Research papers

Understanding of mental health and mental illness by Gujarati young people and their parents

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ABSTRACT

This paper presents an account of a project that explored Gujarati Hindu young people's and their parents' understanding of the terms 'mental health' and 'mental illness' through the use of semi-structured interviews. The sample of 15 parents and 15 young people was selected from an inner city community with a large minority ethnic population in which Gujaratis formed the largest social group in that setting. Thematic analysis identified three key themes: understanding the terms mental health and mental illness; causes of mental health problems; and socio-cultural factors and mental health. These themes showed that neither the young people nor their parents had a consistent understanding of the terms 'mental health' or 'mental illness'. There was also confusion between these terms and that of 'learning disability'. A range of views was presented so it is difficult to conclude that the Gujarati Hindus conceptualise mental health or mental illness in any specific way. It is highly possible that the findings of this study would have been similar for other ethnic groups with similar socio-economic backgrounds. The findings indicate that before patients and communities can be involved in child and adolescent service planning and development, there is considerable work that needs to be undertaken to establish a shared understanding of key terms such as 'mental health' and 'mental illness'.

Keywords: Gujarati, mental health, mental illness, young people

Introduction

Inside Outside (National Institute of Mental Health in England (NIHME), 2003: 31) argued that there is compelling evidence that there is not a single area of mental health in the UK in which black and ethnic minority ethnic groups fare as well as, or better than, the majority white community. The report advocated mandatory training in cultural competencies for all professional staff working in mental health to try and address current disparities. Ministers also accepted a recommendation of the inquiry into the death of David 'Rocky' Bennett (Department of Health, 2003) that training the 40 000 strong existing mental health workforce in cultural competence should become a priority. The NIHME and the Sainsbury Centre for Mental Health (SCMH) Joint Workforce Support Unit (2004) published the ten essential shared capabilities: a framework

for the whole of the mental health workforce. One of these capabilities is respecting diversity. This is defined as 'working in partnership with service users, carers, families and colleagues to provide care and interventions that not only make a positive difference but also do so in ways that respect and value diversity including age, race, culture, disability, gender, spirituality and sexuality'. An appendix highlighted that while all these issues are important, it was acknowledged that there is discrimination in many services so that issues of race and culture require particular attention.

In a review of the relationship between mental health services and African and Caribbean communities, the Sainsbury Centre for Mental Health (2002) considered the usage of terms and their potential impact on the training provided. This report explicitly considered the effect of the confusion that exists in healthcare arenas and of group-based approaches to dealing with cultural diversity.

Whilst training in diversity is clearly an important issue, so too is understanding the views that diverse communities hold about mental health and mental illness. However, none of the reports considered the potentially different usage of the terms 'mental health' and 'mental illness'. It is possible that these views shape ideas about appropriate services for such communities. It is also important that the views of children and young people are taken on board. Children may share the same ethnicity as their parents but have a very different sense of identity if they have experienced growing up in another country. The terms 'mental health' and 'mental illness' are commonly used in health arenas although, as with 'race', 'ethnicity' and 'culture', there is not always clarity as to how they are being used. The Health Advisory Service (1995) provided a definition for mental health in children and adolescents, although how young people and parents understand this is unclear.

It is also widely agreed that conceptualisation and expression of mental distress can vary across cultures (see for example: Goldberg and Hodes, 1992; Bhugra and Cochrane, 1997). Malek (2004) stated that 'mental health' is often confused with the term 'mental illness', although the two refer to quite different states. The evidence suggests that young people already exhibit negative perceptions about 'mental health' and those experiencing such problems (Bailey, 1999), but little is known about how they conceptualise mental health or illness, especially among young people from minority backgrounds. It is also unclear as to whether there are differences between young people's understanding and that of their parents. This project explored Gujarati young people's and their parents' understanding of the terms 'mental health' and 'mental illness' and their views on services for children and young people with mental health problems. This paper focuses on their understanding of these terms.

Method

Participants

The research sample was recruited from an inner city area with a population of 400 000. A substantial proportion of that population are non-white (40%). A neighbourhood centre was identified in the predominantly Gujarati-populated area. Parents of Gujarati origins in India or East Africa and who had children aged 11–16 years were invited to participate by a researcher and a community staff member working together. Fifteen parents and 15 young people agreed to participate in the study. Previous contact with mental health services or experience of mental health problems was neither an inclusion nor an exclusion criterion. Young people with a learning disability that prevented their participation in usual class activities were excluded from the study. Gujarati young people and their parents were selected because this is the largest minority population in the city of Leicester. It is also a well-established and stable community.

Procedure and measure

A semi-structured interview was developed and piloted, based on previous research by the first author on users' perspectives (Dogra, 2000; Taylor and Dogra, 2002) and diversity (Dogra and Karnik, 2003). For this study, interviews were conducted separately with parents and children. The interview initially explored the parent's or child's perceptions of mental health and mental illness. (These perceptions are not reported in this paper, because of the depth of data.) Following this they were asked about their perceptions of services they thought might be appropriate to help manage mental health problems. Interview guides included the participants' views on sources of support within the family, the community, generic and specialist services; experience, knowledge and perceptions of child mental health services, including professional roles, the perceived attitudes of professionals in relation to ethnicity, preferred professional attributes; and suggestions, including mental health awareness, for the improvement of services, both in general and in relation to this specific group. All participants spoke English, therefore no interpreters were required.

Thematic analysis of qualitative data

Interviews were transcribed verbatim. Field notes were also written up after each session, recording reflections on the interviews and initial analytical comments. Each paragraph of the transcript was considered in

close detail, and concepts relevant to participants' perceptions of mental health services were developed and labelled (Pidgeon and Henwood, 1996). Robson (2002) described four different approaches to qualitative analysis, of which the following two were applied in this analysis.

Quasi-statistical approaches

This approach uses word or phrase frequencies and intercorrelations as key methods of determining the relative importance of terms and concepts and is typified by content analysis.

Template approaches

Key codes are determined either on an *a priori* basis, for example, those derived from theory or research questions, or from an initial reading of the data. These codes serve as a template for data analysis and this may change as analysis continues. Text segments, which are empirical evidence for template categories, are identified.

The process of analysis was further informed by the steps outlined by Miles and Huberman (1994):

- read the complete scripts and identify key terms, words, themes and issues
- review field notes and identify further themes
- collate responses to each question and from these identify types of response to issues that the question was based on
- look at the information leading to the development of the schedule and again identify themes
- link the themes with the theory.

The sample size was determined ultimately by practical considerations, but themes had begun to recur in the interviews so that a high level of consistency was achieved. The data analysis was conducted independently by each of the four authors in order to validate the assignment of data to the codes and themes, and improve the reliability of the analysis.

Findings

Data analysis revealed three key themes:

- understanding the terms mental health and mental illness
- causes of mental health problems
- socio-cultural factors and mental health.

Each of these is presented and discussed below.

Understanding the terms mental health and mental illness

This study found that a majority of the participants did not have a clear understanding of the terms 'mental health' and 'mental illness', and they could not distinguish between the two concepts. They were not sure about the meaning of each concept and they viewed the two concepts similarly and as interchangeable. Of participants who felt able to define mental health, the majority defined it as a brain deficiency or dysfunction and abnormal behaviour. For example:

> 'It's just mental health ... people have not got all their brains there I would say. They can't function properly for various reasons. That's what it's always meant to me. But that doesn't mean that they're going to be like that for the rest of their lives. It might just be that they're slow learners or ... The mental health is just an illness that they've not got a choice in the matter ... Mental illness and mental health. Health is actually when you think it's in the mind and an illness is brought up by something.' (Female: age 42 years)

This statement indicates that there may also be confusion between mental health problems and learning disabilities. Nearly half of the young people interviewed thought that mental health was an inherited disease. Those respondents who attempted to distinguish between mental health and mental illnesses thought that mental illness was a disability in the brain, which required hospitalisation, while mental health was caused by stress and anxiety. For example:

> 'It [mental illness] means that he can't do as many things as us, like some people disabled. It [mental health] just means that they are ill and they can't do some of the things we can do. Like for example, we've got a couple of people in our class who can't kick a football and instead of laughing at them, we try and encourage them and help them.' (Male: age 12 years)

Half of the interviewees stated that anyone could have mental health problems at any stage of their life, depending on the lifestyle of the individuals and their social environment, and mental health problems were less severe than illnesses.

> 'Yes, anyone can get mental health illnesses, but not without a reason. Mental health problems often occur among those who live in stressful conditions. The house situation and family support are the most important element in causing mental health problems. For example, if children watch their parents fighting all the time, they think this is norm and they are more likely to be involved in bullying and fighting. Sometime children get depressed because they think the unsettled home life is their fault and they are not fully supported by their parents and siblings. But if families sit and talk together, that minimises the possibilities of having mental problems among children.' (Female: age 43 years)

This suggests that mental health problems are preventable, but also minimises any biological explanation. The majority of respondents identified loneliness, behavioural problems and poor communication skills as the main characteristics displayed by people who are mentally ill.

> 'He acts funny like, he is strange. I see many people talking to themselves … It's like when we stand near him and he's talking to us we might think well, he's nuts but probably if you say a few words to him he might talk back, or at least have someone talking to him.' (Male: age 43 years)

In comparison, young people identified physical and mental disabilities, bullying and psychological problems as the main characteristics displayed by mentally ill people.

> 'They don't talk to people … people that are mental, yeah, have got like special needs and all that. Like we're capable of doing things but they're not capable of doing things by themselves. Sometimes like what they do in the classrooms is not really appropriate and some people might just start laughing at them … They don't know what they're doing … I think if they're behaving strangely I think they should be having lessons by themselves because people want to take the mick.' (Female: age 13 years)

Some young males focused on the role of drugs and self-harm. They thought that people with mental health problems are more likely to be involved in drugs which result in them harming themselves.

> 'Um, take drugs and then … they just do silly things … One person just stabs himself in our school with a pencil … the slightest thing he just hits himself in the head and cuts himself.' (Male: age 14 years)

These findings in this theme are consistent with those reported by Armstrong *et al* (1998).

Causes of mental health problems

Participants were asked about the causes of children's mental health problems. Some respondents were able to recognise the multifactorial nature of mental health problems and cited physical, economical, psychological, social and cultural factors. However, stress and anxiety were given as the main causes of mental health problems.

> 'Um. I think sometimes people are stressed and maybe get sick and sometimes even the weather makes … Maybe, sometimes, you know stress for the kids.' (Male: age 43 years)

Adult respondents focused on loneliness and isolation and economic difficulties. They felt that mental health problems were not readily talked about within the Gujarati community and that a culture of silence exacerbated isolation. Isolation was, in part, felt to be related to immigration and having left extended family and

social networks behind. The conflict between the culture of origin and the culture in which young people find themselves was recognised as a factor in perhaps causing child mental health problems, as were intergenerational difficulties.

> 'If they are born in India or Africa and then being in Britain, it is the three things mixed together. They get more confused because in school, outside, in the society we have to be British. And when they come to home and if you've got parents, grandparents and even great-grandparents who believe in all the family living together, so they might be getting mixed up … different cultures.' (Female: age 51 years)

Young people identified causes for mental illnesses as low self-esteem and school-related stresses, and pressure such as school homework, family problematic relationships and peer groups pressure.

> 'Because probably they do not have friends or are lonely so they become mentally sick … Yeah they are lonely because they got told off by someone or something and then that affects them … Because they're born like with mental illness or diseases or something. Stress and worries about things that young people can't do, for example the freedom to be out with friends at night, this causes them mental stress and sickness. Around us there are rich and poor people, sometimes young people from a poor background wanted to do things similar to those from the rich families; but, of course, they could not afford it. This situation increases young people's worries and they become very stressed and mentally ill.' (Male: age 15 years)

This suggests that family conflict may also be perceived as a potential factor in causing mental health problems. Many young people identified inherited diseases, injuries and brain problems as the main causes of mental illnesses.

> 'It's because sometimes their brain cells don't work or they just got hurt, like some people get injured if they have an accident and it can affect their brain … They can even be born like that – my friend told me that his aunty had an accident when she was pregnant and she fell flat on the floor and his cousin's mentally ill. He's kind of mad, if he does something wrong, even if someone tries to help him, he just starts getting angry.' (Male: age 12 years)

These findings illustrated a generational difference in the way in which respondents identified the causes of mental health problems. Adults focused on economic, cultural and family factors while young people identified bullying, school problems and loneliness. Similar ideas were identified by Li and Browne (2000) who studied 60 adult Asian Canadians who defined a mental health problem in terms of lacking of purpose in life, feeling lonely, difficulties understanding and dealing with a new environment, high anxiety levels, descriptions of mental health problems as somatic illnesses and perceptions of mental illness as serious and potentially untreatable.

Socio-cultural factors and mental health

The findings show that the majority of respondents were reluctant to discuss mental health issues outside the close circle of families and friends.

'In Asian culture when they [people] are mentally depressed they don't feel very free in going talk to people. In this country, if someone is English they will go and look for help and everything to make them better … .' (Female: age 51 years)

More than half of the interviewees said that they preferred to keep mental health problems to themselves, because they feared being labelled and stigmatised.

'Um, yes but then it's hushed up in the families isn't it? Because they might not want to acknowledge that there is a problem. People don't want to know these problems exist. They just want to brush it under the carpet. I see lots of women who are married and you know they're not happy but they can't talk to anybody. So it's a similar case with children. You know there are children there, but who do they go to?' (Female: age 42 years)

Some interviewees stated that they would not talk about mental health because they did not know what to say and were scared that they might hurt other people.

'Um. No, I don't discuss it because like if I don't know anything about it and I might say something that might hurt them, so I just keep it to myself whatever I think … I would come home and ask my mum why this is happening?' (Female: age 13 years)

Some adult respondents said that sometimes they discussed mental health with traditional healers and religious leaders to provide reassurance and advice. In comparison, young people said they sometimes talked to doctors hoping for a cure, and to teachers. Adults were more likely to discuss strange behaviour, violence and hyperactivity, depression, stress related to work and rearing children in a culture different from one they had grown up in. Young people were more likely to discuss family issues; for example the limited freedom they have compared to their peer group; peer relationships. Stigma featured strongly in association with mental health and disability.

'If you see a baby that's been born [with a learning disability], they'll sort of not involve it in everything, they'll tend to put it … aside … You know, they won't take them everywhere. Although I think now it's sort of changing, it is recognised that there is help out there … Like the young lad I was talking about, he goes to a day centre and they bring him out a bit now. Okay, it's not nice for him because everybody stares at them, but I always, if he's at a party, I always go and make the effort to talk to him because I think it's important.' (Female: age 42 years)

The majority of the interviewees were aware of the stigma attached to mental illness and learning disability, but tended to see others as stigmatising rather than acknowledging their own prejudices. Family shame, social exclusion and reduced marriageability were seen as potential results of mental health issues.

'I think they fear they'll be cut off from the community … Yeah. It's like, "Oh don't have anything to do with them because they've got this illness and if we have a child from that family, they'll end up having it. So let's just not get involved with that family". They don't want to bring anybody with mental health; they don't want to bring anybody with disabilities because they think it can be carried on. That's their understanding and that's how they think.' (Female: age 42)

Young people were less likely to mention stigma but did say that they would be reluctant to talk about mental health with others because they fear that they might gossip about them and/or boycott them.

Limitations

This was only a small-scale community sample, which explored concepts that are not necessarily easily understood by those for whom English is the primary language, and the difficulties may have been exacerbated especially with the adults. The sample consisted of English speakers and this may have biased the sample towards those who have been more established in the UK and perhaps more acculturated. There was potential bias in that the sample was self-selected and respondents suggested further potential participants. The sample was limited to Gujarati Hindus, and without further work it would be difficult to comment on whether these findings would be consistent across different groups.

Discussion

This study showed that neither young people nor their parents had a consistent understanding of the terms 'mental health' or 'mental illness'. There was also confusion that these were the same as learning disability. A range of views was presented so it is difficult to conclude that Gujarati Hindus conceptualise mental health or mental illness in any way that is specific to that particular group. It is highly possible that the findings of this study would have been similar for other ethnic groups with similar socio-economic backgrounds. As Sussman (1997) highlighted, all societies have struggled with the impact of mental illness, and rejection and avoidance of mentally disabled people

are common. This is the case even when there are different explanations for mental health problems. It is likely that Gujarati young people and their parents reflect wider community attitudes to mental illness that are, in general, negative (Wolff *et al*, 1996). As Jorm *et al* (1997) say, the beliefs that health practitioners hold about mental disorders differ greatly from those of the general public. There may be greater variation between professionals and the public than between subgroups of the general public. This was more recently confirmed by a Swiss study that found that the general public had little knowledge about mental disorders, particularly depression (Lauber *et al*, 2003).

While clarity about the terms was often lacking, the participants were able to express their views about what they thought should be provided by specialist services. These findings are not presented in detail here, but in summary parents and young people wanted accessible services that were visible in their community. They expected staff to respect them and listen to their concerns. The issue of ethnicity was not specifically identified.

Conclusion

The findings indicate that before patients and communities can be involved in child and adolescent service planning and development, there is considerable work that needs to be undertaken to establish a shared understanding between the public and professionals of the key terms 'mental health' and 'mental illness'.

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