

Variation in knowledge: A personal journey

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Abstract

According to critical realist epistemology, it is possible to justify the existence of differing understandings of the same phenomenon. Such variation, in relation to mental health, could have important theoretical and practical implications. In this article, I explain my journey in relation to my understanding of a specific mental health disorder, Attention Deficit Hyperactivity Disorder (ADHD). Throughout this journey, I have occupied different roles: relative of patients, medical student, general practitioner and researcher. I have also encountered people with a wide range of roles, positions and understandings, such as psychiatrists who advocated the disorder and those who resisted it, academics from other fields and health care professionals who viewed the condition in a different way, patients who were, helped or frustrated, and people who become experts in the field via dissimilar roots. This journey provides an exemplary case for the existence of various positions towards a mental disorder. Finally, I shall discuss the concept of variation in knowledge and explain how medicalisation theory can act as a useful framework for understanding such situations. I also discuss the importance of patients' expertise in future medical-sociological investigations.

Introduction

In this article, I will initially present an introduction to the philosophical theory of knowledge that justifies the possibility of different accounts of phenomena such as mental disorders. Then, by considering one particular viewpoint related to the specific disorder, ADHD, I will describe my personal journey as an exemplary case that presents the possibility of possessing different accounts for the same phenomenon.

The possibility of different understandings

The process of knowledge formation can be influenced by material conditions, social and economic conditions, social positions, power and authorities (Scott and Marshall 2005, p 337) to name but a few. Therefore,

with the emergence of knowledge, it is necessary to investigate its production, aims and context to understand how it has been shaped by other factors (Swidler and Arditi 1994).

The possibility of the co-existence of different views of the same mental disorder is dependent upon the epistemological position adopted. For example, positivism provides limited possibilities for multiple understandings and/or variations in knowledge (concerning the same phenomena). According to a positivist approach, mental disorders are viewed as biological realities and the diagnosis process is considered a discovery of that reality in patients (Benton and Craib 2001). In this perspective, therefore, as there is only one reality, there should be only one explanatory theory as well.

In contrast, a critical realist perspective maintains that 'there is an objectively, potentially knowable, independent reality, but at the same time acknowledges the constructive roles of context, perception and cognition' (Middleton and Shaw 2007, p 293). According to this approach we (i.e., in this instance, social scientists and health care professionals) are perpetually attempting to attain the best possible knowledge; we never consider our current knowledge as the ultimate truth. Critical realism facilitates the acknowledgement of different perspectives existing towards and/or within psychiatry (Middleton 2007, Middleton and Shaw 2007, Middleton 2008). The application of critical realism to psychiatry concedes that no one person can have a universal standpoint and, therefore, variation can be anticipated, as Middleton (2007) has suggested:

No one of the very many theoretical, research and/or therapeutic approaches that might fall under a wide umbrella of mental health research, psychiatry, mental health practice and mental health services can be expected, on its own, to provide the basis of an all-embracing theory or a universally effective family of therapeutic interventions (p 41).

Having introduced the possibility of co-existing understandings of mental disorders, I will now introduce the formal knowledge of ADHD and will then explain my observations relating to people with different viewpoints and their differing social positions. I will then explore their role in the process of production and use of knowledge. These observations will illustrate how different people might understand and relate to the same mental disorder.

Knowledge of ADHD

The phenomenon that is now called ADHD existed symptomatically before the introduction of its formal medical diagnosis, treatment and clinical

title (i.e. ADHD). For example, Wender (2000, p 3) refers to 'fidgety Phil' within a German nursery rhyme (composed 1863), which describes a hyperactive child. However, it wasn't until 1902 that health care professionals first described ADHD in children (Mayes and Rafalovich 2007). Medical knowledge of ADHD has changed over time alongside definitions and knowledge of other psychiatric disorders and their associated guidelines; for example, recently, the disorder has been introduced for adults (American Psychiatric Association 2000).

Although ADHD is introduced as a prevalent disorder and it is extensively studied, it remains a highly controversial topic for discussion (Wolraich 1999, Skounti et al. 2007). Different authors present different perspectives in relation to ADHD. For example, in psychiatric investigations, authors have focused on the development of relevant diagnostic criteria and treatment methods (Wender 1995, Wender et al. 2001). In contrast, medical sociologists consider related social factors, such as the role of pharmaceutical industries in the introduction of ADHD as a disorder (Conrad 1975, Conrad 2006, Conrad and Potter 2000). Similarly, recent expansion of this concept to adults has provoked different reactions in researchers. Wender (1995) refers to the difficulties and limitations of obtaining data from children, and therefore referred to ADHD in adults as an opportunity for obtaining more knowledge of ADHD. Conrad and Potter (2000) were also interested in the emergence of ADHD in adults; however, they viewed it as an example of diagnostic categories' expansion in the process of medicalisation.

The medical model of ADHD implies that it is a valid disorder, caused mainly by genetic-biological factors; therefore, it is possible to correctly diagnose and successfully manage it. However, uncertainties relating to issues such as its recent introduction and the way it is diagnosed and treated, facilitate controversies (Singh 2008, Sarrami-Foroushani 2008). Consequently, some lay people, and even some health care professionals, do not accept the medical model of ADHD (Timimi and Taylor 2004, Baughman and Hovey 2006, Sarrami-Foroushani 2008). A consideration of the various debates currently surrounding ADHD provides the basis for further investigation into this field of mental health.

I will now outline my own personal experience in relation to ADHD-related knowledge. It is notable that although my experience has been related to various positions and understandings of a particular disorder, the topics that I discuss in this article could be applied to aspects of other disorders as well.

My personal Journey

In the following sections I will chronologically present my personal journey within which I explain my experiences observing from different roles in relation to ADHD-related knowledge. This will range from the time when I was a medical student through to being involved in clinical and academic activities. ADHD related knowledge and being a student

The first time that I learnt about ADHD was when I studied medicine in Iran (1992 - 2000). At the time, ADHD was taught as a childhood disorder. My colleagues and I could see the characteristics of childhood ADHD in some adults. However, as it was mentioned that the disorder was limited to children, our suspicions remained passing thoughts. We held passive roles in relation to the presented knowledge and viewed our educational materials as 'windows to the reality out there'. We did not perceive ourselves to be educated enough to access this 'reality', so we did not pursue our ideas on this matter.

ADHD-related knowledge and being a medical researcher

In the final years of my medical education ADHD was introduced for adults as well. The suggested characteristics of an ADHD patient sounded very similar to those people I had known and had suspected of having ADHD. The assumptions that I had held in the previous stage now appeared to be valid. I felt I had found an explanation and a sense of hope for some people that I knew. I became interested in the topic and contacted one of the leading authors in the field of adult ADHD, Professor Paul H. Wender. He introduced me to his book¹ and, for the first time in Iran, I published my Farsi translation of it. I also undertook my medical doctoral dissertation on normalizing a diagnostic tool, which was introduced in the book². During the next couple of years, I performed two review studies on adult ADHD, both of which were published in the formal journal of Iran's Ministry of Health. In both reviews, ADHD had emerged as an important topic that merits further studies. On these occasions, I accepted the available ADHD-related knowledge and held an active role in the dissemination of that knowledge. In fact, ADHD-related knowledge played an important role in my academic activities and became a professional privilege for me; I had more knowledge of ADHD in comparison to my colleagues and the medical model of ADHD fitted well with my social and academic position and provided new opportunities for me.

¹Wender, PH (1995) Attention deficit hyperactivity disorder in adults. New York: Oxford

²The title of my MD thesis is 'Normalizing and evaluating the validity and reliability of the Wender Utah Rating Scale to diagnose ADHD in adults in Isfahan, 1999-2000'

ADHD related knowledge and being a clinician

When I was among the first doctors who were 'aware' of adult ADHD in Iran, I faced disagreement from my clinician colleagues. At the time, according to the regulations of Iran's Ministry of Health, only Consultants could prescribe ADHD-related drugs. Therefore, as a General Practitioner, I had to refer my clients to Psychiatrists. However, in most cases they did not agree with my diagnosis of ADHD and suggested other disorders such as bipolar disorder. I could not find a way to convince my colleagues who were in higher hierarchical positions with more authority. No matter how much 'evidence' I could present, they saw the situation differently. I could not find an easy solution, as in psychiatry there is no objective measure for testing accuracy of a particular opinion. I justified the situation as being the result of 'unawareness' of others and I thought that as the medical model of ADHD was a new area for these experts (in which they felt less equipped and experienced) they preferred utilising different sorts of knowledge.

ADHD-related knowledge and my clients

In addition to the articles that I compiled for Iranian academic journals, I also published articles in public magazines. In these publications I described the characteristics of adults with ADHD and also suggested that treatment for the disorder could change the lives of those affected. Many people who read the articles contacted me and some made personal visits. These persons often believed that they had the disorder and were excited for the anticipated change that may occur in their lives as a result of diagnosis. This observation is confirmed by Conrad and Potter (2000) and Conrad and Leiter (2004) who suggested that the media could increase the knowledge of lay people and not only facilitate an acceptance of medical definitions, but could also lead to requests for the diagnosis and treatment of psychiatric disorders. However, unfortunately, my clients did not, after referral, receive drug therapy due to the aforementioned regulations and the diagnostic approach of my colleague psychiatrists. In addition, as my clients encountered disagreement among health care professionals, they were often discouraged from the account of adult ADHD as an explaining narrative for their condition. Seemingly, variation in perception and approach of clinicians had a profound effect on clients.

Producers of ADHD-related knowledge

Whilst I was involved with the topic of ADHD and focussed my work on it, I regularly expanded my knowledge through different books and articles. I needed that knowledge because of the different roles that I held that of a researcher and a doctor, I had to update my understanding and information;

and, as a relative and a General Practitioner, I wanted to know how to provide support and help for others. In addition, as I faced difficulties because of 'unawareness' of others, I found it necessary to translate a book to increase public and colleague awareness. Therefore, I needed to select the 'best' books that are available on the topic. To do this, I decided to evaluate the books by the degree of knowledge and expertise of their authors. As a result of this, I found that there are different sources for such knowledge and information. In some cases, the knowledge was obtained via formal education and research. For example, on the back cover of Prof. Wender's (1995) book:

Paul H. Wender has been studying, researching, and writing about adults with this disorder for more than twenty-five years, making him the ideal candidate to sort out the current controversy surrounding this often undiagnosed ailment ... Paul H. Wender is distinguished Professor of psychiatry and director of psychiatric research at the university of Utah school of Medicine.

Therefore, the background knowledge informing the book was legitimated by its author being a university professor with a longstanding academic record on the topic. Similarly, other authors were introduced on the back cover of their books as 'Chief of the Adult ADHD Clinic at the University of Massachusetts Medical Centre' (Murphy and LeVert 1995); or 'Assistant Professor of Psychiatry at Harvard Medical School and is in private practice' (Hallowell and Ratey 1994). Again, the sources of knowledge were academic degrees and clinical experiences.

However, there was also another base for the knowledge: on the back cover of Kelly and Ramundo's (2006) book, it was explained that 'both authors have ADD³' and the book is introduced as, 'the first of its kind written for adults with ADD by adults with ADD' (Kelly and Ramundo 2006). In this case, the authors had a claim to knowledge without being formally educated in psychiatry. They had not studied ADHD in universities; rather, their main source of knowledge was their life experiences and observations of their own experiences.

In addition to writing informative materials, these Expert Patients (EPs) also had more active roles in health care and took part in medical treatment of other patients. Kelly and Ramundo, the EPs whom I introduced above, were also 'ADD life coach', as introduced on the back cover of their book (Kelly and Ramundo 2006). However, as health care is a protected realm, people are not allowed to involve themselves in treatment unless they have formal degrees and associated professional certificates. Personal

³Attention Deficit Disorder (another name for ADHD)

experiences are not valued in the same manner as technical expertise, and the appointment of clinicians is not supposed to be based on personal experiences (Gabe et al. 2005, p 93). Therefore, I found that these EPs were involved in a different form of health care termed 'life coaching' and they justified the necessity of their role by pointing to the deficiency in knowledge of other professionals:

ADD is often subtle. Generally it takes personal experience, either with your own ADD or that of close family members, to get it. Most of the professionals who work with ADDult⁴ clients were drawn to the field because they have "in the trenches" knowledge of the disorder. We became ADD coaches because we were so passionate about helping others traverse the same territory we have travelled with very little guidance.

(Kelly and Ramundo 2006, p 2)

The EPs who had performed coaching enjoyed having the privilege of deeper knowledge and better understanding of the condition and adopted the position of professional. They were involved in some medical/health organisations in which coaching had been accepted.

However, it was notable that, although the knowledge that is owned by EPs is largely based on the medical model of ADHD, it holds its unique features. For example, Kelly and Ramundo (2006) discuss concepts that are not seen in the formal version of the medical model, such as mental hygiene or application of meditation. These tips were not based on research, but instead rooted in narratives of EPs. This could potentially present competition in the process of knowledge production.

In addition to the EP phenomenon, I also came across the phenomenon of Patient Experts (PE). This refers to experts who were qualified in related fields such as psychiatry, but also openly declared to be patients as well. In these cases, PEs stated their dual roles publicly as additional support for validity and accuracy of their knowledge. For example, Conrad (2007) uses as examples Dr. Hallowell and Dr. Ratey, who published a best-selling book on adult ADHD (Hallowell and Ratey 1994). Nevertheless, although they were both psychiatrists, they had few records on ADHD research at the time, so they supported their claim to knowledge by conveying that they also have the disorder.

Whilst EPs rely on their experience of disorder as their main source of knowledge, for PEs, revealing the disorder seemed to be an option that they

⁴Adults with ADD

could take, or not. Consequently, it is theoretically possible that some PEs, who obtain knowledge through their personal experiences in addition to their professional training, choose to conceal their disorder because their practice is already legitimated by their professional degrees.

In both cases of EPs or PEs, the disorder was a motivational factor for approaching the topic. However, I have found that people who were motivated by experiencing a disorder in themselves or their close relatives did not all approach it alike. Dr. Malacrida is a sociologist and the discovery of ADHD in her daughter motivated her to investigate the disorder sociologically (Malacrida 2002). Conversely, some authors, such as Baughman and Hovey (2006), have rejected a medical approach to the disorder as they do not accept the concept. I would not, therefore, expect them to claim to have the disorder, even if they found similarities to it in themselves.

Utilising mental health knowledge derived from experiencing a disorder could lead to role confusions, as patients have different rights and obligations to doctors (Gabe et al. 2005). Some EPs' roles become closer to that of a professional's, therefore, conflicting roles, expectations and obligations made it difficult for them to adopt both positions at once. Consequently, to manage the conflicting roles, I observed that EPs might underplay their position as a patient of another professional, by confirming that they have the disorder but avoiding referring to their treatment. Such an example of this is shown in the following excerpt from Kelly and Ramundo (2006), where diagnosis is referred to passively with emphasis then given to their active understanding and the effect of this:

We were newly diagnosed and fired up with the awareness of the impact of ADD on our lives. It was a profound experience ... Something like a religious conversion, as a matter of fact. Complete with the intense zeal displayed by missionaries. We saw the light. ADD was the root of all our life problems

(Kelly and Ramundo 2006, p 1).

Such a position is understandable, as overt reliance on the help of other professionals might jeopardise their own professional status. Similarly, PEs may face a similar challenge in balancing being open about their disorder and referring to it in a way that does not challenge their professional status. For example, Dr. Hallowell speaks about his own role in discovering the condition in himself (Hallowell and Ratey 1994):

As the lectures progressed, I devoured everything I could read on the topic. Not only did I realize that I had ADD, but

I recognized the syndrome in the behaviour of several members of my family as well, which made sense since it is genetically influenced. (p. ix).

ADHD-related knowledge and sociology

When I started the research for my Ph.D. in Sociology, at the University of Nottingham within the UK, I was interested in the sociological exploration of ADHD. I found that ADHD has been sociologically investigated through medicalisation theory, which explores increases in the boundaries of the medical profession (Scott and Marshall 2005). Here, the production of knowledge and its application were not taken for granted and they were viewed as social activities that should be investigated. All the activities that I was involved within, including introducing the concept of ADHD and attempting to solve problems by this framework, were discussed in medicalisation theory:

Medicalisation consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to treat it

(Conrad 1992, p211).

Medicalisation theory attributes different values to medical knowledge. According to Conrad and Schneider (1992, p. 8) medicine is among the 'institutions of social control' similar to the legal system and religion. This suggests that defining ADHD as a disorder could change the way people look at this phenomenon; labelling the phenomenon as a disorder implies that it is a problem, whereas by contrast, some authors believe ADHD is a gift (Hartman 2003). Illich (2003, p 291) refers to problems of medicalisation and classifies the criticisms of medicalisation into categories of direct and indirect iatrogenesis (i.e. problems caused by input from health care professionals (Reber et al. 2009)) and structural problems. In the case of ADHD, direct iatrogenesis could refer to the side effects of medication. An example of indirect iatrogenesis is confirming social settings, such as educational environments; people with anti-medical views suggest that ADHD is not a biological entity and the source of the problem is located in social settings such as educational systems (Baughman and Hovey 2006). Therefore, according to them, educational system are problematic and should be modified; however, medicalisation of people with ADHD defines the situation as an individual problem of situated within those people, alleviating the need for modification of social settings. Reducing people's autonomy by putting them under the control of clinicians could be an example of structural

problems caused by the medicalisation of ADHD. In the same way, Goldstein (1979) states that sociologists criticise medicalisation for two reasons:

First because it omits interpersonal and social factors, especially those based upon social differences, conflicts, and power differentials; and second because it places individuals under the control of the physicians who may employ incarceration, drugs, electro-shock, and other "treatments"... (p. 382).

For Goldstein, medicalisation locates the problem within the patients themselves, rather than in social settings. However, medicalisation theory has positive aspects of the process as well (Gabe et al., 2005). For example, Goldstein (1979) considered some useful practical consequences for the medicalisation of deviant behaviours as mental illnesses, such as:

The implication of diminished responsibility, the control of the situation through diagnosis and treatment by medical as opposed to civil or other authorities, and the directing of attention towards the possibility of organic and/or intrapsychic origins of the problem (p. 382).

The above indicates that sociologists address various different consequences of the medical model of ADHD, and these are in contrast to those considered by medical authors. In the next section I introduce a different type of variation between academics in relation to specific theories of ADHD.

Different sets of ADHD-related knowledge

In the previous sections I have explained how people might hold different views towards ADHD, with such views employing the term 'ADHD' albeit with varying approaches and implications. However, it is possible that the same phenomenon under investigation can also become categorised under a different label altogether, and fall into a different body of knowledge. I came across such a possibility, whilst undertaking my literature review in the first year of my PhD. At that time, I came across a book⁵, which described addictive disorders such as workaholism, alcoholism and sex addiction. In the book, a number of people were introduced that had a biological predisposition to addictions, and who may move from one addiction to another. I read the explanations and diagnostic guidelines that were introduced in the book for such patients and found that the descriptions had considerable overlaps with the one for ADHD. It is feasible that one of the people used in these examples

⁵Coombs, Robert Holman (editor), 2004 ,Handbook of Addictive Disorders, a practical guide to diagnosis and treatment. New Jersey, John Wiley & Sons.

could be diagnosed with ADHD or behavioural addictions, not as two co-existing problems, but as two different explanations for the same condition. The observations that I have described above could have important theoretical and practical implications and I will discuss these implications in the following sections: variation of knowledge, medicalisation theory and expert patients.

Variation in knowledge

In relaying my personal journey in relation to different forms of knowledge (and potential implications) I have intended to stimulate a more critical approach in relation to the existence of variation in knowledge. Such variation could have important implications and it is necessary to investigate its existence in the perception and approach of clinicians. It would be interesting to see whether, similar to my observations, clinicians might have different views on the same case and if they do, what the underlying reasons might be. It is necessary to go more in-depth, and explore more fundamental factors rather than 'unawareness'. Variation in people's understanding is addressed by the sociology of knowledge, which discusses the relationship between people's position, their understandings and knowledge. This is relevant to my observations of some patients who were disappointed by clinicians and, as a result of that frustration, attempted to become involved in the production of knowledge. In these instances, their knowledge is not something recorded in academic books, nor is there only one version of ADHD-related knowledge that people construct for themselves. Seemingly, different people have various understandings, experiences and roles, as I encountered with the differing opinions regarding ADHD-related knowledge, where each advocates their own approach. These actors publish materials, receive grant money and even perform legal actions (Charatan 2000), which may impact upon mental health knowledge.

I will now turn to a discussion of how medicalisation theory could provide a theoretical framework for many aspects of the production and application of medical knowledge.

Medicalisation theory

Medicalisation theory provides a helpful explanation for many aspects of the process of knowledge production and application in which I have been involved. Conrad (2007) refers to the role of patients in the production and establishment of knowledge through various examples, including high profile people talking about their ADHD in magazines, bringing public attention to the diagnosis in adults and the helpfulness of diagnosis and treatment. Conrad

(2007) also gives an example of a patient who established a foundation to distribute information on adult ADHD, using such examples to indicate the way different agents contribute to the expansion of mental health knowledge. He particularly explores the role of 'self-diagnosis' in increasing the rate of diagnosis and treatment of the condition, which is compatible with my own observations.

Medicalisation according to Conrad and Schneider (1992) has five stages (p 266): At first, it is necessary to define the behaviour as deviant, and then to announce a new medical discovery claiming a medical source for the deviance. Subsequently, interest groups from medical or non-medical institutions will advocate the claim, after which the definition should be legally secured and finally the medical definition will be used in medical institutions. According to that framework, I have been involved in the medicalisation process when I was an advocator for the condition, but I faced difficulties in application of the knowledge as it was not legally and institutionally secured.

Moreover, Conrad (1992, p220) suggests that the medicalisation process occurs to varying degrees and, consequently, different phenomena (e.g., ADHD) could be minimally, partly or fully medicalised. He suggests that there might be 'competing definitions', (p220) which could affect the degree of medicalisation. The competition between conceptual frameworks could include medical and non-medical agencies (Conrad 1992) or it could be within the medical realm. These ideas help explain why ADHD was not fully medicalised in Iran, as there were competing definitions, such as other medical labels, that were attributed to my patients.

Current literature on the process of medicalisation explains many aspects of my observations; however, it is also possible to expand upon the current concept. For example, it is interesting to investigate the way that EPs contribute to the process of medicalisation similar to other professionals. The medicalisation, which I refer to, is not necessarily a negative or positive attribution of medicine per se. Rather, I aim to draw attention to the role of EPs in the introduction and application of the medical meaning of the phenomena, with any consequence that it might have. The role of patients in providing a competing definition for mental disorders is not fully explored yet. Therefore, although my observations point towards patients playing a part in the application of medical knowledge, patients might have a more active part in the production of knowledge than currently assumed. Consequently, implication for change in the role of patients is an area for future exploration, as I will discuss in the next section.

Expert patients

In the medical model of ADHD, it is implicitly assumed that health care professionals produce knowledge via research and then apply it to 'passive' patients. However, as discussed, different people play a role in relation to the production and application of knowledge.

There are different reasons for investigating the role of patients in relation to mental health knowledge production. Firstly, that knowledge could be shaped and utilised differently compared with how it has previously been used when generated by health care professionals. The content of mental health knowledge could vary depending on the people who produce it (Brown 1995). Secondly, although the 'formal' clinical mental health knowledge might be produced via non-qualitative studies, narratives of patients (i.e. qualitative data) could have also a crucial role within the application of medical/psychiatric knowledge. Greenhalgh and Hurwitz (1999) explained the importance of patients' narratives:

Narratives of illness provide a framework for approaching a patient's problems holistically, and may uncover diagnostic and therapeutic options ... (p 48)

However, patients are not the exclusive providers of narratives for medicine and psychiatry; Charon (2001) introduced, 'narrative medicine' as based on four different situations:

The effective practice of medicine requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others. Medicine practiced with narrative competence, called narrative medicine ... close reading of literature and reflective writing allows narrative medicine to examine and illuminate 4 of medicine's central narratives situations: physician and patient, physician and self, physician and colleagues, and physician and society. (p 1897)

As I have explained, patients could have active roles in health care and their involvement within the construction of mental health knowledge is not limited to providing narratives to assist doctors. It has been known for a long time that patients with chronic conditions 'might know more than their doctors about their condition' (Donaldson 2003, p 1279). Therefore, despite the traditional idea of patients as passive consumers of health care, Lorig (2002, p 814) puts forward the idea of 'expert patients' (p. 814) who could have an active role (contrasting the traditional view). The UK Department of Health has supported the idea of the 'expert patient' (Department of Health 2001).

Tattersall (2002) addresses the idea:

Many patients are expert in managing their disease, and this could be used to encourage others to become 'key decision makers in the treatment process'. Furthermore, these expert patients could 'contribute their skills and insights for the further improvement of services' ... there should be 'a cultural change ... so that user-led self management can be fully valued and understood by healthcare professionals' (p 227).

Therefore, it is now acknowledged that patients are not passive receivers of knowledge from professionals and can legitimately acquire knowledge via their experience of disorders. These patients are not trained in the same way as health care professionals, and they obtain their knowledge via unplanned experience of living with disorders. EPs and PEs are relevant to a variety of topics in medical sociology such as medicalisation, stigma, the sick role, practitioner-client relationships, lay knowledge and professionalism. It would be useful to consider such topics in relation to EPs and PEs, and to explore theoretical and practical implications. For example, the EP phenomena might have potential for empowering patients and reducing the stigma of disorders; however, this might not necessarily be the case if EPs adopt the role of professionals, whilst avoiding the sick role, as I explained earlier. The implications of EPs and PEs, and their role in knowledge production and application is complex and is an area for further investigation.

Conclusion

The knowledge that patients gain through observing their own experiences may receive greater validity in future. Whilst personal experience is an integral part in knowledge production which is valued in many fields including sociology (Dingwall 1997), unintentional ethnographies of patients still need to be further acknowledged. People, who are unintentionally affected by 'disorders', could produce valuable and important knowledge. Whilst researchers might attempt participant observation in order to penetrate the subjective world of people and view things from their perspectives (Scott and Marshall 2005), patients often learn from their own situation through fulltime observations. Patients can be argued to have direct access to their own feelings and mental state, which are not visible to others. These unintentional ethnographies could provide valuable data not only in terms of accessing the data itself, but in allowing patients to play a role in the production of knowledge itself. My personal journey is a good example of how mental health related knowledge can be understood, applied and produced in

various ways and that critical realism and medicalisation facilitate explaining this. Among various forms of mental health-related knowledge, one particularly interesting form is the knowledge that is based on patients' expertise. This particular form could be usefully explored in future.

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