Disengaging from the Stigma of Mental Illness: A perspective gained from a participatory action research project with the Cork / Kerry Aware Support Group Facilitators

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Abstract

This research explores the perspective of the Cork/Kerry Aware support group facilitators on the stigma of mental illness. Using an interpretive methodology and semi-structured interviews the research found that facilitators view stigma as being created by many interrelated social factors which they themselves have the opportunity to overcome. The findings show that the Cork/Kerry Aware facilitators have tremendous capacity and resolve to deal with the adverse circumstances created by the stigma of mental illness. The author of the research identifies mindfulness-based cognitive therapy as a means to explain how facilitators respond to stigma. Rather than ignoring or reacting to circumstances, mindfulness gives us the opportunity to respond to circumstances in a more informed and objective manner.

Keywords: stigma; mental illness; mindfulness; participatory action research.

Introduction

According to research conducted by the Health Service Executive in 2007 over one third of people in Ireland are afraid to speak to a person with a diagnosis of mental

illness (Chambers, 2007: vii). In the same study 44% of the population thought that one in fifty people or less would 'have a mental health problem at some point in their lives' (Chambers, 2007: 21). This perception by the public is inaccurate as empirical evidence finds that one in four people are likely to experience mental illness at some point in their lives (Stavert, 2007: 182). Aware support groups, for people with a diagnosis of mental illness, meet in many towns and cities across the country to offer support in dealing with the diagnosis of mental illness and also how to respond to the stigma of mental illness (Aware, 2006). It is not just the diagnosis people have to deal with but also the stigma that goes with the diagnosis (Vauth et al., 2007). This research project asks the facilitators of the Aware support groups for their views on the stigma of mental illness.

Background and Rationale

Aware is a voluntary organisation set up in 1985 at St Patrick's Hospital, Dublin. Patients, relatives and mental health professionals participated in the formation of support groups to complement the existing services in the hospital (Aware, 2006). Since then the support groups have spread throughout the country. Aware also disseminates information on mental illness, runs a schools programme, publishes a magazine and funds research into mental illness. The researcher has been a facilitator in the Cork support group for the past five years, has been a user of the mental health services for the past seven years and has conducted the research in collaboration with his fellow facilitators in the Cork / Kerry region. In the research document the term facilitators refers to both the researcher and his fellow facilitators while the term participants refers to all those facilitators including the researcher who participated in the research project. The author of the research document is the researcher. Facilitators of the Aware support groups are either people who have been diagnosed with a mental illness or a close relative of a person who has a diagnosis of a mental illness. Of the facilitators who participated in this research over eighty percent are those who have been diagnosed with a mental illness. Facilitators work for Aware on a voluntary basis and receive regular facilitation training by Aware.

It can be said that the research undertaken is collaborative in nature and shares the qualities of participatory action research. Even though there are many different definitions of participatory action research, they all share a common goal of the researcher releasing large amounts of control and decision making over to the researched (Koch & Kralik, 2006; Brydon-Miller, 2001; Rempfer, 2001). It is therefore fitting that the researcher did not choose the main topic of research but rather let the facilitators identify the area of most concern to them which was stigma. Nevertheless the researcher did control large amounts of the project as he chaired all the meetings, conducted three interviews and is the author of the research document. As the researcher is a user of the mental health services and a facilitator at Aware the project has a user-led approach (Bracken & Thomas, 2005; Rempfer, 2001). This means that it is the people receiving the services supplied by statutory and voluntary organisations who are conducting the research.

The term stigma of mental illness has been chosen for the research. Erving Goffman published his book entitled 'Stigma' in 1963 and since then it has become the main reference point for academics on the topic (Hinshaw, 2007). Drawing on both psychology and sociology, Goffman (1990) describes the world for those with a stigma. A stigma according to Goffman (1990) is an attribute that is 'deeply discrediting' (Goffman, 1990: 13). It is clear from the literature that having a diagnosis of mental illness is 'deeply discrediting'. Lam (2008) describes social surveys from the 1950s to present day which show that mental illness is the worst stigmatising condition above homelessness, epilepsy, homosexuality, HIV and AIDS. Lam (2008) sees stigma created as a result of differences which are deemed unacceptable to society. 'People with a diagnosis of mental illness experience exclusion across every area of social and economic life, from holidays to work, driving cars to raising children.' (Sayce, 2000: 60). When Sayce (2000) reviewed the research she found that people with a diagnosis of mental illness are regarded as tainted and being less favourable to meet than a person with a criminal history. Mental illness is an attribute that places a person in a significant disadvantage to those without a diagnosis of mental illness.

The findings of the research then show how the facilitators deal with this stigma. By using the term stigma of mental illness this research is focusing on people who have been diagnosed by the psychiatric services as being mentally ill. The term stigma of mental illness refers to the stigma of having a diagnosis of a mental illness. This is why the phrase 'a person with a diagnosis of mental illness' will be used repeatedly in this research. Here is the aim of the research project.

Research Aim

The aim of this research project is to find the perspective of Cork / Kerry Aware facilitators on the stigma of mental illness and to show how this perspective assists facilitators in responding to stigma.

Methods and Methodology

Introduction

In order to obtain a thorough understanding of the relevant themes related to the research, the researcher conducted a literature review. This review summarised three themes: the stigma of mental illness, history of mental illness in Ireland and participatory action research. The theoretical perspective of the research which is called interpretivism places the emphasis on how the subjective experience of individuals and groups create the world that we live in (Whimster, 2001). The theoretical perspective supports and informs the methods and methodology. This research employs a qualitative methodology in order to find the perspective of the Aware facilitators on the issue of the stigma of mental illness. This means that the research is interested in descriptive material that has a depth of understanding of what it is like for facilitators to live with the stigma of mental illness (Denzin, 1998). Semi-structured interviews were chosen by the facilitators as the method to obtain this information.

Methodology

The methodology chosen for the research is qualitative. The research is looking to reinforce the theoretical perspective of interpretivism by generating data with the facilitators which is rich in views and opinions (Sarantakos, 1993). A broader

understanding of stigma is being sought, from the perspective of the facilitators that can add to Aware's existing activities. A qualitative approach will compliment the factual information being provided by Aware as it gives a subjective view from service users. A qualitative methodology is appropriate to the interpretive theoretical perspective chosen above (Bryman, 1988). The results sought are not in the form of measurement or quantity but are rather to give a description from experience of what it is like to live with the stigma of mental illness (Denzin, 1998). This gives the reader an understanding of the perspective of the facilitators which clearly fits into the theoretical perspective of interpretivism. The perspective of the facilitators in terms of meanings, understanding and values are not about collecting precise numerical data but becoming familiar with the experience of those living with the stigma of mental illness (Sarantakos, 1993).

Not only are the views of the participants of the research of paramount importance but the participants are given the authority to make decisions within the research process. This is the approach of participatory action research where the subjects of the research, in this case the facilitators, are in control of the research process (Koch & Kralik, 2006; Brydon-Miller, 2001; Rempfer, 2001). Not only did the facilitators become involved in the interviews but they also decided on the main theme of the research, chose a semi-structured interview as the research method and formulated the questions for the interview. The distance then between the researcher and the researched was broken down leaving the facilitators less vulnerable than when a person with a higher perceived status interviews them. There is then a shift in the reliance of the expertise in the medical professional towards those who experiencing the mental condition (Rempfer, 2001). In keeping with this view it is worth noting that the current national policy document for the mental health services in Ireland entitled 'A Vision for Change' aims give more voice, autonomy and decision making to the service user (Expert Group on Mental Health Policy, 2006).

Methods

All facilitators were invited to all meetings and interviews. The total number of facilitators varied between twelve and fifteen. The average attendance for the three

meetings was seven facilitators. The three meetings lasted between one and a half and two hours each. The first two meetings were slotted into official Aware regional meeting time while the third meeting was held in a quiet hotel bar where ideas flowed more easily and suited an open discussion on the research methods. One more meeting is planned to present the findings. Facilitators were interviewed between March and July of 2009. Seven facilitators in total were interviewed. As the researcher is a facilitator he is included as a subject of the research. His subjectivity is exposed in the interview and during the three meetings. This gives the project a reflexive element which further emphasises the interpretive methodology (Sarantakos, 1993). The researcher is not trying to distance himself from the research but rather aims to expose his subjectivity by involving himself in the process. It is worth noting that the transcript from the researcher's interview and comments he made during the meetings show him to have a different perspective compared to the overall findings of the research. However, he is now sympathetic to the overall findings. The research project was supported by our Aware regional officer. Email was used to enable increased collaboration between the five most active participants. They were invited to use email as a means of sharing and building the views they had on the research questions. Email proved useful for sending summaries of meetings, receiving submissions for research questions and organising meetings.

The research method selected by the group of facilitators was a semi-structured interview. A semi-structured interview is appropriate to the interpretive perspective and qualitative methodology as it generated data which was be full of meaning and understanding of how the facilitators relate to the stigma of mental illness (Sarantakos, 1993). During the third meeting seven facilitators were given a choice of a wide variety of research methods. The researcher placed a card with a research method written on it in the middle of a table. The facilitators sat around a table and discussed each method. They agreed on a mixture of closed and open ended questions that would be selected by the facilitators themselves. Following the third meeting the researcher received twelve questions from three facilitators. Two of these submissions were received informally over lunch while the third was received via email. The researcher himself added a further four questions in order to complete the interview

schedule. The researcher also placed the questions in an appropriate order according to Denzin (1998) so that the more personal questions were not asked until the end of the interview. The researcher felt it more sensitive to ask questions relating to direct experiences of stigma towards the end of the interview.

Findings

Overview

This section presents, analyses, interprets the data collected and gives a recommendation from the researcher. We will see a selection of references and quotations from the meetings and interviews held with the facilitators. These references and quotations were selected from the transcripts from interviews and meetings in order to show how the facilitators understood the concept of stigma and how they respond to stigma in their own lives. The transcript was read and reread a number of times until the relevant references and quotations were identified. The researcher then placed all the quotes and references under the two themes. The first theme is called 'What is stigma?' while the second theme is called 'How do facilitators respond to stigma?' What became quickly apparent to the researcher is that these themes merged together to show a high level of understanding from the facilitators on how to deal with the stigma of mental illness. It seems that the experiential knowledge from having no choice but to deal with this stigma of mental illness has forced them to increase their cognitive ability to deal with adverse circumstances (Lam, 2008). From the point of cognitive therapy, gestalt therapy and transactional analysis facilitators express a positive and helpful response to the stigma of mental illness (Stewart and Joines, 1987; Woldt and Toman, 2005; Lam, 2008). Facilitators' perspective can also be explained in sociological terms by showing how the facilitators refuse to internalise the dominant belief system in society. Their response to stigma can be compared to Paulo Freire's theory of conscientization where they liberate themselves from the stigma created by society (Freire, 1985). All these psychological and sociological theories are then summed up in the conclusion through an aspect of mindfulness based cognitive therapy called 'Allowing / Letting Be' (Segal, Williams and Teasdale, 2002).

First Theme: What is Stigma?

During the focus group, the views on the topic of stigma emerged. Straight away we were brought to a common understanding of what is meant by enacted stigma. According to Lam (2008) enacted stigma focuses on the outside forces that stigmatise people. One group of three facilitators after working to try and decide on a definition for stigma said:

> We were trying to pin this down and I am not sure is this officially correct or not but it would be a commonly held attitude which would be based on ignorance or misinformation and it can be discrimination and it can be built up culturally or socially over a long period of time. It can become an accepted idea in the public consciousness going back a long time in history and it can be perpetuated by the media literature, cultural things, television programmes, books anything.

The use of the words 'ignorance or misinformation' referred to in this definition and the very calm way this was read by the facilitator gives a sense of empathy and understanding towards those who stigmatise. The literature review showed the forces of enacted stigma not only in the present day but also from the past which have resulted in a negative attitude towards those with a diagnosis of a mental illness. These are deep seated societal attitudes that could be considered a societal problem rather than something personal against an individual with a diagnosis of mental illness. Stigma is seen here as a concept that people can separate themselves from. In transactional analysis the stigma is described as a script which you can only become free of when you become autonomous with your actions (Stewart and Joines, 1987). Autonomy is achieved here by the facilitator as she is not blaming specific individuals or groups but rather attributing stigma to a wide range of societal circumstances. These points are implied within the quote above which shows an objective non-judgemental understanding of the issue. This quote may not convince the reader at first but when facilitators were asked to give their opinion on what stigma is during the interviews this view was emphasised. In the second interview a facilitator described stigma as a 'fear of the unknown' on the part of people who do not wish to

speak about depression. Bruton (1997) identifies that the behaviour associated with enacted stigma is caused by a fear of people with a diagnosis of mental illness. In the third interview the facilitator is also acknowledging the feelings of the stigmatiser:

> A preconceived notion about depression, mental illness or elation and think everyone is going to be the same and also they are a bit frightened of it. They build it up in their minds as being a lot worse than what it is.

In the fourth interview the lack of understanding and societal views is again expressed which show a degree of empathy towards those who stigmatise:

> An attitude people have to a condition in a human being which they probably don't understand which can be exacerbated by social conditioning and other environmental factors.

During the seventh interview when the researcher was being interviewed by a fellow facilitator he also showed calmness and clarity of understanding towards those who stigmatise:

> I would imagine that some people are use to talking about mental health or depression so the people that aren't are more uncomfortable with it.

More of the facilitators show clearly how they wish to not blame those who stigmatise but be accountable for their own actions. This relates to the second type of stigma Lam (2008) refers to known as perceived stigma. In interview one the facilitator called stigma a 'pejorative label' and went onto say: 'I don't think it is as simple as saying other people stigmatise me. I don't think anyone can stigmatise me unless I stigmatise myself.' During the second meeting a representative facilitator from a group of three facilitators said: 'So it is something you're almost feeling yourself or, you know, whether in fact it is a reality or not you live with the stigma yourself.' When interviewed by a facilitator the researcher stated: 'Stigma happens when a person thinks they are inferior to other people due to having an attribute such as a diagnosis of a mental illness.' According to Lam (2008) if a person thinks themselves

as being inferior, the same as what social environment tells them, they will feel like an inferior person. On the other hand if they see that society has a misunderstanding of the issue then they will not be able to blame themselves for the stigma of mental illness.

There were a couple of occasions when the facilitators did explicitly describe the negative attitude of those who stigmatise. There was a sense of frustration and intolerance in these statements which made them different from the quotes already described and commented upon. They are also describing stigma as something personal rather than societal. During the fourth interview the facilitator described stigma as: 'A person that puts someone else into a bracket and sticks by that attitude.' In the fifth interview on the same date stigma was described as: 'Looking down at someone as if they are someway inferior to you or not as with it.' Both these descriptions and all the other descriptions of stigma by the facilitators fit with the definitions of stigma given in the literature review by Goffman (1990), Sayce (2000) and Lam (2008). All the definitions given by these authors state that a person with a stigma is viewed differently and negatively. This shows that the facilitators have accurate knowledge on the topic they are speaking about.

Second Theme: How do facilitators respond to stigma?

As well as understanding the stigma of mental illness, the facilitators also described how they respond in a way that will not reduce their self worth. Internalising stigma as explained by Lam (2008) reduces self worth as the person with the diagnosis of mental illness believes they are an inferior person. After the series of interviews the researcher started to understand why the stigma of mental illness does not have to determine your own self-worth. There are two aspects to achieving this. The first is to think in societal terms instead of personal terms while the second is to look at society in an objective manner. Freire (1985) describes this as conscientization where societal attitudes have no more power over your own self worth. This happens when a person frees themselves from being completely engaged with society and takes a step back to view objectively what is happening. In the fifth interview the facilitator said:

It comes down to understanding where the stigma originates in other words if you understand the mechanisms of stigma, how it works, how it is created, how it is maintained and how it can be eradicated. It's like if you have an understanding of human nature you will find that understanding allows you to distance yourself from something and consequently it doesn't have an effect on you. You can objectivise the whole thing you can literally stand aside and look at yourself and the other person who is doing this and look at it at a distance almost as if you were reading it out of a book.

This is an inspiring perspective but not one promoted by an industrialised society like Ireland. Functionalism has been the main framework within industrial societies for defining what is normal and what is abnormal (Turner, 2001). As a diagnosis of mental illness is defined as being an abnormality, it is vital that a person with a diagnosis of mental illness does not internalise that belief of being abnormal. Not internalising the diagnosis is not being in denial of the diagnosis but rather being able to have the self worth to be able to choose how to deal with it. In interview three it was said: 'To me I don't have to go around telling people about depression when I don't have to.' In fourth interview on the same night another facilitator described how she was as important as anyone else in society saying: 'You are not away with the fairies and that you have something to add to society.' The facilitators have a high level of understanding of stigma and a determination to see stigma in a way that limits its effects on them. A facilitator in Aware is not your typical person with a diagnosis of mental illness. They would be well educated on mental health issues from attending training days provided by Aware. They would have been clients of many different mental health professionals. They would have listened attentively to how other people deal with stigma within the support groups. Facilitators are educated on the diagnosis of mental illness while society in general is not educated.

Conclusion

Stigma is a topic which applies to many academic disciplines. In particular interest here is how it applies to both psychology and sociology. Transactional analysis, cognitive therapy, functionalism and conscientization were all referred to when

explaining how facilitators understand and respond to stigma. Understanding how society has created stigma allows the facilitators to depersonalise the issue of stigma. Understanding how society has created stigma is of concern to sociology while depersonalising the issue of stigma is of concern to psychology. By being understanding of society rather than in conflict with society the facilitators are finding a way of dealing with the stigma of mental illness. This approach could be summarised by using mindfulness based cognitive therapy. Session five of an eight week programme devised by Segal, Williams and Teasdale (2002) for treating clinical depression shows the importance of letting be the circumstances we find ourselves in. This is a different relationship to stigma than one would expect where we neither internalise the stigma nor react to the stigma. This does not mean ignoring our circumstances but gives us time to respond to stigma in an informed way. Segal, Williams and Teasdale (2002: 241) suggest creating a breathing space in order to deal with adverse circumstances as opposed to reacting or ignoring the circumstances. The breathing space works by using the breath to be mindfully aware of what is happening and thereby prevents us loosing ourselves in judgements. Circumstances such as the stigma of mental illness is then neither accepted nor rejected but just simply understood as a misunderstanding in society as pointed out by the facilitators.

Through the medium of the support groups, facilitators are listening and participating in the search for ways to respond to the stigma of mental illness. When a person is engaged with the stigma of mental illness the stigma controls them however when they disengage from the stigma of mental illness they become free of the stigma. It is when the person disengages that they become self-determined and choose how to respond to the stigma. This is what Thompson (2006) calls elegant challenging where the response to stigma is neither withdrawn nor aggressive. The approach developed in the research of being mindful and objective could be refined into a skill by the facilitators to be used within the Aware support groups. There could be a number of training days to develop this skill. This skill could be used as method for reframing dialogues within the support groups in order to assist support group members to disengage gently from strong emotions. The breathing space technique developed by Segal, Williams and Teasdale (2002: 241) would be one method for achieving this.

Developing the skill would also benefit the facilitator directly. The skill could be developed by the facilitators themselves under the supervision of the support group co-ordinator.

It is important to note that these conclusions come directly from the analysis of the findings by the researcher. At the time of publication the final meeting of the facilitators has not been completed. In the spirit of participatory action research in this final meeting we plan to look at the list of quotes and references, come to our own conclusions and decide on what to do with the results.

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