

Diagnosis as a Resource in the Social Representation of Mental Illness.

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ABSTRACT

The theory of social representations has been applied in empirical research that examines shared understandings of mental illness in different communities. Another line of inquiry, drawing on a number of theoretical perspectives, has dealt with the functions of diagnosis in everyday sense-making regarding mental problems. This paper suggest how the theoretical model of social representation can be extended in order to account for representation as interactive sense-making in which diagnostic concepts serve as a mediating resource. An empirical study of discourse in self-help groups with people sharing experiences of mental health problems is used to explore the role of diagnosis in establishing shared understandings and identity. It is argued that when diagnoses are anchored in lay knowledge, they acquire new meaning potentials and serve new functions for representation that have ontological, epistemological, and moral dimensions.

Keywords: Diagnosis, social representation, self-help groups, cultural tools, meaning potential.

Diagnostic concepts do not only occupy a central position in medical practice but are also ‘deeply embedded in cultural practices of everyday life’ (Duchan & Kovarsky, 2005, p. 2) where they constitute a central feature of thinking and talking about illness. This is reflected in the literature on the functions of diagnosis that deal with diagnosis both as a classification tool in medical culture and as a feature of everyday discourse that has implications for lay conceptualisations of illness and illness identity (see Jutel 2009 for an overview). In the case of mental illness, research has highlighted the role of diagnosis (more specifically the role of DSM: *Diagnostic and statistical manual of mental disorders*, APA, 2013) in large scale processes of medicalization in society (Kutchins & Kirk, 1999) as well as interpretative functions of diagnosis in the sense-making of individuals and in more local contexts, such as self-help groups and other communities where members share certain illness experiences (e.g. Karp, 1992; Bülow, 2004; Giles & Newbold, 2011).

The processes in which scientific concepts and ideas are appropriated in everyday thinking have also been explored in terms of the formation of social representations. In the study *Psychoanalysis – Its Image and Its Public* (1976/2008) Serge Moscovici described how psychoanalytical theories had ‘given rise to a new collective model of psychological life, a new way of categorizing individuals and a new way of relating the normal to the pathological.’ (Moscovici, 2008, p. 104) In this study he described two key processes whereby scientific concepts circulate in society and are transformed in order to be incorporated in the shared knowledge of the general public. The first of these processes he calls *anchoring*, which designates how ‘elements of scientific language pass into everyday language, where they obey new conventions’ (Moscovici, 2008, p. 55). Through this process society transforms the concepts of science into ‘a knowledge that is of use to everyone’ (2008, p. 104). The anchoring of new concepts in already established social knowledge is related to the second process, *objectification*, where the abstract concepts of science are translated into concrete representations and transferred ‘to the level of observation’ (Moscovici, 2008, p. 55).

A number of studies have taken the concept of social representation as a point of departure for examining the construction and transformation of popular understandings of health and illness (Herzlich, 1973; Jovchelovitch & Gervais, 1999; Joffe, 2002). With Denise Jodelet’s (1991) study of representations of madness in a French community as a starting point, it has also been used to investigate everyday knowledge of mental illness in the general public and the

understandings of mental health professionals and clients (Morant, 1995; Foster, 2001; 2003; 2007), as well as the social representations of specific mental illnesses, e.g. depression (Räty et al., 2006) and ADHD (Schmitz et al., 2003).

These studies shed light on the role social representations play in classifying and making sense of illness experiences. For example, when discussing their findings, Schmitz et al., suggest that ‘the social representations of the disorder provide meaning-making structures for the individual’ and that social representations present ‘reference points for the selection categorization and organization of the individual’s perceptions and experiences’ (2003, p. 402). Schmitz et al., thereby point to the relation between shared knowledge at a community level and the application of such knowledge in the processes of meaning-making that individuals engage in. However, they do not elaborate on how this relation can be understood from the point of view of social representations theory – something that Hubert Hermans (2003) touches upon in his comment on their study. Hermans affirm that the theoretical approach of social representations ‘has the advantage of linking the macro level of societal processes with the micro level of individual functioning’ (2003, p. 408) but also suggests that ‘we have to go beyond social representations theory in order to more fully understand the role a clinical diagnosis plays in the organization and reorganization of the self’ (2003, p. 407). The theory of social representations has nevertheless proved to be a useful framework for theorizing the relation between community, knowledge, social practices and identity (Jovchelovitch, 2007; Howarth, 2002a; 2002b). The primary function of social representations has been said to be ‘the construction of social objects that provide a stable pattern of meanings for social actors’ (Duveen, 2001, p. 264), which is also apparent in Juliet Foster’s research on understandings of social representations of mental distress. Here the close relation between representations of such experiences and the creation and maintenance of identities is made clear:

When the object of representation is particularly, and personally, salient for the individual, identity, and the project in which an individual engages in in relation that representation, will be substantially intertwined and, to some extent, interdependent. (Foster, 2007, p. 129)

Foster shows how representations of one’s mental health problems along the dimensions controllability and location involves notions about agency and understanding of how one’s self is

positioned in relation to the problem: the problems can be seen as ‘either something that can be controlled or as something that is in control’, and it might be understood as something that is external or ‘part of the Self’ (Foster, 2007, pp. 161-165). This article will suggest that the theory of social representations can illuminate how diagnostic concepts, that are appropriated from a medical domain of knowledge by processes of anchoring and objectification, can serve as instruments in this kind of sense-making.

PURPOSE

The purpose of this paper is to analyse the role of diagnosis in everyday sense-making of mental problems. Using an empirical study of group discourse about personal experiences of mental illness, I examine the functions that diagnostic concepts have in the construction of meaning of such experiences.

Mental illness presents two interrelated challenges to a person that is trying to understand and make sense of their experiences and problems. The first concerns the abstract, subjective and often elusive nature of mental phenomena – in short, how to conceive of and represent aspects of the mind. The second relates more specifically to the issue of illness experiences, since sense-making here is not only a matter of comprehending illness per se, but as something that is conflated with issues of personal and social identity. Mental illness actualizes questions about self and identity and a diagnosis functions as both a classificatory tool in regards to illness conditions and as a tool for value laden social categorization (which is pertinent in the processes of stigmatization). I focus on the role of diagnosis in the management of these problems and show how a number of things can be accomplished by this ‘naming of illness.’

Further, the paper will discuss theoretical implications of this analysis in terms of social representation. This is done to show how this theoretical model can account for these functions and clarify the way a diagnosis can be seen as an example of shared socio-cultural resources that mediate individual and interactive sense-making. This will allow for a discussion of the anchoring of diagnostic concepts in lay knowledge.

METHOD

The case that will be considered here concerns self-help groups with members who share experiences of mental health problems. Such groups are assumed to constitute communities that provide a forum where members engage in collaborative projects of meaning-making that not only address illness experience per se, but also establish a shared understanding of the meaning of diagnosis and its consequences for identity. In order to investigate such group interaction, open discussion focus groups were carried out with participants recruited from three Swedish mental health service user organizations. These were selected because they bring together persons with different kinds of mental health problems, defined by themselves as ‘anxiety syndromes’, ‘depression and bipolar disorder’, and ‘mental health issues’ more generally. This selection was assumed to provide a variation in the data regarding different kinds of experiences. Self-help groups within these organizations were invited to a moderator led discussion regarding the following topics: (1) their experiences of mental problems and recurring topics in the self-help group, (2) different terms and ways of talking about mental health problems, (3) experiences of talking with others about one’s problems, and (4) their thoughts about different ways to explain mental health problems. The focus group method was adopted as it can be assumed that the way focus group participants draw on socially shared knowledge in order to thematise and elaborate on conversational topics share important similarities with how this is done in other situations. This makes it possible to analyse focus group interaction in order to investigate how knowledge and ideas ‘develop, and operate, within a given cultural context’ (Kitzinger, 1994, p. 116). In other words, the focus group discourse is assumed to simulate sense-making in other situations and, in this case, reflect important features of self-help group discourse (cf. Marková et al., 2007).

Representatives of 15 self-help groups within the three service user organizations were contacted and sent a written information sheet. The representatives then informed the other group members about the research project who discussed the proposition before responding to it. Most of the groups declined to participate in the study, some referring to the sensitive nature of the topic, but six groups accepted the proposal and organised a group session to address the topics introduced by the researcher who participated as a focus group moderator. The size of the focus groups varied between 3-6 participants (n=27) aged 29-68 years. The groups had been meeting on a regular basis, often for a number of years, even though some members had been participating for a much shorter time. The focus groups discussions were carried out in the venues where the self-help groups ordinarily met and followed an open format where the

participants were asked general questions and were encouraged to discuss the topics freely. The moderator intervened mainly in order to facilitate contributions to the discussion by all participants and by encouraging the participants to elaborate on relevant topics.

The project was reviewed by the Regional Ethical Vetting Board in accordance with the Swedish Ethical Review Act (2003:460). In order to comply with the ethical standards, informed consent was obtained from each participant and results have been reported in a way that will not compromise the confidentiality of the respondents (no participant names or any information about the self-help groups are mentioned).

The focus group discussions were audiotaped and the complete recordings (that totalled 100-145 minutes) were transcribed verbatim by the author. The focus group discussions were conducted in Swedish and the quotes that are presented in this text are the author's translations. A thematic qualitative analysis was carried out in order to explore how diagnostic concepts were used and reflected upon in the group discussions (Graneheim & Lundman, 2004). The sections where participants characterised their problems, referred to diagnosis or used diagnostic terms were first coded with regard to manifest and latent content. The codes that emerged in this process were then grouped together under four higher order themes that refer to how the use of diagnosis could be interpreted to serve different functions in sense-making by facilitating different projects that are accomplished through representational activity. The analysis and translations of quotes were presented for evaluation in researcher seminars during the process and colleagues were asked for opinions on drafts of the article in order to ensure rigor and validity in the analysis.

RESULTS

1. Verbalisation and explanation of experience

As a means that make it possible to label and name certain experiences, diagnostic terms are obviously something that facilitates the communication of experience. Some participants in the focus groups also reported how it was not until they had their problems diagnosed (by themselves or by medical professionals) that they felt it was possible for them to communicate their experiences in a way that made sense to others. The lack of diagnosis that some described seemed to leave them in a position where they found no other viable way to communicate the problems

that they experienced in daily life. In many cases, having one's problems diagnosed constituted an important turning point when narrating one's life in the focus groups – a turning point where something deeply personal was made possible to externalise and share with others. As one participant said: *'I can explain to people: "I've got this depression ..."'* (5A)¹. But more fundamentally, participants also reported how a diagnosis in the first place made it possible to make sense of a number of experiences and challenges they have had throughout their lives. Many described how they had experienced problems that varied over different periods and took various forms in different areas of life. Before the diagnosis, these had been interpreted as either: (a) something incomprehensible (*'I couldn't understand what was wrong with me'*, 6C); or (b) something essential or core in who they were, as something in their character or personality (*'I thought I was like that. It was kind of natural to me (...) I was living like that and being like that'*, 3D); or (c) as a sign of madness (*'I thought I was the only one who was like that – that I was going mad, and I felt so terribly ashamed'*, 4B).

Even if the diagnoses of the diagnostic manual DSM² (APA, 2013) generally do not imply the aetiology of the syndromes and conditions, many of the participants described how having their condition named in the diagnostic terms of the manual was felt as being provided with an explanation of its causes – e.g., as if one has feelings of low self-esteem *'because'* one *'has a depression'*. This label made them feel that they *'knew what was going on'* (6C) and that their experiences were not incomprehensible. In some cases this was taken as a reassurance that one was not *'going mad'* – that labelling the experience in diagnostic terms precluded such alternative and more threatening categorizations (cf. Giles & Newbold, 2011; LaFrance, 2007).

This means that one function of diagnosis is to enable the identification of certain individual problems and experiences as a certain kind of phenomena. Such classification assigns personal problems to a psychiatric nosology, frames them as medical conditions and contextualises them within a domain of expert knowledge that is assumed to provide both knowledge about the nature of the problem and an explanation of its causes. It also makes it possible to relate the group members' personal experiences to each other under the assumption that, despite all their

¹ Quotes are attributed to participants by a number designating the focus group and a letter identifying the individual.

² The diagnostic criteria of both the current version of DSM (DSM-5), which is used in Swedish psychiatric services, and the International Classification of Diseases (WHO, 1992), which is used in other parts of Swedish health services, specify the symptoms that must be present in order to apply a diagnostic category. This kind of descriptive diagnoses is not based on assumptions of etiology and thus does not imply the causes of disease.

individual differences, they are essentially of the same kind. This parallels Foster's description of how diagnosis can serve both to define experience and, in a client context, as 'a kind of shorthand in introducing themselves' (Foster, 2007, p. 56).

2. Objectification and reification of illness

In diagnosis, a number of heterogeneous experiences and problems can be attributed to the same illness condition. Some participants talked about a variety of emotional problems and difficulties as '*vague*' (6C) and how these had manifested themselves in different ways over the course of time: '*everything has been awkward for practically my whole life*' (1B). This suggests that the explanatory function of diagnosis might rest on a more fundamental capability of diagnosis to objectify a person's multifaceted illness experiences and a variety of problems as a single entity. Diagnosis mediates the construction of such an 'object of thought' and makes it possible to make sense of changing sensations, emotions, thoughts and impulses in daily life as aspects of this illness entity. For example, one participant describes how she had always been a '*worried and anxious*' person, and how she had experienced different '*bodily symptoms*', such as numbness, when she grew up that neither she nor her family could understand. She consulted doctors several times but were repeatedly told that nothing was wrong with her:

I carried on like that for years until a read about anxiety in a newspaper when I was twenty one years old. Then I felt: 'This is it', and then I could ask for help. (3C)

The diagnostic concept facilitated the construction of a narrative that brought together separate episodes and experiences into a whole and made it possible to represent her illness as something with a discernible *Gestalt*. It became possible to tell an illness narrative that organized past and present experiences as a life with anxiety disorder.

Another consequence of this objectification of illness is that it enables the individual to disassociate oneself from this illness entity by talking about it as something that one 'has' rather than something that one 'is'. Illness can be represented as something outside of one's self rather than something essential of oneself. A consequence of this is the possibility to enter into a 'polemical relation' (Canguilhem, 1998) to the objectified illness entity; illness is something that

can be *'fought'* or acted upon with the help of medication or other means; *'you can get rid of it'* (1B). This can be compared with how Foster (2003) characterises representations of mental illness along the dimensions of control and location. Drawing on this two-dimensional model it seems like the use of diagnosis in representing health problems would facilitate the 'objectification of mental illness as some kind of entity' (Foster, 2007, p. 162) and representations of this illness entity as something external to the self and potentially controllable. This has similarities with how psychiatric discourse has been claimed to invite patients to adopt an understanding of their distress by 'discursively constructing an inner split' between the illness as an object and the subject (Ringer & Holen, 2016, p. 166). Representations in the focus groups also resonate with medical discourse as illness was objectified as a disorder of the individual's mind or brain. For example, participants sometimes identified illness with *'a lack of serotonin'* (3D), *'a chemical imbalance'* (1B) or just *'a problem in the brain'* (1C). By drawing on biomedical frames of reference the illness entity was reified and localized as something concrete. Some participants also explicitly rejected descriptions such as *'mental illness'* or *'mental disorder'* and substantiated the claim that *'my problem is in the brain'* (5A) by accounts of the workings of pharmaceuticals (cf. LaFrance, 2007).

As George Lakoff and Mark Johnson state, our bodies and other physical objects provide the basis for many ontological metaphors that makes it possible to categorize things that are not clearly discrete or bounded and to view 'events, activities, emotions, ideas, etc., as entities and substances' (Lakoff & Johnson, 2003, p. 25). Diagnosis seems to be a resource in sense making that works in a similar way by facilitating objectifying and reifying representations of illness experiences. This is consistent with what Roger Säljö (2002) has called 'our preference for a things ontology' and such background assumptions of naturalism that state that 'matters of the body are considered more "real" than matters of the mind' (LaFrance, 2007, p. 135).

3. Personal identity construction and legitimization

Regardless of whether somatic, psychological or social frameworks were used by the participants to contextualise illness, objectification of illness made it possible to represent it as something separate and alien from the self. For example, depression and anxiety were talked about as something that distorts the image of the afflicted person or something that makes it impossible to

be the kind of person that one ‘really’ is. The participants also talked about how others sometimes fail to make such a distinction between the illness and who the person really is: *‘The image of me that others had wasn’t true – it was false in a way’* (1B). They also told about how they themselves previously had lived with an erroneous understanding of their problems: *‘I thought I was crazy’* (4B). Representations of illness as something that conceals who one really is thereby seem to open up the possibility to restore not only health, but also an authentic self. As a consequence, effective medication could be represented by the participants as not only something that gave some relief from distress but also created a possibility to *‘return to life’* (5B) with better possibilities to realise one’s potentials. Anders Petersen’s description of how antidepressants can be seen as a technique for ‘authentic self-realization’ (Petersen, 2011, p. 20) summarizes this understanding.

The diagnosis obviously has important implications for the representation of the person suffering from illness. As have been extensively described in a number of studies of public beliefs about and attitudes towards people with mental illness, such representations often have a salient moral dimension that is conducive to processes of stigmatization (Angermeyer & Dietrich, 2006). The focus group discussions frequently addressed how psychiatric diagnoses are generally associated with prejudice and are likely to lead to stigmatization in everyday life. When describing the views of the public mental health problems in general were said to be ‘taboo’ (5C) and the term ‘mental disorder’ were said to signify that you are ‘weird’ or ‘worthless’ (3E) while ‘mentally ill’ was equated with a term of abuse (2B).

People really look down on you if you are mentally ill. (...) If your leg is broken, then you are accepted, but if you are depressed or borderline or something, then you are a freak and people don’t want to associate with you. (4A)

But diagnoses were also described as something that can play a positive role in constructions of identity. Moral judgement of behaviour that could be regarded as deviant or as a failure to live up to one’s own and others’ expectations was a reoccurring topic. To have received a diagnosis was here presented as something that one can refer to in order to fend off blame: *‘I’m entitled to act like this because it’s part of my diagnosis’* (4A); *‘Acting weird doesn’t mean you are a bad person, it’s the diagnosis that makes you do that’* (4C). In the narratives told in the focus groups,

having one's problems diagnosed often also constituted a turning point where one realized that many problems were due to illness rather than personal failures or shortcomings:

I thought: 'Everyone else can manage. Why can't I?' (...) I went to the doctor because I was completely run down and just cried. I went there, and he gave me a diagnosis immediately: 'depression'. I didn't understand what was wrong myself, I just didn't get it, I didn't understand. But he saw it immediately and signed me off sick. (3D)

As Annemarie Jutel puts it, the diagnosis certifies the medical nature of the problem and legitimises sickness: 'What was previously a complaint is now a disease.' (2009, p. 278). When diagnosed, problems in daily life no longer imply a weakness of character and personal experience ceases to be 'just' subjective experience. As it is verified by medical expertise it can be ascribed a different ontological status as something incontestable and real. The way that diagnosis detaches the individual's condition from moral judgment corresponds to what has been described in terms of the naturalistic assumptions in medical thinking where it is assumed that 'illnesses "happen" to people and that sickness has no special attraction to virtues or vice.' (Gordon, 1988, p. 29)

In this case, the health problems in question mainly consisted in subjective experiences and all the participants told about how others not only had difficulties to realize the severity of the problems, but they also questioned whether they were really ill in the first place: '*Some say: "You're not ill. You're not that sick. You always look well – you can't be ill." I've even been told that I'm not ill since I wear makeup.*' (4A) The ways that subjective illness experience were contested by others was a common theme in the focus group conversations and diagnosis was presented as crucial in order to have the reality of their illness experience validated (cf. LaFrance, 2007; Bülow, 2004). Authoritative verification through the medical labelling by diagnosis offered a permission to be ill and was pivotal to claims of an identity as ill, rather than someone who is 'weak', 'mad' or 'irresponsible'.

4. Social stratification and collectivisation

As we have seen, diagnosis is not only a tool for the representation of illness experience, but also a tool that can be used in representing the ill person. When considering this role of the diagnosis in the focus group discourse it seems to be working in two different ways. We have seen how it can result in a distancing of illness from the self – a disidentification. But, when talking about other kinds of diagnoses, the participants also construed pictures of people who have had their problems labelled in different ways. Since the diagnostic categories are embedded in social knowledge about what characterize the person who suffers from certain problems (or does not have any such problems that warrants diagnosis), diagnoses are associated with certain characteristics that are attributed to the person with these conditions. They thereby serve as tools that not only categorize different kinds of health problems but also different kinds of people. In the group context this did not only involve personal traits and characteristics that were judged as problematic or conducive to ill health. When talking about their own diagnosis, this was recurrently associated with appreciated personal capabilities and traits, such as ‘*creativity*’, ‘*intelligence*’ (4B) and ‘*an ability to understand others*’ (3E): ‘*We have been gifted with a sensibility that we can develop into something positive.*’ (5A) The shared understanding of how a certain diagnosis is related to such valued personal characteristics, or ‘extra qualities’ (Foster, 2007), thereby serves as a basis for positive identifications with a category of people.

On the other hand, the diagnosis was also used to distance oneself from categories of people with problems that were labelled in other ways – both those who were called ‘*normal people*’ and those who suffer from what was regarded as more severe problems (e.g. ‘*personality disorders*’). Some participants explicitly stated that depression and anxiety syndromes should not be confused with severe mental disorders: ‘*We’re not sick. We’re just as normal as everyone else.*’ (3E); ‘*I know the difference. We don’t belong with mentally ill people.*’ (3B). Neither should their problems be equated with the common problems of everyday life: ‘*I’m signed off sick and can’t walk out the door. It really can’t be compared [with normal problems]*’ (4C). Diagnosis thereby served as a tool for social categorization that amounted to a form of *social stratification* where people and problems were assigned to three different strata:

- (1) ‘*normal people*’ with everyday/normal problems where it is possible to ‘*pull oneself up by the bootstraps*’ and where diagnosis is not applicable,

- (2) people with characteristics that predispose them to problems that involve distress of a kind that cannot be compared to that of normal problems, where diagnosis is appropriate and medical treatment is justified,
- (3) people with profound mental problems or '*serious diagnoses*', '*the really sick*' or '*disturbed*' who were represented in ways that brought their otherness to the fore.

Goffman (1986) and Foster (2007) discuss how such stratification can be understood as a response to stigmatisation. Distinctions similar to those presented here are also described by Karp (1992), who shows how the emphasis on depression as a medical condition can serve to make a distinction from ordinary sadness. Ringer & Holen (2016) also discuss the notion that some people are more 'genuinely' or 'authentically' ill than others. In the focus groups diagnosis was an important element in the making of these social distinctions that were partly accomplished through disassociation from others. But it was also an important means to articulate the common denominator that served as the basis for community, and thereby for constructing social identity. By being used to refer to what was shared by the members of the self-help groups diagnosis could be said to serve a *collectivising function*. Having one's problems identified in this way (by one self or medical expertise) makes it possible to relate one's personal experiences to those of others. Another way of accomplishing this in the focus groups was by representing personal experience in accordance with the narrative structure of a 'co-narrated collectivized story' (Bülow, 2004) of life with depression or anxiety. To a large extent, narrating in the groups can be seen as a collaborative action where the narratives of other participants were taken as a point of departure for telling one's own story. In the group discussions, there were many sequences in which a series of individual stories were told and compared in a way that highlighted similarities, and certain elements and themes in previous stories were elaborated on. In focus group 3, for example, 3C began a narrative account of her own experiences by pointing to similarities with what 3A had just told: '*Well, I also feel that ...*'. When she had finished her account, other participants commented on what were regarded as common features of life with mental illness. This theme was then further elaborated by 3D who introduced her own version of this shared story with the words: '*That is the way I have been living ...*'. This co-narration resulted in a jointly constructed story about life with mental illness in which the event of having one's

problems diagnosed constituted an important turning-point. The distinction between before and after diagnosis was a crucial structural feature of the individual biographies that sometimes was connected to how one got involved in the self-help group.

In parallel to how diagnosis in medical practice makes it possible to link individual cases to the knowledge of a more general kind, in the group context it facilitates the linking of individual cases to the shared knowledge that has been accumulated in the group (cf. Cain, 1991). In the context of the self-help communities, the social import of diagnosis thereby seems to lie in providing a focal point for collectivisation of experience and the formation of shared experiential knowledge. Diagnosis is thereby also of special importance for the community by providing a basis to claim collective expert knowledge in matters regarding a certain kind of condition.

DISCUSSION

Initially I stated that sense-making regarding mental illness presents two problems since it concerns abstract and subjective phenomena that are also related to issues of identity. The analysis of the focus group material suggests how diagnosis can be regarded as a cultural tool that facilitates the management of these problems in everyday discourse by providing means for defining the nature of mental illness and by making certain meanings and identities possible. Diagnostic categories can thus be regarded as resources for sense-making; in group discourse they serve as a means for collaborative representational activities that can serve four interrelated functions:

- 1) to articulate experience as a certain kind of illness, which is linked to a sense of having illness experience explained,
- 2) to objectify and reify experiences in a way that construes illness as an entity, which makes it possible to understand the illness-self relation in new ways,
- 3) to legitimize personal problems and shortcomings in ways that have implications for how personal identity can be constructed,

- 4) to construct social categories and relate them to each other in ways that makes certain social identities possible, and to collectivise individual experience and knowledge in a community context.

Diagnosis as resource in representation of mental illness

The term ‘representation’ has been said to have a double meaning since it can refer to both the activity to represent something (an object) and the observable outcome of that activity: ‘an elaborated idea, a designed object, a representation’ (Bauer & Gaskell, 1999, p. 167). As an activity, social representation is a situated process, and the representation that is produced is something emergent in interaction. Sandra Jovchelovitch’s characterisation of representation in terms of ‘labour’ and ‘communicative action’ is congruent with this:

Representation emerges as a mediating structure between subject – other – object. It is constituted as labour, that is to say, representation structures itself through the labour of communication and action that links subjects to other subjects and to the object world. In this sense it is perfectly plausible to say that representations are communicative action. (Jovchelovitch, 2007, p. 34)

In the case of the focus group interaction this means that the term social representation can be used to designate what is produced in communication in terms of the ‘emergent views that are not reducible to the individuals’ (Hydén & Bülow, 2003, p. 319). If emergent representations corresponds to ‘views’ on topics or objects, this implies that representational activity involves perspectivation, and, consequently, the activity of social representation would imply a joint perspectivation that makes intersubjectivity possible. The social representation of an object in discourse could be said to allow the interlocutors to see and talk about ‘the same thing’:

The temporarily shared social world of the dialogue may be explored in terms of partially shared cognitive-emotive perspectives, and what is made known has to be described in terms

of expansions and/or modification of such an intersubjectively established social world.
(Rommetveit, 1974, p. 123)

But the term social representation is also used in a third sense when it refers to the regularities, recurrent patterns and structures that are revealed in representational acts – the stability across situations that makes it possible to make inferences about the shared knowledge of the community that guides this activity. The third meaning of social representation concerns something situation-transcending; ‘the significant structure which is exhibited in a series of constructive events’ (Wagner, 1996, p. 111) or ‘global structures superimposed on interactions and embodied in traditions of relatively long-term continuities of practices’ (Linell, 1998, p. 61). In other words, social representation in this sense is what accounts for the stability of meaning within a community over a period of time.

These three meanings of the term imply a distinction between a discursive level of situated representational activity that involves perspectivation of an object, and an underlying level of resources that provide the means for such actions. This distinction parallels how Rose et al. distinguishes between ‘the level of immediate social interaction which involves disagreement and argumentation’ and ‘the level of the underlying ground-rules of social representation formation, which make understanding possible’ (Rose et al., 1995, p. 3). In order to account for such a distinction between levels, the basic model for social representation (cf. Bauer & Gaskell, 1999), which comprises a number of interacting subjects (S) who produce a social representation (SR) of an object (O), can be supplemented with an underlying level of shared sociocultural resources (R). In this model (figure 1), social representation designates the intersubjective understanding of a certain object that is produced through discourse mediated by shared resources.

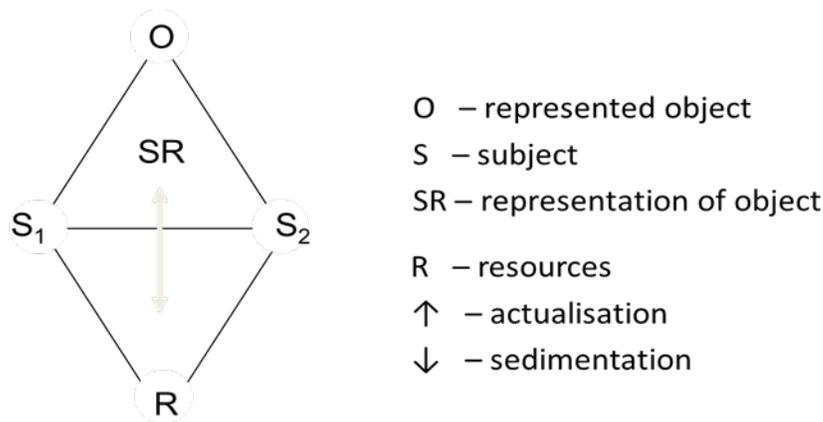


Figure 1: Resources for social representation.

By distinguishing between the underlying level of resources and the discursive level of representation this model accounts for both the actualisation of resources in representational acts and a ‘sedimentation’ (Berger & Luckmann, 1966) of features of these acts. Sedimentation here signifies how meaning and knowledge, as well as forms of representational activity, are added to the existing resources within the community that can be utilized in future discourse on similar topics. This can be compared with how Moscovici states that the repeated use of ‘devices’ such as analogies and generalisations, results in ‘a crystallization as representations stabilize around certain symbols and certain themes.’ (Moscovici, 2008, p. 177)

The resources would account for both the stability of meaning and the possibility of meaning as something shared within a community. However, to term such resources ‘social representations’ is problematic since these are phenomena of a different nature than the situated outcomes of representational activity. Rather than being representations of a certain object, I suggest that the resources should be regarded as *cultural tools* that mediate the activity of joint perspectivation and meaning making in discourse (Vygotsky, 1986; Wertsch, 1991; 1998). As such they would include categories, concepts and semiotic means, as well as the established and routine ways of sense-making. An advantage of such conceptualisation of resources in terms of tools is that a reification of social representations, ‘as if a discrete social representation of health or illness necessarily exists in a simple sense’ (Radley & Billig, 1996, p. 223), can be avoided. Rather, these sociocultural resources could be characterised as *meaning potentials*: ‘potentialities to evoke particular types of discourses, understandings, actions, attitudes etc., given that participants find themselves in particular kinds of contexts’ (Linell, 2009, p. 281f). Or, they could

be regarded as ‘a reservoir whose actualizations vary with context and use’ (Jodelet, 1991, p. 289).

While these resources stabilise sense-making across a variety of situations, they also can be actualised in a highly situated manner in different communicative and representational projects. This is illustrated in the way that the concept of ‘normality’ is used in seemingly contradictory ways in the focus groups. The concept is given different meanings and ascribes different meanings to the person when is used to characterize oneself as normal and when distancing oneself from people described as normal.. The way that diagnostic concepts are used in focus group discourse also shows how they can function in different ways. Participants draw on different meanings of the diagnostic concept to represent illness, to construct identity and to form a sense of self. Different parts of the groups common stock of knowledge is actualised when a diagnosis is used to categorize one’s experiences as a certain type of problem, to objectify illness and relate it to an explanatory framework, to identify with others with similar problems and to distance oneself from other social categories. The different meaning potentials provide the members with a repertoire that can be drawn upon, both individually and jointly, to accomplish different things in sense-making. When Hermans notes how a person use the category of depression in ways that contradict the ‘prototypical models provided by the community’ (Hermans, 2003, p. 413), we can interpret this as an example of how shared resources can be utilized in different ways, rather than as an exception from one unitary social representation.

The anchoring of diagnosis in lay knowledge

The way diagnostic concepts are used in everyday sense-making differs from the way they are used in the medical domain. When transferred from the domain of specialised expert knowledge to lay thinking they undergo processes of anchoring and objectification that have several features similar to the findings in Moscovici’s study of how psychoanalysis was understood and reconstructed in society. Just as psychoanalysis was transformed in the 1950s and 60s into ‘an instrument’ that society can use (Moscovici, 2008, p. 104), the concepts and categories of the expanding nosology of mental disorders are appropriated as tools for lay sense-making. Rather than being a process where a concept is simply transferred to a new domain, anchoring is a process that transforms the original scientific concept. In this process the abstract nature of clinical diagnoses is downplayed and their meaning potentials in the context of specialised expert knowledge gives way to the meaning that is grounded in experiences of everyday life. Rather

than acquiring a fixed meaning, the anchoring of a concept in shared knowledge draws on different sources that provide it with several, often contradictory, ways to perspectivise and understand a certain object. At the same time, experience is a source of new meaning that feeds into the stock of resources and is sedimented when members of a community interact. Moscovici describes a similar reciprocal relation when he states that representation in everyday life is ‘a process that makes concepts and perceptions in some sense interchangeable because they generate one another’ (Moscovici, 2008, p. 15).

Some of the meaning potentials that the anchoring process provides diagnosis with can be assumed to be restricted to the local communities of the self-help groups which have established shared experiential knowledge and a common ground for their communication. Other meaning potentials are more widely shared in society. One of these involves the status that medical knowledge has in society and how the use of diagnostic terms seems to lend some of this status to the representation of experiences and problems that otherwise run the risk of being questioned. It makes it possible not only to categorise a condition as illness, but also as a legitimate medical problem. The diagnostic categories also acquire the character of an ‘explanatory tool’ (Tucker, 2009; Ringer & Holen, 2016) by being anchored to widely shared knowledge of things like the workings of the brain (cf. Schmitz et al., 2003).

It can be concluded then that diagnosis is anchored in both experiential and more widely shared knowledge which gives it meaning potentials that allow it to serve the different functions that the analysis of the focus group discourse has indicated. By enabling a certain categorisation, interpretation and perspectivation of experience, the concept provides *epistemic access* to a segment of reality; it mediates the subject-object relation whereby meaning is given to personal experience. As a tool for the conceptualization of experience, it provides a means for the construction of an object of knowledge, which is also of ontological import since it renders these mental phenomena as ‘real’ and ‘existing’. In addition to this, diagnosis facilitates the collectivisation of experience and provides a basis for the construction of illness identity that has moral dimensions. It fulfils social functions that resonate with Moscovici’s description of social representation as a ‘social instrument’ (Moscovici, 2008, p. 192).

Methodological reflections and conclusion

Even though the participants in the study often expressed quite positive and consensual attitudes in the discussions, diagnosis was not an uncontroversial issue in the focus groups. There were differences in views both within and between groups and the participants did not only present diagnosis as something valuable and important to them. They also articulated what can be considered as a downside to each of the functions that have been discussed here. Typically, the participants expressed feelings of ambivalence and the diagnosis was sometimes talked about as something that is associated with a number of risks. In many ways it seems to be regarded as a double-edged tool with a dilemmatic nature (cf. Tucker, 2009; Ringer & Holen, 2016). For example, while the medical concepts legitimize illness they also actualise a medical model of diagnosis-treatment-cure. However, some participants express views that are hard to reconcile with such a model where illness is objectified and localised to the individual and, sometimes, his or her body. For example, in some personal narratives mental illness was represented as a social phenomenon – a pathology of interaction so to speak – rather than something inherent in the individual. Just as diagnosis for some played an important role to define experience, for others it could be seen as providing an inadequate definition (cf. Foster, 2007). It should also be stressed that while diagnosis in some ways seemed to provide a tool for constructing a positive social identity, the discussions also touched upon the way that psychiatric diagnosis in many social situations could be considered as a stigma with negative effects on identity. Risks were mentioned that resemble the threats to identity that have been described as challenges when becoming ‘a member of diagnostic categories’ (Tucker, 2009). Even though diagnosis seems to be a tool that facilitates sense-making regarding the problems in question, it does not provide an unproblematic way to deal with mental problems or a tool that is sufficient to articulate the many meanings of mental illness. This means that the results presented should not be taken as description of unequivocal views and understandings – rather they point to a number of tensions, contradictions and challenges in representing mental problems.

When considering the transferability of the results two questions also need to be addressed. The first concerns to what extent the focus group discussion can be assumed to mirror important aspects of what is going on when the same persons are meeting as a self-help group. Discussions in the focus group situation, where what is said is recorded and a moderator is present, obviously cannot be regarded as naturally occurring conversations. A second question concerns the extent to which representations in these groups might be representative of sense-making in the wider

service-user community. As has already been mentioned, several groups declined to participate in the study and it is arguable that there might be other differences between those who declined and those who agreed. This means that we cannot claim that the results provide direct insight into neither the sense-making of the self-help groups nor that of the service-user community. However, the similarities with what is reported in other studies seem to indicate that the findings do bear on some prevalent meaning potentials of diagnoses and how these can be used as cultural tools in everyday sense-making.

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