'A LABOUR OF LOVE': A KING'S COLLEGE LONDON PSYCHIATRY SOCIETY EVENT TO CHALLENGE THE STIGMA ATTACHED TO MENTAL HEALTH PROBLEMS IN POST-NATAL WOMEN

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SUMMARY

Background: *On the 9th October 2000, Dr Daksha Emson, a London based psychiatrist with bipolar affective disorder, tragically killed herself and her three-month-old baby daughter during a psychotic episode. An independent inquiry into Dr Emson's death concluded that mental health stigma in the National Health Service was a factor that contributed to her death. Despite the morbidity and mortality attributed to the stigma attached to post-natal mental health problems there are very few programmes that have been developed to challenge it. King's College London Undergraduate Psychiatry Society organized an event entitled, 'A Labour of Love': Perinatal Mental Health to address this issue. The event included a talk from an expert by experience, a mother who developed post-partum mental health problems.*

Design: *We conducted a single-arm, pre-post comparison study on participants who attended the KCL Psych Soc event. Validated stigma scales on knowledge (Mental Health Knowledge Schedule (MAKS)), attitudes (Community Attitudes towards the Mentally Ill (CAMI)) and behaviour (Reported and Intended Behaviour Scale (RIBS)) were administered before and immediately after exposure to the event.*

Results: *27/27 (100%) of participants recruited responded. There was a statistically significant difference in the pre-MAKS score compared to the post-MAKS score (p=0.0003), the pre-RIBS score compared to the post-RIBS score (p=0.0068) and in the pre-CAMI score compared to the post-CAMI score (p=0.0042).*

Discussion: *There were statistically significant reductions in stigma in the domains of knowledge, attitude and behavior following exposure to the KCL Psych Soc event and no adverse effects were reported. Our study revealed that a brief intervention made a highly significant impact and maybe useful in challenging the stigma around post-natal mental illness. However, more research in this area is required to determine if the changes are sustained before we can consider rolling out and scaling up such an initiative nationally and internationally.*

Key words: *stigma - post-natal mental health problems - healthcare students - healthcare professionals*

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BACKGROUND

Prevalence of mental health problems in post-natal women

The term 'postpartum psychiatric disorder' encompasses a spectrum of mental health conditions. Traditionally these conditions were divided into 'baby blues', postnatal depression and postpartum psychosis (Brockington 1981, Edwards 2005), with the latter the most severe. There is now considered to be more of a spectrum and included within this are exacerbations of existing conditions such as obsessive-compulsive disorder (OCD) and bipolar affective disorder, as well as severe anxiety and post traumatic stress disorder (PTSD) (Brockington 2004).

The 'baby blues' affect up to 50-70% of women (O'Hara 1991) and feature lability of emotion and irritability which last up to approximately 10 days postpartum. https://www.womenshealth.gov/a-z-topics/depression-during-and-after-pregnancy

Postnatal mood disorders, particularly postnatal depression, are common with an estimated prevalence of between 15-20% of women affected (Leahy-Warren 2007, Grace 2003), making it the most common complication of childbirth (Jones 2005). Symptoms are described as a 'profound and consistent lowering of mood' with altered thinking and the physical symptoms of depression (Edwards 2005).

The most severe form of postnatal mental health disorders is postpartum psychosis. Often requiring hospita-

lisation (Jones 2005), it affects 1-2 per 1000 women, usually with a rapid clinical onset of between 48-72 hours (Sit 2006, Robertson 2003). It is described by Brockington as 'an acute affective psychosis with florid psychotic symptoms, with manic and depressive mood being approximately equal in occurrence' (Brockington 1981) and is more common in women with a pre-existing diagnosis of bipolar disorder (Di Florio 2014). These conditions have a significant impact on the mother and child as well as their families.

Perinatal depression can lead to a chronic or recurring depression in women (Goodman 2004). It, alongside postpartum psychosis and the other perinatal disorders can affect the relationship between the child and the mother and child development [Grace 2003, Bureau 2009]. Furthermore, in the UK, suicide is the leading cause of death in women in the first year after childbirth (Oates 2003) with most women suffering from postpartum psychosis (Jones 2005). However, it is difficult to estimate the true prevalence of these conditions as many women do not seek help often due to feelings of stigma. Indeed, Hewitt and colleagues (2009), estimated that up to 50% of cases of postnatal depression remain undiagnosed (Hewitt 2009). In one study stigma accounted for 43% of the perceived potential barriers to treatment, second only to lack of time (65%) (Goodman 2009). It is therefore imperative that stigma attached to these conditions is addressed so that women and their families feel able to access the care that they need at a very vulnerable time.

Mental health stigma and strategies to challenge it

Mental health has become a regular feature of newspaper headlines in the UK in recent years.

In 2011, a UK survey showed that 85% of respondents believed people with mental illness experience stigma and discrimination (Liddle 2011). Stigma was described by Ervin Goffman in 1963 as a social construct where a person 'shows evidence of an attribute that makes him different to others' and so is reduced to someone 'with a spoiled identity' (Goffman 1963). Several campaigns run by charities, healthcare organisations and celebrities have begun to tackle the stigma associated with mental health problems, some of which are outlined below.

"Time to Change" was launched in 2007 by charities Mind and Rethink Mental Illness. It aims to improve public attitudes towards those with mental health problems, reduce discrimination and empower people to act to challenge stigma against those with mental illness. (https://www.time-to-change.org.uk/sites/default/files/Stigma%20Shout.pdf)

By working across an abundance of settings including schools, communities, workplaces and social media, national surveys show a 9.6% positive change in overall attitudes to mental health between 2008 and 2016. This is accompanied by a 5.6% increase in people who access mental health services reporting no experienced discrimination in any setting, and a fall in average levels of reported discrimination to 28.4% from 41.6% in response to this campaign (Corker 2016).

"See Me" is a similar campaign run in Scotland, set up to "challenge stigma and discrimination at its roots to enable and empower people who experience mental health problems to live fulfilled lives" (https://www.seemescotland.org/). Through their sub-campaigns including "Power of Okay", "Change Networks", "Pass the Badge" and "Walk a Mile", they aim to break down stigma "one conversation at a time" (https://www.seemescotland.org/).

"Heads Together" is a campaign set up by the Duke and Duchess of Cambridge and Prince Harry in 2016 that works alongside numerous charity partners to tackle stigma, raise awareness and provide help for those with mental health problems. The aim is to encourage open conversation about mental health problems, with examples set by well-known figures such as politician Alastair Campbell, comedian Ruby Wax, cricketer Andrew Flintoff and rapper Professor Green (Stephen Manderson) who have spoken out about their own mental health within this campaign (https://www.headstogether.org.uk/about-heads-together/).

Sources of stigma: Mental health stigma towards and from healthcare professionals

Stigma towards mental illness amongst physicians is possibly higher than in the general population (Dewa 2013) and should be recognised and challenged.

Stigma from healthcare professionals presents several resultant issues, including:

Reluctance for healthcare professionals to declare their own mental illness due to fear of discrimination

In a survey of female physicians in the USA, 45% of respondents felt that having a psychiatric diagnosis would be "embarrassing or shameful" and 69% of respondents would not seek help for a stigma-related reason (Dewa 2013). Fear of discrimination via disciplinary response, i.e. limiting the physicians' ability to work supposedly in order to ensure patient safety, and associated difficulties acquiring medical indemnity and support from colleagues is widely recognised amongst physicians (Wallace 2012).

Reluctance for patients to disclose their mental health problems

Through fear of discrimination by mental health professionals, patients may avoid discussing their mental health problems. With specific reference to perinatal mental illness, studies show that some GPs may attempt to normalise changes in mood in behaviour in the postnatal period, as opposed to actively treating a woman's mood, preventing the woman wishing to seek help again (Bilszta 2010). Lack of empathy or under-

standing by health professionals may also be obstructive, e.g. reports of women receiving comments such as "Suck it up, babies scream!", rather than recognising and understanding their distress (Bilszta 2010).

Creation of barriers to care towards patients with known mental illness

An interim report for the Canadian anti-stigma campaign Opening Minds describes how patients feel "patronised, punished or humiliated" when seeking help for mental health problems (Dewa 2013). Discrimination towards these patients can include voiced negative opinions regarding the patient's chances of recovery, attribution of physical illness to the mental health condition, and refusal to treat mental illness in a medical hospital (Dewa 2013).

The stigma attached to mental health problems in post-natal women

For women who are new mothers there is still much stigma associated with mental health conditions (Edwards 2005). Stigma can have a profound effect, for example; a reluctance to access services as well as a lack of support from family and friends (Edwards 2005, Vogel 2011). It can also lead to social exclusion due to women's concerns over how people may view them. Edwards and colleagues describe how one woman admitted to a mother and a baby unit commented, 'I would have preferred them (her friends) to think I had a physical illness' (Edwards 2005).

Stigma can be divided into that felt internally, with women judging themselves and externally, from family and friends and from society in general. Robertson and colleagues noted how women admitted to a mother and baby unit, used language such as 'freak' to describe themselves (Robertson 2003). Furthermore, Werner and colleagues report how many women feel ashamed of their feelings during what they perceive should be a wonderfully happy time (Werner 2015).

External stigma may be felt due to traditional views surrounding the role of women as nurturers and the 'myth of motherhood' (Tammentie 2004, Knudson-Martin 2009) where becoming a mother is viewed as a natural process. Finding this difficult is seen as a failure, resulting in women feeling stigmatised for not being caring to their infants (Bilszta 2010). This can compound feelings of shame and internalised stigma of being a 'bad mother' as these women feel unable to fulfil their role (Robertson 2003). Liddle and colleagues suggest that this can lead to a downward spiral meaning that self-stigmatisation can contribute to the development and maintenance of postnatal depression (Liddle 2002).

External stigma from friends and family is also felt with Robertson and colleagues noting how one woman's friend's fear of her psychosis led to the decline of their friendship (Robertson 2003) Another powerful presence when considering stigma is the

media. It can act to increase or reduce stigma by publishing sensationalised stories of women committing infanticide or real life empathetic accounts of women managing postpartum mental illness (Goffman 2006, Sanghani 2015, McCormack 2016). Lastly, 'labelling' women with a mental health diagnosis is important when considering stigma. Studies are varied. Edwards and colleagues found that women liked the 'label' of a mental health diagnosis and felt a higher profile for mental illness would help to eliminate stigma. Furthermore, they felt it was comforting as their condition would then be treatable (Edwards 2005). However, Bilstza and colleagues found that women were fearful of the ramifications of being labelled, for example; for social housing and being perceived as a failure (Bilstza 2010).

Challenging the stigma attached to mental health problems in post-natal women

The Maternal Mental Health Alliance (MMHA) comprises more than 80 organisations, including Royal Colleges, charities and other organisations aiming to "improve mental health and wellbeing of women and their children in pregnancy and their first postnatal year". As part of MMHA, the 2Gether NHS Foundation Trust in Gloucestershire has produced a set of postcards, posters, social media publications and website material to improve understanding of perinatal mental illness aiming to reduce associated stigma (http://maternalmentalhealthalliance.org/tackling-stigma-perinatal-mental-illness/).

A newer model of challenging stigma occurs in the form of online forums. The anonymity of online platforms to discuss and disclose perinatal mental illness encourages many experiencing external or internal stigma to avoid associated issues (Moore 2017). The thousands of forums with heavy traffic flow can provide social support that can challenge stigma in a non-judgmental manner; studies suggest that mothers feel these websites "normalise and validate" their stigmatised symptoms, therefore may potentially increase disclosure to healthcare providers (Moore 2017).

Documentaries such as "My baby, psychosis and me" aired on BBC One in February 2016 aim to raise awareness of perinatal mental illness. However, overall, anti-stigma initiatives in perinatal mental health outside the online setting appear to be somewhat lacking, particularly in view of the rapid recognition and expansion of perinatal psychiatry as a subspecialty, with 17 Mother and Baby Units now open across the UK (http://maternalmentalhealthalliance.org/tackling-stigma-perinatal-mental-illness/).

King's College London Psychiatry Soceity

King's College London Psychiatry Society ('KCL PsychSoc') was founded in 2005 and is the oldest university psychiatry society in the UK. KCL Psych Soc

was established to promote psychiatry as a career to medical students, to support those students who wished to consider psychiatry as a career, to raise the profile of mental health issues amongst all student health professionals and to break down the stigma attached to mental illness. The Society is supported by the Institute of Psychiatry, Psychology & Neuroscience and there is no membership fee (http://www.maudsleytraining.com/PsychSoc.htm).

KCL Psych Soc works closely with the Department of Undergraduate Psychiatry at South London & Maudsley NHS Trust and IoPPN to improve the quality of the psychiatry attachments for students.

The Society hosts a series of lectures that are lively and controversial, often featuring eminent speakers, including Professors Simon Baron Cohen, Murray, and Sir Simon Wessely. Most events are open to all, particularly students & staff of King's College London, the IoPPN and South London and Maudsley NHS Trust. (http://www.maudsleytraining.com/PsychSoc.htm).

Figure 1. Leaflet designed by KCL Psychiatry Society used as promotional material to recruit participants for the study

King's College London Psychiatry Soceity Event: Perinatal mental health: A Labour of Love

KCL Psych Soc organized an event entitled, 'Perinatal mental health: A Labour of Love'. The event was publicized on social media (see figure 1) with the following information:

'What is Perinatal Mental Illness? New mothers and babies are vulnerable people. Mental illness during pregnancy and the postpartum period can an enormous impact on the mental health of mothers. Come along to our information event to hear from:

- Ms. Leila Frodsham, Consultant Gynecologist, who will explain what perinatal mental illness is and how it is clinically managed.
- Kathryn Grant, a representative from Action on Postpartum Psychosis (APP), who will be sharing her experiences of mental illness during pregnancy and postpartum period, as well as discussing important organizations and charities that supported her.

METHOD

Study design

This pilot project was a single-arm, pre-post comparison study (O_1 X O_2). We administered validated stigma scales before and after the participants were exposed to the intervention. We then measured if there were any statistically significant changes in stigma variables (knowledge, attitudes and behaviour). We hand distributed paper questionnaires to increase response rates.

Participants

People who attended the KCL Psych Soc event were recruited to participate in the study. KCL Psych Soc publicized the event by producing promotional material and posting it on their social media accounts (including Facebook and Twitter). Attending the event, as well as participation in the study, was voluntary. The participants were informed about anonymity, and each participant had a unique personal code that did not reveal any identifying information. No monetary compensation was offered although free refreshments were provided. Verbal informed consent was obtained. Ethical approval for the study was obtained from the Carrick Institute for Graduate Studies, an Institutional Review Board registered with the National Institute of Health that has a track record for global educational, research and clinical trials.

Stigma scales

Three validated scales were administered 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

Descriptive statistics were performed on the data obtained. The total scores for the MAKS, RIBS and CAMI were calculated with higher scores representing 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 63 participants expressed an interest in attending the event on social media, only 27 attended (43%). However, 27/27 (100%) of the participants who attended the event completed the validated stigma scales before and after exposure to the program.

The occupational/educational background and nationality of each participant is graphically represented in figure 2 and 3 respectively.

The mean pre-MAKS score was 20.81 (Std. Dev. 2.43, 95% Conf. Interval 19.85–21.78) and the mean post-MAKS score was 22.44 (Std. Dev. 1.87, 95% Conf. Interval 21.71–23.18). There was a statistically significant difference in the pre-MAKS score compared to the post-MAKS score (p=0.0003) (see figure 4).

The mean pre-RIBS score was 18.74 (Std. Dev. 1.63, 95% Conf. Interval 18.10–19.39) and the mean post-RIBS score was 19.33 (Std. Dev. 1.27, 95% Conf. Interval 18.83–19.84). There was a statistically significant difference in the pre-RIBS score compared to the post-RIBS score (p=0.0068) (see figure 4).

The mean pre-CAMI score was 13 (Std. Dev 1.78, 95% Conf. Interval 12.30–13.70) and the mean post-CAMI score was 13.74 (Std. Dev. 1.56, 95% Conf. Interval 13.12–14.36). There was a statistically significant difference in the pre-CAMI score compared to the post-CAMI score (p=0.0042) (see figure 4).

The mean pre-ITTA score was 4.37 (Std. Dev 0.69, 95% Conf. Interval 4.10–4.64) and the mean post-ITTA

score was 4.85 (Std. Dev 0.36, 95% Conf. Interval 4.71–5.00). There was a statistically significant difference in the pre-ITTA score compared to the post-ITTA score (p<0.0001) (see figure 4).
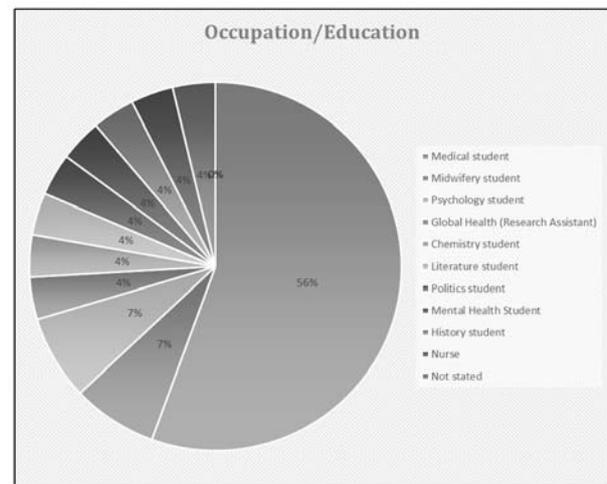

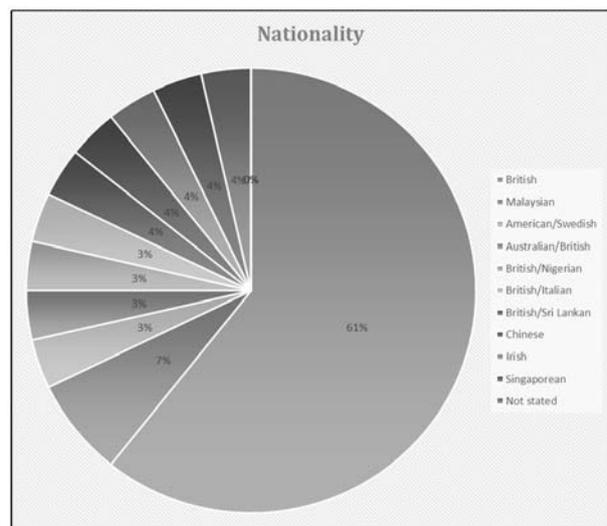**Figure 2.** Educational/occupational background of respondents

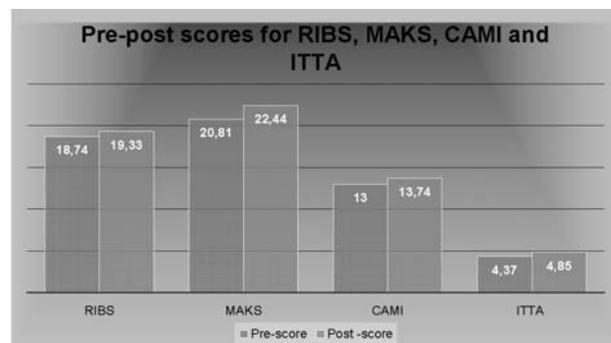**Figure 3.** Nationalities of respondents.

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).

DISCUSSION

There were statistically significant changes in the scores of all stigma scales (MAKS, RIBS and CAMI) indicating reductions in stigma in all domains measured (knowledge, behaviour and attitudes). Our findings are consistent with the results of a recent systematic review and meta-analysis on challenging public stigma in adults that revealed that social contact with someone who has first-hand experience of mental illness is the most effective way of reducing stigma (Corrigan 2012).

The main limitations of this study are the small sample size, making the results vulnerable to type II error, and the absence of a control group means that we cannot exclude the possibility that another factor, other than the intervention, influenced the difference between pre-intervention and post-intervention scores. Another limitation of the study is that we do not know if and for how long the change in attitudes are sustained. The strengths of the study include the use of self-report questionnaires to minimise assessor bias. The pre-intervention post-intervention design made the study easy to replicate.

Notwithstanding the limitations our study, the immediate reductions in stigma in the domains of knowledge, attitude and behaviour suggest that it would be worth while carrying out future research in this area with a prospective study design, a control group and a larger sample size to determine if the event can cause a sustained reduction in stigma.

Given, there is a dearth of programmes that challenge the stigma attached to mental health problems in post-natal women, we see absolutely no reason why such an initiative cannot be rolled out and scaled up nationally i.e. via university psychiatry societies throughout the UK and indeed worldwide.

Dr Daksha Emson was a psychiatrist with bipolar affective disorder who tragically killed herself and her 3-month-old baby daughter during a psychotic episode. An independent inquiry into her death concluded that mental health stigma in the NHS was a contributory factor.

Her death was not the first nor will it be the last. We must work collectively and with a sense of urgency and immediacy if we want to challenge tal health stigma and overcome the barriers to receiving care (Hankir 2013, Hankir 2014).

Contribution of individual authors:

Mao Fong Lim, Isabel Lever, Phillipa Brothwood, Bethany Crocker organized the event, collected the data and conducted a review of the literature.

Frederick R. Carrick and *Rashid Zaman* supervised *Ahmed Hankir*, contributed to the study design and obtained ethical approval.

Charlotte Wilson Jones supervised *Mao Fong Lim, Isabel Lever, Phillipa Brothwood, Bethany Crocker* and reviewed the manuscript.

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