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THE BRITISH MENTAL HEALTH SERVICE USER / SURVIVOR MOVEMENT AND THE EXPERIENCE OF MENTAL DISTRESS

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Esta dissertação não inclui as críticas e sugestões feitas pelo júri

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Para o Lucas,
que não é nada menos
que a minha vida.

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ABSTRACT

The present study examines how engaging with the British service user/survivor movement (SUSM) affected the experience of mental distress of mental health service users. Based upon interviews with participants of this movement, we have analysed their personal experiences of mental distress; the process of engagement with the SUSM and their accounts of the movement's dynamics; the effects of the engagement with the SUSM to their experiences of mental distress. Our results indicated that engaging with this movement allowed for participants to construct more positive meanings for their experience and reconstruct identities. The engagement with the movement also allows for them to develop a new social role. Pressure to conform, internal conflicts within the SUSM and confrontational relations with external actors, however, cause detrimental effects. Overall, engagement has produced a level of subjective transformation to those involved in relation to their mental distress.

Keywords: Mental distress, social movements, service user / survivor movement, UK, health social movements, experience.

RESUMO

O presente estudo dedica-se a compreender como o engajamento com o movimento britânico de usuários/sobreviventes (SUSM) afetou a experiência de sofrimento mental dos usuários participantes. Baseado em entrevistas com ativistas do movimento, nós analisamos suas experiências pessoais; o processo de engajamento com o SUSM e seus relatos da dinâmica do movimento; e finalmente, os efeitos do engajamento com o SUSM para suas experiências de sofrimento mental. Nossos reultados indicaram que o engajamento com o movimento possibilita aos participantes construir sentidos mais positivos para o seu sofrimento mental e reconstruir suas identidades. O engajamento com o movimento também permitiu a eles desenvolver um novo papel social. A pressão grupal e conflitos internos ao SUSM, assim como as relações de confronto com atores externos, no entando, causa efeitos prejudiciais. Em geral, o envolvimento produz um nível de transformação subjetiva para os envolvidos em relação ao seu sofrimento mental.

Palavras-chave: sofrimento mental, movimentos sociais, movimento britânico de usuários/sobreviventes, Reino Unido, movimentos sociais na saúde, experiência.

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INTRODUCTION

Health has become a contentious subject. If healthcare was once determined exclusively by state and professional interests (somewhat guided by scientific knowledge) now the public concerned is increasingly involved in decision-making processes, either through political pressure or through legally sanctioned means. The roots of this change can be located in the transformations of the social role of the "patient" through a complex process of negotiation, conflicts and ruptures, all of which have essentially shaken the previous, more stable configuration of forces.

"Health social movements" have become important collective actors and have had significant impact over health practices and policies (Brown & Zavestoski, 2004). This trend has not gone unnoticed by social scientists, who have been dedicated lately to the study of this topic. Even though they recognise that this "politics of vitality" produces a wide range of effects, as they challenge conventional ways of managing disease and bodies, identities, moralities and subjectivities (Landzelius, 2006), there has been little interest in understanding their subjective effects to people who experience illnesses or health conditions. Likewise, studies about the experience of illness are profuse, but have primarily focused on individual or interpersonal aspects and generally ignored the impact of broader social structure aspects (Pierret, 2003, Brown et al, 2011). These authors argue that the impact of social structure, including the effect of social movements to illness experience is "the problem to be analysed" (Pierret, p.17).

Inserted in this context, we propose to analyse the effects of the British mental health service user / survivor movement (SUSM) to the experience of mental distress. Even though we don't treat mental distress as an illness[1], we part from the hypothesis that the experience of mental distress is also transformed by this health social movement, which is dedicated to challenging mental health practices.

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[1] In this Introduction we will address this subject in more detail.

The British service user / survivor movement

Social movements led by people who have experienced mental distress and have been through the mental healthcare system emerged notably in the 1970s. They have developed specially in the USA, Canada, UK, Netherlands and New Zealand, as a response to perceived injustices and significant power imbalances in the mental health system (N. Crossley, 2006). In the UK, survivors have defined[2] the British SUSM as:

> a term used to describe the existence of numerous individuals who speak out for their own rights and those of others, and local groups and national organisations set up to provide mutual support or to promote the rights of current and former mental health service users to have a voice. (Wallcraft, Sweeney & Read, 2003, p. 3).

The British SUSM is represented by a number of organisations and local groups, led by survivors, who not only protest and campaign for mental health issues, but who also provide self-help and support, participate in consultation processes, advocate for groups and individual's rights, perform educational and training activities and engage in scientific research (Wallcraft et al-, 2003).

The experience of mental distress

There are many ways to comprehend mental health problems. They can be viewed as a consequence of a chemical imbalance in the brain, as learned behaviour or result of distorted beliefs, as deriving from unconscious processes anchored on childhood experiences, as the result of the interplay of social institutions, or as a complex system that involves all of these instances. For some, they are illnesses; for others, they may not be viewed as an illness at all. Anti-psychiatrists sustain that mental illness was an idea created to maintain social control over individuals that portrayed deviant behaviour, or a way of maintaining social order (N. Crossley, 2006).

We won't use the notion of "mental illness" in this study, since we agree that one

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[2] This definition was created by service users researchers, who have later consulted with a wide number of service users involved with SUSM groups if they agreed with this definition, which for the most part they did.

cannot say that mental illnesses are an undisputed reality. The term “mental distress” is generally preferred by the SUSM, because it is a term which does not refer to being ill or having a disorder, but to going through a troubling, confusing period that causes suffering. Mental distress may include symptoms which would usually lead to a diagnosis, such as anxiety, hallucinations or depressed humour, but the notion does not address the barrier of normal and pathological.

We understand that experiences of mental distress are not shaped only by individual, biological or interpersonal circumstances, but also culturally, spatially and historically, by a number of social actors and their interplay, one of them being social movements, and increasingly so. Comprehending mental distress from this point of view allows us to address its interaction with social movements, which is our intent.

Objectives and methodology

The overall aim of this study is to *describe and analyse how has the British service user /survivor movement affected the experience of mental distress of service users / survivors currently or previously engaged in the movement.*

As it can be noticed, we have decided to analyse the experience of service users who are (or were) involved with the movement, instead of service users in general. The direct relationship between activist and SUSM provides us with a clearer view of social movements' effects, as they are directly experienced by participants. Addressing a wider effect would involve an extended insertion into the movement, which we weren't able to perform.

The empirical research was conducted through in-depth interviews with 12 participants, who defined themselves as a part of the British SUSM and who had previous experience of mental distress. They were recruited through two national user-led organisations. Based on grounded theory principles, we analysed the transcribed interviews in order to answer to the aim of the study. Due to limitations of the methodology, we suggest that our results should not be subject to generalisation. They can, however, provide some useful directions for future research on the subject.

Chapter plan

This dissertation is divided in two parts. Part I refers to theoretical review of the main topics that support this research. Part II is dedicated to explaining our methodological approach and presenting the results from the data analysis.

Part I is divided in three chapters. Chapter 1 and 2 are contextualisation chapters, as they discuss the overall social context in which our study is inserted. Chapter 3 is a conceptual chapter, dedicated to the review of some theoretical concepts and previous research that can support the analysis.

Chapter 1: Examines the socio-historical process that led to increased patient protagonism and to the emergence of health social movements. We also define social movements in general and in health, and review some of the literature on the subject.

Chapter 2: The focus is narrowed from health to mental health, and from the international scenario to the British setting. Here we provide a brief history of psychiatry and mental health policies, leading to the emergence of the British service user / survivor movement. We also describe the SUSM through its main organisations, inserted in a historical perspective.

Chapter 3: Reviews the concepts of experience and identity, also relating them to health and mental health. Illness experience and politicised collective identity are some of the specific concepts we discuss. Finally, we review the limited amount of research on experience of mental distress and its relation to social movements.

In Part II the empirical part of this research is presented. Four chapter compose this part. The first, dedicated to methodology and the other three to the result analysis.

Chapter 1: Explains methodological procedures. Details methodological design, characterises the sample of participants, discusses interview procedures, data analysis, limitations to this study and ethical considerations.

Chapter 2: Discusses, from our material, the experience of mental distress, emphasising the construction of meaning, the social experience of mental distress and the effects to identity.

Chapter 3. Analyses participants' process of engagement with the SUSM, specifically focusing on the role of politicised collective identities to the engagement process. Also examines participants' forms of engagement with the movement and the expansion of the “service user role”. Moreover, in this chapter we also look into the different political positions assumed by survivors, identifying the main sources of conflicts within the movement, which are entwined with the experience of mental distress.

Chapter 4: Here we try to answer our research question, focusing on the forms that the SUSM has affected the experience of mental distress of participants. Three main categories of effects were identified: changes in the meaning of mental distress, on the social experience of service users and on their personal identities.

PART I

THEORETICAL REVIEW

Chapter 1:

PATIENT PROTAGONISM AND HEALTH SOCIAL MOVEMENTS

In this chapter, we will first address the transformations in patienthood, attempting to trace the social changes related to this transformation and the issues that surround it. We will then follow the emerging forms of patienthood, linked to a new language and terminology, behaviours and a different relation to medicine, science and the public sphere.

We will then examine the emergence of health social movements and patient protagonism in collective action. Social movements will be briefly defined and characterised, as to share with the reader the underlying conceptions that allow one to speak of "health social movements" as a category, and of the British mental health service user / survivor movement (SUSM) particularly. Thereafter, we will present some theoretical concepts and empirical research that can be useful to understand health social movements as a form of collective action to which the illness experience is central.

1.1 Metamorphoses in the category of the "patient"

Relationships between patients and the medical profession have been subject to significant reconfigurations over the last decades. If the patient role was once defined by a delegation of power in a paternalistic relationship, now patients may distribute themselves in a myriad of patient-related roles, identities and behaviours. This transformation cannot be reduced to a simple evolution - from a passive patient to the oxymoron of an "activist-patient" or an "empowered patient". It is more appropriate to speak of a process within which the patient role becomes more and more *complex*, as tensions are made apparent and new possibilities are constantly being forged. Health-related activism, or health social movements, come to existence within this context, so it seems appropriate to address these transformations before looking into these movements and their characteristics. It will be, however, a brief and summarised overview, where we will be forced to reduce historical accounts to fit a simplified scheme.

The emergence of the modern state and its need to increase and legitimise control over the population are on the roots of the creation of social and health policies. The gradual emergence of a "society of individuals" (Castel, 2003, p.12) was the product of the disaggregation of traditional communities and the gradual overthrowing of the religious order, all propelled by the state. As the state attempted to structure social relations in consequence to the dissolution of communities, it further disconnected individuals from their belonging communities, and accelerated disaggregation (Kaufmann, 2005). Social and health policies were the locus of biopower - strategies and techniques for achieving subjugation of bodies and the control of populations (Foucault, 1978), through which the state was able to increasingly shape and restructure social relations.

This process is not only associated with the creation of the national state, but also with the gradual development of capitalism. In a later period, when capitalism had completely overthrown the previous hierarchical order and achieved enormous success with industrialisation, this need to increase control over the disaggregated population acquired new dimensions. The social unrest provoked by the mass pauperisation of urban population and the posterior emergence of workers' movements turned it into a critical mission. The first initiatives of social insurance, which would form the basis of the welfare state, were mainly aimed at creating a healthy and pacified working class (Paquy, 2004), in a framework of state-promoted industrial development. The later, 20th century welfare state had these concerns in mind as well, as the welfare state thrived in the post-WWII context of national reconstruction, but it also responded to political transformations and to the increased need, not only of workers, but of mass consumers (Woodard, 1962; Esping-Andersen, 1990).

This awareness of health and welfare historical roots as instruments of control allow us to understand the construction of the "patient" and of recent transformations in these power relations. Patients were, until a few decades ago, exactly that – people who patiently[3] awaited and trusted their bodies to medical expertise. Parsons' (1951/1991) theorisation of the sick role provided a sociological framework for this earlier configuration of forces. He describes sickness as a deviation from the norm, and as such it must be regulated by a mechanism of social control to maintain social order. The physician is the agent of social control, with a mandate to reinstitute the patient to normality and preserve the social system. The patient is expected to conform to the "sick role", which is a set of rights and responsibilities accorded to the sick person. One of the obligations of the sick is to pursue

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[3] Interestingly, the Merriam-Webster dictionary defines the adjective patient as "bearing pains or trials calmly or without complaint"

and accept competent professional help, since it is up to the doctor to discriminate sick people from malingerers, not extending the privileges of the sick to the latter. The doctor-patient relationship is, characterised, according to Parsons, by an asymmetry of knowledge and power, in favour of the doctor. The dependent, helpless sick puts himself under the care of the all-knowing doctor – that is the parsonian image of the patient, and it fits very well the period in which it was postulated. During this "golden age" of Medicine (Burnham cited by Betz & O'Connell, 2003), medical doctors were highly trusted and medical science was perceived as being in constant evolution, inevitably leading humanity through a path towards a disease-free world.

However, several factors have led to a gradual erosion of trust in medicine, which turned the paternalistic relationship described by Parsons unsustainable. Population mobility, bureaucratisation, professionalisation and specialisation may be accounted for the decline of the friendly "community doctor" (Betz & O'Connell, 2003). As the full transition to the society of individuals is completed (Kaufmann, 2005), communities no longer serve as a third-parties who mediate the doctor-patient relationship. It gradually becomes an impersonal, market-mediated relationship – one that can no longer be blindly trusted, but is nevertheless necessary. Patients, then, felt trapped in a relationship they could neither alter nor do without Accountability becomes a new word in patient's mouths, and doctors are viewed as "self-interested vendors of a service, and as unworthy of trust as merchants" (Betz & O'Connell, 2003, p.325). Patients try to rebalance this distrustful relationship by actively participating in consultation and treatment, demanding more information about alternative therapies and costs, more precise standards to evaluate results of treatments and compensation when injustice is perceived.

Another important factor for change was the advent of chronic disease, by definition health disorders that that medicine cannot cure, as a problem that afflicts an enormous part of the population. Whilst patients who are struck by acute disease enter the clinical encounter within a context of crisis, favouring a "delegation mode", chronically ill patients will more commonly be subject of regular care for years. Their relationship with their physicians becomes very vulnerable to the frustrations that accompany the care of chronic disease. At the same time, the chronically ill are also summoned to perform themselves a series of medical acts and to make their own treatment choices. They equip themselves with all forms of knowledge available, thus entering a "negotiation mode" that becomes fertile ground for collective action (Barbot, 2002).

The civil rights movement and the so-called "new social movements" of the 1960s collaborated to diffuse a culture and discourse of human rights and people's empowerment that made it possible to question authority in ways that weren't previously imaginable – what Scambler & Kelleher (2006) call a "culture of challenge". New social movements, according to Melucci (cited by Barker & Dale, 1998) are not oriented toward the conquest of political power, but rather toward the control of a field of autonomy or of independence - a revolt against change directed from above, "where the body is a cultural locus of resistance and of desire, opposed to rationalisation" (p.70). In other words, late-modern society would cry out for individual's rights over their bodies in their minds, rejecting state and nearly every kind of authority who would interfere with their liberties.

Transformations in patienthood were registered by sociologists throughout this period (e.g. Coser, Fox, Freidson, Goffman, Roth). They noticed how patients were becoming more active, questioning the legitimacy of medical decisions and amounting to conflict in the doctor-patient relationship (Barbot, 2006; Brown et al., 2011). The perspective of an active, negotiating patient, gradually emerged within social sciences, later originating a line of research on chronic illness that flourished throughout the 1980s and 1990s. Authors like Bury (1982), Charmaz (1983) and Kleinman (1988) have demonstrated how patients learn to manage their illnesses, how they actively try to make sense of their experience and the consequences it has to their relationship with their carers.

Even though chronic illness was acquiring significant prevalence, the idea of an epidemiological transition proved to be only partially correct, as since the 1970's the world has watched the emergence of new infectious diseases and the re-emergence of some which were previously controlled. The HIV/AIDS epidemic was surely an important turning point. AIDS was not only a deadly disease that challenged medical science's response capacity, but this epidemic was also responsible for a simultaneous radicalisation and mass dissemination of patients' movements. The HIV/AIDS movement were responsible for creating new mobilisation strategies and achieved tremendous success with their activism (Barbot, 2002). The balance of power is, thus, completely shaken by these latest events. Both medicine and patients are changed, as they adapt themselves to these new conditions.

Patients were, for the first time, individually and collectively challenging the established powers of medicine and public health. This new, unstable configuration of forces was incorporated by the state through neo-liberal policies that, since the late 1970s, came to dominate the global North. In a context of economic crisis, welfare and health services were reshaped, which happened in the UK through a massive reform of the National Health Service (NHS). Under Conservative government, Britain opted increasingly for a mixture of privatisation and marketisation (Rogers & Pilgrim, 1996). The idea was, rather than privatising the NHS (to which the public opposed), the government would introduce an internal market, providing cost-effective and quality services that would be tailored to the customer's needs. Patients were reconceptualised in policy documents as consumers*,* highlighting managers' accountability for improving the quality and responsiveness of services as seen by patients. While policy was in essence driven by cost-containment (Baggott, Allsop, & Jones, 2005) and the state's wish to break power monopolies of health professionals (Barnes & Bowl, 2001; Clarke, 2007) it also had an effect to the relationship of patients and practitioners within the NHS, with the balance tipping a little bit more to the patient side. Public involvement has, since then, become embedded in the public health system in the UK and in other countries.

Overall, transformations in patienthood have been significant and are still an ongoing process. The emergence of the patient as an empowered actor is a recent achievement and its consequences are still unclear. Nevertheless, this phenomenon shouldn't mask the fact that many people with health problems or illnesses are still very much disenfranchised and remain voiceless in their clinical relationships or within public health services. Not infrequently, people from the lower classes and ethnic minorities are significantly under-represented in this sample of outspoken, rights-conscious patients, and their health problems remain neglected. It is also a phenomenon that is stronger in industrialised developed countries and is not representative of world-wide patients' experiences.

A note on terminology

As Barnes & Bowl (2001) discuss, controversies on terminology take place because language is a "site of struggle" (p.2). The social processes we have just described are related to the abandonment of the term *patient* in health-related activism, rejected because of its connotations of passivity and powerlessness in the therapeutic relationship. A myriad of terms have been used since then, all of which carry, within their meanings, the different contexts that produce them.

Service users is a term that emerged from welfare politics, and is related to the use of public services. It is criticised by a fraction of health activists, which view it as presenting people in a passive relation to state provided services (Barnes & Bowl, 2001). While this contention is acknowledged, it also has served as a unifying concept which has helped groups to form a solidary collective, and has been employed widely in the UK (Beresford, 2005).

Another term that has emerged in the 1980s mental health movement is *survivor*. The activists that adopt this term emphasise their rejection of psychiatry, as they consider themselves to have survived their damaging experience in mental health services.

The term *consumer* is related to a specific context of neo-liberal politics. They introduced the language of consumerism corresponding to the ideals of choice, independent decision-making, active information-seeking behaviour and personal risk management (Baggott et al, 2005). The term consumer is, however, a label that has not been thoroughly accepted by the British public (Clarke, 2009) whilst it has been openly rejected by the British mental health service user / survivor movement (Barnes & Bowl, 2001). The argument, similar to the discussion around "using services", questions the rationale of choice and decision-making when coercion may be used against people with mental health problems. They also question the alleged "value" of the services offered to them (Baggott et al).

In this study, we will employ the four terms according to their contexts. "Service user" and "survivor" will be employed alternatively to refer to the people engaged with the service user / survivor movement (SUSM). The term "service user" may also refer to other people with mental health problems who are not part of the movement, but who engage with mental health services. We will employ "patient" and "consumer" in a limited form, only when addressing the context in which they are inscribed (e.g. the clinical relationship or the framework of consumerism).

1.2 The emergence of Health Social Movements

Defining social movements

Having a particular social movement as the focus of our investigation, it becomes essential to define what constitutes a social movement. There is a field of Sociology dedicated to the study of social movements, composed by different schools of movement analysis who not always agree when it comes to defining social movements[4]. In view of this profusion, we will not attempt to deliver a single, unified definition. It appears that putting in relief the various aspects that make a social movement will be more useful to guide our analysis than simply choosing one of the definitions, as partial as they usually are.

First, it is probably consensual among scholars that social movements are a form of *collective action*, in the sense that they involve social agents working together in various ways, sharing a common project (N. Crossley, 2002), or applying pooled resources to shared interests (Tilly, 2001). Not all collective action, however, qualifies as a social movement. Crowd behaviour, such as mass hysteria or panic, can be a form of collective action, but lack some other important attributes to be a social movement.

One thing that distinguishes crowds and social movements are that the latter, according to Blumer (cited by N. Crossley, 2002) always seek to establish a "new order of life" (p.3), which stems from their dissatisfaction with the current forms of life. Crowds are often dissatisfied, but lack the structure necessary to propose new orders of life. We could add, then, that social movements have a *constructive* side, even though they are often an effort to oppose the current state of affairs. This last statement, however, is not fully accepted by sociologists who study social movements, since it can be argued that conservative, reactionary movements are also social movements, even though their efforts are targeted at maintaining the "status quo". It must be noted, though, that even if social movements not always represent dissatisfaction with the mainstream situation, they are inserted in *conflictual relations*, often having identifiable opponents (Della Porta & Diani, 1999).

Furthermore, social movements can be said to be *relatively durable*, though usually *temporary*. Being durable, they differentiate themselves from a simple protest event – which is a

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[4] It is not our intent to review extensively the literature in Sociology of social movements since our angle of analysis of the British service user /survivor movement is not the internal dynamics of the movement (that has already been done by Crossley, 2006), but rather the movement's impact upon the experience of mental distress.

collective, often constructive and by definition conflictual action, but with a short duration in time. Being temporary, they cannot be mistaken by long-lasting institutions. However, that is a fine line to draw, as many social movements have existed for a considerable amount of time and have no end in sight, so it is hard to say how temporary they are.

Contemporary work on movements is now rediscovering the important role of movement cultures, identity and the affective bonds which pull people together in a social movement. Central to these studies is the concept of *collective identity,* another defining aspect of social movements. Studied by sociologists and social psychologists likewise, collective identity is related to the recognition and the creation of connectedness, producing a sense of common purpose and shared commitment to a cause (Della Porta & Diani, 1999). It is through the creation of a collective identity that single activists are enabled to see themselves as a "we", a common unity, because of a certain degree of emotional investment and shared cognitive definitions (Melucci, 1996).

However, the concept of identity should not mask the fact that social movements tend to be highly dynamic and heterogeneous. In fact, the collective identity should be understood as

> an interactive and shared definition produced by several individuals (…) by 'interactive and shared' I mean a definition that must be conceived as a process because it is constructed and negotiated through a repeated activation of the relationships that link individuals (or groups) (Melucci, 1996, p.70).

The fact that within a social movement members share a collective identity doesn't mean that it is stable or even evident to the members themselves. This is the final aspect of social movements that we would like to highlight: they are intrinsically *heterogeneous,* characterised by a low degree of institutionalisation, a lack of clearly defined boundaries and decision making structures, "a volatility matched by few other social phenomena" (Koopmans cited by N. Crossley, 2002). It is even their lack of internal homogeneity that keeps them from transforming to a more institutionalised form of political involvement, according to Offe (also cited by N. Crossley). They are, essentially, *in movement*, constantly changing and reconfiguring themselves.

Health social movements

Rising expectations among patients and service users, who have become more critical of the biomedical model while demanding rapid access to good quality healthcare, are on the genesis of a new wave of social movements, which centre themselves on struggles related to health and illness.

Brown & Zavestoski (2004) define health social movements (HSMs) as "collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organisations, supporters, networks of cooperation and media" (p.679). These challenges are not necessarily organised, but quite often are. In countries with long tradition of voluntary groups seeking to influence public policy and service provision, these "rising expectations" were embodied in the form of groups, associations or organisations, usually within the voluntary sector (Baggott et al., 2005). These are the collective actors that push forward a social movement's agenda.

Roughly, the emergence of HSMs can be retraced to the 1960s and 1970s, although they have really gained relevance since the 1980s. Some health social movements of the 1960s and 1970s have spawned from new social movement[5]. Throughout the 1970s and 1980s, a variety of HSMs have emerged, such as the disability movement, HIV/AIDS movement, gay and lesbian health movement and mental patient / survivor movement, to name a few (Allsop, Jones, & Baggott, 2004).

One of the characteristics of latter movements is the centrality of the *personal experience of illness* or bodily event to the movement's identity and practices. This personal experience becomes perceived as a shared experience, which leads to the identification with others in a social movement. Brown, Zavestoski, McCormick et al. (2004) call them *embodied health movements,* since they introduce the biological body to social movements, as it can be seen in the disability rights movement or women's health movements. Personal experience of illness is also an important part of the movement's legitimacy, allowing them to challenge science and health practices, for instance.

In HSMs, personal illness experience is transformed into a resource, and the patient becomes the "expert patient" or "expert by experience", blurring the boundary between experts and lay people (McCormick, Brown & Zavestoski, 2003). These movements produce

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[5] For instance, various groups related to maternity and childbirth grew out of the feminist movement.

and diffuse experiential knowledge not only through their interpersonal relations, but also in a systematic and institutionalised form, such as pamphlets, newsletters, internal surveys and participatory practices, running and analysing content of helplines (Allsop et al, 2004).

Many HSMs frequently challenge scientific knowledge and health practices, while also defending the value of their own experiential knowledge. However, individuals who struggle with a disease can hardly afford to ignore science, doctors and treatments. By being highly critical of the science upon which their members' lives may depend, HSMs groups have developed a variety of interactions with scientific endeavours. They may acquire scientific knowledge themselves, raise funds or lobby for research in the themes of their interests, collaborate with scientists who share their views or even engage themselves in scientific research. They simultaneously seek to subvert scientific authority structures while allying with them (Archibald & Crabtree, 2010). Acquiring scientific knowledge becomes key in a context of scientisation of decision-making[6] and in power struggles within the doctor-patient relationship. Facilitated access to information through new technologies, specially the internet means that scientific and medical knowledge is no longer out of the public's reach, as neither are their internal controversies which may serve as windows of opportunities to some groups.

We have so far presented a few characteristics that are common to many HSMs. These similarities, however, should not mask the significant differences between groups united by the term "health social movements". First of all, they deal with various illnesses and conditions. Each of them has their own particular issues and needs, which have to be addressed accordingly. Moreover, groups who have similar interests or who revolve around the same condition may have very different perspectives. Carers groups and service users groups specially may antagonise in their views (e.g. the autism movement documented by Chamak, 2005). As we have already remarked, heterogeneity is a characteristic of social movements, and thus, joining a variety of movements under the same label of "health social movements" will necessarily produce a disparate category. It is, however, a useful one, since it indicates the somewhat recent emergence of a new phenomenon, whose impact in health policies and practices has been documented. It is part of our hypothesis that they also have an important impact in the way people experience their illnesses, which is what we attempt to investigate.

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[6] Scholars have identified the "scientisation of decision-making" as a trend in current politics, which corresponds to the increasing participation of medical and scientific experts in public decision-making, removing questions from the moral and political spheres to the realm of science (Brown & Zavestoski, 2004). This has consequences for HSMs, since political pressure in the health field must be sustained by scientific evidence, and thus, politically engaged patients must become or collaborate with scientific experts to have an influence over public policy.

Chapter 2:

SURVIVORS OF PSYCHIATRY AND MENTAL HEALTH SERVICE USERS: HOW SERVICE USERS' VOICES EMERGE IN MENTAL HEALTH

In this chapter, we narrow the scope of our analysis, going from health, medicine and patient protagonism towards mental health, psychiatry and service user / survivor activism. In section 2.1 we will discuss the ideas and practices that surround madness and mental distress. This will include a brief history of madness and how psychiatry and other knowledges are constituted around this subject, as well as the practices that are created to deal with madness and mental distress, with a special attention to public policies, going from the asylum to community care and later service user involvement[7].

It is in section 2.2 that we begin to address the British service user / survivor movement. We will attempt to delineate the history of the most important groups in the British service user / survivor movement (SUSM), their ideas, achievements, and characterise the movement as a whole focusing on the activities developed by groups and the issues that are important to the movement.

2.1 Mental health policies – from the asylum to service user involvement

The rise of the asylum and the silenced lunatic

"Madness may be as old as mankind", argues British historian Roy Porter (2002, p.10). Supernatural forces were initially thought to be the cause of madness – whether through possession by demons and spirits, work of sorcerers or punishment by the gods. Hippocrates is alleged to be the first to think of madness as a disease of the brain, removing it from the supernatural world. Disturbances such as mania and melancholia were identified and understood through the theory of humorous imbalances. Christianity would reinstate the divine into madness for centuries to come. It could be viewed as either diabolic or holy,

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[7] As our focus narrows to mental health, we also find that national differences become more relevant, specially regarding mental health policies and service user protagonism. Therefore, a large part of this chapter will not be concerned with international aspects, but with developments in the UK.

depending on its manifestations – surely enough, the diabolic madness was much more frequent (Porter, 2002). Medical doctors, however, would still be involved in the care of madness. Inspired by Hippocrates and Galen's works, their treatments included diets, rest, exercise, purgatives, blood-letting, herbal medicines, to name a few.

Family members were responsible for the insane since Greek and Roman laws. The seriously disturbed were kept at home, whilst the harmless were allowed to wander. Either at home or in the village, neglect and cruelty were common towards the insane or the fool. Sending them away, as beggars, was sometimes a form of avoiding the stigma that they lent to the family (Porter, 2002). Towards the end of the Middle Ages, more formal segregation began to emerge, inspired by the Christian duty of charity.

> Lunatics were sometimes locked in towers or dungeons under public auspices. In London the religious house of St Mary of Bethlehem, founded in 1247 and lastingly known as Bethlem ('Bedlam'), was catering for lunatics by the late fourteenth century (…) Religious impulses stimulated many later foundations too, including the asylums set up in eighteenth-century Liverpool, Manchester, Newcastle, and York (Porter, 2002, p. 90).

Descarte's sectioning of body and mind led to new ideas about madness being a delusion, a fault from reasoning – not anymore deriving from humours or spirits, but rather from the mind, or from that mysterious mind-body connection that philosophers failed to locate(Porter, 2002). "Unreason" would no longer be seen, as before, as a danger lurking human experience. Madness would be banished from the world of thought, and soon from the world of men (Foucault, 1961/2006).

Detainment measures gained momentum in the 17th century. In France, the "great confinement" was marked by the creation of the Hôpital Général in 1656. It not only constituted a first step towards the hospitalisation of madness, but it also created a homogenisation of the insane and other prisoners, as it was a moral establishment in the crossroads of charity and punishment (Foucault, 1961/2006). According to Porter (2002), even though it cannot be sustained that the "great confinement" was a common European feature, it is quite clear that throughout the 17th and 18th centuries the deemed mad were increasingly institutionalised, whether in general hospitals, private madhouses, state asylums, workhouses or jails.

These institutions began to be severely criticised in the 18th century leading the way to a "lunacy reform" (N. Crossley, 2006). However, this "criticism (...) led not to the abolition of the madhouse, but to its rebirth, and institutionalization was transformed from a hand-to-mouth expedient into a positive ideal" (Porter, 2002, p. 108). Psychiatry developed inside the asylum, as a practice to manage the inmates, advocating the idea that "the well-designed, well-managed asylum was the machine to restore the insane to health" (p.100). Foucault (1961/2006) argues that the exercise of control in relation to unreason operates through the suppression of irrationality by rational scientific knowledge. Moral reformers like the Tukes in England and Pinel in France viewed madness as a breakdown of rational discipline which needed to be rekindled in order to regain self control. They freed the mad from their chains, but kept them secluded in asylums – an imprisonment justified by humanistic intentions of a moral treatment and, eventually, a cure.

Regarding the personal experience of the asylum inmate, Porter (2002) reproduces reports and diaries from asylum inmates, providing us a valuable glimpse into the experience of the mad in the 18th and 19th century England[8]. It becomes clear that it was an experience marked by being *voiceless.* As Porter (2002) writes:

> The noisiest patients were shunted off into the back wards, and all too often those who were shut up were, indeed, 'shut up'—or at least nobody attended to what they were uttering, there being less communication than excommunication. Visiting an Irish lunatic asylum around 1850, the inspectors were buttonholed by an inmate alleging theft:'they took my language from me.' (p.158).

Whilst the mad were definitely deprived from the possibility of speaking their mind and being listened to, the "alleged lunatics" were the first asylum inmates who managed to speak out against their imprisonment. In the context of the lunacy reform in England, a number of people who claimed they had been wrongly confined in asylums wrote pamphlets criticising the treatment they were subjected to. One of these alleged lunatics was John Perceval, son of an ex-prime minister, who wrote in 1838 "A Narrative of the Treatment Received by a Gentleman, During a State of Mental Derangement". He was appalled by being treated "as if I were a piece of furniture, an image of wood, incapable of desire or will as well as judgement" (Perceval, cited by Porter, p. 160). This case and others of the like were, however, the exception. Mental patients, prior to the second half of the 20th century,

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[8] Roy Porter called for the need to rewrite medical history "from below", arguing that historians should incorporate patient's views in their accounts (Porter, 1985). His History of Madness includes this perspective.

> played a very minimal role in struggle, not least on account of the difficult social and political situation they were in. Only an extremely small number of very well-to-do 'alleged lunatics', such as John Perceval, had their voices of protest heard, and even then their focus was upon the fact that lunacy was 'alleged'. There was no challenge to the category of lunacy itself, only to its wrongful application in this or that case, and there was little attempt, on behalf of alleged lunatics, to defend the rights of the lunatic (N. Crossley, 2006, p.60).

Changes in psychiatric care

Throughout the 19th century, numbers and scale of mental hospitals skyrocketed in all Europe. In England, patient numbers went from around 10,000 in 1800 to ten times that number in 1900 (Porter, 2002). Scull (1993, cited by N. Crossley, 2006) explains this rise in numbers arguing that the existence of the asylum lowered the tolerance thresholds of the community regarding unusual behaviour. Porter's explanation is simpler: that institutionalisation was believed, at the time, to be the solution to all social problems. Whatever the reason, the asylum enjoyed a long existence, with increasingly subtle methods of control, as Foucault (1977) masterly analysed.

At the same time as the asylum was growing, the psychiatric profession was beginning to establish itself more formally, through the creation of journals and associations in the first half of the 19th century. Increasing emphasis was placed on the physical basis of madness, as moral treatment was gradually put aside in favour of common physical treatments that date back to Hippocrates. Setting madness as a disease was important to psychiatry as it allowed a claim on the monopoly of its treatment (N. Crossley, 2006).

However, the asylum proved to be much less effective than it was previously foreseen – it became "a dustbin for hopeless cases" (Porter, 2002, p. 119). By the late 19th century, observers were noting that "the uniform tendency of all asylums is to degenerate from their original object, that of being hospitals for the treatment of insanity, into domiciles for incurable lunatics" (p.120). In Britain, a reform of the asylum took place in the 1930s. In 1930 the Mental Treatment Act established the need for outpatient treatment and aftercare, and it certified three different statuses for patients: voluntary (who had the right to discharge themselves), temporary (who were admitted for a maximum of 6 months) and certified (declared insane by a psychiatrist, they were committed indefinitely). Asylums were officially renamed “mental hospitals” and lunatics as “patients”, evidencing a concern with both medicalisation and humanisation (N. Crossley, 2006).

Many undergoing changes were taking place during early 20th century. Freud's influential work had helped to attenuate the “otherness” of insanity, as neurotic disorders began to be recognised and the idea that mental disorder was not restricted to the insane gradually became widespread. Also, the return of shellshock afflicted soldiers from World War I flooded psychiatric resources and forced the discipline to reconfigure its theories, and to incorporate trauma and psychological perspectives into its framework (Porter, 2002).

The emergence of “office psychiatry” also “widened the definition of mental problems to a group of people who required help, but not incarceration” (N. Crossley, 2006, p.54). Suddenly, psychiatry was freed from the limits of the insane, and a whole new clientele of “normal” people emerged (Horwitz, 2002) – notwithstanding a new competition from psychologists, non-medical psychoanalysts and other emerging mental health professionals. Although psychoanalysis had a limited influence over British psychiatry[9], its cultural impact was boundless, whether in fiction, art or films. By the 1950s, psychological thinking had infiltrated through the public's minds, and ordinary people were increasingly recognising themselves as neurotic or in need of treatment.

In spite of this new climate, not much had changed in British mental hospitals before the 1960s. The number of hospital beds peaked in 1955 at around 150,000. Biological psychiatry reigned, yet mental hospitals remained as custodial as the Victorian asylums, and perhaps even more dangerous, with very high death rates (Rogers & Pilgrim, 1996). Induced malaria, insulin-induced coma, psychosurgery and electric shocks were the new psychiatric treatments, and many iatrogenic deaths are thought to have occurred as a consequence of them. The creation of the National Health Service (NHS) in 1948 didn't bring psychiatric services into a centralised administration, and hospitals remained largely autonomous.

The 1950s saw the invention of psychotropic drugs, mostly anti-psychotic, anti-depressive and tranquillisers. At the same time, after 1955 mental hospitals started to reduce their numbers in Britain. The link is tempting, and many have associated deinstitutionalisation as the result of a technical breakthrough - a “pharmacological revolution”. Even though the advent of drug therapy might have contributed by injecting optimism in the care of mental

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[9] In the UK, psychoanalytical and psychodynamic approaches had restricted success, in contrast to their wide acceptance in the USA or France, for instance, specially in the period of 1920-70s (Porter, 2002).

patients, it is not likely that it was a major contributor for decarceration[10]. N. Crossley (2006) argues that "the mental health field was evolving under the force of its own internal dynamics, generating innovations in practice and ideas. The field was also subject to external pressures and dynamics too, however, the principal these pressures being economic (p. 57).

In any case, the Mental Health Act of 1959 came to make this trend official. It referred, for the first time in official document, of "community care" and implicitly obliged local authorities to set up outpatient services. However, this was not mandatory and no immediate financial support to local authorities was given. Alternatives to the large mental hospitals developed quite slowly – there was no overall organisation of community services and resources were scarce (Bell & Lindley, 2005). It wouldn't be until the late 1970s that deinstitutionalisation would effectively gain momentum.

Anti-psychiatry and controversies around mental illness

While psychiatrists were celebrated and legitimised previously, an influential anti-psychiatry movement emerged in mid-1960s. The times had definitely changed, and a "culture of challenge" (Scambler & Kelleher, 2006) was now widespread, as we remarked in Chapter 1. At this point in time, "critics of the field were regarded not as marginal eccentrics but as major figures in an intellectually prominent counterculture" (Horwitz, 2002). They were, most importantly, psychiatrists themselves.

Anti-psychiatry developed first in Britain, through the works of R.D. Laing and David Cooper in early 1960s. They achieved "star status" within liberal and left-wing circles but also among psychiatric patients. Laing argued that madness had meaning, it carried a potential of liberation in the sense of an "inner voyage" (Porter, 2002; N. Crossley, 2006). At almost the same time, other prominent dissident psychiatrists appeared, (such as Thomas Szasz in the USA and Franco Basaglia in Italy) questioning the reality of mental illness and proposing radical deinstitutionalisation. Moreover, the view that psychiatry was nothing more than an instrument of social control with questionable scientific arguments was supported by

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[10] Goodwin and Scull (both cited by Rogers & Pilgrim, 1996), for instance, argue that a wide variety of psychiatric patients were being discharged, many of whom were not seen as candidates for neuroleptics and therefore were not under drug therapy, such as the elderly and the mentally handicapped. Likewise, there is evidence of documents – in Britain – that prior to the discovery of neuroleptics decarceration was already being discussed.

researchers and authors in other fields, such as Erving Goffman's critic of asylums (Goffman, 1961), Foucault's history of madness (Foucault, 1961/2006) and, later, Rosenham's experiment which attested mental hospitals' failure to distinguish the normal from the insane (Rosenham, 1973).

In Britain, anti-psychiatrists were a small nucleus of people who had very few practical achievements, but who were deeply influential. The anti-psychiatry movement was, in resume, a rupture in discourse (and, in some cases, also in action) as never been seen before, and it changed the way social movements addressed this issue. Moreover, it changed people´s hopes and expectations and that gave way to the emergence of the survivor movement (N. Crossley, 2006).

Other attacks to psychiatry were under way in the USA, which would ultimately lead the psychiatric profession to turn things around and gain the upper hand. By the 1970s, North-American psychiatry was being strongly criticised for its lack of scientific credibility and inability to respond to the challenges of community care. As Horwitz (2002) puts it, "if psychiatry was to survive as a medical discipline, it had no choice but to conform to the intellectual norms of the medical profession" (p. 61).

The response came in the form of the DSM-III (published in 1980, but in draft since 1974). The creators of this diagnostic manual had the task to reconfigure psychiatry as a hard science while, at the same time, keeping psychiatrists' enlarged clientele[11]. Their enterprise was successful beyond belief, as the DSM-III and its subsequent issues were adopted in virtually every country, with the status of diagnostic bibles. One important aspect for the DSM-III's success was the legitimacy lent by the support of social movements and lay advocacy groups[12]. The diagnostic enterprise allowed psychiatry to regain its status among the public and consolidate its place in medical science, while maintaining the enlarged domain of mental illness.

The DSM-III reinforced the previous tendency for a biological view of mental distress. Even though it doesn't officially assume any particular cause of mental disorders, its

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[11] Which included not only the upper-middle-class enthusiasts of psychoanalysis culture but also the socially deviant. Criminals, drug addicts, delinquents, children who had problems in school, alcoholics – all formed a new public to psychodynamic treatments, offered in a variety of institutional settings (Horwitz, 2002).

[12] The DSM-III excluded homosexuality and pre-menstrual syndrome of the domains of mental disorder (a feat celebrated by the gay and feminist movements, respectively) and included post-traumatic stress disorder (advocated by veterans and feminists alike) (Fassin & Rechtman, 2009). Parents of psychotic children were also strong lobbyists for a diagnostic psychiatry that was based in a disease model, as opposed to a psychodynamic model that frequently linked those illnesses to parenting and development – therefore, blaming them for their children's illness (Horwitz, 2002).

organisation in clusters of symptoms implicitly assume underlying diseases. In fact, since the publication of the manual, biological explanations have attained unquestioned primacy in psychiatry. The current dominant explanatory model views mental disorders as neurochemical imbalances, or diseases of the brain. Disciplines like genetics, evolutionary psychology, neuroscience and cognitive science all collude with psychiatry in their view that biology is the ultimate truth of mental illness (Horwitz, 2002).

However, a significant part of mental health professionals (such as psychologists, social workers, nurses and occupational therapists) as well as many sociologists and anthropologists criticise this new wave of biological reductionism, and argue in favour of psychological and social causes of mental distress. Some comprehensive models were created in an attempt to integrate the three kinds of variables, such as the biopsychosocial model. Initially proposed in an enthusiastic manner, it is still formally adopted by most modern mental health teams, where inter-disciplinarity has come to be the norm. In spite of this, this multi-causal view may be driven more by pragmatism, in order to include different professionals' viewpoints, then by a firm belief in the biopsychosocial model (Pilgrim, 2002).

Controversies around mental illness and mental distress have not ceased to exist. As we will discuss in detail ahead, the service user / survivor movement was prominent in diffusing anti-psychiatry views in its early years. Lately, however, the challenges of community treatment and service user involvement in policy and research has led them to develop more sophisticated views, authored by themselves. The most prominent of those views is called the "recovery vision".

The first writings in the US about recovery as a process were a number of published accounts of the first-hand experience of survivors. These accounts, drawing sometimes from the disability movement arguments, showed how some patients who were considered by mental health professionals to have a poor prognosis were overcoming many of their difficulties and discovering ways to live satisfying and contributing lives, despite some continuing problems (Turner-Crowson & Wallcraft, 2002). Recovery is described as a personal process of changing one's attitudes, values, feelings, goals, skills and roles, in order to lead a satisfying, hopeful life (Anthony, 2003). It doesn't focus on symptom remission to define when a person is recovered, as limitations caused by mental distress or illness can still be present, but other factors will be determinant for the person to live a fulfilling life. Some of these factors, according to Turner-Crowson and Wallcraft, are regaining hope, being believed in and encouraged, developing perspective on the past, accepting loss, taking responsibility for one's life, acting to rebuild life, developing relationships, challenging other people's low expectations, developing new meaning and purpose in life. Anthony (1993) provides a distinction of recovery from previous models:

> People with mental illness may have to recover from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from lack of recent opportunities for self-determination; from the negative side effects of unemployment; and from crushed dreams. (…) Recovery is what people with disabilities do. Treatment, case management, and rehabilitation are what helpers do to facilitate recovery (p.13)

As it can be seen, the recovery vision departs from service users' experiential knowledge to develop a new perspective in mental healthcare. It has become increasingly developed and accepted, first in the US and more recently in Britain (Turner-Crowson & Wallcraft, 2002). Now, in order to understand how survivors have gone from the silenced lunatics to producers of knowledge, we must resume our historical review of policies and discuss the emergence of community care and later, of the SUSM.

Community care, consumerism and service user involvement

The Mental Health Act of 1959 was the first document from the British government to speak of "community care" but it has been a very slow and only partially attained process. Decarceration of mental patients and setting up community services wouldn't effectively happen until the 1970s, when the population of mental hospitals started to decrease and alternatives to the asylum to be created. Throughout this decade, however, hospitals were still the priority for mental health funding and community services were somewhat neglected and didn't keep up with the decarceration process (Rogers and Pilgrim, 1996). The goal of fully emptying and closing hospitals, however, was only aggressively pursued in late 80s and 90s (N. Crossley, 2006).

The 1983 Mental Health Act was a loose attempt to improve patient's individual rights. Although it did introduce some new protections for "formal patients"[13], it failed to provide a legal frame for the organisation of better services, which were still largely under-developed.

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[13] Those detained against their will.

(Rogers & Pilgrim, 1996). This half-hearted mental health reform led to an increased level of hardship for people with mental health problems. If they were now less subject to incarceration, they were much more exposed to negligence and lack of care. A small number of high profile incidents, inflamed by intense media coverage, fuelled public fear of mental patients and generated anger against community care. By the end of the 1990s, "even the government was calling community care a failure" (N. Crossley, 2006, p. 58). Since then, the UK has watched an increase in the use of coercive measures. With the closure of large mental hospitals, acute inpatient wards have become increasingly occupied with formal patients (Pilgrim, 2005). This trend recently culminated with the approval of Community Treatment Orders in 2008[14].

Parallel to this, broader changes were in operation regarding public health in the UK. As we have previously addressed, an internal market was introduced to the NHS by Conservative government in the late 1970s. Managers were brought in to administrate services, as they were perceived to be more likely to reflect consumer interests than health and social care professionals. This consumerist ideology, which sees the market as an organising force led by consumer rational choice, continued to direct policies throughout the 90s and under New Labour government into the new millennium (Clarke, 2007).

The rhetoric of a modern health service consumer, eager for choice and voice*,* was overall embraced as a possible figure of citizenship. Consumerist policies were, in some way, catalysers for the development of the mental health service user/survivor movement, despite several limitations and contradictions. While Labour left-wing politics tended to emphasise issues of equitable access and workers' rights within the NHS, it lacked an explicit concern towards patients (their interests were assumed to be the same as the workers', who advocated for them). Consumerist politics became a new hope for psychiatric patients to influence mental health services (Rogers and Pilgrim, 1996). An unexpected alliance was forged between mental patients and Conservative government, who favoured the ideology of consumerism. As Nick Crossley (2006) has found when interviewing activists of the SUSM:

> the break up of the NHS monopoly generated opportunities for some of the more innovative projects they wished to see and allowed them to effectively pioneer and tender for such

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[14] Community Treatment Orders are enforced when a patient is discharged from psychiatric hospital but the clinician understands that "it is necessary for his health or safety or for the protection of other persons" that he is compulsorily treated in the community (Mental health act, 2007, 17A). In practice, he may be forced to take medication, to present himself in mental health services in different occasions or even be "recalled" to hospital, etc. (Mind, 2011).

> schemes. Moreover, they claim that the introduction of a language and philosophy of consumerism, whilst flawed in some respects, has helped to tip the balance of power slightly in their favour, improving their bargaining power within the system. The customer, so the saying goes, knows best, and these particular customers endorse that view (p.59).

Involving service users in health services, however, is not a simple process, specially in mental health. The views of professionals are frequently at odds with service users. The latter may be viewed by professionals as irrational and unreasonable and therefore, without any credibility, while service users are often hostile to psychiatry's practices and knowledge. The result of this conflictual interaction imposed by a top-down public policy is that service users, while increasingly present in decision-making processes, are not always taken into account. (Rogers & Pilgrim, 1996).

2.2 The British service user / survivor movement

As we have seen, in the asylum system mental patients were mostly silenced, and their “needs” were determined by the knowledge of psychiatrists. There was little point in arguing against this system and accusing it of being a form of social control, since this was perceived as being their legitimate function – to protect society from the lunatic, whose human status was not completely assured. However, psychiatry's power endured significant challenges with the shift towards a community-based system of provision. As psychiatry reinvented itself from the role of controller to the carer, they could be criticised for failing to live up to their own standards. Anti-psychiatrists were the first to embody this possibility, and their vociferous criticism created a receptive environment for patients' claims. Being increasingly outside of the asylum or within the asylum but under less strict control, mental patients[15] were able to, for the first time in history, raise their voice, collectively, against the perceived injustices of the system to which they were subjected (N. Crossley, 2006).

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[15] As they were called and called themselves then.

1970s – the first SUSM groups

In 1969 the first British organisation led by people with mental health problems was created. They called themselves People Not Psychiatry (PNP), and their idea was to provide a network of contacts for people experiencing mental distress, as an alternative to psychiatry and mental hospitals, which they rejected. Greatly inspired by anti-psychiatry and counterculture, the PNP was organised in the form of a non-hierarchical network, through which people could reach out to one another and provide emotional and material support (for example, by offering their homes to accommodate a fellow who was going through a crisis). They were originally based in London but already in 1970 PNP had spread all over the UK, allegedly reaching 10.000 members (N. Crossley, 2006), which signals the demand for these kind of initiatives.

The Mental Patients Union (MPU) is the next influential group in the history of the SUSM. Created in 1971 after a patient's strike at a progressive day hospital threatened of closure, the MPU was influenced by Marxist ideology, seeing the oppression of mental patients as part of a wider class struggle. They also grew considerably, receiving some media attention and even creating links with patient groups in continental Europe and the US. Their activism was centred upon legal representation of people involuntarily committed to mental hospitals, as well as publication of pamphlets, informative articles and the providing of alternative services. Internal differences eventually led to the MPU's dissolution in mid-1970s (N. Crossley, 2006).

Even though both British SUSM groups had strong ideological influences from the outside (anti-psychiatry and Marxism), they shared a common premise for their action, which came specifically from internal circles of patient activism. This premise sustains that the experience of mental distress is the basis for a special knowledge, which forms the basis for their actions and claims. As historian Nancy Tomes explains, this idea was completely unheard before:

> As of 1970, then, the claim to have special insight into mental disease by having actually experienced it was a novel assertion. It was on precisely these grounds that ex-patients, as individuals and in groups, began to assert a new entitlement to speak on their own behalf (Tomes, 2006, p. 722)

It must be argued, therefore, that these early groups already shared the main characteristic of the later survivor movement: the belief that the experience of mental distress was not a reason for punishment and imprisonment. Even though it was a painful and difficult experience, it also provided survivors with a special awareness that should be valued positively.

1980s – expansion and consolidation

It should be noted that the organisation of service users in Britain was late in developing compared to the USA, Canada and the Netherlands[16]. Although the MPU and PNP gained some media recognition and wide membership, they still failed to have the impact of their continental and US counterparts. The international context was conducive for further development of service user activism in the UK. The circulation of ideas within Europe around Trieste's influence[17] gave way to the creation of the European Network of Alternatives to Psychiatry (ENAP), formed in Portugal in 1974. In 1982 some British activists decided to launch the British Network for Alternatives to Psychiatry (BNAP). BNAP proved important as a group that further developed the "cultural legacy of anti-psychiatry and a commitment to change" (N. Crossley, 2006, p.153).

After the dissolution of the MPU, some remaining members decided to form the Protection for the Rights of Mental Patients in Treatment, or PROMPT. In 1985 they changed their name to Campaign Against Psychiatric Oppression (CAPO), evidencing a new terminology and discourse, as terms such as "patients" and "treatment" were being left behind and a more challenging stance was adopted. CAPO, having learned from the MPU´s mistakes, remained a small but cohesive group, being able to sustain its radical Marxist views. Both BNAP and CAPO succeeded in drawing attention to the movement and in channelling a demand for change (N. Crossley, 2006)

In 1985, Survivors Speak Out (SSO) was created. Benefiting of a new receptive environment to service user activism created by BNAP and CAPO, and inspired by the success of international groups of survivors, SSO was arguably the most influential

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[16] According to Rogers and Pilgrim (1991), in 1975 the patients' advocacy movement in the Netherlands was sufficiently developed to convene a national meeting with representatives from a number of different patients' councils and organisations. By the 1980s, North-American mental patients' groups were already funded for developing user-led research and mental health services.

[17] In the beginning of the 1980s, Franco Basaglia's experiment of deinstitutionalisation in Trieste, Psichiatria Democratica, became a reference for radical mental health professionals and survivors from the UK. Trieste was, as Crossley names it, a "working utopia" (p.149) that inspired many to change things in the UK, and became a meeting place for the exchange of new ideas in an international, mostly European level.

association in the history of British service user /survivor movement. Among SSO creators was Peter Campbell, still an important figure in the survivor movement. SSO were major campaigners, protesters, with emotional and confrontational techniques borrowed from AIDS activism (such as testimonials, laying of wreaths, etc.). The use of the term “survivor” is in itself indicative of a change in identity, one that represented a further break with medical discourse, the passive role of patients, replacing it with positive connotations of pride and strength. Despite their enormous success, SSO has slowly faded throughout the second part of the 1990s. It's still, however, an important symbol for the survivor movement, and it has left an important legacy (N. Crossley, 2006).

A different approach from SSO was taken by advocacy groups. The Nottingham Advocacy Group (NAG) was created at the same time as SSO. One of the first user-led advocacy groups and highly successful in the local level, they set the base for the creation of the United Kingdom Advocacy Network, or UKAN (Survivor History Group, n.d) in 1990. UKAN was an “umbrella group” for advocacy, which supported the creation of local advocacy groups, providing “starter packs” and networking. They would also come to play a very important role, specially by providing great impulse to the local associative scene (N. Crossley, 2006).

The Hearing Voices Network (HVN) has its roots in a meeting in Trieste, when representatives of the UK survivor movement met Marius Romme, a Dutch psychiatrist who advocated the possibility of dealing with voices in a non-medicalised form. It took a few years until this collaboration was consolidated in the creation of a new group, the Hearing Voices Network, created in 1988 in the city of Manchester (N. Crossley, 2006). They are still active, and their work concentrates on a network of self-help local groups, who share experiences and knowledge about the hearing voices experience, not seen as an illness, but as an experience that should be listened to in a safe, peer-supported environment.

In the 1980's, two of the largest and most relevant mental health charities in the UK, MIND and Rethink, created service user networks within their organisations (MindLink and the National Voices Forum, respectively). This represented a major step for the survivor movement, as it signalled an expansion of their influence and an undeniable effect of their growth.

1990s and 2000s– specialisation, exponential growth and faded radicalism

Throughout the 1990s, the success of national groups dealing with "general issues" allowed for more specialised groups to emerge. Some national organisations were created, centred on specific conditions, such as the aforementioned Hearing Voices Network, the National Self-Harm Network (1994 to present) and No Panic (1991). Other specialised groups focused not on mental health experience but on specific issues, such as ECT Anonymous (1994), or areas of lobbying, like the Schizophrenia Media Agency (N. Crossley, 2006). Borderline UK (created in 2000) and Personality Plus (formed in 2007) were merged in 2009 to create Emergence, a group that offers peer support, advice and information to service users diagnosed with personality disorder. (Emergence, n.d.).

Black and ethnic minorities started to be more contemplated in what is usually perceived as a white, middle class movement through the creation of specific constituency-based groups during the 1990s and 2000s, such as Awaaz in Manchester, Buddies in Bradford, Share in Maudsley Black Action (SIMBA), Black Women and Mental Health in London, Catch-a-Fiya (Wallcraft et al., 2003). The diffusion of the internet was also responsible for the growth and proliferation of smaller, local initiatives, which now had the means to communicate and network with others.

Parallel to this, the opening provided by consumerist policies for patient involvement in services and the very success of the movement led the SUSM to enter a new phase. Survivors were now increasingly participating in government committees and even being paid as consultants for health authorities and a variety of projects. While these transformations have, on one hand, increased service users' bargaining power and made them ever more present in decision-making processes, it also turned many activists away from the voluntary campaigning route. This compromised the movement's initial radicalism, which was overall transformed in collaboration with the mental health system. Even though in late 1990s radical groups like Reclaim Bedlam and Mad Pride emerged with new discursive tactics and activism approaches (N. Crossley, 2006), the majority of SUSM groups have adopted a less critical position towards psychiatry and mental health services.

The end of Survivors Speak Out is a sign of the SUSM transformation, as campaigning is replaced by more extensive collaboration. It also has left an important gap within the movement, which has not disposed of a national organisation which could represent users on the whole until lately. An attempt to respond to this was the creation of the National Service User Network (NSUN) in 2007. This organisation emerged from an initiative of two non-user led mental health charities, which were able to secure a very large amount of funding to set up this group (Survivor History Group, n/d). Because of this history, the NSUN was a controversial endeavour and they have been struggling to gain the confidence of key survivors, who accused NSUN of being "a cynical attempt by the big mental health charities to take over the user movement" (Crepaz-Keay, 2008, n/p). They have only recently, in November 2011, had their first Annual General Meeting, with an election of a new board of trustees, and seem to be on the path of attaining at least part of their initial goals (NSUN, 2011) It remains to be seen if NSUN will answer to the demand for a strong, national representation for service users, capable of bringing this heterogeneous movement together

Today – an overview of SUSM practices and positions

The most recent and comprehensive source of empirical information on the SUSM is the report entitled "On Our Own Terms" (Wallcraft et al.., 2003). This report published the findings of a research conducted in 2001/2002 by service user researchers with a significant proportion of SUSM groups[18], and provides an overview of the movement's current state. The British SUSM today is formed by hundreds of groups, most of which were recently created and are small, local groups. At the time of the research, 42% of the groups were less than 5 years old (formed after 1997), and 75% less than 10 years old (set up after 1992) – see Figure 1. This response shows the significant multiplication of groups after the 1990s, exactly the point when national key groups were losing power and public policies stated that service users and carers had to be involved in local planning.

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[18] They identified 896 service user / survivors groups in the UK, and a little more than a third of them (318 groups) responded their postal survey. These groups have a combined membership of around 9,000 service users / survivors. They also performed interviews, focus groups and visits to group premises to some of these 318 groups. Additionally, they spoke to leaders and project workers from six national service user / survivor networks.

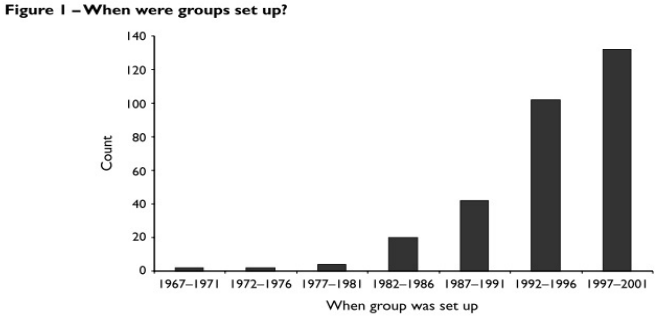

Figure 1. From Wallcraft et al., 2003

Another relevant data from this research regards the main activities performed by groups (Figure 2). *Self-help and support* is the main activity developed by groups, which is coherent with its past as self-help is a core element of the movement since the very beginning Self-help emphasises the value of the personal experience of mental distress as an a credential into helping others with similar needs, arguing that people who share the same experience have at least the same, and quite often more ability to help each other than to be helped by mental health professionals. It has been thought in the beginning of the movement as an alternative to psychiatry. Today, it is hard to assess if self-help groups still share this aim – given our previous discussion, it is more likely that they will be thought as complementary to the mental health system than as alternatives (Wallcraft et al., 2003).

Table 1 – Summary of key findings from the postal survey

Question	Response
When were groups set up?	42% of groups said that they were set up in the last five years rising to 75% in the last ten years and 89% in the last fifteen
What do groups do?	79% self-help and social support 72% consulting with decision makers 69% education and training 41% creative activities 38% campaigning 36% advocacy 28% provide a service other than advocacy

Figure 2. From Wallcraft et al., 2003

The second most referred activity was *consulting with decision makers*. This astonishing result - 72% of service user groups were involved with some kind of consultation in

2001/2002 - agree with our previous analysis of the effect of consumerist policies to the SUSM. According to user's views, these policies (specially the Community Care Act 1990) "enshrined user involvement in community care planning and stimulated further growth of local user groups, but to some extent changed the emphasis of the movement from support and campaigning to local involvement" (Wallcraft et al., 2003, p.14).

The next most popular activity, with 69% of groups involved, is *education and training* for members and other external groups, such as mental health professionals. This can cover a wide range of activities, related to personal growth, recovery, getting a job, or skills for running groups or participating in decision-making instances. Training activities may reproduce scientific knowledge, but it may also be a form of diffusion of experiential knowledge, either to peers or to the outside public. It can arguably be viewed as a more formal – and maybe less aggressive way – of campaigning, in the sense that people get to share their views and ideas in a non controversial way. That is interesting as it illustrates a trend in the service user movement, moving to less confrontational but also influential methods of activism (Wallcraft et al., 2003).

Both training and user involvement bring about matters relating to service users getting paid. They might become employment opportunities, which at the same time carry the issue of professionalisation in the movement, but it also may be perceived as an empowering aspect so that people who have difficulties getting other jobs could have a revenue and stay active (Wallcraft et al., 2003).

The survey also showed that 38% of groups are involved in *campaigning,* just below *creative activities*. This further corroborates the hypothesis of the SUSM being swayed from activism in favour of user involvement and initiatives led by third parties. *Advocacy* is the most usual service provided by local groups (p.17), with 38% of groups involved in this[19]. Advocacy work includes providing support for patients' councils in hospitals or working with people one-to-one, supporting them with their most various needs so that their rights are guaranteed. Other types of *services* were reported by 28% of groups, including drop-ins, befriending services, telephone helplines, social enterprises and recovery support (Wallcraft et al., 2003).

The researchers also mapped the issues that are consensus within the SUSM and the more controversial issues. The commonly shared concerns included: improving quality of

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[19] It may seem low given the service user's history with advocacy, but it must be noticed that providing any kind of service demands a lot from the groups' resources, and therefore, the smaller groups are often incapable of providing this type of service.

services and providing choice; early supportive intervention and alternatives to medical treatment; no extension to compulsion and a right to independent advocacy; elimination of stigma and discrimination. However, there was no consensus regarding these topics: allowing forced treatment in hospital; challenging the biomedical model; accepting drug companies funding; creating links with disabled people's movement; keeping user involvement a priority (Wallcraft et al., 2003)

It seems that the common ground of the movement is not very large, as issues that were found to be shared concerns are almost common sense nowadays. It is hardly arguable that services need to be improved, for instance – but exactly how it should be done is more controversial. The fact that within the SUSM there is no agreement of the role of health professionals and biomedical science is summarised by this quote from a service user:

> Some people don't believe in mental illness and some people do. Some people only believe in a kind of political solution to mental health problems, rather than a social or medical solution. Some people see the mental health system as part of a state-controlled attempt to police them. So, when it comes to things like whether hospitals exist or whether physical treatments should be allowed, it is difficult for people to work together (Wallcraft et al., 2003, p. 50)

Not only the SUSM is divided regarding these main issues, but individual activists also adopt different postures, or what David Armes (2009) has called "discursive tactics". He investigated these internal differences within the SUSM and found four different "discursive repertoires": reformism, rationalisation, pride and professionalism. Reformism is a posture defined by a collaborative stance, proposing that services are on the way to being reformed in partnership with service users, and eventually will become what's expected. Rationalisation involves a pragmatic stance, where service users should adapt to the circumstances which are dictated by their opponents. Pride refers to a celebration of difference and rejection of collaboration and stigma. Finally, professionalism refers to service users being recognised as professionals, gaining respect and being able to produce social change through paid work.

Final comments

The British SUSM is a social movement which emerged in early 1970s, inserted in a context of intense challenges to psychiatry and decarceration of mental patients. Both these events were critical for people with mental health problems to be able to publicly engage in collective action for the first time. Even though it was late in comparison with other countries, the British movement has achieved a significant status within the mental health field. Service user organisations were successful in establishing legitimacy for survivor claims and helped diffuse their message, promoting change in many ways.

This success and growth led the movement to a different phase, where more specialised groups have arisen and more plural views (also less radical) were included. The possibility of revenue from their expertise was also a sign of their success and increased influence, even though it has also meant a shift from campaigning to involvement. Today, the SUSM struggles with these issues, and tries to reorganise itself in a national group, which still hasn't presented the expected results. Service users are, nevertheless, more influential then they ever were, in history, and this is at least partially due to their collective actions as a movement for change.

Chapter 3:

EXPERIENCE AND IDENTITY IN HEALTH AND ILLNESS

Moving from contextualisation to a more theoretical discussion, in this chapter we examine two key concepts – experience and identity – which will be important for our results analysis. We will first conceptualise what we understand by experience and how we intend to grasp this elusive object in this research. Furthermore, we discuss the literature surrounding illness experience, dedicated to the study of chronic illness, which can provide some insight for understanding the experience of mental distress.

Identity has proven to be a central issue to the experience of chronic illness, of mental distress and to understanding social movements. In fact, it has been advocated as a fundamental concept to understanding late modern condition. We will explore this concept, trying to understand the configurations of identity that can be useful to studying the experience of mental distress in a context of political activism. The concept of "politicised collective identity" will also be examined, as it provides a good analytical tool to understand the processes in which we are interested. Following this, we will look briefly into the experience of mental distress, including its relation with social movements and empowerment practices. The brevity is explained by the marginality of these topics in academic research – they are only beginning to be explored.

3.1 Experience and narratives

Renewed interest in experience as a concept is rooted in academic aspirations to reach a "primary reality" which hasn't been touched by cultural discourses (Desjarlais, 1997, p.11). This notion, inherited from romantic thought, recognises experience as a truer, more authentic aspect of life, because it is less mediated, closer to felt realities. Desjarlais argues that the problem viewing experience as *the* authentic domain of life is that the social production of experience and the practices that define it are left invisible. In this author's perspective,

> experience is not a primordial existential given but rather a historically and culturally

> constituted process predicated on certain ways of being in the world. Experience is the result of a specific cultural articulations of selfhood (namely, a sense of self as possessing depth, interiority, unity, stability and the capacity for transcendence) as well as certain social and technological conditions that foster and legitimate that sense of self (p.13)

There has been, he argues, a historical construction of experience, which can be illustrated by the changes in the word's meaning. "Experience" initially denoted external engagement to observed phenomena as a source of knowledge (which the word "experiment" still denounces), in a period where selfhood, privacy and interiority were not, themselves, central concerns in society. Gradually, however, experience became introspective, seen (and lived) as a subjective process of incorporating reality, at the same pace that discourses of interiority and selfhood were gaining pivotal relevance in modern western society.

However, there is much more to experience than pure subjectivity. Experience "has as much to do with collective realities as it does with individual translations and transformations of those realities. It is always simultaneously social and subjective, collective and individual" (Biehl, Good & Kleinman, 2007, p.53). Didier Fassin (2004, cited by Grard, 2011) distinguishes the need to analyse experience in relation to its "social conditions", understood as the way structures and social norms translate themselves in ordinary life, ordinary acts and way of being regarding oneself, others and the world. It alludes to an operation of objectivation, while experience is an operation of subjectivation, where people give shape and meaning to what they currently live, to what they have lived and will live.

Social conditions are an important part of our analysis, as we discuss the world of mental distress being shaped and transformed by social movements, public policies, services, treatments, scientific institutions, to name a few. It is impossible to remove experience from this background. In order to emphasise the social aspect of experience, we will use in this research the terms experience and *social experience*. It is not an effective distinction, as we understand experience as socially constructed. The use of social experience as a separate term is a form of bringing to the forefront the aspects of experience which report to concrete socialisation. Social experience, in our conception, is a part of experience that refers specifically to social interactions.

Analysing such an elusive construct as experience is not a simple process and it is only indirectly that we can approach experience. According to Desjarlais, experience builds something more than a transient, episodic succession of events – it has a lasting effect on the person who undergoes it. In other words, experience transforms the subject[20].

This process of transformation and accumulation in time is sustained by *narratives*, which integrate experience in a more or less coherent sequence, either to the individual or to a community or society. Ricoeur (1991, cited by Kaufmann, 2005) argues that the narrative is a form of ordering reality and events, allowing them to give meaning to the action. According to Desjarlais (1997), narrative has also become more important to experience as the reflexive, introspective subject was emerging – to the point that today, it is only through narrative that we can grasp our lives. It is not, however, a given quality of experience, but one that was gradually created as a part of a wider social process of transformation of experience into what it is today: “an inwardly reflexive, hermeneutically rich process that coheres through time by way of narrative” (p. 17).

It is through exploring narratives that most researchers study experience. The study of illness experience has been based in the study of illness narratives (e.g. Kleinman, 1988). However, it is only with some critical distance that we can take narratives as reflections of experience. Following Saris (1995) and Grard (2011), it is possible to rethink this relationship of narrative and experience by acknowledging the narrative's production conditions. Jamie Saris argues that a narrative of a chronic illness is not a direct account of personal experience, since it is deeply embedded within various institutional structures that influence the production of the story. Whereas the “classical” model would sustain that experience reflects itself in narrative, which is then transformed to a text and interpreted by the researcher to reach the experience itself, Saris' model is complexified by the mediation of institutions. He understands institutions as a broad concept, including technologies, narrative styles and discourses, which are produced and reproduced by culturally and historically situated subjects. Institutions help constitute narratives and are sites of narrative production, separating what is sayable from what is silenced. If we follow Saris, we end up with a less “pure” version of personal experience, but also one that is less naïve and closer to reality.

Going further than that, it must be acknowledged that the narrative hardly ever refers to a simple, unique experience, and even when it does, it hardly ever tells this experience in a single way. Narratives are multiple - the subject offers different versions of a same event, perhaps even contradictory versions, only to glide towards another experience, and then

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[20] This is precisely the difference between the German words *Erfahrung* and *Erlebnis*. Both being translated as “experience”, the first alludes to the experience which you undergo, and which is cumulative and ongoing, whereas the second is an isolated, categorical experience, one which you have (sometimes translated as lived experience).

another, and yet another... This, according to Grard (2011) is an effect of the multiplicity of experience itself.

In conclusion, when we refer to “experience” we will be referring to the inner, reflexive process of transforming the lived (*erlebnis*) into multiple subjective forms that are gathered through the process of narration. Experience is constantly affected by social conditions (social experience) . The very conditions of production of experience are social, as they are transformed in narratives through the filter of institutions. This mediation process guarantees that we never have access to “pure” experience - not even the person herself.

The illness experience

We have argued that treating mental distress as an illness is problematic, because the independent reality of mental illnesses is a factor challenged by many actors, including a great part of the SUSM. However, it must be acknowledged that mental distress is experienced in a very similar way as physical illnesses, since it is socially inserted in an illness framework, which involves doctors, medications and other treatments. Moreover, mental distress can be just as disturbing to the individual's daily life and social relations as physical illnesses. Its long duration brings us to the study of the experience of chronic illness as, perhaps, a topic which can enlighten the experience of mental distress.

When chronic illness appeared as a widespread health problem related to the demographic transition in developed countries, sociologists have turned to the study of chronic illness as an area of human experience. Interactionist studies, pioneered by Strauss and Glaser (1975, cited by Pierret, 2003 and Bury, 2002) started to focus on illness narratives in order to understand how chronic illness impacted on daily life, and have contributed to a solid body of work on this topic. We'll make a very selective and resumed review of this work, discussing only a few concepts that seem relevant to our research.

Bury (1982) has coined the term “biographical disruption” to explain how chronic illness involves fracturing of biography[21]. His argument begins with acknowledging how the individual experiencing chronic illness is faced with the eminence of pain, suffering and possible death, which are normally associated with the “plight of others” (p. 169). The

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[21] The notion of biography, as Bury (1991) explains, suggests that “meaning and context in chronic illness cannot be easily separated” (p. 453).

individual is flooded by uncertainty, related to the course and forms of dealing with his disease, to the meanings of the experience and to disclosing illness to his significant others. Relationships have to be reorganised with the possibility of increased dependency, and the experience of stigma may compel the individual to a strategical retreat from social interactions.

Most importantly, explanations have to be created to deal with this new experience. Medical knowledge is seen as a symbolic system, which both facilitates and constraints understanding. Initially, the patient welcomes the relief of uncertainty and the possibility to hold the disease "at a distance" (p.173) that comes with the diagnosis. But the limitations of medical knowledge soon become evident, and the individual is forced to draw from the "cognitive packages" (p.178) available to construct meaning to his experience, which usually consists of an overlap of lay / moral concerns and scientific knowledge. G. Williams (1984) has found that the gap in medical explanation may be supplemented by "narrative reconstructions", where life events and the person's history are reviewed for meaning to be found. These reconstructions are necessarily co-authored, in relationship with other people and organisations, and embedded in their own previous beliefs and worldview. More recent research on interaction of chronically ill and medical doctors emphasise how patients are incorporating scientific knowledge to renegotiate their identities as patients (Pierret, 2003). Michele Crossley (1998) has shown how some HIV-positive individuals will actively refuse the sick role and chose an "empowerment" stance in the clinical relationship, asserting their experiential authority – despite the contradiction of their complete dependency of medical intervention to survive.

Building explanations helps the individual make sense of his experience and "re-establish credibility in the face of the assault on self-hood which is involved" (Bury, 1991, p.456). Meanings can be related to consequences or to significance. Consequences are managed in the best way possible, and information from other sufferers and self-help groups can help the person figure out how to deal with them. Significance is related to the illness symbolic connotations, which vary greatly according to contexts, and changes through interaction. Uncertainty about the significance of illness to others is always present, as the individual can not always predict their reactions. Significance has a deep effect on social interactions - negative meanings can lead to secrecy, for instance (Bury, 1991).

Even though, as we have argued, experience is simultaneously collective and individual, most of the research on illness experience has been dedicated to personal experience and to its effect upon close interpersonal relationships. Not much study has been done on the relationship of illness experience and broader social structure, such as health policies, healthcare system, patient mobilisation and the media (Pierret, 2003). It is, in the author's point of view, “the problem to be analysed” (p.17) in future research.

3.2 Identities

Identity – the constant remaking of the self

Identity is a concept that has “exploded” in academic and public discourses in the past decades. Freud has initially postulated the concept of identification, evidencing how the individual appropriates available models and images. Erikson was the first to give identity a significant theoretical status, emphasising the “identity crisis” in human development. According to Kaufman (2005)[22], Erikson's concept crystallised identity as a product and not as a process, which answered to a greater social demand – a need for an assurance that the problem of identity could be simply resolved through an evolutionary process, ending up with a finished, stable product. Later, identity would become a concept to be found associated not only with human psychological development, but with culture, nationality, ethnic groups, religions and corporations, to name a few. Social sciences, he argues, have treated identity as a concept that embraces all and explains nothing, as it has been amalgamated with previous concepts such as the individual, self, subjectivity, role and self- image.

Identity becomes the focus of interest exactly in the period where it becomes problematic, uncertain. As we have previously discussed[23], society has gone through a process of disaggregation (accelerated by the emergence of the modern state) which culminated with our current “society of individuals”. The self ceases to be defined by previous social roles, and a multitude of possible roles become available. This is first felt by the 19th century bourgeoisie, but later, with the end of the transition period, becomes the widespread mode of existence. Reflexivity, as Giddens (1990, cited by S. Williams, 2000) suggests, becomes a

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[22] We will rely heavily on Kaufmann's discussion of identity. This author has, in our view, proposed a comprehensive review of the concept in literature, problematising the theoretical confusion that is associated with this term, and proposing a more strict concept of identity.

[23] See page 14.

chronic defining feature of late modernity[24]. The individual now is constrained to define himself in the face of a contradictory socialisation, where a multiplicity of discourses and meanings no longer offer a single path. Identity is, to Kaufmann (2005) the means of responding to this cacophony of meanings. Each instant, in order to think or to act, the late modern self has to guide the individual through this profusion of possibilities. There is a simultaneous injunction to reflexivity, or to "reinvent yourself" (disintegrating meaning) and to "be yourself" or "find yourself", integrating and enclosing meaning. The tired individual finds himself in a difficult position, as Bauman (2004), explains:

> Longing for identity comes from the desire for security, itself an ambiguous feeling. However exhilarating it may be in the short run, however full of promises and vague premonitions of an as yet untried experience, floating without support in a poorly defined space (...) becomes in the long run an unnerving and anxiety-prone condition. On the other hand, a fixed position amidst the infinity of possibilities is not an attractive prospect either (p.29).

Identity serves as a grid through which the individual constructs his self. It is a subjective interpretation of the individual's attributes, which becomes an instrument to reshape the meaning of life, arbitrating the different meanings available. It is not, however, an enterprise of complete free-will. The capacity of arbitrage is limited, as the individual is always the product of his history, and the possibilities for the identity reconstruction are given by his context – the raw material for identity construction is social material. But, the key point is that now, more than ever, this possibility exists, and the individual can take some distance from his social context and rework the constraints of his socialisation. (Kaufmann, 2005).

And how exactly does identity operate? Kaufmann provides some hints of this process, drawing from previous concepts of sociology and social psychology[25]. Self-image, he argues, is the basic instrument of identity. They are imaginary reflections, guiding the individual's position in interactions. But self-images are very brief, almost instantaneous. They are used by identity, or by a type of identity that the author calls *immediate identity,* which corresponds to an operative "working self-concept", pragmatically compacted into an amalgam of images. Contrasting with immediate identity is *biographical identity*. Constructed not

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[24] Kaufmann uses "modernity" or "second modernity" to define the period we are currently living, whereas others, such as Giddens, prefer the term "late modernity" to underscore exactly the kinds of transformation Kaufmann is referring to. We prefer the term late modernity as it seems more clear to define the period that follows the transition period which culminated in the 1960s.

[25] We will only review a few of these concepts.

from images, but as a narrative, it gives coherence to the person's history, expelling the inherent contradictions of his self and providing a direction and a meaning to the individual's life. Between these two relatively opposed modes, the self hides his “multiple identities” (in a non-pathological sense) behind the coherent story of his life, while plurality is always lurking behind.

If the biographical identity attempts to unify the self, when the individual feels trapped in this fiction, identity is able to recreate the self through what Kaufmann (following Markus and Nurius) calls the “possible selves”. Possible selves are “virtual identities” (which are very near to fantasies, imaginary enactments of what the self could be) that have become viable, possible. They are the main form through which identity can be reconstructed. Virtual identities that are judged as achievable, when taking into account personal experience, social context and other people's reactions, are selected to become possible selves. The latter authorizes the reflexive work of the self upon the self, or how identity is reinvented by the subject. However, Kaufmann also stresses how recreating identity requires resources. The individual that disposes of more material, social and cultural resources will have a much larger repertoire of possible selves in order to recreate himself.

While the identity is formed by shared, social material, it can be distinguished from *collective identities*[26]. Collective identities, a central feature of social movements, are connections to collective references which are not only lived, but also imagined by the individual. They can be founded in concrete social interaction with a group, but they are also (and increasingly) based on ideas, stereotypes. They are an incredible source of energy and self-esteem to the identity, as the group can provide a positive identification - not infrequently, through opposition to other groups.

Illness identities - collective and politicised

The experience of chronic illness, as we have seen, has important effects to the identity. As it disrupts biography, it forces the individual to review his biographical narrative and construct meaning for his illness with the available cognitive packages. Individuals may simply reject illness as a part of their identity, but as chronic illness invades daily life this

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[26] See definition in page 20.

becomes increasingly difficult. In a sense, "illness floods identity" (Charmaz, 1983, p. 195). It intrudes upon the sick person's life and the lives of those around them. In the case of chronic illness, the sick person must reconstruct its identity to accommodate this semi-permanent intrusion. Some authors have proposed the term of *illness identity* to refer to this effect. Brown et al. (2004) defined it as "the individual sense of oneself shaped by the physical constraints of illness and by others' social reactions to that illness" (p.60).

What this illness identity will be depends largely on the meanings and narrative reconstruction performed by the person. While it is many times (perhaps most times) lived as a negative experience which is internalised in added negative aspects to identity, some authors have found that illness is not always disruptive to biography. Carricaburu and Pierret (1995) discuss how illness can entail "biographical reinforcement" in some cases. In a study of HIV-positive men's narratives, they found that being HIV-positive led them to reinforce their previous identities (the haemophiliac and the homosexual aspect of their identities, in this case). S. Williams (2000) reviews how recent research showed that different cultural and existential meanings can lead to illness being perceived in a non-disruptive way, and generating positive identities. Charmaz (1991/1997) explains how people with chronic illness may develop positive identities if they regard their illnesses as a path for transformation or self-knowledge.

Post-modernist researchers (reviewed by Bury, 2002) have suggested that biographical disruption or reinforcement would be replaced, in current, late modern configurations, by "biographical reinvention". The reflexive nature of late modern identity may involve not a reconfiguration with an endpoint (stabilisation and normalisation of identity) but an endless cycle of biographical revision and improvement. S. Williams argues that social changes ensue an increased tolerance – and even celebration – of diversity, that virtually alters the experience of chronic illness and the opportunities to reinvent identity. Again, it is sustained that this enlargement depends on resources, and not all individuals of a given society will experience this late modern difference-friendly environment.

Personal identity can be affiliated with different collective identities, as we have argued. When individuals who share an illness identity develop a "cognitive, moral and emotional connection with other illness sufferers, a *collective illness identity* emerges" (Brown et al, 2004, p.60). They begin to perceive themselves as part of this larger group of "peers". This collectivisation may occur through interaction with other people with the same illness:

> Interaction both aids an individual in finding an explanation for a life event and helps to forge a collective identity through the development of a particular discourse and a set of perceptions and ideas on how action should be mobilised. Borkman (1999), in a study of groups in the United States, comments that self-help, mutual-aid groups and new social movements draw on narratives about personal experience to reconstruct negative identities and to plan action. As Rogers and Pilgrim (2001: 109) suggest in relation to mental health users, a particular identity is both 'a ticket to entry and a source of solidarity' (Allsop et al., 2004).

This collective illness identity may be enough to pull individuals together in order to share their experiences, for instance in support or self-help groups. However, if that illness begins to be perceived by the group no longer as a personal problem, but as a social problem, a *politicised* collective illness identity may come into existence. Personal or collective illness identities can become politicised through a number of routes, all related to finding inadequate and growing frustrated with the institutionalized knowledge about a disease or condition (Brown et al, 2011).

Simon and Klandermans (2001) suggest that politicised collective identities emerge when three ingredients are present: awareness of shared grievances, adversarial attributions to blame opponents and the involvement of society by triangulation. In other words, a group must recognise their shared problems, attribute them to someone else (some other group or category in society) and see themselves as members of a larger society, which they request to take sides and support their struggle.

Health social movements actively politicise the collective illness identity by focusing attention on the role of power and politics in shaping the forces that lead to disease. Part of the breast cancer movement, for instance, politicized collective illness identity through its critique of the medicalisation, objectification of the female body and environmental degradation. Transforming identity is an instrument, however, not a goal for social movements. The breast cancer movement at least partially achieved their goal when they were able to transform the "disease regime" of breast cancer, altering the social experience of women with this condition (Klawiter, 2004).

3.3 Experience of mental distress and identity

Grasping the experience of mental distress is not a common theme of research in psychology or psychiatry. As it is suitable for modern scientific disciplines, psychiatry and psychology rely on classifications, models, detailed description of basic processes, preferably derived from experimental studies or – even better – hard technologies like neuroimaging, to understand mental distress. When narratives are employed, they are subjected to the analytical frameworks of the experts, who have little interest in the person's meanings for her experience.

Some exceptions are to be found, however. Geekie and Read (2009), for instance, have authored a book about the experience of madness, where they analyse first person accounts of people who experience psychosis. They have found that each participant held multiple explanations for their psychosis, the majority being related to previous life events, but biological and spiritual explanations were also frequent. Explanations of mental distress often overlapped with their identities – they found that a very common perception of psychosis was as a "disintegration of the self" (p.54). One of their main findings is related to the impact of psychosis upon identity:

> It seemed that the experience of psychosis sometimes shook the very foundations of the person's sense of self, leading the person to question some of the most fundamental aspects of being. One of the most pervasive and troubling features of this was in participants coming to doubt their own perceptions and thoughts about the nature of reality. (…) This commonly led to questions for the individual about his or her own judgements, and a loss of faith in one's self (…) leaving the individual feeling very uncertain and rather fragile. (p.65).

Karp (1996) offered a similar analysis of the experience of depression. Through the use of interviews and of his own experience of depression, the author found that depression affects greatly the person's self and identity. He divided the depressed person's career in four stages. The first is a stage of incoherent, nameless feelings, where the person can't really understand what is happening. The second, when the person concludes that "something is really wrong with *me*", ascribing the feelings of sadness and disconnection to her own self. Then, a crisis stage, where she enters contact with mental health professionals, and fourth, a stage of coming to grips with an illness identity, where they theorise about the causes and evaluate the prospects of getting beyond depression. Each of this moments, the author argues, forces the self to be redefined. The respondents ultimately conclude that they possess deeply impaired selves, not that they experience troubled times, or what would be a "normal" state of sadness.

Another form of understanding the experience of mental distress is through patients' own writings. Jones (1997) has reviewed some of these literary endeavours which attempt to explain this experience. They talk about their struggle with mental distress and the trial of mental healthcare. Some are successful stories, others have no happy endings and tell the damaging effects of mental health treatments. More recently, these first person accounts began to enter the select realm of scientific journals, a fact that illustrates how experiential knowledge is (just) beginning to be valued by academia. Some interesting examples are Leete (1989), Chadwick (2007) and Bassman (2000), but there are many others. Leete explains the management strategies he developed throughout the 20 years he's experienced schizophrenia – like getting rid of paranoid thoughts by asking people to explain things, fighting isolation in a peer-run support group and using certain techniques that calm him down without appearing too "bizarre" (such as using a rocking chair to rock back and forth). Chadwick, a psychologist who also experiences schizophrenia, offers his account in a scientific language that can be better appreciated by his colleagues. He explains in detail a psychotic crisis, and how fair assessments of stigmatising attitudes triggered and were then overblown by his delusions.

Bassman (2000), another survivor-psychologist, describes a terrible experience with services. At 22 years old, in 1966, feeling trapped and miserable in the life he had chosen for himself, he decided he would explore his internal world, inspired by yogis and spiritual leaders. He believed he could do whatever he wished with his mind, and was amazed by the possibilities. As his family found him to be too strange and different, they took him to a psychiatrist. Without exchanging a single word with the doctor, Bassman was committed to a psychiatric hospital. He only remembers, afterwards, waking up naked and heavily sedated in a strange, hospital bed in an isolated room. He sees the stay in hospital as a "training to passivity and dependency" (p. 1399), which is very easy to agree with after reading his account. Even though he acknowledges that he was in a confused psychotic state, he saw some value in that state (which is not infrequent to happen with people who experience altered states of mind). He believes that another kind of help was needed, and resents the deep changes in his identity that recurred from insulin comas and other types of "treatment".

Parts of the experience of mental distress have been incorporated, in recent years, to mainstream fields of research in mental health. This is in line with a current within mental health research that believes personal experiences are important to treat mental distress and promote recovery. The two most prominent aspects of the experience of mental distress that are objects of research are stigma and illness beliefs / explanatory models. The first, addresses how stigma is felt and how it may be internalised by some people, which has a significant negative impact over their recovery (Rishter & Phelan, 2004; Watson et al, 2007; Dinos, 2004). Corrigan and Watson (2002) suggest from their research that self-stigma is associated with the perceived legitimacy of stigmatising behaviours – if the individual believes stigma is legitimate, he is more likely to have low self-esteem and self-efficacy. On the other hand, those who don't recognise the legitimacy of stigma can either be indifferent to it or feel angry towards stigmatising conditions. The difference is mediated by group identification with the stigmatised group. When this identification is present (a collective identity, to use our framework), the person will turn her negative feelings towards the stigmatising group. Otherwise, she may feel indifferent to stigma.

Research on illness beliefs is still incipient but becoming more established, as researchers have found that people with severe mental distress create meanings for their distress which not always coincide with those proclaimed by their doctors or therapists. Some interesting findings of this line of research is that "insight" (understood as "accepting" the idea of mental illness and medical explanations) has found to be associated with depression in psychotic subjects (White, Bebbington, Pearson, Johnson & Ellis, 2000).

Birchwood, Iqbal, Chadwick and Trower (2000) also found that after a psychotic crisis, individuals who felt loss, entrapment[27] and humiliation because of their illness were significantly more depressed than others. This appraisal of their own experience and of its social effects were more important than any other aspect of the psychotic experience to predict depression. The authors suggest that coercive treatment may increase this feeling of loss of control, when in fact control should be promoted. Similarly, Davidson and Strauss (1992) found in their research that the rediscovery and reconstruction of an identity as an active and responsible agent, develops a functional sense of self which is an important aspect of recovery. In order to create this identity, they suggest that a more active and collaborative role for the person is needed. Corin (2002) found through narratives of people who've had a psychotic crisis, that finding the words to convey experience, recovering control over daily life

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[27] Defined as loss of control over self and illness.

and creating a social space where they can be different[28] were the most important aspects to prevent further hospitalisations.

The parallel with chronic illness, then, can be fruitful but only in limited ways. While social isolation, stigma, the need to create meaning, its disruptive and uncertain nature may be shared by both kinds of experiences, the experience of mental distress has further implications to the self and identity because it is the mind that's affected, not the body (or the body in a less important way). Also, it can be argued that, because of this inseparability of self and identity, the stigmatisation of people with mental distress is even a greater problem that the stigmatisation of the chronically ill, and can lead to further mental distress (like post-psychotic depression). Finally, there is no comparison of the ordeal that chronically ill people go through in health services and what can happen to someone with mental health problems. The latter experience treatment against their will and incarceration, in a way that no person with physical illness will ever experience. The damaging effects of these treatments can be much greater.

3.4 Experience of mental distress and service user movements

As we have previously pointed, there aren't many studies on the subject of service user movements effects on the experience of mental distress. Here, we will review the very few that refer to this subject – one directly and others indirectly.

The only study, to our knowledge, that focuses on this specific issue is was performed by Lee (2007). She analysed narratives authored by activists of the North-American, Canadian and British service user / survivor movements. Those narratives were collected from books, articles and internet sites. She uses the framework of empowerment, symbolic violence and social capital to refer to the personal transformations she has noted in these narratives. Basically, she found that survivors narrated their experiences before engaging with the movement as marked by powerlessness and symbolic violence. Specially detrimental were their experiences of coerciveness and repression in mental health services, followed by dependency. They also report having a stigmatized identity and doubting themselves deeply, which led to social isolation, and a general feeling of "broken spirit" - having no hope and giving up.

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[28] She suggests that a certain “positive withdrawal” is needed, where the individual may create a life at the margins, a place where he can be in social contact but not overwhelmed by social interaction.

Among the transformations, she noticed how self-disclosure was made possible and was a first step in the construction of a positive identity. Their experiential knowledge becomes cultural capital, as it is viewed as a form to help others in their journeys and to denounce oppression. Their social capital is also increased through interaction with peers, which breaks with the pattern of isolation previously dominant.

Other researches we've come across were not directed to user-led organisations or movements, but indirectly address this issue, looking at how the experience of mental distress is transformed through empowerment and involvement. Onken and Slaten (2000) have analysed, through the framework of Disability Studies, how people with severe mental illness changed their identities through a disability discourse. They found that participants had intense feelings of shame, comparable to those encountered in other disabled people, as society reacts negatively to their difference. Participants were able to gradually (through seven stages they have identified) transform this identity of shame into a positive identity, associated with disability culture, which celebrates difference as a source of pride (very near to what S. Williams has described). The authors fail, however, to provide a social context for this transformation – they mention in passing "disability groups", but the individuals were recruited from regular social and health services. It is difficult to understand if they are referring to a universal transformation or to a localised effect.

An interesting work on the subject is that which Herman and Musolf (1998) developed in Canada and the USA. They performed an extensive ethnography with more than 300 participants, to study resistance among ex-psychiatric patients. They analyse this process through a culturalist framework, arguing that a sub-culture of resistance emerges among participants, based on the creation of shared rituals to "save face" of deviants. Even though we don't subscribe this culturalist approach, some findings are relevant to us. Although individuals were not engaged within any larger social movement, they initiated these resistance behaviours individually or in small groups, as a form of rejecting the deviant identity that they had internalised after having been through psychiatric hospital. They employed "offensive" and "defensive" strategies. The first included political activism, which they found was the most central in providing a positive non-deviant identity, enhancing self-esteem and finding a new sense of purpose. It also had social consequences, as it propagated a new, positive image of the ex-patient to society, where he is capable of self-determination and political action. Political action was performed exclusively by non-chronic patients, as chronic patients still struggled with the consequences of institutionalisation, side effects from large dosages of medication, and were still placed on highly controlled environments. The authors also refer to a process of "stigma conversion" (Humphreys cited by Herman & Musolf), in which ex-patients reframe stigmatisation not as personal failings but as societal problems, which allows them to develop more positive identities.

With the increased involvement of service users in services and politics, some researchers began to be interested in the therapeutic effects of these participatory practices. Nelson, Lord and Ochoka (2001) have analysed how participation in three mental health services, which operated under an empowerment logic, affected service users. They found increased self-confidence, control over daily life and independence of service. Community integration and creation of positive identities were also found among participants.

Barnes and Bowl (2001) analysed how both participation / consultation practices and self-help initiatives impacted on service users' mental health. They found, from their own research, that participation and consultation activities tended to be detrimental to mental health. Participants reported not being able to make decisions except in very limited terms, and that they usually felt patronised and unheard. Some, however, had positive experiences – they had their input valued and felt they made a difference, however small. These users gained in terms of their perceptions of their own competence and confidence. Regarding self-help, the authors have reviewed grand-scale studies about the effectiveness of this kind of practice (e.g Segal et al, 1993; Trainor et al, 1997). Their evidence supports the idea that self-help groups are generally beneficial to their members. They produce increased self-esteem and confidence, lower dependency, increased community integration, increased sense of control over daily life and construction of positive identities, as service users discover they are able to help others as well as being helped.

Finally, we would like to address an issue related to the rhetoric of empowerment associated to therapeutic effects. Empowerment can be thought as an individual and/or as a collective process. When the emphasis is too strongly on the individual, researchers and mental health practitioners may focus on increasing the cognitive aspects of empowerment, instead of really creating services based on partnership and shared decision-making. Barnes and Bowl (2001) recognise a tendency to reframe empowerment in practices, transforming it into an "intervention technique – something professionals 'do' with their clients" (p. 96). Patients are conceived as recipients of empowerment, in an obvious logic contradiction, since it is arguable whether someone can be empowered *by* anybody else. In this view, participation ceases to be a tool for social change, and becomes aimed at individual change. Conceiving user involvement or activism as a therapeutic tool prevents service users from being, in effect, empowered.

Judi Chamberlin (1978), survivor activist, has a piercing observation about the distinction of therapy and “consciousness raising” activities. While one is firmly grounded in professionals' views and aimed to adapt the individual to society, the second stems from dissatisfactions with this society, and the desire to change it.

> Consciousness raising is not “therapy”. Therapy has as its goal adjusting the individual to the “reality” of his or her own life. Therapists (particularly in mental institutions) seldom question the assumption that the underlying social system is a benign influence on people's behaviour. In a consciousness-raising group, on the other hand, people begin to see that much of what they had viewed as their own individual problems are responses to real frustrations. (p.65)

We share her point of view, and feel that social movements and service user participation should not be instrumentalised as therapy. This doesn't mean, however, that they won't have beneficial consequences for the individuals engaged with them. Judi Chamberlin is one who has thoroughly recognised these consequences. Other authors have also acknowledged that participating in any kind of social movement can have important effects to identity and self-worth (for instance, Andrews, 1991; Della Porta & Diani, 1999, Chapter 4). The process, however, won't be focused on adaptation to a given social configuration, but to challenges to this configuration. So, it is our perspective that engaging with social movements are transforming experiences, even though this is a “side-effect” of a movement that is actually aimed at greater social change. It is expected that when a service user engages with the SUSM, his experience of mental distress will be affected (positively and/or negatively) and his identity reconfigured. The objective of the research is simply to better understand how this process of transformation occurs.

PART II

METHODS AND RESULTS

Chapter 1:

METHODOLOGY

Our methods for conducting the empirical research will be presented in this chapter. First, we will explain how the methodological approach for studying the impact of engagement with the SUSM to the experience of mental distress was designed. Following that, the construction of the sample of participants will be presented, as well as some characteristics of the participants to characterise our sample. The next section deals explains how the in-depth interviews took place and how the interview guide was built. Next, we address data analysis, detailing our approach based on grounded theory. Limitations and ethical considerations will also be addressed in the end.

1.1 Constructing a case and designing a methodological approach

Scholars have pointed to the need of studying the effect of health social movements or patient mobilisation on illness experience (Pierret, 2003; Brown et al, 2011). Our own interest in social movements, health and mental health impelled us to this topic. Being in a foreign continent meant we would have to study an unfamiliar reality – which has its rewards and inconveniences. Literature research led us to find out about the British SUSM. As we read more on the subject, it became clear that it was a well-documented health social movement (the most significant studies are Rogers & Pilgrim, 1991; N. Crossley, 1999, 2004, 2006; Barnes & Bowl, 2001; Wallcraft et al, 2003), which provided the contextualisation needed to approach an unknown field.

Opting for a qualitative method was a logical choice. First, because it is an exploratory research on a topic on which not much is known. Second, because grasping experience would mean that an in-depth understanding was needed. A qualitative research is a more appropriate procedure to analyse individual and social meanings, practices and knowledges, interactions and interrelations (Flick, 2005).

Studying a social movement's impact on personal experience is a challenging task, since it is an object that refers simultaneously to social and psychological processes, while we were concerned to resist the excesses of both social determinism and psychological reductionism. Deciding on a methodology was not helped by the fact that there aren't, to our knowledge, many similar studies on this topic.

However, most of the research produced on illness experience is based on semi-structured, in-depth interviews. Even though some recent criticism has been made on the widespread use of this method and the importance to enrich data from other sources (Bury, 2001), we have decided to follow the tradition of semi-structured interviews. First, because they are an established method to study illness narratives, and were also proven fruitful in research with social movements (Poletta, 1998, 2006; Andrews, 1991; N. Crossley, 2006). Second, because we had some previous experience conducting interviews (in research and clinical settings) and it fitted our time schedule. Even though we believe now that ethnographic and documentary data would certainly have enriched our study, they were not possible choices for our methodological design. We will address this again when discussing the limitations of the study.

Therefore, the chosen methodological design was a qualitative research, based on a case study (the British SUSM) to discuss its effects upon the experience of mental distress. Even though it would be interesting to find if the SUSM had an effect upon British mental health service users' experience on a whole, analysing its impact over the "disease regime" (Klawiter, 2004) and its reflection on service users, this would require a wide knowledge of the SUSM's and of the British context – a knowledge we did not possess and were not in position to build. As a consequence, we decided to conduct in-depth interviews with service users *who were engaged* with the SUSM and find out how this engagement had impacted their experience. This would allow us to analyse a more direct effect on their narratives.

It also, however, involves a possible bias, since activists tend to be very emotionally involved and affiliated with the movement, and would tend to emphasise, perhaps, the positive attributes of being engaged with the movement. Although this has probably happened, to some level, we also found that our participants were able to present some criticism towards the movement. This is what Dubet (1994) has called the "subjective distance" that contemporary individuals maintain with the social system, as they no longer adhere totally to roles or values which have no internal coherence. Likewise, our participants were not totally adherent to the movement, and were able to talk about its conflicts and negative effects as well. Hence, we believe this "bias" was not too pronounced. However, it must be noticed that no unbiased position is possible, since narratives and experience are always socially constructed and mediated.

1.2 Sample

As we have discussed in Part I, a social movement is an informal entity, characterised by a low degree of institutionalisation, a lack of clearly defined boundaries and decision making structures. Hence, locating individuals who are part of a social movement is not simple. We have decided to use organisations and formal groups as a channel to reach these individuals. The first step to construct the sample was building a database of all British service groups and organisations we were able to find online, with their respective contact addresses. This database amounted to 47 groups.

We then contacted each of these groups through e-mail, presenting the research project and requesting if they were interested in disseminating to their contacts the invitation to participate. We received 19 replies from these groups: 5 positive, 4 negative, 7 interested but requesting further information, and 3 informing us that the person in charge was analysing the request[29]. Since we had a significant number of interested groups (12), including some groups with very large constituencies, we decided to filter these groups and select only those that were *service user-led*. This means we excluded user groups and organisations where decisions were not taken by a majority of service users. This, we felt, meant we were one step closer to what the SUSM would represent.

Happily, all the 5 positive responses were from service user-led groups. This has left us with a number of 7 interested user-led organisations, namely: Barking, Havering & Brentwood Mental Health User Group (HUBB), Independent Newham Users Forum (INUF), Survivor History Group, Hearing Voices Network, Emergence, Developing Partners and the National Service User Network (NSUN). As the interviews were scheduled for August 2011, in the end of June we renewed contact with these groups and sent the invitation e-mail that was supposed to be forwarded to their contacts. Unfortunately, at this point 5 groups either decided to withdraw from the study or didn't reply our contacts. This left us with only 2 organisations which, in the end, assisted us with the recruitment: Emergence and NSUN. It

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[29] We never received any further feedback from these three groups.

wasn't such a significant disadvantage because they were among the largest user-led organisations in our database, which means a considerable number of service users was invited to participate in this research. It should be clarified that participants are not necessarily members of these organisations – they were part of their contact lists, but many were involved with different organisations than those two, and most had been through different user organisations and groups throughout their lives.

As we began to be contacted by interested participants, we would explain the terms of the research and ask them *if they viewed themselves as a member of the service user / survivor movement*. We decided to use this self-declared affiliation as the main selection criteria[30]. Those that weren't sure what the SUSM was, we provided a simple explanation, loosely based on the definition proposed by Wallcraft et al (2003). If they remained interested in participating and they fitted the criteria, arrangements for the interview were made.

We were able to perform a number of 12 interviews during the month of August 2011, in 6 different locations in England. While our expectations were greater, it wasn't financially viable for us to stay in the UK for a longer period of time and attempt other forms of contact. However, as it will be seen in the Results section, the interviews were very rich, with a level of openness that perhaps isn't easily encountered. The data was sufficient given the exploratory nature of this research.

In Table 1 we characterise the participants' age and gender, replacing their names with pseudonyms. In Figure 3 their geographic distribution is given in agglomerated form, to guarantee confidentiality.

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[30] Having had first-hand experience of mental distress was obviously an important criteria, but this was already established in the invitation for participants, and so it wasn't necessary to dismiss anyone based on this criteria.

Pseudonym	Gender	Age (years)
Adam	M	40
Annie	F	51
Emma	F	58
Gordon	M	73
Harriet	F	65
Karen	F	35
Marianne	F	62
Ralph	M	61
Roger	M	54
Rose	F	52
Sally	F	42
Valerie	F	40
Total	8 F /4 M	
Mean age		52,75

Table 1. Age and gender of participants

Figure 3. Place of residence of participants / location of interviews[31]

Regarding their experience of mental distress and use of services, the sample was also

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[31] All the interviews were conducted in the cities of residence of participants, with the exception of one who lived in the rural area, and the interview took place in the city nearest to his residence.

very diverse. The severity of mental distress was great in some cases (Roger, Rose, Sally, Valerie) and milder in others (Karen, Annie, Gordon), with the rest of participants lying somewhere in between. Most had been to psychiatric hospitals (Valerie, Ralph, Adam, Marianne, Emma, Sally and Rose) or therapeutic communities (Harriet, Annie, Sally) while some were only treated as outpatients in specialised services or primary care (Karen, Roger, Gordon). This was also very rich since we were able to have an idea of how the different experiences of mental distress were affected by the involvement with the SUSM and vice-versa.

Although we didn't ask for information on instruction levels or income, we can also say that social class and educational background varied greatly. Some participants mentioned coming from poor families (Roger, Ralph, Rose) or having low levels of formal education (Roger, Ralph) while others had Ph.D's (Valerie, Karen, Marianne) or came from middle and upper class environments[32]. More details on participants' biographies, engagement with SUSM, occupation and experience of mental distress will be given in the Results section, as their narratives unravel.

1.3 Interviews and questions

The interview guide was constructed based on Gillham (2000). This author suggests that semi-structured interviews should be constructed in a way to allow the emergence of content during the interview. Very few open-ended questions were created, based on our research interests, and a number of *prompts* was listed to guide the interview. Prompts are points or topics that we needed to make sure were covered by the participant. If the participant brought these topics himself, there was no need to pose a question. Otherwise, the prompt was there as a reminder to question the participant on this topic.

Initially the interview was divided in three parts: the first, about the experience of mental distress, the second about the engagement with the SUSM, and the third about the impact of the SUSM to their experience of mental distress and to the greater social context. Performing a pilot to test the interview guide was not possible, since the questions only make sense for the very specific subject of our research (service users involved in social

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[32] Emma was the only one who mentioned coming from a wealthy family, but most participants were at least middle class judging from their homes or their work positions.

movements). Since we only had access to a very small pool of participants, we decided to use the interview guide without prior testing. The first interview was conducted with Karen. It was a successful interview in many respects and it provided valuable information, but we found that beginning the interview asking about personal experience was too abrupt, and made the participant very defensive of her privacy. So, we decided to start with the question about the SUSM and leave the experience of mental distress for further on, when the participant was more relaxed. We also emphasised more in the initial rapport that the interview would address private matters, but that the participant should disclose only to the point he felt comfortable to talk about.

The other interviews were very satisfactory and no other significant changes were made to the script. The final interview guide can be found in Annex A. Overall, we attempted to follow the participant's narrative, using *probes* to keep the conversation flowing and to develop interesting subjects (i.e. asking for clarification, showing appreciation and understanding, asking for justification and examples, checking the consistency of the narrative, etc. - Gillham, 2000). Patients dictated the pace and sequencing of interviews, and were able to speak as much as they wished, within the concerns of the interview. Most took place in participants' residencies or workplaces, while three were conducted in public venues.

Each interview lasted between 47 and 120 minutes (average of 90,5 minutes). All interviews were recorded in audio, with participants' consent and fully transcribed, to the best of our abilities. The maximum word count of the transcribed interviews was 17.584, the minimum 6.386, and the mean 12.058 words per participant (total of 179 pages of transcribed material). Because of the language barrier, aggravated by some participant's accents, pronunciation or background noise, some words we were unable to decode and transcribe. In Annex B there is a guide of the transcription conventions utilised.

1.4 Data analysis

Data analysis was done according to the inductive strategies of grounded theory (Charmaz, 1995; 2006 – Richards, 2005 and Kaufmann, 2011 were also guiding references to the analysis). As Charmaz (1995) affirms, grounded theory suits well the analysis of "reciprocal effects between individuals and larger social processes (…) typical social psychological topics such as motivation, personal experience, emotions, identity" (p.29). Adopting a grounded theory approach means we didn't depart from pre-conceived hypothesis, but developed our hypothesis from the data available.

All the interviews were coded using Atlas.ti software. We started with line-by-line coding, which was profitable because it forced us to do a very attentive reading of the text, not only coding general themes but discovering the richness of meanings in each line. After the first phase of initial coding, we proceeded to focused coding. In order to select the most significant codes, we found it useful to use Atlas.ti's tool of "network views", where codes can be disposed graphically, in diagrams. Relations between codes were created and similar codes were merged together, to form a more comprehensive code. After narrowing down our codes, we reviewed the coding, and rearranged them as needed to accommodate the data. All codes were defined (using "code comments") to prevent overlap and to make sure they were coherent.

Axial coding, the next step in grounded theory, is done by reassembling the data in categories and subcategories in order to restitute coherence to the data, "converting text into concepts" (Charmaz, 2006, p.61). It was done through "codes families" in the software. Families helped us group codes that related to a similar topic, and filter quotations results. This way, we could assemble codes in broader code families, generate outputs (quotations from interviews related to each code) and check for the consistency of codes and families. Throughout the whole process, we wrote "memos" in order to log our ideas, hypothesis and perceptions during the analysis, which would be the basis for the emerging theory. The use of memos prompts the researcher to analyse his data and his codes, parallel to the process of coding (Charmaz, 2006). Emerging hypothesis and ideas were tested through extensive searches throughout the data, looking for connections, patterns and contradictions.

These procedures required a lot of time and detailed attention to the content of interviews, with which we became intimately familiar. As time and work progressed, we ended up with a somewhat coherent "grounded theory", where some hypothesis grew stronger and others were discarded and abandoned. We synthesised this emergent theory in a short text, were the main ideas and hypothesis were gathered. They were all tested again, through reading outputs, searching text and codes, and final rearrangements in the categories were made, to fit the data. The text was rewritten and formed the basis for the next chapters, where this short text was developed and the most significant quotations from participants narratives were added, to illustrate and sustain our analysis.

1.5 Limitations

There are many limitations to this research that must be acknowledged. First, we approached a subject and a context with which we were unfamiliar. This certainly has granted some advantages. Many participants decided to take part in the research exactly because we were an "outsider" to the context. No previous history linked us to the SUSM groups or specific people within the movement, and this, we believe, was crucial to having such a rich and varied sample. Being completely unknown to participants also made it easier for them to be more open and less concerned with our judgement. Also, many participants mentioned being intrigued by our background, and were thrilled to share their experience with someone from a different continent who was interested in the British context.

However, our quality of outsider also meant we had no insider knowledge and contacts which could have been important to construct a better sample. We relied on the internet as our source of information to construct the groups database, and that is certainly flawed. In addition, it was perhaps our quality of outsider that prompted many of the non-responses from organisations and individuals. We also lacked an insider understanding of the cultural and political context in which participants were inserted. Perhaps we would have asked different questions and would be able to explore their answers more thoroughly, if we were more familiar with this context.

Language was also a barrier. During the interviews, many times we didn't understand fully what the person was saying. Although we interrupted participants frequently to clarify meanings, some specific meanings were only decoded afterwards, in the transcription (while others, neither then). This has probably had an impact on the questions we were able to ask during interviews.

Another problem were the constraints to collect data. As we were only able to be in the UK for one month, it was impossible to perform theoretical sampling (Charmaz, 2006), that is, going back to the field and gathering more data after beginning the analysis. Analysing the data, indeed, pointed to us its incompleteness, and it would have been extremely positive to be able to return to the field and conduct some more interviews. We have already noted how our choice of methods was limited by time, financial and cultural resources. Probably the research would have benefited of participant observations and a further, more extensive contact with the SUSM, which we weren't able to produce.

Finally, it must be acknowledged that the results of this research should be read carefully, as it is an exploratory study, with a small sample of subjects and a series of other limitations which don't allow for generalisation of any kind. However, we are also aware that data is always limited and that a master thesis has modest requirements, which we believe we were able to meet. Furthermore, as an exploratory study it provides some interesting hypotheses for this emerging topic, which could be explored and tested by other researchers in future occasions.

1.6 Ethical considerations

This research was approved by the Ethics Committee of the University of Évora in May 2011 (Document #10039 – Annex C). All participants were explained in detail, first by e-mail and then at the moment of the interview of the objectives of the research and the terms of their participation, including the recording of the interviews. All participated voluntarily and signed a term of informed consent (Annex D).

The only risk we had anticipated was the interview causing the participant to remember bad experiences, and the memory of the experiences having a troubling effect. To control for that, we asked for all participants for feedback after the interview, regarding how they felt during the interview and afterwards. We always received positive responses and no participant referred feeling troubled after the interview.

Confidentiality will be guaranteed in this research, since the names and personal characteristics of participants will be either replaced or removed from all publications. We are also committed to returning the results to the participants. After the discussion of this thesis, we plan to transform the results in a newsletter and send it to participants, so that they can have facilitated access, in non-academic language, to the final research. If requested, access to the full thesis will also be provided to participants.

Chapter 2:

THE EXPERIENCE OF MENTAL DISTRESS

The central question of the present research is to understand the impact that engaging with the mental health service user / survivor movement has upon the experience of mental distress. In order to approach this issue, we have divided the analysis into three sections, each discussing one of the general topics that were already given in the structure of the interviews, and which represent our research interests: the experience of mental distress, the SUSM and the interaction between them.

This chapter examines the experience of mental distress, or how mental distress was experienced in the past and/or is still experienced in the present by the research participants. through their narratives we hope gain some insight on this experience – always bearing in mind the epistemological limitations of studying experience and the limitations of our own study, which we have just discussed. The process of constructing meanings for mental distress will be analysed, as well as the constraints imposed by social conditions, which shape the social experience of mental distress. Also, the effect of mental distress to the personal identities of service users will be explored, as it is apparent that identities need to be rearranged because of this new, disruptive experience.

2.1 Narrating experience

Exactly what each person experiences as their "mental distress" varies greatly. Many talk about an unease at being in the world that might remount to childhood. Most describe a significant moment where it seems it all became too much and the person has their "breakdown" - a point where an invisible line is crossed and everything changes. It is, in a sense, an experience of otherness, where what was deemed as sure becomes unsure. The self is no longer stable or trustworthy - in some cases it never was. Intense emotional pain usually accompanies this alien experience, sometimes so unbearable that attempting on life becomes the only option. But, as life stubbornly continues, the person needs to learn to pick up her pieces and reconstruct her life again – even if just for a few moments, life must regain meaning, somehow.

As we have discussed, immediate experience is out of our reach in this research. The only access to experience we can hope to have is through narratives. As we attempt to have a glimpse into the world of mental distress, we have decided to let the participants, first, speak for themselves. No interpretations will be provided of their narratives in this section, as more words would only add undesirable layers. Clearly, our selection of extracts is already an interference, although inescapable. We have chosen extracts that illustrate the emergence and the singularity of mental distress, whilst maintaining the diversity that characterised the ensemble of participants. It seems coherent to let the reader get acquainted with participants' worlds and experiences, before proceeding to the analysis.

> It started as a three year-old, from where I'm sitting now, in Manchester[33], near the famous Brick Road, where I lived. There was a specific crime family I lived in the same street as. And one day they had a bonfire in the back lane, a big fire, that had been smouldering down, with still flames and red ambers and red hot ashes. And as I walked up to them, with their brother behind us, till they snatched me, just as I walked up to them. And they've thrown me into the middle of this fire, and there was scolding ambers everywhere.
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> And I was like superman flying in the middle of this fire. With my arms stretched out to save myself from these metal springs. And as I landed I started screaming and trying to put myself out of this fire (...) I charged down the lane, I was above myself and watched myself charge down the lane. (…) And all I could see was the four windows of the house. I was in that backyard, but I was also behind myself, watching myself still, which is an incredible experience. Above myself, watching myself. (...) In reality I'm probably actually running down the lane, just seeing what's happening. But because it's so traumatic, and I'm reliving it, I somehow got behind the camera. (…) That's the only way I can describe it, cause it repeats and I kind of got behind the camera somehow. (…) Because I was so traumatised, I really believed I was above myself watching my self. But that's what counts, if you feel like that, that's what you're actually doing in reality, your own reality. That's what actually is real. (*Roger*)

> I was very shy, withdrawn as a child, and I didn't cope very well when I became a young adult. I still couldn't really talk to people. And then I got... I went to teach a training college and I couldn't really cope at teacher's training college. I was very political but I wasn't good at talking to anybody, really. I could talk to one person at a time, or I could get very involved in a particular political thing, but not... I couldn't do relationships. So I had a breakdown, I did one

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[33] All references that could identify participants were anonymised, and replaced by fictional information, only to maintain the flow of narrative. When not possible to provide fictional information because the reference is too specific, the information will simply be suppressed and context will be explained.

year at teacher's training college and I was very bad at teaching, cause I couldn't stand up in front of a class. So I quit. I left the college and then I got very depressed, I took an overdose. And I just didn't see any point in living, really. I couldn't think about it, I didn't know what was going to happen in my life. I just wanted somebody to sort it out for me. (*Marianne*)

It took a long time to work out that it was mental distress, cause I had a lot of physical illnesses. I just ignored how I was feeling and so it came out in migraines and a bad cold that just didn't get better. So I was.. I think I was off work for a good 6 months before they even worked out I was depressed. Cause it was a bad cold, and not talking - to save my throat, of course! (giggle). And just shutting off. But it was all physical symptoms and not thinking about the feelings. (...) I was just all tired and floppy and shut down. (…) I think I mostly felt if they would all just go away and leave me alone, I could be perfectly happy locked away in my room, reading a book, drinking cups of tea and ignoring everything. But people kept wanting me to do things, and go to the doctor, and go to the therapy and come out and talk to them! (giggle). (…) *But*] I wasn't really OK. That was just how I was at the time. But I think you don't really see how bad you are when you're inside something. (*Annie*)

I became ill myself in 1990, because of circumstances like.. There was a mortgage to pay after have … buying a house. It just sky-rocketed under Margaret Thatcher's government. And... my husband and I splitting up because he was not doing his part and having two children to look after and working full time, as a teacher, a primary school teacher, working part time, mainly evenings, doing my own fashion design and occasionally working as a care assistant, looking after the elderly. (…) So basically as a result of all that work, all the stress of the finance, all the stress of a bad relationship, all the stress of looking after the kids, and the jobs themselves, and the fact that I'd also had quite a traumatic childhood, quite a violent past and a very domineering and overbearing mother, and all of these things (collided) and it ended up with me having a nervous breakdown in August 1990. (…) So yeah... So then, that happened. And my children were put at risk. I became paranoid, I thought they were demon possessed and I was doing various things to try to get the demons out of them. And one of them... I bathed them in lukewarm water, and I put nettle in there to try to get the demons out and prayed over them, but obviously it didn't work. And then another time, just driving around, getting rid of stuff that just reminded me of my mother and demons and stuff like that. (*Rose*)

I've always had, when I... was beginning to get depressed, I always had a lot of inexplicable weep. So I'd be sitting, doing something, and all of a sudden I'd be crying. That has happened since then.. (…) And there are times when I'd collapse. Just.. I can remember going for a shower, we were actually away, myself and my wife, we were away in the country, we had a cottage, and there was a shower at the bottom of the stairs, in this cottage. And I went for a shower and I didn't know what had happened to me. She found me some time later, sitting, crying in the shower. I didn't know what had happened myself. (*Gordon*)

My brain overworked. (…) My appetite went, my sleep went, my stability went, and I was in kind of total denial, cause I never had a breakdown, and unfortunately it happened at work, my manic episode, which kind of, didn't do much for my career. I was in total denial. (…) I expected a breakdown to be.. when you just collapse in a heap on the floor. And you know, you're just broken down. But mine was totally different. (...) I began to get a bit paranoid with all the lack of sleep and loss of appetite and all that, losing my security with my partner, because he left. And the only thing I seemed to have control over was my job. And I never not worked, and I always thought “if I don't work, I'm gonna go crazy”.(...) They could see a difference in my behaviour. But I couldn't, or wouldn't admit it to myself. I wouldn't, actually, because I kind of felt different. I had more energy. I did feel different. I felt I had a lot more spirit about me. It was like all the depression I had felt, things had bottled up, was all of a sudden coming out. There was quite a bit of paranoia there, and fear. (…) I actually was sectioned by the police in hospital. I went into work and I trashed my workplace, basically. When I say trashed it, there was no clients in, thank goodness, but I assaulted my boss and - not so he needed hospital treatment or anything, I just basically slapped him and (hhh) (kicked) him, which I'm not proud of at all... (*Sally*)

I first started harming when I was about 17 (…) It makes me feel better once I've done it, for various reasons. So that was why I used it as a management strategy, a coping mechanism, if you like, for so long. (…) At that, 6 years ago, that point, (...) I'd given up medication and I started harming again to manage stuff. And it was quite normal, because that's what I've always done. (…) So I got to this stage when I couldn't really function properly. And I started to hear voices, and I kind of.. the psychiatrists wouldn't give me a diagnosis of psychosis *per se*, but I was getting some ___ hallucinations and things. So that was a kind of a new experience for me. But I kind of accommodated it, “it's just normal”. I had had some experiences with hearing voices when I was younger, on and off, my late teens, early 20's. So I suppose, as I had that, anyway... Yeah, I just kept accommodating things until I literally broke down and I took myself to hospital (…) Eventually I reached a stage where I came home from work, and I was in such a state, I can't even describe that state of mind... That I sat, and I thumped my left thigh... I don't know how long I did it. But it was in.. There was a bruise that was bigger than a dinner plate on my thigh. And it was all raised, and there was big kind of a... It's not even called a bruise, it's called a haematoma or something. It was just a mess! And I thought "have I done that to myself? Yes I have. Oh dear". (*Valerie*)

2.2 Constructing meaning for the experience of mental distress

The most common first response to experiencing mental distress is bewilderment. Many times, the person has absolutely no idea of what is happening and even less on how to cope with it. She feels frightened, confused, puzzled – all that she can be sure is that something's different, probably worse. Ellen Corin (2007) has found the same descriptions of bewilderment when interviewing people about their first psychotic experiences, both in Quebec and in India. Similarly, researchers on illness experience refer to the feeling of "uncertainty" (Bury, 1982). Karp (1996) found that the first stage of the depressed person's career is a period of "inchoate feelings" (p.57). It seems to be a common reaction to the experience of illness and mental distress.

> When I got problems on the degree course I was doing[34], I was totally bewildered, sort of very frightened and it didn't seem to get help at all from anyone, so, I kind of.. except a bit through the church. So it was a very difficult time in that sense. (...) I just didn't know. Because it wasn't really being... I think it was not taken very seriously by anyone. I wasn't getting any help to understand it either. (…) Basically I found it very hard to be sure what it was. (*Harriet*)

In this initial phase of "not knowing", the singularity of the experience and the uncertainty about who is able to help may leave the person in an isolated position.

> I was all alone at first, as a child and a young adult. I was the only one in the world with my problems, and I didn't even know what they were. (*Roger*)

"Making sense" of this experience is an essential task for the person who's living it. Kleinman (1988) proposes that illness experiences must be rendered meaningful by the individual in order to "make over a wild, disordered natural occurrence into a more or less domesticated, mythologized, ritually controlled, therefore cultural experience" (p.48). While the naturalness of mental distress is a point of contention, Kleinman's argument seems to hold some truth for this experience as well.

Roger, for instance, is still actively trying to construct this meaning. Having gone through traumatic, violent and abusive events from a very young age, and since then experiencing an overwhelming despair, which has forced him to attempt on his life several

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[34] Harriet has had her first crisis while she was at university, and had to drop out for a period of time.

times, Roger is still searching, very hard, for a way to understand what is happening to him.

> Q. Let me ask you something. How do you think you've dealt with all this trauma in your life?
> A. Dealt with it's not the word... Trying to, yes, trying to make sense, trying to understand (...) I'm trying to make sense of it. And until I do, or someone else does it for me, I won't understand whether I was born with genetic predisposition of obsessive compulsive disorder... Could be bipolar... Is it personality disorder? Is it something in all four brothers, mother, possibly father - or maybe he was just depressed - but I'm thinking mother side here, something (...) in my family? Could my problems just be related to the real trauma? Was I.. (originally) have a genetic fault that I know the rest of the family's got (…) cause it's a family line there, in a way, from my mother anyway. (...) So, it's so difficult to work out what's actually going on in my mind. (*Roger*)

And how does one go about to make sense of this experience? As it is a process of constructing meaning, cultural references, or "cognitive packages" (Bury, 1982), will be the material from which individual meaning will be built. The person tries to see how the language, values and institutions which are available to her might help her understand what she is going through, or at least discard some possibilities.

Valerie explained how it didn't occur to her, initially, that her problems were medical, since she "hadn't been exposed to that kind of concept, that language". In fact, the repertoire of knowledge and discourses available to the person can be very restricted, in many cases. Participants mentioned how taboo mental health issues were in their families, and how it was almost never discussed. Adam, for instance, had been exposed to mental distress since he was born: his mother had severe mental problems. However, he resents never having been told that she had a "mental illness" - he believes it would have helped him cope with his own mental health problems later on.

> [*when*] my mum's trying to top herself again, and the police and the ambulance is going back and forth, to me that's just what happens! But none of the grown-ups, or any of my friends kind of said.. The word mental illness never came up, not once! I didn't realise what a mental illness was until I was like 25. So I'm repeatedly trying to kill myself, taking overdoses and stuff. (...) From 13 or 12. Right the way through to about 24, 25, I didn't know what mental illness was. (*Adam)*

This taboo, however, silently says something. It conveys the message that mental illness is bad, scary and shameful – it has a moral cover to it. This alludes to another kind of cultural reference that becomes important to people who experience mental distress: the (usually) implicit, unspoken moral judgements that are attached to this experience. They may be part of the person's beliefs, with varying degrees of consciousness, and are on the root of feelings of shame and low self-esteem. These taboos and moral judgements are related intimately with lay beliefs, which are also often (but not necessarily) moral and implicit. Lay beliefs are the product of centuries of collective "making sense" of mental distress, since it is also a puzzling social experience. They are one of the most important references for making sense.

When previous references fail to help a person make sense of her experience, actively searching for explanations becomes essential. Reading self-help or popular science books, looking for religious guidance, talking to whoever is present in the person's life are all tools used to organise one's experience in a narrative form, being able to then turn it into a source of experiential knowledge. It can become a real quest, a lifetime enterprise that reshapes the person's professional career and her personal life. In the attempt to make sense, one might try to formally study mental health, work with mental health-related subjects, make friends with people who have mental health problems or... join a social movement.

Among the participants in this research, very few describe being initially adherent to psychiatric or psychological explanations, mostly because they were not acquainted to them[35]. Organic explanations are sometimes welcome, since they remove some of the guilt that can be attached to moral or lay explanation. Lay people, specially family members, may find it easier to deal and understand a mental health problem if it has a clear aetiology, and even more if it is organic.

> My father went on thinking I had ME [*myalgic encephalomyelitis*] for quite a long time after we decided it was depression! (…) They weren't sure whether I had that [*ME*] for a while, cause I'd had this cold and then I was just all tired and floppy and shut down. And I think that was more acceptable than depression because it was a proper illness. It was a physical illness (giggle). (*Annie*)

Through this active process of "making sense" the person identifies which available

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[35] Perhaps the average age of the sample (nearly 53 years old) helps to explain that, since medicalisation has increased in recent decades. The British resistance to the psychoanalytical invasion (Porter, 2002) can also account for the fact that, historically, the popularisation of psychological and psychiatric language didn't happen as significantly as elsewhere, and mental illness remained identified with "madness" in Britain (that is, with the "other" since nobody in our study began by identifying with the mad).

cultural references are useful to her and organises them into an explanatory model. Kleinman defines explanatory models as "the notions that patients, families, and practitioners have about a specific illness episode". These notions are informal, most often tacit or at least partially tacit, more akin to "justifications for practical action" than "statements of a theoretical and rigorous nature" (1988, p.121). Other authors have found that people with severe mental distress also construct explanatory models for their experiences (e.g. Kinderman, Setzu, Lobban & Salmon, 2006). We have noticed that these explanatory models permeate the participants' narratives of their experiences – although many times they are, like Kleinman suggests, not explicit. Usually there is not a single, unified model, but several, sometimes contradictory models[36], as it would be expected from our discussion of identity, experience and contradictory socialisation.

After some explanations are chosen as valid, they are incorporated to the person's explanatory model. Ralph describes a process of gradually making sense, through establishing a connection between his past and his present day problems. This connection was something he "didn't realise" "until recently" (which he's done through different therapies he's undertaken during his long stay at a psychiatric hospital), but it has already become "obvious" and embedded in his interpretation of his current life. In a similar process, Harriet felt that the picture wasn't complete until she found out some information about when her mother was pregnant with her, and now it also has become part of her explanatory models.

> But going back, in 1964, when I was 14 - and I only found out about this in the last 5 years - I was very mentally distressed. I ran away from home, to London. I was kidnapped for 2 days and raped by a man... Twice over in that period. Though I didn't realise (how that affected me)___ until recently, it was obviously very traumatising. I didn't tell anyone until 20, 30 years and I didn't tell the police, I didn't tell no one. I think it severely traumatised me. (...)
> Yeah, they [*staff in psychiatric hospital*] used to really hurt me, really bad, and I couldn't understand why they'd hurt me. It hurt me cause of my childhood, it always goes back to my childhood. I was never given nothing by my stepfather... When I was raped I was taken advantage of from people. People never showed me that much love and affection, apart from my friend's dad and mum. And I suffered from that, I guess. I'm still suffering from that. It's really hard. (*Ralph*)

> I was gradually beginning to make more sense of what was going on. Although for a long while it did feel there was something more and I didn't actually know what that was until I

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[36] Which doesn't exclude the possibility that one model is usually dominant.

> found that, just after my mother had died, (I was told a bit more about) what be going on when my mother was pregnant with me and, sort of very early years. (…)
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> Just very recently I have been very stressed, which has been related to the behaviour of this new landlord of mine. Unfortunately he's acting in a way which is sort of reviving early family experiences. (*Harriet*)

We also found that explanations of mental distress as illness were largely marginal among participants, even after the person had gone through mental health services. They didn't see themselves as people with illnesses, even though some might use the term mental illness or refer to psychiatric diagnosis. Many, however, did adhere to psychological explanations (psychodynamic or cognitive-behavioural). In general, we have found that they tended to see their mental distress related to past life events, which were framed either as causes or as sources of increased vulnerability (which were then "triggered" by some other life event). This is in agreement with other researches on the subject, which have found that even when an illness label was used, service users tended to provide complex accounts of their experience, including a mixture of physical, social and psychological influences and experiences (Kinderman et al, 2006). The same has been found to happen when lay people attempt to explain mental distress (Alves, 2011).

Perhaps a greater rejection of illness models is to be found in our sample, which is explained by their participation in a movement that is historically linked to anti-psychiatry. However, it is also possible that social explanations are preferred by the participants because they are coherent with their own experience. As explanatory models are forms of incorporating and making sense of experience, they cannot be simply "acquired", as if they were ready-to-wear models, available in culture. Even if there is a process of complete affiliation to a given model, it happens through a process of choice (although not necessarily conscious choice) where experience is taken into account. From our twelve participants, only three did not explicitly refer having had troubled families and difficult childhoods. The majority reported experiences that ranged from having "no love and affection" from family to suffering physical or sexual violence[37]. Moreover, most had experienced hardship or intense stress previous to their crisis. Therefore, in their cases a biological model makes less sense, as their experiences have an enormous weight on how they explain their current distress. In a

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[37] This doesn't mean that they discard medical or biological explanations. As we have seen in a previous extract from Roger's interview, even when trauma is overwhelming, genetic explanations might be considered. But we have found them to be present in a small minority of cases.

perspective of narrative reconstruction (G. Williams, 1984), as participants "bridge the large gap between the clinical reductions and the lost metaphysics" (p.197) they use their life stories and the meanings that make sense to their history.

2.3 The social experience of mental distress

Another important aspect of the experience of mental distress that must be taken into account is how it affects social relations and how it is shaped by constraints imposed by social conditions. In this section, we'll explore the social experience of mental distress, focusing specially on family, employment and mental health services, and discussing the forms of stigmatisation that can be experienced by people with mental health problems.

Experiencing mental distress can affect social relations at least through two different processes. First, because mental distress itself can change the way a person relates to others. As an effect of her mental health problems, a person may become more isolated, suspicious of others, have more difficulty sustaining social interactions, and in extreme cases, even become aggressive towards someone. This "embodied irrationality" (Mulvany, 2000) will affect her direct social relations in a determinant way. Parallel to this, after a person is socially recognised as someone with a mental health problem, others will respond to her in a different manner. She may experience stigmatisation and discrimination in various settings – she may lose her job or not be able to find another, for instance. As she enters the mental healthcare system she will undergo treatments that will alter her experience, for the good or the bad. In the most different social settings, she will discover first-hand what being "mentally ill" or "crazy" means in society.

Families

Families are usually the first to be affected and respond to mental distress, since it has a very strong impact upon families, comparable to the one it has to service users. While service users struggle to make sense and recreate meaning for their experience (for them it is a matter of survival), families can have a more difficult time to accept and understand what the relative with mental distress is going through. While some participants have mentioned receiving positive responses from their families, these reports are very few and usually are accompanied by caveats. From the point of view of most participants, families are most frequently regarded as either unsupportive (mostly because they were disoriented and didn't know how to deal with distress) or prejudicial.

> They [*family members*] were interested in being supportive, but most of them didn't really do feelings very well. (*Annie*)

> But my family don't actually have.. they do have problems accepting my mental health problems and my experiences. (…) So my family isn't actually helpful at all and I see them, engaging with them, when I have a mental health problem, is potentially more damaging than helpful. So it's not like they're a neutral presence - they're actually... they can be actually damaging. (*Valerie*)

Other times, however, it's not that families don't know how to cope with mental distress, or that they try but lack the capacity. When families are too dysfunctional, there is no possible support available. An example is Marianne's family. Her mother was very depressive, her father was deceased and her stepfather, she describes him as a paedophile, as he was always trying to touch her or her girl-friends.

> My family were a nightmare. I can't tell you how bad they were. (…) When I've read about Fred and Rosemary West, it reminds me of the atmosphere in my home. I mean.. I don't know if you know Fred and Rosemary West, the serial killers. They were horrible paedophile serial killers.. And I don't think my stepfather was a killer, but the atmosphere of my house was like what I've read about in the.. Fred and Rosemary's famous serial killer. It was just a really bad, creepy atmosphere. I couldn't be there. I couldn't stand being there for more than a few hours, really. I just had to get out of the place. (...) There was no support. I mean they didn't know how to support me, they were a nightmare. They were the problem! (*Marianne*)

In these cases, when facing mental distress, the person's most common response is to get as far away from her family as possible, in order to remove herself from the environment that is damaging her mental health.

Community and stigma

Stepping outside of the family environment and dealing with the "outside world" will probably put service users in contact with stigmatising experiences – if they haven't had that already within their intimate circles. Stigma can be described as a loss of social status and discrimination triggered by negative stereotypes that have become linked in a particular society to a particular human characteristic (Rishter & Phelan, 2004; Link & Phelan, 2001). According to Rishter and Phelan, the most obvious form of stigma is when the un-stigmatised reject, put down or discriminate against those with the stigmatised status. Mental health service users have widely reported experiencing this kind of stigma (Link et al., 1997; Wahl, 1999; Dickerson et al., 2002, all cited by Rishter & Phelan). Ralph, for instance, refers to the effect of stigma on their possibilities of romantic relationships.

> And of course when you make relationships with anyone, it's hard to tell them that you're in a hospital, (...) I mean, I gotta pay for sessions![38] _______ play poker in the poker league, and I met two lovely... married women there (...) they invited me around. And they said "what do you do?", I said "I'm in hospital". They thought I worked there, and when I told them I was a mental patient, they refused to.. (They told them) "don't let him come in". I could have lied and said I was a worker, I could have gone in and played poker. (*Ralph*)

There are, nevertheless, other ways in which stigma can operate. The authors acknowledge that "the harmful effects of stigma may work through the internal perceptions, beliefs and emotions of the stigmatized person, above and beyond the effects of direct discrimination by others" (Rishter & Phelan, 2004, p.258). This may happens basically in two different ways. First, if the person believes that her condition is socially stigmatised, she may predict and fear others' reactions, suffering a number of negative outcomes such as low self-esteem, demoralisation or impaired social integration. Secondly, the person may herself believe in the negative stereotypes that are associated to mental illness, and feel shame and devaluation when facing herself or others. In other words, stigma can be internalised and damage severely one's identity, self-image and self-esteem. Feeling excluded from the community or isolating oneself from others may be, in some cases, two sides of the same spiral of shame and stigma. As stigmatising beliefs are shared cultural references, those who are subject to stigma are very much aware of how they are perceived, and those beliefs are

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[38] He is referring, we believe, to hiring prostitutes.

probably deeply rooted in their minds.

We have witnessed, in the interviews, the expressions of shame when some participants were telling their stories, specially those that felt at one point losing control over themselves. Sally, for instance, narrates how she felt after learning about what she had done during her first crisis. By the time she left hospital, the feeling of remorse and shame were so overwhelming that her self-esteem was in an all-time low. She didn't care anymore about whether she lived or died.

> And the closer it was coming up to the tribunal, the more medicated I become, and the more (spirit then I'd lost), because I was beginning to read.. I demanded to see my notes, and I began to realise just how bad I was when I first went in hospital. So I was beginning to get a sense of what was happening then. (...) I was full of remorse for what I'd done, so I began to feel really (…) depressed. Incredibly depressed. I just hit the bottle, really badly. (...) It was more a cry for help, I think. It wasn't wanting to go into hospital, it was just... a kind of not caring really, whether I lived or died. (…) I started these courses, typing, computers, homoeopathy, and again, that's when the agoraphobia started kicking in. I had no confidence, it was like I had no... it was almost like I had no brain cells left, that's how I felt. And I was scared of going out because I thought people would think I was a psychopath, you know, like a really dangerous person.
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> Q. Cause people had heard about..
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> A. Yeah, people had heard about what happened (*Sally)*

When we talk about internalisation of stigma, it means that the person's beliefs play an important part, since it is through her belief on stigma that she will predict discrimination. But it is important not to overemphasise the cognitive process and dismiss the reality. Beliefs about stigma are very often grounded in lived experience, not only in general, diffuse ideas about the stereotype of the mentally ill. Sally had real reasons to believe that people were afraid of her.

> The landlady where I lived had changed the locks on the door, because she heard of what happened in my workplace. Which was illegal, what she's done, because I haven't done anything to her. And my boss was still talking to me cause he realised I'd been extremely ill. But she changed the locks, so I was effectively chucked out of where I was living, where I'd lived for four years. (*Sally)*

Disclosing mental distress also becomes a crucial factor for service uses, and sometimes they have to invest an already lacking energy into keeping their mental distress as a secret from others. The person feels that part of her experience and her identity is unwelcome and should be kept a secret. It not only makes it harder to accept and incorporate this experience, but it leaves the person with the feeling that her interactions are superficial and not meaningful, as this important part of who she is has to be kept to herself.

> [F*eeling she was not seen as part of society*] made me kind of often hold back about my experiences, and it's difficult to be a kind of full human being or to form rich relationships if there's quite a lot of yourself that you feel you need to sort of keep hidden. (…) I found it very difficult because I've found I had to push back a lot of myself. Like, that it would be so unwelcome if I brought it out. (…) Then I've found very difficult to feel whole myself, cause it was like, the whole time there's something to leave on a much more superficial level, in terms of my interactions with other people. And not with the whole of myself. (*Harriet*)

Employment

The person's professional career is also affected by mental distress. Most participants report having either lost their jobs, having had to give up work or needing to do some kind of adaptations in their work. Several depend on disability benefits to make a living. Up to 80% of people with mental health problems in Britain are unemployed (Drew et al, 2011). They have the higher unemployment rates among disabled people (Barnes & Bowl, 2001). Masterson and Owen (2006) argue that these figures indicate the negative attitudes of employers towards service users, rather than the disability caused by psychiatric symptoms, as various researches have shown that as many as 60% of people with severe and enduring mental health problems can maintain employment with appropriate support.

The dependency on benefits was a constant theme of interviews, specially because now participants were facing the possibility of losing their benefits because of government politics and expense cuts. Roger explains the dramatic impact that the perspective of losing their only source of revenue might have upon one's mental distress.

> Unemployed suddenly seemed a good thing, cause we used to be stigmatized just by being unemployed, now it's a war on disability and disability benefits (...)
>
> Q. Are you afraid to lose your benefits? Do you think you might?

> A. Silence. Cause one thing, love: the bridge is just over the road. (*Roger*)

When employed, the person with mental health problems might feel pressing needs at her work environment. It is important that she is able to disclose her mental distress in order to have more support from co-workers or to have some adaptations at work done when necessary[39]. However, in an increasingly competitive market with high unemployment rates, people with mental health problems become particularly vulnerable, and supportive environments are scarce. The person may feel the stigma at work, being judged as incapable (specially as intellectually incapable). Karen, for instance, reports having been subject to increased control in one job because she had "problems" with her "mind", and people were afraid of she doing "crazy things" at work or not doing her job properly.

Mental health services

Mental health services are the most central reference to the social experience of mental distress. All of the participants in the research have been through some kind of health / mental health service, usually through long periods of time. Among these services are psychiatric hospitals, therapeutic communities, outcare services (psychiatrists, psychotherapists), primary care services (GPs), supported accommodation (hostels, live-in therapeutic communities), drop-in centres, not to mention peer support groups and user-led services. It is, in some ways, a pre-requisite to be a part of the service user / survivor movement: you must have either *used* services or *survived* to them.

Mental health services can be either empowering and help users to recover or they can be even more devastating than the mental health problems they are trying to cure. Not that infrequently, they can be a mixture of both. The most central aspect of having a positive experience in services is being cared for. This is a dimension that involves real affection - or “tender loving care” as Sally calls it. Adam, for instance, after having been through a long series of services and still experiencing severe mental distress and attempts of suicide, he found one person who has made a difference.

> I was continuously having difficulties and stuff and I wasn't really getting anywhere and I felt like I had hit a brick wall. And then I met someone who went that little extra mile, a

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[39] These adaptations are currently guaranteed by the Disability and Equality Act (2010).

> professional, had a course of treatment that she organised. (…) some one-to-one therapy for 8 months (...) Essentially, the person who organised the treatment arranged for me to go to her training centre to have more in-depth stuff. But she really went out of her way to help me get there, and there's no way that they would have accepted me without her help. And it was all that I needed. I mean I still experience difficulties and all that, but it's something that put me in the best place to do that. (…) I was lucky because I met someone, a professional, who didn't give up in a sense. (*Adam*)

Adam's emphasis is not on the quality of treatment that he received (which of course isn't negligible), but on the fact that the person went "that little extra mile" and "didn't give up" on him. This resonates with other interviews, as participants argued that affective involvement was what mattered most. This is also supported by other survivors' assessments of treatments (e.g. Glass & Arnkoff, 2000). Participants praise health professionals who "work in partnership" (Gordon, with his GP), or who are "supportive" and "explain things" (Annie, also with her GP). Harriet explains her positive experience in a therapeutic community because she found a "warm" and "empathetic environment".

> In the therapeutic community, I think, I kind of got, for the first time in my life, a secure, very warm, very empathetic sort of environment, and you know, I think that made a fundamental change for me in how I felt. (...). It's sometimes put in some of the things that I, looking back, I don't think I ever really had. And that was what made the biggest change. (*Harriet*)

However, most of the narratives are not positive tales of redemption. Given it is a movement that stems from dissatisfaction with mental health services, it is not very surprising to find that the majority of participants had mostly conflictive and difficult experiences with mental health services. Service users report having been through authoritative services, sometimes with clashing interpretations of their distress, where their voice was not heard. One radical example comes from Valerie. Being a homosexual, she was appalled when the psychotherapist she sought for help was determined to change her sexual orientation.

Psychiatric hospitals provide much more extreme examples of bad experiences in mental health services. They were often compared to prisons, either in the sense that they can be punitive or that they provide mere incarceration without any appropriate care or therapeutic purposes. According to Pilgrim (2005), acute inpatients units in Britain have "virtually abandoned their aspiration to be treatment facilities" (p.20)[40]. While compulsory

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[40] This is inserted in a context which we have previously explained – an intensification of coercive measures in

detainment can be valued in some life threatening circumstances, hospitals are entered with the expectation of being places of care. Remarkably, people who have been in hospital in recent years (such as Valerie and Ralph) or those who have been there decades ago (like Emma) have roughly the same perceptions. They shouldn't be like prisons, in participant's views. In fact, Ralph – who has been both to prison and psychiatric hospital – thinks they are *worse* than prisons.

> So Paul [*her husband at the time*] was told how to find this hospital and we got there, and it was dark, there was no lighting to speak of, it was absolutely awful. We've been expecting a brightly lit, modern, nearly modern hospital, with a welcoming entrance and reception.. and instead it was (...) high walls with glass on the top and.. big doors. You know, just like a prison. Absolutely horrible. (*Emma*)
>
> And it was a very... it wasn't a good environment at all. Not a good environment. I mean, I needed to be contained, I needed people to keep an eye on me because my risk of committing suicide was really... I believe.. my self-assessment would be quite high. (…) And it's pretty much akin to be.. Well, my experience of hospitals, it was like prison, it was like prison, it wasn't therapeutic at all. I know that there are some really good therapeutic environments, some hospitals do have, but that was not good. I think partly because it was a locked ward, a wing of the hospital. And it was just about detention, really. (…) You go to hospital your voice is almost absent, being in hospital is really quite incredible (*Valerie).*
>
> Q. Ok. And how was the general experience of being in the hospital for you?
> A. Horrible! Nasty! Really, really... Prison is better! (…) At least in prison, in England, I don't know about anywhere else, but in England, we get a lot of... what's the word for that?... A lot of rights. Mental health patients have got no rights! If you make a complaint about.. in a mental hospital, for example, I used to make complaints all the time (...) but I wouldn't get an answer for a year! (…) If you were here now as one of the nurses in my unit, you could be staying there laughing and talking to 4 or 5 nurses, me, or other people, would knock on the door, and you wouldn't ___ you'd just sit there and carry on. You can get away with that. All I kept getting told by my doctors was “oh, they made a mistake”. And ___ “fuck off!”. If I make a mistake you take my leave off me, or you punish me. I lost my television. Swearing at a nurse I lost my television, I lost the (right) to leave, just for swearing at them. One swear word. Crazy. And yet they can be nasty and horrible, and nothing happens. (…) We had an African nurse, she said “I'll beat you, I'll beat you”. Hang on! You can't say that to a mental patient! But 20 years ago she could probably beat me and get away with it! Luckily now they can't actually do

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the past fifteen years or so, after a period of increased liberties for service users.

> that. (*Ralph*)

> That's my experience and that's the experience of quite a lot of people, who are put on these mental health units, and they're usually on secured wings or locked wards. And with little __ freedom, freedom reduced, (keys jangling), lots of medication, being held down. (…) the treatment you get is not what you would expect. People are not looked after in hospital. They're medicated, they're sedated, they are kept there, they even get rough treatment, they may even be killed in there, this is not a hospital. It's not what a hospital is about. (*Rose*)

These negative experiences allude not only to the lack of proper care and the use of coercive measures, but also to being unheard. It is not too far from the experiences of silenced lunatics of earlier asylums, surprisingly enough. The rights that Ralph is demanding are nothing more than the right to be heard and to be "treated properly", as he calls it elsewhere. Ralph is aware that nurses are not allowed to beat him or any other patients, as those rights have already been conquered a long while back. However, nurses or other health professionals might still exercise power against patients in other ways, such as completely ignoring them as individuals. They refer to the wish for being treated in a friendly environment, where the patient voice is heard and valued, instead of being constantly doubted and ignored. The effects that the experience of going through services has to users, we have found, depend on whether or not they provide for a simultaneous need of *care* and *autonomy*.

While some describe their positive experiences as being crucial in their recovery (like Adam and Harriet, in the fragments above), those that had negative experiences report their detrimental effect to their mental health. Rose, for instance, describes what the experience of psychiatric hospital and other intensive services has done to her:

> And you feel... well, you're traumatised again, and also you feel like a... like a nobody! You fell lessened, (….) you feel worthless, because you think people just (scandalise) and then they treat you like they're scared, they scapegoat you, like everything that goes wrong, you're the one to blame. (*Rose*).

This feeling of being "traumatised again" is also recurrent in participant's narratives. It is a reference to how the experience of being violated and abused can be reinforced in coercive environments, aggravating mental distress and adding to the pre-existent feeling of being vulnerable and powerless.

> One time when I tried to leave, I think a nurse tried to stop me. (...) I was in a lot of pain [*gastric pain*] and I think I was really aggressive towards her. And because I was paranoid and manic, I thought she was quite evil. And I kind of tried to get outside as well, wanting to fight her. And they wouldn't let me go outside. (…) Five people came up, three of them men, and grabbed hold of me down the corridor. The panic alarm went off, and they pulled down my trousers and injected me in a really inhumane way, I would say. (...) I think the way in which it was done... completely... complete loss of dignity, down the hospital corridor, specially with three men. And they didn't really know my history and two of them were... I'm not racist at all, but... two of them were black guys, and I've been raped when I was 21 by a black guy. And it reminded me very much of that kind of violation. I remember screaming out rape cause it just didn't.. All this kind of everyone holding me down on the floor and my trousers being pulled down. I was terrified. (*Sally*)

> Every two weeks in hospital you have to go to a ward round. You got a meeting where you will sit with people, ten people, there'd be two doctors, two nurses, social worker, a lot of people. I've gone in there, and I've bent over it (…) [*the doctor*] said "what are you doing, Kenny?", and I said "well, you might as well fuck me up the ass!" (...) "That's what you're doing to me anyway, you might as well do it properly". I didn't actually (pull down) my trousers or anything, but I was just saying, that's what it felt like, as if they were raping me. Even though they weren't but that's what it felt like. (R*alph)*

As we have already remarked, coerciveness can increase the feeling of loss of control, which is one of the main aspects of post-psychotic depression (Birchwood et al, 2000). Services should promote this feeling of control over one's life (Corin, 2002), not undermine it. Sally presents her view about what she thinks helps recovery:

> It's not all about medication, it's not all about going back to work. It's about the treatment, it's about empathy, putting yourself in other people's shoes, it's about being honest with people, allowing them to take some responsibility for themselves without.. And also taking responsibility for that person if needed. And it's about respect and mutual trust, rapport. You know, we're all only human, we all have our frailties, and it's more about the way you're treated, I think. I know medication can keep you stable, can keep you away from.. If needed, can keep you out of danger. But really the way you're treated makes so much of a difference on the therapeutic value of your care. (*Sally*)

In a nutshell, the social experience of mental distress is extensively marked by the negative meanings attributed to mental distress and by stigmatising experiences. Many times they feel that their social experiences are detrimental to their mental health, even in services where they were supposed to be assisted. The best scenario service users can find is receiving some sort of support and care, which can be significant for their recovery. However, even when this supportive environment is present, it hardly ever is associated with a level of autonomy and recognition of the person's capacities. That's essentially what service users are asking for.

2.4 Identity rearranged

The experience of mental distress is a radically shattering experience, and inseparable from the self (Geekie and Read, 2009; Karp, 1996; Kinderman et al, 2006). The person who thought of herself as strong, is now confronted with her weakness. She saw herself as rational, but she suddenly seems to follow an alien logic. As her mind is overwhelmed by pain, suicide begins to be contemplated as a desperate solution. The self, the individual, are menaced.

Identity "is a permanent system of enclosing and integrating meaning, whose model is totality"[41], Kaufmann (2005, p.73/74) says. While the person tries to make sense of her experience, the reconstructive faculties of identity are put in action. Identity, according to this author, combines fragments of the material and social world, seizing opportunities to turn them into resources. In order to integrate the experience of mental distress into the identity, the person will create an identity of their mental distress (akin to the illness identity, already discussed), where meanings and explanations available in culture are actively chosen and incorporated by individuals, determining who they are in relation to this experience.

The person's history and social context are major constraints to reconstructing identity. As social meanings attached to mental distress are often negative and moral, the identity of mental distress can very frequently be that of a bad or weak person. Valerie recognises her tendency to think of herself as being a "flawed", "useless" and "dysfunctional" individual. For her, this identity is on the basis of her self-harming behaviour, and she tries to convince herself that she has got "mental health problems" or "an illness" (as she says elsewhere) to get rid of the guilt that accompanies her distress. Sally talks about her remorse,

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[41] Free translation from the Portuguese version: a identidade "é um sistema permanente de encerramento e de integração do sentido, cujo modelo é o da totalidade".

shame and “not being proud” of things she's done. She says she would like to have therapy that would focus on her positive aspects, as she tends to forget about them. Ralph is unsure whether he's good or bad, and alternates both identities.

> So my own [*mental health problems*], I saw them as a moral personal flaw. That I was a completely flawed individual, that I was useless, I was dysfunctional. It's actually something to do with me personally, rather than anything... I didn't think it could be fixed. I didn't know what a personality disorder was or anything.. That's kind of my concept of it. So I had, you know... And also, the idea of me punishing myself, that's one little bit of why I started self harm. (...). It fitted with the concept of my problems as a completely flawed, inadequate human being, rather than somebody with mental health problems. (*Valerie*)

> [I *would like therapy to focus on*] the other parts of me that I tend to forget, the positive attributes of my personality, rather than all the negative and.. you know, “I'm an alcoholic” or “I'm not quite with it”, when I'm feeling low, or when I'm manic or whatever. Just feeling excluded, if you see what I mean. (*Sally*)

> I have good days and bad days. I'm a good person. I've been a bad person. I'm a bad person cause I didn't look after my daughter and her mum, but there you go, that's... They say I did do it and I did my best, but I think bad things, sometimes. (…)
> If everyone was like me it would be a good world. Or a bad world, whichever kind of the day I was on. (*Ralph*)

These examples show how fluid identity can be (it is always in process), and how individuals struggle to reinvent themselves. As it is probably apparent by now, the detrimental effects of the identity of mental distress are related to a low self-esteem. Self-esteem, according to Kaufmann, are emotional energy reservoirs which are are filled by positive experiences and drained by negative ones. As identities are also affectively invested, they can increase or diminish self-esteem. Through instances like the “possible selves”, identities can give prominence to certain positive or negative experiences, very akin to the process that Sally would like to go through in therapy.

Vulnerability is a strong attribute of people who experience mental distress, and it may become crystallised in the identity of the victim, as Roger's narrative shows. His narrative is a constant description of his traumas, in a desperate attempt to understand why he was not protected. In his own words, he sees himself as “vulnerable”, “lonely”, “abused”, “desperate”, “stigmatised”, “let down by society”. Similarly, Adam refers seeing himself at one point in his life as “turned away by society”, “left to muddle through” and “struggling”.

Mental health services, as we have already discussed, can be places where service users are “protected” from negative stereotypes of mental distress, where they can reconstruct their identities so that they'll allow them to function better and be happier. Services may help individuals, as Annie puts it, develop “that other side of me that had been hidden away somewhere”. In that sense, they can be highly beneficial to identity. However, they can also reinforce powerlessness, lack of capacity, vulnerability, as they don't allow space for autonomy or creation. We believe to have already emphasised this process.

Another form that services and scientific discourses can affect identity is through diagnosis. It is not rare that they become the basis of their identities, even though it can produce an effect of engulfment by demoralisation and stigma associated with mental illness (Lobban, Barrowclough & Jones, 2003).

> Some people go to hospital quite a few times, and each time is different but sometimes it's worse. And it's also a shock because the first time you think, “oh, it's just a __, it will never happen again”, but if it happens again you think “well, maybe they're right, maybe I'm schizophrenic”. And one day you gotta live with that, deal with that. (*Rose*)

Psychotropic medication also can play an important part in defining identities. As it is a type of medication that deeply alters experience, people who use constantly medication find it difficult to know the difference between their selves and the effects of medication.

> When I was taking loads of drugs, I didn't know what was them and what was me, and sometimes I still don't. (…) The way I was constructed in my childhood, I tend to look at things quite negatively and I have a very low opinion of myself. So I will think, OK, these are the good things, but they're all attributed to my drugs. You know? So I'm quite well there, and I cope with that situation, or I function quite well at work or I've been quite productive, I couldn't do that without the drugs.(*Valerie*)

Another example comes from Emma. She was taking lithium, a mood stabiliser, while being in an abusive relationship with her husband. As she decided to come off lithium, the whole balance of her relationship changed because she experienced things differently.

> So I did come off. And that's when things really went pear-shaped with my husband. Because I suddenly *became me again*. Because lithium keeps you so.. balanced, I was taking it all.. I mean he

> wasn't physically bad but verbally he was terrible. I hadn't at all noticed. It started getting... I noticed! And I got myself really wound up. (giggle). But it was the best thing that could happen, really, cause it got me out of there. (*Emma*)

Summarising, the experience of mental distress is confusing to individuals and disturbing to their identities. Drawing from the concept of illness identity already referred[42] (Brown et al., 2011), we can understand the identity of mental distress as the individual sense of oneself shaped by the constraints of mental distress and by others' social reactions to that illness. People will develop meanings for their experience and incorporate them to their identities, but different meanings will lead to very different lives. People with mental health problems may feel trapped by the social meanings that are culturally available to make sense of mental distress, as they allow them to create identities that are often negative and draining to self-esteem. Going through mental health services – a part of the experience of mental distress – helps individuals reconstruct meaning to their experiences. However, they can either provide positive, fruitful meanings or reinforce the negative meanings that society usually offers.

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[42] See page 51.

Chapter 3:

ENGAGING WITH THE SERVICE USER / SURVIVOR MOVEMENT

This chapter explores the SUSM through the accounts of participants. We will develop here two central concepts to our analysis: the politicised collective identity and the service user role. The *politicised collective identity* will be used as a guiding concept to analyse SUSM dynamics. Participants' process of engagement with the movement provides some indication of how the experience of mental distress is intimately connected to collective action in the SUSM.

Some attention will be dedicated, afterwards, to describe the SUSM activities and political positions, all through the narratives of participants. This will allow us to have a glimpse into the lived world of social movements, as well as to identify the existence of a *service user role*, which guides activists' collective identification with the SUSM and, by consequence, affects their personal identities.

3.1 Process of engagement and the construction of the politicised collective identity

A characteristic of embodied health movements is the centrality of the personal experience of illness or bodily event to the movement's identity and practices. This personal experience becomes perceived as a shared experience, which leads to the identification with others in a social movement (Brown et al, 2004). But how is it that going through an experience of mental distress becomes the basis for engagement in a social movement?

The construction of a collective identity based on the experience of mental distress is essential for engaging with the SUSM. Service users have to perceive themselves as part of this larger group of survivors, with whom they have an affective connection and share common characteristics. This collective identity may be experienced as discovery (a sense of having found one's own “crowd”) but it can also be constructed gradually, through the course of interaction.

A strong motivation to be around other service users and then, to build on this sense of collective identity, is seeking relief for the person's own distress. These self-concerned motivations are sometimes the seed of a future further engagement. Ralph, for instance, has just recently begun to get involved with the service user movement and his engagement is very limited. He is more a consumer of the activities provided by this SUSM organisation than an activist. His position is interesting because it provides us an opportunity to look at social movement engagement stemming from peer support. He initially joined the group looking for an opportunity to socialise and found a very welcoming environment.

> I just seem to fit in with them. It's a.. no one wants nothing from you. You feel wanted. They're very attentive. Not just to my needs but if you have any questions they will try to talk to you the best they can. They treat you with a bit of dignity. And it's fun! (*Ralph*)

He soon went from liking the environment and feeling good there, to identifying with his peers and realising they were in need of help too – help which he realised he could provide. As he got more involved, it was suggested to him that he should join other activities, such as being in a hospital committee as a service user representative or doing lectures in schools about the user perspective. He began to think that problems service users go through can be solved by improving services or "sticking up for people's rights". But, as the next passage implies, this incipient politicisation is deeply connected with his experience of illness, as he survived serious attempts of suicide and began to think of his survival as having a religious meaning. His explanatory model for his distress is structural to his involvement.

> That's what the user movement would be. Me going to meet people, talking to people, and telling my experiences and sharing. And helping them, if I could. (…) and also doing things that help you understand yourself better as well. (…) I'm a good talker and I was told I should go on hospital committees. Recently the hospitals have let service users go on committees.(...) I should have gone on the committee because I stick up for people's rights. (...) And bloody hell, the mental health movement in England needs a hell of a lot of people to stick up for it! (…)
> Q. What made you feel like you wanted to get involved?
> A. Hmm... Because... I've got a lot to give. Also, I took two major overdoses, I should have died. I'm not very religious, but I am a Christian I guess. And He, up there, didn't let me die, He's always keeping me around for something. Wish He would tell me what it was, but I obviously not died for some reason. But I have got a lot to give (...) I suppose people like me they know how to help people. (*Ralph)*

Roger's reasons to fight for the rights of service users are rooted in his collective identity. It is a very powerful motivation because he found in a peer support group the first people who he could “relate to”. He feels the urge to help them, and he shares their grievances with insufficient services or lack of opportunities for social integration. From the peer support group, he began to participate in mental health committees and engage in community activism. His collective identity is politicised by his wish to stand up for the group that's so important to him.

> That's when I met these other people and I thought: right, I've tried all my life, I've carried all my life in isolation, I've met a group of vulnerable people who I can relate to - and that's the key, to relate to. I'm gonna help make a difference! (...) If there's a problem with a mental health service, sort of _____, where service users are gonna be adversely affected, I'm not gonna stand by alien, see this happen. They've got enough problems alone. And I'm one of them! (*Roger*)

Even though self-help groups are sometimes perceived as apolitical and are excluded from studies of social movements (Tomes, 2006; Katz, 1981), we argue that they cannot be separated from the SUSM. Authors like Riessman and Carroll (cited by Barnes and Bowl, 2001) recognise that self-help groups are likely to focus upon two complementary activities – mutual support for individual members and consciousness-raising. They not only develop personal skills and promote individual change, but may also lead to an awareness of the need for social change, encouraging the development of external activities. From our research, we found that support groups can be the entrance door to future activism. They are also political in the sense that they provide alternatives to mainstream mental health services (which is sometimes inserted in a greater political vision of challenging their dominance). Furthermore, support from peers form an affective network within the movement, which not only is the basis of collective identity, but also helps service users through the emotional difficulties of activism.

Survivors who are more politicised may also have, at least in part, some self-concerned motivations, as they may want to get involved as a form of making sense of their own experience (Marianne), or as a form of fighting their own negative identities of mental distress (Valerie). It is interesting to notice how the politicisation of the collective identity doesn't necessarily rule out more self-concerned motivations, related to personal mental distress.

> And I think at least one of the ways I try to counteract my opinion of being inherently bad is to try and do stuff like activism. And trying to get... try to do something good. (*Valerie*)

> It was just great for me because I got to explore something that I'd experienced, which I kept wondering and wondering what it had done to me. I thought sure, it did damage me, but I wanted to know. (*Marianne*)

Emma joined the SUSM through Survivors Speak Out (SSO), one of the major SUSM organisations, which was very active in the 1980s and 1990s. As she narrates how she began to get involved, we see how important the politicised collective identity was to her engagement. She was already in contact with other service users in a day centre, but she felt they were only "passive recipient of services". As she found out about SSO she felt like she had found a group where she belonged. There, she was able to talk about her negative experiences and began to find a political meaning for them. It was a very defining moment for her, as she was then becoming an activist of the survivor cause, which has been significant to her life and her identity. We can also notice how discourse is essential to this process. She recognised herself as a survivor when she heard this word for the first time, and not anymore as a "passive recipient of services" (a term frequently employed within the SUSM, which she didn't know then but she uses now).

> It must have been in the 1980s then. I was in the day centre, I was handed this piece of paper which said that Survivors Speak Out were having a conference or an event (…) Something about that piece of paper really spoke to me. And it was, I think, the word "survivor". I thought nobody had ever talked to me in those terms before. I was just a passive... what they call "a passive recipient of services". I went to this day centre with a lot of other people, also passive recipient of services, and we never talked about the medication we were on, what the side effects were, anything. It was all about knitting and things like that. (…) I went for a weekend to this place, a youth hostel. So not a very posh place at all. And I don't know, 25, 30 people were there who were all talking about mental health, and the mental health system, and how it could be better! And there was this amazing guy called Peter Campbell, whom I'm sure you've heard of, who was the coordinator, if you like, of Survivors Speak Out, who was holding us all together. And we came up with a charter of rights and things like this. And there were people who were saying that psychiatrists should be injected with their own medication, you know, under restraint to see what it felt like, and other people were saying medication was helpful. It was really really amazing. And I always say this, and I talk about it quite a lot, is that for me it was something called a "Paulean moment", I don't know if you know that. You know Paul on the road to Damascus, St. Paul on the road to Damascus saw the light? Well, going to this conference made me see the light, if you like. It made me realize there was more to life

> than what I was living. (*Emma*)

Others are already very politically inclined before joining the movement. Marianne was a feminist, while Rose was always an advocate of Black people's rights. They hold strong beliefs that they feel are not in agreement with the way they were treated in mental health services or how service users should be treated. As service users begin to question the negative aspects of their experience, their previous politicisation leads them to believe they were, at least in part, socially produced - through stigmatisation, poor mental health care, lack of employment opportunities, or that they may have been caused by social inequities in the first place.

> I felt... angry... at the kind of mental health treatment that people receive, at the kind of problems that people have and the kinds of responses they get from mental health services. (…) Had I had the right support at thirteen, I wouldn't have spend my life struggling with different issues, but because it gets framed in very medical terms, even at that age, you're put on antidepressants and sent to a psychiatrist. It's nonsense. (*Karen*)

> And the feminist agenda was very helpful because it.. the way that particularly working class women are treated in our society causes distress and then that distress is medicated. And it's called an illness. And really that.. everything just fell into place very quickly with that. And you could have the thing about capitalism and the working class generally and all that.. I agree with all that, I think to a logic extent mental illness is a social construction which we are forced into. The distress that I felt was to do with my life. And it was medicated and electric shock treatment was completely irrelevant to what was going on to me. (*Marianne*)

> Q. And why do you think that Black people are over represented in the mental health system?
> A. Because of racism. It's as simple as that. Racism from the mainstream, from the police, from the psychiatrists, from the whole mental health system, _____. They are incarcerated, deliberately as far as I'm concerned, taken off the streets, put in prison, in mental health institutions. (*Rose*)

Once the politicised collective identity of mental distress is constructed, it becomes very hard to untangle the elements. Experience of mental distress, connectedness to others, politicisation... all of these elements become interwoven to a point where political and personal are very hard to distinguish. It is mostly because of this strong, emotional personal meaning that mental health issues acquire for individuals that their affiliation to the survivor movement becomes many times so intense and central to their identities.

> In the survivor movement you can do both at once, that's wonderful. “The personal is political”, that was the slogan of the women's movement anyway, but in the user movement we can make that for real. Our personal issues were also political issues. That was very.. that realisation was very strong for me and even in the early 80s. Basically once the penny had dropped and once I got that message, everything else was just kind of building on that really. Yes, I can bring my personal issues and my political issues be used together, and people will share those and people will... we can learn from each other. Yeah that's... (pause 5s) that's how it worked out. (*Marianne*)

The politicised collective identity of mental distress is an important part of the engagement process, we have argued. It is through seeing oneself as part of a collective, who shares the same experience of mental distress and whose experience is, at least partially, made more difficult by society, that our participants have begun to get involved with the SUSM. Not only the construction of the politicised collective identity is essential to engagement, but it also affects survivor's experience of mental distress, as it will be seen in the next chapter.

3.2 The lived world of the SUSM and the service user role

Our interviews were extremely rich in their characterisation of the “lived world” of the SUSM. They provided an insider's perspective of the movement that is invaluable. But because we lack the space to develop these contributions, we will limit the analysis to two main topics. The first, is related to the activities that are performed by service users within the SUSM, and that point to the emergence of an enlarged service user role. The second, to the different political positions within the movement, which lead to internal conflicts that have a significant effect over the experience of mental distress.

The service user role

The SUSM, we have argued, has inaugurated a new discourse, which reframed their experience as a source of valuable knowledge. The creation of consumerist policies in the

1980s offered service users a an "opportunity structure" (N. Crossley, 2006, p.31) for them to be effectively involved in decision-making. Their experiential knowledge was increasingly valued by public authorities and became a "marketable form of cultural capital, which they were able to use to improve both mental health services and their own circumstances" (p.180). Survivors were beginning to get paid for their advice and input, and a whole new area of employment opportunities emerged. They have been, since, reconfigured as important collective actors in the field of mental health.

In order to have an idea of how this enlargement of the field of opportunities is experienced by survivors, we have assembled in Table 2 the activities that participants have reported being directly involved and the positions they have occupied. We also specify if these activities were paid (P), voluntary (V), voluntary with expenses paid (V/E) or not informed (NI). This table reveals a wide variety of possibilities related to the service user role, most of which would have been unthinkable before the SUSM.

Campaigning

- Campaigning for human rights (survivors, BME communities, women, disabled people) – V
- Chairing service user groups in various levels (local / national / European) – V; V/E
- Writing books or articles for various publications (political content about mental health) - V
- Speaking in survivor conferences – V; V/E
- Speaking to the media about mental health from the service user perspective – V
- Producing a documentary for TV with other survivors - V
- Lobbying the government about survivor issues - V
- Fund-raising for service user initiatives - V
- Fund-raising for mental health projects (voluntary sector) - V
- Campaigning against the closure of a therapeutic community - V
- Campaigning against certain government initiatives - V
- Campaigning online - V

User Involvement

- Representing service users in participatory instances with service providers in different levels (local / regional / national) – V; P
- Being a consultant advisor on participation - P
- Reviewing health services - P
- Being a Mental health trust governor /council member (elected representative of the public) - NI

• Developing a service user network within a voluntary group - P • Representing service users in outcomes committee (Dept. of Health) - P • Promoting and supporting service user involvement through specialised organisations - P • Representing service users in professional societies - P • Being a senior manager of user involvement project - P • Interviewing and selecting staff entering the mental health trust - NI
Research
• Conducting research and writing reports on various mental health subjects - P • Evaluating services - P • Developing guidelines for services based on service user experience - P • Coordinating the Experts by Experience group (Dept. of Health) - P • Peer-reviewing publications on mental health - P • Working for commissions that monitor mental healthcare - P • Researching service users' experiences and recovery - P
Self-help and Support
• Mentoring service users who are being discharged from hospital - NI • Facilitating groups or drop-ins in resource centres - P • Managing a project for people with learning difficulties and mental distress - P • Participating in self-help groups - V • Running a user-led crisis service and helpline - NI
Training / education
• Public speaking on various subjects related to mental health in different settings – raising general public awareness - V • Training health professionals and public workers on personality disorder - P • Training service users on public speaking or self-management - NI
Advocacy
• Being an advocate - P • Co-founding and running an advocacy service - NI
Others
• Doing community development activities - V

Table 2. Activities performed by participants in the SUSM

The SUSM, along with consumerist policies, have redefined the service user role, which refers to attributes and expectations associated with being a service user[43]. People with

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[43] We are here using the concept of role provided by Abercrombie, Hill & Turner (2006, p. 332).

mental health problems are now, for the first time in history, allowed and expected to participate in policy and public services. A careful reading of Table 2 demonstrates the plurality of activities that may be performed by service users today.

We have already explained how this enlarged role was accompanied by the creation of a market for survivor expertise. Identifying as service user (and, of course, being competent and having the set of skills required for each position) can now open the doors to an array of opportunities. More than half of the participants in this research were getting paid for their involvement, and for many user involvement (in its various shapes and forms) provided their main source of income. It can also be seen from table 2 that campaigning activities are largely voluntary, while user involvement and other activities are substantially paid. This is in agreement with our previous discussion, that SUSM activists might have been diverted from campaigning because of these employment opportunities.

Political positions and conflicts

As survivors get further involved in consultation processes with the mainstream mental health system that was once perceived as the "enemy", they encounter new problems and issues that weren't determinant before. Also, the growth of the SUSM has increased the internal plurality of views, and the shift to community care has produced a generation of service users who don't have experiences of incarceration and who are generally more sympathetic to the mental healthcare system. While some survivors still hold an oppositional position towards psychiatry, others do not share these views.

Among our participants there weren't any service users who define themselves (or that could be defined) with the most radical side of the spectrum[44]. However, many opposed psychiatry's views and treatments, while at the same time adopting a posture of changing the system "from within", usually being paid for this collaboration. Others are more willing to accept the mainstream health system, its treatments and explanations for distress.

These differences can be apparently explained by two factors: their personal experience with mental health services and the politicisation of this experience. Participants

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[44] Those identified with anti-psychiatry, who advocate the extinction of psychiatric services, or who feel that survivors should never collaborate with mental health professionals or authorities. We have attempted contact with some more radical organisations, but never received any answer from them.

who have been disappointed with services and politicised this bad experience had very critical views towards psychiatry (Karen, Valerie, Rose, Marianne, Emma). This doesn't mean that they have necessarily disengaged with mental health services or that they don't collaborate with the system. On the other hand, service users who've had essentially good experience with services (Annie, Gordon) or who've had bad experiences but don't politicise them entirely (Adam, Ralph, Sally) will end up with a more sympathetic view of services.

We also noted how service users who are more critical towards services tend to be associated with a national sphere of involvement, while those more sympathetic tend to act locally. It is difficult to assess the meaning of this fact – perhaps they are already more critical and tend to get further involved and acquire greater responsibilities, or perhaps the contact with the national movement produces more critical views.

We'll provide an example of different positions using service users' views on medication. As it can be seen from the extracts below, their views differ greatly, and that is based on their personal experience with medication.

> I mean the ECT, I didn't want the ECT, but I was told that's what I had to have. I wasn't forced to have it, but I was kind of pressured to accept it. I didn't want any more of that. I didn't think that was an answer and I didn't think the pills were an answer. (…) I do believe that medication is generally not a good thing, and that people shouldn't rely on it. They shouldn't be given enlarged doses ever. They probably shouldn't be started on it on the beginning, if there's any alternative. (*Marianne*)

> I've always listened closely to people in mental health who'd been anti-medication. I have to say that these have worked. They have certainly worked for me. (*Gordon*)

Apart from previous experiences, politicisation also plays an important part. A contrast can be observed between Sally and Rose. They have both experienced severe mental distress and been long-term users of medication. For both of them, medication provided the desired effects as well as negative side effects, including a level of addiction. As Rose is much more critical to psychiatry, she is also critical of medication. She sees it as a forced addiction and has attempted (successfully, the last time) to discontinue her use. Sally doesn't feel she is able to get off her medication, and is generally grateful for the positive effects, so she doesn't focus much on the side effects.

> But I'm thinking of this stuff around mental health addiction to medication. Because the fact that you're on medication for X many years, one year, two years, six months, twenty-one years, thirty years, forty years... It's an addiction to drugs. Although it's not an addiction where we want to be addicted to. We are forced to take it because this is what our psychiatrist tells us we should have, this is what our psychiatrist nurse tells us we should have, it's what social services tells us we should have, this is what the (link worker) tells us we should have... All these people tell us that we should have this (wonder) medication! Which has all its lovely side effects! Which means that you have to have another lot of medication to counteract the side effects. And your initial complaint isn't necessarily treated or dealt with. (*Rose*)

> I definitely needed medication when I first went in, as much as I resisted it. (…) It certainly calmed me down. But the side effects were kind of a rash, lactation, which was quite embarrassing... I think the medication wasn't too bad, once I came off the injection. (…) I'm on a good dose, quite a high dose of Venlafaxine now, which I think is a really good antidepressant, but it does have side effects, and one of which is it can make you a bit tired, it certainly makes me perspire, what can be really embarrassing. And also I'm on blood pressure pills cause it increases blood pressure, along with smoking and.. if I drink, that's not good, cause I have a high cholesterol as well and high risk of diabetes. (…) I think I probably got quite addicted to diazepam and sleepers, I'm on __ the BNF guideline for them. So that's probably a negative. (…) I'm pretty stable now. I take about fourteen pills a day to maintain that stability. (*Sally*)

These different views produce tensions within the SUSM that are directly experienced by participants. As they notice the divisions within the movement, they are compelled to choose sides. Sometimes their collective identity is contradictory with their experience of mental distress (Valerie) and they will feel the need to justify themselves when criticised by other members of the SUSM. Other times, they will construct a collective identity which is in agreement with their own positions, dismissing the part of the movement that has different views as a different faction (Emma).

> I'm aware of tensions within the movement, around attitudes to treatment. I know that some people completely reject the psychiatric system altogether. People who would probably call themselves survivors. And there are people who identify as mental health service users, who are kind of... They're still engaged with psychiatric treatment, and conventional support for their mental health problems. I would probably count as one of them. (...)
> For some people in the user movement, that compromises my status cause I do use mental health services, I do use a psychotherapist, and I do use medication. But I see, I now see me,

> it's me using medication. And I'm taking active control over managing my mental health rather than being passive and saying to psychiatrists or therapists "just do what you want with me". (*Valerie*)

> Now, some people would say that, as we're involved with the (*name of psychiatrists society*) we've sold out, we're traitors, we're whatever. But those of us who are in there would say "well, we're there so that they don't sell us out, so that they don't"... You know. There's those of us, subsets of the user movement, like the research one, who believe in collaboration and cooperation, and then there's the separatist (giggle) service user movement who don't want to have anything to do with any of that. And in fact don't think people like me should exist. That my role, if you'd like (...) for being service user consultants, is talking to the enemy. And therefore we shouldn't be in the same group. (*Emma*)

Divisions within the SUSM are several, as we have previously discussed[45]. This heterogeneity within the movement can be, on one hand, a positive attribute, since it embraces service users with varied political positions. On the other hand, it is also a source of intense conflict within the movement, and an impediment to their further success.

> That's really very very divisive. People fight for all sorts of things, just different views on compulsory treatment or being white or black or middle class or working class.. There's just.. Oh it's horrible! People who have been in the system a long time, that have been in hospital a lot, sometimes think that they are the only people that matter. And other people think that the people that have been through the system a long time don't understand the issues of survivors now who don't spend a lot of time in hospital because hospitals don't take so many people in. So they're more trying to get good community services. And they say that all these old survivors they don't really understand the issues now, they're out of date... There's a whole new set of questions____ now. So there's fights between those different groups, and then Black people, Asian people think that white people don't get their issues at all, and are all racists - which is probably true. But then the Black people, Asians and the Africans fall out because the Asians get more funding... (giggle). Oh! There's just so many ways that I can't believe it! (*Marianne*)

> But I think that for a lot of people it's quite frustrating as well because there are so many things we haven't made progress on because we're such a disparate group. I think that's the problem. So there are people like me who interpret mental health as being your life events and the way that you then go to relate to other people (…) Whereas I think if you sign up to an illness model, there's a very different attitude (…) and those two models just don´t... There´s a

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[45] See pages 40-41.

> lot of conflict, unspoken conflict between those people, and there is unspoken tension between those people that come from these different perspectives. And I think that's held us back a lot because what we've tried to do.. So, from.. the user movement since the 1980s, because these camps are so.. they cant be reconciled, you can't bring those two together. (*Karen*)

Many feel that more integration is necessary for the SUSM, since conflicts undermines their ability to act together, as a unified movement, and make clear demands, but their heterogeneous nature makes this difficult to achieve. The lack of a single, strong national group is both a sign of this dissent and a factor that prevents consensus from being reached. And even though integration is desirable, it is difficult to accommodate different service user views without losing the movements' character.

> I mean what we need is a platform for our views, whatever views they happen to be. And at the moment, with so many disparate groups (…) And the thing is if you are disparate groups with disparate views, nobody listens to you because they don't know who you are or who to talk to. (*Emma*)

> People with bipolar are going to be interested in bipolar issues, but you... you can't say you shouldn't believe in a disease model, because they do! You know, they thing they've got bipolar. (...) If you got a view that mental illness doesn't exist, there's no point trying to tell people with bipolar that they don't have an illness (...) It's a very very difficult thing to make a survivor organisation work, all mental health system survivors or whatever, when there's just so many experiences, personal experiences, even people with the same label or whatever, there's so many experiences. (*Marianne*)

> So what people have done, they've said that the individual takes the decision about.. how they define and explain their own problems and their own issues. So that means that you, as an individual, in your contacts with health services they need to respect and understand how you interpret and explain your distress and the impact that has on what you need. Which is fine to a certain extent, but it means you have the same model of mental health services, with a little bit of changes, a little bit of tinkering around the edges. And that´s really frustrating for people who (hhh) believe that we need a different approach. That we need to think about things in completely different ways. (*Karen*)

Final comments

The process of engagement in the SUSM is deeply connected to the creation of a politicised collective identity. Sometimes self-concerned motivations or apolitical identification with the peer group can become the basis for joining, and then a political framing of mental distress will emerge. Levels of politicisation vary amongst participants, however. They reflect different political positions within the movement, all rooted in their experiences of mental distress and the meanings ascribed to them.

The SUSM has expanded greatly the service user role on the basis of its own success and because of policy changes. Entering a service user role now provides a wide array of social opportunities for some service users, as mental distress becomes a resource for activism, peer support, work and consultation processes, in a process that is common to other health social movements (Brown et al, 2004; Allsop et al, 2004).

However, the growth of the movement in numbers and increased collaboration with the mental health system have accentuated internal differences within the movement. This heterogeneity has made the SUSM more vulnerable to division and has limited its capacity of action, while paradoxically expanded its scope and made service users almost omnipresent in mental health policy and care.

Chapter 4:

HOW THE SERVICE USER / SURVIVOR MOVEMENT AFFECTS THE EXPERIENCE OF MENTAL DISTRESS

This final part of the results analysis is a more direct examination of the impact that engaging with the mental health SUSM has upon the experience of mental distress. Drawing from the findings of previous chapters, we will discuss how social experience, personal identity and the meaning of mental distress can be transformed by involvement with the SUSM. It is our final argument that the SUSM, through internal and external processes, creates conditions for service users to experience a different social role, to reshape the meanings of their experience and to reconfigure their identities.

4.1 Changing the personal meaning of mental distress

As we have already discussed in Chapter 1, the experience of mental distress requires the person to actively try to “make sense” of it. This is done through her cultural references, which may include family, lay or scientific explanations. The social experience of mental distress, marked by stigma and shame, limits severely service users' opportunities to share their experiences and make sense of them. The person may not only have a hard time explaining to others what she is going through, but she might be afraid to disclose her mental distress to the people around her. Experiencing stigmatisation may also reinforce the negative meanings that the person might have attributed to her mental distress.

Our data indicates that the SUSM may have an effect in this process of making sense, as survivors find an environment that makes it easier for them to accept what they have been through and even to transform their mental distress into a resource. They may find available information and opportunities to build on their explanations of mental distress, as well as a chance to reverse the process of stigma internalisation through politicisation. On the other hand, it is possible that they experience group pressure to adhere to the SUSM's explanatory models, which can have effects upon their experience of distress.

Acceptance and normalisation

The first effect is associated with entering a peer group, which composes a part of the SUSM experience. When service users find themselves among peers, they encounter an environment where moral judgement is much less strict than in outside groups. There, people find the possibility of experiencing social acceptance, as others embrace their stories of distress and their uncommon behaviour. This produces an effect of normalisation, where what was once a stigmatised behaviour or characteristic can be perceived as normal or ordinary[46] by others.

Being accepted makes an important difference to those who have been harshly judged by others and sometimes even more harshly by themselves. Among peers, they report feeling more relaxed, able to "be themselves" with their flaws and weirdness. As many have experienced very difficult relationships in their lives, sometimes having been abused and subject to violence or negligence, this acceptance is something very new to some of them.

> And they've [*service users*] been people that I can talk to most easily. Cause within five minutes of meeting somebody at a conference or something, we can tell each other our life stories. We don't have to talk around... We don't have to hide what's happened to us. And that's.. Being able to be honest about your personal experiences has been so liberating for me! (…) It's enabled me to be who I am and not have to deny who I am in my life. I can talk about my stepfather being a paedophile and people don't go.. You know.. "don't tell me that, that's horrible!" (giggle). (...) And the normal people they were just a problem because they didn't... they couldn't talk about anything important, they were like talking about superficial topics and being respectable.. So yeah, in that way it's been great. Yeah, it's been wonderful, really has helped me. (*Marianne*)

> With peers, either in a therapeutic setting or as friends (...) I don't have as many difficulties with people thinking I'm weird. (…) So if I can't stand being on a situation anymore, I'm just gonna have to say "I can't, I've gotta go, yeah, don't take this personally, I'm just feeling a little bit weird" and then I'll go. (*Valerie*)

> [*In Emergence*], they just accepted me for what I am - he's a nutcase or whatever, I don't care what they thought. And people liked me. (*Ralph*)

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[46] Normalisation is not to be confused with the stigmatised individual attempting to hide or to present himself as normal – this is what Goffman (1963) calls "normification".

An accepting atmosphere allows for the development of self-confidence, which allows people to take on more challenging roles (Gidron & Chesler, 1994, cited by Brown & Lucksted, 2010). It becomes specially important in cases where the experience of mental distress is associated with behaviours that the own person finds difficult to accept (such as violent outbursts) and that cannot be easily incorporated into their identities. Rose has had behaviours during her psychotic crisis that she has found extremely difficult to accept, including an attempt to strangle her baby daughter. She went from psychiatric hospitals to mother-baby units, responded to criminal charges and was nearly put in a high-security psychiatric hospital for law offenders. She found that in hospitals and with her family she was constantly being criticised and judged for those behaviours, of which she was also very ashamed and regretful. She tells her experience of feeling accepted by peers and staff in a day service. The acceptance of others has a sanctioning effect that allows one to move on from these shameful experiences, rebuild their identities, self-confidence and self-trust.

> When I was at a day service, in 1998, 99. We had a user Black Minority Ethnic group. (...). And they had a lady, a young lady, __ recovered, she was a film maker, and she videoed us talking about our stories. And we played it back and I thought, "oh my God... Why did I open my mouth? Why did I say all these things? What are people going to think about me?" But in the end, nobody said anything because they'd all been through some of the things themselves. So really, when I thought they would be scandalised and shunning me, they actually were empathetic, and understood, including the staff. So that's how my self-esteem and confidence built up. (*Rose*)

Being accepted by peers doesn't mean that service users have necessarily a greater capacity of empathy, but that they are more able to understand the aspects of experience related to mental distress because of their history – aspects that can be specially difficult to integrate and to disclose.

> I suppose it's different bits of me are understood in different settings. And it's nice to have that part of me [*experiencing mental distress and going to a therapeutic community*] understood as well as the more technical side, the side that enjoys crafts and all the rest of it. So it is complementary. (*Annie*)

Like Harriet has explained[47], if a part of one's experience has to be hidden from others, it is difficult to "feel whole". Feeling that your mental distress is accepted by others can be a first step in incorporating this part to the self.

Mental distress as a resource

As it was discussed in the previous chapter, a change in the meaning of mental distress has occurred, which has stemmed directly from the survivor movement and has gained cultural relevance. The SUSM has always advocated that service users have a valuable form of knowledge (their experiential knowledge) and they have gradually reframed the meaning of mental distress, from an essentially negative experience, with no added value attached, to a useful resource*,* or a form of cultural capital, as other authors have called it (Lee, 2007; N. Crossley, 2006). This is a process that is characteristic of most embodied health movements, where illness experience is central to the movements' claims and actions (Brown et al, 2004).

Getting involved with the SUSM puts service users in contact with this positive meaning, which will influence their process of constructing significance for their own experience of mental distress. Service users who engage in peer support may find out that their experience has value to others. Similar experiences gives them knowledge and a deeper appreciation of what the other person is going through. Also, as they get further involved, they find that their claims are legitimised because of their lived experience. It is because they have had a breakdown, or have been to a psychiatric hospital that service users have been able to perform the wide array of activities that we have identified through participants. This experience lends them the authority to criticise mental health services in the name of service users, provide input to participation processes and hopefully see some changes happen as consequence. This provides an entirely different status to their experience of mental distress, as their "cries" are transformed in "positive cries", as Roger puts it. Valerie and Sally, below, illustrate how their experiences were valued in different contexts.

> Rather than just seeing myself as a person who was ill, I started slowly to conceive the idea that my experiences could be used in a positive way. (…) And then coming here, to where I work, one of our stated values (...) is recognising the importance of service users and service user

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[47] See page 69.

> experience, to improve social care and mental health services. (…) Actually my status as a service user was actually actively useful, in my job. (…). It was positive, it wasn't a negative thing at all. (…) I'd say that it definitely had an influence on how comfortable and confident I felt to be open about my own status and experiences. (*Valerie*)

> I mean, I've been, just a little while ago, for the trust, I was talking about what I considered to be my experiences of excellence in mental health care. (…) And things like that boost my confidence and they can also help me network, and maybe in the end I can start getting to know people that perhaps I'll be able to get paid employment at the end. (...) You're trying to teach people in the psychiatric field really what's needed on the user perspective. (…) [*it gives me a*] sense of strength, really, in that I'm trying to change things around and use what was a very distressing, and has been very distressing experiences, around toward my advantage and hopefully helping others at the same time. (*Sally*)

If mental distress is socially perceived as a bad thing, within the SUSM survivors can discover a new possible meaning for their experience. Not only they find that their previous experience can be accepted by their peers, but that it can also be a valued resource. This can be an empowering transformation, as it makes it easier to create a positive identity which incorporates their whole biography, without needing to deny or exclude their experience of mental distress from the narratives which constitute their identities. Moreover, as we will discuss further on, many service users are able to use this resource to their benefit, improving their quality of life.

Ways of making sense

If we could summarize what is the main thing people within the SUSM *do*, it is discussing mental health – in a variety of different ways. They talk about in private meetings or in public gatherings, they advocate their views or they share their difficulties, they discuss it in writing and orally, amongst themselves or with other parties. Service users train people on mental health, they campaign on mental health, they do research about it, they try to enhance mental health services. In other words, mental health becomes a central part of their discourses and their lives.

Assuming that the possibilities of discussing mental health (specially mental health problems) are very limited in society[48], the opportunity for doing it in the SUSM are welcomed

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[48] It could be argued that our society is in fact obsessed with discussing private matters and that confession has

by service users. Roger explains how he was denied the opportunity to talk in several occasions, including by mental health professionals, while other participants have also mentioned the difficulties of access to talking therapies in the NHS. Roger, below, gives us an idea of the difficulty that service users can encounter to be able to talk about their experiences. Emma suggests how talking about what has happened to her is a way of “working through” it.

> No one cared to ask. No one allowed me to speak, to tell. And they could have let me tell them. This actually is still true to this day. They wouldn't let me talk in detail about my traumas. As they said, it would too traumatic to talk about my traumas, this from a top psychiatrist, and the top psychologist in the region. They fundamentally agree with that. Denied me the opportunity, like other trauma victims, to talk about their traumas. I find this astounding cause (…) I spoke out to the media. I spoke out to roughly 3 million people about various aspects of my trauma, and yet the psychiatrist would not allow me to talk about it! Because it's too traumatic! (*Roger*)

As they get a chance to talk about their experience with their peers, and be listened, they find that it becomes easier to understand what has happened to them. Like Allsop et al (2004) have found, interaction aids the individual in finding an explanation for his distress. Other authors have highlighted the importance of self-disclosure to transform identity (Lee, 2007) and of “finding the words” to convey experience in order to recover (Corin, 2002). This can be done, in the SUSM, through a variety of ways which includes talking and sharing experience with peers.

> When I first sort of started, thinking about it and talking about it, really put a lot of things in context, which I haven't thought about, it hadn't occurred to me, at all. And partly through talking to other users and survivors. (…) Rather than trying to pretend it doesn't exist, or that it's.. or that the experiences you had are nothing at all.. It's really important to say that they are important. They have been... part of your life. In some cases, sometimes, a large part of your life. And that the way to work through what's happened to you it's to talk about it. And I'm a great believer at that, really. I mean, I'm not saying you have to bang on about it all the time,

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become a new public discourse (Foucault, 1978). In our research, we've found that people had very restricted access to spaces where they could discuss their distress with others, as access to talking therapies is very limited in public health, mental distress is taboo in most families and peer groups appear as one of the only outlets available. But as Roger's narrative in this page shows, he was able to speak about his traumas in front of “3 million people”, as he went on a television show – which attests the modality of discourse Foucault was referring to. Still, he cannot find a mental health professional who wants to listen to him.

> you know, but I think it's important to acknowledge what's happened to you. (*Emma*)

> When I'm writing about, when I'm speaking about it, I make sense (...) cause I'm making a connection. The difference is I'm communicating with another human being. When I'm having these thoughts with invisible people, invisible audience, I'm just having obsessive thoughts. Round and round in my own head. It's not making sense. (*Roger*)

Not only the SUSM provides a space for reflection and sharing of experiences, but it also serves as a source of information about mental health that can help service users pursue credible explanations for their experience. While lay and professional explanations are culturally available, sometimes they are not sufficient for service users, or downright clash with their own previous beliefs. In these cases, they might look for alternatives explanations, and service user / survivor groups might provide an important source of information and reflection.

The British SUSM doesn't advocate a unified explanatory model of mental distress (Beresford, 2002). In the past, it has been known to be opposed to psychiatric explanations, but as the movement grew it was compelled to incorporate views that were much more sympathetic to mainstream models. Some groups advocate an explicit model[49]. Other groups promote the views of Recovery or Self-management, which were created by the survivor movement internationally. Another emerging model for the SUSM is the Social model of madness and mental distress[50], inspired by the social model of disability. Moreover, diverse explanations built from survivors' individual and collective experiences are diffused by SUSM groups through conferences, training activities, publications and other activities. Usually, they are not grouped in a unified model, which creates an intentional polyphony because of a level of openness to different possible explanations.

What we have found from interviews is that the SUSM serves as a repository of information and as a space of reflection for some users, whether or not it comes in the form of a unified model. The eclectic position of the SUSM allows that service users with varied understandings to draw from their knowledge base and complement their own understandings.

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[49] Such as the Hearing Voices Network, who believe that voices are not symptoms of illnesses, but that they have meanings which should be explored (Hearing Voices Network, n/d).

[50] This model argues that service users are disabled by society's inability to cope with their differences, and attempts to shift the emphasis from rehabilitation to civil rights. Some resistance to this model has been documented within the SUSM (Beresford, 2002; Beresford, Nettle & Perring, 2010).

When the person already has a previous belief in one explanation which clashes with services' explanations, she will feel “validated” by finding a group of people who also share it. Harriet and Karen are good examples, as they were already critical of psychiatric explanations and treatments when they engaged with the SUSM. Harriet explains how it was hard for her to find alternatives to this model in the mental health system when she first got involved (late 1980s). Finding others who shared their views strengthened their own understanding of their distress, helping them make sense of their experiences. Valerie illustrates how the movement can offer alternative explanations that entail a search for meaning and information.

> It was helpful to find other people like myself who've got some concerns about the psychiatric system and power imbalances, and a rather narrow drugs-based approach. Cause I know (certainly the understanding way) of mental distress, the standard psychiatric explanations just... they wouldn't help me to make sense of it. And at the same time it didn't really seem to be much else within the standard system in this country. (*Harriet*)

> I think in the national movement, and certainly amongst researchers, there'd be a lot more understanding of life events and the role of trauma, or whatever. And that is validating, if that's how you feel your experiences are. (...) It means you can build on your own understanding of yourself and other people, and you have connections to other people because they have similar experiences to you and find alternative models as restraining as I do. (*Karen*)

> The [*SUSM*] conference I went to, I was exposed to many people's individual and collective understandings of mental distress, as something that wasn't necessarily clinical. I've met with some activists from Ireland, I think, who talked about having a non-consensus reality. I've read stuff about.... Very simple stuff about the brain and how that works.. (…) I've almost educated myself in the different understandings of mental distress, and it's broadened out.. I've become less isolated with my experiences, so I sought different explanations for them. (…) Having been drawn into the movement, I've thought more deeply, more carefully about psychiatry, mental health services and the people who use those services or the people who experience mental health problems or mental distress. It's made me very aware and very literate about everything, so it really has helped. (*Valerie*)

In other cases, the person may agree with the psychiatric model – she accepts diagnostic labels, for instance, or believes in underlying diseases to mental illness – and she finds in the SUSM a place where she can learn more about her illness and improve her repertoire of coping strategies, as certain organisations adopt this framework. Annie, for instance, went through treatment for personality disorder but was never told anything about what it was. When she started training health professionals for a SUSM organisation in partnership with public authorities, she was able to learn more about her diagnosis and how to deal with the problems attached to it, in a way that made sense to her previous beliefs.

> So I was then referred quite quickly to the complex needs service, which is.... I think basically for dealing with personality disorder. Rather than being referred to the local community mental health team here. But nobody ever said personality disorder. I didn't come across the term until after I'd left to the therapeutic community and we started doing all this training. (…) It's a bit clearer now, having done the training course, there's much more in there about the theories and what sort of personality disorders there are. How they're experienced. And yes, I can see particularly the avoidant cluster, obsessive.. yeah I think avoidant is one of the ones.. Bits of those do sound very like me. So, having looked at that, yes it does make more sense. (...) So to a certain extent I know a bit more about the theory behind what's been going on for me, and I can think "well, that's me, and that's not me" and understand a bit how I relate to other people with similar labels as well. (*Annie*)

Even though it might seem almost paradoxical that someone would learn about a psychiatric diagnosis within a movement that was once fully anti-psychiatry, this is the current reality of the SUSM. The idea of choice is now defended by a large part of the movement, as they recognise that different experiences lead to different meanings, and that service users should dispose of various explanatory tools, which they can choose and incorporate as they please. However, as it will be explained next, this internal freedom is limited, and group pressure can be a factor within the movement.

Group pressure and effects of explanations

If the SUSM may seem to be, to a certain extent, a democratic and eclectic environment, we have also demonstrated how internal conflicts can be very intense. It seems that tolerance of different positions may be limited because of the need to create a certain degree of integration or homogeneity within the movement. Goodwin and Jaspers (2009) argue that it because their heterogeneity that social movements can accentuate homogeneity.

Since social movement's boundaries are so hard to define and membership is not formal, ideology becomes a main source of identification: “you are a member of the movement to the degree that you believe what the other people in the movement believe” (p.163). Deviating from ideology may cost the person to feel estranged from the movement, and usually, from the social bonds she has created within it. Hence, pressure to conform can be a major attribute of social movements.

Valerie's narrative provides a fruitful example of how group pressure can play a part in service user's attitudes towards treatments and mental health services, which in the end can have a detrimental effect to mental health. It is quite a large section of the interview, but we feel it is very enlightening about this process, so we will reproduce it here. She begins by explaining how she feels some criticism from people within the SUSM (people she agrees with) because she is compliant with psychiatric treatment.

> Some people are very outspoken and very... Well, not outspoken, they're very political about psychiatry, *which is absolutely right*. But I would potentially - if I was that way inclined - I would feel a bit alienated and criticised for having been through the system, not fought it. I haven't been in a position to fight it for taking medication, for partly doing what I'm told. (…) There are, sometimes - and I think it's part of any social movement - there is an extreme political end that can have a negative impact on people who are developing their own identity within the movement. (*Valerie*)

Further in her interview, Valerie explains how she was influenced by a friend (an ex-service user, but who was did not identify with the SUSM) to get off medication and try to deal with her mental distress in other ways, which were working for her friend. It didn't work for her, as she had a terrible crisis and ended up, for the first time, in psychiatric hospital. After her hospitalisation, she felt her affiliation with the survivor movement was reinforced. She now shared with other activists the “horrendous experience” of being in a psychiatric hospital. She felt she finally understood what they meant by being a “survivor”.

> I'm also aware that... I felt more (giggle) authentic... I mean, this might be just to do with me - but I felt more authentic once I'd had a more extreme experience of mental health crisis, where I ended up in hospital. (...) once I'd had the experience of the really hardcore psychiatric system, and being in a psychiatric hospital, I thought I'd become... it's weird to say but I almost became kind of more.. more confident of my experiences (laughter), more confident to criticise the system! Cause before.. it was not that I felt inauthentic, I just felt I didn't share all

> the experiences a lot of people had. (...). Because that's when you really understand what the term survivor means. Cause it's just such a horrendous experience! (laughter) And I know that's a binding experience for some people, because that's enough to kick you into activism, I think. (giggle) Often! If you were that way inclined, anyway. (...) I perceive myself more clearly as an activist since my experience on the psychiatric, tertiary, secondary psychiatric system. (*Valerie*)

Finally, she analyses how these events can be linked together.

> Sometimes I wonder if it's [*the SUSM*] made me too aware of things.. Like, the idea that I'm not authentic until I've been hospitalised that I've, you know there's this idea of.. that I may be imposing on myself, but I certainly detected it from some.. some parts of the movement that you have to have had the real hardcore experience to really be able to talk about things authentically. (…) But I did go through a period where I didn't do what I was told and I ended up in hospital (giggle), so there may be... (...)
>
> Q. But did that extreme part of the movement affect your decision to get off medication at that point, or did that have nothing to do with it?
>
> A. It might have had some... Because inevitably you will pick up ideas, and I was really really fed up with the way my medication was making me feel. (...) So I was encouraged by this particular friend who doesn't actually affiliate with a service user or survivor, (…) but she had had incredibly bad experiences in the mental health services, she completely rejected psychiatry (...).And I decided to give that a go. It didn't work, but I gave it a go partly because somebody else was giving me an alternative to try, because the drugs weren't working anymore (giggle). So it wasn't actually... I don't feel that for me it wasn't the pressure within the wider service user movement. It was a friendship with a particular individual who didn't actually affiliate with the movement.
>
> But, having said that, what I said earlier about feeling more authentic once I'd been in hospital, and really gone on the quite hardcore end (…) probably did derive from some kind of... I don't know. It's not explicit! And maybe that was just what I was picking as an individual, because I don't ever feel particularly authentic, and I do have an enduring idea of myself as a bad, inadequate person.
>
> So I don't know. The dynamic about the kind of (…) more political anti-psychiatry movement had been very... had had horrendous experiences in hospital, and I felt more authentic once I had been in hospital. But I don't know if that related directly, by having an impact in my mind, if that related directly to the kind of general environment of the movement where there seems to be a quite extreme end, and I was getting... my experiences have aligned more with the more extreme. I don't know (giggle). (*Valerie*)

Analysing her narrative, we are aware that Valerie had been constantly using psychotropic medication since she was 21 years old. She used to go frequently to a GP and eventually started psychotherapy, which she has been doing for 10 years. Because of that, she refers to herself as a "service user". However, she has been in contact with the SUSM also for a long time, and has come to feel a part of the national movement – she shares the collective identity of the SUSM. She's had contact with many frontline activists, some of whom she admires deeply.

She recognises an amount of pressure from people who are against psychiatry, a position she agrees with. However, she didn't feel she was able to discontinue her use of medication because it was necessary to keep her stable. Valerie had a friend who was successfully managing her mental health problems on her own. This friend was not a part of the SUSM, but was very anti-psychiatry, and therefore, shared the views of this radical part of the SUSM. It should also be noticed that Valerie experienced strong side effects from her medication. Occasionally, her medication didn't work so well anymore. She then had to go through a period of switching medications when she would experience instability.

It was on one of those periods that she decided to come off her medication. It is very likely that all three factors contributed to her decision: her friend's experience, the difficulties with medication and the influence of the SUSM. The latter factor Valerie finds harder to accept, but she was eager to be fully recognised as a member of the movement. Being able to disengage with any psychiatric treatment would have been very well seen by her peers.

However, she was unable to do it. She had her worst crisis ever and was hospitalised. Valerie then discovered that her experience granted her a different form of legitimacy – instead of having to reject psychiatry, she was now fully legitimate as a "survivor". That's perhaps what she meant when she wonders if being in the SUSM has made her "too aware of things". She was too identified with the SUSM ideals – her collective identity became stronger than her personal identity. We'll get back to this subject in the next chapter, when discussing the existence of an ideal that guides people's identification with the SUSM.

Some critics would argue, from this narrative, that the SUSM reduces adherence to treatment or compliance, and that would be essentially a bad thing, detrimental to mental health. We would find this argument hard to sustain. Even though in this case it was detrimental, it won't necessarily be true. Many people might try to disengage with services influenced by the SUSM and discover that they could do without medication (like Rose, Emma and Marianne, for instance, have found). On the other hand, many patients decide with their physicians to discontinue use of medication and have poor results, like Valerie did. If we argue that service users are, ultimately, able to take their own decisions about what kind of treatment they want, it is not so serious that the SUSM could influence people to try an alternative, even when it fails.

4.2 Changing the social experience of mental distress

We have argued that a great part of users' experience is characterised by rejection, fear, stigmatisation, moral judgement and a very limited amount of support. People with mental health problems have more difficulty making friends, finding a partner or getting jobs than most people. This negative social experience makes recovery more strenuous, since people have to overcome the social impediments as well as dealing with their mental distress.

The SUSM is fully aware of these social difficulties – they are, in essence, the reasons why the movement emerged in the first place. SUSM groups have created a series of devices to tackle these problems, like various forms of peer support activities – groups, drop-ins, crisis houses, helplines – modelled after their ideals of how service users should be treated in society. They have campaigned against stigma, trying to increase public awareness of the experience of mental distress and lobbied for anti-discrimination legislation.

We have found that engaging with the SUSM changes the social experience of mental distress in several ways. The most obvious is that it supplies to service users a network of peers, which provide emotional and material support when necessary. But much more than that, being a part of this network creates, for many service users, a sense of community and belongingness, which might have beneficial effects. Other effects that could be identified are related to the new role of the service user. It has been previously discussed how people who experience or have experienced mental health problems have gained space in the public sphere. Those service users who are able to use their status favourably will probably enjoy many advantages of this new role.

However, there are the downsides. Openly admitting one's service user status is likely to increase the person's exposure to stigma, depending on which context it is done. Those who perform user involvement activities report being patronised and feeling voiceless, which adds to their mental distress. This is historically a new position for service users, and they face the difficulties of dealing with other professionals in a work environment, very frequently feeling that their status is not really valued by their colleagues. But conflictual relations can be also established with those from within, specially related to the internal conflicts we have previously discussed.

A sense of belonging to a community

Many participants have mentioned having a sense of "community" towards service users / survivors. As isolation and social stigma are important parts of the social experience of mental distress, this sense of belonging to a community has a substantial effect for members. It is, sometimes, the restitution of any possible human contact.

> Yes, right from the beginning it was a big help to me because I felt like I had a community. I felt I had somewhere I could belong. That was very very important to me in the early days. The same as when I was in hospital and had a little group of women (…) Yeah, that's what I really really needed, I think, most of all, was just to be able to communicate because having been a very introverted and shy child, I haven't had much communication as a child. I couldn't talk to other children at school, to anybody really. It was kind of very hard to talk to anybody (who was) part of my life. It wasn't really until I was in hospital that I lived to get through that feeling of being different than everybody else. So it was my community and we could all be different and it was ok (giggle). (*Marianne*)

> I think it's feeling like I've got a community of my own again myself. You know, cause obviously one thing you experience if you have episodes of major mental distress is being very much outside, you know, communities in general. So you know that has been another very important part to me. You know, I've got a community. (*Harriet*)

> I was the only one. Only one in the world. (…) Having being through what I've been through... (...) How could I imagine anyone ever going through that? Where would I witness it, where would I hear about it? (…) When I first met other service users I know now, other patients... And from that moment my life just have been transformed fully for the better, beyond belief. (…) I've met the most incredible people with an array of different problems, different traumas, different types of fears and inabilities. We all had that one thing in common. We had been stigmatised, and let down by society. (*Roger*)

In social movements research, scholars have found that this sense of community can be extremely powerful. Della Porta and Diani (1999) argue that a community formed in the process of struggle "is a very precious thing, and fulfils a lot of needs that are not met in daily life" (p.179). "There is nothing as productive of solidarity as the experience of merging group purposes with the activities of everyday life" argues Rochon (cited by Della Porta & Diani).

In Psychology, this sense of community may be referred as "psychological integration" or "belongingness". Both refer to the extent to which an individual perceives membership, expresses an emotional connection with others and believes in his ability to fulfil needs through neighbours, while exercising influence in the community. When interdependent, mutually supportive relationships form, a sense of community develops. People become attached and committed to that particular setting to which they feel they belong.

These supportive relationships between users may frequently develop into personal relationships such as friendships. This affective network sustains many activities within the SUSM. Survivors may require each other's help when they encounter difficulties related to activism or user involvement. As they share experiences around these subjects, they may find not only encouragement and learn from others' experiential knowledge about the issue, but they can find it impacts on their mental health as well.

> If I was isolated and I had an experience, say, with the manager, who I felt the way he was treating me was due to my mental health problems. I would have that on my own, if I wasn't linked in with other people who may have been in similar situation. I can go refer to them and it helps me with my mental health, because if I'm isolated I will probably go down this spiral, thinking it's all me and end up in some kind of... Well, it wouldn't be a crisis, but I would end up in some sort of mental state, whether slightly paranoid or I would be undermining myself. It's great that I can just e-mail somebody, even if they're busy and in a couple of days I'll get somebody who will help me with my perceptions (giggle). (*Valerie*)

> And again, because that [*working with user involvement*] can be a very very isolated and difficult position, you know, again, I think the survivor movement has sort of helped me to maintain that, because some of the people I can go and talk to when I've had a particularly difficult time with the organisation, or, the group of people that come for training or, things like that. (*Harriet*)

These are experiences of politicisation, in the sense that individual complaints are shared and reframed as social problems. A service user who may have a previous tendency of self-blaming (rooted in his social experience of stigmatisation) may find it very useful to discover others who experience those problems. He will then perceive them as not being related to his own self, but to other circumstances.

This sense of community created by peer support practices can be either a ghetto experience, when the person can only relate to others who have mental distress, or an impulse to a further community integration, being a safe basis from which the individual might build upon. Barnes and Bowl (2001) have found in their own research with survivors from the SUSM that 60 percent of respondents had increased contacts with non-survivors after joining the movement. Harriet and Marianne, for instance, have gone from relating exclusively with survivors to being successful professionals and having regular interactions with non-service users, which they didn't have before. On the other hand, Sally feels she has been unable to cross that bridge, and has kept her relationships exclusively with survivors. She is afraid of the hurtful attitudes of those who don't share her experience.

> And, I guess I felt more secure in terms of reaching out to integrating with community members in general. I feel like I've got some kind of base to do it from, rather than being you know this one isolated person, who's not really seen as part of society (*Harriet*)

> For a long while (…) I thought I could only be friends with psychiatric survivors, cause other people don't understand. But having worked for a lot of national organisations now, I've had friends who haven't had been mental health system survivors. I mean most people have got some.. have had some problems in their lives and can empathise. And it's less of a problem now, I can have friends who are not survivors. (*Marianne*)

> And that's probably where I'm a bit institutionalised, to a certain aspect. (…) I do find it easier to talk to people who've been through mental distress themselves or people who work in it (…) and that have empathy, than talking to.. Like, if I go out with my sister and her crowd, she has a totally different life to me. And I feel my life is very... it hasn't branched out an awful lot because of my experiences and stuff. (…) It's just like they have a totally different life and mental health isn't in the equation, whereas with me, it's almost my life, because I'm surrounded with friends who've experienced it. I almost feel odd being around people who haven't been through those kinds of experiences. (*Sally*)

But even so-called ghetto experiences can have their value for recovery, if they are part of the process of "positive withdrawal" described by Corin (2002). However, there are other downsides to relationship with peers. Some participants describe the challenges of relating to other service users, as they can be more difficult, demanding, temperamental or self-centred than non-service users. They might also simply have greater needs, and not be able to be supportive to another person during their own difficult periods. Sometimes only the fact that they are feeling down can affect others negatively.

> There would be some individual relationships that I have with service users that I find particularly supportive - and I think some service users are particularly good at giving support - and then there are other relationships which would be more destructive than constructive, not so supportive, much more draining, exhausting to be in. (…) pretty much everybody you deal with all of the time are struggling with something, emotionally (...) Depending on how the people are themselves it can be exhausting, because there can be so many demands of you and you have to be so sensitive all the time, cannot upset this person and. that can be so draining. (*Karen*)

> At the same time it [*being around service users*] can be a bit detrimental to me. (…) Because I'm really sensitive, I take everything in, so a lot of my energy can be sapped. Like, many of my friends could probably be sapped (by mine), if I'm depressed (...) because it's so.. people talking about their problems all the time. And, you know, it can be frustrating! So it's got pros and cons really. (*Sally*)

Karen reports these feelings reluctantly. She goes back and forth in her interview, changing her mind about service users being more supportive than other people, and then about how they are more difficult to deal with. She finally admits that she prefers a working environments where service users are not present, which she introduces with this phrase: “I probably shouldn't be saying this, but...”.

It possibly indicates a need, among service users engaged with the SUSM, to sustain the positive aspects of peer support while hiding the negative aspects, because it is so important to their collective identity that they differentiate themselves – positively – from non-service users, and because self-help is one of their ways to sustain the value of their experiential knowledge. So, we have to be careful to accept the idyllic picture that most participants paint of their service user community. It is likely that conflictual relationships, discrimination and rejection are also present service user relationships with peers, although probably to a lesser extent than with those who don't share their experience of mental distress.

The benefits of the “service user” role

As we have previously discussed, the SUSM was at least partially responsible for creating new opportunities for service users to act in the public sphere, through the enlargement of what we called the service user role. One important aspect of this transformation is an increased access to employment through the use of experiential expertise. This is, in itself, a very important effect of the service user movement to activists' lives, when we take into account how exclusion from employment is a major issue for people with mental distress, and an aggravating factor for their recovery.

> I had a really good life using my service user identity. It's enabled me to live well with a mental health condition for many years and earn a bit of money. And the thing is I couldn't get a job otherwise. I would.. I like being self-employed, I like being freelance, because it was stress at work that (did me) in the first place. And because I'm the sort of person that gives 100% or 120%, when everybody else is only doing 50% at work. So I would struggle now to have a “proper job”, in inverted commas. (*Emma*)

As Emma explains (and it's the case for many participants) keeping a “proper job” can be difficult for service users. Not because they are unable to perform the work, but because their distress requires some adaptations that not many employers are willing to offer. That's perhaps another reason why service users are usually consultants (N. Crossley, 2006), since being self-employed allows them a flexibility that cannot be encountered in paid jobs. In this sense, being a part of the SUSM allows them to get this more flexible position.

Whenever they are hired, being “out with the label”, as Emma calls it, can be important in order to get these adaptations. Sometimes, places that hire service users because of their experiential knowledge of mental distress are already workplaces sensitive to their needs.

> [*in her job as a service user researcher*] I can talk openly, confidently about, you know, I´m having a psychiatric assessment tomorrow so I'll be in late, or, you know, my therapy's ending next week. Not necessarily to get support but there is a level of openness and acceptance that's very, sort of... I don't know, it´s just nice (giggle). Yeah, it just makes life much more pleasant. But then, not just that, it´s also how you're seen as a professional as well, because both aspects of your identity are important, so it's the way that people interact with both of them. So, to be seen as somebody that is having a psychiatric assessment, who is going to a therapy, who,

> maybe (hhh) has ex-therapy needs coming off, or whatever, but also as somebody who's capable of running a research project is great. So they don't confuse the two, they don't see it as "she's a little bit mad, she can't work, we need to keep an eye on her". (*Karen*)

> And I came off... I was initially taking it with mirtazapine together, and I came off mirtazapine because mirtazapine was making me.. well it did zombify me a bit, and it made me incredibly sleepy. So, the difficulty of turning up to work, I used to... But fortunately I was able to negotiate that I came in later, because I literally couldn't get into work before about half eleven. Because I could not wake up (…) I think my experience has been really quite unique. I know some academic environments, even if people are working in mental health research, it's very difficult because academics who don't have experience of mental health problems may have all kinds of assumptions about your intellectual capacity and, you know, what you're capable of, and making a lot of assumptions about your brain (laughter). But I'm fortunate that I haven't had that here, and I've.. my status as a service user has always been valued by my colleagues. (*Valerie*)

More than a salary or the possibility to have a flexible work environment, this new role of service users and their status as activists awards them a social recognition that is unprecedented in history. They become known and valued for their work and activism, which is socially perceived as positive, noble. They get opportunities related to their status as service users which perhaps they wouldn't get otherwise: travelling abroad for SUSM conferences, speaking in public, appearing on the media and even meeting the queen were some of the things the participants have done because they were involved with the SUSM. As Roger says, service users now can "stand shoulder to shoulder amongst professionals, highly educated". In Sally's words, being recognised and valued can give one "a sense of wanting to live the life that you're living".

> My mum doesn't understand mental illness at all. She didn't like me saying I was a user involvement coordinator. She liked to say, "oh my daughter works for the trust, is a manager of the trust". But you know there's still that stigma around what I was doing. But for me it was a real... Because, you know, then I was kind of.. wanting to be a real pioneer for the user movement. (…) I think it's important to get recognition, as well, for what you're doing. Not just in monetary terms. In, again, respect. Being valued. Because this all gives you a sense of purpose, a sense of wanting to live the life that you're living. To build a life worth living after a breakdown. (*Sally*)

> We're the service users, or the community activists, that are not paid, not even seen as

> volunteers, paid or unpaid, giving our time to help our community. (…) But when people like me and the rest got together and turned up at these meetings, then we stand shoulder to shoulder amongst professionals, highly educated, including social workers and doctors and all mental health workers and council workers and chief representatives. We were holding our own, not only holding our own... Feeling more intelligible, coming up with the best ideas, being the most productive, being the most keen! (*Roger*)

These last statements, however, also come to show how this expanded social role is still limited. It doesn't prevent stigmatisation (as Sally experienced from her mother) and it doesn't mean that service users will necessarily get paid and have their work valued (as Roger's experience demonstrates). In fact, playing the service user role may even increase their exposure to stigmatisation, as we will now discuss.

Increased exposure to stigmatisation

Many service users have attempted to protect themselves from stigmatisation and hurtful attitudes from those who call themselves "normal", through physical or psychological isolation, for example. They gain a little extra confidence from their peer community, and, attracted by the possibility of improving mental healthcare or public services for service users, or perhaps by the opportunity to engage in paid work, they leave their carefully constructed protective bubbles to participate in service user consultation, or user involvement. Little do they know that they are going straight into the middle of a battlefield.

Historically the organization of public services has relied on the "intimate entanglements of authority and expertise, often in embodied form – the doctor, the social worker, the police officer" (Clarke, 2007, p.170). Since the 1980s, these combinations have been transformed by the new modes of governing created by consumerist policies. The approach of choice and empowerment was seen by their creators as "means to break up producer domination and challenge the forms of paternalism associated with producer power" (p.171). In other words, the government was interested in breaking up the power monopoly of professionals, or producers, who were seen to concentrate decisions in their own hands based on their expertise – decisions that were not always cost-effective, in the government's view. In health policies, the figure of the manager was introduced, but service users were an essential part of their strategy. It was through consumers exercising their "choice" that professional power would be legitimately disarranged (Barnes & Bowl, 2001).

But knowledge and power form a "knot", in Clarke's terms, because of the way

> the different strands of unequal knowledge, unequal power, forms of authority and forms of need remain entangled in the current workings and future prospects of public services. As a result, the knowledge/power knot cannot be easily undone. A populist view of choice and empowerment left organizations struggling with how to balance experience and expertise, or voice and authority (p.172).

Not only organisations were struggling to balance these expertises put in direct confrontation by "populist" politics. From our interviews, it was clear how mental health service users were very much affected – both positively and negatively – because of these political choices. As a collective, they have benefited because it opened up a space for them to be a part of political decision-making. Individually there were benefits too, as we have just discussed about the access to employment and status. However, in many cases service users found themselves in a very fragile position, since they are now directly antagonising with health professionals, who, ultimately, are much more powerful than they are. They feel that they are "tokenised", in the sense that their positions are merely symbolic and not effectively recognised.

> I was a representative at different meetings with the (hh) local service providers, so the authority that provided mental health services through the area has meetings that people can go on as service user representatives. (…) The professionals were there to talk to each other, and every time a service user spoke it was seen as an irritation, getting in the way of people trying to get their work done. So it was a pretty horrible experience, really. (…) It´s quite a frustrating experience to have and it kind of mirrors your experiences in mental health services anyway. So, you go from mental health services where people don't really listen to what you have to say, or what you think is going on for you, to being a service user representative, where they don't really listen to what you got to say (giggle), what was going on for service users. (…) It's quite painful and difficult. (…) It's just tokenism. They don't have service users sitting there because they want to listen to what they say, they have service users sitting there because it looks great on paper to say we have service users at these meetings. (*Karen*)

Service users find themselves stigmatised again, but in this context stigma is used politically, to maintain deep rooted power monopolies. Many participants have referred being dismissed in user involvement activities because of their service user status. When convenient, their words may be reframed as being the words of someone who's unwell, with a disturbed rationality because of their "mental illness". Paradoxically, when service users are perceived by their opponents as being articulate and providing rationally constructed arguments, they are dismissed for not being representative of service users. They are caught in a "double bind" (Barnes & Bowl, p.126) which comes to show how in many cases the actual power remains on the hands of professionals, who can decide on who's legitimate enough to represent service users

> It can get messy in a sense that I am someone who still uses services, so I don't want (...) what I'm saying to be viewed as someone who's slightly unwell or "this is the reason he's saying that". It's truthful, it's open, and it's a genuine view of how I think people are feeling and what their needs are. Not anything to do with me feeling unwell or anything. (…) But sometimes it can be picked up in the wrong way. And it is such a sensitive thing in the movement because I don't know, sometimes it's how it's interpreted that gets me a little bit concerned. I don't want it to be attached to something of a mental health nature (…) So that makes me a little bit nervous. (*Adam*)

> They either have us in the meeting and take no notice of you because, you know, "you're not a representative user because youre not really doing anything", or if you´ve found your voice and you´re quite articulate and angry and able to say what people think, then you´re not a real service user, so you get dismissed on that acccount. Either way you lose, and not have a voice, either way. (*Karen*)

The effects of this combative context are emotionally felt by participants. Karen mentioned several times this effect of "mirroring past experiences", in the sense that participation activities may reinforce previous experiences of being voiceless, powerless, ignored or discredited. Furthermore, the views that survivors hold in consultations and user involvement are very personal to them, as they are deeply attached to who they are. When they are dismissed this can have a devastating effect.

> It's very demanding emotionally [*engaging with user involvement*]. Although I do suppose it's something I want to do, but it can be quite high cost emotionally. Like, I'd be talking about promoting training and things that are very personal to me, which matter to me in terms of.... Not just in terms of academic or professional sense, but actually in a very personal level. And

> so, if it's a pill, you know, the emotional drainage can be much stronger. (…) It's certainly not at all unusual that people go downhill in terms of mental distress exactly because of the user involvement work that they're involved in and trying to promote. (...) So I suppose if I wanted an easy life I wouldn't be doing this at all (laughter). (*Harriet*)

As political as these strategies are, they are felt by service users as personal. Sally's narrative also comes to show how, even though structural and political conditions were in the roots of her inability to perform adequately a consultant job, in the end she attributes the failure to herself. She has a rational interpretation of the situation that understands these conditions, but her lack of confidence and self-esteem and her internalised stigma have a stronger hold of the way she is able to explain the final outcome.

> So I think when government policy came in, that you gotta have user involvement, it was encouraged, and you were supposed to have this kind of resource, I think the trust weren't ready, my local trust weren't ready. Because I didn't have an office to go into[51] (...) we didn't have any computers, to begin with, for the first couple of months. We didn't even have mobile phones. But we were, everybody knew, the user involvement project had started, and everybody wanted a piece of us. (…) But I think the last straw for me was when.. (...) I was told that our office would have to be placed in a hospital grounds. I just thought, this just isn't (on). Cause I thought there's gonna be lots of users who would like to express their views, but they are going to be too afraid to come into the hospital, because of experiences they've had. And so I didn't feel I could give a truthful, clear account of what was going on, and that went against my values. (…) To begin with, it [*having this job as involvement coordinator*] really gave me a sense of status. Made me feel part of the community again, and I didn't feel ashamed, and I didn't feel embarrassed. And you know, it was paid work, it was good money. (…) In the end I felt I failed. Then it [*resigning from the post*] probably did me more harm than good afterwards. (...) I felt ashamed of myself for not being able to hold down that job. So it was that kind of cycle of negativity again. (*Sally*)

Through Sally's and other participant's narratives, it can be seen that to a certain extent service users' increased participation is an effect of “populist” policies (Clarke, 2007). Services were suddenly required to incorporate service users in healthcare with little previous preparation. Service users are requested to perform this high-complexity jobs without the necessary support and infra-structure. Not only that, but they are still largely disenfranchised in consultation instances, as the major decisory power still lies firmly on the side of health

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[51] Sally was a user involvement coordinator for the mental health trust in her area.

professionals and managers. In agreement with Barnes and Bowls' findings (2001), most service users found their experiences in involvement as frustrating and disempowering, since they highlight the restrictions placed upon their actions and the limits to what they can achieve.

The effect of internal conflicts

Political differences within the movement are the source of conflict, as we've examined earlier. While ideological conflicts are an intrinsic part of social movements, or any political activity, for this matter, it seems that for some survivors it can have a specially detrimental effect.

It is hard to say if infighting and dissent is more detrimental to service users than to other activists in social movements, as we don't really have much information about the effect of this kind of conflicts to mental health. It is possible that people who enter into politics are more thick-skinned to begin with, or more able to deal with conflicts in a way that it won't be so bruising for them. But people who join the SUSM have mental distress as their common ground. The people we have interviewed have talked about their vulnerability, their sensitivity to criticism, to other people's judgements. Some of them can be, in a sense, more easily hurt because of their condition.

Marianne is the participant who expresses best the effects of these conflicts because she's had the most prominent role in the SUSM. As Marianne was a national leader, she was very exposed to the infighting that sometimes is not present within the smaller, local groups. She eventually gave up her role in the SUSM because of the effect it had to her mental health.

> Because we all have different ways about.. views on what should be changed, people fight about it. (…) I do feel that I can't get involved in that anymore because it's just too painful really. I wish them well and I hope it does work. But I just had to choose the things I can do now, that I feel I can make an input into, not try to be involved nationally. Because you just put yourself out to be shot at. (giggle). Very sad, but that's the way it is. You got to be very very tough and how can you be, if you're a mental health system survivor? You can't be hard enough... I can't be anyway! (*Marianne*)

Emma, on the other hand has also been involved in national organisations and has experienced this direct criticism, but she feels it is possible to just "put it to one side and not let it affect you" on behalf of the greater good. Perhaps this effect can be circumscribed to personal characteristics, like a certain vulnerability to criticism which many participants reported. Also, it's SUSM leaders who are more exposed to this kind of distress, as they are the target of criticism and they can't really choose to be in contact only with their partisans.

> I mean I have fallen out with one particular survivor in an international group, which has caused me terrible grief. She's just been ever so critical with me. I can't hack it, really. (…)
> I don't feel damaged by the user movement itself. I do feel slightly damaged by some of the stuff I read. But no, I'm not damaged by it at all, really. No. I'm contradicting myself. Because it's.. there are always people you can talk to. You can always start your own movement (giggle) if you want to. You don't have to be affected, you just have to try to put it to one side and not let it affect you, because the greater good is more important, if you know what I mean. So it's just (something) with some people over there, and they got every right to say what they're saying, but I don't want to have anything to do with it. Or something. And I don't have to. (*Emma*)

It has already been said that in the SUSM political issues are lived as more personal, because activism is related to personal experience and identities. So everything can be very "raw and painful", to use Marianne's words. Locally, these big issues are not so much at stake, but they can also have an effect. Adam has found that to be truthful to his views he has to separate the personal side from the political side. If he becomes too close to someone, he might find it too difficult to contradict them when their views clash. Therefore, he feels an ethical need to keep from making friends in the political environment and to assert himself to get his views across even when they are not consensual. It's not easy for him to put himself in this combative posture.

> I've also found that I needed to assert myself because... An example is I am someone who's used services, and there were times when I wasn't able to say what I wanted to say and be really friendly with the person that I was saying it to. For example, I have a really good relationship but if I felt that I was saying something that was wrong, (…) I found it really difficult having a good relationship, and being the voice that I wanted to be. So I've had to reset my boundaries and not be as close to someone as I would like to be, just so I can say what I say. But that's probably a failure on my part more than anything else. (…) [*I'm struggling to*] assert myself to get my voice out there and then I can't do that and be really friendly with someone because I know sometimes I'm challenging what they're saying and I'm saying that I don't agree with you.

> Because I really don't agree with them sometimes. (...)
>
> Q. That can be very demanding of you as well..?
>
> A. Enormously demanding! (*Adam*)

Although this effect is probably circumscribed to a fraction of the activists, it has to be acknowledged that being exposed to internal conflicts and criticism can have an effect over mental health, as Marianne's comment reinforces:

> A lot of people do feel that the survivor movement in England is not good for your mental health, apparently. I heard from a lot of survivors. It's just very bruising. And I've seen the same in a lot of the European groups. That people can be very hurtful to each other. (*Marianne)*

It seems that the SUSM, on one hand, provides service users with a sense of community and belonging to a group, an affiliation that ultimately can expand their possibilities of action in the social sphere. It promotes inclusion through flexible and rewarding jobs, that allow some survivors to perform a work that is meaningful to them. On the other hand, it involves being exposed to conflictual relations, either external or internal, that emphasise their disadvantages or that affect them in a personal level. These can be bruising and disempowering experiences that add to the service users' mental distress.

4.3 Changing personal identity

The experience of mental distress compels individuals to rearrange their identities, through a reflexive work on the self which is done from the raw material of cultural references available. According to Rogers and Pilgrim (2005), the most common attributes awarded to people with mental health problems are highly negative: unintelligibility, incompetence, lack of credibility and violence. Internalising this meanings will produce an identity that is most likely that of the irrational, stupid, untrustworthy or immoral person. Alves (2011) has found that images of the violent madman are still alive and well in contemporary society[52], and that mental illness is interpreted by lay people as an "identity

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[52] Her study refers to Portuguese society, but other authors have found the same stereotype very disseminated in British society.

flaw"[53] (p.255). At its best, people with mental health problems can identify with the discourse of illness or trauma, and build the identities of the vulnerable, helpless, the victim. This way, they won't incorporate so much the negative values of other explanations, but they will be perceive themselves as having a very restrict possibility to act in the world. Engaging with the SUSM might help them construct a different identity.

Identity, agency and voice

Activists within the SUSM have a shared social experience of mental distress that form the basis for their political beliefs. As they begin to get involved and take part in some of the different forms of collective action, they start to react to perceived injustices they have personally experienced. They politicise their experience and reframe internalised stigma in a social context. Although it is not an automatic, instant process, they begin to question their identities: am I really that bad? As they take an active part to promote the social change they want, they begin to wonder: am I really that helpless and vulnerable?

Rose explains the process through which she was able to regain confidence in herself and in her capacity to change the things she felt weren't right. By talking tirelessly about the injustices she perceived in her own life and in other people's lives, she is not only promoting awareness and fighting the stigmatised views that have hurt her so much. She is also rewriting her history in some way, righting previous wrongs. Acting in the present to address injustices from the past is a form of taking back control over her own life, which she had lost completely.

> Talking to other people, specially women who have had mental health distress (...) helping them in their lives, like __ represent them in tribunal, employment, stuff like that or, going to the GP with them, or just hearing their stories, made me know that I'm not on my own and that there's truth amongst that. That it's not a lost cause, that we can still fight the cause (…) I just keep talking, I just keep saying I'll never stop talking, I talk about the Lord[54], I talk about my mental health experiences, I talk about everything because for me that's therapeutic, for one thing. It is... empowering, getting empowered back again (…) I tell other people about the situation. People don't know! And they don't understand what it is to be mentally ill. They

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[53] "Um defeito identitário" in Portuguese.

[54] Rose is an adventist. Advocating in favour of the oppressed, for her, is part of a religious and spiritual duty, and speaking about God is always associated with her advocacy.

> don't understand what you go through as a "me". What people think, and you feel ashamed. Mentally ill person, to come back into society, to face people. You know what it is, you know what you've done, when you're ill, and they've all held it against you, you've been to prison for that. You've been to mental institutions for that. ___. and then to come back to society and have to face people again, some people that don't know you, you have to face that and accept that. (…) When these people put you in hospital, and they bring you home, to your own home, or a new home, or wherever they put you, or a hostel, your life is not your own! You can't do jack! And if you say "no", it's like "how dare you say that, you have to be compliant. What do you mean -No?". And so then, you're walking on eggshells all the time (…) [*now*] I have control over my life. No one tells me what to do. If I don't want to work, I don't go to work, if I don't wanna do something, I don't do it, if I want to do something, I'll do it. (*Rose*)

The identity changes, from frail to fighter, and this new-found strength may allow the survivor to take a more empowered approach to services, social relationships and their own personal life. Emma tells a story about how she was able to come off her medication after joining the survivor movement. Her GP had suggested to her that she could try to discontinue her use of psychotropic medication, but her psychiatrist was against it. Initially, she decided to follow the psychiatrist's suggestion:

> So I stayed on it for a while. And then about six months later I went back to the GP and by that time I've been to the survivor conference and got... started to be aware, you see? And I said to him "you know, I think you're right. Perhaps it is about time I came off the medication". And he was totally "What? What? What? What's happened this morning?" (giggle). (*Emma*)

As the person begins to see some results of her actions, this identity of agency is reinforced. She feels she is "making a difference", as many participants have mentioned. The concept of self-efficacy (Bandura, 1994) can be useful to explain this process. The author argues that perceived self-efficacy is the person's beliefs about her "capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (p.71). People who have a strong sense of efficacy tend to take on challenging tasks and maintain strong commitment to them, even in the face of failure. It produces personal accomplishments, reduces stress and lowers vulnerability to depression. It can be, therefore, an important step to recovery.

When this self-efficacy is attached to action that is meaningful to the person, i.e., action that is intimately connected to the person's beliefs, it can provide a new purpose for life – which can be important in lives where purpose seems to be gone. Kaufmann (2005) explains how identity must construct the meaning of life, which is no longer provided unambiguously by social institutions. Identity "creates a little melody, which gives meaning to life. A little melody without which everything falls apart"[55] (p.71). When this little melody is vigorous and strong – or at least slightly more than it was – life becomes more purposeful and meaningful.

Participants also discuss how they were able to find their "voice", as they usually refer to the process of having the courage to speak their minds, standing up for their beliefs and being heard in return.

> And before one meeting, a chief executive of the mental health trust, just a few years ago, he whispered in my ear before we were getting coffee, right before the meeting started. He said "Roger, please... No awkward questions". Cause he knew what I was like. And not in a bad way, but I'd give them tough questions. If there was a problem, I would challenge it. I did then, I do it now, I will in the future. (*Roger*)

> It's made me confident. Made me more confident, especially with the advocacy we've done, it's made me feel that actually I have a voice, that I am intelligent. I always been able to tell that__ but I am a writer, for one thing, (…) I (understand) that the fact that people (are rude) to me doesn't say that I'm mad. Just means that they don't agree. And if they think I'm mad it's their business, but I'm still writing what I'm saying. (*Rose*)

Roger's extract above, although somewhat amusing, reveals the difficulty for service users to find their voice. Services now are, in theory, interested in consumer's voices, but they should be both "responsible and reasonable" (Clarke, 2007). The chief executive's whisper was implying that. Despite this injunction, Roger didn't mind, as his identity, just like Rose's, had been transformed and his capacity to challenge injustices became central to who he is.

The process of finding voice, it seems, can be related to having certain beliefs which become more important than the person's social inhibitions or lack of confidence. The person somehow finds a strength to reconstruct herself because of the magnitude of her commitment.

> I used to hate public speaking. And I (was) someone enormously intimidated, sitting in a room with all these commissioners and chief execs and stuff. When I found out how much he

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[55] Free translation from Portuguese: "inventa uma pequena música, que dá sentido à vida. Pequena música sem a qual tudo se desmorona".

> earned [*the chief executive*], I thought “who am I to sit here and challenge this man, who does all this?”. And it took a while for me to, again, say “none of that doesn't matter. If it's important and you think that it needs to be said and it's helpful, then say it!” (*Adam*)

Kinderman et al (2006) have noticed in their sample of outpatients diagnosed with schizophrenia, a tendency for passiveness, lack of agency and motivation for their lives. They didn't see any future ahead of them, and felt resignation towards this situation. Davidson and Strauss (1992) argue that rebuilding an identity as an active and responsible agent develops a functional sense of self which is crucial to recovery. Other authors have emphasised the need to recover control over daily life (Corin, 2002; Birchwood et al, 2000). It seems that being part of the SUSM has given back some of this agency to participants.

Reversing internalised stigma

Internalising stigma happens through incorporation of negative stereotypes to the person's identity. The person may think (consciously or unconsciously) that stigmatising beliefs are accurate. As a consequence, the person will identify herself with the stereotype and feel shame when she perceives her mental distress as a demeaning characteristic of which she cannot get rid (Corrigan & Watson, 2002). Even alone, the person may feel self-hate and self-derogation (Goffman, 1963).

Being a part of a social movement, the person may begin to question these stereotypes as she comes into contact with politicised views of mental distress. Through what social movements commonly refer to as a “consciousness raising” process, SUSM groups can be places where survivors begin to reframe their suffering and insert it into a scenery of oppression and social control of those deemed mad. While it may be debatable if this view is justified, it can have the effect of reversing (or at least attenuating) internalised stigma. This is in agreement with the process of “stigma conversion” identified by Humphreys among homosexual activists and by Herman and Musolf among ex-patients of psychiatric hospitals who engaged in resistance practices (Humphreys, cited by Herman & Musolf, 1998).

As the levels of politicisation and critique vary among different groups, this process we are describing may only operate in a part of the SUSM, the most political and critical faction. It has been observed on some participants' narratives. Rose's story is probably the most evident case. As we have mentioned, she was already a Black people's rights defender and politicised when she had her breakdown. But the extreme nature of her mental distress has affected her in a fundamental way, and it was hard for her to respond to stigmatising remarks, as she was remorseful and shameful about her history. Engaging with the SUSM provided her with an opportunity to reinsert her experience of mental distress in her previous frame of Black peoples' activism against racism and discrimination, and she began to fight back.

> I was empowered before, I lost it in hospital, I got it back again. (…) And I started to understand the politics, the bigger picture. Not just the fact that I'd been ill, I'd been through traumatic experiences, my life had fallen apart and I had to pick it up bit by bit, but the fact that it was part of a bigger picture. That African people were_____. And it's a country-wide, it's a worldwide thing. (...) If you have an emotion, to show too much about, I know the Algerians in France, Moroccan, all that kind of stuff, mainly Black or Arab type, get a bad deal as well. (…) If I show any other emotion, I'm going mad? If you're angry, does that mean you're mad? Of course you were gonna say no. But because we're labelled service users, you're mad, mentally ill, that's it; you're not allowed to have any kind of emotion, you're just supposed to (feel) even, be doped up, sedated, drugged up, calm, compliant, not asking questions.. "Don't question what medication you're on, don't question what type of medication, don't question how much they give you, just take all of it, just do, just shut up and put up!". Shut up and put up, that's what they want. That's not me. I never was and never will be. And because I'm a fighter and I'm not compliant, that's why I'm here where I am today. (*Rose*)

In previous researches (Corrigan & Watson, 2002; Watson, Corrigan, Larson & Sells, 2007), findings indicate that not recognising the legitimacy of stigmatising behaviours ("I'm not allowed to be angry?") and having a high identification with a peer group ("being part of a bigger picture") have an effect of increased self-esteem and self-efficacy. This can be seen in Rose's story and many others', and is crucial to the construction of a positive identity.

Role models

The SUSM has been carried through by many survivor leaders. People like Peter Campbell, Diana Rose, Peter Beresford, Jan Wallcraft, Mary Nettle, Louise Pembroke, David Crepaz-Keay (who were all cited by participants) have been important leaders of the SUSM, among others. They were pioneers in several ways, since they created a path for survivors to be recognised as successful, admirable, strong and capable individuals. They were not afraid to talk about their experience, nor to be vocal and angry at the injustices they perceived. They have made careers out of their identities of mental distress, and been influential in improving the situation for service users. Those leaders and many others were at least partially responsible for enlarging the possibilities of what service users could do, in the sense that they carved out the service user role with their pioneering actions. But more than contributing to improve service users' social experience, they also have some effect over service user identities, as positive role models.

Role models don't have to be, necessarily, the nationally recognised SUSM leaders. Instead, they can be much more anonymous, local examples of successful service users. They can be, for instance, the drop-in centre manager, who was once a member of the group and now is coordinating it. Successful service users – whether embodied as accomplished researchers or local group facilitators – provide for their peers examples of just how far service users are able to go. The next extracts show how this is an important process of developing identity, in all levels of collective action.

> And I count myself really fortunate to have, very early on my career, been in the same organisations as Diana Rose and then being in the same organisation as Peter Beresford (giggle), who for me is one of the most important people in the British service user movement. (…) Seeing those people and being kind of involved with those people has been amazingly important for me, I think, in me trying to find a professional identity, which incorporates my background, my mental health background as well. Because I could see these really well-respected people, who had very very good academic careers, were very open, and their work was very valued, based on their experiences, based on their activism as well. (*Valerie*)

> I realised that everybody in charge there are volunteers, no one is paid. Two of the people that were in my Emergence group (...) are both directors of the company! I bloody didn't know that until.. I thought they were just people like me! But they all have illnesses, they all have problems! (*Ralph*)

> I went to a place, which is the place I voluntarily work for now, and I'd do voluntary work there co-facilitating a women's group. I really enjoyed that because, as I say, people from hospital were referred there. It improved my confidence, and you would see their confidence improving, because the good thing about there is that they would ask people to help and be

> support workers. And I can't remember if any of them got therapeutic earnings[56] or not, but the fact is that you had good role models, and you could see people go a bit, a step up on their journey. (…) Whereas people who have just come out of hospital, they're lowest in confidence, lowest that they could be, seeing other people kind of branch out, is a real inspiration. (*Sally*)

As we have discussed, "possible selves" is identity's most central form of reconstruction (Kaufmann, 2005). We argue that SUSM role models enlarge the scope of a person's possible selves. As these successful service user have overcome their difficulties and seized available opportunities - or created them – they alter the regime of possibilities available to identity. Because of their example, a virtual identity that was once judged as infeasible may now be reassessed and become a possible self, or an idea that will guide the identity in her process of reconstruction.

And it is an ongoing process as well, since service users who were able to reinvent their identities and assume a public role will then promote a further enlargement of the field of social possibilities, and inspire others while they're doing it. As Adam, who was able to profit from the enlarged service user role and now advocates for service users to "come out" with their problems. His argument that it is OK to have had mental health problems is reinforced by his practical example, as he was a person who disclosed his experience publicly for the first time when he was running for governor.

> With me, when I make my statement[57], even though ___ was my first attempt to kill myself when I was 12, because I was trying to put myself out there and become a public document. And when __ in the building and locally people would just... they couldn't believe that that was me, or that I'm someone who's had those types of experiences because it wasn't something that I talked to about people who aren't using services. (…)
> So I'm asking for us or for people in this kind of movement to encourage people to be, and to support people to be little braver about it and to find strength within each other to feel ok about it. And then hopefully that will project something on a scale outside where people begin to say "well, they're ok about it, it doesn't seem too scary" or whatever. You know, be more ok about it. (*Adam*)

The importance of positive role models cannot be underestimated since a few decades

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[56] People who are on disability benefits are allowed to engage in paid work as long as it doesn't surpass a maximum amount of weekly earnings. If they do surpass this limit, they have to give up their benefits.

[57] As Adam was a candidate for public representative in the mental health trust, he had to prepare a statement, where he presented himself to the electors and discussed his views. This was the first time that Adam "came out" and disclosed his experience of mental distress to his neighbours and community.

ago it was nearly impossible to find examples of successful service users anywhere. People with mental health problems would meet each other almost exclusively in mental health services, where they'd be surrounded by the unwell. Outside of this sphere, they would keep their mental distress as secret as possible. Also, it must be acknowledged that our society is not very keen in publicising the conquests of mental health patients. So, these role models allow service users not only to believe that they can recover, but also that they can conciliate their mental distress with achievements in private and public life.

Ideal service users

The final topic effect to the identity we would like to address is a detrimental effect that has been observed in some narratives. There seems to be an implicit ideal of the activist / service user, a guiding stereotype that serves as a parameter for comparison within and outside the SUSM. When the gap between the ideal and the self is too great, the person may be criticised and rejected by her peers (and by others outside the SUSM).

The existence of an ideal, or a guiding stereotype of the service user / survivor is something that was already indicated by some of the commentaries we've made. Valerie's story of being criticised for using psychiatric treatments or feeling more authentic within the movement after hospitalisation[58] allude to an implicit ideal of a legitimate survivor activist. In her story, the stereotype is associated with experiencing the “hardcore psychiatric system”, surviving it and then rejecting it.

The “double bind” we have discussed[59] also indicates this ideal. It is used by health professionals as a way to disregard service users' opinions and limit their power. In this reference model, the ideal service user (the one who is a legitimate representative of service users) is someone who's had a severe experience of mental distress and has recovered, but only to a certain, optimal level. He needs to be recovered enough to be an operative, rational and reasonable representative but not so much that he becomes “normal” and no longer bears the characteristics expected of service users (whichever they may be). While characteristics associated with mental distress were not found to be rejected within the movement, certainly

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[58] See pages 117-119.

[59] See page 129.

being too “normal” can undermine a person's status within the peer group.

These implicit ideals suggest what the service user / survivor should be in order to receive recognition. As an ideal type, it regulates the symbolic references of SUSM activists, and those who are perceived to be too deviant from the SUSM ideals may feel alienated by their peers, in a process of internal stigmatisation. Karen is the participant who better expresses this conflict. She talks about an “inverse status” within SUSM groups, that is associated with this process of being discredited as a representative or service users.

> There was also, eventually, when I was part of those users groups there was a lot of competition for who had the worst mental health problems (…) Where in normal society the weller you are, the better, you know, you just aim to be mentally very healthy. It's like all of that got flipped on its head and the worse you are, the more treatments you were getting, the more invasive the surgery, the more outside your control the treatments were, as well, the more people people felt validated by it. So, everything got a bit, I think that's a bit screwed up. (…) So that can be quite exhausting and dull (giggle) (…) I mean, nobody really spoke to me like that. But the fact that you´re supposed to engage in this competitive dialogue about who's got the worse problems.. Yeah. I'm sure that's unspoken. (…) To be seen by others as a grown member of the service user movement I think you'd have to be a hardcore service user, experienced maybe a psychotic breakdown, experienced treatment without your consent, in a confined setting, like a hospital, to have periods away from work all the time, to not be able to sustain a job necessarily, to not be a "professional" service user, as people sometimes see it. (...)
>
> Q. And that comes from service users?
>
> A. Service users, yeah, definitely, and professionals as well, to some extent. Definitely from both. Yeah, no, definitely it comes from both. (*Karen*)

This paradox evoked by Karen and other participants is not hard to understand. As mental distress can be incapacitating at times, people may find it very challenging to interact with others and perform daily tasks during difficult periods. Being an activist, supporting peers or doing service development, to name a few activities, are demanding activities. So, it is quite natural that not all service users will be able to do this kinds of activities all the time. Given this, it is a consequence that the people who are most involved in the SUSM will be either:

- people whose mental distress is less intense in nature;
- people who are recovered, i.e. people who no longer have mental health problems, but who did experience them at some point, including severe mental distress;
- or people who still experience severe mental distress but are in stages where it is less

intense and they can manage their own problems - either with or without the help of mental healthcare.

Service users who fall into the first category may be questioned if they really represent the majority of service users. This is the case of Karen, and she experiences this discredit.

> I'm seen by others as not a proper member of the service user movement, because I've been to university, and not long out of university I got a job. I was relatively young, for people who have mental health problems often go there much older and I went to the university when I was 21, which was older than many but still, younger than much service users. So, I don´t know if I would ever get seen as a part of the user movement. (*Karen*)

The ones who fall in the third category, however, may be questioned for being “unwell”, like it has happened to Adam[60]. There seems to be one stance, however, where service user legitimacy is almost unquestionable, the “holy grail” of user representativeness: having a severe crisis and being committed to psychiatric hospital, specially against their will. Being hospitalised is a socially recognised attestation of “madness”. And because psychiatric hospitals are usually such unsatisfactory environments (to use a light word) many activists have begun their social movement careers after these kinds of experience. It is both something that they *share* and that *identifies* them. So it becomes a selective trait.

If identity is both a “ticket to entry and a source of solidarity” within the SUSM (Rogers & Pilgrim, 2001, cited by Allsop et al, 2004), it can also be a ticket to exit and a source of discrimination, in some cases. When identity ideals become too rigid, they may become exclusive and unsolidary. All of this is transmitted in subtle ways, or through what Karen calls a "principle of competition" for having the worst mental health problems.

Even though going to a psychiatric hospital is a frightening and devastating experience in most cases, it can have interesting consequences regarding one's affiliation and legitimacy within the SUM. On the other hand, those who don't share the same characteristics can be, paradoxically, stigmatised for being “too normal”. It is a process that can be hurtful when the person feels rejected by the group to which she already belongs and whose collective identity she shares.

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[60] See page 116.

DISCUSSION OF RESULTS

In this study, we have attempted to answer this question: what effect engaging with the British SUSM has upon service users / survivors' experience of mental distress? Although this study has several limitations that don't allow for generalisation, it seems that our findings could provide some indications for future research on a virtually unexplored subject.

We have argued that the SUSM impacts in the experience of mental distress through changes in:

a) the meaning service users / survivors construct for their mental distress
b) the social experience of mental distress
c) their personal identities

We will address each of these findings separately.

Meaning of mental distress

Mental distress is lived as a disruptive experience. Similarly to the outset of chronic illness, a biographical disruption is experienced (Bury, 1982) by the person who goes through their first "breakdown", suicide attempts or the deep emotional pain that accompanies mental distress. After an initial phase of bewilderment, the person is then compelled to "make sense" of this experience, creating their own personal meaning for it. As meaning is constructed through available cultural references related to mental distress, the person will usually construct significance associating their experience with negative attributes, the dominant explanations in our culture.

Upon engagement with SUSM groups and organisations, survivors encounter a group of peers within which they are able to reconstruct a more positive meaning to their experience. They might feel that, for the first time, their experience can be accepted by others – even the most shameful aspects of their past and the attitudes they regret. This produces a sanctioning effect that normalises their experience, and they might reframe it in terms of "difference" instead of "flaw". Furthermore, by entering the realm of a social movement where the experience of mental health problems legitimates their claims and is seen as a source of experiential knowledge, they might be able to reshape the meaning of mental distress as a resource. Mental distress may become, then, not only a neutral attribute, but a positive one.

The SUSM also provides an opportunity for talking about their backgrounds within this protected environment, which most participants have not found anywhere else, not even in mental health services. They are able to, collectively, perform their "narrative reconstructions" (G. Williams, 1984). Associated with this, survivors encounter within the movement a profusion of explanatory models for their mental distress. Some may be similar to scientific explanatory models, while others are constructed within the movement, building upon the collective experiential knowledge. Through talking, being listened and being in contact with alternative explanations, they are afforded a valuable opportunity to develop their own meanings from an expanded reservoir of references which wasn't available before. Many feel their personal explanations, which were in disagreement with mainstream models, are validated by their peers, while others, who weren't able to construct a solid meaning before, may find it easier to build significance through this intensive interaction and profusion of information.

However, we have also found indication that there can be a level of group pressure within some circles of the SUSM, where their explanations for mental distress are imposed to other members through subtle methods. This pressure to conform is not rare within social movements, as their heterogeneous nature may create a force to accentuate homogeneity (Goodwin & Jaspers, 2009). This can have detrimental effects if service users, on the one hand, fail to conform and experience criticism from their peers, or if they try to conform and adhere to explanation and consequent practices that are not in agreement with their experience.

Social experience

Service users' social experience is marked by society's interpretation of mental distress. As people with mental health problems are perceived to be untrustworthy, violent, incompetent or unintelligible (Rogers & Pilgrim, 2005), they are likely to be stigmatised for their condition. We have found that our participants lacked strong support networks, and had experienced difficulties keeping their jobs after the outset of mental distress. Coercive and authoritative mental health services reproduce and reinforce this negative experience, increasing their feelings of vulnerability and loss of control over life.

The SUSM may provide for service users a community of peers which breaks their patterns of social isolation and fear of stigma. These accepting and friendly environments allow them to feel like they belong somewhere, and a new collective identity can be constructed. They can then move on to expand their contacts with the wider community, from this baseline security. This affective network, on the other hand, supports the SUSM actions and helps survivors to overcome the challenges that are part of political engagement. However, some participants have mentioned that contact with other service users could also be detrimental to their mental health, as they found peers may be too emotionally demanding and difficult to deal with.

Social experience is also transformed by engaging with the movement because it provides access to an expanded "service user role". We have explained how actions from the SUSM, combined with a certain political context, have enlarged the field of action for service users in the public sphere. They are now able to perform an array of paid and voluntary activities, which is something historically new. This awards them with a social recognition that wasn't possible before, unless their experience of mental distress was kept a secret. Now, disclosing experience becomes the key to accessing these possibilities. This way, the SUSM provides a kind of social integration, as community healthcare was hardly ever able to achieve. Employment and freelance work are now possible, as service user expertise is increasingly valued as a resource. This has an extremely positive effect for people who are among the most excluded from employment opportunities.

This enlarged social role, however, involves a greater exposure to stigmatisation, as service users abandon their "protective bubbles" and enter the confrontational realm of politics and science, usually in a discredited position. Some participants have felt deeply the effects of having their legitimacy or their rational capacity questioned, being treated as if they were "invisible" and feeling "tokenised", as their presence in most participatory instances is required by law but not desired by all. When they feel they have been heard and taken seriously, they can experience their self-confidence raise and feel better about themselves. However, this is the minority of cases, and it is most likely that service users will feel disempowered and undermined in this kind of activities.

A final aspect associated with the social experience are the intense internal conflicts that take place within the SUSM. Survivors who get more involved with the movement and reach positions of political relevance might find themselves severely criticised because of the positions they assume – whichever they are – since the SUSM is a very heterogeneous movement, fractured by several divisive issues. As mental distress is an experience which is hard to separate from the self, getting involved with a movement parting from previous experience becomes not only a political enterprise but also a personal one. Private issues are deeply entwined with political activism, and that makes survivors more vulnerable to political attacks, which can have a detrimental effect to their mental health.

Identity

Involvement with the SUSM also engenders a transformation of identity. Through collective action, service users incorporate the positive identity of the fighter, the activist, rejecting the passive posture they are offered in therapeutic relationships and elsewhere. As they engage in action aimed at the transformation of a social reality to which they are very committed, they discover themselves as agents, and recreate purpose for their lives. They might find themselves more sure of their value and able to voice their opinions without fear.

Internalised stigma can be reversed through the process of politicisation, where stigmatising beliefs that were incorporated to the self lose their legitimacy and are converted to "rightful anger" (Corrigan & Watson, 2002). This also frees survivors from constrictions to their identities, and allows them to recreate themselves. In this process, successful service users from the SUSM serve as role models, and help them create new "possible selves" (Kaufmann, 2005), which assist their projects of recreating identity.

As in other categories, we also found a negative effect of the SUSM related to identity. Again, the tendency towards homogeneity can be felt negatively by service users, as they can be excluded and criticised for not sharing certain identity traits that identify the SUSM. Paradoxically, this has to do with being "too normal", in a sense, as the person who has experienced milder mental distress might feel rejected by the group. It is an implicit process that is felt through an internal competitiveness. This might have a negative effect to the identity, as the person feels she doesn't fit the model of the "ideal service user" promoted within the movement, and is rejected for that.

Implications of findings

It must be emphasised one more time that these results derive from a small sample of service users, which perhaps don't reflect the overall SUSM. We were lucky, however, to dispose of a varied sample of participants, which has enriched the analysis with different perspectives. Apart from the limits of the sample, we also recognise limitations of methodological procedures. A more sound analysis could have been produced if we had been able to have a further insertion in the fieldwork. Participant observation in movement activities, informal interaction with members and additional interviews with the same subjects would all have contributed to this process[61].

Our findings indicate, nevertheless, that the process of engagement with this social movement has had a significant effect to participants' experience of mental distress. Overall, more positive effects were encountered, even though some detrimental effects have also been reported. It is, however, an overall *transformation* process that occurs to the individual, as he is inserted in this context where his experience of mental distress has a very different meaning than it has in other social spaces.

We believe this is an important topic for future research, since social movements in health and mental health are a recent phenomenon, still poorly understood by social sciences and which have produced not only significant social change but also, as we've noticed, subjective change.

Finally, we resume our previous criticism of the use of empowerment as an "intervention technique" (Barnes & Bowl, 2001, p. 96), which utilises social movements and survivor involvement as a therapeutic tool. According to this view, the positive effects of collective action – such as increased confidence, autonomy or sense of control – could be gained without challenging significantly current power imbalances or producing real social change. If empowerment is understood as an individual asset and not as a social process, these kinds of distortions occur. This is one of the reasons we weren't interested, in this research, to "assess outcomes" of social movement involvement as if it were therapy, and this is why

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[61] A more detailed discussion of the study's limitations can be found at the Methodology section – page 69.

symptom remission wasn't ever in question. If there is one framework of mental health that this study could contribute to, it would be to the idea of recovery as it was envisioned by the survivor movement. Recovery is associated not with cure or reducing symptoms, but with recovering from stigma, from the iatrogenic effects of treatments, from lack of social opportunities and from negative identities and "crushed dreams" (Anthony, 1993, p.13). In this sense, there is no question that the SUSM has assisted the recovery of survivors. Whether or not they still display symptoms, attempt suicide or rely on medication depends on each case and in a greater variety of factors which we didn't attempt to investigate. But they certainly have been able to challenge stigmatising views, reconstruct spoiled identities and reclaim a space in society they were denied. In this sense, there is obvious transformation.

CONCLUDING COMMENTS

The emergence of health social movements is related to a series of social transformations that have reconfigured the possibilities of action for those that receive healthcare treatments. The normative authority of health professionals is now subject to challenges by service users, while the latter have become instrumental in breaking the power monopoly of the former from a consumerist point of view. Overall, partnership and empowerment have become "buzz words" in healthcare policies, embraced by government and practitioners alike. There is still, however, a wide gap between rhetoric and practice, as service users real power in decision-making processes remains very limited. Raised expectations and failed implementation only fuel health-related activism and increase the level of contention.

In mental health, service users / survivors have also challenged psychiatry and mental healthcare practices. They arguably compose the more disenfranchised group among healthcare recipients – historically ascribed sub-human status and treated in the most abject ways, they are still subject to compulsory hospitalisation and treatment, in the name of their own and other's safety and well-being. After anti-psychiatry and the shift to community care, survivors were, for the first time, in a position to "speak out". In the UK, they have done so through a variety of groups and organisations, which have changed considerably the political landscape. With the creation of consumerist policies, they were incorporated to the healthcare system and suddenly experienced a proliferation of service user groups and initiatives throughout the whole of Britain.

We have departed from this context to ask the following question: what is the effect of the British service user / survivor movement (SUSM) to the experience of mental distress? As our possibilities of fieldwork investigation were limited, we decided to further narrow our question, and analyse only the effect of the SUSM to the service users / survivors who were actively engaged with this movement. This would allow us to address the more direct transformations of the movement, on those who engage in mental health activism.

Our results have indicated that engaging with this movement provides a level of subjective transformation to those involved. They are able to construct different, more positive meanings for their experience of mental distress, and consequently to construct identities that are not only marked by stigmatising views of themselves, but that portrays them as activists, fighters, agents of social change. Moreover, the engagement with the movement allows for them to develop a new social role, which provides them social recognition while including their background as people with mental health problems.

Engaging with the movement has some detrimental effects as well. Pressure to conform within the movement can make survivors feel criticised and rejected when they don't fit a certain standard or don't follow certain implicit precepts. Internal conflicts within the SUSM cause some service users to feel hurt by other's survivors attitudes. Moreover, when interacting with external actors, such as health professionals and government representatives, service users may feel damaged by their patronising and confrontational attitudes. When they enter this new arena of political dispute, their emotional difficulties can be intensified.

Our exploratory study appears to provide a possible point of departure for future research. More comprehensive studies with multi-method approaches and larger samples could investigate these effects in order to verify our results. As health and mental health related activism gain significance in current society, they impact not only on social discourses and practices around illness and mental distress, but also on the ways they are personally lived. While activists feel these effects more directly, it is likely that collective action protagonised by service users affects the way mental distress and chronic physical illnesses are experienced in general. These are still topics that remain to be analysed.

REFERENCES

Abercrombie, N., Hill, S. & Turner, B.S. (2006) *The Penguin Dictionary of Sociology*. London: Penguin Books.

Allsop, J., Jones, K., & Baggott, R. (2004). Health consumer groups in the UK : a new social movement ? *Sociology of Health and Illness*, *26*(6), 737-756.

Alves, F. (2011). *A doença mental nem sempre é doença – Racionalidades leigas sobre saúde e doença mental.* Porto: Ed. Afrontamento.

Andrews, M. (1991). *Lifetimes of commitment - Aging, politics, psychology.* New York: Cambridge University Press.

Anthony, W. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, *16* (4), 11–23.

Archibald, M. E., & Crabtree, C. (2010). Health social movements in the United States: An overview. *Sociology Compass*, *4*(5), 334-343.

Armes, D. (2009). Mission informed discursive tactics of British mental health service-user/survivor movement (BSUSM) resistance to formalization pressures accompanying contractual relationships with purchasing authorities. *Journal of Mental Health*, *18*(4), 344-352.

Baggott, R., Allsop, J., & Jones, K. (2005). *Speaking for patients and carers: Health consumer groups and the policy process*. Basingstoke, UK: Palgrave Macmillan.

Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), *Encyclopedia of human behavior-v.4* (pp. 71-81). New York: Academic Press.

Barbot, J. (2002). *Les malades en mouvements - La médecine et la science à l'épreuve du SIDA*. Paris: Balland.

Barbot, J. (2006). How to build an 'active' patient? The work of AIDS associations in France. *Social Science & Medicine*, *62*, 538-551.

Barker, C., & Dale, G. (1998). Protest waves in western Europe: A critique of 'New Social Movement' theory. *Critical Sociology*, *24*(1-2), 65–104.

Barnes, M. (2007) A final brick in the wall? A history of the Nottingham Advocacy Group. Retrieved from http://studymore.org.uk/NAGhis.pdf.

Barnes, M., & Bowl, R. (2001). *Taking over the asylum - Empowerment and mental health*. London: Palgrave.

Bassman, R. (2000). Agents, not objects: our fights to be. *Journal of Clinical Psychology*, *56*(11), 1395-1411.

Bell, A., & Lindley, P. (2005). *Beyond the water towers - The unfinished revolution in mental health services 1985-2005*. London: The Sainsbury Centre for Mental Health.

Beresford, P. (2002). Thinking about 'mental health': Towards a social model. *Journal of Mental Health*, *11*(6), 581-584.

Beresford, P. (2005). 'Service user': regressive or liberatory terminology? *Disability & Society*, *20*(4), 469-477.

Beresford, P., Nettle, M. & Perring, R. (2010). Towards a social model of madness and distress ? Exploring what service users say. Research report. London: Joseph Rowntree Foundation. Retrieved from: http://www.jrf.org.uk/publications/social-model-madness-distress.

Betz, M., & O'Connell, L. (2003). Changing doctor-patient relationships and the rise in concern for accountability. In Conrad, P. & Leiter, V. (Eds.) *Health and health care as social problems* (pp.317-330). Lanham, MD: Rowman & Littlefield Publishing Group.

Biehl, J. G., Good, B., & Kleinman, A. (2007). *Subjectivity: ethnographic investigations*. Berkeley and Los Angeles: University of California Press.

Birchwood, M., Iqbal, Z., Chadwick, P., & Trower, P. (2000). Cognitive approach to depression and suicidal thinking in psychosis - Testing the validity of a social ranking model. *The British Journal of Psychiatry*, *177*(6), 522-528.

Brown, L.D. & Lucksted, A. (2010). Theoretical foundations of mental health self-help. In Brown, L. D., & Wituk, S. (Eds.), *Mental Health Self-Help* (pp. 19-38). New York: Springer.

Brown, P., & Zavestoski, S. (2004). Social movements in health: an introduction. *Sociology of Health and Illness*, *26*(6), 679-94.

Brown, P., Morello-Frosch, R., Zavestoski, S., Senier, L., Altman, R. G., Hoover, E., McCormick, S., et al. (2011). Health social movements: Advancing traditional medical sociology concepts. In Pescosolido, B., Martin, J. & McLeod, J.D. & Rogers, A.(Eds.), *Handbook of the sociology of health, illness and healing - A blueprint for the 21st century* (pp. 117-138). New York: Springer.

Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Altman, R. G. (2004). Embodied health movements: New approaches to social movements in health. *Sociology of Health and Illness*, *26*(1), 50-80.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, *4*(2), 167-183.

Bury, M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness*, *13*(4), 451-468.

Bury, M. (2002). Sociological theory and chronic illness: Current perspectives and debates. *Österreichische Zeitschrift für Soziologie*, *27*(4), 7-22.

Carricaburu, D., & Pierret, J. (1995). From biographical disruption to biographical reinforcement: the case of HIV-positive men. *Sociology of Health and Illness*, *17*(1), 65-88.

Castel, R. (2003). *L'insecurité sociale – Qu'est-ce qu'être protégé?* Paris: Seuil.

Chadwick, P. K. (2007). Peer-professional first-person account: Schizophrenia from the inside. Phenomenology and the integration of causes and meanings. *Schizophrenia Bulletin*, *33*(1), 166-173.

Chamak, B. (2005). Les transformations des représentations de l'autisme et de sa prise en charge : Le rôle des associations en France. *Cahiers de Recherches Sociologiques*, *41*, 171-192.

Chamberlin, J. (1978). *On our own: Patient-controlled alternatives to the mental health system.* New York: Hawthorne.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill.

Sociology of health and illness, *5*(2), 168-195.

Charmaz, K. (1997). *Good days, bad days: The self in chronic illness and time.* New Jersey: Rutgers University Press. (Original work published 1991).

Charmaz, K. (1995). Grounded theory. In J. A. Smith, R. Harré, & L. Van Langenhove (Eds.), *Rethinking methods in psychology* (pp. 27-49). London: Sage.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* London: Sage.

Clarke, J. (2007). Unsettled connections: Citizens, consumers and the reform of public services. *Journal of Consumer Culture*, *7*(2), 159-178.

Clarke, J. (2009). Parler de citoyenneté : Discours gouvernementaux et vernaculaires. *Anthropologie et Societés*, *33*(2), 43-62.

Corin, E. (2002). Se rétablir après une crise psychotique : Ouvrir une voie? Retrouver sa voix? *Santé Mentale au Québec*, *27*(1), 65-82.

Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, *9*, 35-53.

Crepaz-Keay, D. (2008). About the National Service User Network. *Openmind,* 149. Retrieved from http://www.mind.org.uk/campaigns_and_issues/report_and_resources/814_about_ the_national _survivor_user_network.

Crossley, M. (1998). "Sick Role" or "Empowerment"? The Ambiguities of Life with an HIV Positive Diagnosis. *Sociology of Health and Illness*, *20*(4), 507-531.

Crossley, N. (1999). Working utopias and social movements: An investigation using case study materials from radical mental health movements in Britain. *Sociology*, *33*(4), 809-830.

Crossley, N. (2002). *Making sense of social movements.* Buckingham, UK: Open University Press.

Crossley, N. (2004). Not being mentally ill - Social movements, system survivors and the oppositional habitus. *Anthropology & Medicine*, *11*(2), 161-180.

Crossley, N. (2006). *Contesting Psychiatry*. London and New York: Routledge.

Davidson, L. & Strauss, J.S. (1992). Sense of self in recovery from severe mental illness. *British Journal of Medical Psychology*, *65* (2), 131–145.

Della Porta, D., & Diani, M. (1999). *Social movements - an introduction.* Oxford, UK: Blackwell.

Desjarlais, R. (1997). *Shelter blues - Sanity and selfhood among the homeless.* Philadelphia, PA: University of Pennsylvania Press.

Dinos, S. (2004). Stigma: the feelings and experiences of 46 people with mental illness: Qualitative study. *The British Journal of Psychiatry*, *184*(2), 176-181.

Drew, N., Funk, M., Tang, S., Lamichhane, J., Chávez, E., Katontoka, S., Pathare, S., et al. (2011). Human rights violations of people with mental and psychosocial disabilities: an unresolved global crisis. *Lancet*, *6736*(11), 1-12.

Dubet F. (1994). *Sociologie de l'expérience.* Paris: Seuil.

Emergence. (n.d.). Personality disorder diagnosis. Retrieved from http://www.emergenceplus.org.uk/what-is-personality-disorder/94-diagnosis.html

Esping-Andersen, G. (1991). As três políticas econômicas do Welfare State. *Lua Nova* (24), 85-116. (Original work published 1990).

Fassin, D., & Rechtman, R. (2009). *The empire of trauma - an inquiry into the condition of victimhood.* Princeton: Princeton University Press.

Flick, U. (2005). *Métodos qualitativos na investigação científica.* Lisboa: Monitor.

Foucault, M. (2006). *History of Madness.* Abingdon, UK: Routledge. (Original work published 1961).

Foucault, M. (1977). *Discipline and punish: The birth of the prison*. London: Penguin.

Foucault, M. (1978). *The history of sexuality – Volume 1: an introduction.* New York: Pantheon Books.

Geekie, J., & Read, J. (2009). *Making sense of madness - Contesting the meaning of schizophrenia.* New York: Routledge.

Gillham, B. (2000). *The research interview.* London and New York: Continuum.

Glass, C. R., & Arnkoff, D. B. (2000). Consumers' perspectives on helpful and hindering factors in mental health treatment. *Journal of Clinical Psychology*, *56*(11), 1467-1480.

Goffman, E. (1961). *Asylums.* Harmondsworth, UK: Penguin.

Goffman, E. (1963). *Stigma.* London: Penguin.

Goodwin, J. & Jasper, J.M. (2009). *The social movements reader: Cases and concepts.* Chichester: Blackwell.

Grard, J. (2011). *Frontières invisibles - L'expérience de personnes prises en charge au long cours par la psychiatrie publique en France.* (Unpublished doctoral dissertation). EHESS, Paris.

Hearing Voices Network (n/d). *Information: about the network.* Retrieved from www.hearing-voices.org/information.html.

Herman, N., & Musolf, G. R. (1998). Resistance among ex-psychiatric patients. Expressive and instrumental rituals. *Journal of Contemporary Ethnography*, *26*(4), 426-449.

Horwitz, A. V. (2002). *Creating mental illness.* Chicago: The University of Chicago Press.

Jones, A. H. (1997). Literature and medicine: Narratives of mental illness. *Lancet*, *350* (9074), 359-362.

Karp, D. A. (1996) *Speaking of sadness. Depression, disconnection and the meanings of illness.* New York: Oxford University Press.

Kaufmann, J-C. (2005). *A invenção de si – Uma teoria da identidade.* Lisboa: Instituto Piaget.

Kaufmann, J-C. (2011). *L'entretien comprehensif.* Paris: Armand Colin.

Kinderman, P., Setzu, E., Lobban, F., & Salmon, P. (2006). Illness beliefs in schizophrenia. *Social Science & Medicine*, *63*(7), 1900-1911.

Klawiter, M. (2004). Breast cancer in two regimes : The impact of social movements on illness experience. *Sociology of Health and Illness*, *26*(6), 845-874.

Kleinman, A. (1988). *The illness narratives - suffering, healing & the human condition*. New York: Basic Books.

Landzelius, K. (2006). Introduction: Patient organization movements and new metamorphoses in patienthood. *Social science & medicine*, *62*(3), 529-537.

Lee, J.-E. (2007). *Experience as social and cultural capital: From objects of symbolic violence to empowered selves in mental health. An exploratory study.* (Unpublished undergraduate dissertation). University of Winnipeg.

Leete, E. (1989). How I perceive and manage my illness. *Schizophrenia Bulletin*, *15*(2), 197-200.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*, 363-85.

Lobban, F., Barrowclough, C., & Jones, S. (2003). A review of the role of illness models in severe mental illness. *Clinical Psychology Review*, *23*(2), 171-196.

Masterson, S., & Owen, S. (2006). Mental health service user's social and individual empowerment: Using theories of power to elucidate far-reaching strategies. *Journal of Mental Health*, *15*(1), 19-34.

McCormick, S., Brown, P., & Zavestoski, S. (2003). The personal is scientific, the scientific is political: The public paradigm of the environmental breast cancer movement. *Sociological Forum*, *18*(4), 545-576.

Melucci, A. (1996). *Challenging codes: Collective action in the information age*. Cambridge, MA: Cambridge University Press.

Mental Health Act – 17A (2007). Retrieved from www.legislation.gov.uk/ukpga/2007/12/contents.

Mind (2011). Briefing 1: amendments made to the Mental Health Act 1983 by the Mental Health Act 2007. Retrieved from: www.mind.org.uk/help/rights_and_legislation /briefing_1_ amendments_made_to_the_ mental_health_act_1983_by.

Mulvany, J. (2000). Disability, impairment or illness? The relevance of the social model of disability to the study of mental disorder. *Sociology of Health and Illness*, *22*(5), 582-601.

Nelson, G., Lord, J., & Ochocka, J. (2001). Empowerment and mental health in community: narratives of psychiatric consumer/survivors. *Journal of Community & Applied Social Psychology*, *11*(2), 125-142.

NSUN (2011). NSUN annual report – executive summary. Retrieved from http://www.nsun.org.uk/modules/downloadable_files/assets/nsun-annual-report-executive-summary-2010---2011-final.pdf.

Onken, S. J., & Slaten, E. (2000). Disability identity formation and affirmation : The experiences of persons with severe mental illness. *Sociological Practice: A Journal of Clinical and Applied Sociology*, *2*(2), 99-111.

Paquy, L. (2004). *European social protection systems in perspective.* Blankso: Compostela Group / Fundação Calouste Gulbenkian.

Parsons, T. (2001). *The Social System*. London: Routledge. (Original work published 1951).

Pierret, J. (2003). The illness experience : State of knowledge and perspectives for research. *Sociology of Health and Illness*, *25*(Silver Anniversary Issue), 4 - 22.

Pilgrim, D. (2002). The biopsychosocial model in Anglo-American psychiatry: Past, present and future? *Journal of Mental Health*, *11*(6), 585-594.

Pilgrim, D. (2005). Protest and co-option. The voice of mental health service users. In Bell, A., & Lindley, P., *Beyond the water towers - The unfinished revolution in mental health services 1985-2005* (pp. 17-26). London: The Sainsbury Centre for Mental Health.

Polletta, F. (1998). Contending stories : Narrative in social movements. *Qualitative Sociology*, *21*(4), 419-446.

Polletta, F. (2006). *It was like a fever: Storytelling in protest and politics.* Chicago: The University of Chicago Press.

Porter, R. (2002). *Madness: A brief history*. New York: Oxford University Press.

Richards, L. (2005). *Handling qualitative data – A practical guide*. London: Sage.

Rishter, J. B., & Phelan, J. C. (2004). Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry Research*, *129*, 257-265.

Rogers, A., & Pilgrim, D. (1991). 'Pulling down churches': accounting for the British Mental Health Users' Movement. *Sociology of Health and Illness*, *13*(2), 129-148.

Rogers, A., & Pilgrim, D. (1996). *Mental health policy in Britain: A critical introduction*. Basingstoke, UK and London: Macmillan Press.

Rosenham, D. L. (1973). On being sane in insane places. *Science*, *179*, 250-258.

Saris, A. J. (1995). Telling stories: Life histories, illness narratives, and institutional landscapes. *Culture, Medicine and Psychiatry*, *19*(1), 39–72.

Scambler, G., & Kelleher, D. (2006). New social and health movements: Issues of representation and change. *Critical Public Health*, *16*(3), 219-231.

Simon, B., & Klandermans, B. (2001). Politicized collective identity. A social psychological analysis. *The American Psychologist*, *56*(4), 319-331.

Survivor History Group. (n.d.). *Mental health and survivors' movements and context.* Retrieved from http://studymore.org.uk/mpu.htm.

Tilly, C. (2001). Collective Action. In Stearns, P.N. (Ed.), *Encyclopedia of European social history - from 1350 to 2000* (pp. 189-203). New York: Charles Scribner's Sons.

Tomes, N. (2007). Patient empowerment and the dilemmas of late-modern medicalisation. *Lancet*, *369*(9562), 698-700.

Turner-Crowson, J., & Wallcraft, J. (2002). The Recovery Vision for mental health services and research: a British perspective. *Psychiatric Rehabilitation Journal*, *25*(3), 245-254.

Wallcraft, J., Read, J., & Sweeney, A. (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.

Watson, A. C., Corrigan, P., Larson, J. E., & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophrenia Bulletin*, *33*(6), 1312-1318.

White, R., Bebbington, P., Pearson, J., Johnson, S., & Ellis, D. (2000). The social context of insight in schizophrenia. *Social psychiatry and psychiatric epidemiology*, *35*(11), 500-507.

Williams, G. (1984). The genesis of chronic illness: narrative re-construction. *Sociology of Health and Illness*, *6*(2), 175-200.

Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness ? Reflections on a core concept. *Sociology of Health and Illness*, *22*(1), 40-67.

Woodard, C. (1962). Reality and social reform: the transition from laissez-faire to the welfare state. *The Yale Law Journal*, *72* (2), 286-328.

ANNEX A – INTERVIEW GUIDE

A) RAPPORT

- Explain the research -
- Offer Term of Informed Consent
- Give time to read or read out loud
- Explain items of Term:
    - Recording
    - Confidentiality
    - Risks
    - Right to leave
    - Length
- Ask to sign
- Record

B) INTERVIEW

1. I would like to start by getting some basic information,

- like your birth date?
- Do you live here in … ?
- What's your main occupation?

2. First I would like you to tell me a bit about the service user / survivor movement. How did you first get involved with it?

- Prompts:
    - first time heard about it
    - reasons to adhere
    - prior relationship with people, if any
    - process of joining, feelings, receptivity
    - activities participated
    - current situation

2a. Do you see yourself as a part of it?

- Prompts
    - identification (do you identify with it? / do you feel like one of them? What do you think you have in common with them?)

3.Now I would like you to tell me more about your first experience with mental distress. Just feel free to talk about whatever you think it's important so I can understand how this first experience happened. (how did it start, what happened, how did you feel about it, what did you think about it, how did people react?...)

- Prompts:
    - individual: feelings, explanations, information

    - friends, family, community, co-workers: actions, explanations, personal assessment of their role
    - treatment, if any: whose decision, reasons, how was 1st contact w/ MH services, if any, explanations, personal assessment of their role

3a. So, after that, what happened?

- Prompts:
    - changes / continuity and reasons for them: actions, feelings, explanations, information

3b. How would you describe your current situation?

- Prompts
    - individual feelings, explanations, information
    - social network
    - treatment
    - vision of self involving mental distress

4. Do you think getting involved with the movement changed the way you experience mental distress?

- Prompts
    - explanations for distress
    - social aspect
    - activities and consequences

4. Now, the last thing I want to ask you is this: do you think that the British user movement, in a more general way, has succeeded in improving the lives of people that experience mental distress?

- Prompts
    - examples and explanations
    - direct
    - indirect

5. Would you like to add anything else?

C) CLOSURE

- Turn off recorder
- Thanks
- Feedback

Annex B - Transcription Conventions

Convention	Meaning
(pause 4.5s)	Silence - pause in seconds
word	Word emphasised by participant's own intonation
(hhhh)	Audible breath, sigh
__________	Words we were not able to comprehend and transcribe (the length of the dash refers to the length of the passage)
(word)	Uncertain transcription, represent our “best guess” of what the person said
(…)	Suppressed text from the original transcription (used in extracts)
(giggle) (laughter)	Short giggle or a longer laughter
(*word*)	Explanation of behaviour or specific intonation of the participant
wor--	Interrupted word
…	Unconcluded sentence or reticent intonation
[*word*]	Context to which participant is referring, which is not explicit in the given passage (used in extracts)
Word	Passages we have decided to highlight, but that don't correspond to the participant's intonation (used in extracts)

Annex C - Ethics Committee Approval

Documento 1 0 0 3 9

Comissão de Ética - Área de Saúde e Bem-Estar
Universidade de Évora

A Comissão de Ética vem deste modo informar que os seus membros, Professor Doutor Armando Raimundo, Professor Doutor Peter Vogelaere e Professor Doutor Jorge Fernandes deliberaram dar, na reunião do dia 25 de Maio de 2011, o Parecer Positivo para a realização do Projecto "O movimento britânico de utentes de serviços de saúde mental e a experiência do sofrimento psiquico" da investigadora Carolina Seibel Chassot.

O Presidente da Comissão de Ética

(Professor Doutor Peter Vogelaere)

ANNEX D- TERM OF INFORMED CONSENT

Term of Informed Consent

Consent to take part in a research study: the British mental health user movement and the experience of mental distress

Researcher: Carolina Seibel Chassot
E-mail: carolchassot@gmail.com.
Phone: 07 751 931080 (mobile)

I would like you to join this research study.

If you are a user involved with the British user movement, I would like to ask you to join this research study.

You are free to say yes or no, or to drop out after joining. There is no penalty or loss of benefits if you say no.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully. You can ask me if there is anything that is not clear or if you would like more information.

Why am I doing this study?

I am doing this study to understand how has the British mental health user movement affected the experience of mental distress of users - currently or previously - engaged in the movement.

Some studies have indicated that different health movements (such as the breast cancer movement) may change the way people experience the illness that the movement address (such as breast cancer). For instance, a health movement may challenge people's assumptions on what causes the disease, change the way it is treated, work to diminish stigma or provide alternatives for help, and in these ways change how people experience and live that disease.

I would like to understand a little bit more about how this happens in the field of mental health as well. This study is different from previous studies in health movements because it deals with mental distress and not illnesses, but it is similar because I am interested in understanding how people's experiences are changed (or not) by a health movement. I chose to study the British user movement because it is internationally relevant, well documented and was accessible to me in view of my resources.

What do you have to do?

If you decide to participate, I would interview you and ask you some questions about your experience of mental distress and about your participation in the user movement.

The length of the interview may vary from 1 to 2 hours. If you want, we could take a break or even stop and continue at some other date.

Are there any risks?

I believe there are no major risks involved for the participant in this research.

The only risk I can now anticipate is the possibility of the interview causing you to remember bad experiences, and the memory of the experiences can have a troubling effect.

To minimise this risk, I will keep from asking questions that may be regarded as too intimate, so that you may decide if you want to bring certain topics to discussion or not. In the same way, if I ask you something that you do not wish to respond, you are free to do so, or even interrupt the interview if you preferred.

What are the benefits?

I do not know if this study will benefit participants. I hope the information learned will help to understand better mental health movements and people's experience of mental distress. I will be glad to share the results of the study afterwards with you.

What about your privacy?

The interview will be recorded in audio. This is very important in order to analyse the results afterwards. If you do not wish to have the interview recorded, you are free to say so and the interview will be cancelled.

The recordings of the interview will be kept with me for 5 years, and afterwards they will be destroyed. It is important to keep record to prove that the interview has happened, but they will only be heard by myself and my research tutor (Mrs. Felismina Mendes, PhD).

I am not going to identify you at any point of this research. The only person that will know your identity is myself and my tutor.

The results of the research will be public, but I will be very careful so that you cannot be identified by any one that reads the results. I may do it by changing your name and any information that is specific to you (your profession, your neighbourhood, etc.)

Will you be paid to be in this study?

There is no payment for being in this study. This study is not financed in any way, so there are no resources to pay for participation.

What are your rights?

You do not have to join this study. There will be no negative consequences if you decide not to participate.

If you join this study, you do not have to stay in it. You may stop at any time (even before you start). There is no penalty for stopping.

Signature

If you have read this form (or had it read to you), asked necessary questions, and agree to participate, please sign:

____

Signature and Printed Name

Researcher's statement

I have discussed the research study, including procedures and risks, with the person signing above. A copy of the signed consent form will be given to the participant.

____

Carolina Seibel Chassot

Date: ____/____/______