Psychiatria Danubina, 2017; Vol. 29, Suppl. 3, pp 279-284 *Conference paper*

THE FEDERATION OF STUDENT ISLAMIC SOCIETIES PROGRAMME TO CHALLENGE MENTAL HEALTH STIGMA IN MUSLIM COMMUNITIES IN IRELAND: THE FOSIS DUBLIN STUDY

Ahmed Hankir[1,2,3], Hannah Pendegast[4], Frederick R. Carrick[2,5,6] & Rashid Zaman[2,7]

[1]Department of Psychiatry, Carrick Institute for Graduate Studies, Cape Canaveral, FL, USA
[2]Bedfordshire Centre for Mental Health Research in Association with Cambridge University, Cambridge, UK
[3]Leeds York Partnership Foundation Trust, Leeds, UK
[4]Leeds University School of Medicine, Leeds, UK
[5]Department of Neurology, Carrick Institute for Graduate Studies, Cape Canaveral, FL, USA
[6]Harvard Macy and MGH Institutes, Boston, MA, USA
[7]Department of Psychiatry, University of Cambridge, Cambridge, UK

SUMMARY

Background: *Mental health problems are common in Muslim communities however due to fear of exposure to stigmatization many people in this group continue to suffer in silence despite the availability of effective treatment. The Federation of Student Islamic Societies (FOSIS) organized the first ever Muslim mental health conference in Ireland to challenge the stigma attached to mental health problems in Muslims and to encourage care seeking in this group. As far as the authors are aware there are no intervention studies on mental health stigma in Muslim communities reported in the literature.*

Design: *We conducted a single arm, pre-post comparison study on Muslims who attended the FOSIS mental health conference in University College Dublin, Ireland. Validated stigma scales measuring knowledge (Mental Health Knowledge Schedule (MAKS)), attitudes (Community Attitudes towards the Mentally Ill (CAMI)) and behaviour (Reported and Intended Behaviour Scale (RIBS)) were administered on participants before exposure to the programme and immediately afterwards.*

Results: *18/150 (12%) of participants completed the pre-post RIBS scale and pre-post MAKS scale and 16/150 (10.5%) of participants completed the pre-post CAMI scale. There were statistically significant differences in the pre-RIBS score compared to the post-RIBS score (p=0.0262) and the pre-MAKS score compared to the post-MAKS score (p=0.0003) but not in the pre-CAMI score compared to the post-CAMI score (p=0.6214).*

Discussion: *To the best of our knowledge, the FOSIS Dublin Study is the first intervention study on mental health stigma in Muslim communities to be published. The results of our study provide provisional support that a 'bespoke' Muslim mental health conference comprised of talks and workshops by experts in mental health, scholars in Islam and a lecture delivered by a Muslim with first-hand experience of a mental health problem are associated with reductions in stigma. More robust research with a longitudinal study design, larger sample sizes and a control group are needed to determine if such events can cause a sustained reduction in mental health stigma in Muslim communities.*

Key words: *stigma – Muslims – Islamophobia - experts by experience - psychological problems*

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Background

Mental health problems are common and can affect anyone, regardless of race or religion (Baxter et al 2013). Indeed, 1 in 4 of us at some point in our lives will experience a mental illness (WHO "mhGAP: Mental Health Gap Action Programme: scaling up care for mental, neurological and substance use disorders", 2008; from http://www.who.int/mental_health/mhgap_final_english.pdf).

Anxiety - the most common of all mental disorders - currently affects approximately one in 13 people (7.3 percent) worldwide (Baxter et al 2014). According to the World Health Organization (WHO), 350 million people throughout the world suffer from depression (http://www.who.int/mediacentre/factsheets/fs369/en/). The Global Burden of Disease Study revealed that the rates of mental disorders are on the rise with depressive illness projected to be the leading cause of morbidity worldwide by 2020 (Ferrari et al. 2012).

There are 1.7 billion Muslims on the planet and Islam is the fasting growing religion in the world (Walpole et al 2013). Globally, Muslims are the second largest faith community. Although Islam has been reported to be a protective factor against some types of psychological problems (Hankir et al 2013, Hankir et al 2015), mental illness is endemic in the Muslim world, particularly in Middle Eastern and North African (MENA) nations such as Egypt and Lebanon (Eloul et al 2009). The rates of mental illness are also especially elevated in Palestine and Syrian people sporadically dispersed in refugee camps in the Levant due to exposure to conflict, displacement and other myriad factors (Al-Ghzawi et al 2014).

In Muslim minority countries, there is a higher prevalence of Common Mental Disorders (CMD) in some Muslim groups compared to the general population. Weich and colleagues conducted a cross-sectional survey of 4281 adults aged 16-74 years living in private households in England. The authors concluded that middle-aged Irish and Pakistani men, and older Indian

and Pakistani women, had significantly higher rates of CMD than their White counterparts (Weich et al 2004).

Determinants of psychological distress in Muslims

The social determinants of mental ill health such as unemployment and poverty apply to both Muslims and non-Muslims alike (Marmot 2005). Other factors such as the rise of radicalization (Sheridan 2006), the demonization of Muslims in the media (Shaver et al 2017) and the immigration crisis (Anderson et al 2014) contribute and collude to heightened levels of Islamophobia which, in and of itself, has been demonstrated to be associated with psychological distress in Muslims (Kunst et al 2013). Rubin and colleagues at King's College London conducted a cross-sectional survey of a representative sample of 1000 Londoners on the behavioural and psychological reactions to the suicide bombings in London on 7 July 2005. The investigators revealed that being Muslim was associated with a greater presence of substantial stress and speculated that the fear of backlash (in the form of Islamophobic attacks) was a factor that contributed to psychological distress in this group (Rubin et al 2005).

Psychological distress and mental health problems in Ireland

Health Research Board (HRB) is the lead agency supporting and funding health research in Ireland. The Health Research Board National Psychological Wellbeing and Distress Survey (HRB NPWDS) was the first national survey that measured the extent of psychological wellbeing and distress within the Irish population. The NPWDS was a telephone survey of a nationally representative random sample of 2,711 adults aged 18 years and over and living in private households (Tedstone et al 2007).

Most of the respondents in the NPWDS study reported 'good or very good' mental health in the past year, with 15% reporting 'less than good' mental health. A total of 66% of the respondents had a score of zero on the General Health Questionnaire version 12 (GHQ12) indicating elevated levels of wellbeing while current psychological distress was evident in a total of 12% of the sample (one in eight). Females were more likely to exhibit signs of distress on the GHQ12 as opposed to males, and the youngest and oldest age groups were least likely to exhibit distress. However, the NPWDS did not report on the religious background of respondents and therefore there was no data available on the levels of psychological distress in Muslims living in Ireland (Tedstone et al 2007).

There are approximately 63,000 Muslims living in the Republic of Ireland and, as far as the authors are aware, no studies have been conducted to date that measure the levels of psychological distress in this group.

Mental health stigma

Stigma is a Greek word that, in its origins, refers to a scar from a burn or cut to the skin of criminals, slaves or traitors. The mutilation was a sign of disgrace, indicating to all that these people should be avoided and shunned. More recently, renowned 20th century American sociologist Irving Goffman defined stigma as, "A deeply discrediting attribute that reduces the bearer from a whole and usual person to a tainted and discounted one… The individual [is thus] disqualified from full social acceptance." (Goffman 1963).

Stigma is an umbrella term that can be deconstructed into three main components: Problems of knowledge (ignorance), problems of attitude (prejudice) and problems of behaviour (discrimination) (Thornicroft et al 2007). Stigma is a barrier to accessing and using mental healthcare services, and many people with mental illness continue to suffer in silence despite the availability of effective treatment.

The three main strategies to challenge stigma are through protest, education and contact. Stigma expert Patrick Corrigan conducted recent research in the US revealing that the most effective way of reducing public stigma in adults was through social contact (Corrigan et al 2012). Corrigan argues that service-users are "experts by experience" and as such should operate at the vanguard of any campaign to reduce stigma. He adds that healthcare professionals with first-hand experience of mental illness, or "Wounded Healers" could play a powerful and special role in reducing stigma (Corrigan et al 2002).

Pioneered by Professor Patrick Corrigan and colleagues, the Honest, Open and Proud program (HOPp), formerly known as Coming Out Proud (COP), offers support to people with mental illness who must make the difficult decision between concealment and disclosure (http://comingoutproudprogram.org/). Research has revealed that COP is associated with immediate reductions in stigma stress-related variables (Rusch et al 2014).

Jung's archetype, 'The Wounded Healer'

In psychology, Carl Jung used the term, 'The Wounded Healer' as an archetypal dynamic to describe a phenomenon that may take place in the relationship between analyst and patient. Jung used the Wounded Healer archetype in relation to himself whereby, "A good half of every treatment that probes at all deeply consists in the doctor's examining himself…it is his own hurt that gives a measure of his power to heal..."

Jung drew from the epoch of the ancient Greek myths of Chiron, the wounded centaur, and his student Asclepius, who later became the mythological god of medicine and healing. The 'Wounded Healer' archetype, however, can be found across the world's traditions and belief systems, from shamanism, where it is believed that a healer must first be wounded before they can truly heal another, to messianic prophecies in the Old Testament, "By his wounds we are healed."

The Wounded Healer anti-stigma programme

'The Wounded Healer' (TWH) is a contact-based, anti-stigma programme conceived by AH under the supervision of his mentor RZ. TWH has been described as an innovative method of teaching that blends the performing arts with psychiatry. AH is a Royal College of Psychiatrists award-winning doctor with first-hand experience of an 'enduring' mental illness and by being honest, open and proud through the vehicle of TWH he shares his story of recovery. Themain aims of TWH are to engage, enthuse, enthral and to educate to debunk myths, challenge stigma and encourage care-seeking (Hankir et al. 2014).

Through the vehicle of TWH, AH provides many examples of accomplished people with mental illness, from famous celebrities and athletes to politicians and healthcare professionals, who are agents of positive change who make important contributions to society. AH raises awareness that psychiatric issues can even be advantageous since healthcare professionals, for example, report becoming more insightful, empathetic and driven because of their mental illness. Psychiatric issues are also known to be associated with creativity and many renowned artists attribute their brilliance to their psychopathology (Hankir et al 2013).

TWH protests inaccurate portrayals of people with psychopathology and inspires audiences to deconstruct and reformulate their perceptions by debunking myths and educating them with facts. TWH reveals that people with mental illness are peace-loving, law-abiding, responsible and caring human beings and that they can recover, succeed and achieve excellence in what they do. AH is ardently advocates for 'parity' and not 'pity' for people with mental illness (Hankir et al 2013).

Mental health stigma in the Muslim community

Research on mental health stigma in Muslim communities is sparse. Descriptive studies have revealed that there are elevated levels of mental health stigma in Muslim communities worldwide. Tabassum and colleagues conducted a study to investigate the attitudes of Pakistani families living in an urban area of the UK towards people mental health issues. None of the participants in the study reported that they would be willing to marry a person with mental illness, only half expressed a willingness to socialize with such a person, and less than a quarter reported that they would consider a close relationship with them (Tabassum et al 2000).

In a study conducted by Shibre and colleagues on Muslim participants from Somalia, seventy-five percent of respondents reported experiencing stigma due to a relative with mental illness and 36.5% reported that other community members would be unwilling to marry into their family because of the mental illness (36.5%) (Shibre et al 2001).

With respect to stigma and care seeking for mental health problems, a study conducted on Muslims residing in Australia revealed that almost all respondents indicated that stigma was the most significant barrier to accessing and using mental-health services (Youssef & Deane 2006).

Ciftci and colleagues conducted a review of the literature on mental health stigma in Muslim communities and could not find any existing anti-stigma intervention evaluations (Ciftci et al 2012).

The Federation of Student Islamic Societies Ireland mental health conference

The Federation of Student Islamic Societies (FOSIS) is a national umbrella organization aimed at supporting and representing Islamic societies at colleges and universities in the United Kingdom and Ireland. FOSIS was established in 1963 and is one of the oldest Muslim student organizations in the United Kingdom.

On the 25th March 2017 FOSIS Ireland held the first ever Muslim mental health conference in Ireland in University College Dublin (Figure 1). The FOSIS Ireland Remove the Label Mental Health Conference was a 1 day event comprised of lectures and workshops delivered by experts in mental health and Islam. The event also included the Wounded Healer performance, a contact-based program conceived and delivered by a Muslim doctor with first-hand experience of psychological distress.

Figure 1. Promotional material to recruit participants for the FOSIS Dublin Study

The Federation of Student Islamic Societies programme to challenge mental health stigma in Muslim Communities in Ireland: The FOSIS Dublin study

Our group at Cambridge conducted the first ever intervention study challenging mental health stigma in Muslim communities. This pilot project was a single arm, pre-post comparison study. Validated stigma scales on knowledge, attitudes and behavior were administered on participants before and immediately after exposure to the intervention.

Participants

Muslims who attended the FOSIS Ireland Remove the Label Mental Health Conference were recruited to participate (n=150). The participants completed the forms anonymously and no monetary compensation was offered. Students were in a state of equipoise and verbal informed consent was obtained. Ethical approval for the

study was obtained from the Carrick Institute for Graduate Studies, an Institutional Review Board registered in USA for educational, research and clinical trials. We recruited participants and publicised the event by using promotional material that was posted on social media and on the FOSIS and Islamic Societies' websites (see Figure 1).

Measures

Three measures of stigma and discrimination were used to measure mental health-related knowledge, attitudes and behaviour.

Mental Illness Knowledge Scale (MAKS)

MAKS has been designed to measure mental health-related knowledge among the general public and evaluate anti-stigma interventions (Evans-Lacko et al. 2010). It comprised six items (1-6) on stigma-related mental health knowledge areas and six items (7-12) on the classification of various conditions as mental illness. Participants were asked to indicate whether they agreed or disagreed with the items on a five-point Likert scale.

Reported and Intended Behaviour Scales (RIBS)

RIBS has been designed to measure mental health-related behavioural discrimination among the general public and document behavioural trends (Evans-Lacko et al. 2011). It comprised four items (1-4) which assess the prevalence of behaviour and four items (5-8) which on intended behaviour in the same contexts. Participants were asked to indicate whether they agreed or disagreed with items 5-8 on a five-point Likert scale.

Community Attitudes to the Mentally Ill (CAMI).

CAMI has been designed to measure mental health-related attitudes among the general public. The following three items were used:

- One of the main causes of mental illness is a lack of self-discipline and will-power;
- There is something about people with mental illness that makes it easy to tell them from normal people;
- It is frightening to think of people with mental problems living in residential neighbourhoods.

Participants were asked to indicate whether they agreed or disagreed with the three statements on a five-point Likert scale.

In addition to this, participants were asked to complete a short form requesting demographic data, evaluate the intervention using free-text comments and indicate whether they agreed or disagreed with the following statement on a five-point Likert scale *"I feel inspired to raise awareness of the importance of mental health and to take action to challenge stigma."*

Statistical analysis

The total scores for the MAKS, RIBS, CAMI and the statement on feeling inspired to act to challenge stigma were calculated with higher scores indicating less stigmatising responses. A paired sample t-test was conducted to compare pre-intervention and post-intervention scores. Results were considered significant at $p \leq 0.05$.

RESULTS

Although 150 participants attended the event, response rates were very poor. 18/150 (12%) of participants completed the pre-post RIBS scale, 18/150 (12%) of participants completed the pre-post MAKS scale, 16/150 (10.5%) of participants completed the pre-post CAMI scale and 15/150 (10%) of participants completed the pre-post question, 'I feel inspired to raise awareness of the importance of mental health and to take action to challenge stigma (ITTA)'.

The mean age of participants was 20.4 years (Std. Dev. 8.93, min 13, max 48). The occupational/educational background and place of birth of each participant is graphically represented in Figure 2 and 3 respectively.

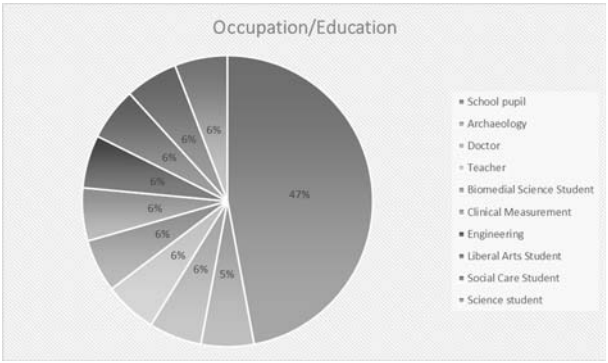

Figure 2. Occupation/Education

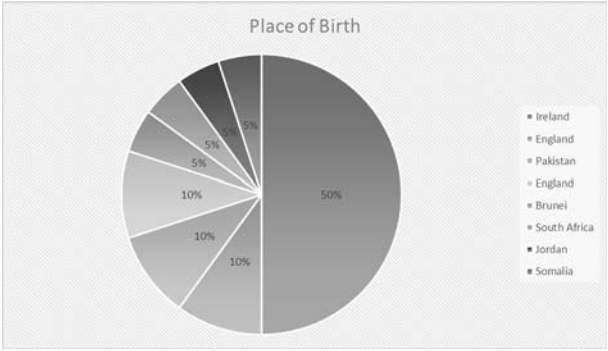

Figure 3. Place of Birth

The mean pre-RIBS score was 15.83 (Std. Dev. 3.33, 95% Conf. Interval 14.18–17.49) and the mean post-RIBS score was 17.61 (Std. Dev. 3.10, 95% Conf. Interval 16.23–18.99). There was a statistically significant difference in the pre-RIBS score compared to the post-RIBS score (p=0.0262) (see Figure 4).

The mean pre-MAKS score was 22 (Std. Dev. 2.43, 95% Conf. Interval 20.86–23.14) and the mean post-MAKS score was 24.6 (Std. Dev. 2.64, 95% Conf. Interval 23.47–25.73). There was a statistically significant difference in the pre-MAKS score compared to the post-MAKS score (p=0.0003) (see Figure 4).

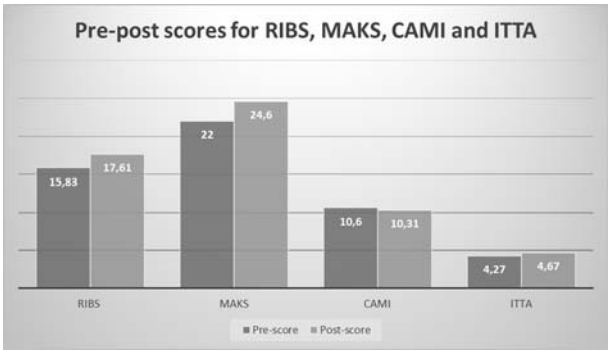

Figure 4. Pre-post scores for RIBS, MAKS, CAMI and ITTA (RIBS- Reported and Intended Behavior Scales, MAKS- Mental Health Knowledge Schedule, CAMI- Community Attitudes to the Mentally Ill, ITTA- Inspired to Take Action to challenge mental health stigma)

The mean pre-CAMI score was 10.06 (Std. Dev 2.77, 95% Conf. Interval 8.59–11.54) and the mean post-CAMI score was 10.31 (Std. Dev 1.98, 95% Conf. Interval 8.76–11.87). There was no statistically significant difference in the pre-CAMI score compared to the post-CAMI score (p=0.6214) (see Figure 4).

The mean pre-ITTA score was 4.27 (Std. Dev 0.59, 95% Conf. Interval 3.94–4.60) and the mean post-ITTA score was 4.67 (Std. Dev 0.49, 95% Conf. Interval 4.40–4.94). There was a statistically significant difference in the pre-ITTA score compared to the post-ITTA score (p=0.0086) (see Figure 4).

DISCUSSION

As far as the authors are aware, this was the first ever intervention study on mental health stigma in Muslim communities published in the literature. With regards to our study, there was a large sample size (n=150) however there was a very poor response rate even though we printed out paper questionnaires for participants to complete which, in our experience, usually improves response rates (Hankir et al. 2014).

Nonetheless, our study did reveal that there were statistically significant reductions in stigma in the domains of mental health knowledge and reported and intended behaviour but not in attitudes towards the mentally ill. Our findings are encouraging and provide provisional support that mental health conferences comprised of talks and lectures from experts in Islam and mental health as well as a talk from an 'expert by experience' are associated with reductions in stigma variables in Muslim communities. However, we must interpret the results of our study with caution since there is no evidence to prove that participants will have lower levels of stigma when interacting with people outside of a controlled setting who have mental health problems.

The main limitation of our study was the small sample size. Also, the participants who attended the event were 'self-selecting' i.e. they may already have had an interest in mental health and relatively lower levels of stigma compared to Muslims who didn't attend the event (hence there was a selection bias). A larger sample size, a comparison group and a longitudinal design might help to control for such confounding factors. Due to the limitations of our study, our results are not representative or generalizable but do provide provisional support for future more robust research.

CONCLUSION

Since there are heightened levels of Islamophobia, we can expect for the rates of psychological problems in Muslim people to increase. People, Muslims and non-Muslims alike, with mental health problems must fight a crippling battle on two fronts: Dealing with the cruel symptoms of the mental illness itself and enduring the egregious effects of stigma and discrimination. To combat stigma, we must normalize mental illness as we do physical illness and stand together in solidarity.

Everyone has a role to play in challenging stigma. For policy-makers, ensuring that sufficient resources are allocated and secured for the provision of mental health services is crucial. For patients, overcoming self-stigma and seeking care is a vital step towards recovery. Indeed, for the wider society, reducing stigma from the public can lower the barriers to mental health services for those who urgently need them.

Acknowledgements:

We would like to thank the organizing committee of the Federation or Student Islamic Societies Ireland Branch for distributing the questionnaires and for collecting the data.

Conflict of interest: *None to declare.*

Contribution of individual authors:

Ahmed Hankir conceived the study, and conducted the review of the literature.

Hannah Pendegast collected the data.

Frederick R. Carrick & Rashid Zaman supervised Ahmed Hankir, revised the drafts of the manuscripts and verified the veracity of the paper.

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Correspondence:
Ahmed Hankir MBChB, PG Cert Psych, PG Cert Epi
Leeds York Partnership NHS Foundation Trust
Cambridge, UK
E-mail: ahmedzakaria@doctors.org.uk