madness is understood as an experience that can happen to anybody, which profoundly challenges the biomedical understanding that targets particular populations and defines those who experience madness as a categorically separate group. Rather than probing madness and seeking explanations for it, some authors actually question ‘normality’, and they are suspicious of some people’s inability ever to go mad.

Replacing the search for ever more sophisticated ‘normalising’ interventions with the principle of accepting madness and making efforts to enlarge the space allowed for it, could have far-reaching transformative implications for the communities and societies in which we live. These findings suggest that unmaking the division between ‘mad’ and ‘sane’ is one of the core aspects of disrupting the dominant paradigm.

Working towards a different approach requires learning to accept madness and expand the room allowed for it both within ourselves and our relationships and within the broader systems in which we live. As Knight (2009, 43) puts it:

> "Accepting a person's unusual beliefs is similar to accepting another's religion as being valid without having to personally share it."

In the next research phase, it may be useful to discuss *the limits of this acceptance and whether these are any different from the other limits that we inevitably pose and negotiate with each other.*

5. Generating meaning and learning from madness

The authors do not romanticise or idealise madness. Their accounts describe the experience as a profound personal and existential crisis. And yet, despite all the accompanying hardships, they perceive these crises as important learning opportunities and chances to grow. Experiences of madness make sense in the context of a person's life and are therefore not just a burden that one needs to get rid of.

Some authors claim that even extreme states of mind entail logic and truth. Among other things, they see states of madness as particular ways of knowing. If, however, madness is to be understood and learned from, then it first needs to be taken out of its segregated social place and recognised as a valid human experience. Many of the authors report being denied both the space to understand their own madness and any chance to learn how to cope with it. This is different from learning strategies for reaching 'normality'. Several accounts reiterate that allowing madness rather than suppressing it might be the best way to respond. Because we are not usually allowed to have the experience at all, we are likewise denied any opportunity to learn how to deal with it on our own terms.

Learning how to live with/through/after madness, or knowing how to 'be mad', seems key to avoiding being subjected to unwanted interventions and treatments. Some authors describe how it was actually the experience of madness that taught them how to live and become who they are.

The journey through madness is usually risky and difficult. Generally, the authors do not recommend this experience though they clearly value it. While diverse and always highly individual, their accounts attest, over and over, to the possibility of 'reaching the other side' (O'Hagan 1993, Shimrat 1998, Bassman 2012, Jesperson 2016).

These findings ultimately point us to a question that has been formulated by O'Hagan (2014, 116): "Is madness such a bad thing? […] *How different would our experience of madness be if it was valued and given status?*" (emphasis added)

6. The transformative potential of madness

Despite describing madness as a tough experience, a number of the authors highlight the important potential for change that this experience entails. Madness is not only a visible manifestation of things going wrong but also a powerful call to make substantial changes and a chance to put those changes into effect. The approach taken to madness is crucial for deciding where that experience will ultimately lead, whether its potential for positive change will be realised and whether a ‘breakdown’ will eventually become a ‘breakthrough’.

When writing about the transformative potential of madness, many authors mention taking responsibility for themselves and for their lives. The right to make our own choices and to take risks is seen as vital for personal growth and achieving change. Such processes of change are – however – not understood as fixed or as having a designated (happy) ending. Many accounts describe ever-evolving ways of coping with and understanding madness.

Aside from the transformative potential for the individual, the authors also make clear that changing the ways in which we deal with our own and with other people’s madness could have equally transformative effects on the communities where we live. In this context, questions about our own agency and about taking responsibility for enabling such changes are all posed in the first-person plural.

That madness can lead to positive life changes and that the way that we approach it – both individually and as a society – plays a decisive role in bringing about these changes, are certainly points of agreement. However, various attempts to capture how these processes work exactly, to integrate this knowledge into existing concepts of ‘help’ and treatment and even to invent new ones, have largely failed to change the dominant discourse about madness. There is increasing recognition and analysis of the reality that first-person knowledge is being appropriated and co-opted in ways that do not alter but preserve the status quo in psychiatric research and practice (Russo and Beresford 2015, Beresford and Russo 2016a, Penney and Prescott 2016, McWade 2016). Fabris (2016) reflects on possible ways to avoid these scenarios. He suggests that “our ideas about how to move to less coercive ways, even ‘systems’ of interaction, cannot be packaged; they are perpetual beginnings” (p. 105).

In light of all this, I would like us to further consider some key questions: *What principles and values in our approach to madness could allow us to preserve – and make full use of – its potential?* What can we do at the same time in order to prevent our stances from being understood and applied as the latest methods and techniques? How do we “pull our dreams out of each other in as many languages as we can find to describe them”? (Shive 2008, 186)

7. Concepts of madness

Several authors explain the framework that they apply in their work or even give a name to their own approach or model of madness. There is significant overlap across the concepts and frameworks presented. While the authors use different names and prioritise different aspects of madness and distress, their understandings do not oppose but rather complement and echo one another. I believe that these concepts speak to other findings of this inquiry and affirm that "having our strong body of knowledge, framed outside a medical model, can be better than seeking an overarching monolithic theory which can overshadow us" (Beresford 2015, 258). For this reason, instead of attempting to merge these models, I wanted to explore with my interview partners *what they consider to be the central features of an approach to madness based in first-person knowledges and what could be the best way to work together in that direction.*

Appendix C: Participant information sheet

College of Health and Life Sciences

Department of Clinical Sciences

Towards a first-person defined model of madness

Research Participant Information Sheet

This is an invitation to take part in a survivor-controlled research project, which I am undertaking as part of my PhD studies. The term ‘survivor-controlled’ reflects the understanding of the roles in the research process, which is quite different from the understanding in clinical studies. There are two central aspects to this approach: the first is that as a researcher, I am not neutral about the topic under investigation because my own experiences of madness and psychiatric treatment also inform my work. The second is that being a participant in this study does not just mean giving information; it also involves taking part in the next stage of making sense and drawing conclusions about the information collected.

The deliberate use of the term madness in this PhD is an effort to reclaim and re-appropriate this human experience from the framework of individual pathology. It also speaks to the fact that *madness* is a term of choice in some parts of the political movement of people who have experienced psychiatric treatment and altered states of mind.

Please take some time to read over the information below before deciding whether you would like to take part in this study. This document outlines the background and purpose of the study as well as what it will involve. If anything is still unclear or you would like more information, please feel free to contact me at any time. I am happy to answer any further enquiries.

Background and aim of the study

This study explores the possibility of coming to a new understanding of madness and distress rooted in the knowledge of the people who go through these experiences. Based on the analytical work of authors who identify as mental health service users/psychiatric survivors, this project investigates the potential emergence of a social model of madness. It is grounded in the values and principles of survivor-controlled research in mental health, and at the same time, aims to help develop a theoretical framework to underpin that research approach. This project is designed as a small-scale, systematic quest for a framework which is valid for and adequate to the complexity of experiences of madness. While aiming to move us towards this framework, this inquiry does not seek in any way to establish some ultimate model which will finally and completely capture all our diverse and unique experiences.

The findings of this research will not be its most important outcome; the research process itself is at least equally important. Through that process, I aim to explore not only the accumulated knowledge of authors who identify as mental health service users/psychiatric survivors, but also the very possibility of a collective process of advancing our own knowledge. This study will therefore serve as a methodological and ethical example of the value of interaction, shared identity and dialogue in generating knowledge and understanding complex human experiences. Such an approach is directly opposed to the trends of observation, measurement and interpretation that dominate current mental health research.

Methodology

The study has three main phases:

1. Analysis of a selection of research reports, conceptual and analytical work and individual narratives written by service users/survivors
2. Individual interviews with some of the author experts (maximum 20)
3. Expert focus groups with interview partners from phase 2 (three groups with 6-7 participants per group)

So far, the first phase of the study has been completed, and I am inviting you to join the study in phases 2 and 3.

Phase 2 (interviews) will continue the work that I started when analysing the published work of user/survivor authors. The interviews aim to collect more opinions and information that can move us towards advancing our own non-clinical understanding of madness. The individual interviews will take place between September and December 2016.

The focus groups are meant to improve and deepen the initial analysis of the interviews done by me. Your participation in a focus group is just as important as your participation in the interview. The focus groups are planned for the period between February to April 2017. Each focus group will have the same topic guide and involve the presentation and discussion of the findings from the interviews.

Why have I been invited to take part?

I am inviting you to participate because you are an author and/or activist whose work is relevant to the topic of this study. You are invited on the basis of your expertise and your contribution to the international movement of people with psychiatric experience and our knowledge base. I am looking for expert participants who are interested in contributing further ideas and thoughts within a collaborative research process. Due to the many constraints of the study, a maximum of 20 people will take part.

As participation is entirely voluntary, it is up to you to decide whether or not to join this study. If you do choose to take part, you will receive an interim report on the findings from phase 1. You will also be given a consent form to be signed by both you and me. You are free to withdraw at any time without giving a reason.

What does taking part in this study involve?

Your participation involves an individual interview and taking part in one focus group. You also have the option to give feedback on the draft report of findings from phases 2 and 3.

The interview will take place via Skype or phone (landline). If you are uncomfortable with this, we may be able to arrange an interview in person but depending on the geographical distance between us, this will be subject to possibilities arising.

The interview will cover approx. 10 topics emerging from my analysis of the published work of users/survivors (phase one). Before the interview, you will receive an interim document from me summarising the phase one findings, but reading this is not essential for your participation in the interview. The interview topics will relate to your work to date and your opinions about social approaches to madness. When giving your perspective, you may want to mention your personal experiences, but they are not included in any of the interview topics. The main focus of the interview is your opinions, and I will not specifically ask about your personal experiences. The estimated duration of the interview is 1 to 1.5 hours. Within two months of the interview, you will receive an interview transcript for you to check and amend as you wish.

Due to the geographic spread of the participants, the focus groups will be held via Skype or Google Hangouts. A maximum of 7 participants will be invited. The findings from the individual interviews will be presented and discussed. The estimated duration of each focus group is 2 hours.

When considering whether to take part in this study, please think about *both* the interview and the focus group. The latter is an essential part of this research approach: it is a chance for everyone to learn about the findings from the interviews and discuss and analyse those findings in more depth together. Agreeing to join this study as a participant means that you are willing to take part in both an interview and one focus group.

Finally, I will send the draft report of findings from the interviews and the focus groups to all the participants. Your comments and/or general feedback will be most welcome but not obligatory. I would, however, explicitly ask that you not share the materials I send you with anybody as they will be part of a work in progress and still unpublished at that stage.

Are there any potential disadvantages and risks?

One risk is that the people involved (the other participants including myself as a researcher) will have very different opinions about the topics under investigation and because of this, you will not be happy with the overall outcome. I hope that the focus groups will help us achieve common ground on some of the values and principles that we all consider important for connecting and advancing our collective knowledge of madness.

Neither the interview nor the focus group discussion has the goal of inquiring into biographical information. At the beginning of the focus groups, all participants will be asked to respect confidentiality. This will be part of the ground rules that seek to create a safe and non-judgemental space for everyone.

If you experience any distress during the interview or the focus group, you will, of course, be free to discontinue at any time. If you wish, we will also look together for the best support options for you.

What are the possible benefits of taking part?

The experience of jointly developing a user/survivor-defined framework for thinking about and understanding madness may have benefits for all our future work in this field. I hope that the overall experience of participating - both in terms of the process and its findings - will be rewarding and also inspire and stimulate your own projects.

Will my participation in this study be kept anonymous?

This is entirely up to you. In conventional research, participants are assured anonymity. This means that they contribute to research without their comments being traceable back to them. You can choose to remain anonymous in this research and/or give yourself a pseudonym. But you can also choose not to stay anonymous. Since you will be contributing your ideas and thoughts, I would be happy to acknowledge your name in the report and all related publications. This means that the ideas and thoughts you contribute will be directly attributed to you as may well be direct quotes from what you've said. These will be permanently accessible to the public, both when the PhD and other associated publications are completed, as well as through conference presentations. The choice about remaining anonymous or not is entirely yours and will not affect your participation in the study.

You may also defer your decision about whether or not to stay anonymous. The latest time for your decision is one month after you receive the draft of the final report.

I am not in a position to give an absolute guarantee about the confidentiality of any personal information that is shared in the focus group since this will depend on all participants' respect for confidentiality. However, I will include this topic in the ground rules for focus groups and do my very best to convey its importance.

What will happen to the results of the research study?

The findings from this study will be part of my PhD thesis to be submitted to Brunel University by the end of 2018 at the latest. After obtaining a PhD, I plan to adapt this thesis into a book and disseminate the findings in a range of publications with the aim of increasing the visibility and influence of survivors' own knowledge.

Who is organising and funding the research?

This research is being overseen by my PhD supervision team at Brunel University London, Department of Clinical Sciences: Prof. Peter Beresford, Dr. Elizabeth McKay and Dr. Debbie Kramer-Roy. The project is entirely self-funded. Because of this I am not in a position to offer any reimbursement for your contribution.

Who has reviewed the study?

This research has been approved by the Research Ethics Committee of the Department of Clinical Sciences, Brunel University. In case of any query or complaint, please contact the Chair of the Committee via john.barker@brunel.ac.uk

Contact persons for more information

Jasna Russo, Email: Jasmina.Russo@brunel.ac.uk
Peter Beresford, Email: Peter.Beresford@brunel.ac.uk

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Thank you very much for considering taking part in this study. If you would like to participate, please keep this Information Sheet and the signed consent form for your records.

Appendix D: Participant consent form

College of Health and Life Sciences

Department of Clinical Sciences

CONSENT FORM

‘Towards a first-person defined model of madness’

Please initial the appropriate box	YES	NO
Have you read the Research Participant Information Sheet?		
Have you had an opportunity to ask questions and discuss this study?		
Have you received satisfactory answers to all your questions?		
Who have you spoken to?		
Do you understand that you have a choice in regard of whether you want your participation to be anonymous or not?		
• I wish to stay anonymous.		
• I wish my real name as a study participant to appear in the report and any related publication.		
• I wish the pseudonym to be used for me in the report and any related publication.		
• I will inform the researcher about my decision regarding my anonymity after I have seen the draft final report.		
Do you understand that you are free to withdraw from the study:		

• at any time		
• without having to give a reason for withdrawing		
Do you understand that the participation in the study consists of both the interview and one focus group?		
Do you agree to your interview being recorded?		
Do you agree to the focus group discussion being recorded?		
Do you agree that the words you say may be used as quotations when the study is written up or published?		
Do you agree to take part in this study?		

Signature of Research Participant:

Date:

Name of the Research Participant in Capitals:

Name of researcher:

Signature of researcher:

Appendix E: Interview topic guide

College of Health and Life Sciences

Department of Clinical Sciences

Towards a first-person defined model of madness

Expert interviews: Topic Guide

The interview is semi-structured. The following list sets out the main topics to be covered with some prompts:

1. **The findings from the analysis of publications in phase 1**
    - Did you have a chance to read the interim report from phase one? If yes, is there anything you would like to say about it?
    - How do you feel about the way your own work was included/presented?
    - Are there aspects of your own work that you find relevant to the topic and that weren't included? Would you like to say something about them?

2. **Understandings/explanations of madness**
    - Do you see some common threads in the work of authors included in this research? What do you think about the prospect of connecting our work something more coherent? *Alternatively: Do you see some common threads in the variety of individual experiences/explanations of madness? What do you think about the possibility of connecting different individual explanations into something more coherent?*
    - Do you think such efforts make sense? What might be the benefits of these efforts?
    - Do you see any disadvantages in this kind of project?

- You might remember from the report Louise Pembroke's words that it is unhelpful and damaging to 'group people's distress'? What do you think about adopting that kind of principle when moving towards our own framework?

3. **Language for talking about madness**
    - What do you think is the most important thing about the way we use language when talking about madness?
    - One question that emerged from my work with written sources is - How do we create a discourse of madness that does not 'other' this experience or draw another line between madness and sanity? What are your thoughts on that?

4. **Inequality and madness**
    - As we know the experiences of madness intersect with the different positions we occupy in society in regard to race and ethnicity, class and gender. The publications included in the first phase of this research were English language works only and their authors are predominantly white. Besides this being due to many constraints of this study, this disproportion also mirrors the systems we live in and the reality that among other things not all of us have the same opportunities to work and/or be published. So being aware that there is already a significant bias built into this project I wonder how can we disrupt it and proceed without producing more inequalities and injustice. What are your thoughts on how can we ensure that our work encompasses as many different realities as possible and that its outcomes are widely owned?

5. **Transformative potential of madness**
    - What do you think about the potential of madness to become a transformative experience, capable of improving people's lives?
    - Moving away from the meanings of madness for the individuals who go through these experiences, do you think that madness might hold meaning for the society that we live in? What are your thoughts about its transformative potential on a more general/collective level?
    - Can you imagine the interplay between madness and society if there were no biomedical approach and institution of psychiatry to govern it? How could that be like?

- Are there limits to acceptance of madness and are these any different from the other limits that we inevitably pose and negotiate with each other?

6. **Social model of madness**
    - What are your thoughts on the possibility of users/survivors jointly developing a model of madness based on our own experiences?
    - What could be the advantages of such project? Are there any disadvantages?
    - Do you have any thoughts about a suitable methodology/approach to developing our own model?
    - Can you suggest some core values and principles for this model? Are there any other features you consider important?

7. **Social model of disability**
    - Are you familiar with the social model of disability? What are your thoughts and feelings about this model?
    - How do you see the prospects of applying the social model of disability to madness?

8. **Further thoughts and expectations of this study**
    - Have you come across the field of Mad Studies? What is your understanding of/feeling about Mad Studies? Do you see this project in relation to that field?
    - What are your expectations of this study? What do you think should come out of it?
    - Is there anything else that you would like to add?

Appendix F: Interview analysis - coding frame

NODE	Sources	References
I. Interim report		
1. Familiarity with the report?	12	12
2. Inclusion of participant's own work	8	9
3. Approvals	9	11
4. Further thoughts and comments	8	13
5. Criticism	3	4
6. My responses	1	2
II. Common threads in personal experiences		
7. Questioning whether this search is a good idea	8	9
8. Commonalities vs. categories	2	2
9. Individual vs. common in experiences	2	3
10. Common ground in our work	3	3
11. Need for language	1	1
12. Need for further work	1	1
13. Experiences of surveillance	1	1
14. Values attached to categories	1	1
III. Language		
15. Shortcomings of language	1	1
16. Power of words	5	5
17. De-medicalising language	2	2
18. Being non-prescriptive	1	1
19. Othering and non-othering language	10	13
20. Compromising in communication	1	1
21. Importance of the first-person voice	3	3
22. Importance of variety	2	2
23. Multilingualism	1	1
24. Need to refine language	1	1
25. Need to resist definitions	1	1

26. Privilege and exclusion	1	1
27. Self-identification	3	3
28. Use of ordinary language	1	1
IV. Explanations of madness		
29. Against any explanation	3	5
30. Need for a counter-explanation	6	7
31. Against categorisation	2	2
32. Against a unitary explanation	3	3
33. Moving away from binary logics	3	3
34. Blackness, whiteness and the role of research	1	1
35. Deconstruction of shame	1	1
36. First-person vs. third-person knowledge	1	1
37. Focusing on context	2	2
38. Casting the biomedical model aside	3	6
39. Models vs. values	1	1
V. Intersections of madness		
40. Race vs. racialisation	1	1
41. Injustice related to class and gender	2	2
42. White dominance in the survivor movement and research	3	6
43. Safe spaces	1	1
44. Naming and addressing inequalities	6	7
45. Moving beyond written sources	6	7
46. Not talking on behalf of anyone else	1	1
47. Not assigning identities to anyone	1	1
48. Taking responsibility for exclusions	3	3
49. Focusing on commonalities	3	3
50. Working together, drafting principles together	1	2
VI. Meanings of madness		
51. Individual transformation	8	9
52. Meanings related to society and social change	8	9

53. Impacts of our knowledge on mainstream	2	2
VII. If there were no psychiatry…		
54. Role of collective fear	2	2
55. Lack of readiness of society	2	2
56. A better world	3	3
57. Re-learning to care for each other	4	5
VIII. Limits to the acceptance of madness		
58. Desire for no limits	2	2
59. Equal treatment and same limits for everyone	6	6
60. Anarchy, policing and self-interest	2	2
61. Communicating and just being with	2	2
62. Need to undo images of madness	3	3
IX. Our own model		
63. Core values	10	13
64. Difficulties	1	2
65. Methodology	4	6
66. Room for variety	3	4
67. Need for our own model	3	5
X. Social model of disability		
68. Familiarity with the social model?	10	12
69. Applicability to madness	10	14
XI. Mad Studies		
70. Familiarity with Mad Studies?	9	9
71. Feelings and/or opinions	6	9
72. ‘Mad’ as a problematic concept	6	9
XII. Feedback		
73. About the interview	6	8
74. About this research	3	6
XIII. Expectations of this study and comments		
75. Need to continue this work	8	9
76. Need for wide non-academic dissemination	6	9

77. Caution re. cooptation	3	3
78. Contributing to ‘official’ knowledge	2	2
79. Continuing to expose the biomedical model	1	1
80. Addressing racism	1	1
81. Allowing room for conflict	1	1

Appendix G: Brunel University London Ethics Approval

College of Health
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Department of Clinical Sciences

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24 June 2015

Proposer: Jasmina Russo

Title: Towards a first-person defined model of madness

Reference: 15/05/PhD/06

LETTER OF APPROVAL

The Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee’s earlier review of the above application.

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.

Please note that:

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the Research Ethics Committee
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.
- The Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.
- may not undertake any research activity if you are not a registered student of Brunel University or if you cease to become registered, including abeyance or temporary withdrawal. As a deregistered student you would not be insured to undertake research activity. Research activity includes the recruitment of participants, undertaking consent procedures and collection of data. Breach of this requirement constitutes research misconduct and is a disciplinary offence.

Dr Alexander Nowicky
Research Ethics Committee of the Department of Clinical Sciences