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Abstract

The diagnosis of mental ill health continues to attract substantial stigma in western society with evidence suggesting public attitudes to be increasingly negative. Recent reviews have highlighted the extensive research on the nature of this stigma but the limited work on the development of strategies to challenge the stigma. The aim of this case study was to explore the potential of researchers and mental health service users (MHSU) working collaboratively to identify the main problems the service users experience in their everyday lives and to produce a video challenging the negative image of mental ill health. Discussions were held with volunteers involved in a mental health media action group; all volunteers had been or were currently MHSU. These discussions identified a variety of problems including difficulties in everyday social interaction and negative portrayal of mental ill health in the media. A short video was developed with volunteers summarising the issues they had raised: this was subsequently shown to a wider audience. The MHSUs reported considerable personal benefits of participation in the project. The paper discusses these findings and the process of producing the video.

Keywords: Public attitudes; Video; Collaborative research

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Using participatory video to challenge the stigma of mental illness: a case study

Introduction

Despite advances in the treatment of different forms of mental ill health it continues to attract substantial stigmatisation. Some researchers have reported the effect of this stigmatisation as more debilitating and difficult to overcome than the illness itself (Corrigan, 1998; Corrigan & Penn, 1999; Wahl, 1999). Whilst most people would seem to be aware that mental health service users (MHSUs) face a wide variety of social challenges (Link, Cullen, Struening, Shrout & Dohrenwend, 1989) there is limited evidence that this awareness has led to an improvement in public attitudes to mental ill health. Instead it has been reported that such attitudes have become increasingly negative in recent years (Phelan, Link, Stueve, & Pescosolido, 2000).

Stigmatisation of mental ill health is due to a variety of factors including limited public knowledge of the illness and negative media portrayals (Link, 1987). Media portrayal of mental ill health is typified by sensationalism. Dangerousness, violence, criminality and unpredictability are often common themes in newspaper stories about mental ill health. Rose (1998) found that in news items that featured MHSUs 65% concerned acts of violence against others. This is despite substantial evidence to the contrary (e.g., Swanson, Holzer, Ganju, and Jono, 1990). A recent content analysis of prime-time television programmes found that characters with mental health problems were ten times more likely to be violent criminals than other characters (Diefenbach, & West, 2007). Stories of recovery or of MHSUs' positive accomplishments are rare (Wahl, 2003). Whilst research has suggested that the ratio of negative to positive stories has decreased, negative stories continue to outnumber the positive (Nairn, Coverdale and Claasen, 2001).

A recent review by Gee, Khalaf and McGarty (2007) of interventions designed to reduce stigma about mental illness identified three broad categories: education, contact and protest. Educational interventions are designed to counter false beliefs about mental illness through the provision of more accurate information. Evaluation of different educational approaches found variable amounts of success leading Gee et al to concluded that 'education alone may not be enough' (p. 100).

Contact interventions seek to increase contact between MHSUs and others. Research has found that an individual's familiarity with mental ill health increases their understanding and in turn reduces the stigma attached to and desire for social distance from MHSUs (Link & Cullen, 1983; Angermeyer, Matschinger & Corrigan, 2004). The effectiveness of familiarity in reducing prejudice and stereotypes can be maintained not only through direct contact with those with a mental illness but also through stereotype disconfirming media

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presentations (Reinke, Corrigan, Leonhard, Lundin & Kubiak, 2004). Evaluation of several interventions again found varying degrees of success dependent upon the target audience and the type of mental illness (Gee, Khalaf & McGarty, 2007).

Protest interventions involve engaging MHSUs and others in campaigns to challenge public and media stereotypes. The involvement of current and former MHSUs in campaigns has a long history. Reports from the 1620s on the "Petition of Poor Distracted Folk of Bedlam" (Wallcraft & Bryant, 2003) illustrate such involvement. More recently, user involvement has strengthened through networks such as the European Network of Users and Survivors of Psychiatry (ENUSP) which campaigns for the restoration of full civil rights for people who have been detained or treated by the psychiatric system (Rose, 2008). However, evaluation of such protest approaches (e.g. Corrigan and Penn, 1999) suggests that although they can be effective in improving conditions for MHSUs and improving media reportage there is less evidence of the impact on public attitudes. There is also limited information on the processes involved in developing such protests.

Interest in the use of videos and films in various forms of health advocacy has increased with the development of low cost video cameras (Gregory, Caldwell, Avri & Harding, 2005). Recent research by Stewart, Riecker, Scott, Tanaka and Riecken (2008) has confirmed the positive impact of such video making on marginalised youth who participated in the production of a video about health and wellness. There is a need to explore further the processes involved in the production of such videos. Such research requires detailed case studies (Yin, 2009) that can identify the various processes involved. The purpose of this paper is to develop a detailed account of the production of an advocacy video exploring the social experience of being identified as MHSUs, through collaboration between university-based researchers and a group of MHSUs. It aimed to explore the particular challenges that MHSUs report experiencing in everyday life, to describe the processes involved in the collaborative production of a film about those issues and to investigate the impact of this film both on MHSU volunteers and on the wider public.

Preparation

Methods

We worked with a local voluntary organisation that involves individuals with experience of being MHSUs. The organisation's aim is to challenge the stigma of mental illness by working with the media and the general public to promote more positive and realistic images of MHSUs. Through this organisation we recruited four volunteers (two males and two females) to the project. Each volunteer was invited to take part in a study in

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which they would be co-researchers in the development of a short film about mental ill-health. They were reminded of counselling services available in the event that such services should be required. After the first discussion group one female volunteer opted out of continuing with the project but allowed her group discussion data to be kept on record and used in the film. The names used in this paper (Adam, Sam, Ashleigh and Anne) are pseudonyms and collectively they are termed volunteers.

The study ran over an eight week period, with weekly meetings at the group offices, in the form of group discussions lasting between 60 and 90 minutes; initially these were researcher led but soon became volunteer led. These sessions were tape-recorded and subsequently transcribed. The first meeting was concerned with explaining the core idea of the project, receiving feedback from volunteers and beginning discussion on problems they had faced in everyday interaction as a result of being a MHSU. Subsequent meetings centred on recapping the previous session, identifying issues to focus on and planning a film with the aim of clarifying misconceptions held by members of the public about mental illness that the volunteers had experienced. The aim of the film, clarifying public misconceptions about mental illness, was jointly agreed between the MHSUs and researchers after emerging as a recurrent issue.

After each session a basic thematic analysis (Braun & Clarke, 2006) of the discussion transcripts was conducted by the researchers. The following week a graphic representation of the analysis was presented to the volunteers allowing them the opportunity to clarify any points they felt had been misunderstood. Providing the volunteers with a copy of the transcripts and these interim analyses ensured that different views were represented and that the project remained collaborative. Over the series of group discussions three recurrent points of discussion were identified by the group as their core priorities regarding changing public perceptions of mental health service users.

The project was approved by the School of Psychology Research Ethics Committee.

Results

Label: The volunteers frequently referred to the hidden nature of mental illness. The lack of obvious physical features meant that it could be concealed. The volunteers felt that once they were identified as having a mental illness, people's reaction to them changed. Adam described it as having 'a label […] put on you'. The frequent use of the term label indicated an acceptance of the labelling theories of mental health developed by Scheff (1966) which Foster (2007) has noted are widely used in the MHSU community.

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Comparisons were drawn between the response of the public to the label 'cancer' or 'disability'. The volunteers felt that these labels attracted sympathy whilst mental ill health was treated with disdain. Adam felt that the term mental illness was generally perceived as a shameful, 'dirty word'. Sam attributed this perception to the 'lack of understanding … they don't seem to understand what it really is you are suffering from'. Adam, however, felt that despite enhanced knowledge people remained apprehensive about mental illness: 'society knows about mental health but they don't choose to accept people who are unwell'. Despite public education, the volunteers perceived a public anxiety about mental illness. It was something that had to be controlled (cf. Foster, 2007).

In particular, the volunteers discussed the process of internalising the stigma attached to mental illness label. Ashleigh put it this way:

'I think there's another kettle when we talk about stigma from society, but also self stigma . . . there is such a strong stigma in society we then apply this to ourselves'. The volunteers found it difficult to challenge the stigma attached to mental illness. It seemed all pervasive. The acceptance and internalisation of the stigma associated with mental illness resulted in self-doubt among the volunteers. As Anne said, 'I can't take myself seriously'. The label was described by Adam as 'a double whammy' that added to the immediate distress of the illness. More specifically, he continued, 'if you start fighting the label which is put on you then you've got another battle on your hands'. Thus it was evident that the volunteers were not just aware of the label but also considered strategies of resisting it. However, it was generally felt that this battle was futile in that once the label had been applied there was little the individual could do to remove it and its connotations. Some of the volunteers felt the pervasiveness of the label meant it was difficult to resist the social pressures to conform to it. As Ashleigh said: 'the label gives you an identity and it's very easy to always feel that you have to live up to it'.

Consequences: The social consequences reported included frequent exclusion from social interaction, the difficulty maintaining friendships, problems at work and accessing housing as a result of being identified as a MHSU. Once other people became aware of what Adam described as their 'hidden illness' they were treated according to what Ashleigh termed a 'preconceived idea'. According to Ashleigh this prevented the public from viewing mental ill health as 'serious illness' but more as a character aberration. They were perceived as a threat and excluded from various activities. As Sam said: 'you do lose friends [leading to] social isolation'. It also had implications for accessing services and housing. For example, Sam recalled the difficulty finding a place to live: 'he said he wouldn't let me the place'.

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Media: The volunteers agreed that the primary factor in sustaining the stigma of mental illness was the media. Sam said: 'the way the media misinterprets everything, it's sort of violence, you know, almost criminal behaviour'. Adam described the media as being 'like a magnet - they pick up on the negativity' in order to create a newsworthy article. Anne felt that this search for a sensational story was also fed by 'the ignorance as well'. The effect of the media was pervasive in that, as Ashleigh said, it is 'around us all the time, you can't get away from it'. Ashleigh felt that the popular media was important since for many people, 'their only source of education unless, they know someone whose been affected, is the media'. For Adam, the media was being 'irresponsible' and all the volunteers agreed with Ashleigh that there was a need to challenge public misperceptions by 'bringing it [mental illness] into everyday conversation'.

Film production and evaluation

Methods

It was agreed to produce a short film based on the topics that had been generated during discussion. The film consisted of three sections, viz. newspapers, the general public and the television, with each volunteer taking the role of 'section manager' for one section, i.e. taking the lead on producing one section. The section managers discussed ideas for the development and production of their section with the rest of the group such that although each section would have one individual's stamp they would fit together to produce a more integrated film. During discussions two volunteers indicated that they would prefer others to act out the main script with them only featuring in one or two clips or providing a voiceover. Eight students were recruited to act out various roles under the guidance provided by volunteers.

Filming took place around the group offices and in the local town centre where shoppers were interviewed. Throughout filming the volunteers directed the clips, reshooting when they determined it was necessary. The role of camera operator was fulfilled by one of the investigators guided by a volunteer. When all individual clips and interviews had been filmed each section manager decided what should be used in the film and gave final instructions for editing. This was particularly important for the manager of the 'Public' section where the aim was to create a montage of different views. Time was set aside to meet and review the clips to determine which were the most suitable to convey the messages.

Upon completion of the first draft of the film a screening was held for the volunteers. This provided the opportunity for them to view each other's work and to determine what parts of the film needed to be further

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edited. The crux of this session was dedicated to determining whether or not the film achieved its central aim of challenging the misconceptions surrounding mental ill health highlighted in earlier discussions.

During the discussion about the media section, one of the volunteers posed the question 'whose job is it to educate people about mental illness?' The answer to this question helped focus the aim of the film. It was they themselves who were educating the public about common misconceptions concerning people with mental illness and the title 'The Unheard Voice' was agreed. After discussion it was decided to organize the film into three rounds, as in a boxing match, which was symbolic of their fight against negative representations of mental illness in newspapers, television and among the general public.

The first round addressed newspaper coverage of a mental health hospital that was to open in the local area. The aim was to highlight the number of people who experience poor mental health and how newspapers through their inaccurate reporting were spreading unnecessary fear. This round had the theme 'media as a false educator' and was based on the media extracts that presented a particularly erroneous image of mental illness. The volunteer in charge of this section used a collage of images with an introduction incorporating the music from the movie 'Psycho' and voiceovers. Students who were recruited to represent the voice of MHSUs were placed in front of a backdrop of newspaper headlines with words such as 'violence' highlighted.

The second round concerning the general public was designed to address the misconceptions held by the general public. This was placed in the middle of the more factual rounds to demonstrate how people's perceptions of mental ill health were shaped by the media. One volunteer interviewed people in the local town to create a montage of responses. Interview prompts included providing residents with a list of negative descriptions of someone with mental ill health and asking which words should be removed. The list was read out on the film so the audience could consider their own response. Filming of this section was challenging due the unwillingness of members of the general public to participate. The main issue was concerned with finding members of the public who were willing to answer the questions and be filmed, a problem overcome by allowing a full day for interviewing.

The final round concerned television. This round was designed to parody television soap operas, news and comedy shows. Satire was used to highlight the often ludicrous depictions of mental illness. Each negative media comment was followed by a retort by one of the volunteers. For example, details of the number of prime time television characters with a mental illness carrying out a violent act were followed by details of the actual crime figures. This section ended with the question 'Where does the joke end?'

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The film was shown to an audience of 15 adults recruited from a local business. Before and after viewing, they were asked to complete a short questionnaire to assess their perceptions of mental illness. The questionnaire was based on a standardised measure of attitudes to mental illness (Crisp, Gelder, Rix, Meltzer & Rowlands, 2000) and included 26 statements grouped into six categories. Audience members were informed that the film had been written, directed and produced by MHSUs and that on occasion students played some parts but were guided by the volunteers. After showing the film, the questionnaire was again administered to the audience members with the questions reordered and a section requesting feedback on the film added.

Results

Feedback from the volunteers on completion of the film was positive but restrained. For example Sam stated 'I believe the project has had a positive impact on me personally'. They particularly felt that the active nature of the project contributed to increased confidence. As Sam stated:

> 'I find that one of the great problems of mental illness is that when you find yourself well, there are a great many barriers there to preclude you from leading a so-called "normal life". Being included in such a project, therefore, can help rebuild some confidence or motivation'.

There was reflection on how the film was an important means of challenging common misconceptions about metal illness. Sam continued:

> 'If we can finally undo some of the stigma which surrounds mental ill health then I think it would make a lot of people's lives better, including my own. I remember when I first fell ill in my early twenties and at that time I was very unaware of how people would react to my disease. It is only later that I realise how stigma can almost become the problem itself. The social alienation which results from mental ill health and which I find a great problem I think is largely down to the stigma which surrounds it'.

Overall, the consensus was that the project had had a positive impact on all of the volunteers.

Comparison of the questionnaire responses before and after viewing the video showed some evidence of impact. Although the differences did not reach significance there was at least one statement within all six categories where there was evidence of a more positive attitude after the film.

Some members of the audience also added positive comments about the content of the film and felt that it had achieved the aim of challenging misconceptions about mental illness. For example, the film was described by one viewer as 'thought provoking and informative … the script was well written and to the point'. Another

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described how the film had confirmed their own perception of the media portrayal of mental illness as being distorted and that it 'manipulates local bias for easy headlines'.

Discussion

The collaborative nature of the project in which the volunteers not only discussed their experiences of mental illness but also collaborated in the production of an advocacy video had an energising effect on all involved. The volunteers were keen to move from describing their experiences to challenging the pervasive stigma associated with mental illness. It was quickly apparent that although some were hesitant initially they were keen to become involved in this process of challenge. The reluctance of some to participate centred on the issue of 'coming out'. They did not want other people to know they had mental health problems thus illustrating their desire to 'pass' with their friends and employers. Those who did agree to participate were very enthusiastic once they had made the decision.

In her commentary on race as stigma Howarth (2006) has suggested that by coming together in dialogue, debate and critique, members of a stigmatised group can become aware of themselves as agents not objects. She emphasised that alone the individual cannot develop the confidence and emotional strength to challenge stigma but can do so in combination with others. This study demonstrates this process in action. Through the process of film-making the volunteers demonstrated their collective resistance to the dominant negative view of mental ill health and grew in confidence about their own abilities.

Further, the volunteers felt that people should be educated, not just about mental ill health but mental health in general. The short-term positive (although non-significant) impact of viewing the video by a general audience demonstrates the broader value of this form of video action. Taken together with the general enthusiasm of the volunteers to participate in the project, future campaigns against mental health stigma that involve users can contribute to challenging the negative media portrayal of MHSUs.

The volunteers referred to the perceived negative social representation (Moscovici, 2000) of mental ill health held by the general public and promoted by images in the popular media. Foster (2007) discussed the various strategies that MHSUs use to manage these negative social representations in everyday life. In this study the volunteers referred to the pressure to accept and internalise them. There was a tension between rejecting the dominant social representation and internalising it. The volunteers felt that rejecting the perceived negative social representation was difficult to do alone but through participating in a collaborative video project it became more clearly an option.

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The concerns identified by the volunteers were similar to those identified in previous research (e.g., Link, Cullen, Frank, & Wozniak, 1987; Foster, 2007). However, whereas previous research stopped after characterising the nature of the dominant negative social representations of mental illness, this study proceeded to involve a group of MHSUs to challenge the dominant negative view. By symbolically demonstrating the role of the media it was able to draw attention to the contradictions in the representations of mental illness and encourage reflection on these issues among members of the public. The involvement of MHSUs in all aspects of the video production served to accentuate these contradictions among viewers and further illustrated the potential value of collaborative advocacy video production in combating the stigma of mental illness.

Finally, the use of the video making added to our understanding of the use of the arts in collaborative research projects (Murray & Gray, 2008). Through combining arts production with research it is possible to increase our understanding of the phenomenon as well as contribute to enhancing the quality of life of those involved.

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